

THE MEANING OF MEDICATION-TAKING:
A QUALITATIVE STUDY OF THE MEDICATION-TAKING
OF SCHIZOPHRENIC CLIENTS LIVING IN THE COMMUNITY

by

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ABSTRACT

THE MEANING OF MEDICATION-TAKING:
A Qualitative Study of the Medication-Taking of Schizophrenic
Clients Living in the Community

This study was designed to investigate clients' rationales for their health behaviors. Specifically, the study problem was to understand the subjective meaning of the medication-taking behavior of schizophrenic clients. Previous research on health behaviors had been particularly concerned with compliance, that is, "the extent to which patient behavior coincided with medical or health advice" (Haynes, Taylor, and Sackett 1979). Studies of compliance rarely included the clients' perspectives towards their health behaviors. Therefore the purpose of this study was to describe schizophrenic clients' medication-taking behaviors and their explanations for those behaviors within the context of their everyday life.

Eleven out-patients diagnosed as schizophrenic participated in the study, nine clients typifying a long-term client population and two clients typifying a short-term client population. All participants were prescribed oral anti-psychotic medication and lived in community settings in which they were responsible for their medication-taking. In the course of one or two interviews, each participant and the researcher constructed an account of the participant's medication-taking. Using content analysis, this data was then used to identify themes and concepts reflective of the participants' perspectives towards medication-taking. The presentation of this descriptive data was organized around five major content areas: medication-taking practises, current perspectives towards medication-taking, the context of medication-taking, the moral implications of medication-taking, and the influence of others on medication-taking.

The participants' accounts of their medication-taking illustrate the importance of determining the clients' perspectives in order to understand and work with clients and their health behaviors. Current practise in health care advocates patient participation in the determination and management of therapeutic regimens such as medication-taking.

The research data was also used in another way. The participants' accounts were compared to research and literature in the field of compliance, supporting or questioning various factors supposed relevant to schizophrenic clients' medication-taking. In providing this alternative perspective, the qualitative data illustrates the way in which previous conceptualizations of medication-taking as "compliance" influenced how client behavior was studied and hence understood. Based on the understanding of medication-taking developed in this study, implications for health care were discussed and suggestions for further research were made.

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CHAPTER I: INTRODUCTION

INTRODUCTION TO PROBLEM AND PURPOSE

This study addresses the problem of patient compliance, using a qualitative approach which emphasizes understanding the individual's perspective towards his or her own health behavior.

Patient compliance, "the extent to which a patient's behavior coincides with medical or health advice" (Haynes, Taylor, and Sackett 1979, p. 2) is an increasingly important issue in health care. Previous studies have considered the extent of compliance with scheduled appointments, short-term and long-term medication-taking, diets, exercise, cessation of smoking, scheduled diagnostic tests, and prescription-filling (Haynes, Taylor, and Sackett 1979; Berkowitz et al. 1963). Assuming that therapeutic outcome is related to the successful implementation of the therapeutic regimen, these studies, which have identified substantial rates of non-compliance, warrant attention from health professionals.

A variety of research perspectives have been used to study compliance. Although Chapter Two will explore research approaches to compliance, the following overview provides a context for the approach taken in this study.

The word "compliance" implies a model of the patient-practitioner relationship which emphasizes the power and authority of the practitioner and the responsibility of the patient to comply. Comply is defined as "to conform or adapt one's actions to another's wishes, to a rule, or to a necessity," and is synonymous with obey (Webster's 1976, p. 231). Adopting this perspective on the patient-practitioner relationship, studies have conceptualized non-compliance as deviance. That is, assuming

adherence to the prescribed pattern as "normal," variations from this pattern are considered "deviant."

Research focussed on patient characteristics which would account for such deviance: demographic and personality variables, health beliefs and the nature of the patient's medical problem. The characteristics of the medical regimen were also studied, indicating a recognition that non-compliance could be attributed to non-patient variables.

Ideas concerning the nature of the practitioner-patient relationship have changed; accordingly, some studies have focussed on compliance as an interpersonal phenomenon. These studies related compliance to aspects of the practitioner-patient relationship such as communication patterns and the patient's comprehension of the regimen relative to the amount of health teaching. The terms adherence, negotiation, and therapeutic alliance have replaced "compliance" in some of the recent studies, reflecting these changes.

In a discussion of nursing and compliance, Hogue (1979, p. 248) states "nurses are interested in helping people participate effectively in plans to promote health, treat disease, or effect rehabilitation," placing compliance within the context of the nurse-patient relationship. Nurses in many settings assume considerable responsibility for monitoring and promoting medication compliance. Nursing has tended to assume lack of knowledge of the illness and the prescribed regimen as a major determinant of non-compliance and has advocated patient teaching. However, the efficacy of patient teaching programs has been questioned, necessitating that nursing explore other approaches to this health care problem: "Transmitting information alone is not enough to overcome non-compliance" (Hogue 1979, p. 253).

The need to know more about compliance has been documented in reviews of existing literature (Haynes, Taylor, and Sackett 1979). Becker and Maiman (1975, p. 11) stated "it seems fair to assert, after an extensive survey of the literature, that patient non-compliance has been the best documented, but least understood, health-related behavior." Particularly lacking in compliance research are studies which emphasize the understanding of compliant and non-compliant behavior from the client's own frame of reference. Stimson (1974, p. 103) suggested that the problem of compliance be studied from the perspective of the patient, assuming that "almost anyone can be a defaulter at some time or another."

This study investigates the phenomenon of compliance from the patient's perspective, specifically the perspective of schizophrenic out-patients. A large proportion of schizophrenic out-patients are known to take less anti-psychotic medication than the dosage prescribed. Van Putten (1974) has estimated this proportion to range from 24-63%, which can be compared to approximately 50% for long-term medication regimens in general (Haynes, Taylor, and Sackett 1979). As medication is one of the major treatment modalities with this client population, and studies have documented higher relapse rates amongst those clients discontinuing medication, medication compliance is of particular concern. Studies with schizophrenic clients have identified client/illness characteristics which predispose to non-compliance. However, no studies have been located investigating the perspective of schizophrenic clients towards their medication-taking.

STATEMENT OF PROBLEM AND PURPOSE

The general problem addressed by the study is the lack of knowledge of clients' rationales for health behavior. More specifically, the study

problem is to understand the subjective meaning of the medication-taking behavior of schizophrenic clients. Subjective meaning is defined as the aim, intent, sense, and significance of the medication-taking behavior as perceived by the client.

The purpose of this study is to describe schizophrenic clients' medication-taking behaviors and their explanations for those behaviors within the context of their everyday life.

The descriptive data obtained in this study is used in two ways:

- 1) To discuss the existing research and literature concerning compliance in an explanatory way: to support or question the various proposed factors assumed relevant to schizophrenic clients' medication-taking.

- 2) To contribute to practitioners' understanding of clients' experiences and beliefs. Current literature concerning medication-prescribing has emphasized the need for therapeutic alliances in which clients participate in the self-regulation of their medication. Nursing literature supports this approach to medication management. In order to achieve truly therapeutic alliances, practitioners must understand and value the clients' experiences and beliefs concerning their medication.

DEFINITION OF TERMS

The following terms are defined to further clarify the problem and purpose.

Understand: To have a clear idea; to grasp the significance or nature of something.

Medication-taking behavior: The pattern and amount of oral anti-psychotic medication taken, as reported by the client. Anti-psychotic medications are specified as phenothiazines, butyrophenones, thioxanthenes, dihydro-indolones, and dibenzoxazepines.

Schizophrenic client: A client of Greater Vancouver Mental Health Service, diagnosed as schizophrenic, who is between the ages 20-59 years, resides in the community, and is responsible for taking his/her own medications.

Explanations: Clients' descriptions of reasons, causes, or motives of their actions, in this case, their medication-taking behavior.

Context of everyday life: The client's daily living, including routines, events, and relationships with others, in relation to medication-taking.

INTRODUCTION TO THIS STUDY'S METHODOLOGY

Quantitative and qualitative research not only involve different research methods, but reflect "views about the social world which are philosophically, ideologically, and epistemologically distinct" (Rist, 1979, p. 17). Quantitative research is based on the positivistic or naturalistic approach: that social reality can be represented by definable and quantifiable social facts, which are independent of the experience of any particular individual. Research data is seen as independent of the researcher, stressing the objectivity and reliability of the study design (Rist 1979; Davis 1978). The theoretical framework selected for the quantitative research directs the ordering of the observed phenomenon.

Qualitative research is based on the phenomenological approach: that social reality is known subjectively, by understanding how those involved interpret and give meaning to the situation. Research is seen as a social enterprise, requiring reflexivity on the part of the researcher. Questions about the research methods and procedures become an integral part of its structural content. The researcher enters the research situation with a minimal number of structured expectations (Davis 1978; Diers 1979; Rist 1979).

In qualitative research, the usual notions of representative sampling

and reliability and validity of instruments and data do not apply. Research participants are selected in order to answer the research questions that are posed (Lindemann 1974). The criteria for judging the adequacy of the research is the richness of the data and the credibility of the concepts and theory presented (Davis 1978; Diers 1979).

These differing research perspectives give rise to different assumptions and limitations. The following assumptions and limitations have been identified for this study.

A. Assumptions

It is assumed that these clients can speak for themselves. Psychiatric clients, particularly those with psychotic illness experiences, are often disqualified as legitimately speaking for themselves. Although the study proposes to understand the subjective meaning of the clients' experiences (hence any subjective experience could be assumed sufficient), the validity of the study findings assumes that the clients construct reasonable accounts of their medication-taking. As the study participants live in community settings where they are responsible for medication-taking, as well as other everyday activities, they are assumed to be making reasoned choices in regards to medication-taking.

B. Limitations

1. The sampling process was bound by time, rather than the sampling principle of richness of data.
2. The participants' failure to report freely limits the degree to which the study achieves its purpose. As participants may have been exposed to considerable persuasion to take medication, and as the researcher made contact with the participants via the agency, participants may have

been guarded in their accounts of medication-taking. The degree to which participants felt free to express their patterns and explanations of medication-taking is discussed in Chapter Three.

ORGANIZATION OF THIS STUDY

This study is organized in the following manner. Chapter Two presents a review of the literature, which provides a conceptual background for addressing the problem. Chapter Three describes methodology, including a discussion of the process of constructing accounts. Chapter Four presents the data gathered: the schizophrenic clients' accounts of their medication-taking and their explanations for this behavior. Chapter Five is a discussion of the compliance literature reviewed in Chapter Two vis à vis the research data presented in Chapter Four. Chapter Six contains a summary of the study.

CHAPTER II: REVIEW OF THE LITERATURE

Chapter II provides a conceptual background for the development of the study's problem and purpose, differentiating the research perspective adopted by this study from previous research. As the problem and purpose of this study evolved from the researcher's review of compliance, a review of the literature on compliance is the major focus of this chapter. There will also be a discussion of drug therapy used with clients diagnosed as schizophrenic.

