Relationship Between Knowledge, Hopelessness and Adherence to Prescribed Regimens in Psychiatric Patients

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Chapter I

Introduction

Psychiatric patients often fail to take prescribed medication and attend follow-up appointments after hospital discharge. This lack of adherence is a critical problem for mental health patients and professionals. It is reported that 25% to 50% of discharged psychiatric patients do not take their medication as prescribed (Appleton, 1982). Lauck and Bigelow (1982), in a study exploring follow through on psychiatric referrals from an emergency room, found that 55% of patients did not attend their appointments. Other investigators have found missed initial appointment rates of 57% (Overall & Aronson, 1963) and 56% (Kluger & Karras, 1983).

Most articles regarding the issue of the patient's active participation in his/her treatment program use the concept compliance to denote participation, and non-compliance to denote non-participation. Recent articles, however, question the use of this concept as it carries with it a connotation of hierarchical values, putting the care provider in a "one up" position, and the patient in a "one down" position (Stanitis & Ryan, 1982). The concept of

compliance implies judgments about the patient made by the provider. Even though the majority of authors whose work was reviewed in preparation for this study used the concept "compliance," the concept "adherence" is used for this study. Although not perfect, the concept adherence infers less value judgment than the concept compliance. Adherence is a behavioral outcome stemming from personal traits and characteristics of the patient which may be influenced by the environment and the care provider (Kim, 1983).

While acute episodes of mental illness cannot be totally eliminated, even with perfect adherence to follow-up plans (Hartman, Kind, Meyer, Muller, & Steuber, 1980), the rehospitalization of decompensated patients could be markedly reduced with improved adherence (Appleton, 1982). Ashburn (1981) estimates that 20% to 25% of all hospitalizations may be the result of non-adherence with the medication regimen.

The "revolving door" syndrome of repeated and frequent hospitalizations of psychiatric patients is extremely costly. One day of hospitalization in a public institution costs in the neighborhood of $200, while a day in a private care facility can cost double or triple that amount. Many chronically mentally ill individuals are unable to be gainfully employed by virtue of their illness and do not

have insurance, thus the cost of their care is assumed by tax-supported programs.

There is an emotional cost, as well, to the patient who continues to require rehospitalization. Each admission can be perceived by the patient as a defeat in the battle to maintain autonomy and independent living. Confidence and motivation are lost as the patient assumes his/her sick role behavior (Lovejoy, 1982).

Practicing nurses express frustration and concern regarding rehospitalizations. Patients functioning adequately upon discharge from a hospital often return in a decompensated state. Hospital staff describe feelings of helplessness and exhibit behaviors of patient-blaming and patient-avoiding when chronically mentally ill individuals are frequently rehospitalized (Roberts, 1978).

Adherence has been studied extensively in patients who suffer from non-psychiatric illnesses. Much has been learned about why patients do and do not take their medication as prescribed and what facilitates regular attendance at appointments with their practitioner (Marston, 1970). Persons who are mentally ill, however, have periods when their judgment is seriously impaired, as for example, when denial is strong or when thought disturbances interfere with logical thinking (Youssef, 1983). It is unlikely that findings regarding adherence to outpatient treatment plans

in persons with illnesses such as high blood pressure or diabetes can be applied to persons with psychiatric disorders (Blackwell, 1978).

One way in which nurses attempt to increase adherence is by patient teaching (Cohen & Amdur, 1981; O'Brien, 1979; Smith, 1981). Nurses use a variety of teaching methods to increase the psychiatric patients' knowledge of their illness and medication (Osguthorpe, Roper, & Saunders, 1983). Although a positive correlation has been assumed by many, the relationship between knowledge and adherence to recommended treatment in the psychiatric population has not been firmly established.

If it is true that patient knowledge is related positively to adherence, there are consequences to providing inadequate teaching programs. Patients who do not know about their illness and medications are not able to be reliable participants in their own care (Becker & Maiman, 1980). They may not be able to recognize early warning signs of decompensation and, as a result, may need hospitalization more frequently, sometimes as involuntary patients. Without knowledge they may not be equipped to discern subtle effects of medication and, as a result, may tend to experience more adverse reactions to their medications. They may continue to take more or less medication than is needed without seeking adjustments from

the prescriber. It would be naive to believe that knowledge alone would eliminate adherence and adjustment difficulties, but it would also be naive to assume that knowledge does not influence adherence in a psychiatric population.

There are other factors which affect patients' adherence and adjustment. Patients' affective state and attitudinal set will influence their willingness to adhere to recommended treatment plans (Green, 1976). Hospitalized psychiatric patients are often in a state of despair, and may have thoughts that their future is hopeless (Yalom, 1985). Patients who feel a high degree of hopelessness will not have the expectation that treatment could help alleviate their suffering. One might expect that if such negative feelings and thoughts continue unabated, adherence to treatment recommendations following hospital discharge would be less likely (Frank, 1984). Unless the presence of high levels of hopelessness is recognized and alleviated by therapeutic interventions, even the most carefully construed after-care plan may not benefit the patient.

The purpose of this study is to examine the concepts of knowledge and hopelessness, and how these concepts relate to adherence in psychiatric patients following discharge from hospital settings into the community. It is important to discover the nature of the relationship between the independent variables of knowledge and hopelessness and how

they relate to adherence to specific aspects of post hospital discharge treatment plans. Another component of this study will be to attempt to determine how the two independent variables, knowledge and hopelessness, relate to one another.

Review of the Literature

The review of the literature includes studies having to do with adherence in the general population and the psychiatric population. Following that, a review of literature pertaining to the specific concepts of hopelessness and knowledge as they relate to adherence will be presented.

Adherence. Adherence is the extent to which the patient's behavior conforms to the recommended treatment regimen (Sackett, 1976). It is a behavioral outcome of many influential variables. There is no positive or negative judgment implied by the concept of adherence in this study, and the definition stands regardless of the way in which adherence behaviors occur.

The measurement of adherence has been undertaken by many researchers using direct methods such as measuring blood levels of medication, and indirect methods such as self report. Although direct measurement methods are more reliable than indirect methods, they are often more invasive and costly. Measurement error occurs in both direct and

indirect methods necessitating research results to be interpreted cautiously.

Despite the difficulty in conceptualizing and operationalizing the concept of adherence, comprehensive reviews of adherence literature have made it possible for some generalizations to be made regarding variables which influence adherence to treatment plans. Factors which appear to influence the patient's adherence with prescribed regimens include care provider variables, client variables, and variables inherent in the regimen itself.

Provider characteristics which appear to be related to adherence include patient involvement in care planning, provider approachability and relationship with the client, continuity of care, the provider's belief in the efficacy of the treatment, patient reminders, and adequacy of the discharge plan. Involving the patient as an active participant in the process of establishing a plan of care has been suggested to increase the likelihood of adherence in theories set forth by Becker and Maiman (1980), and Sarnecky and Sarnecky (1984). A review of empirical studies by Docherty and Fiester (1985) and a study of 46 psychiatric outpatients (Lauck & Bigelow, 1982) support patient inclusion as being significant. Podell and Gary (1976), in their review of adherence studies, have suggested that the approachability of the care provider in terms of providing

personalized, continuous, convenient, and courteous care improves adherence to treatment regimens. Care providers with "low approachability" are confronted with emotional resistance in their patients resulting in lower adherence rates. In one empirical study, patients who perceived a lack of warmth in their practitioner had lower rates of adherence (Komaroff, 1976). Three separate reviews of adherence research concluded that a positive provider/client relationship was related to increased adherence (Connelly, 1978; Docherty & Fiester, 1985; Matthews & Hingson, 1977). Docherty and Fiester's empirical review also concluded that the availability of providers to offer continuity of care was reported to positively effect adherence behaviors.

Frank (1975) developed the theory that practitioners' attitudes have a profound effect on patient adherence in that patients are more likely to adhere to treatment recommendations if the practitioner believes in the efficacy of the interventions. Providing visual reminders was found to be significantly related to increased adherence in a controlled study of 79 hypertensive patients (Gabriel, Gagnon, & Bryan, 1977). The adequacy of discharge planning in terms of linking persons to the appropriate facilities to meet their specific individual needs, was related to significantly increased treatment adherence and decreased rates of early rehospitalization in a follow-up study of 119

schizophrenic patients followed for one year after hospital discharge (Caton, Goldstein, Serrano, & Bender, 1984).

Reviews of empirical studies (Docherty & Fiester, 1985; Marston, 1970; Matthews & Hingson, 1977) have failed to demonstrate a correlation between any demographic variables and adherence. However, there are a number of other client variables that may influence adherence. Client variables that may influence adherence include attitudes and beliefs regarding illness and treatment regimens, history of adherence behaviors, magnitude of support systems, attitudes of family members, patient perception of illness severity, consequences of poor adherence, and, possibly, patient knowledge. Podell and Gary's review indicated that patients who deny the presence of illness are less likely to adhere to treatment regimens, while Matthews and Hingson's review reported that patients who feel susceptible to the problems and complications of an illness are more likely to adhere. In the opinion of Green (1976), adherence will be increased when the patient believes that the regimen is important for maintaining health. Patient skepticism about the effectiveness of treatment makes poor adherence probable according to a review of studies and opinions by Blackwell (1978).

Becker and Maiman's theory holds that a client who has had poor adherence in the past can be predicted to have

adherence problems in the future. In a review of six studies that examined the relationship between patient adherence and family influence, Haynes (1976) concluded that a client whose support system is sparse or non-existent is less likely to adhere than one who has many persons who provide support. Negative attitudes on the part of family members, however, may adversely affect adherence according to an untested opinion (Mantonakis, Markidos, Kontaxakis, & Liakos, 1985). According to Marston (1970) in a comprehensive review of empirical studies, the client's perception of the severity of his illness appears to influence adherence. The client who perceives his/her illness as severe is predicted to be more likely to follow the recommended treatment than the client who perceives his/her illness as minor. The client's perception of severity may not reflect actual severity, however. In another review of studies and opinion, Blackwell concluded that adherence was found to decrease when the consequences of non-adherence are not immediate or dramatic, such as with chronic diseases.

The relationship between the patient's level of knowledge regarding illness and the treatment regimen, and adherence remains controversial. The literature search done for this study revealed that many studies support knowledge as having a positive correlation with treatment adherence.

The literature reviews done by Blackwell (1978), Davidhizar (1982), and Komaroff (1976) support knowledge as a positive influence on adherence, as do the individual studies of Lauck and Bigelow (1982), Tagliacozzo and Ima (1970), and Youssef (1983). Almost as many authors predict that knowledge does not influence adherence. Three comprehensive literature reviews (Docherty & Fiester, 1985; Marston, 1970; Matthews & Hingson, 1977) and two individual studies (Parkin, Henney, Quirk, & Crooks, 1976; Tagliacozzo, Luskin, Lashof, & Ima, 1974) do not support knowledge as being directly related to treatment adherence. The theory of Sarnecky and Sarnecky, also, does not support a direct relationship. Knowledge as a variable will be discussed in more detail under its own subheading in this paper.

According to a study of 125 chronically mentally ill individuals (Atwood & Beck, 1985), regimen characteristics were found to be more significantly related to adherence to outpatient follow-up care than patient characteristics. Factors in the treatment regimen which appear to be negatively related to adherence include complex drug schedules such as numerous times, doses, and numbers of pills. The negative influence of complex drug schedules on adherence was supported in the literature reviews of Blackwell (1978), Komaroff (1976), Podell and Gary (1976) and in the studies of Gabriel, Gagnon, and Bryan (1977) and

Parkin, Henney, Quirk, and Crooks (1976). Becker and Maiman theorized that tailoring the regimen to individual situations and resources improves adherence rates. VanPutten has studied medication adherence in chronically mentally ill individuals over the years. His work bore out a consistent relationship between untoward side effects of medication and poor adherence to medication prescription (VanPutten, 1974; VanPutten, May, & Marder, 1984). Diamond (1985), in his recent review of adherence studies, concluded that even in the absence of objective side effects, an emotional cost-benefit analysis by patients may determine that taking medication, despite reducing symptoms, comes at too great an expense to their subjectively experienced quality of life.

