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THE DESIGN OF AN INSTRUMENT TO EXPLORE THE RELATIONSHIP BETWEEN SELECTED VARIABLES AND COMPLIANCE WITH THE PRESCRIBED MEDICATION REGIMEN BY NONINSTITUTIONALIZED ADULT SCHIZOPHRENIC CHILDREN AS PERCEIVED BY THEIR PARENTS

by

Pamela Kathleen Brown [redacted]

A SCHOLARLY PROJECT

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1986

ABSTRACT

THE DESIGN OF AN INSTRUMENT TO EXPLORE THE RELATIONSHIP BETWEEN SELECTED VARIABLES AND COMPLIANCE WITH THE PRESCRIBED MEDICATION REGIMEN BY NONINSTITUTIONALIZED ADULT SCHIZOPHRENIC CHILDREN AS PERCEIVED BY THEIR PARENTS

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The purpose of this project was to design and pre-test an instrument to explore the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents. Five respondents from SHARE, the family support group affiliated with the National Alliance for the Mentally Ill in Kalamazoo, Michigan participated in the instrument pre-test.

The instrument was revised upon examination of the pre-test results. Parents do have perceptions that they wish to share, but they may perceive medication compliance in other ways besides having direct knowledge of their children's adherence to the prescribed medication regimen. Employment status was suggested as a significant variable in the schizophrenic's ability to comply. Lastly, other persons who have significant, ongoing interactions with a schizophrenic client may be able to provide the nurse with information which would improve health outcomes of noninstitutionalized schizophrenic clients.

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CHAPTER ONE

THE PROBLEM

Introduction

The advent of psychotropic drugs in the 1950's brought a huge exodus of patients from state mental hospitals into the community. The Community Mental Health Centers Act of 1963, in an effort to reduce expenditures for chronically ill patients, changed the direction of care for mental patients by moving the locus of treatment to the community. With the availability of effective psychotherapeutic drugs and a growing number of community treatment options, the majority of schizophrenics can be maintained in their home communities (Schizophrenia, Is There An Answer?, 1981). Between 1957 and 1981 an 8% reduction in state hospital populations was achieved in the United States (Maney, 1981).

For psychotherapeutic drugs to be effective in controlling the symptoms of schizophrenia so that the chronic patient is able to live in the community, however, the patient must comply with the prescribed

medication regimen. A limited body of knowledge exists regarding compliance among noninstitutionalized schizophrenic persons. Yet re-hospitalization of chronic schizophrenic clients has been clearly linked to non-compliance with prescribed medication and treatment regimens (Davis, 1975; Mason, 1963; Serban and Thomas, 1974; Marder, 1983).

Compliance is partly a result of an individual's interactions with significant others and with his or her environment (Dracup and Meleis, 1981). Factors which influence an individual's health actions include interpersonal variables such as family patterns of health care and expectations of significant others (Pender, 1982). These patterns and expectations are created within a family system which includes two components -- the parent and the child. Each parent-child dyad within the family system lives out its own unique history within the pattern of family life and in interaction with the larger environment of which it is a part. A child internalizes perceptions during the period of early communication with parents which are later challenged during interactions with peers and authority figures (Erickson, 1950). The family's expectations, values, attitudes and taboos are experienced by both the parent and the child over a period of several years, placing the parent in a

unique position to interpret future transitions and crises from the same historical perspective as the child.

This unique ability of the parent is of particular relevance to the study of compliance among schizophrenic clients. Schizophrenia is a chronic disease with usual onset during young adulthood (DMS III, 1980). Schizophrenics by definition have difficulty in establishing and maintaining interpersonal relationships and have fewer experiences which challenge perceptions internalized during early parent-child interactions. The perceptions of the schizophrenic person regarding the likelihood of health action are challenged as less than reliable due to the nature of the thought disorder accompanying schizophrenia (Serban and Thomas, 1974; McEvoy et al. 1981; Renton et al. 1963). Therefore, when it becomes difficult or impossible to communicate with a schizophrenic client because of altered thoughts and perceptions, interactions with that schizophrenic's parent who shares a history with his or her child is warranted. Rather than relying on the health care provider to interpret the reasons for non-compliance, a need exists to examine the perceptions of the primary referrral group, the parents, to more clearly determine variables related to compliance by the noninstitutionalized schizophrenic client living in the community.

Numerous variables have been related to non-compliance with medication regimens among psychiatric illness (Lin et al. 1979; Van Putten, 1976), selected aspects of the treatment regimen (Van Putten, 1974; Slater, 1981; McEvoy et al. 1981), and satisfaction with community out-patient care (McCranie and Mizell, 1978; Salter et al. 1981). In previous studies, the primary sources of data have been direct interviews with the schizophrenic clients. But past researchers (Serban and Thomas, 1974; McEvoy et al. 1981; Van Putten, 1976) have acknowledged the limitations of this method, i.e., low percentages of these clients have an understanding of their illness, their need for treatment, or their motivation toward health action. An understanding of the causes of medication non-compliance among schizophrenic clients is essential to obtain cooperation and responsible participation of these clients in a therapeutic regimen that will maintain the schizophrenic in a noninstitutionalized environment. The purpose of this scholarly project is to design and pretest an instrument to explore the relationship between both selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents. The instrument will be designed to answer the following questions:

The Research Question

What selected variablesare related to adult non-institutionalized schizophrenic children's compliance with the prescribed medication regimen as perceived by their parents?

Subresearch Questions:

1. What is the relationship between adult noninstitutionalized schizophrenic children's insight into their diagnosis of schizophrenia and their compliance with the prescribed medication regimen as perceived by their parents?

2. What is the relationship between adult non-institutionalized schizophrenic children's response to the nature of the prescribed medication and their compliance as perceived by their parents?

    a. What is the relationship between adult noninstitutionalized schizophrenic children's understanding of their need for medications to treat the symptoms of schizophrenia and their compliance with the prescribed medication regimen as perceived by their parents?

    b. What is the relationship between adult noninstitutionalized schizophrenic children's side effects from the prescribed medications and their compliance with the prescribed medication regiman as perceived by their parents?

    c. What is the relationship between the complexity of adult noninstitutionalized schizophrenic children's prescribed medication regimens and their compliance with the regimen as perceived by their parents?

3. What is the relationship between adult non-institutionalized schizophrenic children's satisfaction with noninstitutional care and their compliance with the prescribed medication regimen as perceived by their parents?

Definition of Concepts

The variables to be examined in this project are parental perceptions of their adult noninstitutionalized schizophrenic children's insight into the diagnosis of schizophrenia, reponse to the nature of the medication regimen, and satisfaction with noninstitutional care as related to the parental perceptions of their children's compliance with the prescribed medication regimen.

The Noninstitutionalized Schizophrenic Client

Schizophrenia is described by Snyder and Liberman (1981) as a disorder marked by severe problems in living, working, self-care, socializing, thinking, and feeling. Schizophrenia is a chronic illness that intereferes with interpersonal relationships, thought and mood. As a result of thought disturbances, the schizophrenic individual lacks insight into the motivation for his or her behavior. The schizophrenic is a person with impaired thought processes and relationships in interaction with his or her environment.

As a result of the deinstitutionalization movement of the 1960s, a fifty percent reduction of state

hospital populations has been achieved in the United States in less than twenty years (Flagg, 1982). A significant number of persons who would otherwise have been institutionalized now reside in single room hotels, nursing homes, boarding homes, cooperative apartments, group homes, foster-care homes or halfway houses (Flagg, 1982). For purposes of this study, the noninstitutionalized schizophrenic client is a person who has been diagnosed according to The Diagnostic and Statistical Manual of Psychiatric Disorders (1980) as having the mental illness schizophrenia with resulting difficulties in interpersonal relationships and self care and who is prescribed medication to control symptoms of his or her illness while living outside of an established inpatient treatment setting.

Parent

The family is a social system composed of individual and dyadic subsystems that interact with each other and with the suprasystem (Horton, 1985). The parent and child are subsystems with boundaries which filter the kind and the rate of flow of inputs to and outputs from each subsystem. Parent and child interface at the point at which their boundaries meet and form a dyadic system which filters inputs to and outputs from other systems. Significant information is processed and communicated within the parent-child subsystem.

According to Anderson and Carter (1974), as both parent and child grow their interactions become more complex and their behaviors demonstrate the interactional territory of belonging. Members of families possess affectional ties or some type of bonding and cohesion (Anderson and Carter, 1974). These subtle communications are transacted from an early age in the parent-child system and influence later experiences and behaviors. Boundary relationships tie the elements of the system together into a meaningful whole providing important transactions for study. For purposes of this study the prarent is a person who is in interaction with the adult schizophrenic child and who has exchanged information with that child within the context of larger systems that both have experienced.

Perceptions

Perceptions are defined by King (1981, pp. 20-29) as human transactions that organize, interpret, and transform information from sensation and memory. The input which is assimilated is based on past experiences, the concept of self, and biological heritage. Perception gives meaning to one's experiences and influences one's hehavior. Perception represents one's image of reality: the awareness of persons, objects, and events. Since perceptions of

the schizophrenic may represent an altered image of reality, for the purpose of this study the parent's interpretation of the adult noninstitutionalized schizophrenic child's experiences and behaviors will be examined. Perceptions for study will be the parental perceptions of adult schizophrenic children's insight into their diagnosis of schizophrenia, response to the nature of the medication regimen, satisfaction with noninstitutional care, and compliance.

Perceived Compliance with the Prescribed Medication Regimen

Compliance is defined as the extent to which a person's behavior coincides with medical or health advice (Haynes, Sackett, and Taylor, 1979). DeMatteo and DiNicola (1982) identify the terms adherence, obedience, cooperation, concordance, collaboration, and therapeutic alliance as being used interchangably to describe patients who comply with a treatment plan. Linden (1981) explaines therapeutic compliance as patient performance evaluated according to the expectations established for a particular patient by his/her physician. A significant number of patients do not meet the expectations of the health care provider.

The regulation of medication to control the symptoms of schizophrenia is a major goal when preparing the client for community placement. Drug treatment is,

in many cases, of primary importance in the treatment of psychiatric disorders with 80 to 90% of all discharged mental patients placed on medications (Buckwalter and Kerfoot, 1982). There is a wide range of individual requirements for phenothiazine and other antipsychotic medications used in the treatment of schizophrenia. The majority of these medications require daily divided dosages (McEvoy, McQuarrie, Douglas, and Schmadel, 1984).

Compliance with the prescribed medication regimen is related to the psychiatric client's ability to function in the community and to not require rehospitalization. Most psychiatric patients who relapse and are rehospitalized have failed to take their medications (Mason, 1963); Serban and Thomas, 1974; Davis, 1975; Youssef, 1983). Sanders, Smith, and Weinman (1967) suggest patients may underestimate medication problems they experience in the community setting. For purposes of this study, compliance with the prescribed medication regimen is defined as the extent to which the schizophrenic client's behavior coincides with the individually determiend plan of medication prescribed to control the symptoms of schizophrenia as reported by the parents. This project will explore the relationship between both selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult

schizophrenic children as perceived by their parents.

Variables Affecting Compliance With The Medication Regimen

Youssef (1983) asserts that failure to adhere to prescribed medication regimens is one of the major unsolved therapeutic problems confronting health care professionals. Despite a growing body of knowledge on treatment compliance, the issue remains inadequately studied. Variables researched in general include level of knowledge about the medications (Sackett et al., 1975; Given, Given, and Simoni, 1978), complexity of the medication regimen (Greene et al., 1982; Sackett, 1977), patient-provider relationship (Charney et al., 1967), perceived benefits of the medication (Given, Given, and Simoni, 1978), and side effects of various medications (Dixon, Stradling, and Wootton, 1957; Kirscht et al., 1977; Hershey et al., 1980). The variables to be examined in this study are parents' perceptions of their children's insight into the diagnosis of schizophrenia, response to the nature of the medication regimen, and satisfaction with noninstitutional care.

Perceived insight into diagnosis of schizophrenia

Lin et al. (1979) found that less than one third of the patients they studied had insight into their illness. Their findings were confirmed by Van Putten (1976) who found that insight was related to compliance with medication. Similarly, McEvoy et al. (1981) found that few chronic schizophrenic patients perceive that they have a mental illness. An understanding of the client's insight into his/her diagnosis then, is a critical factor to be considered in determining the extent to which the client's behavior coincides with health advice. For the purposes of this study, perceived insight into the diagnosis of schizophrenia is defined as the parental perception of the adult child's view of himself or herself as mentally ill with the chronic illness called schizophrenia.

Perceived response to the nature of the medication regimen: Need for medication

McEvoy et al. (1981) measured attitudes of chronic schizophrenic patients toward their illness and treatment and found that only 47% of the patients felt that they needed medications and only 44% believed that they would need medication in the future. Those patients who reported that they were ill were more likely to report a need for medication. For purposes of this study, need for medication is defined as the parent's

perception of the schizophrenic adult child's view that he or she needs medication to control the symptoms of schizophrenia.

Perceived nature of the medication regimen: Side Effects

Adverse effects of antipsychotic medications are numerous and may involve almost all organ systems. While some of the adverse effects of these medications are attributed to the actions of the drugs on the central and autonomic nervous systems, other side effects are thought to by hypersensitivity reactions (McEvoy, McQuarrie, Douglas and Schmadel, 1984). Among chronic schizophrenic patients, Van Putten (1974) found that drug-reluctant patients experienced more extrapyramidal side effects of antipsychotic drugs than did drug-receptive patients. Similarly, Michaux (1961) found that dosage deviations was significantly related to appearance of side effects. These findings were confirmed by Hartigan del Campo et al. (1983) who found that 60% of schizophrenics who admitted to discontinuing medications gave side effects as their reason. For purposes of this study, side effects are defined as the parents' perception that medications cause adverse responses for their adult schizophrenic children, thereby causing their child not to follow the prescribed medication regimen.

Perceived Satisfaction with Noninstitutional Care

Numerous services are available in the community to assist the chronic schizophrenic client with day to day problems that arise including management of medications. McCranie and Mizell (1978) found that there was a decreased likelihood of rehospitalization among chronic patients who had kept their aftercare appointments and Slater et al. (1981) found that more severely ill patients with increased hospitalizations and appointments were less satisfied with their outpatient care than other clinic patients. An understanding of the client's contentment with the available services is important in determining the benefit the client derives from the service. For purposes of this study, perceived satisfaction with noninstitutional services is defined as the parental perception that available services meet the adult schizophrenic child's desire for service to achieve compliance with the medication regimen.

Modifying Variables

Modifying variables included in the instruments for possible relationships to the parents' perception of the adult noninstitutionalized schizophrenic child's compliance with the prescribed medication regimen include age of both the parent and child since age is an indicator of the length of ongoing parent-child transactions.

In addition marital status of the adult-child, living arrangements of the adult child and frequency and nature of the contact between parent and child will be included as these variables are measures of the validity the parents' perception of their childs situation. Those adult children who are single and living with the parent or in face to face contact with the parent at least once per week would be most likely to communicate their concerns to their parent. The relationship of the parent to the adult child (i.e. father or mother) will be included in the instrument as a modifying variable along with family income, race, and educational preparation in an attempt to further explore Holden and Lewine's (1982) finding that the majority of concerned family members who responded to a survey on satisfaction with mental health services were white, well-educated mothers of schizophrenic clients. Family income and educational preparation may also be an indicator of the available family resources that have been mobilized in an attempt to improve the child's situation. Since different anti-psychotic medications may cause different side effects and side effects of medications have been reported as a major reason for discontinuing medications (Van Putten, 1974; Hartigan del Campo et. al., 1983), the names of the adult child's prescribed medications as reported by the parents could be examined for correlations

between specific medications prescribed for noninstitutionalized clients and the incidence of side effects. Lastly, since both Serban and Thomas (1974) and Hartigan del Campo et. al., (1983) reported unemployment as a predictor of readmission, employment status of the adult non-institutionalized child will be included in the instruments to explore its modifying effects on the variables under study.

Extraneous Variables

There are a host of variables related to compliance which are beyond the scope of this project design. Examples of extraneous variables that will be excluded from the development of this instrument include duration of the adult child's schizophrenia, level of knowledge about the medication prescribed, and type of noninstitutional services received by the adult child. Although it is acknowledged that these and possibly other variables could effect the adult noninstitutionalized schizophrenic child's compliance with the prescribed medication regimen, it is beyond the scope of this project to explore those variables.

Assumptions:

The following assumptions are made in this research study:

1. Schizophrenia is a chronic, incurable mental

disease requiring ongoing treatment.

2. Compliance with a therapeutic medication regimen is a health behavior that will improve current and future health states for the schizophrenic client.

3. Parents will be aware of their child's compliance behavior and will answer questions honestly and to the best of their ability.

4. Parents will be aware of variables related to their child's compliance with the medication regimen.

5. The concept of perception as defined in this study is a real and measurable phenomenon.

6. The testing instruments are sensitive to parental perceptions regarding compliance of the adult child.

7. Although data are collected at only one point in time, the perceptions studied are stable and immutable.

Limitations:

The following limitations are acknowledged:

1. Subjects who agree to participate in this study may be different from those who refuse. Therefore it is possible that the findings are not representative of all parents of schizophrenic adult children in primary care settings.

2. The need to express a socially desirable reponse may effect the responses of the participants.

3. Data from the pre-test cannot be assumed to be normally distributed due to the small sample size.

4. The small sample size is a non-probability (convenience) sample and, therefore, may not be generalizable to other individuals in similar situations or settings.

5. Perceptions of variables related to the schizophrenic clients' medication compliance are limited to one parent's perceptions and may not take into consideration other family members' perceptions.

6. All possible variables related to compliance are not addressed in this study. Findings may acutally be due to other interrelated factors. For example, knowledge of the medication regimen may be a significant variable but the thought and perceptual disorders accompanying schizophrenia make it difficult to obtain reliable data regarding the adult child's knowledge of the medication regimen.

7. Reliability and validity of the instrument have not been previously established and a larger sample size will be required to do so.

Overview of Chapters

This scholarly project is presented in six chapters. In Chapter I, the background and purpose of the project, the research question and subresearch questions, the

definition of concepts, and the assumptions and limitations have been presented. In Chapter II the concepts and relevant theory will be integrated into a conceptual framework for study. A review of the literature is presented in Chapter III for the purpose of linking this project with studies by others concerning compliance with medications among schizophrenic clients. The pretesting procedures, development of the instruments, proposed research design and human rights protection are presented in Chapter IV nad a discussion of findings from the pretest is presented in Chapter V.

Conclusions and recommendations for future research and implications for advanced nursing practice, nursing service and education will comprise Chapter VI.

CHAPTER TWO

CONCEPTS AND FRAMEWORK

Overview

This chapter will begin with a discussion of the noninstitutionalized schizophrenic client and the parent. Then, material on compliance with the prescribed medication regimen will be presented along with a discussion of the variables related to compliance with the medication regimen. Variables presented are perceived insight into the diagnosis of schizophrenia, perceived response to the nature of the medication regimen -- need for medication, side effects of the medication, and complexity of the regimen -- and, finally, satisfaction with noninstitutional care. Last, family ystems theory and King's Goal Atttainment Theory, which provide the theoretical basis for study, will be discussed.

The purpose of this project is to design and pretest an instrument to examine the relationship between both selected variables and compliance with the prescribed medication regimen by the adult noninstitutionalized schizophrenic child as perceived by the parent.

The Noninstitutionalized Schizophrenic Client

The second half of the twentieth century has been a period of growth for the study of mental illnesses. Care and treatment of persons with schizophrenia has progressed from years of long-term custodial care associated with the controversial treatments of electroconvulsive therapy and insulin coma to community-based noninstitutaional treatment. Treatment approaches utilize psychotherapuetic medications, group therapies, socialization activities and vocational rehabilitation. It is beyhond the scope of this study to deal with all of these approaches, but the author will examine selected variables perceived to relate to compliance with the prescribed medication regimen by the adult noninstitutionalized schizophrenic child as perceived by the parent.

Schizophrenia, named by Eugene Bleuler (1857-1939), was originally characterized by the symptoms of autism, ambivalence, inappropriate effect, and associative looseness. Now thought to be more than one disorder with more than one etiology, schizophrenics exhibit multiple complex symptoms. Schizophrenia is a chronic illness that may be either slow and insidious or sudden and severe in onset. Affected individuals have difficulties with interpersonal relationships, thought and mood resulting in severe problems in working, socializating, self-care, and self-concept.

The Diagnostic and Statistical Manual of Mental Disorders, III edition (1980) identifies the following criteria for diagnosis of schizophrenia:

A. At least one of the following during a phase of illness:

   1. Bizarre delusions, such as delusions of being controlled, thought broadcasting, thought insertion, or thought withdrawal.

   2. Somatic, grandiose, religious, nihilistic or other delusions without persecutory or jealousy content.

   3. Delusions with persecutory or jealousy content if accompanied by hallucinations of any type.

   4. Auditory hallucinations in which either a voice keeps up a running commentary on the individual's behavior or thoughts, or two or more voices converse with each other.

   5. Auditory hallucinations on several occasions with content of more than one or two words, having no apparent relation to depression or elation.

   6. Incoherence, marked lossening of associations, markedly illogical thinking, or marked poverty of content of speech if associated with at least one of the following:

      a. blunted, flat, or inappropriate affect.
      b. delusion or hallucinations.
      c. catatonic or other grossly disorganized behavior.

B. Deterioration from a previous level of functioning in such areas as work, social relations, and self-care.

C. Duration: Coptinuous signs of the illness for at least six months at some time during the person's life, with some signs of illness at present. The six-month period must include an active phase during which there were symptoms from A, with or without a prodromal or residual phase, as defined below:

Prodromal phase: A clear deterioration in funtioning before the active phase of the illness not due to disturbance in mood or to a Substance Use Disorder and involving at least two of the symptoms noted below.

Residual phase: Persistence following the active phase of the illness, of at least two of the symptoms noted below, not due to a disturbance in mood or to a Substance Use Disorder.

Prodromal or Residual Symptoms:

1. Social isolations or withdrawal.
2. Marked impairment in rol funtioning as wage-earner, student, or homemaker.
3. Markedly peculiar behavior (e.g. collecting garbarge, talking to self in public, or boarding food.)
4. Marked impairment in personal hygiene and grooming.
5. Blunted, flat or inappropriate effect.
6. Degressive, vague, overelaborate, circumstantial or metaphorical speech.
7. Odd or bizarre ideation, or magical thinking, e.g. supersititiousness, clairvoyance, telepathy, "sixth sense", "others can tell my feelings", overvalued ideas; ideas of reference.
8. Usual perceptual experiences, e.g. recurrent illusions, sensing the presence of a force or person not actually present.

D. The full depressive or manic syndrome, if present, developed after any psychotic symptoms, or was brief in duration relative to the duration of the psychiatric symptoms in A.

E. Onset of prodromal or active phase of the illness before age 45.

F. Not due to any Organic Mental Disorder or Mental Retardation.

(DSM III, 1980, Table 16-6)

The American Psychiatric Association published the preceeding criteria in 1980 to improve reliability and clinical objectivity in psychiatric diagnostic categories. Though the system is complex, the DSM III represents the curent state of knowledge about diagnosing mental disorders and has been adopted for use in most facilities throughout the United States (Spetzer, Williams and Skodol, 1980).

It has been postulated that szhiophrenia is caused by biochemical disturbances in the brain. Wise and Stein (1973) found evidence that aberant dopamine metabolites produce schizophrenic symptoms by causing a prolonged or permanent depletion of brain catecholamines. Carlsson and Lindqvist (1973) note that central dopaminergic receptors are blocked by all effective antipsychotic drugs. It is hypothesized that biochemical neurotransmitters may eventually explain schizophrenia, but, as yet, most attempts to duplicate these findings have been inconclusive (Wilson and Kneisl, 1983). Still, the discovery of antipsychotic medications has enabled schizophrenic persons who would have otherwise been hospitalized to return to their homes and their communities.

The movement of schizophrenic patients into the community has been described as one of the most significant achievements of modern psychiatric treatment (Guy and Gross, 1967). Increasing percentages of chronic psychiatric patients have never had extended hospitalizations while some have had only brief stays in community-based impatient facilities (Bachrach, 1984). Today's young adult chronic clients are found on the

rolls of public mental hospitals, general hospitals, community mental health centers, private psychiatric hospitals and a variety of outpatient mental health facilities (Bachrach, 1983). A growing number are found among the vagrant street people in urban areas (Schwartz and Goldfinger, 1981; Prevost, 1982). This reform movement has not been effective in maintaining the clients' optimum level of functioning in the community. The majority of the young adult chronic patients in the community tend to be non-compliant (Schwartz and Goldfinger, 1981; Pepper and Ryglewicz, 1982).

Rehospitalization as a result of not complying with a medication regimen is well documented in the literature (Mason, 1963; Serban and Thomas, 1974; Davis, 1975; Marder, 1983). During florid episodes of schizophrenia, the client is stablized on anti-psychotic medications and taught about the medication and the need to continue the medications in the community. But even the client who is knowledgeable about the medications and has developed strategies for compliance under the guidance of professional staff is often unprepared for the situations encountered in the community noninstitutional setting. The revolving door of community treatment continues to turn and large numbers of clients live with their psychoses until the severity of the symptoms require them to be rehospitalized.

In summary, evidence exists to support the fact that although the exact cause of schizophrenia is unknown, the discovery of antipsychotic medications has led to effective noninstitutionalized treatment of schizophrenic clients. Nevertheless, if the client does not comply with the prescribed medication regimen, the symptoms of schiozphrenia reappear and hospitalization may be required. Thought disorders, perceptual disorders, and problems with motivations due to schizophrenia, impair social interactions and interpersonal relationships and the schizophrenic client may not be able to effectively verbalize what motivates his or her health behaviors. The parent who has a history and regular contact with the adult schizophrenic child is in a unique position to interpret the health behaviors of that child based on past transactions and experiences with the child.

The Parent

Significant information is communicated over time within the parent-child relationship. The human infant goes through a relatively long dependency period relying on the parent for physical and psychological survival. As both parent and child grow, their interactions become more complex and affectional ties or bonds are developed (Anderson and Carter, 1973). During this period of growth, the parents are the primary

reference group sharing values, attitudes, expectations, and experiences with the child. Anthony (1970) describes a sense of compassion that envelopes the family members of a mentally ill client and enables them to see the situation from the client's perspective.

In the schizophrenic's lifetime it is likely that the parent is the person who has had the most interaction with the adult child. With the onset of schizophrenia, the number and quality of interpersonal relationships outside the immediate family decrease and deterioriation occurs in work, social relations and self-care (DSM III, 1980). The parent who regularly interacts with and shares a history with the adult schizophrenic child is in a unique position to exchange his or her perceptions with health care providers that will improve assessment of variables related to compliance with the prescribed medication regimen.

Perception

Perceptions are defined as human transactions based on current images of reality and past experiences that organize, interpret, and transform information from sensation and memory (King, 1981). A parent and child view each other and their situations through communications, past experiences and environmental interactions. The parent and child who regularly interact view each other and each presenting situation from a unique

historical perspective. They have developed a bonding relationship over time that has assimilated past experiences and behavioral responses to hundreds of situations impacting the family system.