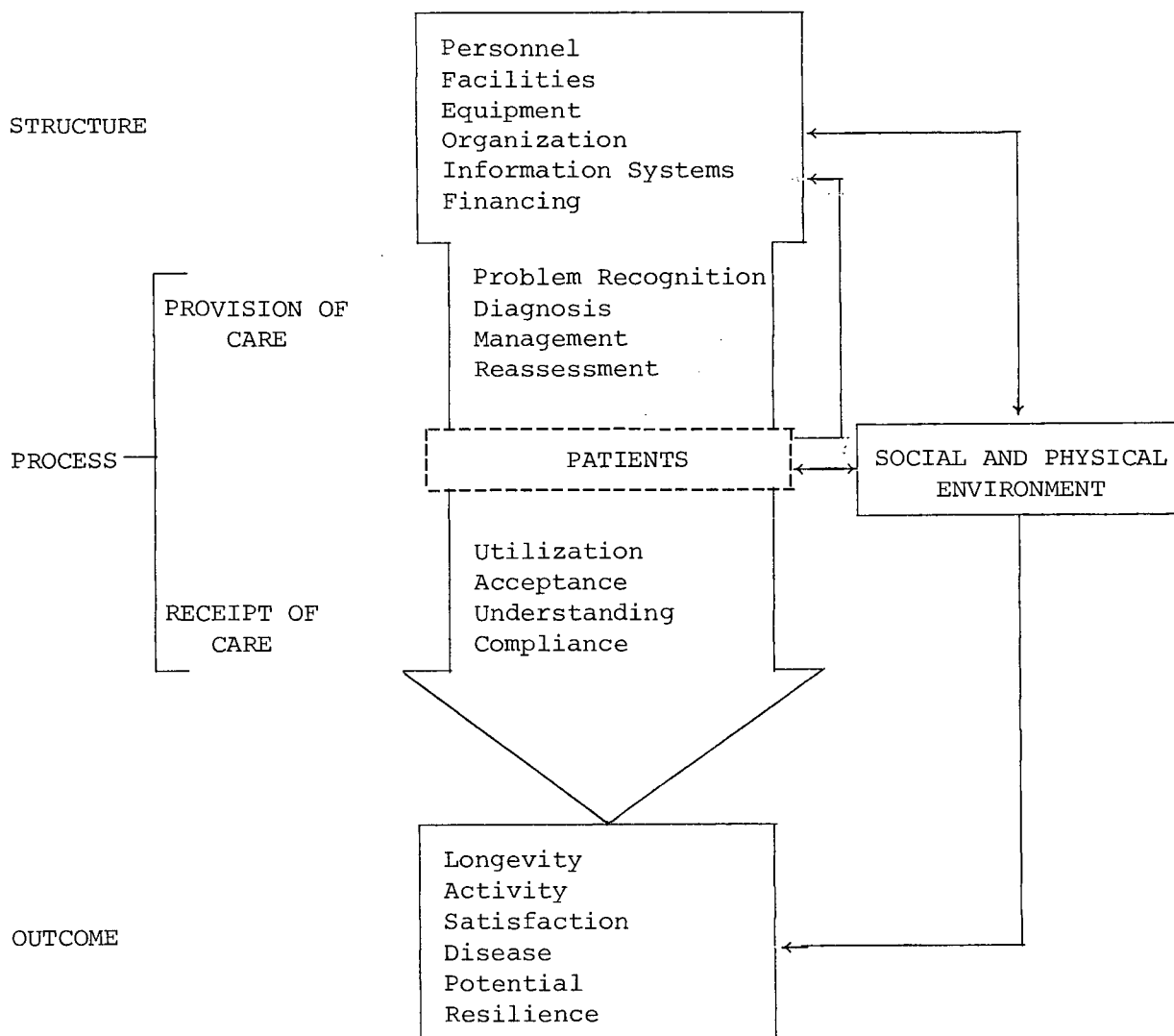
INTRODUCTION TO COMPLIANCE LITERATURE

A. Compliance and the Process of Health Care

In seeking to understand compliance, it is useful to locate compliance research within the realm of health care research. Starfield's (1973) model emphasizes compliance research as concerned with the process of health care, occasionally linking process/compliance and outcome (Figure 1, p. 9).

The Starfield (1973) model illustrates two important considerations regarding the choice of compliance as the organizing framework for this literature review. Firstly, this model reflects a practitioner-researcher's perspective of important concepts in health care. This model does not represent a patient's construction of health care; the patient's point of view of the important process concepts and the desired outcome might be entirely different. As emphasized by the many who support "humanization" and "consumerism" in health care, the perspectives of patients and practitioners do differ. The word compliance portrays both the power and the perspective of the health care system; the newer term, therapeutic alliance, implies shared power.

Figure 1: The Dynamics of Health Outcome
(Starfield 1973, p. 134)



Secondly, this model also clearly indicates that compliance is only one relevant concept within health care process research. Other process concepts, including some not portrayed in the model, are also relevant to conceptualizing patient health behaviors such as medication-taking. The choice of compliance as the organizing centre for the literature review is related to the purpose of this study. Although compliance has been

used, other health care process concepts, such as self-care, may prove to be more germane to the understanding of medication-taking.

B. Problems in Compliance Research

In order to more fully appreciate the complexities and limitations of compliance research, problems associated with compliance research will now be discussed.

Firstly, as client population samples have generally been drawn from health care facilities, those patients labelled non-compliant have been those attending the facility. The group of "non-compliers" who have chosen to drop out of the health care system are rarely included in studies. Thus, the studies are examining only one variation of non-compliance. For this reason, longitudinal studies have been proposed, following clients from first contact with an agency (Haynes, Taylor, and Sackett 1979).

Secondly, there is the question of generalizations amongst disease entities and health behaviors. Is there an over-all phenomenon compliance or is it only meaningful to look at specific situations?

It is not known to what extent compliance is influenced by the specific disease and illness. Psychiatric illnesses are associated with higher rates of non-compliance. Other illnesses have similar rates of non-compliance, however, whether the reasons for these rates are similar is not known. This lack of knowledge has led to recommendations that research focus on particular disease categories (Sackett and Haynes 1976).

Similarly, non-compliance as a consistent behavior pattern has shown varied results. Studies of various health behaviors (Berkowitz et al. 1963; Marston 1970) indicate individuals have differing compliance rates among these health behaviors. For example, one cannot assume the degree

to which a person attends a clinic is the same degree with which the person will take medication. However, Willcox, Gillan, and Hare (1965) reported consistency in non-compliance with one behavior, medication-taking, based on several urine tests over an apparent two-three month time period. The general consensus on this issue is that there is no distinct defaulter for whom non-compliance can be predicted for all health behaviors (Blackwell 1973a).

Thirdly, different definitions of compliance and non-compliance, as well as different methods of measurement, limit the comparisons and summarizations to be made. How are compliance and non-compliance operationalized? For example, does one define compliance as a behavior or an attitude (Davis, 1968)? Some studies (Willcox, Gillan, and Hare 1965; Mason, Forrest, Forrest, and Butler 1963) with schizophrenic patients have used Forrest urine tests to determine compliance. Patients were categorized as compliant or non-compliant based on some level of medication in the urine. Using these urine levels, these researchers concluded that patients were non-compliant, regardless of what the patients' intentions were: that is, deliberately not taking the drug, attempts at self-regulation, forgetting, or even taking as prescribed with testing errors accounting for the discrepancy. Michaux's study (1961) of psychiatric outpatients classified patients according to both resistance (attitude) and deviation from prescribed dosage (behavior) in order to account for the attitudinal and behavioral aspects of compliance. Self-report measures are generally stated to be less accurate than objective measures such as urine tests or pill counts. However, the default rate for Michaux's study, based on self-report, was 52%, and consistent with the other out-patient rates using objective measures.

Finally, if compliance is considered only in terms of determining accurate rates, a behavioral definition would suffice. However, as these studies have approached compliance as something desirable, patient attitude and comprehension would appear to be an important aspect in understanding and intervening in this process. For compliance research in general, Blackwell's comment is relevant and congruent with the purpose of this study: "An obvious short-coming of many studies on drug deviation is that they have used objective indices without questioning the patient" (1972, p. 846). Earlier studies are of limited usefulness because they did not address the linkages between the factors associated with compliance, attitudes, knowledge, and behaviors.

The studies which will be reported in this literature review should be considered in view of these issues concerning compliance research.

REVIEW OF COMPLIANCE LITERATURE

Having made these introductory remarks, the literature on compliance will now be viewed. Deliberately excluded from this review is research concerned specifically with compliance amongst the elderly and consideration of therapeutic interventions for improving compliance. The determinants of compliance and non-compliance, particularly medication-taking in schizophrenia, are the concern of this review. Various theoretical perspectives towards human behavior will be reflected in the following approaches towards compliance.

This literature review on compliance is grouped into the following categories: a) studies determining rates and factors associated with compliance, b) the Health Belief Model, c) the clinician-patient relationship, d) the client's perspective, and e) combined approaches to compliance.

A. Studies Determining Rates and Factors Associated with Compliance

This large group of studies typically focusses on identifying the rates and factors associated with compliance and non-compliance. These factors often take the form of correlations, hence predictors of non-compliance, and variables to be manipulated to improve compliance, rather than the form of explanations of compliance and non-compliance. A variety of health-related behaviors and patient diagnostic categories have been studied. Medication-taking for chronic diseases including tuberculosis, schizophrenia, anemia, rheumatoid arthritis, and more recently hypertension, has received considerable attention (Blackwell 1972; Haynes, Taylor, and Sackett 1979).

There are numerous difficulties with the comparison and summarization of these studies, related to the problems of compliance research previously discussed. Reviewers have commented on the confusing and contradictory data (Sackett and Haynes 1976; Marston 1970; Gillum and Barsky 1974; Blackwell 1973a). Regardless of these difficulties, these reviewers have typically made the following generalizations, which are supported by the author's survey of the studies included in this category.

1) Rates of Compliance: Marston (1970) reported the widest variation of non-compliance rates, from 4-100%. Haynes, Taylor, and Sackett (1979) averaged the rates of compliance with different long-term medication regimens for different illnesses to be about 50%.

2) Patient Characteristics: "Demographic variables such as age, sex, socio-economic status, education, religion, marital status, and race, when examined apart from other variables have rarely been predictive of compliance with medical recommendations" (Marston 1970, p. 317). This statement was generally agreed upon by other reviewers, with a qualifier

concerning extremes of age: the young and old have higher non-compliance rates (Blackwell 1973a).

The personality characteristics of non-compliers was one of the most contradictory areas within this research. Although some studies have identified traits of non-compliers, such as hostility and aggression (Blackwell 1972), the research focus has now shifted from identifying the patient's individual traits to examining the patient-physician interaction, which will be a separate topic in this review.

The patient's living situation has been correlated with compliance -- living alone, poverty, unemployment, and family instability and disharmony contributed to non-compliance (Blackwell 1973b). Conversely, family stability and support promoted compliance (Sackett and Haynes 1976).

3) Features of the Illness: Chronic illness, especially when treatment is prolonged, prophylactic, or suppressive in nature, and when the consequences of stopping therapy may be delayed, was associated with higher non-compliance rates (Blackwell 1973a). As well, psychiatric diagnoses, including schizophrenia, were related to higher non-compliance rates (Haynes, Taylor, and Sackett 1979; Blackwell 1973a).