Hopelessness. The review of the literature on hopelessness will discuss differentiating hope from hopelessness; the effects of hopelessness on staff and patients; the psychodynamic, existential, and cognitive conceptual development of hopelessness; and the possibility of a curvilinear relationship between hopelessness and adherence. Empirical studies regarding hopelessness are also discussed.

During the initial stage of this research an attempt was made to define and utilize the concept of hope, and to study its relationship to adherence. However, in reviewing

the literature, it was found to be difficult to distinguish the concept of hope from the concepts of quality of life (Lehman, Ward, & Linn, 1982) and purpose in life (Crumbaugh, 1968; Lamb, 1982). It is important in the process of theory development to further refine and operationalize the concept of hope in terms that can eventually be utilized in the clinical practice of nursing.

While current literature regarding hope can offer some general guidelines for nursing assessment of patients (Obayuwana, Collins, Carter, Rao, Mathura, & Wilson, 1982), the instillation of hope remains highly individualized, and interventions must be tailored to reflect individual patient's needs (Diamond, 1985). For example, clinical staff may feel that the use of medication in the treatment of an illness is a symbol of hope, in that it reflects the expectation that help is available to the patient. However, not all patients perceive the use of medication as a symbol of hope; rather, they may perceive it as an indication of their own vulnerability and as an intimation of their mortality. Such a perception on the part of a patient makes poor adherence to a medication regimen very probable (Blackwell, 1978). Because of the difficulties inherent in attempting to define and operationalize the concept of hope, the concept hopelessness was used in this study.

Hopelessness may be a critical factor in hospitalized psychiatric patients and may be significant in determining whether or not a patient has the motivation to adhere to recommended follow-up care after hospital discharge. When staff feel hopeless, feelings of hopelessness increase in the patient (Krauss & Slavinsky, 1982, pp. 56-57; Roberts, 1978, pp. 172-194). Whether knowingly or not, expectations on the part of staff are relayed to patients with mental disorders. Negative stereotypes associated with a diagnosis such as schizophrenia lead to self-fulfilling prophecies and result in defeat, despair, and immobilization on the part of patients (Lovejoy, 1982). Roberts describes hopelessness on the part of staff toward patients as a defense mechanism that protects clinicians from experiencing anger or blame towards self or towards the patient when a patient fails to achieve staff expectations.

A psychodynamic approach toward hopelessness is described by Melges and Bowlby (1969). Hope and hopelessness represent opposite expectations or outlooks in life and are determined by early life experiences. Hope is the resultant belief that a plan of action will be successful in meeting a goal. Hopelessness is the anticipation of failure of obtaining goals. Obayuwana (1980) defines hopelessness as a feeling that one is unable

to cope with environmental changes, and that nothing available can be effective in promoting positive changes.

Existential approaches toward hopelessness focus on how it affects prognosis and motivation for seeking psychotherapy. Jourard (1967) writes:

> Trust and hope don't cause healing. They are healing. . . . Continued distrust and hopelessness in a patient undergoing any kind of therapy may be regarded as indications that the disintegration process is unremitting. The patient's acquiescence to "determiners" of his existence is persisting, and may culminate in death, or in a total withdrawal into psychosis. (p. 33)

Frank (1974, pp. 312-318) states that demoralization, the feeling of being hopeless and helpless, is a common characteristic of all clients seeking psychotherapy, despite diagnosis. In later writing, Frank (1984) defines hopelessness as being synonymous with demoralization. Yalom (1985, pp. 70-111) cites the presence of hopelessness as a significant factor to be addressed by all of the psychotherapies, and the alleviation of hopelessness as one of the major tasks of the therapist in existential psychotherapy. This is particularly true, he states, in inpatient psychiatric groups, as such patients enter the hospital in a state of utter demoralization.

Much of the literature regarding hopelessness is tied to the related concept of depression. Exceptions to this are found in Beck, Weissman, Lester, and Trexler (1974) and Minkoff, Bergman, Beck, and Beck (1973) who differentiate between hopelessness and depression. Their studies have given empirical support to the finding that hopelessness is a distinct entity and is more directly related to the seriousness of suicidal intention than is clinical depression. Beck, Kovacs, and Weissman (1975) define hopelessness as a cognitive distortion or impaired reasoning. The patient systematically misconstrues experiences in a negative manner and anticipates a negative result from any attempt to achieve goals. Such a cognitive approach to the concept of hopelessness appears to be clear, precise, and measurable and will be used in this study. Studies done by Beck and his associates in the development of the Hopelessness Scale will be further described in the methods section of this paper.

It has been suggested, although not empirically tested, that a curvilinear relationship may exist between level of hopelessness and adherence to follow-up care (Talley & King, 1984, pp. 85-104). While hopelessness is necessary for a person to perceive the need for psychotherapy, "not all demoralized people come for psychotherapy." "Some are so demoralized, such as those on skid row, that it never occurs

to them that help is available" (Frank, 1984, p. 34). A great degree of hopelessness results in a feeling of futility and in the belief that others cannot relieve distress. This would preclude the seeking of help from a professional. An absence of hopelessness would indicate the perception that nothing is wrong that merits clinical intervention. Yalom (1985), while not addressing hopelessness specifically, suggests such a curvilinear relationship in terms of patient discomfort and motivation for therapy. Patients with either too much or too little comfort are usually unwilling to invest in therapy. Patients with moderately high levels of discomfort may be willing to pay a high price and work more stringently to achieve treatment goals than patients who experience extremes in levels of discomfort.

Despite compelling theoretical rationale, no studies exploring the possibility of a curvilinear relationship between hopelessness and adherence to follow-up care were found in reviewing the literature. Only one study was found which examined the relationship between demoralization and adherence. In a prospective study, Tessler and Mason (1979) used a simple summated scale to measure demoralization, defined as feeling hopeless and helpless, to see what relationship existed between demoralization and adherence to recommended outpatient follow-up care in 146 hospitalized

psychiatric patients. This study confirmed the belief that demoralized patients are more receptive to psychotherapy, and a positive relationship was found between high levels of demoralization and high rates of adherence ($r = .22$, $p < .02$). A critical limitation of the study is the fact that the broad concept of despair which includes both hopelessness and helplessness, was utilized as one of several independent variables. The instrument used to measure this concept was limited to four items and despite citing an internal consistency of .75 (Chronbach's Alpha), no other attempts to produce reliability or validity were found. With such a limited instrument the outcome scores of demoralization were simply high or low and the potential for examining the possibility of a curvilinear relationship between the two variables was lost.

Because of the limited research on the relationship between hopelessness and adherence, further study is indicated. The assumptions that hopelessness is a critical factor in determining motivation for adherence and that a moderately high level of hopelessness will yield higher adherence rates needed to be tested. In this way, nursing skills of assessment, planning of care and nursing interventions with patients experiencing hopelessness would have a more sound research base.

Knowledge. Knowledge is defined as adequate comprehension of information which allows the patient to plan and follow through with goal selection and goal-directed behavior (Osguthorpe, Roper, & Saunders, 1983). Literature addressing the concept of patient knowledge regarding illness and medication generally also addresses the related concept of patient education. For example, Cohen and Amdur (1981) organized medication groups for outpatient psychiatric patients for the purpose of educating them about their medication. They believed that education increased adherence and reduced troublesome side effects. They did not address the intercedent variable of knowledge and did not subject their hypothesis to empirical testing. Sclafani (1977) writes about the issue of the patient's right to be informed and how adherence improves:

> It is apparent that patients have a right to understand what is happening around them, and that mounting evidence indicates when people who have emotional problems are provided with planned educational experiences and take an active participating role in their own care, that they are able to cope with and follow prescribed treatment programs more adequately than those individuals who are not offered comparable experiences. (p. 14)

Neizo and Murphy (1983) provided medication instruction to 60 patients on an acute psychiatric unit with the goal of increasing adherence. A follow-up evaluation was conducted to which 30 patients responded. Sixty-eight percent of the respondents indicated "quite a bit" or "greatly" increased understanding, and 65% indicated "quite a bit" or "greatly" increased positive attitude about psychiatric medication. However, adherence measurements were not taken nor correlated with the measurements of attitude and understanding. An additional weakness of this study is the 50% response rate from participants. Questions regarding the non-responding participants were raised. Did the non-respondents' understanding and attitude increase, remain unchanged, or, perhaps, decrease?

Lane (1981) proposed an innovative plan of self-medication for the psychiatric patient. She linked education to increased knowledge, involvement, and self-care to the outcome of increased control of symptoms. She placed emphasis on self-care as the essential component. Her proposal has not apparently been put into practice, nor tested. Although a positive correlation between knowledge and compliance was assumed by this writer, she did not subject her hypotheses to empirical tests.

Recent research has focused on the question of whether teaching increases knowledge in psychiatric patients.

Whiteside (1983) conducted an experiment with 28 subjects to test the correlation between structured educational programs and increased knowledge about medications. Her results indicated that the subjects in the education group showed significant improvements from pre-test to post-test whereas the control group showed no significant improvement. McCay (1984) conducted a similar study of 16 psychiatric patients and included knowledge about illness as well as knowledge about medication. Her findings indicated that patients did not significantly improve their knowledge of medication following patient education, but did significantly improve their knowledge pertaining to their illness. Smith (1981) administered a questionnaire to 30 psychiatric patients prior to discharge to assess their level of knowledge of medication. She found that 25 of 30 patients had inadequate knowledge. On the basis of her findings, she instituted an educational program for these patients but did not report on its effectiveness in terms of increased knowledge. The aforementioned authors did not address any possible relationship between knowledge and adherence.

One recent study did test the link between patient education and adherence. Youssef (1983) conducted a study with 36 affectively-disordered patients being discharged from an inpatient facility. Half the patients were randomly placed in a directive educational program, half remained as

the control group. Patients in the education group attended sessions twice weekly and were presented with information on drug action, side effects, importance of medication, and reasons why patients stop taking medication. The control group members were instructed about how to take medication in the routine manner on the day of discharge by the nurse. The patients were followed for six months after hospital discharge and measures of medication adherence were taken using the pill-count method. Exactly how the researchers measured adherence and differentiated it from non-adherence in each patient is not clear. Results indicated that the education group members had significantly higher rates of adherence than control group members.

Several limitations of this study are noted. The fact that subjects in only one diagnostic category were asked to participate limits the generalizability of the results and justifies further investigation with other diagnostic groups. In addition, the author has made a conceptual "leap" in assuming that the process of educating patients did, in fact, increase their knowledge and that this increased knowledge resulted in better adherence to prescribed treatment. Subject knowledge was not measured, leaving some speculation that perhaps other, unidentified variables were related to increased adherence.

Adherence to recommended treatment has been studied extensively over the last several decades. The specific relationship between knowledge of illness and prescribed medication and adherence has received some attention among selected patient populations. Only one study was found which addressed the correlation between knowledge and adherence in the psychiatric population.

The literature review suggested that further investigation was warranted regarding adherence in psychiatric patients. It suggested that a relationship may exist between hopelessness and adherence, and between knowledge and adherence. One might also speculate that hopelessness and knowledge might influence each other. Since relationships between these concepts were suggested, and since hopelessness and knowledge are measurable variables that can be influenced by nursing interventions, a study of the relationships between these variables was proposed.

Conceptual Framework

In reviewing the literature for an appropriate conceptual framework, no theories were found to contain a relationship between the concepts of hopelessness and knowledge. However, according to Melges (1982, p. 179), one of the effects of hopelessness is the perception that future opportunities are constricted. Hopelessness makes a

person's appraisal of future events biased in a negative manner and effects a person's thinking, perception, and actions. Because of an expected frustration, goals cannot be achieved. Hopelessness is a disruptive influence and interferes with a person's ability to structure or follow through with goal-directed activity. Adherence behaviors of taking medication and attending outpatient appointments may be less likely to occur if a high degree of hopelessness exists. Again, a curvilinear relationship is suggested between levels of hopelessness and adherence behaviors. High levels of hopelessness could lead to a "What's the use?" response while an absence of hopelessness could be accompanied by the perception that nothing is threatening enough to merit clinical intervention, precluding actions that would result in adherence.