Family patterns of health care and expectations of significant others are related to family health behaviors (Pender, 1982). Therefore, the parent and child, as components of the family system, view events from the same reference background are are more likely than health team members to share a similar view of health action. When interaction is distorted between health care provider and client, as is the case with the adult schizophrenic, the view of the parent is particularly important to an accurate assessment of variables related to health action. The parental perceptions of the child's compliance and of the variables related to compliance with the prescribed medication regimen provide health team members with a more accurate picture of the adult schizophrenic child's health behavior.

Perceived Compliance With The Prescribed Medication Regimen

Numerous definitions of compliance are recorded in the literature. DiNicola and DiMattero (1982) identify the terms adherence, obedience, cooperation, concordance, collaboration and therapeutic alliance

as being used interchangeably by health care providers to describe patients who comply with a treatment plan. The term compliance is the most commonly used term in the health literature and the term 'patient compliance' is the key concept utilized in the Index Medicus for literature related to a client following health care advice. Linden (1981) explains therapeutic compliance as patient performance evaluated according to the expectations established for a particular patient by his or her physician. For purposes of this research, perceived compliance is defined as the parental perception of the extent to which an adult noninstitutionalized schiozphrenic client's behavior coincides with medical advice (Haynes, Sackett, and Taylor, 1979).

A regimen is defined as a mode or system of management and is derived from the latin word 'regimen' meaning guidance (Webster, 1981). Therapeutic guidance in the form of the advised medication regimen is intended by the provider to result in a desired outcome, i.e., the management of the symptoms of schizophrenia in order that the client may live a comfortable life outside of an institutional setting. Compliance with the prescribed regimen is central to achieving the desired outcome of keeping the client in the community.

Eighty to ninety percent of all discharged mental patients are advised on a medication regimen (Buckwalter and Kerfoot, 1982). Serban and Thomas (1974) studied acute and chronic schiozphrenics and found that a failure to comply with the medication regimen led to a need for re-hospitalization. Mason (1963) found that most psychiatric patients who are rehospitalized have been those who failed to follow their prescribed medication regimen after discharge. In a review of the medical literature, Davidhazar (1982) found twenty variables correlated with medication compliance by schiozphrenics treated as outpatients. Among these were the following six:

1. a minimum number of side effects
2. simple instructions about the treatment regimen
3. simple instructions on the prescription container
4. accurate perception of the seriousness of the illness
5. understanding of the benefits of the treatment regimen
6. a dependable individual or institution in the community

Compliance of the patient to the prescribed medication regimen is clearly linked to preventing recurrence of schizophrenic symptomology (Mason, 1963; Serban and Thomas, 1974; Davis, 1975; Marder, 1983) and a host of variables have been postulated to relate to compliance.

The purpose of this project is to design and pre-test an instrument to explore the relationship between both selected variables and compliance with the prescribed medication regimen by nonistituionalized adult schiozphrenic children as perceived by their parents.

Variables Related to Compliance With The Prescribed Medication Regimen

Numerous variables have been related to compliance with treatment regimens (Sackett et.al., 1975; Greene et. al., 1982; Charney et. al., 1967; Given, Given and Simoni, 1978), but little research has been done to explore variables related to compliance with medication regimens by chronically ill schizophrenic clients even though failure to comply with the medication regimen has been shown to be related to recurrence of symptoms and rehospitalization (Mason, 1963; Serban and Thomas, 1974; Youssef, 1983). The purpose of this project is to design and pre-test an instrument that will explore the relationship between both adult schizophrenic children's compliance with the therapeutic regimen and the selected variables of insight into the diagnosis of schizophrenia, response to the nature of the medication regimen, and satisfaction with noninstitutional care, as perceived by their parents.

Client Insight Into The The Diagnosis of Schizophrenia

The client's understanding of his or her mental illness has been shown to effect compliance with the antipsychotic medication regimen. Lin et. al. (1979) determined that only 31 percent of the schizophrenic clients they studied had insight into their illness. Although they were unable to find statistically significant correlations between insight into the diagnosis of schizophrenia and perceived benefits of medication, they concluded that insight was one of the factors that seemed to be involved in compliance behavior.

Van Putten et al. (1976) studied two groups of schizophrenic clients -- habitual compliers and habitual non-compliers. They found that insight into illness was positively correlated with compliance behavior. They also found that clients who exhibited grandiosity were less likely to have insight into their mental illness and were more likely to be non-compliant with medication and treatment regimens than clients who had no grandiose characteristics.

In a study by McEvoy et al. (1981), only thirteen percent of rehospitalized patients acknowledged that they had a mental illness and only about one-fourth of those studied recognized their need for readmission to the hospital. Although some clients acknowledged

their diagnosis of schiozphrenia, many of those same clients denied that repeated hospitalizations were for treatment of psychiatric illness, and a significant number reported that they did not have adequate understanding of their illness (Hartigan del Campo et al. 1983).

If a chronic schizophrenic client does not perceive that he or she has a mental illness we cannot expect that client to follow a therapeutic regimen to manage that illness. The parental perception of the client's insight into his or her diagnosis offers us a clue as to what type of health action will be taken.

Response to the Nature of the Medication Regimen: Need for Medications

Although some clients acknowledge their diagnosis of schizophrenia, they often disagree with the advice of the health providers that medication is needed for control of symptoms. Once the client is stablized on medications following an acute psychotic episode it becomes difficult to convince the client that he or she should continue taking the medication. Because omission of one dose of medication is unlikely to cause a relapse, the client sees this as proof that the medication is unnecessary. In the study by McEvoy et al. (1981) in which inpatients were interviewed about their need for medication, one-third felt

that they needed medication at the time of hospitalization, and only twenty-nine percent felt that they would need medication in the future.

In a study of outpatients in a Verterans Administration mental hygiene clinic, McClellan and Cowan (1970) found that a small number of the clients were not taking any medication and that a substantial number of the clients were taking less than the prescribed amount, but that these clients were not volunteering this information to their therapist at the clinic. Although the reasons for this decrease in medications or omission of medications were not clear, one of the possible explanations is that the clients did not feel that they needed to take the medication as prescribed. Again, an examination of parental perceptions of the adult schizophrenic child's perceived need for medication, based on a different context of interaction with that client than the provider-patient context, might give the health care provider some clues as to what variables will influence the client's compliance with the prescribed medication regimen.

Response to the Nature of the Medication Regimen: Side Effects

Thirty-seven percent of clients taking the antipscychotic medication chlorpromazine experience dry mouth, twenty-three percent develop blurred vision,

thirteen percent become constipated, twenty-three percent develop nasal stuffiness and four percent experience nausea and vomiting (American Hospital Formulary Service, 1982; McEvoy et al., 1984). These anticholinergic effects are the most common but are usually considered to be tolerable by clients. Other common and sometimes frightening adverse reactions are the extrapyramidal effects of dystonic reactions,pseudoparkinsonism and akathesias, and the irreversable effects of tardive dyskinesia which are usually a result of long-term antipsychotic drug treatment (Wilson and Kneisl, 1983). Van Putten (1974) proposed that drug reluctance was often the result of extrapyramidal effects. Slater (1981) found extrapyramidal side effects higher in patients who relapse than in the general outpatient group, and Michaux (1961) found that compliance decreases in psychiatric patients as severity and incidence of side effects increase. Besides extrapyramidal and anticholinergic side effects, clients may experience skin reactions, photosensitivity, endocrine changes resulting in lactation, amenorrhea or impotence, postural hypotension, jaundice, and sedation. The medication which best controls the client's schizophrenia may cause uncomfortable, socially unacceptable or frightening adverse reactions. Since clients may not interact with providers to report medication side effects and since significant side effects of medications may influence clients' decisions

to comply with the prescribed medication regimen, an examination of parental perceptions of side effects experienced by their schizophrenic children is warranted.

Response to the Nature of the Medication Regimen: Complexity

Davis (1968) found that the less complex the regimen, the more likely the client was to adhere to the plan. Patients are more likely to remember to take a single daily dose of medication than multiple doses throughout the day (Buckwalter and Kerfoot, 1982). Greene et al. (1982) identified the complexity of the medication regimen, as measured by the number of drugs prescribed for a patient, to be a significant factor in compliance behavior: the more drugs prescribed for a patient, the less likely he or she was to be compliant. The medication regimen for a schizophrenic client may consist of more than one antipsychotic medication as well as medication to control side effects of the drugs.

Wilson and Enoch (1967) found an increase in compliance when evaluated by urine screens for phenothiazines after schizophrenic clients were switched from tablets to the same liquid medication. Powell et al. (1977) found that an increased number of doses of medication was associated with lower rates of

compliance among psychiatric aftercare patients. Although few studies have dealt with complexity of the regimen for schizophrenic clients taking anti-psychotic medications in the noninstitutional setting, related studies show this to be a variable in need of research. During interactions and experiences with their schizophrenic adult children, parents may perceive whether complexity of the medication regimen influences their child's compliance with the medication regimen.

Satisfaction with Noninstitutional Care

Consumer satisfaction has been shown to impact utilization of health services and several aspects of satisfaction have been identified. Haynes (1976) found a consistent negative relationship between waitint time and poor compliance -- block scheduling, physician lateness, patient lateness, and "no shows" were among the most frequent reasons cited for dissatisfaction and non-compliance. In her review of the medical literature, Davidhizar (1982) found four variables influencing compliance in schizophrenic outpatients -- caring and concern by the health professional, specific and regularly scheduled follow-up appointments, monitoring of the treatment regimen by a health professional, and a dependable individual or institution in the community. The client's view of the health care system as it affects him or her in the

noninstituional setting is related to compliance with the therapeutic regimen. It is essential to examine satisfaction with noninstitutional services in ambulatory settings where health care providers manage the medication regimen in order for the client to comply with the plan.

The client is the best judge of the provider's concern, accessibility, compassion and respect. McCranie and Mizell (1978) found a significant relationship between more aftercare visits and a decreased likelihood of rehospitalization. They interviewed clients regarding the effectiveness of aftercare services and suggested a need for more studies of client's perceptions of aftercare.

Slater et al. (1981) found that low levels of satisfaction with mental health care by severely ill patients were associated with increased hospitalization and appointments. Most studies of patient satisfaction, however, produce very high levels of satisfaction leading to questions regarding the validity of the scales. Slater et al. (1982) cites possible variables influencing high validity found for patient satisfaction scales including the patient's wish to please the evaluator, the use of positively worded statements, the use of direct questions about a specific setting and the fact that the patient may indeed be very

satisfied with the care being received. It is the author's belief that the parent, through regular interactions with the client in the noninstitutional setting, perceives the client's satisfaction with mental health care free of the biases which might occur within the provider-client interaction. Perceptions of the parent, based on interactions with the adult noninstitutionalized child, provide another means to assess the client's sisatisfaction with noninstitutuional care which should not be ignored if we are to understand compliance with the medication regimen among schizophrenic clients.

In summary, schizophrenia is a complex and only partially understood chronic mental illness. Although medication has been proven to be an effective treatment, controlling symptoms and allowing schizophrenic persons to live outside of institutions, large numbers of schizophrenic persons do not follow their prescribed medication regimen and must return periodically or indefintely to institutional environments. Parental perceptions could be useful in assessing the variables that influence the adult noninstitutionalized schizoprhenic's compliance with the medication regimen.

Family Systems Theory and Applicability To Instrument Design

The twentieth century has brought increasing interest in looking at the world with regard to interconnectedness of phenomenona rather than separateness. One of the applications of this viewpoint is the use of systems theory by family theorists in an attempt to understand and treat the human family (Young, 1985). General Systems theory (von Bertalanffy et. al., 1968) is utilized by family theorists to understand the relationship of the parts within the family system (Bowen, 1978; Terkelson, 1980; Hall and Weaver, 1985); Holman and Burr, 1980). Each person is a subsystem of the family and interactions between the subsystems, create child/child subsystems, parent/parent subsystems, and parent/child subsystems. A chronic illness of one family member subsystem influences the interrelationships within the family system and impacts the overall wellness of the family system.

A system is any group of parts that have particular relationships and interactions with one another (Young, 1985). The health care system, with its professional team members as subsystems, interacts with the chronically ill client, a subsystem of the larger family system. But when the interaction between the professional and the client is distorted due to the client's illness,

exploration of the perceptions of the parent, a part of the parent/child subsystem, may offer the health care professional needed information to achieve goals with the ill client.

Von Bertalanffy (1968) identifies a system as a complex of elements standing in interaction with each other. All living systems are open systems separated from the environment by boundaries. A boundary is defined by observing interactions among the parts of the system and by the needs and interests of the observer (Young, 1985). Boundaries are selectively permeable, allowing inflow and outflow of energy. Relatively open boundaries allow for significant exchange of information while closed boundaries are rigid and limit the inputs into the outputs from the system.

The energy in a system is described in two concepts: entropy which refers to the degradation of energy in a system resulting in less energy available for the work of growth and maintenance of the system, and negentropy which increases energy available for organization and differentiation of the system (Young, 1985). Energy and information always flow together. Information processing is the change of information as it moves from one point to another over space (Hazzard, 1971). The meaning of the information is significant to the system processing

it and is subject to the distorting effects that occur between input and output.

Another characteristic of a system is that of nonsummativity or wholeness meaning that the sum of the whole system in interaction is different that its parts. The parts of a system are called subsystems and a change in any one subsystem leads to changes in the other subsystems and in the whole of the relationship. Systems and subsystems fit into heirarchical order but may also overlap with other systems and subsystems. Systems and subsystems exist in a constant state of change. Continual adjustment and feedback among and between systems results in homeostasis, that is, a steady state of inputs and outputs. Positive feedback moves the system away from the steady state to a higher level of development. Negative feedback maintains the system within its present homeostasic limits and prevents deviations from the steady state.

The study of family systems with families of psychiatric patients began in the early 1950s (Young, 1985). Jackson and colleagues (1967) represent the family systems theory school of thought that pays particular attention to various forms of communiation. The focus is on control, homeostasis, and feedback mechanisms within the family system. More recently, Doherty and Baird (1983) refer to the provider-patient

relationship as a triangle rather than a dyad and identify the therapeutic triangle to include the subsystems of the health profesional, the patient, and the patient's family as the focus of health intervention. Doherty and Baird suggest that health care providers need to recognize that family members can provide useful information about patients. For purposes of this study, the parent and child within the larger family system will be examined.

Each noninstitutionalized adult schizophrenic person is a subsystem of a family system and of other community systems. Homeostasis refers to regulation within certain limits (Young, 1985). For the chronic schizophrenic client living in the community, homeostasis is the range of limits within which the adult chil'ds behaviors are regulated and accepted in the community noninstitutional setting. If these behaviors extend beyond the range of acceptability, then the schizophrenic person is subject to instituionalization. Compliance with the medication regimen is a significant factor in maintaining homeostasis of the noninstitutionalized schizophrenic client (Davis, 1975; Serban and Thomas, 1974; Marder, 1983).

Traditionally, the health care system has attempted to manage the medication regimen to achieve homeostasis of the schizophrenic client in the noninstitutional setting. But there is inadequate exchange of information

between the adult noninstitutionalized client and the health care provider in the area of compliance with medications (McClellan and Cowan, 1970). The subsystem of the parent exists in relationship to the subsystem of the noninstitutionalized adult schizophrenic child. Permeable boundaries between parent and child allow for exchange of information in the parent-child relationship.

Figure 1 illustrates the relationships and communication exchanges between the health care provider, the noninstituionalized adult schizophrenic client, and his or her parent. As components of a family system, the client and the parent have a shared boundary through which information is exchanged. The parent and child have a clear perception (straight arrows) of the information they exchange based on past experiences and perceptions they have shared prior to and during illness as members of the same family system.

In comparison, the health care provider has shared information and perceptions with the schizophrenic client for a relatively short period of time--the time during which the client has been mentally ill with schizophrenia. The nature of the perceptual and thought disorders accompanying schizophrenia distort the health care provider's perceptions of the schizophrenic client's behavior and conversation as well as distorting the client's perception of the providers counsel and

treatment (wavy arrows). The health care provider has no other basis for understanding the client's actions than the information gained from the present "during illness" relationship. During illness, the client may be unable to trust the professional enough to attempt to make his needs known or the client may not perceive a need to talk to the professional at all. Therefore, ongoing assessment of the parental perceptions of the schizophrenic client's motivations and health behaviors shold offer the health care provider a clearer exchange of significant information regarding variables that relate to compliance with the treatment regimen than interaction with the ill client alone. Recognition of these variables is a critical step in planning a treatment program that is acceptable to the schizophrenic client.

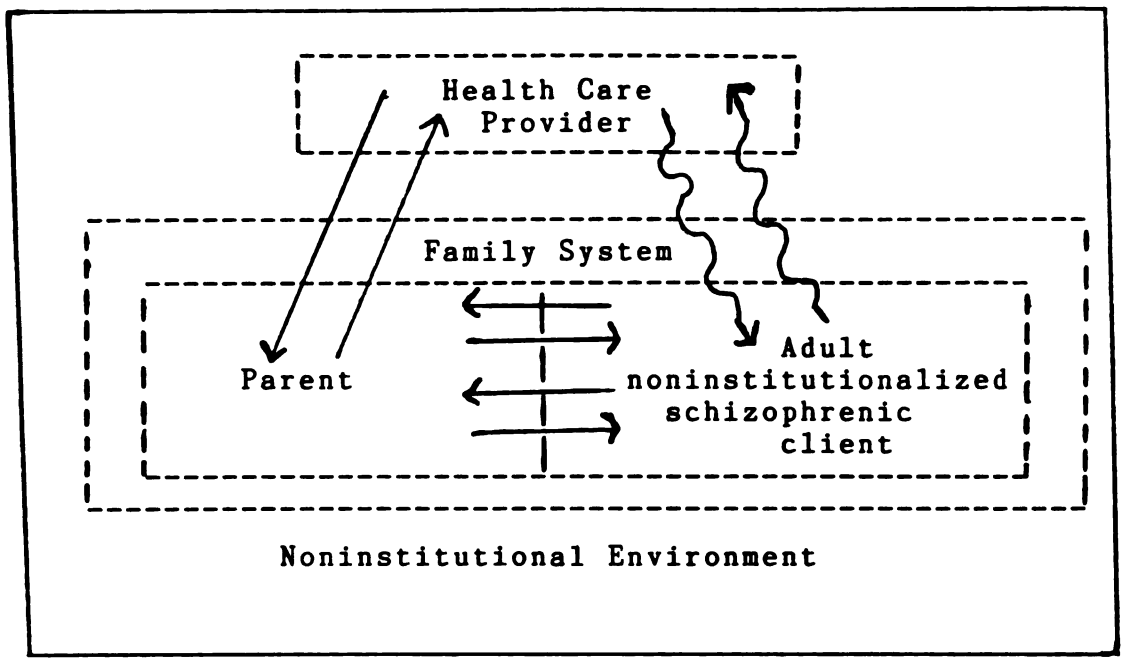

Figure 1. Exchange of information across boundaries between parent and child subsystems of the family system and the health care provider in the noninstitutional environment.

clear exchange
distorted exchange
----- semipermeable boundaries

Theory of Goal Attainment: Relationship of Nursing Theory to Instrument Design

Imogene King (1981) identifies the focus of nursing care as human beings who are open systems interacting with their environment. Nursing is defined as a process of human interaction between nurse and client whereby each perceives the other and the situation. Through communication, nurse and client set goals, explore means and agree on means to achieve goals (p. 144).

King focuses on individuals interacting with other human beings including family members and health care providers. Interactions are important to nursing in that mutual transactions (goal attainments) are the result of communicated information between client and nurse. Two interacting human beings present a complex set of variables with each individual bringing personal knowledge, needs, goals, expectations, perceptions and past experiences to the interaction process. Interactions are dynamic and unidirectional. The experience of any interaction is unique in that the time, place, circumstances and persons involved can never be repeated. The process of interaction represents a sequence of verbal and non-verbal behaviors between client and nurse that are goal directed.

Roles identify interactive relationships and modes of communication (King, 1981). Role is a set of behaviors expected when occupying a position in a social system (e.g. the nurse, the parent, the schizophrenic child) and is an essential concept to understanding nurse-client interactions. The client or parent gives information to the nurse and the nurse shares information with the client. Each learns his/her role from functioning in a variety of social systems including the family, the school, peers, and the health care system.

Interactions between nurses and patients are goal oriented and effective when the perceptions of those interacting are accurate. Misunderstanding of role and distortion in perception, for whatever the reason, may influence the nursing process and the outcome of care.

King (1981) believes that the nursing process is a mode of action applied through knowledge to care for the well, ill and dying. The nursing process is implemented through perception, judgment, action, reaction, interaction, and transaction in which the nurse assists the client to cope with his or her individual situation and promote health. The nurse may be asisting the client to cope with the fact that his or her perception of the situation is not realistic. Figure 2 illustrates King's model of the process of clear nurse-client interaction (1981).

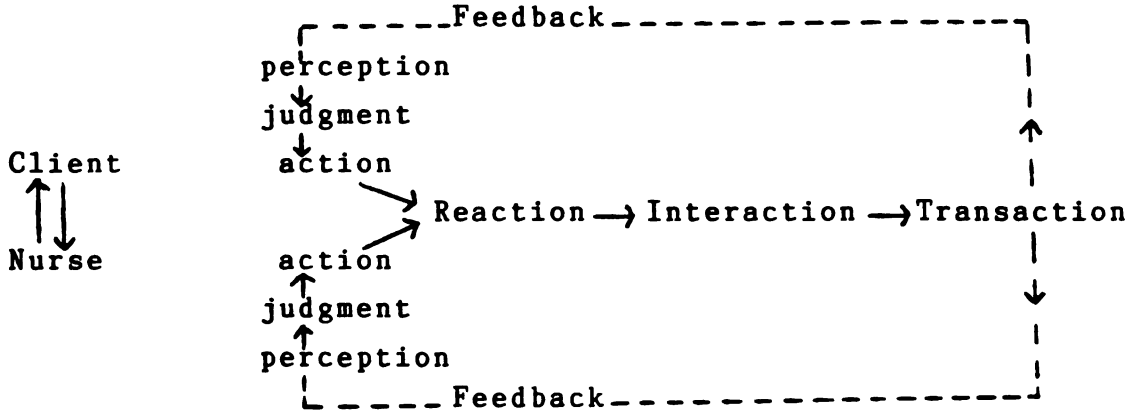

Figure 2. A process of human interaction, King, 1981.

According to King (1981), perceptions are unique subjective, representations of reality which give meaning to experiences. For example, the client's perception of his or her illness, the effectiveness of the treatment regimen and the complexity of a medication regimen give meaning to experiences. Judgments are the result of valuing perceived events and objects. Actions, both verbal and non-verbal, are behaviors based on judgments, which have been derived from one's perceptions. The client reacts to his or her unique perception of the envrionment and experience. Interaction according to King, is a process of perception and communication between person and envrionment. As nurse and client set goals, they interact to bring together knowledge, needs, experiences, and perceptions toward goal attainment. Transactions are observable behaviors of human beings in achievement of valued goals.

When a client develops a schizophrenic illness, he or she is likely to experience unusual perceptions, impaired ability to communicate throughts and feelings, hallucinatory experiences, and delusional thinking which influence the client's judgment, actions and reactions. Mutual goal setting with a schizophrenic client presents a unique challenge to the nurse. Perceptions of parents, based on experiences over the years with the schizophrenic child, will assist nurses to set mutual goals with schizophrenic individuals to

obtain, maintain, and restore health. Figure 3 is a diagram of an expanded interaction model which includes the perceptions of the parent in the assessment of variables related to compliance by the schizophrenic adult child. The nurse interacts with the parent of the schizophrenic client to assess the parental perceptions of the client's insight into the diagnosis of schizophrenia, the response to the nature of the medication regimen -- need for medications, side effects of medications, and complexity of the medication regimen -- and the client's satisfaction with noninstitutional care. Thus, the nurse receives feedback from the parent that may alter the nurse's perception of the cleint's situation. Based on additional information from the parent, the nurse interact with the schizophrenic client to develop mutually acceptable interventions that will increase the likelihood of compliance with the medication regimen (transaction) resulting in homeostasis of the client with his or her environment.

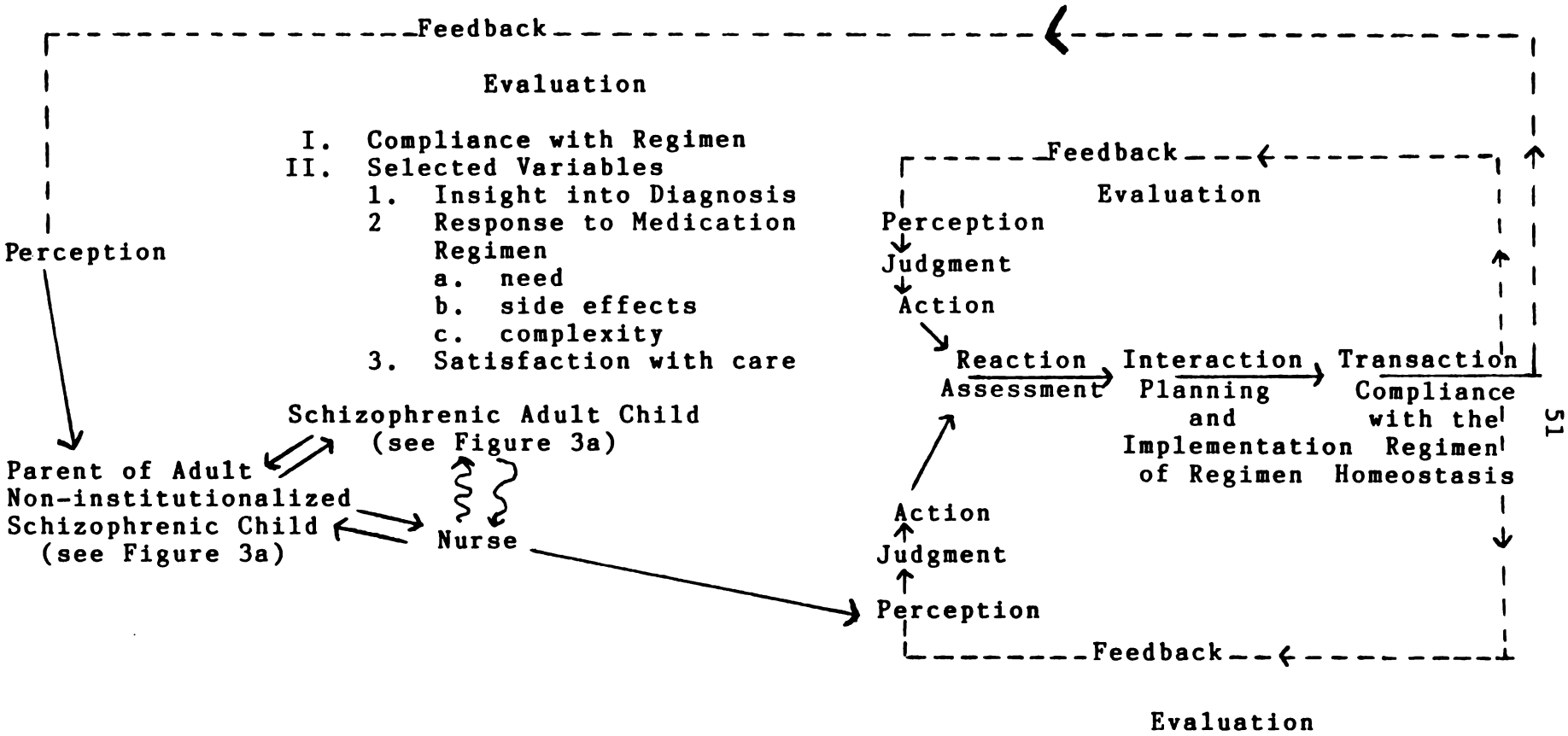

Figure 3. Expanded interaction model illustrating distortion in interaction between schizophrenic client and nurse and exploration of the relationship between compliance with the prescribed medication regimen and selected variables as perceived by the parent.