4) The Regimen: All reviews were in agreement that complexity of regimen was a factor associated with non-compliance: the over-all amount of change required by the individual, and the number of different medications. Frequency of dose was assumed a factor but this has been questioned (Blackwell 1979). Side effects, commonly felt to be important, were cited by Blackwell (1973a) and Marston (1970), but disagreement with the effect of side effects has been expressed by Haynes, Taylor, and Sackett (1979). Compliance decreased with time on the regimen.

5) The Health Care Setting: The setting, or "structural" factors,

as they would be termed in the Starfield (1973) diagram (see p. 9) include factors such as the frequency of appointments, waiting time, and costs. Extended supervision was said to increase compliance (Blackwell 1979); accordingly inpatients had higher rates of compliance than outpatients.

Whereas the former generalizations have been made based on general compliance research, those studies concerned with medication-taking in schizophrenic client populations will now be examined.

Studies of inpatient schizophrenics have associated non-compliance with such factors as paranoid symptoms (Wilson and Enoch 1967), closed ward versus open ward (Richards 1964), and less favorable attitudes towards medication, home, parents, and authority (Richards 1964).

Three studies were conducted using psychiatric patients with varying diagnoses and medications, including anti-psychotic drugs (Willcox, Gillan, and Hare 1965; McClellan, and Cowan 1970; Michaux 1961). Willcox et al. stated that "our findings do little to elucidate the reasons why patients omit their drugs" (1965, p. 792). Age, sex, intelligence, and side effects were not seen as influential, but living alone was. Contrary to this, Michaux (1961) noted positive correlations between resistant attitude towards medication, dosage deviation, and side effects of the medication. McClellan and Cowan concluded "a substantial number of patients apparently adjust dosage to their own self-identified needs and that this is in the direction of scaling the dosage downward...it is of some consequence that such large numbers of patients do not feel free to inform their therapists of this change" (1970, p. 1773).

Johnson and Freeman (1973) studied a schizophrenic out-patient population receiving long-acting injectable phenothiazines. They determined

their non-compliance rate of 18% was better than the average for that population. "The reasons for patients refusing further injections were difficult to isolate, but included volitional defects or other residual symptoms of the illness, failure to appreciate or accept the need for continued medication, real or imagined side effects, and social inconveniences" (Johnson and Freeman 1973, p. 117).

Serban and Thomas (1974) studied medication-taking as part of a study about the attitudes and behaviors of 125 acute and 516 chronic schizophrenic patients regarding ambulatory treatment, using a population of hospitalized patients. Although 60% of the acute and 67.8% of the chronic patients stated that they believed regular use of medication would be helpful, only 32% of the acute and 29.3% of the chronic patients stated they had taken it. The study stated: "further questioning in order to determine if the attitude was due to failure to understand the importance of medication revealed that both acute and chronic patients would discontinue medication if: they felt they no longer needed it, taking medication interfered with their activities, taking medication made them feel different from others, and they felt no difference in their condition after forgetting to take medication" (Serban and Thomas 1974, p. 992). About 28% of the patients in both groups felt reminders would be of use to them and another 20% stated they would definitely not take medications.

Finally, the work of Van Putten (1974; 1978; Van Putten, Crumpton and Yale 1976) will be mentioned. Using both community and hospital-based clients, Van Putten has been studying the drug compliance of schizophrenic patients, emphasizing the need for working alliances. Van Putten (1974) related non-compliance to extrapyramidal symptoms of the drugs, particularly akathisia. A further study on "hard-core drug refusers" in

which patients indicated that symptoms of depression and anxiety on the part of drug takers versus grandiosity on the part of drug non-takers were the best predictors (Van Putten et al. 1976).

In summary, the general studies of compliance described rates and correlations of factors associated with compliance but not explanations as to how and why those factors were associated with compliance. In addition to correlations, the literature on schizophrenic patients' compliance with medication provided some notions as to why schizophrenic patients do or do not take medication. However, as these explanations were not generally the principal focus of these studies, we do not know the research methods by which these explanations were obtained, whether it be data from patients or the researchers' inferences.

B. The Health Belief Model

Recognizing the importance of patients' perspectives, several socio-psychological models which incorporate the individual's perceptions have been developed to predict health behaviors (Suchman, 1967; Horn 1976; Jenkins 1979). The most widely known and extensively tested is the Health Belief Model. Proposed by Rosenstock (1966), the model was described as: "The variables in the model deal with the subjective world of the individual...the focus in the application of the model is to link current subjective states of the individual with current health behavior" (Rosenstock, 1966, p. 98). The model was primarily based on the work of Lewin, although other social-psychological theories, generally termed value-expectancy theories, can be correlated with the model (Maiman and Becker 1974). Two classes of variables account for the individual's motivation: the psychological state of readiness to take action, which is based on the

individual's perceived susceptibility to and perceived seriousness of the health threat; and the extent to which a particular course of action is believed to reduce the threat, that is, the perceived benefits of taking action and barriers to taking action. The model also incorporates cues to action, which are triggers for the appropriate action. The model assumes the theoretical relationship that attitudes determine behavior and it has been criticized by those unable to accept that assumption.

The model was originally developed to account for preventive health behaviors, but it has been applied more widely, using the concepts health behavior, illness behavior, and sick-role behavior (Kasl and Cobb 1966). Briefly, health behavior equates to preventive actions, in the absence of symptoms; illness behavior equates to actions taken by an individual to define and remedy a perceived illness; and thirdly, sick-role behavior equates to activities undertaken to get well (Kasl and Cobb 1966). Compliance behaviors are considered as sick-role behaviors.

Becker has done the most extensive testing of the model in predicting compliance behavior (Becker, Drachman, and Kirscht 1972a and 1972b; Becker and Maiman 1975). The Health Belief Model, as reformulated by Becker and associates for predicting and explaining sick-role behaviors, is presented on the following page (Figure 2). In a study conducted in a pediatric setting (Becker, Drachman, and Kirscht 1972a), compliance was examined as a process involving learning (the name of the medication, the number of times a day it is to be given, and the date of the follow-up appointment) and subsequent behavior (administering the medication and keeping the follow-up appointment). The motivations, value of threat reduction, and probability of action reducing the threat were tested by means of a questionnaire for quantitative analysis, and then correlated

READINESS TO UNDERTAKE
RECOMMENDED SICK ROLE BEHAVIOR

MODIFYING AND ENABLING
FACTORS

SICK ROLE
BEHAVIORS

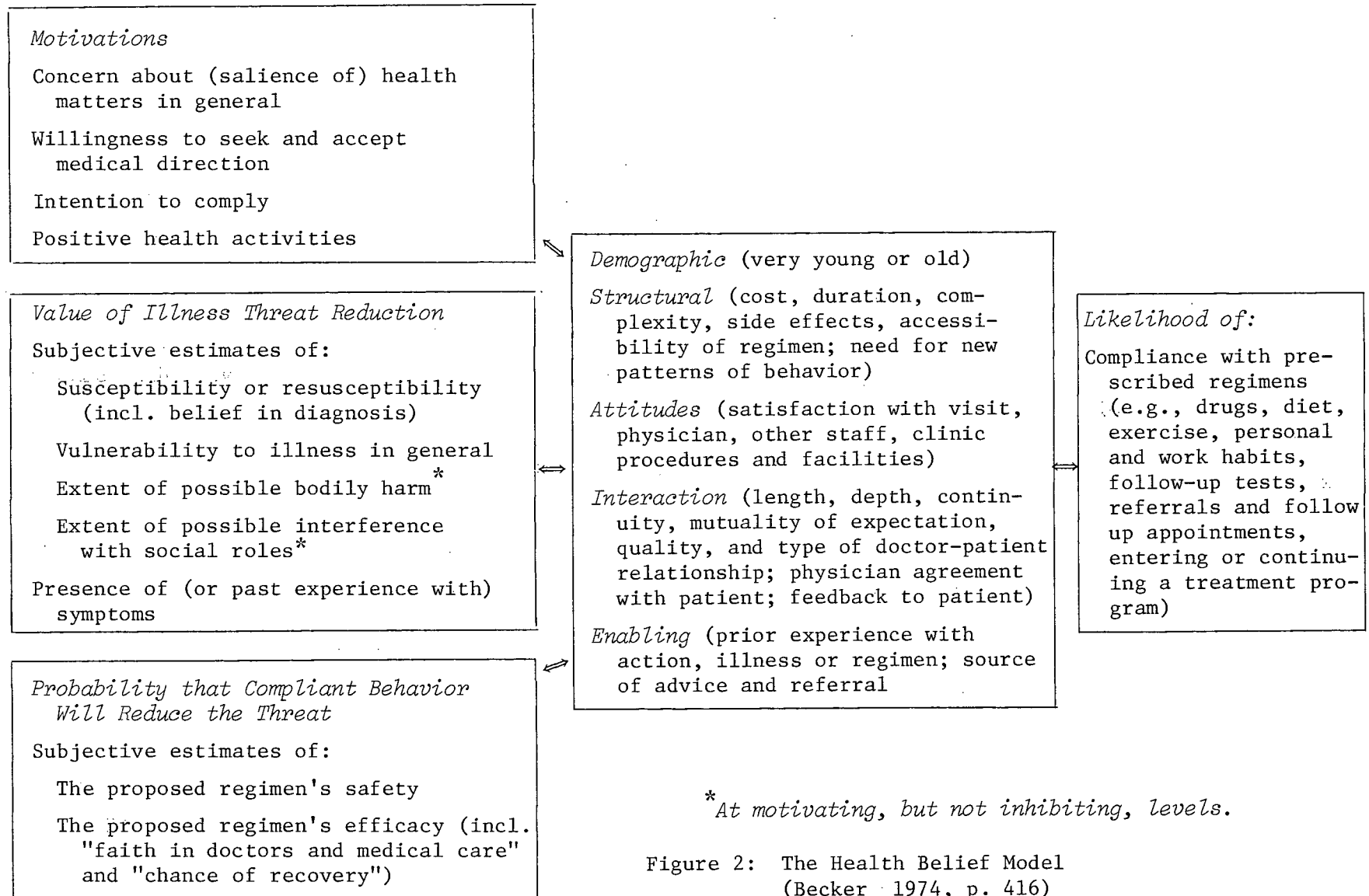


Figure 2: The Health Belief Model
(Becker 1974, p. 416)

with the compliant behaviors. The authors concluded the model appeared useful although not all categories correlated significantly with either the knowledge or behavioral aspects of compliance.

Although this model has not been implemented in investigations of compliance with psychiatric clients, a similar perspective is demonstrated by a study relating insight and adherence to medication in chronic schizophrenics (Lin, Spiga, and Fortsch 1979). Insight was defined as a recognition of the existence of problems and the need for medical intervention. Those patients who had insight, perceived benefits from medication, and also perceived a relationship between the two were more likely to take medication than those who did not have insight nor perceived benefits. However, this combination failed to be a statistically significant factor in discriminating adhering from non-adhering patients. A similar approach was adopted by Nelson et al. (1975) who found that the "acceptance of the premise that they were psychiatrically disturbed, were anxious about their symptoms and were motivated to resolve their personal sense of disturbance" were positively correlated to compliance (p. 1237).