Knowledge and perception also appear to be closely related. Cummings, Becker, and Maile (1980) attempt to bring together most major models which explain health related actions. Variables from all models were partitioned on the basis of their structural similarities which were evaluated using Smallest Space Analysis. Items were clustered and placed close to other items of a similar or associated nature. Knowledge items were located in close proximity to items dealing with perception and evaluation of symptoms, leading to a speculation that an association

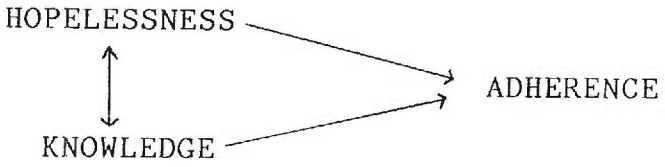
between these two groups may exist. Specific relationships between items or clusters were not examined. It is reasonable to assume that a person's thinking, perception, and actions are affected by knowledge as well as hopelessness and that decreased levels of knowledge may result in interference with adherence. High levels of knowledge, in effecting a person's thinking and perception, could expand rather than constrict perceived opportunities and may enhance a person's ability to follow through with goal-directed activity.

Increased levels of hopelessness may decrease motivation to attain and use knowledge, again, because of perceived constricted opportunities, and because of the negative bias in appraisal of events. According to cognitive theory, negative thoughts interfere with a person's ability to accurately perceive or to act upon incoming stimuli (Beck, Rush, & Shaw, 1980). Negative cognitions such as hopelessness lead to self-defeating behavior. For example, despite being given information regarding what steps to take to alleviate depression, a patient may not feel that he could successfully undertake such steps. If negative cognitive constructs interfere, patients may be convinced that corrective steps are not available to them, or that such steps are doomed to failure from the outset. A negative attitude toward the future may

lead to a decision not to try. Applying Beck's cognitive theory to the current study, the attitude of hopelessness can be perceived as undermining the potential benefits of knowledge about one's illness and medication, and perhaps influencing adherence.

Increased levels of knowledge may decrease hopelessness as it expands perceived opportunities (because the patient knows about them), and reduce the expectation of frustration in the future. Snygg and Combs (1949, p. 226) theorized that one way education (knowledge) promotes intelligent behavior is by removing psychological restraints (such as hopelessness). An inverse relationship may exist between hopelessness and knowledge.

Diagramatically, the relationship between the independent variables of hopelessness and knowledge and dependent variable of adherence may appear as follows:



The Research Questions

1. What is the nature of the relationship between hopelessness, and adherence to prescribed medication and follow-up appointment?

2. What is the nature of the relationship between knowledge of medications and illness, and adherence to prescribed medication and follow-up appointment?

3. What is the nature of the relationship between knowledge of medications and illness, and hopelessness?

Chapter II

Methods

This section describes the design, setting, subject selection, procedures, data-collection instruments, validity, protection of subjects, and analysis of the study. Within the section on data collection, the development of the instruments is discussed.

Design. A non-experimental, exploratory design was used in this study. The rationale for a non-experimental approach is that direct manipulation of the independent variables is not indicated during this early stage of research regarding these variables. Instead, levels of hopelessness and knowledge were measured in each subject and correlated with the dependent variable, adherence to follow-up care.

Setting. Selecting subjects from a wide array of hospitals and geographical locations would increase the generalizability of the findings but was impractical given the resource limitations of this study. It was feasible, however, to draw subjects from two inpatient facilities that are quite different in nature. Subjects were selected from the inpatient population at the psychiatric crisis unit of a large metropolitan teaching hospital and from the psychiatric unit of a medium sized general hospital in a community 100 miles away. The two nurse researchers met

with administrative personnel of the two units to describe the aim of the research and to gain support and approval for carrying out the research on the two units. An orientation program was conducted for unit staff to provide an explanation of the criteria for selection, what was to be measured, what impact this study might have on the patient, and potential benefits to be gained. In this way, staff members would have knowledge of what transpired between researchers and patients and why the researchers needed to have access to hospital records. Thrice weekly reviews of all inpatients on both units kept the researchers informed of potential subjects admitted into each unit.

The Hawthorne effect was controlled by having the nurse researchers select and approach potential subjects (instead of nursing staff), and by excluding patients for whom the nurse researchers provided care in the course of their employment. Experimenter effects were controlled by delayed scoring of the Hopelessness Scale and Knowledge Questionnaire until after the follow-up contact had occurred.

Subject Selection. A convenience sample was to be recruited until at least 30 subjects completed the study. No assumptions, such as normal distribution, may be made about this sample of chronically mentally ill individuals but a sample of greater than 30 was chosen so that the data

distribution will be closer to a normal curve (Williams, 1981, p. 262). Criteria for inclusion and rationale are as follows:

1. Subjects were 18 years of age or older with an upper age limit of 60. The lower age limit assured that the subject would be of legal age to consent while the upper age limit avoided skewing the results with data from subjects who may have been experiencing forgetfulness or other cognitive deficits.

2. Subjects were able to understand and have proficient verbal use of the English language. Neither researcher had the skill to conduct the study protocol in any other language. This criteria also eliminated those who were cognitively impaired to the point of being unable to give informed consent.

3. Subjects were able to sit and attend to the research protocol for a 20-minute period of time. This criteria was intended to help eliminate subjects who had a severe attention deficit and those who were not sufficiently recovered from their illness to keep their attention focused for the necessary length of time.

4. Subjects were hospitalized for at least 48 hours prior to discharge allowing time for some treatment to have occurred before they were approached by the nurse researchers.

5. Subjects were diagnosed as schizophrenic or as having a major affective disorder (American Psychiatric Association, 1980). Because chronic illness with repeated acute episodes make the issue of treatment adherence critical, the subjects were selected from the chronically mentally ill population. The above diagnoses are those identified by this state's Mental Health Division as being included in the category of chronic mental illness.

6. Subjects were discharged with a prescription for a neuroleptic medication, antidepressant medication, lithium carbonate and/or a side effect medication. These medications are the most frequently prescribed and commonly used for chronic mental illness.

7. Subjects had a follow-up appointment scheduled prior to hospital discharge or be willing and able to schedule his or her own appointment. The outcome variable was a measurement of adherence to medication prescription and to attendance at the first follow-up appointment, thus those conditions had to exist for subjects to be included.

8. Subjects who did not have telephones lived within a 10-mile radius of the city in which the hospital was located. This criteria would make home visits possible within the time limits specified in the protocol.

Procedures and data collection. Persons who met the selection criteria were identified as possible subjects by

the nurse researchers. One of the two nurse researchers then informed the subject about the study and invited his or her participation. Informed consent was obtained from each subject prior to the collection of data (see Appendix A). Subjects were to be interviewed no less than one hour and no more than 48 hours prior to discharge from the hospital and measures of hopelessness and knowledge were obtained. Since hopelessness and knowledge measurements were intended to be taken at "time of discharge," the upper limit of 48 hours was selected. The lower limit of one hour was necessary to eliminate the hurried or distracted responses which might have been obtained from subjects who were in the process of being discharged.

Each subject was contacted by telephone for the purpose of administration of the adherence questionnaire within five days following their scheduled follow-up appointment. For patients who were to be making their own follow-up appointments, an initial contact was made between the 10th and 15th post-hospital day. If the follow-up appointment had not occurred, the researcher asked when that appointment was to take place and recontacted the subject within five days following that time. If the subject had not called for an appointment by the 10th post-hospital day he or she was considered nonadherent for follow-up appointment. If the subject could not be reached by telephone, one attempt was

made to make a home visit. If the home visit was unsuccessful, adherence measures would not be collected on that subject. An appointment card with the time of the expected home visit was given to all subjects without telephones to increase the likelihood of successful home visits.

Demographic and identifying information was collected from the subject's medical record (Appendix B). Information such as name, address, and phone number was obtained to permit follow-up contact for the collection of information on the adherence portion of the study. Demographic variables of age, gender, race, employment status, and marital status helped describe the study sample, as did information about whether the patient was involuntary during his or her hospital stay, length of hospital stay, and whether the patient discontinued medication prior to hospital admission. Additional information obtained from the record included the diagnosis (to compare with the subject's knowledge of his or her diagnosis), medication at discharge (to compare with the subject's knowledge of his or her discharge medication) and follow-up appointment time and place (for purposes of measuring attendance adherence).

The hopelessness and knowledge questionnaires were read to each subject to allow subjects who have difficulty reading or writing to be included in the study. Verbal

administration of these questionnaires served several other purposes. Consistency between administration of the tools was obtained, as the adherence questionnaire must be read to the subject by telephone. The knowledge questionnaire was somewhat complicated for the average subject and he or she may have been helped by some verbal prompts from the researcher to understand what was being asked. It was thought that the intrusiveness inherent in the questionnaires might be reduced somewhat by allowing personal contact between researcher and subject for data collection. In addition, it was projected there would be fewer subjects "lost" due to subjects forgetting to fill out self-administered questionnaires and/or questionnaires getting lost or mislaid in the hospital.

Hopelessness, defined as a negative attitude towards future events, was measured using Beck's Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974) which was read to each subject. Their "true" and "false" responses were recorded and totaled. Each "true" response to a negative statement received one point while each "false" response to a positive statement received one point. Obtained scores had a potential range from zero for no hopelessness to 20 for the highest level of hopelessness (Appendix C).

Validity is the degree to which an instrument measures what it intends to measure. Beck, Weissman, Lester, and Trexler (1974) describe at length their attempts to establish validity during the development of the Hopelessness Scale by pretesting the instrument with depressed and nondepressed patients and obtaining feedback from them as well as from expert clinicians regarding the appropriateness of the selected items. The internal consistency of the scale measured by a coefficient alpha (KR-20) resulted in a reliability coefficient of .93. Concurrent validity was judged to be adequate by administering the Hopelessness Scale with another measure of hopelessness, the Stuart Future Test (α = .60, $p < .001$), as well as the pessimism item on the Beck Depression Inventory (α = .63, $p < .001$). Factor analysis revealed that the Hopelessness Scale measures three areas associated with negative expectations about the future. Those areas tapped by the Hopelessness Scale are affective, motivational, and cognitive in nature.

Reliability of the Hopelessness Scale in criminal (KR-20 = .83) and general (KR-20 = .86) psychiatric populations was supported, although when used in a college student sample, reliability is decreased (KR- 20 = .65) (Durham, 1982). In addition Durham found a restriction of range of hopelessness scores among the students. College students

had a mean hopelessness score of 2.32 (SD = 2.25) while the psychiatric subjects had a mean score of 6.04 (SD = 4.67). The difference in scores is significant ($F = 89.75$, $p < .001$), supporting the validity of the scale as psychiatric patients would be expected to have a higher degree of hopelessness. However, items 4, 5, and 13 show no differences in the percentage of college students and the percentage of psychiatric patients who responded in a hopeless manner, raising a question of the usefulness of the three items in assessing hopelessness. The questionable items in the Hopelessness Scale were included in this study. Inter-item correlations were used to assess the reliability of the Hopelessness Scale among the subjects tested.

The practicality of the Hopelessness Scale is high. It has only 20 items to be scored true or false. This gives a high degree of utility for research purposes. The time taken to administer the tool is approximately 10 minutes.

Measuring the variable of patient knowledge has been accomplished in nursing research primarily by one of two methods. In studies where teaching methods are being compared the subject is usually given a "test" both before and after the teaching program. The "tests" usually consist of true and false items or multiple choice items and are more objective in the sense that the responses are either right or wrong. The second method which has been used in

research to measure patient knowledge is the open-ended questionnaire. Using this format subjects have the opportunity to disclose what they know in their own words. If administered orally, the questionnaire enables a verbal exchange between the researcher and the subject allowing more subtle and less well-developed knowledge to be exposed and included in the data collection. The questionnaire, then, would be more effective at measuring the intended concept of knowledge but less efficient. Open-ended questionnaires have a drawback in that it is difficult to achieve consistency in scoring between raters.

No appropriate questionnaire to measure knowledge was found in the literature. Instruments used in previous studies were subjective, without explanations regarding how the researchers determined if answers were "right" or "wrong," or the instrument measured only knowledge of medication. The empirical study done by McCay (1984) indicated that knowledge of medication and knowledge of illness may change at different rates and under different circumstances. For this reason, measuring knowledge of medication and of illness was undertaken in this study.