Parent of Adult Noninstitutionalized

Schizophrenic Child

1. Age
2. Marital Status
3. Frequency and Nature of Contact with adult child
4. Education
5. Relationship to child
6. Race
7. Income

Schizophrenic Adult Child

1. Age
2. Marital Status
3. Frequency and Nature of contact with parents
4. Education
5. Living Arrangements
6. Medication
7. Employment Status

Figure 3a. Modifying variables to be examined for relationships to compliance with the prescribed medication and slected variables as perceived by the parent.

According to King (1981), the concept of environment includes three open, interacting, and dynamic systems - personal (the individual), interpersonal systems (groups), and social systems (society). The individual's perceptions of self, body image, growth and development, and time and space are personal systems important to the individuals' interactions and behaviors. These perceptions influence the way in which the individual responds to persons, events and objects encountered in his or her life. Over time the individual's own body growth and development affect body image and perceptions of self, which also influences his or her use of space during verbal and non-verbal communication.

Interpersonal systems (the individual's interactions with other human beings) include, among others, family members and health care providers. Interpersonal systems are dependent upon roles, interactions, communications, transactions and stress. A role is defined as a set of behaviors expected of persons occupying a position in a social system (King, 1981, p. 147). The role of parent is to foster the growth and development of a child and assist that child to achieve a positive self-image. The role of the nurse is based on knowledge, skills and values of the profession and is enacted during interacting relationships with clients to achieve goals. Both parent and nurse

are in interaction with the adult schizophrenic child and both view the clients stressors from a different perspective.

Stress is a dynamic environmental state in which the individual interacts with others and with situations in the environment to maintain growth, development and performance which are events, persons or objects which cause a narrowing of perception and limit rational decision-making. The illness event of schizophrenia is a stressor which interferes with the client's interactions with others, including the nurse.

As a member of a family unit from birth, a human being develops perceptions and values based on family experiences. King (1981) considers the family a social system because it exhibits structure, status, roles, and social interaction. Beliefs and customs are transmitted to the children with in the primary group of the family as social experiences occur. These early experiences plus the child's biological inheritance greatly influence the individual's behavior. The perceptions and judgements that develop from early family interactions are pertinent variables affecting the individual's actions and reactions. King believes that knowledge of the influences of social systems on the behaviors of individuals and groups is relevant to nursing. Figure 4 illustrates a diagram of interacting personal, interpersonal and social systems.

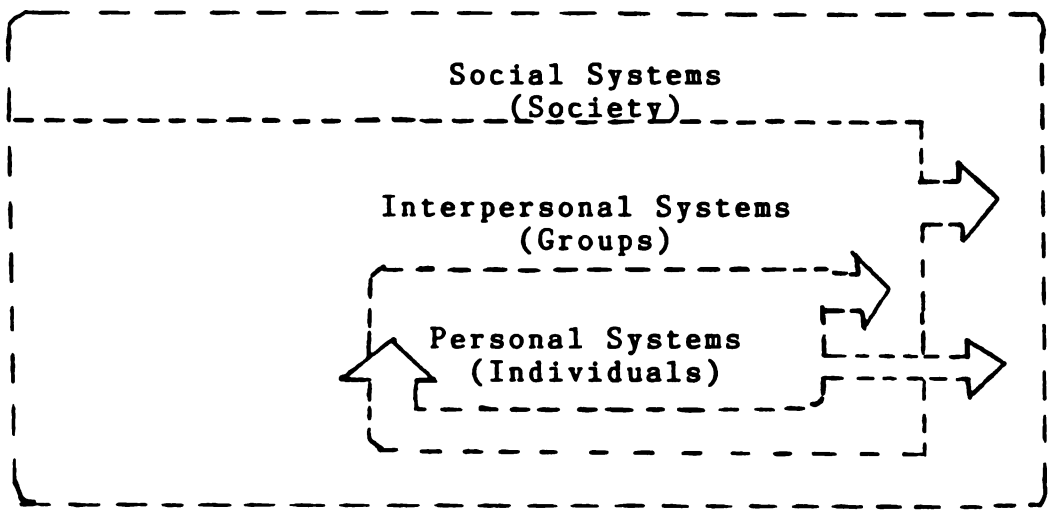

Figure 4. A conceptual framework for nursing: dynamic interaction systems, King, 1981.

In her goal attainment theory of 1981, King views the nurse as working in mutuality with the client, the client's family members, and the society to explore means toward goal attainment and correct or minimize probelms (disturbances). Goal attainment involves communication with client and family members to prevent and resolve problems. King (1981) defines communication as a process whereby information is given from one person to another, directly or indirectly (p. 146). Communication relating to specific nursing situations between nurse and client and nurse and family member provides information that assists individuals to make decisions leading to goal attainment.

Communication is the information component of the interactions between client, family members and nurse which facilitates clearer perceptions of each others judgements and actions. As the nurse communicates with the client and his or her interpersonal and social systems, the perception of the nurse more closely approximates the client's reality and reaction to the environment. Greater understanding of the client's situation, derived from interactions with all three interacting environmental systems, leads to transactions and mutual goal setting with the client. Nurse and client are then able to explore and agree on means to achieve those goals.

Compliance with the prescribed medication regimen is the goal to be attained with noninstitutionalized schizophrenic clients. Compliance with the medication regimen has been shown to reduce the need for re-hospitalization among chronic patients (Hogarty and Goldberg, 1973; Davis, 1975; Hartmann, et al. 1980). Yet many schizophrenic clients do not follow the prescribed regimen and require repeated impatient treatment. Interpersonal interactions between parent and nurse regarding the schizophrenic client's situation provide additional feedback that assists the nurse to effectively plan toward goal attainment in mutuality with the noninstitutionalized schizophrenic client.

Implications for Nursing: Relationship to the Nursing Process

The problem of compliance with the medication regimen by noninstitutionalized schizophrenic clients is a complex one. Nurses can utilize family systems theory and King's goal attainment theory to implement the nursing process and to assist the client to achieve a positive health outcome. In addition to perceptions, judgments, knowledge, skills, and abilities brought to the relationship by the nurse and the schizophrenic client, the parent's perceptions are sought to improve accurate assessment of the client's situation.

The nurse assesses the parent's perception of variables that influence his or her adult noninstitutionalized child's compliance with the medication regimen. Variables to be examined include the parental perception of the adult noninstitutionalized child's insight into the diagnosis of schizophrenia, the response to the nature of the medication regimen including the need for medication, side effects of the medications, and the complexity of the medication regimen, and finally, the parental perception of the child's satisfaction with noninstitutional care. In this assessment phase of the nursing process, the nurse, the parent, and the client collaborate. An effective plan of care is only as valid as the assessmet from which

it is drawn.

Communications with parents provide a broader basis for planning and mutually indentifying problems and goals during interactions with the client. The means to achieve goals are explored and agreed upon with the client based on a more complete understanding of the client's personal, interpersonal and social systems. The nurse is aware of perceived variables influencing compliance behavior and is able to facilitate behaviors that maintain health. It is at this point that transactions between client and nurse begin. According to King, compliance behavior is an indication of transaction. Effective interactions pave the way for compliance with the medication regimen to control the symptoms of chronic schizophrenia, thus increasing the client's ability to live in homeostasis with the noninstitutional environment.

Summary

In summary, King's theory of goal attainment and family systems theory provide a framework for nursing care. Family systems theory provides the nurse with a guide to assess the client in relation to interfacing subsystems, systems, and suprasystems. King's conceptual framework suggests assessment of the client's personal, interpersonal, and social systems and outlines the interaction process whereby perceptions and communications lead to mutual goal setting and goal attainment. This conceptual framework provides the nurse with a rationale for exploring the relationship between both selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents.

CHAPTER III

REVIEW OF THE LITERATURE

Overview

In this chapter relevant literature will be presented pertaining to the maintenance of the chronically ill schizophrenic client in the community and the antipsychotic medication regimen. Next, literature concerning compliance measures and compliance behavior among psychiatric clients will be reviewed. Literature will also be included to support the exploration of parental perceptions of the adult child's compliance with a medication regimen. Finally, the review will include literature pertaining to the study variables of insight into the diagnosis of schizophrenia, response to the nature of the medication regimen: need for medication, side effects of medications, and complexity of the medication regimen, and satisfaction with noninstitutional services as perceived by parents to relate to compliance. Recent research findings and analysis of the results applicable to these concepts will be presented.

The Noninstitutionalized Chronic Schizophrenic Client

Successful pharmacological treatment of acute psychotic episodes has allowed psychiatric clients to be discharged to community living situations but has not proven to be a cure for schizophrenia. Treatment of chronic schizophrenia is aimed at the control of symptoms of the illness with antipsychotic medications. The results of several studies have documented the significance of medications in preventing rehospitalization among chronically ill schizophrenic clients.

Caffey et al. (1964) studied 259 inpatients with schizophrenia in a Veterans Administration Hospital; 171 patients receiving placebos and 88 receiving maintenance antipsychotic medications. It was hypothesized that the placebo group would relapse within the four-month study period. Relapse occurred among 45% of the 171 patients switched to placebos in comparison to 4 of the 88 patients (5%) treated with maintenance antipsychotic medications. Random assignment and double blind procedures were utilized. The population consisted of both male and female patients who had already stabilized on the antipsychotic medication chlorpromazine or thioridazine. No report is made of significance levels, drop-out rate or procedures used to compare the two study groups prior to implementation of the study design.

Hogarty and Goldberg (1973) carried out a study of 361 schizophrenic patients in United States hospitals to determine the effect of antipsychotic medications on prevention of relapse among chronically ill schizophrenic patients. Random assignment was used to select patients for the chlorpromazine drug group (N=187) and the placebo group (N=174) and double-blind controls were implemented over a twelve-month study period. The authors concluded that maintaining clients on antipsychotic medication was effective in preventing relapse as evidenced by a 67% relapse rate among patients in the placebo group as compared to a 30% relapse rate among patients in the drug group. Variance between original study groups and dropout rates were not reported.

In a review of double-blind maintenance phenothiazine drug studies, Davis (1975) evaluated twenty-four studies of schizophrenic patients done in a variety of settings: private, state, Veterans Administration Hospitals; and inpatient and outpatient facilities in the United States and England. All twenty four studies divided subjects into one group of patients maintained on a phenothizaine and one group of patients maintained on double-blind identical placebos. In all studies, many more patients relapsed on placebo than on medication. The Fisher exact test was used to compute a phi correlation for each study. A positive correlation

indicates that the drug prevents relapse. Phi correlations for the twenty-four studies ranged from 0.16 to 0.59. No negative correlations were found. The Fleiss modification was used to compare studies since rate of relapse varied from study to study. The findings showed that the degree of association between studies was similar and that there was an overwhelming statistical evidence that antipsychotic drugs prevent relapse in schizophrenia. Overall, 65 percent of patients who received placebos relapsed while only 30 percent who received maintenance antipsychotics relapsed.

Guidelines for clinical practice discussed at the German Research Foundation's 1979 workshop are as follows: A patient with chronic schizophrenia of at least a year's duration should be continued on maintenance therapy indefintely to prevent relapse of schizophrenic symptoms (Hartmann, et al. 1980). In addition, Hartmann concludes that the effiacacy of antipsychotic drugs in forestalling relapse may preclude further placebo controlled research studies.

In summary, antipsychotic medications have become an accepted method of treating the symptoms of schizophrenia for the chronically ill patient. However, there still remains a large number of chronic schizophrenic patients who do relapse because they do not follow the prescribed plan of treatment with antipsychotic medications. As Torrey (1983) states, the person who does not

take the prescribed antipsychotic medications has a significant chance of being rehospitalized. Therefore, interventions to ensure long-term compliance with therapy are crucial to preventing relapse among chronically ill clients with schizophrenia.

Compliance as a Health Care Concern

Client compliance with therapeutic regimens has been a concern in potentially all areas of health treatment and outcome management. A considerable volume of literature exists on the subject of compliance with the therapeutic regimen (Blackwell, 1976; DiNicola and DiMatteo, 1982; Haynes, Taylor and Sackett, 1979). DiNicola and DiMatteo (1982) identify the terms adherence, obedience, cooperation, concordance, collaboration, and therapeutic alliance as being used interchangeably with compliance by health care providers.

The conceptual definition of compliance is the subject of controversy, Linden (1981) differentiates therapeutic compliance from other types of compliance. Therapeutic Compliance is client behavior that meets the therapeutic recommendations specifically identified for a particular client. Standard compliance is client behavior in terms of the general expectation for the treatment regimen. Aspirational Compliance is defined as the patient's performance based on his or her own expectations. These definitions all relate to patient

performance, i.e. observable behavior of the patient.

The nursing diagnosis of noncompliance has been challenged as labeling the client uncooperative and as implying coercion in the nurse-client relationship (Stanitis and Ryan, 1982). Compliance, however, is the usual term referred to in the health literature and the term 'patient compliance' is the key concept utilized in the Index Medicus for information related to a client following health care advice.

Although there is a growing body of literature on patient compliance, there are few empirical studies that provide information on compliance behaviors of mentally ill patients. In the existing studies involving psychiatric patients, compliance has been defined as: adherence to a prescribed treatment regimen (Paolillo and Moore, 1984; Youssef, 1983); and as taking medication as prescribed (Blackwell, 1972). The definitions do not imply judgement or fault by either client or health provider but do support that client behavior coincides with health advice (Haynes, et al., 1979).

In summary, the study of compliance has many components - client participation, provider expectation, provider repsonsibility, client choice -- but the definitions used in most studies involving psychiatric patients most commonly are descriptive of the extent to which the client's behavior coincides with therapeutic recommendations.

Approaches to Data Analysis

There are two broad approaches to the analysis of research data. Quantitative data consist of numerically quantified data that can be analyzed using statistical procedures for the purpose of describing phenomena or assessing the magnitude and reliability of relationships among them. Statistical procedures enable the researcher to reduce, summarize, organize, evaluate and interpret numerical information obtained from empirical observations and measurements. Some investigators argue that statistical analysis is the only acceptable method of objectively and scientifically determining the relationshps between variables, while others assert that the use of numbers disguises potential bias and lacks sensitivity to the understanding of real relationships (Polit and Hungler, 1983). Although numerous methods of statistical analysis are available to the investigator, appropriate statistics must be used for analysis of the data and an adequate sample size must be available.

Qualitative data consists of detailed descriptions of people, events, situations or observed behavior (Polit and Hungler, 1983). Qualitative analysis lends itself to the discovery of important underlying dimensions and relationships, but is criticized for being subjective and difficult to work with using a large sample. Other criticisms of qualitative analysis are that qualitative methods are inappropriate for

establishing causality or testing hypotheses, and that qualitative methods tend to yield vast amounts of data from small, non-randomized samples limiting the generalizability of the findings.

An understanding of human behaviors is probably best advanced by judicious and combined use of both qualitative and quantitative data (Polit and Hungler, 1983). A review of the literature concerning medication compliance among psychiatric clients finds a limited number of empirical studies, some of which are highly quantitative and others highly qualitative in approach.

Compliance Measures

Blackwell (1972) reported on a variety of methods which have been used to detect that an individual is not taking medication as prescribed including interview, tablet estimates, stool markers, urine testing, and monitoring of the frequency of dispensing prescriptions. When these methods are used, Blackwell (1972) found that 25-50 percent of the population studied consisted of 'drug defaulters.' While the majority of the methods cited appear to have been quantitative in nature, there is a lack of information regarding the empirical studies for which these methods were used.

Gordis (1979) reported techniques of measuring medication compliance and listed two major methods of measurement, direct and indirect. Direct methods of

measuring the drug itself, its metabolites, or its markers in urine or blood are subject to differences among individuals in absorption, distribution, metabolism, and excretion of the medciation. Indirect methods of measuring compliance include physician assessment, therapeutic outcome, pill counts, and interviews. Gordis (1979) identified environmental effects, effects of concurrent therapy, provider compliance or non-compliance with current expert opinion, and unexpected client sensitivity to treatment as also influencing compliance behavior. Physician assessment of client compliance was found to be the least accurate method of measuring compliance and not much better than chance estimate (Gordis, 1979). Reasons for the discrepancy between physician estimates of compliance and actual compliance rates may be due to lack of knowledge concerning the magnitude of the compliance problem, to a low degree of suspicion that patients are not taking their medication, or to limited involvement in the physician-patient relationship (Davidhizar, 1982).

Experienced therapists were shown by McClellan and Cowan (1970) to be in error up to 20 percent of the time when predicting whether outpatients were taking their drugs. McClellan and Cowan used a convenience sample of outpatients seen in a Veterans Administration

Mental Hygiene clinic over a three year period. Of 355 patients eligible for the study on the basis that they were taking one or more phenothiazines and/or imipramine, 286 patients (81%) actually were tested. Of the 19% not tested, the largest group was made up of patients who did not have an appointment in the clinic during the time of the study. Only one patient refused to participate. The Forrest test (a urine screen that will measure phenothiazines and imipramine over the preceeding 24 hour period) was used in addition to verbal report of the patient to measure compliance. Each therapist was also asked to indicate if he thought the patient was taking his medication as prescribed. The results for all of the drugs were that only 8% of the patients tested were found not to be taking any of the prescribed drug. Nevertheless, 24% were judged to be taking significantly less than the amount prescribed. Therapists erred in 20% of their predictions. Of the 56 wrong predictions, 40 (71%) erred in the direction of believing that the patient was not taking this drug or drugs as prescribed when in fact he was. Sixteen wrong predictions (29%) were in the directions of believing the patient was taking his medication as prescribed when in fact he was not.

Limitations of McClellan and Cowan's study are

that a convenience sample was used which may not be representative of the population and that not all patients were schizophrenic and not all were chronically ill. Compliance percentages between medications and prescribed drug or therapist prediction were reported. The professional discipline of the therapists was not clear. Still, it is significant to note that providers were not highly reliable predictors of compliance behavior by their patients. The indirect method of using therapeutic outcome for a measurement of compliance poses significant problems to the psychiatric patient. Outcomes may depend on other factors including the variability of the symptoms of the mental illness. Dunbar (1979) cautions against the use of therapeutic outcome as a measure of compliance due to the fact that the clinician may not seek the optimal therapy and because some patients may not achieve a therapeutic goal even though they are fully compliant.

Studies on pill counts were compared to studies of urine and blood tests for accuracy in measuring compliance behaviors (Gordis, 1979). Problems occur when the patient does not bring their pill container to the appointment with the provider leading to a lack of information for the pill count method. As Blackwell (1972) points out, an empty prescription container does not guarantee compliance with the medication regimen.

Glanz (1980) believes that clinicians can obtain valid information by interviewing the client. Interview studies reviewed by Gordis were conducted with mental patients, patients on PAS, and with pediatric patients. There was agreement that noncompliers can be identified by interview techniques but that the interview method of measurement is less valid for identifying persons who do comply. Generally, clients overreported compliance and underreported noncompliance (Gordis, 1979). Haynes et al. (1979) found the self report by interview to be a more reliable measure of compliance than blood pressure, urine tests, or blood tests when compared to pill counts. In a series of randomized trials, stated compliance by interview correlated best with pill count ($r=.74$, $p<.0001$). Their sample was of 135 newly treated male hypertensive patients who were studied over a six month period. On the assumption that the pill count is the most accurate measurement of compliance, interviewing was found to be a useful approach to assessment of compliance with antihypertensive therapy.

Valid assessment of compliance by interview depends on what questions are asked and how they are asked (Glanz, 1980). However, accuracy of patient report by interview depends on memory and clear thought processes. Erratic medication taking may be related to a poor memory or impaired thought processes which in turn will

hinder data collection regarding the compliance level. As Blackwell (1972) points out, illness is a factor associated with compliance behavior. The nature of the thought disturbances of schizophrenia make the self report by interview method of measurement a questionable measure of compliance behavior for schizophrenic persons.

Dunbar (1979) identifies several approaches to assessing compliance with a drug regimen: biological indexes, clinician ratings, patient self report, pill counts, and direct observation by utilizing staff members for the hospitalized patient or family members or friends for the at-home patient. No studies were uncovered by the author that utilized family members in assessing compliance with a medication regimen among any psychiatric patients. Davidhizar (1982) suggests that compliance by persons with schizphrenia is a research issue for the nurse, and based on her review of medical and nursing studies on compliance by schizophrenic persons, identifies a need to compare factors identified by patient, doctor, nurse, and family members as responsible for the noncompliance of specific individuals to determine differences in perception.

A review of literature on compliance measurement is limited by the comparison of one imperfect measure to another. Although authors have found client interview to be one of the most satisfactory methods for measuring compliance, the effectiveness of patient interview is

more problematic with schizophrenic clients. Comprehensive interviews with parents may provide one of the most satisfactory qualitative methods for measurement of compliance by schizophrenic persons if done with attention to interview attitude and question phrasing, but the interview method is limited by its lack of generalizability and its inappropriateness for establishing causality or testing hypotheses.

Parental Perceptions of the Noninstitutionalized Schizophrenic Client

Families of psychiatric patients have long been a focus of interest and concern to health care professionals (Clausen and Yarrow, 19855; Kreisman and Joy, 1974; Goldstein et. al., 1978). Increasingly, providers are systematically working with members of a patient's family for the purposes of prevention, treatment, management and rehabilitation of biospychosocial problems (Doherty, 1985). The deinstitutionalzation movement has resulted in schizophrenic clients returning to their homes and their home communities and having more interactions with their parents and siblings. However, little research has been done to determine perceptions of these family members regarding the management and rehabilitation of the schizophrenic in the community environment.

Evans and Bullard (1960) studied the family as a

potential resource in the rehabilitation of the chronic schizophrenic client. The families of twenty-four randomly sampled inpatient schizophrenic clients between the ages of 25 and 50 were interviewed by a psychiatric social worker to determine their perception of the patient's illness, the number of family visits to the client and their attitude toward the patient's release from the hospital. All patients were being treated with tranquilizing drugs and social therapies for six months with the aim of rehabilitation and discharge. Evans and Bullard found that although seventeen of the twenty-four patients had lost one parent, and five had lost both parents, the remaining parent, the siblings and collateral relatives remained interested and did visit the client even after prolonged hospitalizations. Half of the clients were visited at least once a week and an additional five patients were visited once a month. Female patients were visited more often than males, but the numbers of male and female patients in the study were not identified. A wide variety of opinion was expressed regarding family perceptions of the patient's illness. Seven families said that the illness was incurable while fifteen families felt the illness to be curable or did not know. There was a correlation between the length of the illness and family perceptions of the client's chances of recovery. The longer the patient had been hospitalized, the less

likely the family was to feel that there was a chance for recovery. Evans' and Bullard's results are in accord with studies that indicate that the prognosis for a patient becomes worse as the length of hospitalization increases. Most families who saw the patient's illness as being curable favored release, and families of women patients favored release more often than families of men, who expressed fear of aggressive acts. Family members who frequently visited the patient were most interested in the client's discharge, and were found not to have unrealistic expectations of the clients. The family's attitude toward release did not correlate with the patient's age or the length of hospitalization.

Limitations of the Evans and Bullard study include a small number of cases (24) making the data unsuitable for statistically significant data analysis, and a failure to randomly select families for the study. Although the clients for the study were randomly selected, data were not broken down into discrete categories of parental perceptions versus sibling perceptions versus collateral relatives perceptions. The specific type of schizophrenic diagnosis was identified but no relationships were identified between the family member's attitude toward discharge and the degree of regressive symptomology demonstrated by the client prior to treatment. The most significant contributions of this study are that it does demonstrate that there are family members

who maintain an interest in their schizophrenic relatives and that these family members do have perceptions that may assist the health care professional to manage the client's illness in the community.

Deykin (1961) described the social adjustment of thirteen schizophrenic patients who had been hospitalized for five years or more, transferred to an acute treatment center for six months or one year, and then discharged into their home communities. In this descriptive study, family members or persons in the community who had close contact with the patient after discharge were interviewed by a social worker. Of the thirteen patients, nine were living with close family members and four were living in the community in a half-way house or by themselves. Eleven of the thirteen had attained satisfactory adjustment in terms of personal appearances and psychiatric functioning, social funtioning (which included patient's responsibility for himself and others, taking his medication, and employment), and interpersonal relationshps (the degree of involvement with his environment and his interaction with family members). Two patients had not attained satisfactory adjustment, although no explanation was given for their failure to adjust, and one of these two had to be rehospitalized. The factors identified as contributing to the successful discharge and satisfactory adjustment by the patient were the use of

medications, the family's tolerance and support, and careful discharge planning by the social worker. Although suffering from the limitations of a qualitative study, Deykin's study demonstrates that information is obtained from persons including family members who have close contact with noninstitutionalized clients. Deykin suggests that proper investigation of family perceptions might increase the discharge rates of chronic schizophrenic clients. It is this author's contention that assessment of family perceptions, specifically those of concerned parents, will not only increase discharge rates but will decrease recidivism rates by decreasing the distortion in communication and interaction that occurs between the schizophrenic client and the health care provider.

Hatfield (1979) surveyed family caregivers of schizophrenics who were members of a local self-help group to determine their needs for coping with their ill relatives. Of 250 mailed questionnaires, 107 were returned. Eighteen questionnaires were not usable leaving 89 usable returns for data tabulation. Respondents were relatives most responsible for the patient's care. They were parents of the schizophrenic client in 85% of the cases; the rest were spouses, siblings, and other close relatives. Respondents were primarily female, middle to late middle age, middle to upper income, with husbands employed in professional, government or military

occupations in Virginia and Maryland. The typical patient in the study was male (71%), in his 20's (55%), and ill between 1 and 9 years (55%). These mostly chronic patients were living in parental homes (57%) and in hospitals (17%), with the remaining 26% living in group homes or independently. Hatfield found that family members often remain interested and willing to help their relatives but are not included when it comes to planning for treatment and rehabilitation of their ill relative. Among the needs identified by the family members were the need for someone to talk to, someone to share feelings and problems with, and the need for knowledge and practical techniques for coping with the illness of their family member.

Although this study particularly addresses the need for support of caregivers and it limited to one sample of respondents that is not representative of all relatives of schizophrenic individuals, Hatfield acknowledges a need for collaboration with families regarding the chronic schizophrenic client. An exchange of information with interested parents and other family members serves not only to meet the needs of the family member for information and someone to discuss problems with, but it also provides first hand knowledge of the schizophrenic client to the health care professional.