As mentioned previously, the Health Belief Model has utilized the concept "sick-role" behavior in reference to compliance. Sick-role has been questioned as a relevant concept for chronic illnesses such as schizophrenia. Kasl (1974), reviewing the Health Belief Model and chronic illnesses, felt that modifications were necessary for chronic illnesses. Modifications are needed to account for: the person's "at-risk" status, despite feeling well; complying with treatment despite no change in health status and an indefinite treatment period; and the non-medical, that is, life-styling which may be prescribed. The notion that the "sick-role" may not reflect the social role situation of the chronic patient was supported

by a study of compliance among glaucoma patients using eye drops (Vincent 1971). The formulation of an "at-risk" role might prove useful in chronic illness. As well, Kasl (1974) suggests the Health Belief Model needs to incorporate the concepts of lay referral systems; social support; the influence of the doctor-patient relationship; and socioculturally determined expectations and perceptions of pain and symptoms, health and illness, and the sick-role.

In summary, the Health Belief Model, a model emphasizing patients' subjective perceptions, has been used in a limited way in predicting compliance. Some see it as promising (Haynes, Taylor, and Sackett 1979), however, nursing studies (Hogue 1979) using the model have not proven its usefulness in predicting health behavior. Modifications have been suggested to increase its usefulness in conceptualizing relevant variables for chronic illness.

C. The Clinician-Patient Relationship

Both the studies of factors influencing compliance and the Health Belief Model place primary emphasis on the patient in the study of non-compliance. A different perspective on the determinants is offered by studies focussing on the clinician-patient relationship (predominantly studies of the doctor-patient relationship).

Davis studied the structure and process of the doctor-patient interaction, using Bales' problem-solving orientation as the theoretical formulation for the study (Davis 1971). Bales' orientation assumes that both doctors and patients have internalized conceptions of the institutionalized patterns of behavior appropriate for the doctor-patient interaction. Successful problem-solving will consist of both task behaviors (Adaptive-

Instrumental behaviors) and social-emotional behaviors (Integrative-Expressive behaviors) performed in these institutionalized ways.

Tape-recorded doctor-patient interactions were coded into the categories for Interaction Process Analysis. Davis concluded that 37% of the patients were non-compliant; personal and social attributes of the patients were unrelated to the compliance. "Non-compliant behavior was explained by increased difficulty of communication and attempts by doctors and patients to control each other" (Davis 1968, p. 279).

Korsch and associates (Korsch, Gozzi, and Vida 1968; Francis, Korsch, and Morris 1969; Vida, Korsch, and Morris 1969; Freemon, Negrete, Davis, and Korsch 1971) studied the doctor-patient relationship in a pediatric setting, focussing on the verbal interaction between the mothers and doctors. The doctor-mother interaction was related to patient satisfaction and patient compliance, both measured via an interview with the mother. The interactions were analyzed in several ways: according to descriptions of the interviews by the mother, by identifying instances of "doctor blockages" (communication blocks identified by listening to taped interviews), and also adopting Davis' approach, the Bales' Interaction Process Analysis. "Outcome of the medical communications, in terms of the patient's satisfaction and follow through on medical advice, was favorably influenced by having a physician who was friendly; expressed solidarity with the mother; took some time to discuss non-medical, social subjects and showed an interest in her; and gave her the impression of offering information freely, without her having to request it, or feeling excessively questioned by him" (Freemon, Negrete, Davis, and Korsch 1971, p. 310). Patient satisfaction and compliance were highly correlated, although not synonymous. Factors other than the doctor-patient relationship influencing compliance

were thought to be the seriousness of the illness as perceived by the mother, the complexity of the instructions, and practical circumstances (Francis, Korsch, and Morris 1969).

Svarstad (1977) sought a meaningful conceptual model for studying physician-patient communications and patient conformity, believing Bales' framework to be inadequate. The study question was "Why do physicians sometimes fail to achieve the patients' conformity with medication advice?" (Svarstad 1977, p. 223). Two major dimensions of physician communication were identified: the physician's effort to instruct the patient and the physician's effort to motivate the patient. The physician's effort to motivate was evaluated in terms of influence processes such as friendliness, justification, authority, and emphasis. Patient conformity (compliance) was positively associated with the physician effort to motivate and the amount of physician instruction. Hulka et al. (1975) also studied the patient's comprehension of the medication regime, assuming that compliant behavior can only occur as a result of appropriate communication from the doctor. There has been considerable emphasis on the clinician's instructional behavior and the corresponding result, patient comprehension, in relation to compliance. Their perceived importance has contributed to the development of patient education programs.

Studies of the physician-patient relationship and its effect on medication-taking have rarely been done in psychiatry, especially with the long-term medication-taking of schizophrenic clients, although the literature supports the notion of the importance of a co-operative relationship. "The most neglected variable in the literature on psychiatric adherence has been the clinician-patient interaction" (Eisenthal et al. 1979, p. 394). A study by Eisenthal et al. (1979), using intake interviews conducted at a

psychiatric "walk-in" clinic with both physician and non-physician staff, demonstrated that a negotiated approach resulted in greater adherence to the disposition plan. The negotiated approach assumes that patients have distinct perspectives regarding their problems and regarding treatment. Effective planning requires the clinician to "strive to understand the patient's perspective, recognize the legitimacy of conflicts when they occur, and negotiate their resolution" (Eisenthal et al. 1979, p. 394). Some of the work in regards to medication-taking and the doctor-patient relationship has been done under the rubric of "non-specific factors in drug therapy;" although this research area tends to focus more on variables influencing drug effect than on compliance.

In summarizing the work which has been presented on the clinician-patient relationship, different aspects of this relationship are emphasized in each study. These aspects include: role expectations and role fulfillment in the management of the problem-solving interaction, the physician's ability to communicate in a personalized way with patients, the physician's instructional and motivational effort, and the clinician's ability to negotiate a treatment plan suitable to the client.

D. The Client's Perspective

The next perspective on compliance to be discussed is similar to the perspective of this study. Clients or patients are seen as actively defining their situation, exercising judgment in decisions in their lives, and dealing with a variety of competing demands in their everyday lives. In the course of these activities, non-compliance is seen as expected in some circumstances. This general perspective can be contrasted with the perspective which viewed the "normal" patient as a passive and obedient

subject, accepting the authority of the health care system to prescribe his/her behaviors. There are several variations of this general perspective.

Studies under the rubric of "self-care" are examples of this perspective. Acknowledging that what can be defined as health behavior can be very broad or very narrow, these studies seek to understand the ways in which people do care for themselves, individually and as families (Roghamann, Hecht, and Haggert 1973; Levin, Katz, and Holst 1976). Self-care is depicted as a social process, with family, friends, and the health care system influencing the individual, sometimes in competing ways (Barofsky 1978; Pratt 1973). Self-medication is recognized as a long-standing and common activity within our culture, as well as other cultures (Leake 1965). People make judgments independent of physicians in regard to both prescription and non-prescription drugs (Dunnell and Cartwright 1972; Knapp and Knapp 1972). Rather than seeking compliance, which is suggestive of coercion or conformity, Barofsky suggests the goal of health care should be to enhance self-care, based upon negotiation between the individual and the health care provider (Barofsky 1978).

Although the next group of studies has not been grouped with self-care, they could easily be subsumed within that approach. These studies seek to understand the patient's response to an illness, depicting the steps taken by an individual as he attempts to solve a health problem (Fabrega 1973; Chrisman 1976 and 1977). The health-seeking process (Chrisman 1977) is depicted as five steps: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and adherence.

Two studies (Stimson 1974; Hayes-Bautista 1976) focus specifically on the individual's problem-solving in regards to adherence or compliance.

Stimson concluded that a person will "evaluate the doctor's actions and instructions, and make his own decision about his use of medications.... The patient is repeatedly faced with the problem of whether he is doing the right thing with regard to his health" (1974, p. 103). Hayes-Bautista (1976) analyzed patients' (urban Chicano women) perceptions and explanations of their non-compliant behavior. Non-compliance was seen as a modification of a treatment plan, "to gain a modicum of control in an interaction with a practitioner in order to obtain satisfaction with the treatment" (Hayes-Bautista 1976, p. 234). It was acknowledged that non-compliance could also be based on other reasons, such as forgetting, although reasons other than the control issues were not developed in the paper. These studies, although not focussing on either the schizophrenic patient population or long-term medication-taking, offer some suggestions as to how clients might perceive and explain their medication-taking behavior.

Although not specifically focussed on compliance, studies of the everyday realities of living with chronic illness give insights into the patient's perspective towards medication-taking. Key assumptions in this approach are that the chronically ill person is concerned with managing his life, and the demands of health regimens will be managed by the patient in his efforts to make a life for himself (Reif 1975). This approach could also be incorporated under the self-care concept.

Studies concerned with living with chronic mental illness have been done using a symbolic interactionist approach towards labeling deviance, viewing deviance as a result of a process of societal definition (Scheff 1975). The career of a mental patient is depicted in stages -- compliance behavior in the community being the concern of the post-patient phase (Spitzer and Denzin 1968). The discreditation and difficulties of re-

integration associated with chronic mental illness are themes in this literature (Miller 1973; Goffman 1961). Stigma is considered a major concept in understanding the life of a discharged mental patient (Cumming and Cumming 1968; Goffman 1963). Although these studies generally do not provide explanations for medication-taking, they suggest influences on how patients might perceive their medication-taking. One study on community care for psychotic patients (Darley and Kenny 1971) postulated that patients felt uncertain as to what constituted "normality" and hence relied on drugs to prevent themselves from experiencing strong emotions, which they viewed as abnormal.

The studies which have thus far been included in the discussion of the client's perspective have been generally reflective of a sociological perspective of health and illness, and patient-hood. Another theoretical stance is presented by anthropologists. While incorporating concepts such as illness behavior and thus attaching relevance to the health-seeking frameworks proposed by Fabrega and Chrisman, the anthropological viewpoint is concerned with culture and its influence on behavior. Health behavior is determined by health culture, which is defined as "all the phenomenon associated with the maintenance of well-being and problems of sickness with which people cope in traditional ways within their own social networks" (Weidman 1975). This definition includes a cognitive dimension, beliefs and values, and a social system dimension, the organization of health care.

The orthodox "scientific" medical system is viewed as a distinct ideological system, often in conflict with the patient's view of the situation. The need to understand the patients' views, their Explanatory Model as termed by Kleinman (1978), is important in understanding health behavior

such as compliance. Studies invoking this paradigm illustrate how behavior labeled as non-compliant and, even given psychiatric labels to account for the divergence in perspective, are understandable within that individual's health culture (Redlener and Scott 1979; MacGregor 1967).

Studies reflecting the client's perspective contrast with those studies done from the practitioner's perspective. Non-compliance may be viewed as a valid course of action from the client's perspective. Compliance emerges as a concept which cannot be viewed simply as a distinct behavior, but must be seen within the complexity of an individual's life.

E. Combined Approaches to Compliance

As our understanding of compliance has become increasingly complex, so have the models for research. Several models exist which incorporate two or more of the approaches discussed in the following sections. For example, two models have been put forward which combine aspects of an interpersonal approach and the social-psychological models. Toledo, Hughes, and Sims (1979) presented an approach for the management of non-compliance among parents of children with cardiac problems. The approach utilized Rogers' client-centered therapy in the interview situations, combined with identification of parent perceptions similar to those outlined in the Health Belief Model (Toledo, Hughes, and Sims 1979).