The Knowledge Questionnaire (Appendix D) was developed by the nurse researchers to measure the subject's knowledge level regarding his or her illness and medication prior to hospital discharge. It is a combination of the two methods

most often used and just described. It is a "test" which has right and wrong answers yet provides the subject the opportunity to answer some of the questions in his or her own words. It is designed to be administered by the researcher and takes no more than 10 minutes to complete. Correct responses are outlined in the scoring key. Items for this questionnaire were selected after reviewing other nursing studies regarding medication adherence in the psychiatric patient. An attempt was made to measure those pieces of information that, if known, would assist the patient in managing his or her illness and would allow the patient to communicate clearly about his or her illness and treatment to health-care professionals. Pretesting of this instrument and its scoring method was done on five patients. Question 6 was found to be confusing and was revised for clarity.

Three practicing mental health nurses who have knowledge and experience with research were asked to review the Knowledge Questionnaire for face validity (Appendix E). As a result of this review, the numbering of the Knowledge Questionnaire was changed to provide greater clarity and ease in coding responses. In addition, question 7 was reworded to prevent overly general responses. Scores ranged from zero to 100% and it was expected that subjects' scores would vary widely within that range.

Hypothetically, a subject who received a score of 50% might have had responses like the following: He would believe that he has a mental illness and could identify the kind of illness he has. He would respond that, maybe, his illness is serious and that he would not be likely to have another episode of mental illness. He would know the name of one of his two prescribed medications and know the dose and schedule of only one of them. He would know what one medication was intended to do for him but would not be aware of any common side effects of either medication.

The Adherence Questionnaire, also developed by the nurse researchers, was used to collect information regarding the level of adherence (Appendix F). Subjects were telephoned at home for this interview, or, if there was no phone, one attempt was made to make a home visit for the interview. Adherence was measured by self-reported attendance at the initial outpatient appointment following hospital discharge and self reports regarding the frequency and accuracy in taking prescribed medications. No adequate means of measuring self reported adherence was found in the literature. Instruments reviewed generally allowed only dichotomous responses of adherence or non-adherence. The Adherence Questionnaire was developed by the researchers for this study to increase the range of responses by documenting partial adherence.

The Adherence Questionnaire was also subjected to review by the same practicing nurses as reviewed the Knowledge Questionnaire. As a result of their review, a question was added to the follow-up appointment section of that instrument.

Scores were expected to range from zero, reflecting no adherence, to 100%, reflecting perfect adherence. For example, a score of 50% might be representative of a patient who did not attend the follow-up appointment but did call to make another appointment and who takes one medication exactly as prescribed but does not take another medication at all. Scores reflecting less than complete adherence to the prescribed medication regimen may be a result of either an alteration in the frequency of taking the drug or an alteration in the amount of the drug taken. Adherence was given a range so that subjects who have partial adherence behavior could be documented as such, thus increasing the reliability of the findings.

Scoring of the Knowledge Questionnaire and the Adherence Questionnaire was not totally objective in that some judgments needed to be made by the researcher. Because the subject responds to items on these instruments in his or her own words, some discrepancy was expected as to what value the response might warrant. To increase interrater consistency, all instruments were scored independently by

one researcher and, then, independently by the other. Rules were developed to resolve any disagreements between researchers and were applied to all subjects' responses.

Validity. The internal validity of this study has to do with the extent to which the dependent variable, adherence, was actually correlated with the independent variables, levels of hopelessness, and knowledge (Polit & Hungler, 1983, p. 615). Competing variables were not controlled, rather they were examined and documented. Factors which may have led to increases in initial follow-up care and were addressed in the literature review include care-provider characteristics, client characteristics, and characteristics of the follow-up regimen. History and maturation effects were expected and not controlled. Since this study was non-experimental, information was gathered from each subject, to the extent that he or she was aware, regarding changes in himself or the environment that led to the adherence outcome. A selection threat existed in that all subjects were voluntary. The results of this study had to take into consideration the possibility that the patients who were willing to participate in the study might be those patients who were more likely to adhere to treatment regimens. It was not known whether there would be a "testing" threat to internal validity. It was possible that the initial measurements of hopelessness and knowledge

sensitized subjects to the issue of adherence. If so, it was hoped that the open-ended question at the conclusion of the study would document such effects. There was expected to be a loss of subjects between the time of discharge and the follow-up contact. Recruitment of subjects proceeded, however, until resources for this study were exhausted. Since data on adherence was not known on subjects who did not complete the study, these subjects were excluded from the correlational tests.

Protection of subjects. Subjects were assured confidentiality in that their primary health-care providers were not informed of the data collected. One exception was made clear to the subject at the outset in reviewing the consent form. If it was discovered in the course of the study, that the subject was in a potentially harmful situation, the appropriate agency and/or health care provider would be informed as quickly as the situation warranted. Both researchers were master's degree candidates in mental health nursing, each with a minimum of eight years experience working with mentally ill individuals, and were qualified to judge the seriousness of the situation.

There was no personal gain for the subjects in this study and that fact was made clear at the time of informed consent (Appendix A). The knowledge gained as a result of

this study may benefit psychiatric patients in the future and mental health professionals who provide for their care.

The risk to the subjects was minimal in that nothing was manipulated in their care. There was an element of invasion when subjects were contacted at home for data collection. Subjects were informed of this potential breach of privacy prior to consenting to participate. In order to make follow-up contact possible the subject's identity remained with the data until follow-up contact had been completed. At that point each subject was assigned a code number and personal identity was removed from the records.

Analysis. Frequency distributions were computed for all variables. Pearson's correlation coefficient was used to examine the strength of the relationship between hopelessness and knowledge levels, as well as between knowledge and adherence levels. The eta coefficient was used to determine if the relationship between hopelessness and adherence was curvilinear as expected (Phillips, 1978, p. 59). The internal consistency reliability of measures of hopelessness, knowledge, and adherence were examined using Cronbach's alpha. Scattergrams were constructed to provide a visual depiction of the relationship between pairs of the three variables of interest in the study.

Chapter III

Results

The results of the data analysis are presented in this section. First, the sample characteristics will be described. Data analysis will then be presented for each of the research questions. Findings regarding the measurement instruments will be discussed including internal consistency reliability tests on the Hopelessness Scale, Knowledge Questionnaire, and Adherence Questionnaire. Finally, other findings are presented which are not specifically related to the research questions.

Sample Characteristics

Subjects were selected from the chronically mentally ill population hospitalized on one of two inpatient psychiatric units; one in a metropolitan teaching hospital and the other in a community hospital. Data collection was conducted over a five-month period of time, during which approximately 80 potential subjects were identified. Of those 80, only 19 subjects completed the study. Reasons for which patients were not included are as follows:

1. Patient refusal by those voicing fear of the consent form and/or fear of participation.

2. Patient refusal by those practicing newly learned assertiveness skills, learning to say "no."

3. Patients who were transferred to another treatment facility rather than discharged.

4. Patients who were discharged to court for a commitment hearing.

5. Patients who were rapidly discharged.

6. Patient unapproachability due to high levels of dangerousness.

7. Physician refusal to have his/her patients included.

8. Inability to locate subjects for the follow-up portion of the study.

These factors will be more fully discussed in the following chapter.

The sample consisted of 19 subjects distributed almost equally between the metropolitan teaching hospital and the community hospital. The majority of the subjects were male, unemployed, and single with a diagnosis of schizophrenia. Their ages ranged from 20 to 57 with a mean age of 36.

Table 1 displays the demographic variables of the sample by location while Table 2 displays the descriptive variables of the sample by location. Although demographic variables are similar, it is interesting to note the differences in the descriptive characteristics between patients in the two hospital settings. The metropolitan teaching psychiatric unit had subjects who had a shorter

Table 1

Demographic Variables by Location

Characteristic	Metropolitan Hospital (n = 10)	Community Hospital (n = 9)	Total (n = 19)
Location of Subjects	53%	47%	100%
Age - Years			
Range	25-57	20-53	20-57
Mean	35	37	36
Gender			
Males	70%	67%	68%
Females	30%	33%	32%
Employment Status			
Part time	30%	11%	21%
Unemployed	70%	67%	68%
Homemaker	0%	22%	11%
Marital Status			
Married	10%	11%	10%
Divorced	30%	33%	32%
Single	60%	56%	58%

Table 2

Demographic Variables by Location

Characteristic	Metropolitan Hospital (n = 10)	Community Hospital (n = 9)	Total (n = 19)
Length of Hospital Stay - Days			
Range	3-15	7-33	3-33
Mean	9.6	19.3	14.2
Involuntary Status[a]	60%	11%	37%
Stopped Medication before Hospitalization			
Yes	90%	22%	58.0%
Partially	0%	22%	10.5%
No	10%	33%	21.0%
Not Applicable	0%	22%	10.5%
Diagnosis			
Bipolar	20%	44%	31.0%
Depression	20%	11%	16.0%
Schizophrenia	40%	44%	42.0%
Schizoaffective	20%	0%	10.0%
Medication Regimen at Discharge			
Lithium only	20%	0%	10.5%
Neuroleptic only	10%	33%	21.0%
Antidepressant only	20%	0%	10.5%
Side effect med. only	0%	0%	0.0%
Combination	50%	67%	58.0%

[a]Percent of subjects who were involuntary sometime during the hospital stay under study.

hospital stay, were more likely to have been hospitalized against their will and to have stopped taking psychotropic medication prior to hospital admission. Even though there were some differences between subjects from the two settings, subjects from both settings were combined for data analysis to form a more heterogeneous sample. The groups are displayed separately in the tables for the interest of the reader only.

In the sample as a whole, over one-third of the subjects were hospitalized on an involuntary status at some time during the hospital stay examined in this study. Since adherence to medication prescription after hospital discharge was a variable to be studied in this project, information was collected regarding whether the subject had been non-adherent with medication prior to the hospital stay under study. Two-thirds of the subjects had either completely stopped taking medication or were partially non-adherent prior to this hospitalization. Because complex medication regimens are suggested in the literature to be related to poor adherence to medication-taking behavior, data were collected regarding the number of medications prescribed upon hospital discharge. The majority of subjects had complex medication regimens, with multiple rather than single medications being prescribed at the time of hospital discharge.

Research Questions

As indicated, this study examined three research questions. The first research question asks: What is the nature of the relationship between hopelessness and adherence to prescribed medication and follow-up appointment? In order to examine the relationship between hopelessness and adherence the subjects completed the Hopelessness Scale while hospitalized. Items on the Adherence Questionnaire were determined by the researcher during a telephone or face-to-face interview following hospital discharge. These scores were examined on a scatterplot and are displayed in Figure 1. Visually, there did not appear to be a relationship between these two variables in this sample. Conceptually, it was reasonable to believe that a curvilinear relationship might be present. Therefore, to empirically test for a correlation between hopelessness and adherence, an eta correlation was selected. The eta correlation does not require that the relationship between two variables be linear (Glass & Hopkins, 1984, p. 84). When subjects' scores on the Hopelessness Scale were correlated with their scores on the Adherence Questionnaire, no significant relationship was found (*eta* = .14, *p* = .11).