Holden and Lewine (1982) surveyed families of chronically mentally ill individuals to determine how they evaluated their contact with mental health professionals and the services received. Of 500 surveys mailed to seven conveniently-selected family groups in five different geographical areas of the United States, 41% were returned which is a typical response rate for surveys of this kind. Survey questions were in a forced-choice format with open-ended questions. Additional comments were elicited regarding concerns not covered in the survey. Respondents were typically female and mothers of the ill individual. At the time of the survey, 33% of the ill patients were living at home, 40% were in some type of group living arrangement, and 27% were inpatients. The majority of the ill relatives had received a diagnoses of schizophrenia (71%); the remaining 29% had multiple diagnoses, diagnoses unknown to family members or diagnoses of chronic mental illness other than schizophrenia. Seventy-one percent of the ill relatives were male, and 56% were between the ages of 25 and 34. The results of Holden and Lewine's study were that family members reported dissatisfaction both with the nature and level of their involvement in treatment; they reported they felt left out and ignored by professionals and that they lacked confidence in individuals making the decisions regarding the ill family member. Ninety-eight percent of the family members

who reported dissatisfaction with professional preferred increased contact. Family members were dissatisfied with failure of professionals to provide information about the illness and its management, and expressed concern about the lack of follow-up monitoring of medication with 95% of ill individuals having been prescribed medication. Sixty-one percent of the respondents who indicated dissatisfaction with the use of medication (n=18) reported that their greatest concern was that the medication was not checked properly. Thirty-two percent of those dissatisfied in Holden and Lewine's study felt that there was too much medication, 9% felt that there was too little medication, and 4% felt that medication was changed too frequently.

Survey data of this sort are limited by sampling bias since the respondents are not representative of all family members of schizophrenic clients: they were predominately white, well-educated mothers who were actively involved in mental health issues. No correlations were calculated to explore the interrelationships among variables. Still, qualitative analysis demonstrates that parents, particularly mothers of schizophrenic cleints, are not satisfied with available professional resources and do not feel that they receive enough information about their family member's illness or its management, including medication management.

Family members do perceive that ill clients receive too much medication, or too little medication, or that medication is changed too frequently and yet there is no evidence that this information is received by the health care professionals.

Studies such as these conducted by Deykin (1961), Hatfield (1979, and Holden and Lewine (1982), lend support to the need for collaboration with family members toward the achievement of desired client outcome. Doherty (1985) refers to the provider/patient relationship as a triangle rather than a dyad, with the family as a part of the core of therapeutic intervention. Doherty and Baird (1983) identify four levels of primary care involvement with families. The first level is that of minimal involvement with families only as necessary and practical, the level at which the schizophrenic client's family members currently feel they are involved. The second level moves toward a focus on the patient and the family as persons with feelings and interpersonal bonds that need attention. It is at this level that families need information about the patient and can, in fact, provide useful information to the provider. Interaction with parents to determine their perceptions of their schizophrenic child's situation represents a willingness to collaborate with patients and their families to provide effective health care.

According to Doherty and Baird (1983), the move from level two to level three represents a shift to a more humanistic approach that emphasizes effective care of patients and their families in addition to treating and preventing disease. The fourth level of intervention with families represents a shift into a systems perspective where one sees patients and oneself as members of larger systems, and is aware of one's own participation in the therapeutic triangle, the health care system, one's own family system and the larger community systems (Doherty, 1985). This is the level for true collaboration and systematic family intervention which is most conducive to goal attainment.

Little research exists to describe what occurs between professionals, patients and families. Health care professionals are only beginning to recognize the potential contributions of family members. The schizophrenic client has been isolated by his/her illness; his or her parents are in a unique position to interpret and clarify the needs and concerns of their schizophrenic child to the professional in order to achieve desired health outcomes.

In summary, research is needed to describe what occurs between professionals, patients and families to show that intervening with families does make a difference. Exploring perceptions of family members

of the chronically ill schizophrenic client is a step toward client compliance with the medication regimen and client homeostasis with the community. Existing data are primarily qualitative in nature and differences among the perceptions of mothers, fathers, and siblings or other family members are not clear. No studies were found which examined family or parental perceptions of compliance behavior among chronically-ill schizophrenic clients. Still, there are data to support the premise that family members, particularly parents, do have information about their ill relatives which they would like to share with professionals (Hatfield, 1979; Holden and Lewine, 1982). Health care professionals, on the other hand, need additional information to identify variables that relate to compliance with medication regimens among noninstitutionalized schizophrenic clients if they are to decrease recidivism rates and maintain clients in the community. An examination of parental perceptions of selected variables related to the adult noninstitutionalized schizophrenic child's compliance with a medication regimen is deserving of further study.

Variables Affecting Compliance With The Medication Regimen Among Psychiatric Patients

Numerous factors have been identified in the research as relating to compliance behavior among

psychiatric patients. Yet, past research has left many unanswered questions. Noncompliance with treatment regimens is a frequent occurrence among schizophrenic clients in spite of what health professionals consider to be proven benefits of the phenothiazine medications in treating the symptoms of schizophrenia. The deinstitutionalization movement of the 1960s has resulted in more chronic patients living in the community who are responsible for their own care. Problems for the outpatient include mistakes in administration, self-imposed dosage adjustments, and omitting or stopping medication (Davidhizar, 1982). Although it should not be assumed that compliance always results in a subsequently improved state of health, it is known that recurrent episodes of illness are related to the client's noncompliance with medications (Davis, 1975).

While there is an abundance of literature on factors influencing compliance with medical regimens, there is a limited amount of research done specifically on variables related to compliance behavior for individuals with schizopohrenia. Fewer than thirty studies were found in reviewing literature between 1958 and 1986 concerning compliance behavior among psychiatric patients (Haynes, Taylor, and Sackett, 1979; Davidhizar, 1982). Among the available research studies of variables affecting compliance with the medication regimen

by psychiatric patients, few studies build on previous studies and few correlates are drawn between variables. Literature will be reviewed for this project to explore the selected variables of insight into the diagnosis of schizophrenia; response to the nature of the medication regimen: need for medications, side effects of medications, and complexity of the medication regimen; and satisfaction with noninstitutional care by adult noninstitutionalized schizophrenic children as perceived by their parents.

Insight Into The Diagnosis of Schizophrenia

Van Putten, Crumpton and Yale (1976) studied the extremes of drug compliance by two groups of drug-responsive patients -- twenty-nine drug refusers who invariably discontinued medications only to be readmitted several months later, and 30 drug-compliers who habitually came in for their medication refills or injections. The hypothesis was that grandiosity is associated with maintenance drug refusal and that dysphoric effects of depression and anxiety are characteristic of drug compliers.

All subjects in Van Puten, Crumptom and Yale's study were male, met the World Health Organization's criteria for the diagnosis of schizophrenia, and were followed both inpatient and outpatient for at least two and one half years. Of 101 potential study patients, the extremes of compliance and noncompliance behaviors

were selected for study which limits generalizability to clients who sometimes comply and sometimes do not. Drug compliance was assessed by the staff member who had the closest relationship with the client (usually the treating psychiatrist or social worker) and staff members were unaware of the hypothesis being tested. The two groups were approximately the same size and no drop-outs were reported.

The Brief Psychiatric Rating Scale was used to rate degree of grandiosity, the Global Assessment Scale was used to rate the clients' level of functioning at the time of discharge, and the client was evaluated as having insight if he acknowledged some awareness of the illness. The findings of the three year study were that the psychiatric clients who rated highter on depression and anxiety were more likely to be compliant, and the clients who refused their drugs rated higher in grandiosity. There was a negative correlation between grandiosity and anxiety ($r=-.59$, $p<.0005$), and between grandiosity and depressions ($r=-.57$, $p<.0005$). Anxiety and depression were positively correlated ($r=.73$). Insight into illness was found to be a weaker predictor of drug compliance than grandiosity or anxiety yet still statistically significant by the chi-square test ($x^2=7.77$; $df=1$; $p<.01$). There was found to be a negative correlation between grandiosity and insight ($r=-.52$, $p<.0005$). Drug refusers were found

to have less insight into illness at admission as they vigorously denied mental illness, and the drug refusers were found to be hospitalized considerably more often against their will, to be notably sicker at discharge, and to be less cooperative in attitude toward the psychiatrist. Van Putten, Crumpton and Yale concluded that grandiosity and anxiety were the best predictors of compliance behavior among chronic schizophrenic clients, but that insight was also a significant predictor of the extremes of compliance behavior.

The major limitations of Van Putten, Crumpton and Yale's study (1976) are that it was not a prospective study but instead supported clinical observation, and that there was no scaled data on the status of insight into illness at the time of discharge but only the observation that the client in some way acknowledged that he had been ill. Scaled data on insight into illness might have led to more statistically significant results. It is interesting to note for the purposes of this study that compliance was assessed by the staff member having the closest relationship to the client utilizing the observations of significant others.

Lin, Spigma and Fortsch (1979) studied 100 persons with chronic schizophrenia for insight into illness, perceived benefits of medication, and for the perceived relation between those two factors. They asked the

chronic patients three questions to assess insight: "Do you think you had to be in the hospital?", "Do you think you had to see a psychiatrist?", and "Do you think you had to see a Doctor?". Only 31 of 100 patients were found to have insight into their condition as evidenced by a yes answer to any of the three questions. The patients were also asked if they benefitted from medications. Conclusions of the researchers were that patients who had insight or who reported that they benefitted from medication were more likely to report adherence to their prescribed medication regimen. This study suffers from the limitations of qualitative analysis and it is questionable as to whether any one of the three questions asked to determine the clients insight are reflective of actual insight into the diagnosis of schizophrenia as clients may think they should see a doctor for 'nerves' or some other symptom unrelated to their schizophrenia. These questions might be better used to identify perceived needs of the client rather than insight into the diagnosis of schizophrenia.

McEvoy, Aland, Wilson, Guy, and Hawkins (1981) interviewed chronic schizophrenic inpatients (n=45) to determine their understanding of their illness and need for treatment. All study participants met the DSM III criteria for schizophrenia and all had been readmitted to an institutional setting from three to thirty-four

years following first hospitalization. The 23 men in the group had a median age of 33 years, while the 22 women in the group had a median age of 40 years. All paitents had been receiving an antipsychotic medication for at least three months before interview. The client's degree of insight was rated from poor (0) to fair (0.5) to good (1.0). Clients were judged to have good insight if they reported that they had an illness that affected mental functioning; that the illness led to the hospitalization, was still present, and would probably continue to be present in the future; and that the medication they received at least minimally diminished the symptoms of the illness. The results of the study showed that only 27% of the clients had a good understanding of their need for admission to the hospital, and only 13% felt that they had a mental illness. Thirty-three percent of the subjects felt that they needed medication and 29% felt that they would need medication in the future. There was a small positive correlation between patient beliefs that they had a mental illness and their reported need for medication ($r=.32$, $p>.05$). There was reported to be no significant difference beween the scores of males and females in the study. No reliability or validity was reported for their 11 question open-ended intervieweing instrument. The reseachers concluded that the majority of schizophrenic clients approach the question of drug

compliance with no real realization that they have any illness or need for treatment.

The study by McEvoy and associates (1981) is limited by the fact that all the clients interviewed were hospitalized at the time of interview and although they were on medications, it can be assumed that their illness was not sufficiently controlled to the level at which they could live in the community. Therefore, their insight and judgement were likely to be impaired at the time of interview. The question remains as to whether insight of the discharged client living in the community is any better. If clients are living in the community with little insight into their illness, then this study supports the fact that they would also report little need for medication to treat that illness.

Hartigan del Campo, Carr and Correa (1983) used a convenience sample to study a small group of well-documented schizophrenics to determine their attitudes toward illness and their understanding of their illness and their medications. The sample population consisted of 25 hospitalized male patients at the Veterans Administration Medical Center in Biloxi, Mississippi. All were diagnosed as schizophrenic prior to the age of 30 and were under the age of 35 years when selected for the study. Of 46 eligible patients, only 25 formed the study group because 11 who were eligible left the

hospital against medical advice and 10 refused to participate in the study. Researchers examined demographic data with the major findings that 68% of the study participants were unemployed (n=17), and 76% (n=19) were on compensation or some form of government assistance. Forty percent of the veterans (n=10) reported living with parents at the time of hospitalization.

Patients were asked to state the reason for their hospitalization after the administration of an MMPI and Shipley Institute of Living Inventories. The subjects were divided into two categories based on their responses: those who accepted (n=13) and those who denied their illness (n=12). No significant personality variables were found between the two groups. The researcher found that 80% (n=20) either failed to continued advised treatment, discontinued taking medications completely, or discontinued both treatment and medication. This information was obtained by patient report or documentation in the record. Investigators were not able to document failure to comply in the remaining 20% who reported compliance although two of the five had previous documented histories of failure to comply with outpatient treatment. When asked whether they felt they had a psychiatric illness and to identify the reasons for their current hospitalization, 76% (n=19) stated that they had a psychiatric condition but 48% denied that their current hospitalization was for the treatment

of that condition. Hartigan del Campo and associates concluded that significant numbers of previously hospitalized schizophrenics discontinued medication, treatment or both prior to rehospitalization and that factors involved in non-compliance with treatment for this study group appeared to include patient attitudes toward an understanding of their illness with 44% reporting that they did not understand their condition. No correlations were reported between those who had some degree of insight into their illness and those who reported that they did have an adequate understanding of their illness.

Although this was a small-scale study, previous studies are cited and built upon. The study is one of few empirical approaches by nurses undertaken to determine how non-compliant schizophrenic patients perceive their illness and treatment. The researchers did report on the number of eligible patients who refused to participate or left the hospital against medical advice, and considered them at risk for non-compliance with treatment along with the 80% of participants who reported noncompliance with previous discharge plans. This study points to a need for further study by nurses concerning compliance with treatment among established schizophrenic clients in outpatient as well as inpatient settings.

In summary, the studies which have been done to determine how insight into the diagnosis of schizophrenia influences compliance with the treatment regimen have been done on a small scale, primarily with male hospitalized clients. Although patient interviews have been used to determine compliance, observations and reports of others close to the client have been also used. Further research is needed to determine the relationship between insight into illness and compliance with treatment, particularly with females and with clients living outside of hospital settings.

Response to the Nature of the Medication Regimen

Davidhizar (1982) identifies therapy factors as one of four major areas of research of variables influencing compliance. For purposes of this study, literature concerning need for medication, side effects of medications, and complexity of the medication regimen will be examined.

Need for Medication

In the study done by McEvoy, Aland, Wilson, Guy and Hawkins (1981), 45 chronic schizophrenic inpatients wre interviewed individually using a semi-structured interview guide regarding their need for medication. The sampling method was not identified. Although 98%

were aware that they were taking medication, only 33% reported any need for medication when asked the following questions: "Do you believe you need to take 'nerve medicine' or medicine for a mental illness?", Does the medicine you take here do you any good?", and "When you are discharged, will you need to take medication?". Only 29% of the participants believed that they would need medication in the future. All patients had been receiving antipsychotic medications for at least three months prior to interview. Of the 23 men and 22 women in the group, no significant differences were reported between scores of males and females in the study. As previously reported, the clients' beliefs that they had a mental illness correlated positively with their reported need for medication ($r=-.32$, $p<.05$). The researchers concluded that those patients who reported they were ill were more likely to report a need for medication.

Limitations of this study include a small sample size and lack of a clear sample selection process. The fact that all clients were presumably being forced to take medication by nature of their hospitalization, although the majority felt that they did not need medication, leads one to consider who was conducting the interviews and whether the client might be responding to the authority requiring him or her to take the medications when asked if he/she feels medications are needed.

In the descriptive study by Hartigan del Campo, Carr and Correa (1983), a small group of previously diagnosed male schizophrenic clients were asked if they had been taught about their medication by mental health professionals. Fifty-two percent of the convenience sample (n=25) indicated that they did not possess an adequate understanding of the medication. Questions asked by the clients in regard to their medications included the name of the medication, the reason for using it, possible side effects, concerns about the need to receive shots, and whether medication would be needed the rest of one's life. Although the sample size is small and limited to male, chronically ill clients, findings demonstrate that a significant number of clients do not understand their medications; this implies that a client who does not know the purpose or effects of the medications would be unlikely to perceive a need for that medication.

Patient education in schizophrenia and patient response to medication programs is an area which is beginning to receive formal study (Hitchens, 1977; Batey and Ledbetter, 1982; and Whiteside, 1983). Further study is needed to determine if and how compliance is influenced by the clients perceived need for medications and insight into his or her illness. In addition, evaluation of medication teaching programs

for schizophrenic clients is essential to determine if formal education increases recognition of need for medication among chronically ill schizophrenic patients.

Side Effects of Antipsychotic Medications

Michaux (1961) studied 180 adult male psychiatric outpatients in 22 Veteran's Administration Mental Hygiene Clinics to determine the relationships among and between side effects of antipsychotics, resistent attitudes to medications and dosage deviations. All clients were under the age of fifty years and had not taken medication for three weeks prior to the beginning of the study. In addition to individual psychotherapy as a primary treatment mode, the clients were randomly assigned to one of four medication groups receiving either chlorpromazine, meprobamate, pehnobarbital or a placebo on a double blind basis for eight weeks. Of 142 subjects in the main study group, the most common side effects were drowsiness, lethargy, tension, restlessness, excitement, weakness, fatigue, vivid dreams, nausea and gastrointestinal discomfort, dry mouth and headache or hangover. Two patients had to be removed from the study because of severe side effects to the medications, skin rash and depression related to phenobarbital.

Michaux found that the type of medication was not statistically significant in determining resultant

side effects. Placebo receivers also experienced some side effects. The researchers did state that the relationship between side-effects and dosage deviation was positive and significant ($p>.05$) although the correlation was not reported. Michaux found that patients with no side effects (41%) were much less likely to deviate from their prescribed medication schedule than those who experienced one or two side effects (67%).

Several limitations are apparent in the Michaux study. Of 180 participants initally identified, 37 participants were removed from the study after being identified as "excessive dosage deviators." These patients were identified as being more hostile and agressive and some refused medications after starting treatment. This group of 37 was essentially no difference, by t-test, in number of reported side effects at the end of the first week of the program, yet no explanation is given for how many doses of medications these participants received. In addition, the eight week duration of the study may not be sufficiently long for participants to experience some of the side effects of medications, particularly of chlorpromazine which was the only antipsychotic medication studied. No dosage levels were reported which might explain the finding that there no significant differences in the reported side effects of all drugs and the placebos.

Tabulations of side effects did not take into account the persistence or non-recurrence of side effects beyond the visit at which they were intially reported. Consequently, if side effects had been weighted to reflect their duration and medication dosage, placebo patients might have scored lower than active-drug patients. No evaluation of the group participants for diagnoses or personality characteristics is reported prior to beginning the medicatons. In summary, of the 142 participants in the main study groups, there was reported to be a relationship between side effects and dosage deviations, but the findings may have been more significant if extreme dosage deviators had not been excluded and if the study had been conducted over a longer period of time.

Van Putten (1974) studied a group of clients (N=85) for over a two-year period focusing on the effects of extrapyramidal side effects of the antipsychotic medications on compliance with treatment. The study was conducted at a university-affiliated Veterans Administration Hospital and study participants ranged in age from 21 to 64, with an average of three to four admissions each to a hospital for mental illness. Sixty-eight participants were female and seventeen were male. Eighty-two of the 85 participants met the criteria for the diagnosis of schizophrenia and the other three were classified as being borderline. All

were taking antipsychotic medications (clorpromazine, thioridazine, trifluoperazine or fluphenazine) for the treatment of their schizophrenia. These medications have the adverse effects of inducing extrapyramidal effects -- akathesia, akinesia, tremor, and dystonia. Van Putten found that the reluctance of 89% of the drug reluctant clients (n=39) to take their antipsychotic medication was related to the presnce of the extrapyramidal effects, especially akathesia (x^2=41.62, df=1, p=<.001). Of the 46 non drug-reluctant participants, 20% experienced extrapyramidal effects that were controlled by other medications or described as not being severe. Van Putten concluded that chronically ill schizphrenic clients are more likely to take their antipsychotic medications if extrapyramidal effects can be avoided or controlled than if the client experiences even temporary extrapyramidal effects. The more minor side effects of sedation and anticholinergic effects were not seen as posing a factor in drug refusal.

Strengths of Van Putten's study were that all clients were diagnosed as having chronic schizophrenia and were known to the staff for at least two years, and that the clients were exclusively prescribed antipsychotic medications with the addition of Artane (an antiparkinson agent) to control the extrapyramidal effects when the medication was effective. Both male

and female clients were studied. Since the clients were known to the examiners, rather bias cannot be ruled out because the examiners were familiar with the participants' treatment even though the raters were unaware of the hypothesis being tested. All participants were accounted for with no drop-out rate reported. The fact that the majority of the participants were female and none dropped out may be worthy of further study since Michaux's study (1961) of all male participants found a high dropout rate among aggressive and hostile participants.

Hartigan del Campo, Carr, and Correa (1983) studied 25 male consecutively admitted veterans hospitalized at a long-term care facility in Mississippi. All carried the diagnosis of schizophrenia on a previous admission and were under the age of 35 years when selected for the study. Participants were interviewed by Hartigan del Campo and associates regarding their medication use and additional data were collected from their medical records. Researchers found that 80% of the participants did not comply with aftercare treatment which was significant by the Chi Sqare test ($p < .01$). Two of the remaining five participants had histories of failure to comply with outpatient treatment. Per patient report, 11 of 17 patients who admitted discontinuing medications completely while in aftercare in the community gave side effects of the medications

as their rationale. This corroborates Van Puttens findings that significant numbers of patients discontinuing and altering medications do so because of the side effects of the medications. Although the Hartigan del Campo study is small, it does cite and build on previous research. The researchers utilize direct patient interview to determine the client's perceptions of variables influencing their compliance which is advocated by Glanz (1980) and Haynes et al. (1980). The study is one of the few empirical approaches by nurses undertaken to determine the perceptions of the client regarding their illness and treatment. More study by nurses and others is needed to determine perceived variables influencing compliance with the prescribed medication regimen.

In summary, side effects of medications, especially those extrapyramidal effects occurring among chronically ill schizophrenic clients are perceived by some clients to be significant enough for them to stop taking their prescribed medications. The extent of this problem is not clear. Further study is needed to determine the nature and the extent of the schizophrenic client's side effects of medications if health care providers are to recognize the problem as a variable in maintaining the schizophrenic client in the community. The intent of this study is to obtain additional perceptions from parents regarding the nature of the side effects as an

influencing variable in compliance with the prescribed medication regimen of the noninstitutionalized schizophrenic child.

Complexity of the Medication Regimen

Blackwell (1972) identifies the complexity of multiple medications or treatments as discouraging compliance among pediatric, geratric and arthritis clients. Greene et al. (1982) identified the complexity of the medication regimen, as measured by the number of drugs prescribed for a patient, to be a significant factor in compliance behavior: the more drugs prescribed for a patient, the less likely he or she was to be compliant. Greene and colleagues studied 190 chronically ill patients randomly selected by computer at an outpatient clinic. Cross-sectional data were obtained using in-home interviews and the medical records. No psychiatric clients were included in the study group. Complexity of the medication regimen was inversely correlated with compliance ($r=-0.35$, $p<0.001$) supporting the hypothesis that the more complex the regimen, the less likely the patient will be to comply. Although this study did not deal with chronic psychiatric patients, the findings do imply a need for further research to determine whether complexity of the regimen is a factor in compliance among psychiatric patients as well.

Michaux (1961) studied 142 male mentally ill outpatients selected in order as they applied for treatment and randomly assigned to one of five treatment groups. Michaux found that deviations from the prescribed dosage of medications were usually considered by the physician to have been involuntary and most typically related to changes in the patients' daily routines. Medications were prescribed four times per day in a double blind study. The prescribing physician saw the clients once per week after their psychotherapy session and the physician was then asked several yes or no questions including "Has the patient manifested any serious resistance to medication?" and "Has the patient deviated from prescribed dosage amount or frequency?". Very rarely did any patient deviate from the prescription in the direction of increasing his dosage. Virtually all deviations consisted of skipping one or more doses or days, and usually occurred in conjunction with some irregularity or change in the patient's daily routine which did not facilitate observing a medication schedule calling for one capsule after each meal and one at bedtime. Although Michaux correlated dosage deviation with resistant attitudes toward taking medications and found that resistance and deviation were positively correlated at a statistically significant level (o-.32, $p < .001$), it is significant to note that of the 142 patients

in Michaux's main study, 74 were identified by the prescribing physician as deviating from their prescribed medication plan but only 20% of those held resistant attitudes about the medications. This finding suggests that clients may deviate from a medication schedule because the schedule is too complicated to fit with their daily routines.

Limitations of the Michaux study include a lack of reported data about the extreme dosage deviators who were eliminated from the study and possible rater bias of the prescribing physician when asked to rate the clients resistance to medications and dosage deviation. The physicians apparently used a combination of patient report and their own subjective impressions to answer the yes and no questions. The results of the data might have been different if the psychotherapist or another rater had been collecting data on patient reports of deviation from the medication schedule. In summary, there is inconclusive information as to why clients deviate from their prescribed medication regimen, but the complexity of the medication schedule may be a significant variable.

Buckwalter and Kerfoot (1982) identify compliance issues as being key for the 80-90% of all psychiatric patients who are placed on medications at discharge. One of the problems they identify is that clients have difficulty remembering to take their medications

because of the differing time schedules. Clients are more likely to remember to take a single daily dose than multiple doses, but not all medications are amenable to this type of scheduling (Buckwalter and Kerfoot, 1982). Buckwalter's study (cited in Buckwalter and Kerfoot, 1982) used several predischarge teaching techniques that were found to be effective in helping clients to be compliant with the schedule of their medications. Association with a routine event, use of plastic drug dispensers, checklists, and altering the schedule of medication intake to avoid interfering with job functioning were among the techniques incorporated into teaching plans in conjunction with teaching the clients about their medications and possible side effects. Although no statistical analyses were reported and no further information is given on the size of Buckwalter's unpublished study, this study is one of very few conducted by psychiatric nurses to document techniques that appear to be effective in improving the client's ability to adhere to the medication regimen.

In summary, complexity of the medication regimen has been shown to be inversely related to compliance among chronically ill patients, but no empirical studies demonstrate a clear relationship between complexity and compliance among chronically ill psychiatric patients. Some psychiatric clients do not adhere to their

medication regimens because of difficulties in following the schedule of medication intake, and teaching plans have been developed with positive results which assist the client to remember the schedule or to alter the schedule to meet with their daily routines. More data are needed to clarify that complexity is indeed a factor in compliance as well as to determine what aspects of the scheduled regimen present the most problems for the chronically ill schizophrenic client in the community noninstitutionalized setting.

Satisfaction with Noninstitutional Services

Numerous aftercare services exist in communities for the noninstitutionalized schizophrenic client. Their purpose is to provide supportive services, medication follow-up and individual psychotherapy as needed by their clients. Literature focuses on pharmocological and nonpharmocological interventions that have been implemented with psychiatric clients, but major studies to date have not reflected established standards for community treatment programs that maintain chronically ill schizophrenic clients in the community. The patient's perceptions of the provider-patient relationship has been shown to influence compliance with clinical advice (Slater, Linn, and Harris, 1982). Consumer opinions are particularly needed in ambulatory care settings where providers have less

control over adherence to treatments prescribed than they might have in a hospital setting. In addition, parental perceptions of the services available to the adult schizophrenic child provide information that can assist the providers of care to strengthen their relationships with clients and to develop standards of care that will maintain the client in the community setting.