Another group of researchers constructed a model predicting adherence to treatment for hypertension, including concepts relevant to the Health Belief Model, such as motivation and perceived usefulness of the adherent behavior (Caplan et al. 1976). Other important concepts were social support and health information. Social support was defined subjectively and could come from a variety of sources: family, doctor, nurses, and

friends. The model, revised following testing, is shown on the next page (Figure 3).

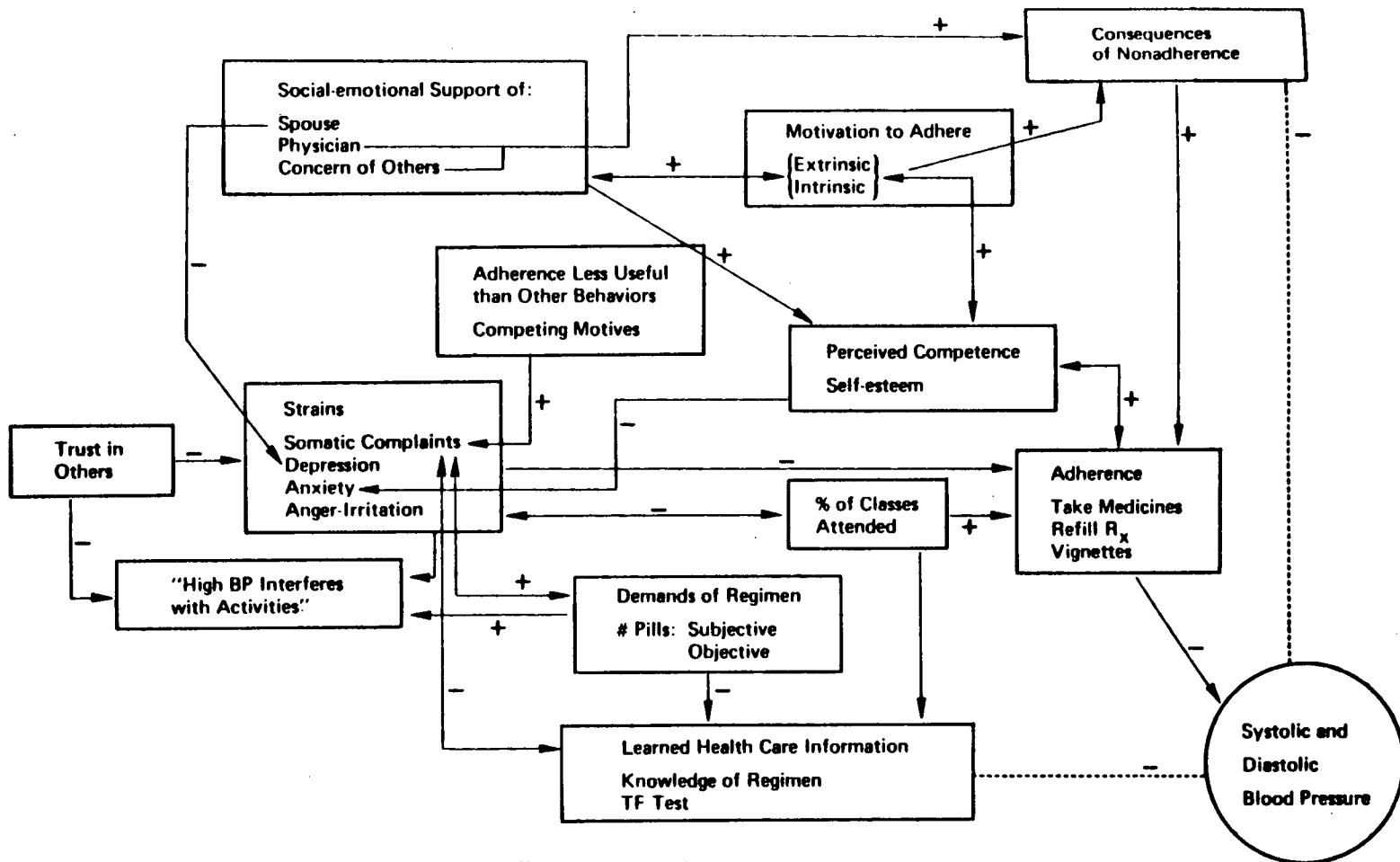
Christensen (1978) proposed a modification of the Health Belief Model that incorporated the dynamics of the physician-patient relationship and the processes through which patient's perceptions are formulated. "The model adopts the perspective of the patient who constantly reassesses the decision to comply (and the extent of compliance) with prescribed instructions as he seeks medical help and proceeds through convalescence" (Christensen 1978, p. 182).

Jenkins (1979) developed the broadest conceptual model for health-related behavior. It includes beliefs, including those of the Health Belief Model; motives; actions; and the environment, which includes health providers, the immediate social environment, and cultural factors.

F. Summary of the Review of the Compliance Literature

A progression is evident when one reviews the research in the field of compliance. Studies initially identified the existence and the rates of non-compliance, then identified factors associated with non-compliance, and finally sought explanations for non-compliance. Studies have become increasingly complex in regards to these explanations. There is an awareness of the importance of the client's perceptions, as demonstrated by the number of models which incorporate subjective data. As well, recent models of compliance include the importance of interpersonal relationships, both with health care providers and the significant others in the client's life. The growing emphasis placed on the client's perceptions and the social environment lend support to the perspective adopted by this study.

Figure 3: Model of Adherence to Treatment for Hypertension
(Caplan et al. 1976, p. 143)



Interpretation of the main effects among variables used to test a model of adherence. (Arrows indicate the direction of hypothesized causal relationships. Double headed arrows suggest a reciprocal causality. Dotted arrows indicate a derived rather than direct effect. The signs indicate the direction of the obtained correlations. Arrows entering a panel refer to a specific variable within the panel.)

This summary concludes the review of compliance literature. The final section of this chapter will be concerned with drug therapy used with clients diagnosed as schizophrenic.

DRUG THERAPY IN SCHIZOPHRENIA

A. Purpose of This Discussion

This discussion of drug therapy in schizophrenia has two purposes:

1. To consider the efficacy of drug therapy in the treatment of schizophrenia. Concern about compliance is only relevant if the regimen is efficacious, otherwise compliance will only increase the patient's chance of incurring the deleterious effects of treatment with no proven benefits.
2. To present the theoretical framework of psychiatry in regards to the use of medication in the treatment of schizophrenia. The theoretical framework presented here will be based on literature, not specific clinicians, but it is hoped that this framework will be generally representative of the clinicians' perspectives. The clinician's perspective determines the prescribed medication patterns and influences the client's perspective of the situation.

B. Schizophrenia: Etiology, Diagnosis, and Prognosis

What is schizophrenia? This question is widely debated. Labeling theorists like Scheff (1975) and radical psychiatrists such as Szasz (1968) question the existence of a diagnostic category "schizophrenia." Psychiatrists vary in theories of etiology, diagnostic criteria, and possible prognosis, questioning even if schizophrenia as it is now described is one disease or several. This review will not attempt to present a discussion of all these issues. Rather, the aim is to describe generally

accepted stances in regards to etiology, diagnosis, and prognosis.

Proposed etiologies of schizophrenia have been classified as biological (genetic and biochemical), psychological (psychoanalytic and behavior theory), and social (cultural and family) (Wilson and Kneisl 1979). At this time, biological theories appear to be receiving more research attention and gaining dominance (Hansell 1978), however, many clinicians continue to attribute schizophrenia to a combination of all these etiological factors.

Bleuler first originated the use of the term schizophrenia. "Bleuler's system of schizophrenia is often referred to as the four A's: association, affect, autism, and ambivalence" (Freedman, Kaplan, and Sadock 1976, p. 437). A variety of diagnostic frameworks have been developed, leading to many definitions of schizophrenia. Concern about the clinical definitions of schizophrenia in terms of relevance to recent research, diagnostic reliability, prognostic usefulness, and the consequences of labeling has led to a redefinition of schizophrenia in the DSM III (Spitzer, Andreasen, and Endicott 1978).

DSM III describes the essential features of schizophrenia as: "the presence of certain psychotic features during the active phase of the illness, characteristic symptoms involving multiple psychological processes, deterioration from a previous level of functioning, onset before age 45, and a duration of at least six months....At some phase of the illness schizophrenia always involves delusions, hallucinations, or certain disturbances in the form of thought" (p. 181).

The DSM III describes several courses for schizophrenia: subchronic, chronic, subchronic with acute exacerbation, chronic with acute exacerbation, and in remission. It states that a complete return to premorbid

functioning is unusual, but not excluded -- the incidence unknown.

Studies have been concerned with the identification of factors associated with a good prognosis (Stephens 1978; Vaillant 1978a, 1978b; Strauss and Carpenter 1978). One approach has been the differentiation of process and reactive schizophrenia, reactive schizophrenia having a more rapid onset and a good prognosis. Although these categories are not generally agreed upon, DSM III has reserved the term schizophrenia for illnesses with at least a six month duration, thereby excluding shorter duration psychotic episodes.

Strauss and Carpenter (1978) have divided outcome into four categories, which they see as largely independent of one another: symptom severity, duration of hospitalization, social relations functioning, and occupational functioning. With each of these categories except symptom severity, the previous level of functioning in that category is the best predictor of outcome. Cross-cultural studies have revealed interesting data concerning outcome. Industrialized nations have poorer rates of outcome than non-industrial countries, suggesting societal expectations influence the course of the illness (Waxler 1979).

C. The Efficacy of Drug Therapy

The previous section has described schizophrenia as a generally chronic illness, but with possible remission. What role does medication play in the course of this illness? Many consider the introduction of medication to have revolutionized the treatment of schizophrenia. The use of major tranquilizers in the treatment of acute episodes appears to be relatively undisputed (Stephens 1978; Davis 1976). As mentioned in Chapter One, medication is one of the major treatment modalities with

long-term schizophrenic patients. Studies have documented that medication is beneficial in preventing relapse in terms of rehospitalization (Hogerty, Goldberg, et al. 1973). Cessation of medication, that is, non-compliance, is a confounding variable in studies directed at testing the efficacy of medications. A further complication is awareness of the non-specific aspects of drug therapy (including what has been commonly referred to as the placebo effect), although it is felt "that the non-specific factors in treatment response are considerably less powerful in schizophrenia than are the specific effects of the drug" (Cole, Bonato, and Goldberg 1968, p. 126).

However, along with the conviction that maintenance anti-psychotic medication is indicated in the treatment of schizophrenia, there is growing awareness that not all patients will benefit. As well, the long-term side effects, in particular tardive dyskinesia, are so debilitating as to require serious consideration of drug therapy. There are two groups of patients who might be best treated without medication: those who do well without them and those who do very poorly with or without drugs (Marder et al. 1979). As well, Davis (1975) notes that occasionally chronically ill patients will do better when drugs are withdrawn. Thus the picture becomes blurred. From the point of view of compliance research, some clients may experience no clinical change regardless of medication-taking practices. From another point of view, the clinician is confronted with the medication-prescribing decisions of: what patient?, on what medication?, at what dosage?, and for how long? Although research is being conducted to identify those clients who would benefit most from medication (Marder et al. 1979), and some guidelines are emerging, this is a developing and inexact science at this time.