Research question two asks: What is the nature of the relationship between knowledge of medication and illness, and adherence to prescribed medication and follow-up

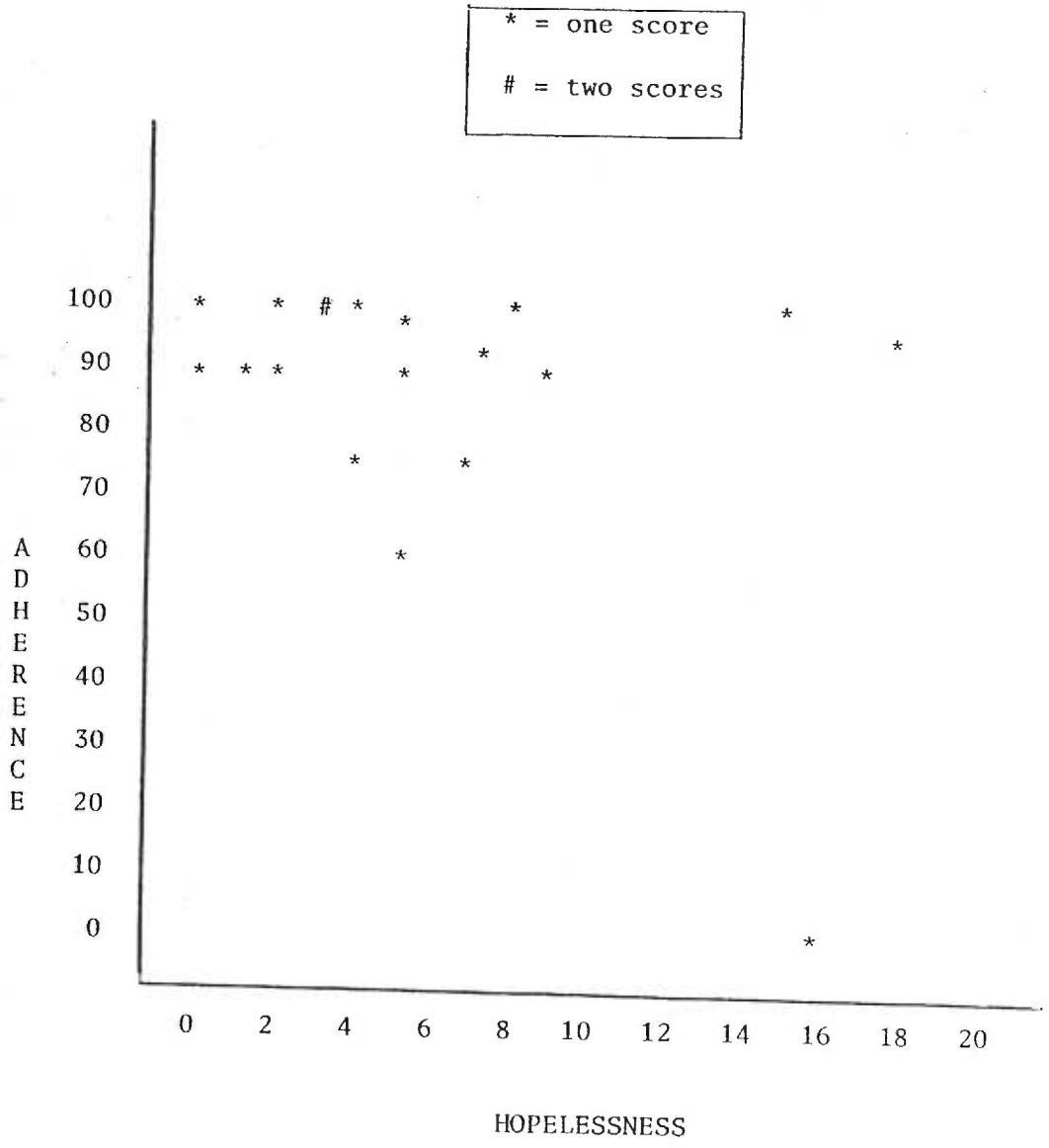


Figure 1. Correlation of Hopelessness and Adherence scores.

appointment? In order to examine the relationship between knowledge and adherence, responses to items on the Knowledge Questionnaire were obtained from each subject prior to hospital discharge. Adherence scores were determined during a post-discharge interview. Scores on the Knowledge Questionnaire and scores on the Adherence Questionnaire were spread on a scatterplot (Figure 2). The scatterplot did not appear to support a relationship between knowledge and adherence. A Pearson's coefficient was calculated to test for a correlation between knowledge and adherence. No significant relationship was found (r = .19, p = .42).

The third research question was: What is the nature of the relationship between knowledge of medications and illness, and hopelessness? To answer this question, again a scatterplot was constructed using the scores on the Knowledge Questionnaire and the Hopelessness Scale (Figure 3). The scatterplot was not supportive of a relationship between these two variables. To test for correlation, a Pearson's correlation coefficient was applied to this data. No significant relationship was found (r = .28, p = .24).

Measurement Instruments

This section will report the obtained scores on all three variables of this study: hopelessness, knowledge, and adherence. Internal consistency reliability was examined for the Hopelessness Scale, the Knowledge Questionnaire, and

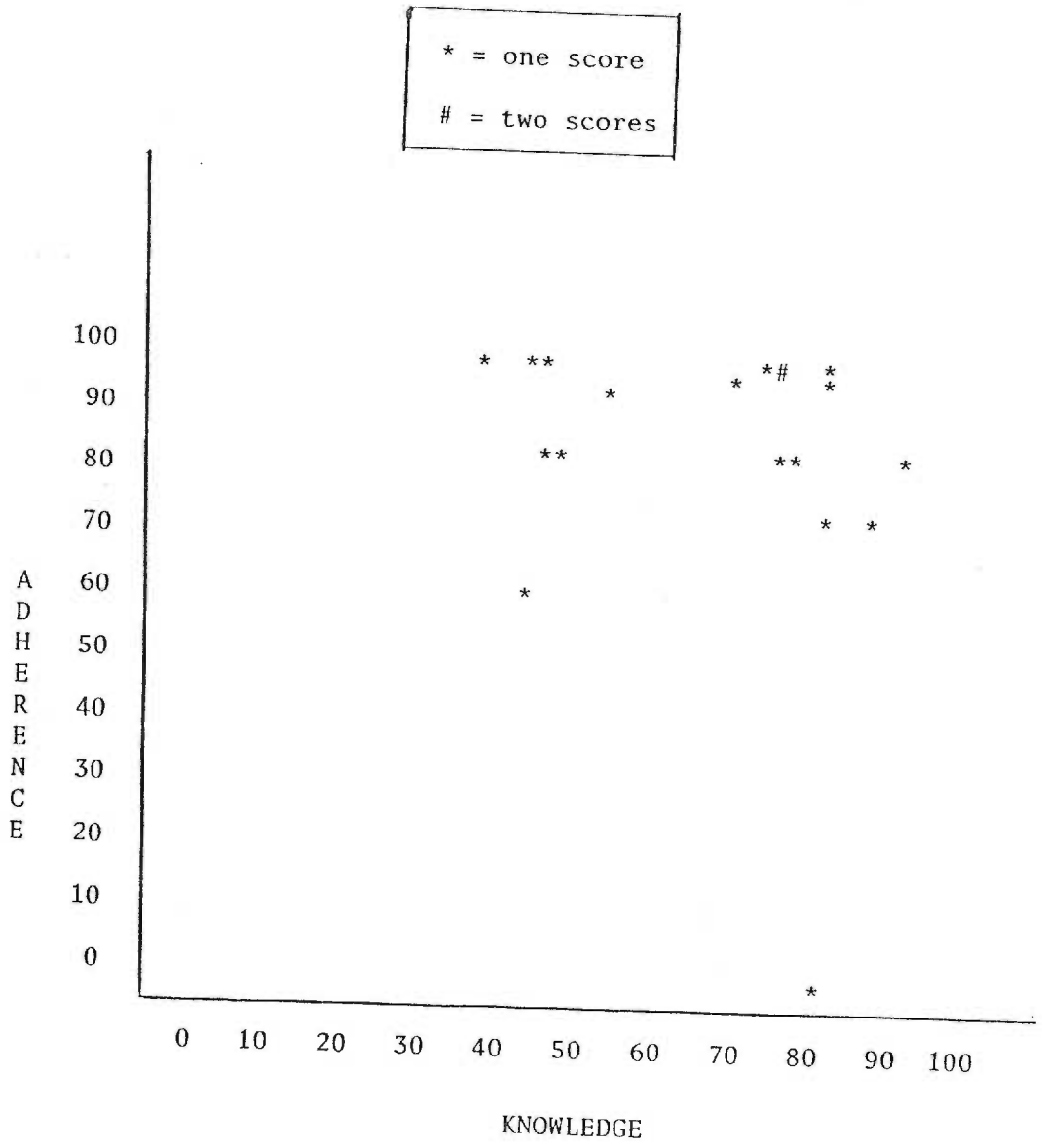


Figure 2. Correlation of Knowledge and Adherence scores.

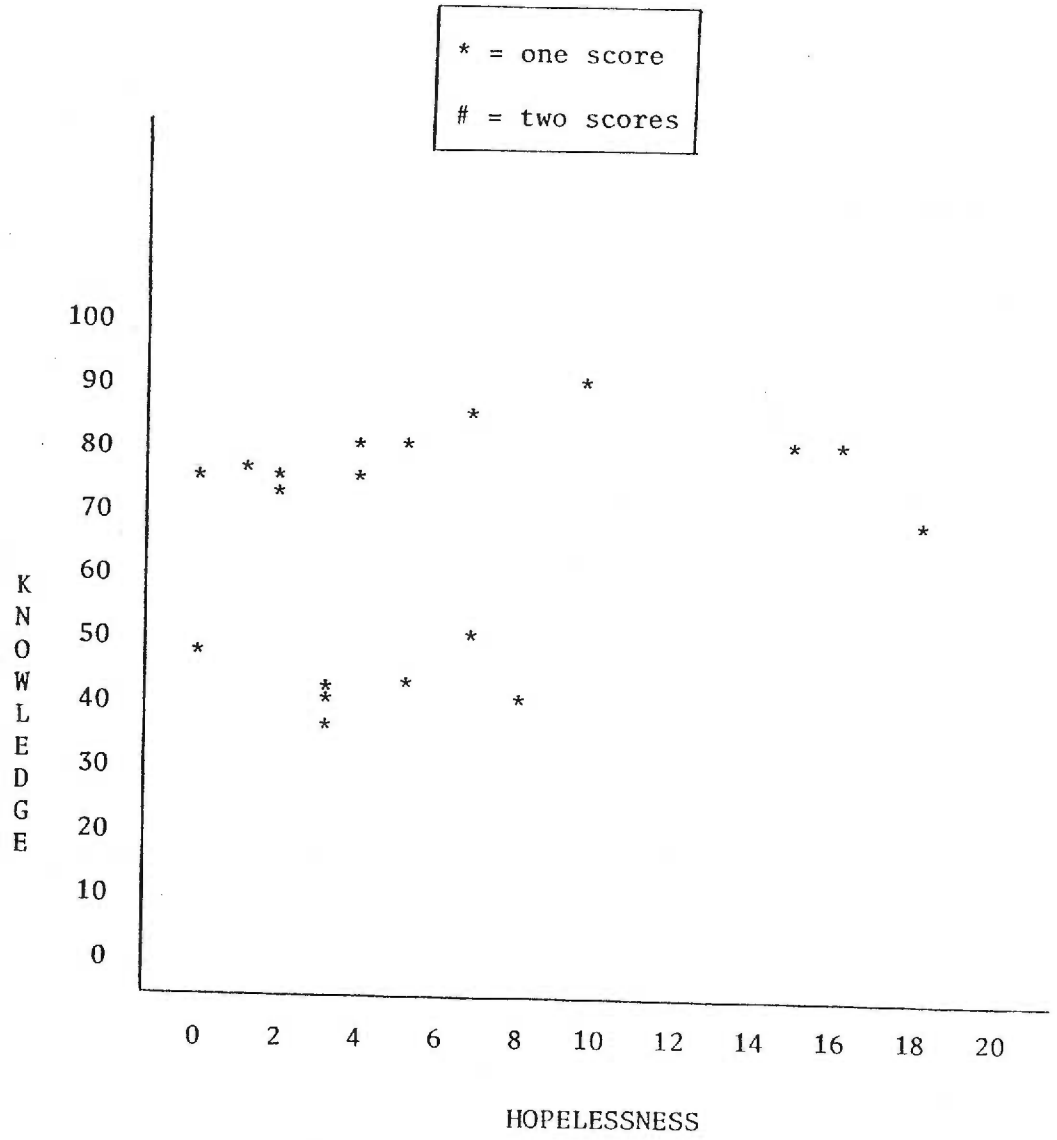


Figure 3. Correlation of Hopelessness and Knowledge scores.

the Adherence Questionnaire to determine their acceptability in measuring the concepts they were intended to measure. According to Polit and Hungler (1983, p. 393), an inter-item correlation of .60 or .70 is sufficient for general purposes such as comparing scores between groups. If decisions are to be made about an individual based on the score on an instrument, the inter-item correlation of the instrument needs to be .90 or higher.

Hopelessness. The Hopelessness Scale is a well-established tool which has 20 true/false items. A wide range of scores was obtained on the Hopelessness Scale. Out of a possible 0-20 points, the range was 0-18, with a mean of 6.00 (s.d. 5.37). This approximated the mean of 6.04 (s.d. 4.67) found among psychiatric subjects in prior testing of the instrument (Durham, 1982).