McCranie and Mizell (1978) sampled 421 clients who had previously been hospitalized for treatment of a mental illness over a one to four year period. Of the 421 clients in the study, 167 were rehospitalized at least once during the follow-up period. A majority of the clients carried the diagnosis of schizophrenia. Study participants made from one to sixty-five visits to aftercare services over the study period. Findings were that there was a significant relationship between the number of aftercare visits and the decreased likelihood of rehospitalization especially among more chronic and psychotic patients. An additional finding was that aftercare attendees were most likely to be white, female, unmarried and schizophrenic. The author suggested that more studies of patient perceptions of aftercare are needed to determine what influences clients to comply with treatment.

Although the data reported in the McCranie and Mizell study are lacking statistical analyses and

fail to report any drop-out rates, it is one of few studies of chronically ill schizophrenic clients that involves a significant percentage of females in the study groups. Although not conclusive, it is interesting to note that the female clients were more compliant than the male clients. This is in contrast to studies of Veterans which show large numbers of males to be noncompliant. The finding that aftercare visits lead to a decreased likelihood for rehospitalization is without adequate statistical documentation. Also of concern is the fact that "afterare" services are never clearly defined.

In a study of ex-hospital clients, all of whom had been labeled psychotic at one time, Denner and Halprin (1975) divided aftercare clients (n=72) into three treatment groups -- medication only, medication plus individual therapy, and medicaton plus therapy plus group experiences -- and interviewed them regarding their perceptions of their aftercare experiences. All clients had been hospitalized more than once in a state hospital. Although the severity of their symptoms was not recorded, all clients in this study did experience psychotic episodes and most were diagnosed as chronic schizophrenics. The majority of clients in each treatment group were receiving an antipsychotic drug (Thorazine, Prolixin, Mellaril). The staff consisted of social workers, paraprofessionals, a nurse, a psychologist and a part-time psychiatrist.

Denner and Halprin's findings were that the client in the medication-only group were less inclined than others receiving medications and therapy to see either the clinic or the medication as preventing rehospitalization and were the only group to report that the clinic was responsible for preventing reshospitalization to the extent that the medication was effective. When asked their perception of why a person goes back to the hospital, the medication-only group emphasized worsening symptoms or had no pertinent response. In comparison, the group of clients on medications but also involved in individual or group meetings gave high ratings to the clinic and the treatment programs for keeping them out of the hospital, and they tended to stress therapy failure as the primary cause of rehospitalization. Neither sex, age or degree of psychiatric impairment were significantly related to response variance. Overall, the clients receiving medication only were more negative in their perceptions of their aftercare regimens than those receiving medications plus supportive services. Denner and Halprin conclude that aftercare should not be medication alone -- that agressive aftercare programs are needed which go beyond dispensing medications and include supportive professional relationshps and social and activity programs.

Denner and Halprin used a convenience sample of all chronic clients in this clinic. No drop outs are reported. Data were obtained both by telephone and face-to-face interview which may account for differing responses by participants. Although 116 clients were contacted, only 72 (62%) actually participated in the study. Analysis of variance was done to compare the subgroups of respondents and Spearman rank correlation coefficients were determined between the questions for the various subgroups. Although this study examines perceptions of clients about their care, it does not examine outcomes of the clients in relation to whether medication-only, medication-plus-therapy or medication-plus-group experiences achieved the best results in terms of keeping the schizophrenic clients out of the hospital. Still, the perceptions of consumers of services are important to determining the effectiveness of available services. If the consumer perceives mental health services negatively it is unlikely that he or she will utilize these services that exist for the purpose of maintaining the client in the community.

Caton (1981) studied 119 new chronic patients entering community treatment programs in New York City and found that all of the participants had been referred to the programs for psychopharmocological treatment and various psychosocial therapies based in outpatient clinics. All of Caton's participants were schizophrenic

clients considered to be at high risk for rehospitalization. Of 134 subjects selected initially for the study, 89% (n=19) were successfully followed over a one year period of time by obtaining data from family, friends, landlords, and therapists. Only 17% complied with the prescribed treatment plan during the post-discharge year according to their self-reports. Those who complied were significantly more likely to remain out of the hospital than those who reported non-compliance with medications. The one-year rehospitalization rate was 58%, and 28% of the patients had multiple hospitalization during the study year. No attempt was made to control or to manipulate the community treatment given to study subjects as the goal of this study was to examine naturally occurring patterns of care. Caton concluded that current community treatment programs are not working well for the young adult chronic schizophrenic.

Although Caton's study group was drawn from a convenience sample of noninstitutionalized clients, the findings do demonstrate a need to determine what factors were operating to assist the participants to comply with the treatment plan and thus remain out of the hospital. It is also of importance to note for the purposes of this study that family members as well as others with close contacts with the study participants were asked to provide information as to the participants'

aftercare course.

Holden and Lewine (1982) surveyed members of family support groups of the mentally ill throughout the United States to assess their satisfaction with mental health services received and with mental health professionals. Of the 500 surveys mailed, 203 were returned. The respondents were not a representative sample of relatives of schizophrenic individuals as the majority were white females with a higher degree of education than the general public. The respondents were typically mothers of the schizophrenic individual with a high degree of concern for their ill child. The majority of ill family members had received a diagnosis of schizophrenia (71%; n=145); the remaining 29% had multiple diagnoses, diagnoses unknown to family members, or diagnoses of other chronic mental illnesses besides schizophrenia. Family members reported feeling guilty and defensive, left out, or ignored by professionals. A primary source of dissatisfaction was the failure of professionals to provide families with basic information about the illness and its management from the time of diagnosis through the period of the patient's reentry into the community. Families also reported that professionals were least helpful in directing them toward community resources and cited difficulties in finding

suitable living arrangements and employment for the ill member. Other concerns were lack of supervision and medication follow-up. Fifty-three percent of responding family members were given information about why medications were being used, and only 24% were informed about the possibility of side effects. Sixty-three percent were dissatisfied with the use of medication with their family member. In addition, 59% reported that in periods of crisis, resources in the community were inadequate.

Holden and Lewine challenged health care professionals to reevaluate the level and nature of their contacts with some families of schizophrenic clients. They suggest formation of a working relationship with family members to enhance recognition of the problems in the aftercare of chronically ill patients. Although survey data of this type are open to problems of sampling bias and reliability and validity, survey respondents consistently identify perceived problems inherent in the services provided to the noninstitutionalized schizophrenic client. Concerned parents and family members do have information to offer that may assist health care professionals to improve the services offered to noninstitutionalized clients toward the goal of an improved compliance with the treatment plan.

In summary, noninstitutional community services for the chronically ill schizophrenic have a low rate of success in maintaining these clients out of the hospital for any length of time. Conflicting information exists on whether community aftercare services decrease recidivism. It seems apparent that lack of compliance with aftercare appointments may be a factor in medication noncompliance as well. Therefore, it is essential to determine the clients' perceptions of the aftercare services as a means of correcting deficiencies and promoting improved mental health services for the chronically ill. Parents and family members report negative perceptions of the care that is offered to their ill members and to themselves. Further assessment of their perceptions of the client's situation should be helpful in making noninstitutional mental health services more satisfying to clients with resultant increased interaction with providers of care and improved compliance to the prescribed medication regimen by the schizophrenic client.

Summary

Although antipsychotic medications have been shown to be an effective method for treating the symptoms of schizophrenia and improving the schizophrenic client's ability to live in the community, significant numbers of schizophrenic clients do not follow the prescribed

medication regimen and are rehospitalized. A dearth of research exists to document what variables relate to compliance with the prescribed medication regimen by schizophrenic clients. Efforts to research related variables are hampered by the schizophrenic client's altered perceptions and impaired thought processes and communications resulting from the schizophrenia.

Recently, family members have been asked their views regarding outpatient services and management and rehabilitation of their schizophrenic family members in the community. Qualitative studies and models for family intervention suggest that parents who have regular contact with the schizophrenic client have perceptions to share with health care providers that will assist the provider to gain a better understanding of the client's situation. The purpose of this project is to design and pre-test an instrument to explore the relationships between both selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents. This instrument will provide a tool for collecting data that will contribute to a better understanding of the variables related to compliance with the prescribed medication regimen by chronically ill schizophrenic clients.

Identification of perceived variables related to compliance with the medication regimen should improve nurse-client interactions toward the goal of maintaining the schizophrenic client in a noninstitutional environment. In Chapter IV, the design and development of the instrument and pre-testing procedures will be presented.

CHAPTER IV

METHODOLOGY

Overview

The purpose of this project is to design and pre-test an instrument to explore the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents. In this chapter, the methods adopted to address this issue are described. The instrument will be pre-tested for literacy and to judge the overall responsiveness of parents to future research.

Purpose of the Project

The purpose of this project is to design and pre-test an instrument that would answer the following research question:

What selected variables are related to adult noninstitutionalized schizophrenic children's compliance with the prescribed medication regimen as perceived by their parents?

Subresearch Questions:

1. What is the relationship between adult non-institutionalized schizophrenic children's insight into their diagnosis of schizophrenia and their compliance with the prescribed medication regimen as perceived by their parents?

2. What is the relationship between adult non-institutionalized schizophrenic children's response to the nature of the prescribed medication regimen and their compliance as perceived by their parents?

    a. What is the relationship between adult noninstitutionalized schizophrenic children's understanding of their need for medications to treat the symptoms of schizophrenia and their compliance with the prescribed medication regimen as perceived by their parents?

    b. What is the relationship between adult noninstitutionalized schizophrenic children's side effects from the prescribed medications and their compliance with the prescribed medication regimen as perceived by their parents?

    c. What is the relationship between the complexity of adult noninstitutionalized schizophrenic children's prescribed medication reigmens and their compliance with the regimen as perceived by their parents?

3. What is the relationship between adult non-institutionalized schizophrenic children's satisfaction with noninstitutional care and their compliance with the prescribed medication regimen as perceived by their parents?

Pre-test Methodology: Respondents

To pretest the instrument, five respondents will be drawn from a pool of parents who attend the monthly meetings of SHARE, the family support group affiliated with the National Alliance for the Mentally Ill, in Kalamazoo, Michigan. To be eligible for inclusion, parents must meet the following criteria: (1) parent of a single, never-married adult noninstitutionalized schizophrenic child aged 18 to 65 years; (2) parent of an adult child with an established diagnosis of schizophrenia; (3) parent of an adult child with a prescribed psychotropic medication regimen; (4) parent who has face-to-face contact with his or her adult noninstitutionalized schizophrenic child at least once per week; and (5) able to read and write English.

Procedures for Pre-testing the Instrument

Data will be collected by means of structured questionnaires. The researcher will meet with a group of approximately twenty members who attend the monthly meeting of SHARE, the family support group affiliated with the National Alliance for the Mentally Ill, in Kalamazoo, Michigan. The researcher will describe the purpose of the instrument, its potential benefits to society, and the requirements for participation in the pre-test of the instrument.

It is expected that at least five of the attending

parents will meet the research criteria and will be willing to participate. Subjects willing to participate will be asked to sign a consent form after the meeting; those wishing additional information will be given the opportunity to ask questions of the researcher after the meeting. Questionnaires will then be hand distributed by the researcher after all questions have been answered and consent to participate has been signed by the participants. All respondents will complete the questionnaires at the same time. Questionnaires will be numbered to coincide with the numbers on the consent forms, but no list of names will be made. Instructions will be given by the researcher to complete the questionnaire and to return it to the researcher prior to leaving.

Respondents will be asked their reactions to the overall content and readibility of the questionnaire and to record comments about it. Subjects wishing a report on the results of the pretest of the instrument will be asked to leave their names and addresses with the researcher and a follow-up letter will be sent to them when the results are tabulated.

Responses collected from these questionnaires will by analyzed qualitatively. A code book will be used to transform data into symbols compatible with computer analysis for the purpose of improving the instrument.

The rights of the participants will be protected

using the standards of the Michigan State University Committee on Research Involving Human Subjects. There will be no physical or psychological risks to the participants involved in this pre-test. The pre-test will, however, deal with a subject which some parents may not find comfortable discussing. Therefore, participation will be completely voluntary and participants will be informed of the nature of the research and of their right to withdraw at any time from the pretest before they agree to participate. No tape recordings will be used. Responses will be used to improve the questionnaire only. While parents derive no direct benefits, the parents who participate in the pre-test should enjoy the opportunity to provide information which recognizes their contributions toward improving noninstitutional care for chronically ill schizophrenic clients.

Development of Instruments

The Parent Interview Scale was developed by the investigator based on a review of A Satisfaction With Mental Health Care Scale (Slater, Linn, and Harris, 1982) and a review of the literature concerning medication compliance among chronic schizophrenic clients. Statements to determine perceptual dimensions among parents were then identified.

The Satisfaction With Mental Health Care (SMHC) scale developed by Slater, Linn, and Harris (1982) was

constructed primarily as a research tool to assess outpatient psychiatric care from the patient's point of view as part of an overall attempt to improve the quality of outpatient care. The scale contains 32 items with a four point Likert-type format of strongly agree to strongly disagree. Responses are assigned one for agreement with a positively stated item and four for agreement with a negatively stated item. Some items are reverse scored to minimize the influence of response set.

After preliminary pretesting, the SMHC scale was administered to 20 patients randomly selected from 170 patients in an outpatient Veterans Administration Medical Center mental health clinic with teaching programs in psychiatry, nursing, and pharmacy. Test-retest reliability was the only reliability reported with the retest being administered one week after the initial rating. The two sets of ratings were correlated (intraclass) and six items were eliminated from further consideration after finding that those six had less than r=.50 values. The remaining 32 items all had above r=.50. Although this is not a high level of reliability, lower reliabilities may be acceptable in the case of new scales and those still being refined (Polit and Hungler, 1983).

Pearson Product Moment correlations resulted in a small positive correlation between patient responses and estimates of the treatment staff on how satisfied they thought the patient to be with the services ($r=.13$, $p<.05$)

as well as their own assessment of the patient's progress in treatment ($r=0.18$, $p<.05$). In addition, assuming that satisfaction should be associated with utilization and keeping scheduled appointments, student t-tests between mean satisfaction scores among patients who consistently kept their appointments and "no show" patients were compared. The SMHC scores of the two groups differed significantly ($t=2.96$, $p< 0.01$) with the no-show group being less satisfied. While these figures are lower than one would wish to find, the SMHC scale measured the dimensions of satisfaction with the operation of the clinic, the therapeutic relationship, attitudes about prevention, and planning and access to care.

Retesting of the SMHC Scale was done one week after the first test which for psychiatric patients is likely to be a better predictor of stability than waiting for a month or more and risking disturbed thought processes or perceptions that would confound the stability of the score. The SMHC scale was found to be a reliable (by test-retest) method of assessing satisfaction with outpatient mental health care, and was suggested for use in further consumer evaluations of mental health care. No other scales relating to consumer satisfaction with psychiatric out-patient care were uncovered. This scale was constructed as a research tool to assess mental health care and as yet is not fully researched, especially in different populations.

Staff perceptions are used as a measure of validity in the Slater Satisfaction with Mental Health Care Scale and the accuracy of staff perceptions of client satisfaction is questionable. Validity is difficult to establish and solid evidence supporting the validity of most psychologically-oriented measures is almost never available (Polit and Hungler, 1983). Content validity is based on judgement and careful consideration of the attributes to be measured. Factor analysis was done on the SMHC scale to identify clusters of variables that represent a unitary attribute. This type of construct validity provides a means for looking at convergent and discriminant validity of a large set of measures. Statistical measures such as factor analysis have been frequently used in attitude scale development in other areas but, according to Slater, are rarely used in scales to measure consumer satisfaction. Further evidence to support the validity of this new tool may be gained by assessing parental perceptions of consumer satisfaction with the parents taking the role of "expert."

Items were adapted by the investigator from the SMHC scale (1982) for the purpose of assessing parental perceptions of the schizophrenic child's satisfaction with oupatient mental health services rather than the consumer or staff perceptions. Adaptions from the SMHC Scale are as follows: items 19 and 20 on the Parent Interview Scale are adapted from item 1 on the SMHC "I am able to

get an appointment whenever I need one"; items 21 and 22 on the PI Scale are adapted from item 11 on the SMHC "I like my therapist"; item 23 on the PI Scale is adapted from SMHC item 7 "My therapist does not seem concerned about what happens to me" and SMHC item 31 "Staff care about you as a person"; and item 24 on the PI Scale is adapted from SMHC item 24 "The treatment is helping me" and SMHC item 28 "Treatment could help someone avoid hospitalization".

Item 25 on the Parent Interview Scale is adapted from SMHC item 3 "Appointments should be scheduled at more convenient times" and SMHC item 19 "the system for scheduling appointments works well"; item 26 on the PI Scale is adapted from SMHC item 17 "My therapist understands my problems" and SMHC item 23 "I can discuss my problems with my therapist"; item 27 on the PI Scale is adapted from SMHC item 30 "I am satisfied with my care"; and item 28 on the PI Scale is adapted from SMHC item 24 "The treatment is helping me" (See Appendix A for all items).

Based on a review of the literature, additional items were developed by the author to assess parental perception of the adult child's medication compliance, parental perception of the adult child's insight into the diagnosis of schizophrenia, and parental perception of the adult child's response to the nature of the medication regimen. Validity refers to the degree to which an instrument

measures what it is designed to measure. There are no objective methods of assuring the adequate content coverage of an instrument, but one way to evaluate the validity of the instrument is to have experts in the content area analyze the items to see if they represent adequately the hypothetical content in correct proportions (Polit and Hungler, 1983). The content validity of an instrument is based on judgment. The Parent Interview Scale was developed by reviewing the literature and by interviewing experts, and is based on the knowledge and judgement of the investigator.

Summary of Responses

Responses from the pre-test of the instrument will be summarized to determine variations in responses to scale items and will be used to improve the instrument. The results from the pre-test of the instrument would provide the basis to design a larger study to answer the research questions outlined earlier.

Operationalization of Study Variables

Perceived compliance with the prescribed medication regimen is defined as the extent to which the schizophrenic client's behavior coincides with the individually determined plan of medication prescribed to control the symptoms of schizophrenia as perceived by the parents. Question I asks the parent to write in, to the best of his or her knowledge, the name of each medication, the frequency, and the dose that is currently prescribed for his or her adult schizophrenic child. A limitation of this method of determining the prescribed regimen is that the parents may not have an accurate knowledge of this information. The use of an open ended question to assess the parents' knowledge of the prescribed regimen decreases the chance that the parent might guess on a response.

Perceived compliance will be measured against Question I, what the parent knows the schedule to be, using a set of three questions in the Parent Interview Scale (appendix A; II through IV). Questions II through IV then ask the parent's perception of the extent to which the child adheres to the prescribed medication plan as the parent knows it using a Likert-type scale to indicate "all of the time", "more than half of the time", "less than half of the time", or "none of the time". Numerical scores will be assigned to each of the possible responses on items II, III and IV such that a low score will indicate a high degree of perceived compliance.

Pereived insight into the diagnosis of schizophrenia is defined as the parental perception of the adult child's view of himself or herself as mentally ill with the chronic illness called schizophrenia. The dimensions included are: (1) view of self as having the illness called schizophrenia (item 1), and (2) understanding of the illness called schizophrenia (items 2,3,4). The format of the questions will be a statement followed by a four-point Likert scale on which the respondent will indicate his/her agreement with the statement, i.e. "strongly agree", "agree", "disagree", and "strongly disagree". Numerical scores will be assigned such that a low score will be indicative of a high degree of perceived insight into the diagnosis of schizophrenia.

Perceived response to the nature of the medication regimen is the parental perception concerning selected dimensions of the prescribed medication regimen. The dimensions included are: (1) the adult child's understanding of the need for medications to treat the symptoms of his/her schizophrenia (items 5,6,7,8,9), (2) side effects of the medications (items 10,11,12,13), and (3) complexity of the medication regimen (items 14-18) on the Parent Interview Scale (See Appendix A). Numerical scores will be assigned to each of the possible responses such that a low score in the area of need will indicate a high degree of perceived understanding of the need for medications to treat the symptoms of schizophrenia. In

the area of side effects, a low score for item 10 will indicate a low degree of side effects, but low numerical scores for items 11, 12, and 13 will indicate a high degree of side effects. The dimension of complexity will be scored such that low scores on items 15 through 18 will indicate a high degree of complexity of the regimen, and a low score on item 14 will indicate a low degree of complexity.

Perceived satisfaction with noninstitutional care is defined as the parental perception that available services meet the adult schizophrenic child's desire for service. The dimensions included in the instrument are (1) access to care (items 19,20,25), therapeutic relationship (items 21,22,26) and overall care (items 23, 24, 27, 28). Numerical scores will be assigned to each of the possible responses such that a low score indicates a high degree of perceived satisfaction with care.

Modifying variables are defined as variables that moderate the predictive validity of a test (Borg and Gall, 1979). Sociodemographic data about age, race, educational level and marital status of the parent, and family income status will be elicited with items 1-5 on the Sociodemographic Scale (Appendix A). In addition, living arrangements of the adult child, frequency and nature of the contact between parent and child, and education and employment status of the adult child will be elicited along with the criteria for inclusion into the study on

the Intake Information Survey (Appendix A). Name of the antipsychotic medication(s) prescribed will be identified from Item I of the Questionnaire (Appendix A). These modifying variables will be explored for adequacy and variation among responses.

Extraneous variables are defined as variables which confound the relationship between the independent and the dependent variables (Polit and Hungler, 1983). Examples of extraneous variables which may influence the research findings, but which will not be measured in this pre-test, include duration of the adult child's schizophrenia, level of knowledge about the medication prescribed, and type of noninstitutional services received by the adult child. In the following section, a discussion of potential design for a larger study will be presented.

Proposed Research Design and Sample

A survey design could be used to answer the research question "What selected variables are related to adult noninstitutionalized schizophrenic children's compliance with the prescribed medication regimen as perceived by their parents?" A nonprobability convenience sample could be drawn from parents who are on the mailing list of the State Alliance for The Mentally Ill of Michigan, which is affiliated with the National Alliance For The Mentally Ill in the United States.

Criteria for the sample would be: (1) parent of a single, never-married, adult noninstitutionalized schizophrenic child aged 18 to 65 years; (2) parent of an adult child with an established diagnosis of schizophrenia; (3) parent of an adult child with a prescribed psychtropic medication regimen; (4) parent who has face-to-face contact with his or her adult noninstitutionalized schizophrenic child at least once per week; and (5) able to read and write English.

Proposed Data Collection: Future Research

Data would be collected by means of structured questionnaires. The researcher would advertise in the monthly newsletter of the State Alliance for The Mentally Ill of Michigan (circulation approximately one thousand households) for interested parents meeting the study criteria. The researcher would describe the purpose of

the study, its potential benefits to society, and the requirements for participation in the study. Interested parents would then contact the researcher by telephone or by mail and have an opportunity to have any additional questions answered. All telephone and mail costs would be paid for by the researcher and/or outside monies.

Subjects willing to participate would be asked to sign a consent form that would be mailed to them along with a copy of the instrument developed from the results of the pre-test and a stamped envelope pre-addressed to the researcher. Questionnaires would be numbered to coincide with the names and addresses of the interested respondents so that follow-up contact could be made by the researcher if the questionnaire is not returned. Subjects wishing a report of the results of the questionnaire would so indicate upon returning their questionnaires and a follow-up letter would be sent to them when the results were tabulated. Data collected would be used in aggregate form only. All lists of names and addresses of interested and participating respondents would be destroyed by the researcher when the research data had been tabulated.

The rights of the participants would be protected by the researcher using the standards of the Michigan State University Committee on Research Involving Human Subjects. It is anticipated that there would not be any physical or psychological risks to the participants involved in this research study. Nevertheless, because the research would

deal with a subject which some parents may not find comfortable discussing, participation would be completely voluntary and participants would be informed of their right to withdraw at any time from the study group before they agreed to participate. No tape recordings would be used. Data would be released in aggregate form only. While parents would derive no direct benefits, the parents who participate in the study might find the results interesting and informative, and, hopefully, would enjoy the opportunity to provide information which would recognize their contributions toward improving noninstitutional care for chronic schizophrenic clients.

Proposed Methodology: Validity and Reliability of Scale

Validity refers to the degree to which an instrument measures what it is designed to measure. There are no objective methods of assuring the adequate content coverage of an instrument, but one way to evaluate validity of an instrument would be to have experts in the content area analyze the items to see if they adequately represent the hypothetical content in correct proportions (Polit and Hungler, 1983). The Parent Interview Scale has been developed by reviewing the literature and by interviewing experts. In addition, knowledge and judgement of the investigator provide a basis for content validity, and the results of a pre-test of the instrument, using respondents that are similar to the proposed sample

population, should provide information to improve the instrument and further support its validity.

The reliability of an instrument is the degree of consistency with which the instrument measures the attribute it is supposed to be measuring. The less the scores of an instrument are influenced by error, the more reliable is the instrument. Because the Parent Interview Scale is multidimensional, internal consistency reliability would be evaluated for each subscale. According to Polit and Hungler (1983), the single most useful index of reliability is Cronbach's Alpha (or coefficient alpha). The reliability coefficient of coefficient alpha ranges from 0.00 to 1.00. The higher the coefficient, the more stable the measure. There is no standard for what a reliability coefficient should be, but coefficients in the vicinity of .60 to .70 are probably sufficient for group level comparisons (Polit and Hungler, 1983). Alpha coefficients for the subparts of all returned Parent Interview Scales would be computed to support the reliability of this instrument in a research study.

Proposed Statistical Analysis: Future Research

Descriptive and inferential statistical techniques would be used to describe the sample and to answer the research question if a research study were to be undertaken. Descriptive statistics would be used to

analyze sociodemographic variables, i.e. range, distribution, percentages and means. Pearson product moment correlations (Pearson r) would be calculated to describe the relationships not predictable in advance among and between the modifying variables of age, race, education, relationship to the adult child, family income status, name of antipsychotic medication prescribed, living arrangements and employment status of the adult child; and of the relationships among and between the major study variables of (1) the adult child's insight into the diagnosis of schizophrenia, (2) the adult child's response to the nature of the medication regimen, and (3) the adult child's satisfaction with noninstitutional care, as perceived by the parent.

Point by point correlations could be calculated to describe the relationship between perceived compliance and perceived insight to the diagnosis, between perceived compliance and perceived need for the medications, between perceived compliance and side effects of the medications, between perceived compliance and perceived complexity of the medication regimen, and between perceived compliance and perceived satisfaction with noninstitutional care.

According to Borg and Gall (1979), the Pearson r describes the strength of relationships between two variables, both of which are continuous scores. The correlation coefficient of Pearson product moment is a numerical index that expresses the direction and magnitude

of the relationship. The value ranges from -1.00 to 1.00. All correlations that fall between -1.00 and 0.00 are negative relationships, and correlations that fall between 0.00 and 1.00 are positive relationships (Polit and Hungler, 1983). For this proposed study, the criteria for the strength of the correlations between the variables would be taken from Borg and Gall (1979,p.513-514): 0.00 to 0.20 is indicative of no relationship, 0.20 to 0.35 is a low relationship, 0.35 to 0.85 is a moderate relationship, and 0.85 to 1.00 is a high to perfect relationship. The proposed level of significance (p) would be 0.05.