D. Medication Regimens

Having identified that a proportion of schizophrenic patients require long-term medication therapy, generally accepted ideas concerning anti-psychotic medication regimens will now be discussed. Regardless of recommended medications, dosages, and duration of treatment, one important variable emphasized in the literature is the importance of individual factors, for example metabolic differences, in response to the drugs. These factors necessitate consideration of each patient's individual situation (Hamilton 1968; Mendel 1975).

Anti-psychotic medications -- phenothiazines, butyrophenones, thioxanthenes, dihydro-indolones, and dibenzoxazepines -- are thought to be generally equally effective in treating schizophrenia. Criteria for choosing the appropriate medication for each patient are: the side effects of the various medications, the physician's knowledge about the medication, cost, and the patient's drug history (Appleton and Davis 1973). The side effects vary; they can include sedation, hypotension, atropine-like side effects, phototoxicity, and extrapyramidal side effects such as dyskinesia, akinesia, and akathisia (Appleton and Davis 1973). Anti-parkinsonian drugs are prescribed to minimize some of these side effects; practice varies as to whether to prescribe anti-parkinsonian drugs routinely or as side effects occur.

While prescribing guidelines do exist, recommended dosages for both acute and chronic care can vary widely. The recommended strategy is to titrate on an individual basis, with cautions about both over- and under-medicating. Hence considerable onus is placed on the practitioner to determine what is a suitable dosage for each client, "the minimum dosage for optimal functioning" (Appleton and Davis 1973, p. 48). In order to

minimize the deleterious effects of long-term medications, drug holidays, regular periods of time without medication, have been recommended. These holidays are possible due to the slow excretion of the medication allowing withdrawal of the drugs for short time periods. Trials of both lowered dosages and drug-free periods are also recommended to ascertain patients' continuing medication requirements (Davis 1975).

The work on compliance and schizophrenia has been reviewed in the preceding sections of this chapter. Although the majority of anti-psychotic medications are in tablet form, a few long-acting injectable medications have been developed and are recommended for "patients who cannot be trusted to take their pills" (Appleton and Davis 1973, p. 49). Once-daily dosage schedules are suggested for patients on long-term oral medications.

The nature of the practitioner-patient relationship in regard to medication management has had an interesting history in psychiatry. Initially, many psychotherapists eschewed the notion of prescribing medication as it would distort the psychotherapeutic, in most cases psychoanalytic, relationship. As medications became more accepted, practitioners prescribed medication, but patient input in this process tended to be minimal, as was the case for medical practice in general. However, psychiatry had the additional complications of both the issue of the patient's rationality and the notion of the unconscious, which encouraged practitioners to infer motivations in regards to medication-taking rather than seek out the patient's opinions and conscious motivations.

As previously mentioned, the recommended trend in health care is toward a therapeutic alliance, both practitioner and patient participating in the decision-making. Hansell (1978) has suggested schizophrenics be involved in the self-regulation of their medication, adjusting their med-

ications within a prescribed range according to such factors as side effects, life stresses, and onset of symptoms. Both educational materials and group experiences designed to enhance the patient's ability for self-regulation are recommended (Hansell 1978). This is a dramatic shift from the discussion as to whether patients should be informed of side effects of medications (Myers and Calvert 1979).

E. Conclusion

This discussion has presented schizophrenia as an illness with possible long-term, if not life-long, disability. Maintenance medication is highly desirable for some schizophrenics. However, clinical decisions must be made as to which clients will benefit from medications and also as to what medication regimen is most suitable. The participation of the client in these decisions is now being advocated.

As mentioned in the introduction to this section, the efficacy of drug therapy has been considered in order that the relevance of the phenomenon "compliance" can be more fully evaluated. This discussion has displayed the perspective of scientific medicine as represented in articles, texts, etc. towards medication-taking. This perspective can be compared with that of the clients represented in Chapter Four and will be discussed in Chapter Five.

CHAPTER III: METHODOLOGY

INTRODUCTION

This chapter describes how the research data was obtained. The following topics will be discussed: the selection of participants, data collection, data analysis, and ethical considerations.

As described in Chapter One, the research methodology used in this study was guided by studies done within the qualitative paradigm. Such works include Stoddard (1974), Becker (1973), Lindemann (1974), Blaxter (1976), Cottle (1977), and Filstead (1970).

THE SELECTION OF PARTICIPANTS

This study is concerned with medication-taking in persons diagnosed as schizophrenic. The medications in question are oral anti-psychotic medications. It has been suggested that compliance research is most meaningful if done with a specific client group and an acknowledged efficacious regimen for that population. Thus, the client group studied is a logical group from the standpoint of compliance research. Whether this client group is a logical category from their (the clients') perspective is not known. Perhaps all patients on all medications share some or even all of the perspectives of this group. As comparative work has not been done, what might be logical groupings based on the clients' perspectives are not known at this time. There were advantages in studying a specific client population and a specific regimen for the researcher as comparisons could be easily made between the perspectives shared by the clients and the perspectives of scientific medicine.

The initial group for the study was a long-term or chronic population

group. The criteria for selecting this group were:

- age 25-59 years
- a minimum of two hospitalizations with the discharge diagnosis of schizophrenia
- residing in his/her own residence, or a residential facility in which the client has responsibility for taking his/her own medication, for at least six months
- currently being prescribed (although not necessarily always taking) oral anti-psychotic medications: phenothiazines, butyrophenones, thioxanthenes, dihydroindolones, and dibenzoxapines
- able to converse in English

The rationales for these criteria will be discussed briefly. The upper age limit of 59 years was set to deliberately exclude persons who might be classified as elderly, due to the unique medication-taking difficulties that have been associated with that group. The lower age limit of no younger than 25 years and the minimum of two hospitalizations with a diagnosis of schizophrenia was due to the emphasis on a typical long-term or chronic population. The residence requirements and the limitation to oral medications were designed to obtain subjects who were responsible for the administration of their medications, and therefore would have some notions directing their medication-taking as well as the opportunity to adapt medication-taking to their everyday life. Ten such participants were sought. Clients in residential care, on injectable medications, or recently discharged were excluded from this initial sample for these reasons.

The procedure by which this group was obtained will now be described. Using the criteria provided by the researcher, the therapists at two

Greater Vancouver Mental Health Service Community Care Teams identified suitable subjects from their client populations. The therapists then informed potential subjects of the study, using an information letter provided by the researcher (Appendix A). If a client agreed to participate, two consent forms were signed (Appendix B and C). One form (B) was concerned with consent for participating in the study and specified: there was no risk to subjects from participating, the subject's participation was voluntary, that subjects might withdraw at any time, that refusal to participate in the study or withdrawal from the study in no way interfered with the treatment received, and that any information personally identifying the subject would remain strictly confidential. The second consent form (C) was necessary for permission for the audio-taping of the interviews. When the consent forms were signed, the therapist notified the researcher who then contacted the subject by phone, or mail when the subject did not have a phone, to arrange a mutually convenient time to meet.

In the course of obtaining suitable subjects, the researcher was made aware of the large number of schizophrenic clients who are on injectable medications as compared with those on oral medications, thereby limiting the number of potential subjects. This awareness also raised questions as to whether those persons on oral medications would be typical of the chronic population at large. As well, several clients approached by the therapists did not wish to participate and two persons who had signed consent forms withdrew from the study prior to the first interview. These events raise the question "who are those persons that agreed to participate?"

The researcher's common-sense appraisal of this patient group, which ultimately consisted of nine subjects, two males and seven females, was

that they were in fact typical of the chronic population at large. Their ages ranged from 30 years to the mid-50's, the length of time on anti-psychotic medication varied from 5 years to about 25 years. A wide variety of commonly-used anti-psychotic medications were represented, for example, chlorpromazine, haloperidol, trifluoperazine, and thioridazine. One person was receiving injectable medication, fluphenazine, in addition to oral medications; four others had been on long-acting injectable medications in the past. Most subjects had more than the minimum of two hospitalizations, some of these hospitalizations lasting ten-fifteen years. The living situations varied: four were living on their own; three with their families, either spouses or offspring; and two in group situations. Two persons were employed on a full-time basis; some were employed part-time, including work-shops and equivalent situations; and some were unemployed outside the home.

As is typical in qualitative research, the design of the study had made provision for additional participants as might be necessary to answer research questions arising in the process of investigation (Lindemann 1974). The need for additional participants in this study was identified when it was determined that one member of the chronic population group interviewed did not meet the criteria for that group. Rather, this subject was representative of a short-term or acute illness population. This subject presented notions about medication-taking which appeared to be related to a "short-term illness" perspective. In order to more fully appreciate the similarities and differences in a "short-term" versus a "long-term" perspective additional "short-term" subjects were sought. Only one such subject (using the two G.V.M.H.S. Teams used previously) was willing to participate in the study. The criteria describing the

two "short-term" subjects are: age 20-30 years; only one psychiatric hospitalization, with a discharge diagnosis of schizophrenia; and discharge from hospital within the past eight months. The criteria related to type of residence, types of medication, and ability to converse in English were the same as with the previous group.

DATA COLLECTION

The data was collected via interviews. Ten subjects were interviewed twice, as had been planned. A second interview was not sought with the one additional subject meeting the short-term criteria. The interviews were taped, although mechanical taping difficulties encountered in three interviews necessitated that the researcher use written notes as well for those situations. The interviews varied from about forty to ninety minutes in length.

A written interview guide was developed (Appendix D). Based on Schutz' (1967) notion of a course-of-action*, the interview guide included past, present, and future influences on the participants' actions. As the researcher was seeking the subject's perspective, the researcher attempted to use open-ended questions and explore the meaning of the subject's responses. In the first interview situation with each subject, the guide served as a screening device to check whether all significant areas had been covered. It also served as an interview tool in situations where the subject tended to be reserved during the interview. The guide was modified in the course of these initial interviews. The second interview with each subject was based on questions which arose from the analysis of the initial interviews.

* A course-of action is a useful way of understanding human behavior which directs consideration of the past and future motives and goals of the individual, and the context of the individual's environment relevant to that action (Schutz 1967).

Two aspects of the data collection process will be discussed in greater depth, to describe more fully the process of qualitative research. These aspects are the construction of an account and the management of the interview situation.

A. The Construction of an Account

The term account is used in reference to the descriptive data reported in this study. The use of the term account recognizes that knowledge is constructed; knowledge or "facts" of events are dependent on the interpretations and characterizations of the participants. The accounts of medication-taking presented in this study represent the subjects' perspectives at that point in time, as constructed by both the subjects and the researcher.

The construction of an account is an active process for both the participants and the researcher.

R*: Do you think being off of the medication had anything to do with your going to the hospital?

S*: Oh, gosh no -- uh -- it might have, it might have -- to an extent it might have. I might have been able to talk about my problems instead of jus' letting it all get in my head and having all those awful thoughts.

R: I'm thinking about this 'lazy feeling' that you get; you, you relate that to being on pills?