The alpha reliability of the Hopelessness Scale for this sample was .90, indicating a high correlation between the individual items on the scale. The item that correlated the least with other items in the scale was number 9, "I just don't get the breaks, and there's no reason to believe I will in the future." This item had an item-scale correlation of .05. If Item 9 were deleted, the alpha coefficient would increase very slightly to .91. Such a small increment does not warrant omission of the item from the scale. Three other items, numbers 3, 5, and 10 had

item-scale correlations that were less than .30. The deletions of these three items from the scale would produce even smaller increases in the reliability coefficient. Based on these data a decision was made to retain all items of the Hopelessness Scale for the analysis in this study.

Although no evidence was found to support the existence of a curvilinear relationship between hopelessness and adherence, some interesting findings were revealed in the use of this measure. As stated, the deletion of Item 9 would slightly increase the reliability of the instrument. This finding was not substantiated on past reliability testing (Durham, 1982). The item that did appear slightly questionable in terms of reliability in both previously published research and the current study was Item 5, "I have enough time to accomplish the things I most want to do." This item taps future time perspective as well as perceived goal setting and obtaining ability. Both are important in the concept of hopelessness, and for that reason should not be excluded from the scale. However, perhaps rewording the item, or having the item focus on a single rather than multiple dimensions of the concept would be beneficial in both clarity of the question and a higher reliability of the item. The previous researchers have commented that the phrase "enough time" may be an age-related rather than an attitude-related response.

Knowledge. The Knowledge Questionnaire consisted of eight items, four designed to measure knowledge of illness, and four designed to measure knowledge of prescribed medication. Scores on the Knowledge Questionnaire had a potential range of 0-100. In the study, subjects scored from 40.6 to 90.6 with a mean score of 66.2 (s.d. 18).

The internal consistency of the Knowledge Questionnaire using the alpha coefficient was computed to be .43. This instrument was developed to measure two aspects of knowledge, knowledge regarding illness and knowledge regarding prescribed medication. Therefore, the alpha coefficient would be expected to be lower than the standard of .70. No attempts were made to improve the internal consistency of this measure before analysis, thus the analysis was done using scores on all eight items of this scale. The Knowledge Questionnaire will be discussed further in the discussion chapter.

Adherence. The Adherence Questionnaire which contained only two quantitative items had an alpha coefficient of .81, indicating that subjects who attended their follow-up appointment also tended to adhere to their medication regimen. Scores on the adherence measure (with a possible range of 0-100) ranged, in the study, from 0 (total lack of adherence) to 100 (perfect adherence). Subjects' scores were high, with a mean of 86. There was one subject who

scored zero on this measure and if that score were disregarded, all subject scores would have been above 60.

The subject who scored zero on adherence behaviors was a middle aged unemployed single male, with a diagnosis of depression and suicide attempt. He had been admitted on a court hold against his stated will, and had stopped taking prescribed antidepressants prior to entering the hospital because "someone stole them." He lived alone in a hotel in a large metropolitan area. His knowledge score was relatively high (81.25), and he had a high hopelessness score of 16. His reason for not following through on either taking medication or attending his follow-up appointment was, "It never did me no good anyway."

Qualitative data were collected to discern reasons subjects had for adhering or not adhering to the prescribed treatment regimen. These data reveal multiple reasons cited for not adhering to medication regimens. One subject did not take a prescribed minor tranquilizer out of fear of its addictive potential. One subject admitted to forgetting occasional doses of lithium. Some stopped all medication due to side effects, or to the feeling that, "I'm too wise to listen to the doctors." One subject stopped his medication for several of the reasons cited above. Some subjects reported taking medications as prescribed, with a family member assisting, or no longer forgetting doses since

the schedule had been changed to once daily. One subject increased his dose of neuroleptic medication on days that he went to work.

Additional Findings

There were two interesting and unanticipated findings that emerged during data analysis. The first finding was a group of seven subjects who had significantly lower knowledge scores on the Knowledge Questionnaire. They were identified on both scatterplots which included knowledge scores. The other finding involved a large group of subjects who could not be located for the administration of adherence measures and who had significantly higher hopelessness scores. Information regarding these two groups are presented in this section.

Since the seven subjects with low knowledge scores were set apart from the other subjects in a noticeable manner on the scatterplots, all known characteristics of this group were identified and compared to characteristics of the remaining subjects (Table 3). The subjects with low knowledge scores had a mean knowledge score of 43.75 while the remaining subjects had a mean knowledge score of 78.91 ($t = -10.76$, $p < .001$). Other characteristics which seemed to be different from those of the rest of the subjects were a larger percentage of males, a longer hospital stay, a larger percentage of subjects who were involuntary patients

Table 3

Variables of Low Knowledge Sub-Group

Variable	Subjects with Low Knowledge Scores (n = 7)	All Others in Sample (n = 12)	Test	Significance
Age, Mean (years)	32	38	t = -1.090	ns
Gender - Male	6 (86%)	7 (58%)	X^2 = 2.29	ns
Length of Stay in Days, Mean	16.7	12.7	t = 1.079	ns
Location - Metropolitan Hospital	4 (57%)	6 (50%)	X^2 = .076	ns
Unemployed	5 (71%)	8 (67%)	X^2 = .035	ns
Marital Status - Single	4 (57%)	7 (58%)	X^2 = .0006	ns
Involuntary	3 (43%)	4 (33%)	X^2 = .151	ns
Not taking medication w/admitted	5 (71%)[a]	7 (58%)	X^2 = .297	ns
Diagnosis - Schizophrenia	5 (71%)	3 (25%)	X^2 = 3.810	ns
Combination of Medication Prescribed at Discharge	5 (71%)	6 (50%)	X^2 = .787	ns
Hopelessness Score, Mean	4.43	6.92	t = .994	ns
Knowledge Score, Mean	43.75	78.91	t = -10.76	$p < .001$
Adherence Score, Mean	90.21	83.79	t = .566	ns

[a]The other two subjects in the Low Knowledge subgroup did not have any medication prescribed.

sometime during the hospitalization under study, more subjects who had discontinued taking prescribed medication prior to hospital admission, more subjects diagnosed schizophrenic, more subjects who had combinations of medications prescribed at time of hospital discharge, lower mean hopelessness score, and higher mean adherence score. Tests were applied to compare differences between characteristics of the subjects with low knowledge scores and those of the remaining subjects. Although no significant differences were found, the subjects with low knowledge scores were much more likely ($\underline{x}^2 = 3.81$, df = 1) to have a diagnosis of schizophrenia than were those with high knowledge scores. The number of subjects in the study and the number with low knowledge scores were small which made reaching a level of significance difficult. Had the sample size been larger, significant differences between the groups may have been realized.

The second unexpected finding involved a group of subjects who agreed to be in the study but were unable to be contacted for the administration of the Adherence Questionnaire. Nine such subjects were from the metropolitan teaching hospital, and one was from the community hospital. In attempting to locate the subjects, it was found that some had given the researcher a temporary respite hotel or other emergency shelter as a place of

residence. By the time of their initial follow-up appointment, they were no longer living in the emergency housing, and no forwarding address or telephone number was available. Attempts at contacting other of these subjects revealed disconnected or wrong telephone numbers.

The ten subjects who were lost to follow-up had significantly higher hopelessness scores than those who completed the study (Table 4). It would seem that a higher hopelessness score in the lost-to-follow-up group may be related to a group characteristic of transience. Another possibility is that of a response set bias in the direction of negativity on the scale, which would result in a higher hopelessness score.

Because data is not available for follow-up on this group of subjects, only a tentative statement can be made about the relationship between a higher hopelessness rating and adherence to follow-up care. However, the finding that a higher hopelessness score exists in those who are lost to follow-up deserves further study.

Table 4

Hopelessness Scores

	Range	Mean	Standard Deviation
Subjects who completed the study (n = 19)	1-18	5.9	±5.37
Subjects who did not complete the study (n =10)	6-19	12.8	±4.34

t = 1.806, 27 df; $p < .05$

Chapter IV

Discussion

The purpose of this project was to examine the relationships between the chronically mentally ill patient's level of hopelessness, knowledge regarding his or her illness and medication, and adherence behaviors following hospital discharge. This section discusses the sample and research questions and offers possible explanations for the results.

The Sample

The sample for this study was smaller than intended due to difficulties in obtaining subjects, therefore, this section elaborates on those difficulties encountered in both research locations. In addition, difficulties due to the type of subject sought are identified. Finally, the selection bias in this study will be explored.

Several factors led to difficulties in obtaining subjects for the study. In both settings it was difficult to obtain subjects with paranoid disorders. Although exact numbers are not known, some subjects with a diagnosed paranoid disorder, such as paranoid schizophrenia, refused to participate in the study. Some were ambivalent, but declined when the consent form was reviewed, due to a pervasive suspiciousness that could not be alleviated with explanations from the researcher. One such subject

consented, but when the home visit to complete the follow-up questionnaire was attempted, she refused to answer the door. The apartment manager where the subject lived informed the researcher that the subject was indeed home, had just obtained an additional PRN dose of medication for anxiety, and had retreated into her apartment. A note left by the researcher requesting either an alternate appointment date or a phone contact with the subject elicited no response.

The group of subjects that were not located for follow-up appears to represent a transient population, with no correct address or current phone number upon hospital discharge. The resulting elimination from the study of this segment of the psychiatric population is critical and supports the supposition that the remaining sample of subjects may not be representative of the chronically mentally ill population.

In the community hospital, the largest impediment to obtaining subjects was the sudden discharge of many potential subjects. A decision to discharge the patient would be made, and was often accomplished within 30 to 60 minutes. Although absolute data were not collected regarding this group, it is estimated that nearly half of the patients who met the criteria for inclusion in the study were not included because of rapid hospital discharge.

Another impediment to subject participation which occurred in the community hospital was the refusal of physicians to allow their patients to be approached by the researcher. It is estimated that approximately 15% of patients who were appropriate for the study were not included for this reason. This was not a problem in the metropolitan teaching hospital where both nursing and medical staff were supportive of nursing research.

An additional factor that was unanticipated by the researchers contributed to the probable selection of an unrepresentative sample. An unknown number of potential subjects who met the criteria for inclusion in the study were not approached by the researchers due to exhibiting behavior that was deemed too hostile, threatening or dangerous to approach. Such potential subjects typically spent their hospital stay confined to a security room due to their violent behavior, did not improve significantly, and were often discharged directly to court for commitment hearings.

The time taken to gather data was unexpectedly long, despite the estimate generated during pretesting procedures. A total of 19 subjects rather than the planned minimum of 30 was obtained during the data-collection period. Nineteen subjects is an inadequate sample size to approximate a normal distribution among the population under study. What

remained for the purpose of testing the research questions represents a small sample that may not represent the population of chronically mentally ill individuals and has a skewed range of adherence scores. The lack of statistically significant findings from such a sample is therefore inconclusive.

Research Questions

Discussion of research question 1.

The research question regarding the relationship between hopelessness and adherence was based on a review of literature that suggested a curvilinear relationship. A correlation was not supported in this study, but based on a small and apparently nonrepresentative sample, the possibility of a curvilinear relationship can neither be supported or refuted.

Previous analysis regarding the Hopelessness Scale support that its internal consistency as an instrument is high. Findings from this study as well as findings from previous studies demonstrate that the reliability surpasses the criteria needed for utilization for research purposes. The instrument could be used clinically in assessing levels of hopelessness among psychiatric patients.

Low variability in scores on the Adherence Questionnaire may be partly responsible for the lack of a significant relationship between hopelessness and adherence. The Adherence Questionnaire measured adherence only for the

period of time between hospital discharge and the first follow-up appointment. It is reasonable to believe that patients might be more likely to follow the prescribed regimen initially, and then have increased difficulty adhering to the regimen as time passes. Therefore measuring adherence over a longer period of time may produce a wider range of responses.

It is also possible that subjects were not truthful in their responses, wishing to be perceived as "good" patients. In this project, the researchers sensed that one area in particular may have been susceptable to response bias. When the researcher interviewed the subjects by telephone and asked the subject, "What medications are you taking, and how are you taking them?" the responses were occasionally somewhat rote, with the subject seemingly reading the labels of his medication bottles or reaching into his memory to recall how the medicine was supposed to be taken. The researchers suggest that future use of this instrument include the item "About how often did you miss a dose of medication?" In this way, the researcher might receive a more accurate report of medication-taking behavior.