A multiple regression correlation would be used to determine the relationship among and between the variables. The multiple regression technique may be employed to determine whether two or more of the predictor variables can be combined to predict each aspect of the compliance criterion better than any one predictor variable alone (Borg and Gall, 1979). The correlation describes the strength of the relationship among several independent variables and one dependent variable.

In summary, compliance is the criterion that the instrument would be attempting to predict. Inferential statistics would be used to test the hypotheses using the data developed by the proposed research study.

Summary

In this chapter, the methods used to design and pre-test the instrument have been described and discussed. The specific topics presented were the research question and subquestions, the respondents for the pre-test, human rights protection and procedures for pre-testing the instrument, development of the instrument, and operationalization of study variables. In addition, a research design, sample, and data collection procedure was proposed along with a plan for statistical analysis of data that could be used in future research. In Chapter V results of the instrument pre-test will be presented.

CHAPTER V

RESULTS OF THE INSTRUMENT PRE-TEST

Overview

In this chapter, a description of the pre-test respondendents is presented. A discussion of the questions and concerns of the respondents to this instrument will be included. Data from the pre-test will be presented for the purpose of examining and improving the instrument. In the concluding section, a summary of the results of each section of the pre-test will be presented.

Pre-test Respondents

Four members of the Kalamazoo S.H.A.R.E. group, an affiliate of the National Alliance of the Mentally Ill, completed the instrument. With the exception of one father, all fourteen members attending the support meeting on April 26, 1986 were mothers of schizophrenic adult children. All four pre-test respondents were mothers.

Age. The age of the respondents ranged from 42 to 64, with three of the four in the 56-65 category.

Race. All respondents were white.

Marital Status. Two of the four respondents were

married, one divorced, and one respondent identified herself as both divorced and widowed.

Income. The total yearly income of the four respondents ranged from $10,000 to $44,900 with two of the respondents identifying themselves as in the $15,000 to $19,000 category.

Educational Level. All four of the respondents had at least a high school education or GED. One respondent had an additional one year of college/technical training, and one respondent had five or more years of college/technical training.

Summary and Implications

In Table 1 the distribution of the participants by sociodemographic and modifying variables is depicted. Based on the attendance at the group meetings, it may be significant to note that all respondents were white mothers. In the area of marital status, the same respondent identified herself as divorced and widowed indicating that this item needs to be modified to "current" marital status or that the respondent be directed to select the one best answer on the sociodemographic section of the questionairre.

Table 1. Distribution and Percentage of Respondents by Demographics And Modifying Variables

	Number of Respondents	Percentage
Age	(n=4)	
24-35	-	-
36-45	1	25
46-55	-	-
56-65	3	75
66-75	-	-
Race/Ethnic Background	(n=4)	
White	4	100
Black	-	-
Mexican-American	-	-
American Indian	-	-
Oriental	-	-
Other (Specify)	-	-
Marital Status	(n=4)	
Married	2	50
Single, Never Married	-	-
Separated	-	-
Divorced	2	50
Widowed	1	25
Sex	(n=4)	
Male	-	-
Female	4	100
Income	(n=4)	
Below $5,000		
$5,000-$9,999		
$10,000-$14,999	1	25
$15,000-$19,999	2	50
$20,000-$24,999	-	-
$25,000-$29,999	-	-
$30,000-$34,999	-	-
$35,000-$39,999	-	-
$40,000-$44,999	1	25
$45,000 or over	-	-

Table 1 (Continued)

	Number of Respondents	Percentage
Educational Level	(n=4)	
Less than high school	-	-
High School Graduate/GED	2	50
One year College/ Technical Training	1	25
Two year College/ Technical Training	-	-
Three years College/ Technical Training	-	-
Four Years College/ Technical Training	-	-
Five or More Yars College/ Technical Training	1	25

Characteristics of Adult Schizophrenic Children

In accordance with the criteria for the pre-test, all parents identified their children as having been diagnosed by a psychiatrist to have schizophrenia and all had been prescribed medication to treat the symptoms of the schizophrenia.

Age of child. One child was identified as being 22 years old; the other three were listed as 34, 36 and 36.

Marital Status of Child. Three children met the criteria for being "single, never married". One mother stated that her son had been married only briefly several years ago and stated she felt that she knew her son's behaviors and beliefs better than anyone else "because he lives with me."

Place of Residence of the Child. Respondents indicated that none of their children were institutionalized. One child lived with the mother and one child lived alone independently. Two respondents selected 'other': one wrote that her child lived "independently with her two sons, aged 3 and 11", and the other respondent indicated that her child lived "independently with a male companion."

Frequency of Face-to-Face Contact. One respondent answered that she had daily face-to-face contact with her son (this was the respondent who shared her home with her son), and one respondent indicated that she had face-to-face contact 1 to 6 times per week with her child.

The third respondent checked both daily and 1 to 6 times per week contact; when asked about her response, she indicated that she most often saw her child daily but occasionally missed a day since the child was living independently. The fourth respondent indicated that she saw her child face-to-face less than once per week; when asked about her response, she indicated that she saw her child 'face-to-face' approximately 2 or 3 times per month and talked with her by phone at least once per week. It is notable that this mother did not know exactly what medication, dose or frequency had been prescribed for her daughter (and therefore was not eligible for inclusion in the pre-test) but she indicated that she knew that her daughter took her medication because she could "carry on a normal telephone conversation" Other statements made by this respondent were that "She has definitely learned that she must take her meds and is very consistent to avoid psychosis" and " I know when she isn't taking them because I get strange phone calls at 3 a.m." This respondent was the mother of the child who was living independently with a male companion.

Educational Level of the Child. Two children had completed a high school education or GED; one respondent indicated that her child had completed one and one-half years of college; and the fourth respondent indicated that her child had completed four years of college.

Employment Status of Child. The majority of

respondents indicated that their children were not employed. Only one respondent indicated that her child was employed 21 to 30 hours per week. Additional comments by respondents indicated that they felt this was an important area for study. They felt that their children would function better if they had a "regular job." One respondent indicated that I should ask whether the child had a regular job or was employed at a sheltered workshop. Another respondent indicated that whether or not the child received Social Security Disability was an indicator of their working status and that, in fact, any attempts at a "decent" job meant that the disability would be discontinued whether or not the child was successful at the job. Loss of disability benefits at the same time the adult child was trying to succeed at even a low-paying regular job was generally agreed by the respondents to be a stressor that had in the past caused their children to decompensate and in two cases, to not follow their medication regimen as they should.

Sex of the Child. Although this question was not specifically addressed on the intake information, written comments by respondents indicated that three of their children were female and one was male.

Summary and Implications: Characteristics of Children

The distribution of characteristics of adult schizophrenic children, as reported by respondents, is

depicted in table 2. Results of the pre-test indicate that an item might be added to identify the sex of the adult child, and items number four and five should be modified to indicate the child's current marital status and living arrangements. It appears that although some adult schizophrenic children have been married in the past, they currently have closest contact with the parent (e.g. actually live with the parent), and that other adult schizophrenic children who are single, never married, live with another companion who is likely to have a better knowledge of the adult child's behavior than the parent. Perhaps, additional items should be added to ask the questions "With whom does this child live?" and "Who takes responsibility for administering this child's medications?"

For item number 9, further exploration of employment status seems indicated. If the child is employed, it may be significant to ask whether this is sheltered work or a 'regular job'. Respondents also indicate that the child's disability status may be related to whether they work and that compliance with the prescribed medication regimen may be related to their success in maintaining an adequately paying job.

TAble 2. Distribution and Percentages of Characteristics of Adult Children As Reported by Respondents

Item	Number of Respondents	Percentage
1. Has your child been diagnosed by a psychiatrist to have schizophrenia?	(n-4)	
yes	4	100
no	-	-
2. What is your relationship to this child?	(n-4)	
mother	4	100
father	-	-
other	-	-
3. How old is this child?	(n-4)	
18-24	1	25
25-31	-	-
32-38	3	75
39-45	-	-
46-52	-	-
53-59	-	-
60-65	-	-
4. Has the child ever been married?	(n-4)	
yes	1 (not currently)	25
no	3	50
5. Where does this child reside?	(n-4)	
in your home	1	25
supervised community placement	-	-
independently by him or herself	1	25
other	2	50
6. Has this child had medication prescribed by a doctor for the treatment of schizophrenia?	(n-4)	
yes	4	100
no	-	-

Table 2 (Continued)

Item	Number of Respondents	Percentage
7. How often do you see and talk with your child face-to-face?	(n-4)	
daily	2	50
from 1 to 6 times per week	1	25
less than once per week	1	25
never	-	-
8. What is the highest educational level this child has acheived?	(n-4)	
less than high school	2	50
high school graduate/GED	1	25
One year College/ Technical Training	1	1
Two years College/ Technical Training	1	1
Three years College/ Technical Training	-	-
Four years College/ Technical Training	1	25
Five or more years College or Technical Training	-	-
9. How many hours per week is this child currently employed?	(n-4)	
none	3	75
one to ten hours/week	-	-
eleven to twenty hours/week	-	-
21-30 hour/week	1	25
31-40 hours/week	-	-
more than 40 hours/week	-	-

Perceived Compliance: Results of the Pre-test

In this section, the results of the instrument exploring the parent's perception of the child's compliance with the prescribed medication regimen will be discussed.

Of the four respondents, three of the four could state names, dosages, and frequency of the prescribed medication. The fourth respondent could not state what the prescribed regimen was, but did write in that "She [the child] has definitely learned that she must take her meds and is very consistent to avoid psychosis."

Respondent number one reported that her child took all four of the prescribed medications all of the time. Three of the medications were for the treatment of psychosis while the fourth medication was for the treatment of hypertension. In verbal discussion of the questionairre with this respondent, she stated that she knew that her son took the medications all of the time "because I give them to him." This same respondent was confused by III and IV of the perceived compliance section of the pre-test instrument (appendix A) and stated "I didn't fill that in--it's the same as II isn't it?" Upon clarification, she stated that her son did take all the prescribed number of pills at all of the prescribed times (denoted by () on table 3).

Respondent number two was able to state the name of her child's one prescribed medication, dosage and

frequency, and in section II responded that the child takes the medication all of the time. As with respondent number one, this respondent did not complete section III and IV of perceived compliance. She stated she thought that those sections were to be used if more than one medication was prescribed. When clarified, she stated her child took the right number of pills at the right time, 'all of the time'.

Respondent number three did complete sections II, III, and IV after stating the child's prescribed medication, dose and frequency, but circled both 'all of the time'(1) and 'more than half of the time'(2) for taking the medication (II) and taking the prescribed number (III) on medication number one. For medication number two, she circled 'more than half of the time' (2) and 'less than half of the time' (3) for taking the prescribed medication and taking the prescribed number of pills. For section IV on perceived compliance, she selected only 'more than half of the time' (2) for both medications.

Respondent number four did not know the name of the medication, frequency, or dose of the prescribed medication her child was supposed to be taking. However, she did write in that her child is "very consistent to avoid psychosis." When asked how she knows whether her child is taking her medications, she replied, "She calls me at three in the morning--like the time she called from

Ohio in the middle of winter, she was in a phone booth with no coat and no shoes," and "She can carry on a normal telephone conversation when she takes her meds." Respondent number four was the respondent who had less than weekly face-to-face contact with her schizophrenic child but spoke to her child frequently by telephone. This was also the respondent whose chld was unmarried but living with a male companion.

A potential fifth respondent approached me as she was leaving and stated, "You don't want this filled out if my son doesn't take medications, right?" When I asked if the child had been prescribed medications she responded "Oh, yes, but he has never taken them because he refuses to take them--he doesn't think he needs them." When I reexplained that I would indeed like her to complete the questionairre, she agreed to do so and mail it to me, but to date that response has not been received.

Summary and Implications: Perceived Compliance

The results of the pre-test responses are depicted in table 3. Results appear to suggest that those parents who have face-to-face contact at least 1 to 6 times per week do have knowledge of their child's prescribed medication regimen. Although respondent number four had less contact and, therefore, did not meet the criteria for the pre-test, her comments indicate that there may by other means of measuring perceived compliance with the regimen

Table 3.

Perceived Compliance With Prescribed Medication Regimen

I. Prescribed Regimen (Respondent #1)	II. Takes Med.	III. Prescribed Number	IV. Recommended Time
Med #1 Stelazine 5 mg, daily	1	- (1)	- (1)
Med #2 Norpramin 50 mg, 2 tsbs am & pm 1 tab at noon	1	- (1)	- (1)
Med #3 Litobid 300 mg, 2 caps, 3 times daily	1	- (1)	- (1)
Med #4 Naldolol 1 tsb, 2 times daily	1	- (1)	- (1)
Prescribed Regimen (Respondent #2)			
Med #1 Mellaril 1 pill, 1 time daily	1	- (1)	- (1)
Prescribed Regimen (Respondent #3)			
Med #1 Lithium 1 pill, 2 times daily	1-2	1-2	2
Med #2 Triavil 1 pill, 2 or 3 times daily	2-3	2-3	2
Prescribed Regimen (Respondent #4)			
Unknown	"She has defintely learned that she must take her meds andis very consistent to avoid psychosis."		

Key ( ) = not an original response, response obtained by direct interview.

1 = All of the time
2 = More than ½ of the time
3 = Less than ½ of the time
4 = None of the above

besides having the parent identify what the regimen is. It may be helpful to ask the parent how they know that the child takes the medication as prescribed if they perceive this to be true.

The confusion of the respondents about sections III and IV suggests that the current questionnaire is not clear and needs to be modified. In addition, the fact that the instructions were not clear to the potential respondent whose son refused to take medications suggests that a question related to whether the child takes the prescribed medication should be addressed first, and then filtered into subsets such that those who do not take the prescribed medications would skip to the sections of the questionairre that address selected variables on the Likert-type scale. Those who respond that their child does take the prescribed medication would be led into the questions regarding what those medications are and whether the right dosages are taken at the right times prior to going on to the scaled items. Based on the results of this pre-test, clarification of the perceived compliance section of the questionnaire would be essential prior to attempting further study with this instrument.

Variables Related to Compliance: Pre-test Results

In this section, the pre-test results of the portion of the instrument which explores selected variables related to compliance with the medication regimen as perceived by the parent will be discussed. Selected items for the pre-test included questions developed to elicit the parents' perceptions of their adult children's insight into the diagnosis of schizophrenia, the parents' perceptions of the nature of their adult children's response to the prescribed medication regimen, and their adult children's satisfaction with noninstitutional care as perceived by the parents. All instrument items will be examined for sensitivity to the concept in question.

Perceived insight into the diagnosis of schizophrenia is explored with questions one through four. With the exceptions of item number two "my child understands that schizophrenia is not a curable disease," a variety of responses were obtained, including extremes of the Likert-type scale items. All respondents answered item number two as 'agree.' Verbal questions and discussions with the respondents elicited no concerns about items one through four. In table 4, the distribution of responses to the pre-test items in the area of insight into diagnosis is depicted.

Perceived response to the nature of the medication regimen is explored with items five through eighteen. Items five through nine examine perceived need for

Table 4. Perceived Insight Into the Diagnosis of Schizophrenia

ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE	NO RESPONSE
1. My child understands that he or she has the mental illness called schizophrenia.	2		2		
2. My child understands that schizophrenia is not a curable disease.		4			
3. My child understands that schizophrenia can be treated with medications.	1	2		1	
4. My child understands that schizophrenia requires a long-term medication plan.	2	1		1	

medications to treat the symptoms of schizophrenia. Extreme scores were elicited for all items and no concerns were verbalized by the respondents (see table 5 for the distribution of responses to these pre-test items). Perceived side effects of medications are explored with items ten through thirteen. Only one extreme score was elicited on these items. All items were answered and no questions or concerns relating to these items were uncovered during interviews with the respondents. The distribution of responses to the items exploring medication side effects is depicted in table 6. Perceived complexity of the medication regimen is explored with items fourteen through eighteen. One respondent did not answer items fourteen, fifteen, seventeen, and eighteen but instead wrote in her response "never says" for these items. Of the remaining responses there is very little variability--all chose 'disagree' for these items except two respondents who answered item fourteen as 'agree.' No concerns were voiced by respondents about these items during face-to-face interview. In table 7, the distribution of responses to the items pertaining to perceived complexity of the regimen is illustrated.

Perceived satisfaction with noninstitutional care is explored with items nineteen through twenty-eight. For the dimension of therapeutic relationship with the providers of services, extreme scores were obtained for items twenty-one, twenty-two and twenty-six, but one

Table 5. Perceived Response to the Nature of the Medication Regimen: Need for Medications to Treat the Symptoms of Schizophrenia

ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE	NO RESPONSE
5. My child believes that medications are useful in treating the symptoms of schizophrenia.	1	2		1	
6. My child believes that medications are useful in treating his or her own mental illness.	2	1		1	
7. My child believes that he or she currently needs medications to control symptoms of his/her schizophrenia.	2	1		1	
8. My child believes tht he or she will need medication to control symptoms of schizophrenia in the future.	2		1	1	
9. My child believes that medications are useful in controlling symptoms of schizophrenia so that he/she is able to avoid hospitalization.	2	1	1		

Tables 6. Pereceived Response to the Nature of the Medication Regimen: Perceived Side Effects of Medication

ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE	NO RESPONSE
10. My child believes that the medication prescribed for him/her is the right medication for him/her.		3		1	
11. My child believes that he/she experiences too many side effects from the prescribed medications.		2	2		
12. My child believes he/she experiences severe side effects from prescribed meciations.			4		
13. My child believes that side effects of prescribed medications interfere with his/her day-to-day activities.		1	3		

Table 7. Perceived Response to the Nature of the Medication Regimen: Perceived Complexity of the Medication Regimen

ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE	NO RESPONSE
14. My child believes that his/her medication schedule fits well with his/her daily routine.		2	1		1 "Never Says"
15. My child believes he/she takes medications too many times per day.			3		1 "Never Says"
16. My child believes his/her medications should be scheduled at more convenient times.			4		1 "Never Says"
17. My child believes he/she takes too many medications at a time.			3		1 "Never Says"
18. My child believes he/she is prescribed too many different medications.			3		1 "Never Says"

respondent had no response because her child "did not have a nurse or therapist" (item twenty-two). The ddistribution of responses for the items exploring the dimension of therapeutic relationship is depicted in table 8. Table 9 is an illustration of the distribution of resonses for the dimension of overall care and shows that one respondent could not answer items twenty-seven and twenty-eight. She stated and wrote on the questionnaire that her child "never says." This was the respondent who shared her home with her adult noninstitutionalized child. Access to care was explored with items nineteen, twenty, and twenty-five on the questionnaire. All items were answered by respondents and no concerns were raised. Extreme scores were obtained on the access to care items as depicted in Table 10.

Summary and Implications: Selected Variables

Analysis of the pre-test responses suggests that items relating to perceived side effects of medication and perceived complexity of the regimen may not adequately discriminate significant perceptions of the parent in these areas. Modification and further pre-testing of the instrument would assist in determining the sensitivity of these items. In the area of perceived satisfaction with noninstitutional care, the response obtained for item twenty-two suggest that it is important to identify who manages the adult child's care and who prescribes the

Table 8. Perceived Satisfaction With Noninstitutional Care:

	ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONG DISAGREE	NO RESPONSE
	Therapeutic Relationship Dimension:					
21.	My child likes his/her psychiatrist		3		1	
22.	My child likes his/her nurse or therapist.	1	2			1 "Doesn't Have One"
26.	My child feels that he/she can discuss medication problems with his/her psychiatrist	1	1	1	1	

Table 9.

	Overall Care Dimension					
23.	My child feels that the staff care about him/her as a person.	1	2		1	
24.	My child feels that keeping appointments with the staff helps to keep him or her out of the hospital.		3	1		
27.	My child feels satisfied with his or her noninstitutional care.		3			1 "Never Says"
28.	My child feels that he/she is making progress with the treatment being received.		2		1	1 "Never Says"

Table 10. Perceived Satisfaction With Noninstitutional Care

	ITEM	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE	NO RESPONSE
	Aceess to Care Dimension					
19.	My child feels he/she is able to get an appointment with a psychiatrist whenever he/she wants one.	1	2	1		
20.	My child finds he/she is able to get an appointment with a nurse or therapist whenever he/she wants one.	1	2		1	
25.	My child feels that he/she is able to schedule appointments at convenience times.	1	2		1	

medication in an earlier part of the questionnaire. Items on satisfaction could then pertain more specifically (see Chapter VI) to the therapeutic relationship with the identified provider of services, as well as access to that person or persons, and then satisfaction with overall care. In addition, it is recognized that items twenty-seven and twenty-eight may be threatening to a parent who is providing the noninstitutional 'care' in his/her own home. Clarification of this item as it pertains to the services provided by professionals may be in order.

Finally, the question arises as to whether the perceptions elicited by the instrument are the children's perceptions of selected variables related to their compliance with the prescribed regimen or whether the responses obtained are the perceptions of the parents themselves. Other comments of the respondents included "My child still affects me even though I don't see her as much as I would like to," "They're always a part of you," "I think I know him better than anyone else," and "When she's in trouble she calls me--after almost twenty years of this, I pretty much know what she needs." Additional statements by S.H.A.R.E. group members indicated that they attended the family support group meeting to ventilate their frustrations with their children and with the systems of community treatment. Parents also expressed a need for more information for themselves about their

children's treatments and medications. The need for a central resource to identify available programs for their children and the need for improved access to the providers of mental health services are evidenced by their commnets "You can't get past the receptionist and the receptionist doesn't know anything," "We're just the parent!, "What rights do we have?"

Summary

In Chapter V, the results of the pre-test (Parent Interview Scale, appendix A) and the concerns and questions of the respondents have been discussed. Implications and recommendations for improving the instrument for future research will be identified in Chapter VI. Conclusions based on the results of the pre-test will be discussed in Chapter VI and potential contributions to nursing theory and research will be explored. Implications for nursing education, advanced nursing practice, and primary care will be presented.

CHAPTER VI

RECOMMENDATIONS AND IMPLICATIONS

Overview

In Chapter VI, recommendations for modification of the instrument will be discussed and a revised instrument will be presented. Implications for advanced nursing practice, primary care, education, and research will be offered.

Recommendations for Modifying the Instrument

An examination of the results of the pre-test of the Parent Interview Scale by the investigator suggests that parents do have perceptions about their adult noninstitutionalized schizophrenic children that they wish to share with health professionals. Modifications, however, should be made in the instrument prior to conducting a larger research study.

In the Intake Information section of the original instrument (Appendix A), questions asking about the adult child's living arrangements and marital status were not adequate to account for the responses.

Modifications need to be made to account for the adult schizophrenic child who is unmarried but living with another adult in an independent living situation and also to account for the previsouly married child who is currently living with a parent.

The criteria for future study should reflect the current interpersonal interaction between the child and the parent. For purposes of this study, it is significant to collect data from parents whose adult children live with them at the present time, but a current live-in relationship with another person would suggest that the parent might not be the best person for the nurse to interact with to explore the adult child's situation as it relates to compliance with the prescribed medication regimen. If the frequency and nature of interaction between parent and child is more significant than the parent-child role relationship, then other persons with close significant ties to the schizophrenic adult may also be able to provide information to the nurse that would clarify perceptions in pursuit of goal attainment with the schizophrenic client. Items 5 through 10 on the Revised Parent Interview Scale would clarify the nature of the current parent/child relationship.

Another related area needing closer examination, based on the pre-test, is the area of responsibility for administration of the adult child's medications.

Previous consideration was not given to the fact that parental administration of the medications might influence the adult child's compliance with the regimen as well as the parent's knowledge of the prescribed plan. It would be pertinent to ask who takes responsibility for the administration of the adult child's medications when exploring selected variables related to compliance with the plan since the instrument might not discriminate btween compliance behavior of the child and of the parent. Item 20 on the Revised Parent Interview Scale asks who assumes responsibility for medication administration (see Appendix B).

A major problem uncovered with the pre-test was that parents did not understand the section which asked them to circle the degree of their child's compliance with each prescribed medication. Item II (Appendix A) which asked whether the child took the medications was actually a combination of item III (prescribed number) and item IV (recommended time). An even greater problem is suggested by the fact that one of the respondents did not respond to the questionnaire because she interpreted it to mean that responses were <u>not</u> desired from respondents whose children refused to take prescribed medications. This respondent's view suggests that without modification, the scale would only explore the perceptions of the parents whose children are compliant with the prescribed regimens. In the

Revised Parent Interview Scale (Appendix B), items 21 and 22 offer the parent the option of responding negatively to the questionnaire and still offering their perceptions of selected variables that may relate to that failure to comply. For those parents who perceive that their children do comply at least to some extent, item 23 would ask their knowledge of the regimen, and items 24 and 25 would ask them to what extent the child is compliant (see Appendix B for revised items).

Several comments were made by respondents suggesting that there are other ways than actual knowledge of the number of pills and frequency of administration that they know whether the schizophrenic child is compliant. Because their responses suggest that the child's actions as well as verbal statements are indicators of compliance with medications, an open-ended item might be added (item 22, RPIS) which asks the parent <u>how</u> they know whether the child is/is not compliant with medications. Is it the child's ability to care for basic needs on a day-to-day basis? Is it going to work and getting there on time? No research studies were uncovered to suggest how the parent might perceive the schizophrenic child's compliance. Further exploration in this area would be helpful to future compliance studies among psychiatric clients.

Another area of concern that parents suggested should be of concern to the study of compliance with medications is the area of the child's employment status. The consensus among the pre-test respondents was that employment of the child was positively related to compliance with medications. They pointed out, however, that the type of job the child held was important; holding a 'regular job' seemed to be related to maintaining the prescribed medication schedule. But, holding a regular job also put the child at risk to loose disability benefits during the time of employment. Parents felt that a loss of financial assistance at the time when the adult child was trying to be self-supporting was related to a decrease in medication taking and in daily functioning. Research by Serban and Thomas (1974) and Hartigan del Campo et. al. (1983) found that unemployment was a significant predictor of rehospitalization of the chronic schizophrenic client. Therefore, the Revised Parent Interview Scale contains four items to explore whether the child is employed and the nature of that employment (see items 12, 13, 14 and 15, Appendix B).

In Part II of the original questionnaire pertaining to the selected variables related to compliance, respondents' selections varied across all responses in the areas of perceived insight into the diagnosis of schizophrenia and perceived need for medications.

Although the pre-test group contained only a small number of respondents, questions 1 through 9 seems to constitute a satisfactory scale for exploring these concepts.

Responses to questionnaire items relating to perceived side effects of medications resulted in a low variation of responses. For perceived side effects of medications only one response was in the strongly agree category, and the majority fell in the agree or disagree categories. Since research by Michaux (1961), Van Putten (1974), and Hartigan del Campo et. al. (1983) indicated that side effects of antipsychotic medications were related to discontinuance of medications, questions 10 through 13 may not adequately discriminate parent perceptions. These questions, then, may need to be modified to identify specific side effects of the medications (e.g., sedation, dry mouth, dystonias, and akathesias). It is also important to note, however, that all but one of the respondents perceived their children to be fairly compliant. The one exception was the mother who did not complete the questionnaire. Therefore, the lack of variation in responses among these items raises a question: Do more compliant children actually experience fewer side effects from their medications than children who are non - compliant, a finding that would coincide with previous research.