S: No -- I never really thought about it until now.

R: I see. Uh-huh. What do you think 'the laziness' is due - ?

S: Well, come to think of it, I think it is uh from the pills because they quiet me down so much.

* R symbolizes the researcher.

* S symbolizes the subject/participant.

These particular examples were chosen to illustrate the way in which both the subject and the researcher, in making sense of the situation, construct the account. Although the researcher's intent was to obtain the subject's view of the situation, the researcher's own interpretive competence necessarily contributes to account construction. In seeking to understand the participants, the researcher tended to listen, recount, reword, ask for elaboration, and summarize. The researcher was conscious of the problems of influencing the accounts by assuming too active a role in the interview. This was particularly a problem when discussing those topics which subjects found difficult to discuss, for whatever reasons.

R: I'm afraid to say more because I'm afraid that I put words into your mouth if I say too much about it, so I guess I'd better just leave that!

Becker and Geer (1970) note people may

...not tell an interviewer all the things he might want to know. This may be because they do not want to, feeling that to speak of some particular subject would be impolitic, impolite, or insensitive, because they do not think to and because the interviewer does not have enough information to inquire into the matter, or because they are not able to.... Many events occur in the life of a social group and the experience of an individual so regularly and uninterruptedly, or so quietly and unnoticed, that people are hardly aware of them, and do not think to comment on them...or they may never have become aware of them at all and be unable to answer even direct questions (Becker and Geer 1970, p. 130).

The researcher's experience is consistent with those comments, as subjects had difficulties verbalizing some ideas and appeared uncomfortable discussing some subjects, such as the moral implications of medication-taking and their current negotiations with health professionals in regards to the medications.

S: I've never had to explain it, because I very seldom tell anyone about it.

S: I don't know -- I just, I just sort of like, like the,

like that -- I don't know. I just sort of like it that way, you know.

The types of issues which subjects find difficult to discuss will vary according to their individual situations, but those issues will also vary according to how they view the interviewer. The knowledge that the researcher was a nurse who had worked in community mental health influenced their responses. For example, the subjects' hesitancy in describing their perceptions of the actions of the medication was influenced, as they were concerned about the scientific adequacy of their responses. This knowledge of the researcher also hampered the degree to which the researcher could assume a neutral, naive approach to some of the data; this approach is useful in discussing "taken-for-granted" aspects of their experience. However, the nursing role also gave a legitimacy to inquiries which, as stated by the subjects, gave subjects confidence in the researcher's "sense" and encouraged them to "go into the specifics."

The accounts were also influenced by the subjects' agendas for the interviews and what they perceived the researcher's purpose to be. The researcher attempted to elicit this information from the subjects.

S: So you must grow too from this, in making, uh, sense out of what everybody says and trying to understand it.

R: Can you just tell me about how it was that you decided to tell me about those?

S: Well that was your study.

R: Uh-hmm.

S: That was just your study, that's all.

R: What were your expectations about what we would be talking about?

S: Well, nothing really, I just thought, "Well, it's a young

girl doing her thesis, and she just wants to know about medications. She may," and you may pass -- and, um, I don't know, you may become a great doctor or something (laughs) or a great nurse, or whatever you're going in for. I don't know.

Subjects were also concerned about their performance, if they were doing an adequate job for the researcher's purposes. In some instances, subjects requested knowledge of the questions to be asked in the next interview in order to "explain things better to you."

S: I just hope I'm telling you things -- I think I'm helping you though.

R: Uh-hmm.

S: There wouldn't be many people that would talk about some of the things --

S: I feel very foolish saying that, I think I'm not helping you.

R: Oh, why, why do you feel that way?

S: Uh, I don't know, maybe I'm so quiet that I don't say very much.

S: ...last time, sometimes I had to think so long for an answer. Well, sometimes I thought, "well you'd get more help or learn more from someone quick with the answers."

Accounts are subject to change, as persons redefine their situation. Subjects gave evidence of how their definitions of the situation had changed over time by comparing their current perspectives with their past perspectives. As well, subjects "remembered" things in the course of the interviews, which thus changed the account. The content of the first and second interviews was generally quite consistent in terms of major concerns and the way in which events were described. However, discrepancies were evident and could be classified under three categories: re-evaluation of former statements resulting in a desire to change the account; a change

in the situation, such as a change in medication, resulting in a re-evaluation and redefinition of the situation; and changes in the second account contradicting some information in the first account with no explanation offered. Re-evaluation of former statements and "correcting" the account took the form of a letter to the researcher in one situation. In another situation, a subject commenced the second interview by "correcting" some aspects of the first interview.

The ideological influences on the content of the accounts could be identified as the subjects' own sense making/lay ideology; scientific ideology; and religious ideology. The researcher attempted to suspend the therapist's perspective, based on scientific ideology, and pursue the sense making practices of the subjects. However, the therapist's perspective no doubt influenced what was pursued and what wasn't; therapist/researcher role conflict is also apparent in the management of the interview situation.

B. Management of the Interview Situation

In the previous discussion, the construction of the accounts was addressed. The management of the interview views the interview situation as a situation-to-be-managed from the researcher's point of view.

Both the researcher's and subject's anxiety are elements of the accounts. As mentioned previously, therapist/researcher role conflict was a source of anxiety to the researcher, working out such problems as how openly sensitive to be in regards to a participant's anxiety level and how active to be in anxiety reduction. Although there is a good deal of overlap in good interviewing techniques for research and good interviewing techniques for therapy (Davis 1978), there were both style and content issues which needed to be worked out in the process of doing the interviews. Situations in which subjects expressed strong emotions such as

sadness or anger, self-deprecating ideas, or suicidal thoughts requiring further explorations presented particular problems in this area.

Another source of management difficulty arose in the form of interview circumstances: events such as mechanical tape-recorder difficulties, other persons present or dropping-in during the interviews, time constraints imposed by the subjects, and one subject being "taken by surprise" due to a misunderstanding of interview dates. The researcher was in the position of being a guest in people's homes and yet having to take the initiative in discussing with the subjects how these situations were to be managed. For example, did the subject wish to continue the interview in the presence of another person? Subjects expressed and appeared more comfortable than the researcher felt in relation to the presence of others.

The fact that subjects also have purposes for the interviews was mentioned in connection with the construction of the accounts. These purposes present situations to be managed by the researcher, particularly if the researcher feels unable to meet the expectations of the subject. Occasionally subjects would ask the researcher's opinion about everyday life matters, for example, "Would you be scared without, without a door without any screws on it?" (The door lock had some screws missing.) More difficult was the situation in which the subject hoped the outcome of the interviews would be advisement "as to what pills I should take."

Participants would also ask questions about the medication and their illness in the course of the interviews. The researcher used a variety of techniques to deal with these questions. Most frequently the question was treated as data for further discussion. The researcher asked whether this was something about which the subject was concerned or reflected the

question back to the subject: "what do you think about that?" Occasionally, due to the direct or repeated nature of the question, the researcher would explain the nature of her role to the subjects, indicating she was not in a position to give information. One subject responded to this information with "Tell me later," indicating her/his notions that the researcher was "in face" or "in role" at that time, but that that role could be abandoned later. On rare occasions, when further attempts for information were made, the researcher dealt with the question as if it were a statement and no response was given.

In the situation described concerning management of the subjects' purposes and the subjects' questions, the researcher was aware of inequities in terms of information exchange and this would be commented upon: "I think it has been somewhat difficult for you in that, you know, as we talked about the first time, I can't give you any feedback." In this way, the subjects' desires were acknowledged, and thus subjects did not appear to be resentful when their requests were not met.

DATA ANALYSIS

Before discussing the way in which the data was analyzed, it seems important to state the perspective of the researcher in analyzing the accounts. These accounts were viewed as descriptions of and explanations for medication-taking, produced by competent* members of this group. These accounts were not viewed as displays of psychopathology, although someone adopting this perspective might obtain data adequate to support that view. By pursuing the clients' perspectives towards their situations,

* The term competent is used to mean the claim that the individual is able to manage his everyday affairs without interference (Garfinkel 1967).

the researcher was able to accept the accounts as how people make sense of their situation. Very rarely was the researcher faced with information that "did not make sense" in relation to the situation being described. These judgments are the researcher's common-sense judgments. By whose standards is an account to be judged? If scientific ideology was used as the measure of plausibility and acceptability, these accounts would be seen as inadequate. Because the participants used lay terminology and logic, science would see this logic and terminology as incorrect or inadequate.

The data was transcribed and analyzed following each interview. The data was not analyzed according to categories determined by a pre-selected theory as to why clients do or do not take medications. Rather, the analysis of the data was directed towards the development of themes and concepts which had meaning for the subjects. The process of data analysis involved inferring, questioning, and modifying these themes and concepts. The data provided by the subjects directed the researcher to expand the focus of the interviews from the specific area of medication-taking to much broader areas of illness, treatment, and normality/deviance. Thus the themes tended to develop in the direction of concrete to abstract. As mentioned earlier, analysis of data pertaining to chronic versus acute illness experiences led to the selection of a second subject group. The differences and similarities of the two groups will be discussed in Chapter Four.

Consultation was sought from two members of the Thesis Committee, and three others familiar with qualitative research. This consultation served to stimulate conceptualization of the data in a variety of ways, and to verify the researcher's organization of the data. At the conclusion of the interviewing, segments of the accounts were sorted according to the

identified themes and concepts, which reflected both process and content aspects of the accounts. Analysis of the data within these categories served to enrich the descriptions of, and explicate linkages amongst, the themes and concepts.

Although others did make valuable contributions to the data analysis, the final organization of the data is both the creation and the responsibility of the researcher.

ETHICAL CONSIDERATIONS ENCOUNTERED IN THE RESEARCH PROCESS

Ethical considerations have been discussed in relation to participant selection: the way in which subjects were approached and the nature of the consent forms signed. As well, the project design provided for the erasure of the tapes and the shredding of the transcripts upon completion of the thesis. The subjects' ethical rights thus appeared to be well attended. A brief summary of the research will also be sent to the participants.

However, in the course of conducting this research, unanticipated ethical concerns arose.

In the process of interviewing, the researcher became aware of the increasing commitment to and identification with the subjects, a sense of the study being "their study" as well as the researcher's. This led to concerns about the presentation of the data in regard to the level of inference and the possibility of distortion, the decision being to present data with which the subjects could identify. Qualitative studies vary greatly in the level of inference to which analysis can be taken. Another aspect of this commitment was an awareness that others might use the data in ways not intended by the researcher, for example, as proof of the "ignorance"

or "unreliability" of the subjects. The researcher felt committed to present the data with sensitivity and to influence others to interpret the data "in good faith."

Confidentiality issues also arose in the course of the study. How to manage information exchange concerning the study with persons other than the subject? For example, what to tell other persons in the home when calling concerning the study and how to respond to therapist queries as to "how did things go?" Confidentiality issues in terms of the use of excerpts from the transcripts also became apparent. Although it had been stated that no names or other identifying data^{*} would be used when reporting data, the idiosyncratic nature of subjects' accounts brought into question the possibility that individuals would be identifiable from their statements alone. This risk appears unavoidable in qualitative research.