A third explanation for the high level of adherence found in this study sample has to do with the sample selection. Subjects who were approached for inclusion and agreed to participate may also be those subjects who would

follow treatment regimens more faithfully. Subjects who were not approached (those who were too dangerous or did not meet selection criteria) or those who refused to participate and who were possibly more paranoid may have had lower adherence rates had they been measured.

Discussion of research question 2. The analysis of the data did not support a relationship between knowledge and adherence in this study. The literature suggests many variables which may influence an individual's ability and/or willingness to adhere to the prescribed treatment regimen. It is also reasonable to believe that a variety of variables would influence a person's ability to access, retain, and use knowledge. Since both are complex concepts, a single measure does not reliably tap the various aspects. For example, it is not known whether schizophrenia affects an individual's ability to make use of knowledge. Data regarding the subjects who had low knowledge scores in this study is suggestive of a difference between knowledge levels among schizophrenics compared to those with other diagnoses, even though the differences failed to reach a significant level.

The small sample size in this study with its high mean adherence level, shed very little light on the possible relationship between knowledge and adherence. A larger

sample or adherence measured over time might have produced more meaningful results.

Both of the instruments used to answer this research question were created specifically for this study. Thus they have not undergone empirical testing for validity, except for that which was done in conjunction with this study. The ability of the tools to measure that which they were intended to measure is untested. It is unknown whether the Knowledge Questionnaire taps into the specific information that would help a patient make adherence enhancing decisions. The degree to which the Adherence Questionnaire actually measures accurate adherence is also unknown. Therefore, the results of the analysis regarding this research question are inconclusive.

Discussion of research question 3. A relationship between hopelessness and knowledge was not supported in the data analysis. The data regarding these variables is, perhaps, the most reliable due to the acceptable range of scores on both variables and the fact that the Hopelessness Scale is a well established and reliable tool. Doubt remains, however, regarding the untested Knowledge Questionnaire. Results are also less reliable due to the small size of the sample of subjects who may not be representative of all chronically mentally ill individuals.

Since knowledge is a complex variable, the different aspects of knowledge should be addressed. For example, it is unknown whether hopelessness may influence the ability of one to access resources of information, or may affect the ability of one to recall information. Hopelessness may even affect some aspect of knowledge currently unrecognized.

Chapter V

Summary and Conclusions

This chapter will summarize the study. Limitations will be reviewed and implications of the findings for nursing practice and future research will be presented.

Summary

Patient adherence to prescribed treatment regimens following hospital discharge is a critical problem among the chronically mentally ill. One variable which was thought to influence levels of adherence was hopelessness. Another variable which seemed to be related to adherence was the patient's knowledge regarding his or her illness and prescribed medication.

This study was undertaken in an effort to further explore the relationships between hopelessness and adherence, and knowledge and adherence. Through an exploratory design hopelessness and knowledge were measured on chronically mentally ill subjects who were hospitalized. Demographic and descriptive variables were also collected. The subjects were then contacted after hospital discharge and measurements were taken of their adherence to prescribed treatment. Hopelessness was measured using Beck's Hopelessness Scale. Knowledge and adherence were measured with instruments developed by the researchers for that purpose. Correlational tests were then applied to the data.

The data analysis did not support a significant relationship between any of the major variables. Small sample size and high levels of adherence in this sample are possible explanations for the results. It appears as though the sample selection criteria and self-exclusion possibilities may have biased the sample in the direction of those who might be more likely to adhere.

An intriguing group of seven subjects was identified who had low knowledge scores. Demographic and descriptive data of this subgroup were examined and compared to the entire sample. The diagnosis of schizophrenia emerged as a variable that may be related to low knowledge levels.

A group of 10 subjects did not complete the study because the researchers could not locate them for the follow-up interview. This group's mean hopelessness score was significantly higher than those who completed the study. These subjects appeared to be transient and may represent the homeless mentally ill.

The instruments used in this study were examined for reliability. One item on the Hopelessness Scale appeared to be ambiguous, as it had in previous studies, and rewording the item is suggested. Reliability of the Knowledge Questionnaire could be increased by considering knowledge as an adherence enhancer and altering those items which do not seem to enhance adherence. The Adherence Questionnaire

seemed to have a weakness in supporting a positive response bias. Suggestions for altering that portion of the Adherence Questionnaire are made.

Limitations of the Study

There are a number of limitations that affect the generalizability of the findings from this study. The small size of the sample limits the variability of scores and reduces the likelihood that this sample is representative of the chronically mentally ill population intended for this study. Some paranoid patients refused participation, and many homeless and severely ill subjects were lost to follow-up. Several patients were not approached for inclusion because their physicians would not allow it. Many potential subjects were lost because of precipitous discharge from the hospital or because they were considered too dangerous to approach for inclusion.

Another limitation is the result of using newly developed instruments to measure knowledge and adherence. Reliability and validity of these instruments has not been investigated thoroughly. Finally, an aspect of the design which limits interpretation of the findings is the short time during which adherence was measured. Studying adherence over a longer time would likely give more meaningful results.

Recommendations for Future Research

Although the expected outcomes were not obtained in this study, there remains several areas of potential utility of the findings in the area of future research. Replication of this study with a larger sample size would yield results that would more closely approximate a representative sample of the chronically mentally ill population found in hospital settings. Replication of the study with a large sample would lend more credibility to the findings, whether in the direction of support or nonsupport of the existence of relationships between the major variables.

One of the unexpected outcomes of the study was the identification of a particular group of subjects who were not available for follow-up interviews. It has been suggested that this group may suffer from more severe symptoms of illness, from a transient lifestyle, or both. The currently well-publicized crisis of homelessness among the mentally ill deserves further study. This will present a challenge to future researchers, since the current study indicates that a prospective study design is impractical and exceedingly difficult with this select group of subjects. Although speculative in nature, the finding of a high hopelessness score in this lost-to-follow-up group raises the question of a possible correlation between hopelessness and homelessness.

It has been suggested in previous research that hopelessness correlates more directly with suicide than does depression. To continue in a speculative vein, perhaps the risk of suicide is greater in those with more acute illness and/or patients who are homeless. Such questions merit further study by nurse researchers.

Those patients who refused to participate in even the preliminary data collection present an interesting problem. One suggestion for future research is to examine the extent to which patients with paranoid disorders contribute to the revolving door syndrome that is frustrating to caregivers and that led to the development of this study. Partial exclusion of this portion of the population from this study by means of self-selection (or self-exclusion) would indicate that a less intrusive means of collecting data than a formal interview or questionnaire should be considered.

The unanticipated discovery of a cluster of subjects with low knowledge scores merits further study. Further exploration of the characteristics of this group may enable nurses to more easily identify patients who may be at risk for more severe complications of illness arising out of a lack of knowledge. The diagnosis of schizophrenia may, in some way, be related to accessing or using knowledge and warrants further study.

The development of instruments to measure knowledge and adherence are valuable outcomes of this study, and invite further research. The Knowledge Questionnaire explores areas of illness and medication, and gives results that have a broad range. Attempts to refine the definition of knowledge as it relates to adherence presents a research challenge. If improved, this instrument could be used by nurses in a variety of specialty areas for future research.

The Adherence Questionnaire is the only one known to the researchers that allows a range of possible scores. The inclusion of partial adherence in the outcome score increases the range of scores and, therefore, the reliability of the scale. Testing the reliability of self-reported adherence would clarify the value of this instrument for further research. The inclusion of an additional question directly addressing the topic of missed doses of medication may elicit more specific and truthful responses from patients. Another area for possible research is to follow patients over a longer period of time, beyond the initial outpatient appointment. This would increase the validity of the instrument by more accurately reflecting changes in adherence behaviors as they occur over time. In addition, the relationship between adherence to initial appointments and subsequent appointments could be examined.

Despite the lack of significant relationships between the major variables and limitations of this study, the study has value in suggesting several areas of future research. Development of both the Knowledge Questionnaire and the Adherence Questionnaire might add to the pool of reliable instruments available to measure concepts critical to the practice of nursing. Difficulties in obtaining fearful clients as subjects decreased the representativeness of the sample but clarified areas that need to be addressed in future research with this population. Finally, the concepts of hopelessness and the homeless mentally ill, and knowledge among those with diagnoses of schizophrenia warrant special research attention.

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Appendix A

Oregon Health Sciences University

Consent to be a Research Subject

Nurse researchers, Nancy Sulliger and Leslie Myers, are doing a study called Relationship Between Knowledge, Hopelessness, and Adherence to Prescribed Regimens in Psychiatric Patients. The study is to help nurses learn more about what helps a patient to follow through with treatment after they are discharged from the hospital. Because I am an adult on a psychiatric unit, and because I will have certain medicine to take after I leave the hospital, I am being invited to be a subject in the study. If I agree to be in the study, the following will happen:

1. One of the nurse researchers will ask me a list of questions about my hospitalization and about the medicine I take. The time needed for talking with the nurse is about 20 minutes.

2. The answers I give will be used in the study, but will not be identified as mine. When the results of the study are written, nobody will know my name or how I answered the questions. The only time my answers will not be confidential is if the nurse researcher believes that I am in a potentially harmful situation, in which case, she will notify the appropriate professional person or agency.

3. The nurse that asks me the questions will call me after I leave the hospital and will ask me some questions that will take about five minutes to answer. If I do not have a telephone, one of the nurse researchers will come to my home to ask the questions.

4. There are no expected risks to me if I agree to be in the study. Some people, however, may feel uncomfortable talking about their feelings or about why they are in the hospital.

5. There will be no cost to me or direct benefit to me from being in the study. Nurses may learn more about patients' feelings, and about what patients know about illness and medication. Patients in the future may benefit from this study.

6. I can choose whether or not I want to be a part of the nursing study. I may also withdraw from the study at any time. My choosing not to participate in the study will in no way influence the treatment I receive at this hospital. If I do not want to continue in the study, I should tell one of the nurse researchers. I will then be dropped from the study and will be contacted no more.

7. I will receive a copy of this consent form.

> The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call Dr. Michael Baird, M.D., at (503) 225-8014.

I have had my questions answered about this study. I have read this consent form and agree to participate in this study.

Date	Subject's Signature
Date	Witness

Appendix B

Demographics and Identifying Information

Subject's Name_____ I.D.#_____

Address (and Directions)_____

_____

Phone_____ Message Phone_____

Age_____ Gender: M F Length of Stay_____ days

Location: Portland Area Hospital Eugene Area Hospital

Employment Status: Full time Part time Unemployed

Homemaker Other

Marital Status: Married Divorced Widowed Living as Married

Single Other

Involuntary status at any time during this hospital stay? yes no

Had medication been discontinued prior to this admission? yes partially

no not applicable

Diagnosis:_____

Medication Prescribed at Discharge

	Psychiatric	Not psychiatric
1._____		
2._____		
3._____		
4._____		
5._____		
6._____		

Follow up Appointment

Date_____ Time_____ Place_____

Appendix C

Beck's Hopelessness Scale

ITEM (with scoring key)	TRUE	FALSE
1. I look forward to the future with hope and enthusiasm.	0	1
2. I might as well give up because I can't make things better for myself.	1	0
3. When things are going badly, I am helped by knowing they can't stay that way forever.	0	1
4. I can't imagine what my life would be like in ten years.	1	0
5. I have enough time to accomplish the things I want to do.	0	1
6. In the future, I expect to succeed in what concerns me most.	0	1
7. My future seems dark to me.	1	0
8. I expect to get more of the good things in life than the average person.	0	1
9. I just don't get the breaks, and there's no reason to believe I will in the future.	1	0
10. My past experiences have prepared me well for my future.	0	1
11. All I can see ahead of me is unpleasantness rather than pleasantness.	1	0
12. I don't expect to get what I really want.	1	0
13. When I look ahead to the future, I expect I will be happier than I am now.	0	1
14. Things just won't work out the way I want them to.	1	0
15. I have great faith in the future.	0	1
16. I never get what I want so it's foolish to want anything.	1	0
17. It is very unlikely that I will get any real satisfaction in the future.	1	0
18. The future seems vague and uncertain to me.	1	0
19. I can look forward to more good times than bad times.	0	1
20. There's no use in really trying to get something I want because I probably won't get it.	1	0

Appendix D

Knowledge Questionnaire

1. Do you believe you have a mental illness? _____ No _____ Maybe _____ Yes

2. I am interested in what mental illness you have. . . . What is the name of it? _____

3. Is this illness serious? _____ No _____ Maybe _____ Yes

4. Is it likely that you will have another bout (or episode) of this illness in the future? _____ No _____ Maybe _____ Yes

5. What medications are you taking now? (one point each)	6. How much medicine do you take and when? Dose (1/2 point each)	6. How much medicine do you take and when? Schedule (1/2 point each)	7. Describe what this medication is specifically supposed to do for you. (one point each)	8. List one side effect that might occur with each medication. (one point each)
a)	a)		a)	a)
b)	b)		b)	b)
c)	c)		c)	c)
d)	d)		d)	d)
e)	e)		e)	e)
f)	f)		f)	f)
5 total ____/____	6 total ____/____		7 total ____/____	8 total ____/____

Total scores = $\frac{\text{actual points}}{\text{potential points}}$

Mean % Items 1-8 = _____ %

Appendix D

Knowledge Questionnaire

Scoring Key

The following responses are correct. "Don't know" responses are incorrect.