There was almost no variation in responses to the question measuring perceived complexity of the medication regimen, One respondent consistently wrote in question marks and "never says," while the other three respondents disagreed with most of the items. The lack of variation in responses indicates that these questions are not adequate to discriminate the concept of complexity of the regimen. A review of the literature by the investigator showed no empirical studies among psychiatric patients which demonstrated a clear relationship between complexity of the regimen and compliance. Yet, Greene et. al. (1982) found that among chronically ill non-psychiatric patients, complexity of the regimen was inversely related to compliance. Therefore, modification of the questions relating to the concept of complexity of the regimen should be modified. Pre-testing of the modified questions (see Appendix B, items 14 through 18) should be carried out in order to develop questions which will discriminate perceived complexity among psychiatric clients.

Three dimensions of perceived satisfaction with noninstitutional care were explored: access to care, therapeutic relationship, and overall care. One of the problems uncovered by the pre-test of the instrument was that not all clients had a nurse or a therapist and there was no way of knowing what professional the client

was perceived to be satisfied with. Therefore, the Revised Parent Interview Scale (Appendix B) asks the parent in Part I who prescribes the child's medications (item 17) and what other health professionals the child might have appointments with for the purpose of managing his or her medications (Part I, RPIS, Items 17 and 18). This modification should give a clearer view of the child's satisfaction with the therapeutic relationship (part II, Appendix B, items 21, 22, 26). This modification also should clarify the access to care dimension (items 19 and 20 and 25) which may be significantly related to satisfaction with care. The overall care dimension revealed less variation among the respondents, with one parent responding "never says" to two of the items. Modifications of questions 23, 24, 27, and 28 (see Appendix B, Part II, items 23, 24, 27, 28) have been developed by the investigator for further pre-testing in an attempt to improve response variation prior to further research with this instrument.

In summary, modifications have been made to the Parent Interview Scale based on the findings of the pre-test. The revised questionnaire will be easier for the respondent to understand. Additional information in regards to living arrangements, employment, income, provider of services, responsibility for medication administration, and indicators of <u>how</u> the parent perceives

whether the adult child is or is not compliant with the prescribed medication regimen will be determined. After a second pre-test of the instrument it will be critical to determine whether parents believe that they are being asked to respond even when their child is not compliant with the regimen, and whether those items in question discriminate the concepts to be measured.

A limitation of this questionnaire is that it elicits the parental perception of the child's compliance with the prescribed regimen as well as the parental perception of selected variables related to compliance by the noninstitutionalized adult child. The directions on the instrument must clearly indicate that the investigator is requesting the parental perception of the child's view of his or her sitatution and not the parent's personal view of whether the child has schizophrenia or whether the available services meet the child's needs.

Major serendipitous findings of the pre-test were that (1) the parent may perceive compliance in other ways besides having direct knowledge of the prescribed regimen and the child's dose-by-dose adherence, (2) employment status may be a significant variable in maintaining the client's functional ability to comply and/or to remain in the community, and (3) persons other than parents having sufficient, on-going interactions with the

schizophrenic client may be able to provide information to the nurse about the schizophrenic's view of his or her situation that would aid in planning for mutual goal attainment between client and nurse. In the next section, implications for nursing research, education, advanced nursing practice and primary care will be presented.

Implications for Future Nursing Research

The pre-test of this instrument has implications for nursing research, some methodological and others suggesting related issues in need of research. Implications for future nursing research include:

1. Pre-test findings reaffirm the need for further research to understand the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents.

2. Due to the complexity of the instrument, the revised Parent Interview Scale should be re-tested with a similar group of parents.

3. The revised instrument should be tested on a larger scale and in other areas of the country to increase the generalizability of the findings.

4. Modifying variables need to be reevaluated in future research. Based on the qualitative results of this pre-test, parents telive that employment status is

highly significant to their children's outcome. Since parents had several questions about medications used in the treatment of schizophrenia, parental knowledge of schizophrenia and its treatment needs closer examination. The duration and severity of the schizophrenia may also be a significant variable in the client's level of functioning affecting medication compliance and the therapeutic outcome since the amounts of medications prescribed seem to be highly variable.

5. A limitation of this instrument is that it measures the parental perception of compliance and not actual compliance. Objective measures of the child's compliance such as urinetesting for phenothiazine level, are needed although there are limitations to currently available methods of direct measurement. Multiple concurent measures of the adult child's compliance (self-report, nurse report, urine screens, and pill counts) would improve the validity of the measurement of compliance.

6. Further research is needed to determine the correlation between the adult child's actual compliance determined by using multiple concurrent direct and indirect measures and the parental perceptions of that compliance.

7. Replication of existing studies is needed to evaluate the effectiveness of antipsychotic medication

regimens in the treatment of schizophrenia. Of particular interest is research to identify therapeutic outcomes for the client living in a noninstitutionalized setting.

8. Experimental studies are needed to evaluate the effectiveness of interventions used to improve compliance with the prescribed medication regimen. Several plans for teaching schizophrenic clients about their medications were found in the literature but no empirical research has been found that examines the outcomes of these teaching plans.

9. Personal interviews should be conducted with a number of potential respondents prior to attempting study in underresearched areas. The results of this pre-test suggest that how parents perceive compliance is not clearly recognized. Descriptive research is needed to determine what behaviors are perceived by parents or significant others to indicate that the adult child is taking medications as prescribed.

10. Further research could be carried out to investigate the client's compliance and selected variables as perceived by significant others the client identifies. This research might clarify whether the role relationship between parent and child or the interaction itself is most significant to clear perceptions of compliance.

11. The instrument could be modified to elicit the perceptions of significant others. Those perceptions

of the schizophrenic's view of his/her situation could be compared to parental perceptions to explore the comparative validity of each measure.

12. Further study is needed to show that what goes on between the nurse, and parent, and the adult child does make a difference to the desired outcome of homeostasis of the schizophrenic client with the noninstitutional environment.

13. An examination of the perceptions of parents of adult noninstitutionalized schizophrenic children who are not members of a family support group should be conducted to determine whether the group support of the parent produces different results in the perceptions of parents.

14. An examination of parental perceptions of adult children who have other types of chronic mental illnesses might increase the generalizability of the findings by suggesting that parental perceptions are pertinent to goal attainment with adult children who have affective or paranoid disorders as well as schizophrenia.

15. Comparisons of perceived compliance and selected variables could be made between adult children with difference diagnostic subtypes of schizophrenia to determine whether some groups are different from others. For example, are selected variables related to compliance among paranoid schizophrenics

different than those among undifferentiated schizophrenics.

16. Research is needed to correlate compliance problems among mentally ill clients and clients with other chronic health problems such as diabetes mellitus and hypertension. An expanded body of knowledge about compliance and chronic illnesses including schizophrenia will help to bring mental illness into the broader context of health care.

In summary, little research has been done in the area of compliance among noninstitutionalized schizophrenic clients even though the illness poses a significant threat to the long-term health of the population. Practicing nurses have ongoing interactions with schizophrenic clients, their parents, and their family members and are in a position to conduct research and implement their findings to improve the quality of their health care.

Implications for Nursing Practice

The purpose of this project was to design and pretest an instrument to explore the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized adult schizophrenic children as perceived by their parents. Incidental to the findings of the pretest of the instrument, informal conversations with parents confirmed the beliefs of the researcher that parents do have information about their adult schizophrenic children that they are anxious to share with health care professionals. Parents have numerous concerns about the system of mental health care they believe fails to meet their children's needs. The fact that they do want to talk to nurses implies that care for their noninstitutionalized schizophrenic children is important to them and that they are eager to offer their views on their children's situations.

According to Rose (1983), alienation from professionals is a major concern of families of the mentally ill. To utilize the view of the parents of the adult schizophrenic client the nurse in advanced practice must first establish trust with the parent by listening to their concerns and respecting their views of the situation. As trust is established, the nurse takes into account the parental perception of the adult child's situation. In King's (1981) goal attainment theory,

compliance with the therapeutic regimen is an indicator that mutual transaction has occurred and has been preceded by accurate assessment.

Nursing diagnoses are formulated based on impressions and judgments of the nurse, and are tested to contribute to the advancement of nursing theory and standards of care (Gordon, 1982). Nursing diagnoses applicable to the chronic schizophrenic client might include:

1. Impaired verbal communication related to poverty of content of speech resulting in need for clarification in perceptions via the parent.

2. Potential for noncompliance related to thought disturbances and impaired insight resulting in need for identification of view of self as having the illness schizophrenia.

3. Potential for noncompliance related to response to the nature of the medication regimen resulting in need for identification of relationship between compliance and understanding of need for medications, side effects of medications, and complexity of the medication regimen.

4. Potentital for noncompliance related to dissatisfaction with noninstitutional care resulting in need for recognition of desired services.

Nursing diagnoses applicable to the parents of the noninstitutionalized chronically ill schizophrenic client might include:

1. Ineffective family coping related to chronicity of illness resulting in need for ventilation of feelings and expression of concerns.

2. Knowledge deficit: schizophrenia and medication treatment related to lack of interaction with health care providers resulting in need for education about illness and management.

3. Powerlessness related to perceived lack of control over currently available mental health services resulting in need for group support and problem solving skills.

The nurse in advanced practice utilizes theory, based on significant research findings, to establish standards of care for the services provided. When little or no research exists in an area of practice, it becomes necessary for the nurse to pursue systematic and scientific investigation of clinical problems to test existing nursing theories. The development of this instrument for the purpose of exploring the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized schizophrenic children as perceived by their parents is

in reponse to a clear need for a tool that will assist nurses to understand and interact with mentally-ill clients toward goal attainment. In addition, the development of this instrument provides an opportunity for nurses to advance nursing knowledge and to define their roles, expertise, and contributions to health care for the mentally ill.

Historically, the nurse with undergraduate preparation has served as an adjunctive member of the interdisciplinary team providing care to large numbers of chronically-ill schizophrenic clients. An instrument that seeks to identify health needs of chronically-ill clients assist the nurse in advanced practice to exchange information and participate in problem management as an equal member of the team of professionals responsible for positive client outcomes. The development of the Parent Interview Scale provides a means for the nurse to systematically and deliberatively interact with clients and their parents to bring about changes to the current mental health system which all too often blames the paernts for their children's rehospitalization.

Health care providers need to be more aware of the desire of parents to work with the team of health care professional to improve their children's situations. The recognition that parents have a unique ability to

interpret transitions and crises from the same historical perspective as their mentally ill noninstitutionalized children would bring about changes in community treatment that include the parent in the planning and evaluation process. Parents need more information and an opportunity to ventilate their feelings, both positive and negative, about their adult schizophrenic children. The nurse serving as a consultant to parents utilizes a problem-solving process and provides information regarding health care to lay groups, Family support groups are often unaware of the expertise of the nurse and lack knowledge of available resources for the care of their children. The nurse in advanced practice collaborates with the parent and the client to facilitate achievement of health oriented goals and assists the health care system to evaluate and develop the resources necessary to provide comprehensive mental and physical health care. Present nursing and family theory suggest that inclusion of the parent will contribute to goal attainment, that is, compliance with the prescribed medication regimen and maintainance of the chronically ill schizophrenic client in the noninstitutional setting.

Feedback gained from parents of noninstitutionalized schizophrenic clients could be utilized by the nurse in advanced practice to collaborate with the physician regarding the complexity of the medication regimen and

the side effects being experienced by the client. All too often, the client never reports any difficulty with the prescribed regimen but simply alters or discontinues the medication plan on his or her own. Accurate assessment of the nature of the client's response to the medication regimen assists the Clinical Nurse Specialist to interact with the client and view the whole of the client's situation in order to plan individualized strategies to promote compliance with the prescribed regimen. For example, dosing dispensers, checklists, and pairing medication administration with routine events might assist the client to adhere to the plan. In addition to the feedback received from the schizophrenic client, the nurse would have ongoing feedback from the parent of that client to affirm or deny the usefulness of the plan in achieving the goal of compliance with the prescribed regimen.

Although published articles cite examples of medication teaching groups for chronic psychiatric clients, patient education alone has not been proven to motivate continued medication taking among chronically ill patients (Battle, Halliburton, & Wallston, 1982). The nurse in advanced practice applies learning theories to assist clients and family members to identify and meet their health education needs. Parental perceptions of their adult schizophrenic children's medication

response provides the nurse with a clearer perception of the child's learning needs. The nurse in advanced practice might education the schizophrenic child about adverse effects of medication as well as stressors that interefere with his/her ability to maintain the medication regimen and about problem-solving strategies to reduce those stressors.

In addition to teaching the client about the side effects of antipsychotic medications, communications skills might be practiced so that the client is able to relay experiences with the side effects to the health care provider for reevaluation. The schizophrenic client should know the name of his/her Clinical Nurse Specialist and know how to contact the CNS if difficulties are encountered with the medication, the regimen, or activities of daily living. Assertive communication skills may need to be taught to the client to enable him/her to get past receptionists to discuss problems and concerns directly with the CNS.

The nurse is an advocate for the client and works to promote a transfer of responsibility to the client as he or she improves skills for self-care. The written and verbal communication skills required to apply for a job, to apply for disability, to pay a bill, or to get a prescription filled may need to be modeled and taught

to the schizophrenic client to enable him or her to utilize resources and comply with the medication regimen. If the schizophrenic client is unable to communicate and interact with others in the community or to utilize available resources, the risk of exacerbation of illness increases.

Doherty (1985) states that education involves teaching families about issues such as health problems, medical treatment, stress, coping with illness, and handling a difficult child. In their model for primary care family intervention, Doherty and Baird (1983) illustrate that family members, including parents, need information about the client and can, in fact, provide useful information to the provider. Parents of schizophrenic children need information regarding realistic expectations of their chronically ill child, rationale for long-term medication treatment and current information on the biochemical aspects of drug treatment in schizophrenia. The Clinical Nurse Specialist could initiate contact with the paent to explain early symptoms of deterioration or signs of failure to take medications as well as to discuss with the parent when and who to contact if these concerns arise.

As a counselor, the nurse in advanced practice could explore problems that arise between parent and child with each one individually and then both together.

The parent, as well as the adult child, could turn to the CNS for stabilzing human support when having difficulties coping with chronic illness of their child. Both parents and child must know of the availability of the CNS and how and when to contact the CNS for help in a crisis. Anticipatory planning with parent and child and role playing excercises could provide practice for contacting the CNS when counsel is needed. Parents may have health problems themselves and often need to recognize the impact of the child's difficulties on their own health. Stress management and problem-solving skils might be helpful to the parent who has ongoing contact with their schizophrenic child. Eliciting parental perceptions of the adult child's situation builds trust in the nurse-parent relationship and allows the parent to ask questions and to receive information from the nurse. Interactions between the Clinical Nurse Specialist and the parent facilitate the goal of maintaining the adult schizophrenic child in the community.

Finally, it is up to the nurse in advanced practice to assume responsibility for moving the care of the mentally ill into the broader context of health care. The separation of physical health care and mental health care for the chronic schizophrenic client is costly and not in the best interest of the client.

At the local level, the Family Clinical Nurse Specialist could contract with the county community health center to manage the care of the noninstitutionalized schizophrenic clients residing in he community. The Clinical Nurse Specialist could also meet with Clinical Social Workers responsible for discharge planning at regional psychiatric inpatient facilities and offer follow-up care to newly discharged clients returning to the CNS's practice community. Successful nursing care management of chronic schizophrenics would provide an alternative family practice model for community outpatient care.

As members of Community Mental Health Advisory Boards, Clinical Nurse Specialists would be in a position to plan for more cost efficient, quality mental health care. Speaking to lay groups about physical and mental health issues might be a beginning for removing some of the stereotyped barriers associated with mental illnesses. Public awareness of the roles of the CNS and various options for mental health care would promote change in the present system.

On the Federal, State and local level, research findings by nurses in advanced practice might suggest alternative family practice programs that could be funded collaboratively by the Departments of Mental Health and Public Health, perhaps decreasing

administrative costs and reducing treatment expenses of repeated rehospitalizations for chronically ill schizophrenics. Families could have their schizophrenic members seen in their own family practice settings rather than developing totally new provider relationships with community mental health. Nurses in advanced practice would have the opportunity to see the family members as well as the client and would be in a better position to support parents during difficult times with their children, achieving a higher quality of care than currently exists for both parents and their adult children.

The Family Clinical Nurse Specialist should support and consult for local and state affiliate groups of the National Alliance for the Mentally Ill, helping to increase their members and network of professional resource persons. Collaboration and mutual support between families and nurses in advanced practice could make a significant impact on legislators to respond to current needs and change the structure of community treatment, bringing mental health care under the umbrella of health care in general, and utilizing Clinical Nurse Specialists as primary care managers of total health care.

Research and active involvement in mental health care issues will place the care of chronically mentally

ill clients in competition for health care dollars with other chronic illnesses such as diabetes and heart disease. Schizophrenia is "shockingly underresearched" with only fouteen dollars per year per patient spent on research, far below other chronic illnesses (Torrey, 1985). The need exists; parents and other family members are requesting they be heard; nurses need to gather the support of their profession and to make the public aware that schizophrenia and other mental illnesses are health problems as significant as cancer and heart disease. To garner the support of the nursing profession, however, nurses in advanced practice must strive for change in the education of nurses.

Implications for Nursing Education

According to Haggerty (1983), nursing is defined by what is taught in nursing schools. Although nurses in advanced practice have graduate preparation in the care of chronically ill clients, the majority of nurses in psychiatric nursing and primary care clinics are products of nursing programs emphasizing acute care. Few nurses without graduate preparation are enthusiastic about the care of chronically ill clients. It is critical that nursing school curricula emphasize ongoing care for clients with mental illnesses such as schizophrenia as well as diabetes, hypertension, and arthritis.

Nursing students need to learn coping strategies to effectively intervene with the chronically ill client as well as the curative interventions of acute care.

To broaden the focus of nursing, nursing faculty with graduate preparation must lead colleagues to recognize the need for change through formal research and informal interactions. All too often, nursing education reinforces the stereotype that the mentally ill are 'hopeless' and forever institutinalized. The nurse in advanced practice should lead the way in changing those perceptions. Continuing education programs and professional nursing journals must reflect the current status of nursing research and research in other disciplines related to the care of the mentally ill. Expert opinion and successful case study examples of schizophrenic clients who have been successful in the community need to be published in nursing journals which have large circulations among practicing nurses. Nurses in advanced practice must speak out about the challenges and rewards of working with the chronically mentally ill client. Practicing nurses must be exposed to current findings and treatment approaches in order to dispel the mythical stereotypes.

Nursing education must adopt a conceptual framework that recognizes nursing's contribution to the care of the chronically ill psychiatric client. The

ideal conceptual framework would guide curriculum development away from its current emphasis on acute technological nursing care to an integrated, longer-term approach involving the family or significant others with the client in all biopsychosocial aspects of ongoing health care. A conceptual focus on nurse-client interaction in an open systems would be appropriate for all chronically ill clients who must adhere to a prescribed regimen in order to maximize self care ability. For example, the theory of goal attainment (King, 1981) supports the nurse-client interaction necessary to achieve compliance with a prescribed regimen and, combined with the self-care concepts of Orem (1980), would guide education and practice to look at a larger 'picture' in the health care of persons with chronic illnesses. Although there are similarities on King's Goal Attainment Theory and the self care concepts of Orem (e.g. both involve interpersonal systems and the nursing process), there are some inherent differences between the two. A major difference is that Orem (1980) makes the assumption that <u>awareness</u> of relevant factors and their meanings is a prerequisite for self care, a more intrapsychic approach than King's (1981) perception-judgement-action-reaction. Whereas Orem focuses on client self care, the chronically ill 'compensated' schizophrenic may need the direction and motivation of others to begin working on immediate,

short term goals. Without medications, many schizophrenic clients are unable or unwilling to assume any self-care responsibility and are, in fact, hospitalized against their wills. Only with medication treatment do some of these clients begin to develop an awareness of their problems. If well controlled on medications, then the client is able to participate in more self care decisions. Medication's effectivenessness is dependent on the schizophrenic client's adherence to the prescribed regimen. Through nurse-client interactions, the goal of medication compliance can be achieved. The schizophrenic client then has an improved awareness to the medication regimen and has a better chance of managing self care in the community.

Nurses in education must stay current, test theory, and contribute to the body of knowledge about problems faced by noninstitutionalized schizophrenic clients. Textbooks reflecting nursing theory and family systems theory and integrating psychiatric nursing into other nursing areas help to blur the distinction currently made between mental and physical illnesses. Committee participation by the Clinical Nurse Specialist in selection of texts that emphasize compliance issues and long-term care is a beginning; but more theory and research findings need to be included in textbooks to give direction to nursing practice problems. All too often,

what the student reads in the textbook doesn't work in the real world of nursing and the student is unprepared to utilize existing theories to develop new approaches to care.

To improve the care given to the chronically ill schizophrenic client, nurses need further education in the biochemical aspects of drug treatment. Nurses must recognize drug therapy as a primary treatment resulting in an alteration of the level of neurotransmitters in the brain to stabilize the mental illness. Diagrams and videotaped presentations would be especially helpful in educational programs to illustrate the complex biochemical occurrences in the brain that are increasingly gaining acceptance as key causes of mental illness. Nurse educators must provide information on these recent developments in nursing journals and continuing education programs. Nurses need to understand how psychotropic medications work and to recognize that community psychiatric nursing is not just 'passing medications.' As nurses gain an understanding of the medications, they can be instrumental in identifying what medications are most distressing to clients in community settings and recommend change.

Continuing education for nurses must include discharge planning considerations for clients and families. Most importantly, the nurse must recognize the parent

and other concerned family members as members of the health team and as resources to the ongoing quality care of discharged schizophrenic clients. The development of an instrument to explore the relationship between perceived compliance and selected variables with the mediation regimen as perceived by parents of noninstitutionalized children is a beginning step in obtaining parent feedback and recognizing parent contributions to care. As nurses and parents work together, a profesional relationship develops in which the nurse learns more about the client's situation and in which parents can learn strategies from the nurse to assist their children to deal with side effects of medications or to recognize a need to regular medications in consultation with a professional.

Educational programs which are aimed at recognizing what information parents and family members have to offer as well as practical strategies for managing a schizophrenic individual at home should be developed by nurses in advanced practice and shared with other practicing nurses and nurse educators. Nursing will continue to be defined by what all nurses are being taught to incorporate in their practices. Nurses in advanced practice must accept the challenge to lead the way in educating clients, family members and other nurses about the needs of the chronically ill schizophrenic

client attempting to achieve homeostasis in the non-institutional environment. Community based primary care provides the arena for education, research, and nursing practice.

Implications for Primary Care

Primary care has been described as the integral core of nursing. Nurses in primary care are responsible for providing comprehensive, coordinated and continuous care to clients and their families. Schizophrenia is a significant chronic illness requiring long-term mamangement and resulting in severe disability if untreated. Compliance with a prescribed regimen of psychotropic medications has been shown to improve the client's ability to remain out of an institution and in the community.

Primary care is community based, offering the client and his or her family members 24-hour access to services for both acute care and monitoring of long-term chronic illness. An important role for the Clinical Nurse Specialist in primary care is to collaborate with the client to develop a regimen that will help him or her to adapt to a changing health status. In addition, the nurse in primary care maintains a continuous relationship with the family members and the client's community and is able to view the whole of the client's interrelated

systems. The nurse in advanced practice in primary care assumes accountability for clear identification of client problems, treatment of the client's response to health problems, and outcomes of the treatment by means of collaboration with the client and the family.

Primary care is an appropriate method of managing the care of the noninstitutionalized schizophrenic client. Rather than treating the schizophrenia in isolation from other health care problems, it should be managed as any other chronic disease. Potential schizophrenic clients could be identified through contacts with parents or significant others. The CNS could call on the client's provider to offer nursing case management services in the primary care setting to the stable client. Primary care involves the schizophrenic client and his or her family in management of the illness and assists them to cope with the social stressors of being labeled mentally ill as well as the day-to-day stressors of working and self-care. As a case manager, the Clinical Nurse Specialist in primary care coordinates the client's secondary and tertiary care when needed and supports the family members to cope with their ill member.

The goal of compliance with a medication regimen has been shown to decrease the need for rehospitalization among schizophrenic clients, thereby reducing the costs of care for the overall health care system. At

the same time, the primary care nurse can provide health promotion and health maintenance services, limiting the need for the client to have to seek these services elsewhere and, more importantly, offering clients and their family members a full range of health care services from familiar providers. Physical examinations, weight control, treatment of acute physical illnesses, management of chronic illnesses, and examination of the total client outcome are all health services that can be provided by the Clinical Nurse Specialist.

Ongoing communication between nurses, parents, family members and other health team members promotes interactions and feedback toward mutual goal attainment. With some modification, the instrument developed for this project could serve as an assessment tool to clarify the nurse's perceptions of the schizophrenic client's situation and also to provide the parents an opportunity to talk about their concerns and the effect of the schizophrenic illness on their family life. Together, the nurse and the parent can review the information on the tool, assess the adult child's needs, strengths and limitations, and with the schizophrenic adult child, plan strategies that will facilitate compliance with the prescribed medication regimen and noninstitutionalization.

Relationship to Conceptual Framework

Development of this instrument to explore the relationship between selected variables and compliance with the prescribed medication regimen by noninstitutionalized schizophrenic adult children as peceived by their paents offers the nurse significant information toward improved health outcomes. King (1981) defines nursing as a process of human interaction between nurse and client whereby each perceives the other and the situation. Recognition of the variables related to compliance is a critical step in planning a treatment regimen acceptable to the schizophrenic client. When the client's communications with the nurse are impaired due to schizophrenia, the nurse should interact with the parent subsystem of the parent/child system to gain additional feedback and clear perceptions to bring to the nurse-client relationship. Adherence of the client to the prescribed regimen is an important factor in maintaining the schizophrenic client in the non-institutional environment.

The parental perception of compliance and the selected variables of insight into the diagnosis of schizophrenia, the nature of the response to the medication regimen: need for medications, side effects of medications, and complexity of the regimen, and satisfaction with noninstitutional care, may alter the nurse's

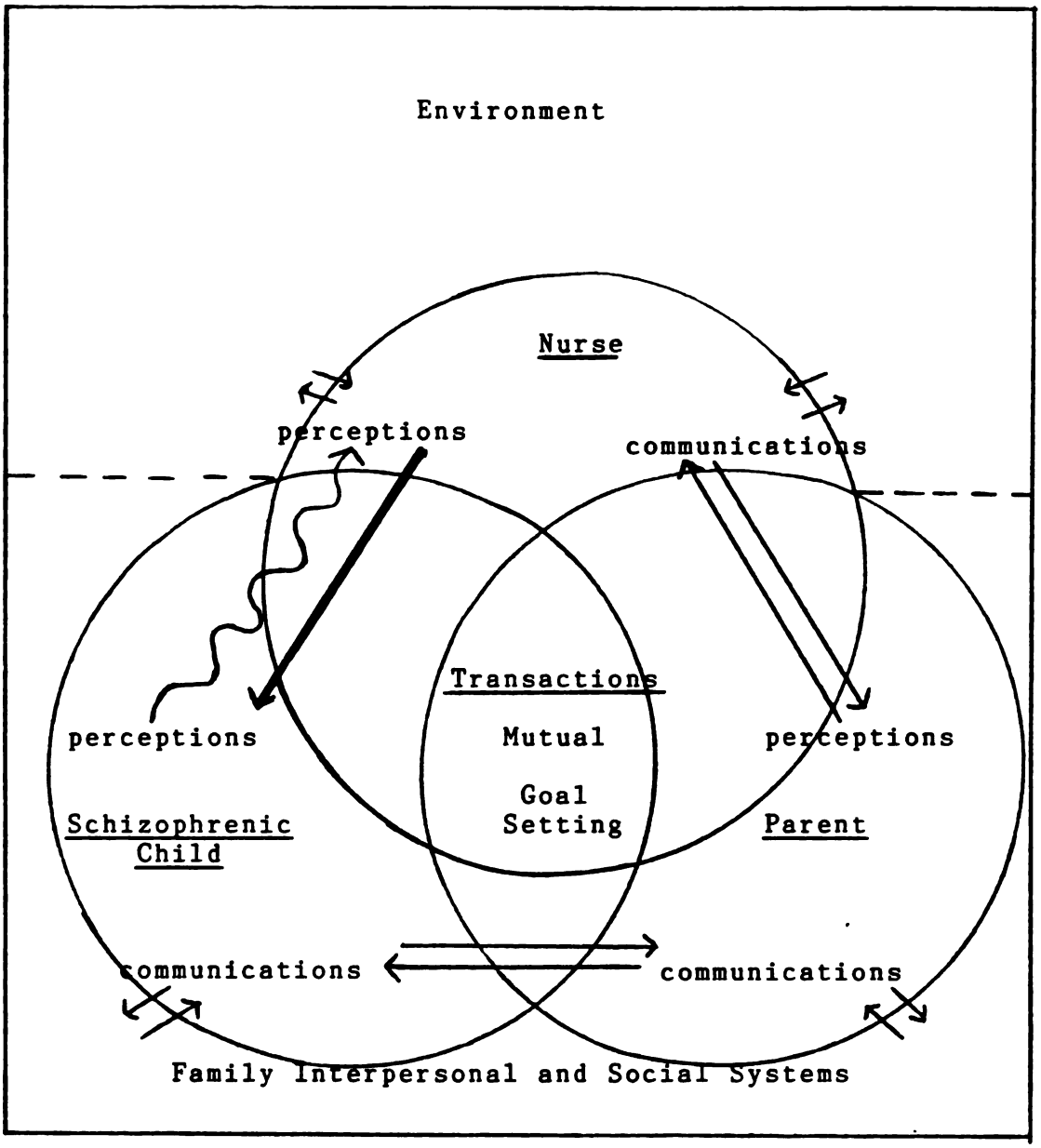

Fig. 5. Adapted from King, I. Theory of Goal Attainment A Theory for Nursing. New York: John Wiley and Sons, 1981.

perception of the adult noninstitutinalized schizophrenic client's situation in a manner such that interactions will increase the likelihood of compliance with the medication regimen (transaction) resulting in homeostasis of the schizophrenic client with the noninstitutional environment. The diagram in figure 5 illustrates goal attainment based upon interaction of the schizophrenic client, the parent, and the nurse. Clear communications (straight arrows) exist between parent and child and between parent and nurse. This exchange of information with the parent has assisted the nurse to gain a better understanding of the adult schizophrenic child's situation and react to send more pertinent messages to him or her. Although the returning message from the schizophrenic child may still be distorted (wavy arrows) due to the nature of the thought disorder accompanying schizophrenia, ongoing interactions with the parent clarify the client's situation and improve the chances for mutual goal setting and transactions to occur.

CONCLUSION

In conclusion, the investigator's analysis of the findings from this pre-test support the models explained in Chapter II (figure 3). Further testing and research is needed to determine what the parental perceptions are, how the parents perceive compliance by their child, and

whether the nurse's interactions with the parent will improve the adult child's ability to remain in the noninstitutional environment.

APPENDICES

APPENDIX A

Pre-test Questionnaire

PARENT INTAKE INFORMATION

1. Has your child been diagnosed by a psychiatrist to have schizophrenia? (CHECK ONE)

   a. yes _____
   b. no _____

3. What is your relationship to this child?

   a. mother _____
   b. father _____
   c. other (WRITEN IN) _____

3. How old is this child? (WRITE IN) _____

4. Has this child ever been married? (CHECK ONE)

   a. yes _____
   b. no _____

5. Where does this child reside? (CHECK ONE)

   a. in your home _____
   b. in supervised placement in the community _____
   c. independently, by him or herself _____
   d. other (WRITE IN) _____

6. Has this child had medication prescribed by a doctor for the treatment of schizophrenia? (CHECK ONE)

   a. yes _____
   b. no _____

7. How often do you see and talk with your child face-to-face? (CHECK ONE)

   a. daily _____
   b. from one to six times per week _____
   c. less than once per week _____
   d. never _____

8. What is the highest educational level this child has achieved? (CHECK ONE)

   a. less than high school _____
   b. high school graduate or G.E.D. _____
   c. one year college or technical training _____
   d. two years college or technical training _____
   e. three years college or technical training _____
   f. four years college or technical training _____
   g. five or more years college or technical training _____

9. How many hour per week is this child currently employed? (CHECK ONE)

   a. none_____
   b. one to ten hours per week _____
   c. eleven to twenty hours per week _____
   d. 21 to 30 hours per week _____
   e. 31 to 40 hours per week _____
   f. more than 40 hours per week _____

QUESTIONNAIRE

EACH PARENT OF A SCHIZOPHRENIC CHILD HAS CERTAIN VIEWS ABOUT WHAT INFLUENCES THAT CHILD'S SITUATION. SINCE I AM TRYING TO GET YOUR VIEWS OF YOUR CHILD'S SITUATION, PLEASE INDICATE THE EXTENT OF YOUR AGREEMENT WITH EACH STATEMENT. ANSWER EACH QUESTION ACCORDING TO WHAT YOU BELIEVE TO BE TRUE, NOT ACCORDING TO WHAT YOU THINK THE ANSWER SHOULD BE. THERE ARE NO RIGHT OR WRONG ANSWERS.

I. IN THE FOLLOWING SPACES WRITE IN:

a. THE NAME OF EACH MEDICATION CURRENTLY PRESCRIBED TO TREAT YOUR CHILD'S SCHIZOPHRENIA

b. THE NUMBER OF TIMES PER DAY YOUR CHILD IS SUPPOSED TO TAKE THAT MEDICATION

c. THE NUMBER OF PILLS YOUR CHILD IS SUPPOSED TO TAKE EACH TIME

	Name of medication	Times per day	Number of pills
#1.	_____	_____	_____
#2.	_____	_____	_____
#3.	_____	_____	_____
#4.	_____	_____	_____

II. MY CHILD TAKES THE PRESCRIBED MEDICATION(S): (CIRCLE ONE CATEGORY FOR EACH MEDICATION LISTED ABOVE)

	all of the time	more than ½ of the time	less than ½ of the time	none of the time
Med #1	1	2	3	4
Med #2	1	2	3	4
Med #3	1	2	3	4
Med #4	1	2	3	4

III. MY CHILD TAKES THE PRESCRIBED NUMBER OF PILLS, (CIRCLE ONE CATEGORY FOR EACH MEDICATION LISTED)

	all of the time	more than ½ of the time	less than ½ of the time	none of the time
Med #1	1	2	3	4
Med #2	1	2	3	4
Med #3	1	2	3	4
Med #4	1	2	3	4

IV. MY CHILD TAKES THE MEDICATION AT THE RECOMMENDED TIME OF DAY: (CIRCLE ONE CATEGORY FOR EACH MEDICATION LISTED)

	all of the time	more than ½ of the time	less than ½ of the time	none of the time
Med #1	1	2	3	4
Med #2	1	2	3	4
Med #3	1	2	3	4
Med #4	1	2	3	4

ALL OF THE REMAINING ITEMS ARE TO BE CIRCLED AS FOLLOWS:

If you strongly agree with the statement, circle STRONGLY AGREE
If you agree with the statement, circle AGREE
If you disagree with the statement, circle DISAGREE
If you strongly disagree with the statement, circle STRONGLY DISAGREE

1. My child understands that he or she has the mental illness called sczhiophrenia.

Strongly Agree Agree Disagree Strongly Disagree

2. My child understands that schizophrenia is not a curable disease.

Strongly Agree Agree Disagree Strongly Disagree

3. My child understands that schizophrenia can be treated with medication.

Strongly Agree	Agree	Disagree	Strongly Disagree

4. My child understands that schizophrenia requires a long-term medication plan.

Strongly Agee	Agree	Disagree	Strongly Disagree

5. My child believes that medications are useful in treating the symptoms of schizophrenia.

Strongly Agree	Agree	Disagree	Strongly Disagree

6. My child believes that medications are useful in treating his or her own mental illness.

Strongly Agree	Agree	Disagree	Strongly Disagree

7. My child believes that he or she currently needs medications to control symptoms of his/her schizophrenia.

Strongly Agree	Agree	Disagree	Strongly Disagree

8. My child believes that he or she will need medication to control symptoms of sczhiophrenia in the future.

Strongly Agree	Agree	Disagree	Strongly Disagree

9. My child believes that medications are useful in controlling symptoms of schizophrenia so that he/she is able to avoid hospitalization.

Strongly Agree	Agree	Disagree	Strongly Disagree

10. My child believes that the medication prescribed for him/her is the right medication for him/her.

Strongly Agree	Agree	Disagree	Strongly Disagree

11. My child believes that he/she experiences too many side effects from the prescribed medications.

Strongly Agree	Agree	Disagree	Strongly Disagree

12. My child believes he/she experiences <u>severe</u> side effects from prescribed medications.

Strongly Agree	Agree	Disagree	Strongly Disagree

13. My child believes that side effects of prescribed medications interfere with his/her day-to-day activities.

Strongly Agree	Agree	Disagree	Strongly Disagree

14. My child believes that his/her medication schedule fits well with his/her daily routine.

Strongly Agree	Agree	Disagree	Strongly Disagree

15. My child believes he/she takes medications too many times per day.

Strongly Agree	Agree	Disagree	Strongly Disagree

16. My child believes his/her medications should be scheduled at more convenient times.

Strongly Agree	Agree	Disagree	Strongly Disagree

17. My child believes he/she takes too many medications at a time.

Strongly Agree	Agree	Disagree	Strongly Disagree

18. My child believes he/she is prescribed too many different medications.

Strongly Agree	Agree	Disagree	Strongly Disagree

19. My child feels he/she is able to get an appointment with a psychiatrist whenever he or she wants one.

Strongly Agree	Agree	Disagree	Strongly Disagree

20. My child feels he/she is able to get an appointment with a nurse or therapist whenever he or she wants one.

Strongly Agree	Agree	Disagree	Strongly Disagree

21. My child likes his or her psychiatrist.

Strongly Agree	Agree	Disagree	Strongly Disagree

22. My child likes his/her nurse or therapist.

Strongly Agree	Agree	Disagree	Strongly Disagree

23. My child feels that the staff care about his/her as a person.

Strongly Agree	Agree	Disagree	Strongly Disagree

24. My child feels that keeping appointments with the staff helps to keep him or her out of the hospital.

Strongly Agree	Agree	Disagree	Strongly Disagree

25. My child feels that he/she is able to schedule appointments at convenient times.

Strongly Agree	Agree	Disagree	Strongly Disagree

26. My child feels that he/she can discuss medication problems with his/her psychiatrist.

Strongly Agree	Agree	Disagree	Strongly Disagree

27. My child feels satisfied with his or her noninstitutional care.

Strongly Agree	Agree	Disagree	Strongly Disagree

28. My child feels that he/she is making progress with the treatment being received.

Strongly Agree	Agree	Disagree	Strongly Disagree

SOCIODEMOGRAPHIC

The following questions describe general things about you. Please answer all the questions to the best of your ability.

1. How old were you on your last birthday?
   (WRITE IN) _____

2. What is your racial or ethnic background?
   (CHECK ONE)

   1. White _____
   2. Black _____
   3. Mexican-American _____
   4. American Indian _____
   5. Oriental _____
   6. Other (Specify) _____

3. What is your marital status? (CHECK ONE)

   1. Married _____
   2. Single, never married _____
   3. Separated _____
   4. Divorced _____
   5. Widowed _____

4. Taking all sources of money into consideration, what was your family's total income before taxes and other deductions for the past 12 months? (CHECK ONE)

   1. Below $5,000 _____
   2. $5,000-$9,999 _____
   3. $10,000-$14,999 _____
   4. $15,000-$19,999 _____
   5. $20,000-$24,999 _____
   6. $25,000-$29,999 _____
   7. $30,000-$34,999 _____
   8. $35,000-$39,999 _____
   9. $40,000-$44,999 _____
   10. $45,000 or over _____

5. What is the highest level of education you have completed? (CHECK ONE)

   1. less than high school _____
   2. high schol graduate or GED _____
   3. one year college or technical training _____
   4. two years college or technical training _____
   5. three years college or technical training _____
   6. four years college or technical training _____
   7. five or more years college or technical training _____

APPENDIX B

Revised Parent Interview Scale

(Revised) Parent Interview Scale

Part I Questionnaire

Part I of this Questionnaire asks you to provide information about your child that researchers and other parents believe is important. There are no right or wrong answers. Please select your response by placing a check mark in the appropriate blank or writing in the answer where requested.

1. Has your child been diagnosed by a psychiatrist to have schizophrenia?

   1) yes _____
   2) no _____

2. How old is your child? (write in) _____

3. What is the sex of your child?

   1) male _____
   2) female _____

4. What is your relationship to this child?

   1) mother _____
   2) father _____
   3) other (specify) _____

5. Do you see and talk to your child face-to-face from one to several times per week?

   1) yes _____
      if yes, skip to question #8

   2) no _____
      if no, GO ON to question #6 below

      6. What type of contact do you have with your child? (check all that apply)

         1) face-to-face _____
         2) telephone _____
         3) letters _____
         4) other (specify) _____

         GO ON to question #7

      7. How often do you have these contacts with your child?

         (write in) ----------

         Please GO ON to question #8

8. What are your child's current living arrangements?

   1) lives in your home _____
   2) lives alone _____
   3) lives with another adult _____
   4) lives with his/her children _____
   5) lives in a supervised home in the community _____
   6) other (specify) _____

9. Is your child currently married and living with a spouse?

   1) yes _____ (221)
      if yes, Skip to page _____

   2) no _____
      if no, GO ON to question #10 below

      10. Which one of these categories most closely applies to your child? (select only)

          1) single, never married ____
          2) separated ____
          3) divorced ____
          4) living with boyfriend/ girlfriend ____
          5) widowed ____

          Please GO ON to Question #11

      11. What is the highest educational level your child has achieved?

          1) less than high school ____
          2) high school graduate or G.E.D. ____
          3) one year of college or technical training ____
          4) two years of college or technical training ____
          5) three years of college or technical training ____
          6) four years of college or technical training ____
          7) five or more years of college or technical training ____

          Please GO ON to question #12 below

12. Does your child have a job?

1) no _____
if no, skip to Question #15

2) yes _____
if yes, please GO ON to Question #13

13. Where does your child work?

1) sheltered workshop _____
2) work activity center _____
3) regular job in the community _____
4) other (specify) _____

Please GO ON to Question #14

14. How many hours per week is your child employed for pay?

1) none _____
2) 1 to 10 hours per week _____
3) 11 to 20 hours per week _____
4) 21 to 30 hours per week _____
5) 31 to 40 hours per week _____
6) other (specify) _____

Please GO ON to Question #15

15. What is your child's primary source of income?

1) general assistance _____
2) social security disability _____
3) his or her employment _____
4) other (specify) _____

Please GO ON to Question #16

16. Is your child supposed to take medications to treat the symptoms of his or her schizophrenia?

1) no _____
if no, Skip to page (2b1)

2) yes _____
if yes, please GO ON to Question #17

17. Who prescribed your child's medications for the treatment of schizophrenia?

1) psychiatrist _____
2) psychologist _____
3) family physician _____
4) other (specify) _____

Please GO ON to Question #18

18. Does your child have regular appointments with any other professional for the purpose of managing his/her medication plan?

1) no _____
if no, Skip to Question #20

2) yes _____
if yes, GO ON to Question #19

19. Who else does your child see regarding his/her medication?

1) nurse _____
2) social worker _____
3) psychologist _____
4) other (specify) _____

20. Who assumes responsibility for whether your child takes his/her medication or not?

a) your child (takes own responsibility) _____
b) you _____
c) a friend _____
d) other (specify) _____

Please GO ON to Question #21

21. Does your child take the medication(s) as prescribed?

1) no _____
2) yes _____

Please GO ON to Question #22

22. How do you know when your child is or is not taking his/her prescribed medications?

(Write in) _____

_____

_____

_____

_____

If your child takes medications, Please GO ON to Question #23

If your child never takes medications, Skip to Part II, pg. (216)

23. In the following spaces write in the Name, Dosage, and Time of Day of each medication your child is supposed to take for the treatment of schizophrenia?

	Name of Medication	Dosage (Amount)	Times of Day
#1			
#2			
#3			
#4			

Please GO ON to Question #24

FOR EACH MEDICATION LISTED IN QUESTION #23, CIRCLE ONE APPROPRIATE CATEGORY IN #24 AND #25

24. MY CHILD TAKES THE PRESCRIBED DOSAGE (AMOUNT):

	all of the time	more than ½ of the time	less than ½ of the time	none of the time
Med #1	1	2	3	4
Med #2	1	2	3	4
Med #3	1	2	3	4
Med #4	1	2	3	4

25. MY CHILD TAKES THE MEDICATION AT THE RECOMMENDED TIME OF DAY:

	all of the time	more than ½ of the time	less than ½ of the time	none of the time
Med #1	1	2	3	4
Med #2	1	2	3	4
Med #3	1	2	3	4
Med #4	1	2	3	4

Now GO ON to Part II of the Questionnaire

Part II

EACH PARENT OF A SCHIZOPHRENIC CHILD HAS CERTAIN VIEWS ABOUT WHAT INFLUENCES THAT CHILD'S SITUATION. SINCE I AM TRYING TO GET YOUR VIEWS OF YOUR CHILD'S SITUATION, PLEASE INDICATE THE EXTENT OF YOUR AGREEMENT WITH EACH STATEMENT. ANSWER EACH QUESTION ACCORDING TO WHAT YOU BELIEVE TO BE TRUE, NOT ACCORDING TO WHAT YOU THINK THE ANSWER SHOULD BE. THERE ARE NO RIGHT OR WRONG ANSWERS.

ALL OF THE REMAINING ITEMS ARE TO BE CIRCLED AS FOLLOWS:

If you strongly agree with the statement, circle STRONGLY AGREE
If you agree with the statement, circle AGREE
If you disagree with the statement circle DISAGREE
If you strongly disagree with the statement, circle STRONGLY DISAGREE

1. My child understands that he or she has the mental illness called schizophrenia.

Strongly Agree	Agree	Disagree	Strongly Disagree

2. My child understands that schizophrenia is not a curable disease.

Strongly Agree	Agree	Disagree	Strongly Disagree

3. My child understands that schizophrenia can be treated with medications.

Strongly Agree	Agree	Disagree	Strongly Disagree

4. My child understands that schizophrenia requires a long-term medication plan.

Strongly Agree	Agree	Disagree	Strongly Disagree

5. My child believes that medications are useful in treating the symptoms of schizophrenia.

Strongly Agree	Agree	Disagree	Strongly Disagree

6. My child believes that medications are useful in treating his or her own mental illness.

Strongly Agree	Agree	Disagree	Strongly Disagree

7. My child believes that he or she currently needs medications to control symptoms of his/her schizophrenia.

Strongly Agree	Agree	Disagree	Strongly Disagree

8. My child believes that he or she will need medication to control symptoms of schizophrenia in the future.

Strongly Agree	Agree	Disagree	Strongly Disagree

9. My child believes that medications are useful in controlling symptoms of schizophrenia so that he/she is able to avoid hospitalization.

Strongly Agree | Agree | Disagree | Strongly Disagree

10. My child believes that the medication prescribed for him/her causes uncomfortable side effects for most people.

Strongly Agree | Agree | Disagree | Strongly Disagree

11. My child believes that he/she experiences uncomfortable side effects from the prescribed medications.

Strongly Agree | Agree | Disagree | Strongly Disagree

12. My child believes he/she experiences <u>severe</u> side effects from prescribed medications.

Strongly Agree | Agree | Disagree | Strongly Disagree

13. My child believes that side effects of prescribed medications frequently interfere with his/her day-to-day activities.

Strongly Agree | Agree | Disagree | Strongly Disagree

14. My child believes that his/her medication schedule fits well with his/her daily routine.

Strongly Agree | Aree | Disagree | Strongly Disagree

15. My child believes he/she would like to take medications fewer times per day.

Strongly Agree | Agree | Disagree | Strongly Disagree

16. My child believes he/she would follow the treatment plan better if he did not have to take medications so many times per day.

Srongly Agree | Agree | Disagree | Strongly Disagree

17. My child believes he/she is supposed to take too many different kinds of medications at a time.

Strongly Agree	Agree	Disagree	Strongly Disagree

18. My child believes his/her medication schedule is easy to adhere to.

Strongly Agree	Agree	Disagree	Strongly Disagree

19. My child feels he/she is able to get an appointment with a psychiatrist whenever he or she wants one.

Strongly Agree	Agree	Disagree	Strongly Disagree

20. My child feels he/she is able to get an appointment with the person who manages his/her medications whenever he or she wants one.

Strongly Agree	Agree	Disagree	Strongly Disagree

21. My child likes his or her psychiatrist.

Strongly Agree	Agree	Disagree	Strongly Disagree

22. My child likes the person who manages his/her medications.

Strongly Agree	Agree	Disagree	Strongly Disagree

23. My child feels that the staff care about his/her as a person.

Strongly Agree	Agree	Disagree	Strongly Disagree

24. My child feels that keeping appointments with the staff keeps him or her out of the hospital.

Strongly Agree	Agree	Disagree	Strongly Disagree

25. My child feels that he/she is able to schedule appointments at convenience times.

Strongly Agree	Agree	Disagree	Strongly Disagree

26. My child feels that he/she can discuss medication problems with his/her psychiatrist or the person who otherwise manages his/her care.

Strongly Agree	Agree	Disagree	Strongly Disagree

27. My child feels satisfied with the mental health services available to him/her in the community.

Strongly Agree	Agree	Disagree	Strongly Disagree

28. My child feels that he/she is making steady progress with the treatment being received.

Strongly Agree	Agree	Disagree	Strongly Disagree

This is the end of Part II of the Questionnaire. Please complete the Sociodemographic information.

SOCIODEMOGRAPHIC

The following questions describe general things about you. Please answer all the questions to the best of your ability.

1. How old were you on your last birthday? (WRITE IN)

   _____

2. What is your racial or ethnic background? (CHECK ONE)

   1. White _____
   2. Black _____
   3. Mexican-American _____
   4. American Indian _____
   5. Oriental _____
   6. Other (Specify) _____

3. What is your current marital status? (CHECK ONE)

   1. Single, never married _____
   2. Married
   3. Separated _____
   4. Divorced _____
   5. Widowed _____

4. Taking all sources of money into consideration, what was your family's total income before taxes and other deductions for the past 12 months? (CHECK ONE)

   1. Below $5,000 _____
   2. $5,000-$9,999 _____
   3. $10,000-$14,999 _____
   4. $15,000-$19,999 _____
   5. $20,000-$24,999 _____
   6. $25,000-$29,999 _____
   7. $30,000-$34,999 _____
   8. $35,000-$39,999 _____
   9. $40,000-$44,999 _____
   10. $45,000 or over _____

5. What is the highest level of education you have completed? (CHECK ONE)

   1. less than high school _____
   2. high school graduate or G.E.D. _____
   3. one year college or technical training _____
   4. two years college or technical training _____
   5. three years college or technical training _____
   6. four years college or technical training _____
   7. five or more years college or technical training _____

Thank you for completing the Questionnaire. Please return to the researcher.

APPENDIX C

Contact Letter

April 1, 1986

64373 Parkwoods
Paw Paw, Michigan 49079
616-657-4594 (home)
616-782-5113, ext. 245 (work)

Mrs. Katherine Harris, President
SHARE of Kalamazoo
c/o Edison Neighborhood Center
1331 Race Street
Kalamazoo, Michigan 49001

Dear Mrs. Harris,

I plan to begin my study of "Parental Perceptions of Variables Influencing Compliance With a Medication Regimen among noninstitutionalized Adult Children with Schizophrenia" on April 7. I will plan to address SHARE of Kalamazoo, an affiliate of the National Alliance for the Mentally Ill, on April 26 to explain the pretest of my instrument to potential participants.

In brief, I will distribute a written questionnaire to parents who consent to participate in the study and who meet the following requirements:

1. a participant must be the parent of an adult person, age 18 or over, who has been diagnosed to have schizophrenia and who has been prescribed medication
2. The adult child must reside in a noninstitutional community setting
3. only one parent of a child is asked to respond

Participants will be asked to return the questionnaire before or after the meeting or to return the questionnaire to the researcher in the envelope provided. It is expected that the questionnaire will take approximately 30 minutes to complete.

As we have discussed, the rights of the participants will be protected. Each participant will sign a consent form describing the nature of the research and informing him/her that answers will be held confidential and will be used only for the purpose of improving the instrument. Participants may withdraw from the study at any time. Code numbers rather than names will be used on all response forms and data will be released only in aggregate form.

Should you have any questions, I will be glad to answer them as will my advisors, Dr. Barbara Given and Brigid Warren, M.S.N., at Michigan State University, 517-355-6526.

Sincerely,

Pamela K. Brown
cc: B. Given, B. Warren 222

APPENDIX D

Consent Form

Consent Form

Medications provide one type of management for schizophrenia but some clients have a difficult time taking the medications as prescribed. Researchers at the College of Nursing at Michigan State University are asking parents of adult persons with schizophrenia what influences their adult child to follow or not follow the prescribed medication plan. Results from this part of the research will be used to improve the instruments for use in a research study.

In this survey, you will be asked a number of questions about your view of your child's perceptions, expectations, knowledge, and experiences with taking medications and receiving care in the community. You will be asked to give information about such things as your marital status, age, ethnic background, education and family income, and we will also ask you to tell us if any of the questions are offensive, hard to understand or not clear.

By signing this form, I understand that:

1. I have freely consented to take part in this study.

2. The study has been explained to me. Furthermore, I understand the explanation that has been given to me and what my participation will involve.

3. I am free to discontinue my participation in the study at any time without penalty and without affecting the care I or my child receive.

4. My responses will be treated with strict confidence and all participants will remain anonymous.

5. I will be responding to written information.

6. It will take approximately 30 minutes to complete the questionnaires.

7. I am not guaranteed any beneficial results from my participation in this study.

8. Results of the study will be made available to me at my request.

Signed: _____

Date: _____

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