1. Yes (must be affirmative); "maybe" responses are given half credit.

2. To be correct, response must be consistent with diagnosis on hospital record.

   For bipolar disorder, also correct. . . .
   manic-depressive disorder
   major affective disorder

   For depression, also correct. . . .
   major affective disorder

   For schizophrenia, any kind, the word schizophrenia must be included.

   The respondent need not be specific about which kind.

3. Yes (must be affirmative); "maybe" responses are given half credit.

4. Yes (must be affirmative); "maybe" responses are given half credit.

5. For lithium, must include the word lithium. Need not be specific about brand.

   For neuroleptics, must be named by commercial or generic name.

   For antidepressants, must be named by commercial or generic name.

   For side-effect medication, must be named by commercial or generic name.

6. Credit is given for knowing the correct milligram dosage (50%) and/or the correct schedule (50%). Medications used to treat other than psychiatric disorders will be disregarded.

7. For antidepressants, the word depression must be included in the description.

   For side-effect medication, the words "side effects" must be included in the description, or a specific side effect mentioned.

   For Lithium, the response must include reference to depression, "low," mania, "high," mood, or some indication that the medication is intended to smooth out the "ups and downs" or "highs and lows." For example, the response "I'll take lithium for my 'highs,'" is acceptable as a correct response.

   For neuroleptics, correct responses must include reference to a reduction of psychotic behaviors or symptoms. For example, "I take navane to stop hallucinations," or "I take mellaril to help with my paranoia," are correct responses. "The medicine helps me straighten out my thinking," is also a correct response. "I take haldol to relax me," or "I use trilafon to help me sleep," are not correct responses.

8. Antidepressants

Blurred vision or eye pain	Constipation
Confusion	Dizziness
Fainting	Drowsiness
Hallucinations	Dry mouth
Irregular heart beat	Headache
Problems in urination	Increased appetite for sweets
Seizures	Nausea
Skin rash and itching	Tiredness or weakness
Shakiness	Weight gain or loss
Sore throat and fever	

Side Effect Medication

Drowsiness	Dizziness
Fast heart beat	Tiredness or weakness
Problems in urinating	Headache
Dry mouth	Nausea
Blurred vision	Light headedness
Agitation	Constipation

Lithium

Nausea and vomiting	Diarrhea
Shakiness and tremor	Dizziness
Drowsiness, weakness	Dry mouth
Mental confusion	Increased thirst
Slurred speech	Increased urination
Pains in lower stomach	Skin eruption or rash
Swelling of hands and feet	Lack of coordination

Neuroleptics

Difficult urination	Skin rashes
Eye problems	Blurred vision
Excitement	Fainting
Constipation	Decreased sweating
Muscle spasms	Drowsiness
Restlessness	Dry mouth
Shuffling walk	Nasal congestion
Fine movements of tongue	Sore throat and fever
Trembling hands and fingers	Yellow eyes and skin
Unusually fast heart beat	Dizziness or lightheadedness
Tic-like movements of head, neck, face, and mouth	

(Listing of side effects from the American Medical Association, 1983)

Appendix D

Knowledge Questionnaire

Scoring Format

Items 1, 3, and 4: No = 0%, Maybe = 50%, Yes = 100%

Item 2: Correct response = 100%, Incorrect response = 0%

Items 5 through 8, give the percentage of correct response as follows:

6	correct	of	6	possible	=	100%
5.5	"	"	6	"	=	92%
5	"	"	6	"	=	83%
4.5	"	"	6	"	=	75%
4	"	"	6	"	=	67%
3.5	"	"	6	"	=	58%
3	"	"	6	"	=	50%
2.5	"	"	6	"	=	42%
2	"	"	6	"	=	33%
1.5	"	"	6	"	=	25%
1	"	"	6	"	=	17%
0.5	"	"	6	"	=	8%
0	"	"	6	"	=	0%

5	correct	of	5	possible	=	100%
4.5	"	"	5	"	=	90%
4	"	"	5	"	=	80%
3.5	"	"	5	"	=	70%
3	"	"	5	"	=	60%
2.5	"	"	5	"	=	50%
2	"	"	5	"	=	40%
1.5	"	"	5	"	=	30%
1	"	"	5	"	=	20%
0.5	"	"	5	"	=	10%
0	"	"	5	"	=	0%

4	correct	of	4	possible	=	100%
3.5	"	"	4	"	=	88%
3	"	"	4	"	=	75%
2.5	"	"	4	"	=	63%
2	"	"	4	"	=	50%
1.5	"	"	4	"	=	38%
1	"	"	4	"	=	25%
0.5	"	"	4	"	=	13%
0	"	"	4	"	=	0%

3	correct	of	3	possible	=	100%
2.5	"	"	3	"	=	83%
2	"	"	3	"	=	67%
1.5	"	"	3	"	=	50%
1	"	"	3	"	=	33%
0.5	"	"	3	"	=	17%
0	"	"	3	"	=	0%

2	correct	of	2	possible	=	100%
1.5	"	"	2	"	=	75%
1	"	"	2	"	=	50%
0.5	"	"	2	"	=	25%
0	"	"	2	"	=	0%

1	correct	of	1	possible	=	100%
1.5	"	"	1	"	=	50%
0	"	"	1	"	=	0%

Then calculate a mean percentage for all items, for example:

Item 1 = 50%
Item 2 = 0%
Item 3 = 100%
Item 4 = 50%
Item 5 = 17%
Item 6 = 38%
Item 7 = 75%
Item 8 = 40%

Total = 370

$$8 \overline{)\ 370} \quad \underline{46.25} = \text{mean percentage}$$

Appendix E

Face Validity Questionnaire

1. Do the items on the Knowledge Questionnaire (Appendix D) adequately cover the domain of knowledge regarding an individual's mental illness and prescribed medication used to treat their illness? If not, please comment.

2. Are the items of the Knowledge Questionnaire limited to the domain of knowledge regarding illness and medication? If not, please comment.

Comments: _____

_____

_____

_____

3. Do the items on the Adherence Questionnaire (Appendix F) adequately cover the domain of adherence to prescribed medication and initial out-patient followup appointment after hospital discharge? If not, please comment.

4. Are the items on the Adherence Questionnaire limited to the domain of adherence to prescribed medication and initial out-patient followup appointment after hospital discharge? If not, please comment.

Comments: _____

_____

_____

_____

(Polit, D. & Hungler, B., 1983)

Appendix F

Adherence Questionnaire

_____, this is _____
(Subject's Name) (Researcher's Name)

Do you recall when you were discharged from _____,
(Name of Hospital)

you were asked if you would participate in a research study? I'm calling now to ask you a few questions which would complete our study. Do you have a few minutes to answer some questions for me? (If not, ask if another time would be better.)

1. You had an appointment at _____ on
(Name of Office or Clinic)
_____.
(Date of Appointment)

Did you go to that appointment?

Yes (4) No -- Why were you unable to go? _____

_____

Did you contact the clinic or doctor?

Yes No (1) -- Why not? _____

_____

Did you make another appointment?

Yes (3) No (2) -- Why not? _____

_____

Item #1 score (1-4) _____

2. The doctor prescribed some medication for you to take at home. Will you tell me one by one what medicine you are taking and how often you take it?

Medication	A. Dose (0-1)	B. Schedule (0-1)	C. Clinical Assessment Factor (+ or-.5)	Score
	A1	B1	C1	/2= %
	A2	B2	C2	/2= %
	A3	B3	C3	/2= %
	A4	B4	C4	/2= %
	A5	B5	C5	/2= %
	A6	B6	C6	/2= %
			Item 2 mean score =	%

Total Adherence Score: Item 1 _____ %

Item 2 _____ %
(mean)

Mean @ Items 1 and 2 = _____ %

If the subject is not taking prescribed medication in the prescribed amount, why not? _____

_____

_____

Appendix F

Adherence Questionnaire Scoring Format

Item 1: 1 = 0%
2 = 33%
3 = 67%
4 = 100%

Item 2: Scores for this item will reflect how closely the subject's medication-taking behavior matches the prescription. The clinical assessment factor allows the researcher to make a clinical judgment regarding medication taken. For example, the subject who takes no medication regularly but generally takes one PRN dose daily would receive a score of 0.5 to reflect the fact that some of the prescribed medication was taken.

For each medication, calculate adherence score with range of 0-2. Clinical assessment factor of 0.5 may be added or subtracted to each individual medication score. Use of the clinical assessment factor may not cause score to exceed range of 0-2. Each score is converted to a percentage score as follows:

2	correct	of	2	possible	(2/2)	= 100%
1.5	"	"	2	"	(1.5/2)	= 75%
1	"	"	2	"	(1/2)	= 50%
0.5	"	"	2	"	(0.5/2)	= 25%
0	"	"	2	"	(0/2)	= 0%

The mean percentage of all medication items is then calculated.

Total adherence score is calculated by obtaining the mean percentage of Items 1 and 2.

AN ABSTRACT OF THE RESEARCH PROJECT OF

LESLIE MYERS, R.N., B.S.N.

AND

NANCY SULLIGER, R.N., B.A.

FOR THE MASTER OF SCIENCE

DATE OF RECEIVING DEGREE: June 10, 1988

TITLE: The Relationship Between Knowledge, Hopelessness and Adherence to Prescribed Regimens in Psychiatric Patients

APPROVED: [redacted]
Sarah Porter-Tibbetts, R.N., M.S., M.R.P., Advisor

Patient adherence to prescribed treatment following hospital discharge is a critical problem among the chronically mentally ill. One variable which is thought to influence levels of adherence is hopelessness. Another variable which seems to be related to adherence is the patient's knowledge regarding his or her illness and prescribed medication.

This study was undertaken in an effort to further explore the relationships between hopelessness and adherence, and knowledge and adherence. Through an exploratory design hopelessness and knowledge were measured on chronically mentally ill subjects who were hospitalized. Demographic and descriptive data were also collected.

Following discharge from the hospital, the subjects were then contacted and measurements were taken of their adherence to prescribed treatment. Hopelessness was measured using Beck's Hopelessness Scale. Knowledge and adherence were measured with instruments developed by the researchers for that purpose. Correlational tests were then applied to the data.

The data analysis did not reveal significant relationships between any of the major variables. Small sample size and high levels of adherence in this sample are possible explanations for the results. It appears as though the sample selection criteria and self-exclusion possibilities may have biased the sample in the direction of those who might be more likely to adhere.

Since 10 subjects did not complete the study (were not available for the adherence measure), examination was made of their hopelessness and knowledge scores in comparison to those who did complete the study. Hopelessness scores among those who did not complete the study were significantly higher than among those who did complete the study.

A group of seven subjects were identified who had low knowledge scores. Demographic and descriptive data of this subgroup were examined and compared to the data from the entire sample. Differences were identified in their gender, involuntary status, non-adherence to medication regimens at

time of admission, diagnosis and type of medication prescribed at hospital discharge.

The instruments used in this study were examined for internal consistency. One item on the Hopelessness Scale appeared to be ambiguous, as it had in previous studies, and rewording the item was suggested. The Adherence Questionnaire seemed to have a weakness in supporting a positive response bias. Suggestions for altering that portion of the Adherence Questionnaire were made.