The final ethical issue involves informed consent. One question which arose in the researcher's thoughts was whether the subject's family would view the subject as competent to give consent to participate -- apparently the families did as this was never an issue. The other, more important question was the issue of truly informed consent. Subjects had been informed that this study was concerned with medication-taking, but were not informed that the study was concerned with the medication-taking of schizophrenic clients. As the researcher did not question subjects as to their diagnostic understanding, the researcher is aware of only one subject who classifies her/himself as schizophrenic. How would the other subjects react to being part of this study, or, for that matter, being diagnosed

* Due to the small numbers of male participants, female doctors, and male non-physician therapists involved, standardized pronouns will be used in quoting from the accounts: masculine pronouns for the therapists and doctors, and feminine pronouns for the participants. This will be done for purposes of confidentiality.

and treated as schizophrenic? This issue is a problem for psychiatry in general. As this problem was only identified in the course of research, and the issue is much more general than this study, no procedural changes were made.

SUMMARY

This chapter on methodology outlined both the procedures and the flavor of the qualitative research process. The products of this process, the subjects' accounts of their medication-taking behavior and their explanations for those behaviors, will be presented in the following chapter.

CHAPTER IV: THE PARTICIPANTS' ACCOUNTS

INTRODUCTION

This chapter presents the participants' accounts of their medication-taking. It is directed towards describing schizophrenic clients' medication-taking behaviors and their explanations for those behaviors within the context of their everyday life. Each participant presented a unique account, although there tended to be similarities amongst certain accounts. However, whilst recognizing the unique nature of each individual's experience, the researcher's purpose has been to identify themes and concepts which reflect the group's perspective.

The five major content areas discussed in this chapter are medication-taking practises, current perspectives towards medication-taking, the context of medication-taking, the moral implications of medication-taking, and the influence of others on medication-taking. The organization of these content areas represents a progression from the specific aspects of medication-taking, the everyday patterns of medication-taking and variations of these patterns, to more general aspects of the subjects' experiences related to medication-taking, such as their illness and treatment experiences.

Chapter Three described two separate client groups, a short-term and a long-term group, which participated in the study. In some parts of this discussion, these groups were taken as one; at other times, comparisons were made. The reader is advised to assume unity in these two groups unless directed otherwise.

MEDICATION-TAKING PRACTISES

A. Everyday Practises

The interview discussions of medication-taking practises began with a description of what might be called the everyday pattern of medication-taking, a typical day. Emerging from these discussions were the practises developed by participants for taking medication on an everyday basis, as well as the problems and decisions encountered.

Generally, participants indicated that the actual taking of medication was not a great interference in their everyday life.

R: I had asked you before about taking it three times a day, and, um, I wonder how does that fit in to your sort of everyday activities?

S: Very simple.

As might be expected, the less frequently medications were to be taken during the day, the less interference was expressed by the participants.

All participants established schedules but varied as to the rigidity of these schedules. Schedules might be based on specific times of the day or related to particular points in the routine such as "before bed" or "as soon as I get up in the morning." The way in which medication was prescribed contributed to these differences. Medications prescribed once, twice, or three times daily, for example, gave participants latitude in adjusting the pill-taking to their own daily schedules.

S: It just said twice a day, you can take them in the morning, or at suppertime, or lunchtime, or at suppertime, or whenever I guess.

Some participants based their medication-taking schedule on hospital practises.

R: How did you come to decide on those times?

S: Well they were the times given to me in the hospital.

Others used their own judgment for the decision:

R: How did you decide on that, on those particular times of the day to take the medication?

S: I didn't know -- I just tried it out and it seemed to work out so --.

One participant based her decision to take the two daily doses within three hours of one another because "they're always on my mind, maybe that's what it is, if I don't do it, you know, get it over with." Changes in the daily pattern caused changes in medication-taking: sleeping in until noon may cause a morning dose to be missed if the participant also takes a noon dose, or a pill seen as helpful to sleeping may be taken in the afternoon if the participant missed the previous evening dose and feels tired.

The scheduling is influenced by participants' notions of how frequently medications may be and should be taken. Many participants mentioned that it was best to have medications "well spaced out during the day." One participant calculated the times to take medication by dividing the waking day by the number of doses in order to space doses evenly. Another participant attributed her notion of "no more than every four hours" to the doctor's advice. Several participants mentioned that longer spaces of time than usual between medications, or even forgetting doses, were not critical because the medications are "long range ones." Concerns about sufficient space between dosages prohibited some participants from taking medications too close together, feeling it was preferable to miss a dose rather than risk "an overdosage." One participant stated, "I'll take less but I'll never take more," and reflected that this practise was related to being pleased about taking less as well as concerns about "overdosage."

Those participants who took medication at bedtime had variations in

practise. Some participants expressed not taking medication at bedtime if they should go to bed too late, to avoid drowsiness in the morning. There was also the problem of falling asleep without taking the medication and whether to get up and take the pill if one wakes up during the night.

S: I'll be lying, and it'll be around 9 or 10 o'clock, and I'll go to bed and watch television.

R: Uh-hmm.

S: And it's too early to take it, and so therefore I sleep. Now when I was really sick, I would wake up at 2 o'clock, and take this medication, because they had stressed this whole thing, 'you must take your medication.'

R: Uh-huh.

S: And then I was awake all the rest of the night. So I decided that my sleep was more important than taking the pill.

One participant expressed liking to take the pill well in advance of bedtime.

S: Before I fall asleep, I don't want to fall asleep doped up, I want to feel the effect of it and all the effect of it before I fall asleep. And if I get the pills reduced, I'm not lying there while they're reducing, while I'm slowly going down, but I'm already feeling the effect of the reduction, you know, the -- after I take them, before I go to bed.

The decision of whether or not to take medications when out in public will be discussed in regards to the moral implications and information management. Many participants did take medications with them and some had special pill containers or medicine bottles for that purpose. One participant expressed "never going out of the house without my pills." Many women were in the habit of keeping the medications in their purse which then assured that they had access to the pills wherever they were. However, for some participants, unexpected or longer-than-expected outings were a source of variation in the regular medication-taking pattern, resulting in

delayed or missed doses. Again, the extended action of the medication was seen to minimize the problems of such an occurrence -- "doesn't really matter, like it does not affect that much." Holidays were planned in advance to ensure an adequate supply of medication.

In conjunction with notions about when medications should be taken, notions about how medication should be taken were described. Variations existed in whether medications should be taken with meals, and, if so, before or after; and whether medication should be taken with a liquid, and if so, any particular liquid. Some participants felt that these questions were immaterial and took the pills in a variety of ways, including completely alone. However, other participants had fixed patterns, sometimes based on hospital experience.

S: Go for breakfast, and right after you go for breakfast, you had to take your medication. Similarly at the lunchtime, you just go for the lunch and then after the lunch, there was medication. So I just had an idea, from there, that it has to be taken after the meal, right, so I tried to, tried to space it out by that, so I could take it with my meal.

S: I usually take them after I've eaten.

R: Uh-huh.

S: I don't know, I've never been told whether it was important or not, I usually have breakfast and then take a pill.

R: You had mentioned something, you know, about the way that you usually take medication and that was about, uh --

S: Taking them after meals.

R: Right, taking it after meals. That you had found that if you took medication on an empty stomach, that --

S: It made me feel a little bit nauseated. Uh, I, it, not as good as taking it after anyway. Uh, I suppose gastric juices work, reacting with something.

Medications were taken with water, ovaltine, milk, and juices. Again, some participants were more fixed in their practise than others. These practises had also developed from a variety of sources.

S: I usually take it with a half a cup of ovaltine.

R: Uh-huh.

S: I think I've heard that pills are better for you if you take them with something with a bit of milk in them; it lines your stomach.

S: Well, well, I told you to take them with water, didn't I? Not to take them just by swallowing.

R: Uh-huh.

S: It seems to have a better effect on you if you take them with some liquid.

S: Like while at the hospital, I was given medication with pineapple juice.

R: Uh-huh.

S: And when I just got home, the first week or two, I really did the same thing, like I just went and bought the pineapple juice and I thought that's the only thing, was to take medication with, right.

R: Uh-huh.

S: But after that, then I thought, you know, it has juice, it can be any juice, it can be orange juice or pineapple juice, or any other juice, so I stuck to orange juice from there on.

R: Uh-hmm.

S: And I've tried taking it by the water, too. With, with the water, and it doesn't, it doesn't really make much difference, but with the water I guess it was, I found it was affecting me more. Like when I took it with the water, but then I've been stuck, I've stuck to the orange juice. I just take my medication with orange juice, Tang.

Thus far, everyday medication-taking practises have been discussed, as well as some of the circumstances which arise to alter these everyday

practises. Other sources of variation to these practises will now be discussed.

B. Variations in Everyday Practises

1. *Remembering and Forgetting*

Some participants stated they never forgot -- "I always remember, because I'm on a schedule." However, most participants stated that they sometimes forgot the medication -- "I forget occasionally, but I usually do it as a matter of habit." The terms used, such as "a habit," "a system," and "a schedule," convey the integration of the medication-taking within the participants' daily lives. One participant stated that she frequently did not take one newly prescribed medication (which was not an anti-psychotic medication) because she's "not in the system of it":

S: Well, I've had trouble. It's a new kind of medication and I'm not in the system of it, and so, I hardly ever remember to take it.

The pills that were missed were often the mid-day doses. Some participants used memory aids, such as placing the day's supply of pills in a separate place so that it could be determined how many had been taken, or the use of a sign to remind the participant. One participant's spouse took an active role by administering two of the three daily doses of the medication.

The participants' responses to forgetting doses varied depending on when they became aware that they had forgotten as well as beliefs about spacing medications, over-dosage, and the medication's length of action which have been discussed.

2. *Deliberate Variations*

Forgetting was described by participants as an unintentional change in the medication-taking pattern. Deliberate variations were also described.

In fact, one such variation was called "forgetting," but was differentiated from "really forgetting." This forgetting was described as not making an effort to remember due to less commitment to medication-taking.

R: In the past when you had difficulty remembering about the pills?

S: I didn't want to take them.

R: I see.

S: And that's what made me forget about them.

Other forms of deliberate variation are reducing the daily dose.

S: Oh well, I just, if I feel I don't need something, I'm cutting down on it.

R: Uh-hmm.

S: You know, like that one that says "take three times a day." I only take them twice a day because I, unless I really feel I need them three times, then I'll take the third one. Otherwise I'm only taking two of those instead of three. And I'm doing all right.

This participant and others related their need for medication to the amount of stress which they were experiencing. They emphasized the importance of taking medication as prescribed during these stressful times.

S: Well, I can't take a lot of excitement.

R: Uh-hmm.

S: Like at Christmas time, or that. I can't take a lot of excitement. That's another thing.

R: So, when that happens, what do you do then?

S: Well, I just make sure I take my pills as prescribed around that time, that I don't cut any out.

Other circumstances necessitating deliberate changes in medication-taking were physical sickness such as the flu and consumption of alcohol. Some participants stated that they continued to take medications regardless of their physical health; others stopped medications due to physical

problems.

S: I had the flu and I couldn't even keep water down. I didn't take any prescriptions.

S: If you had the flu, say, and you're throwing up, and you're ill, and you have to stay in bed, it's bad to take the pills.

S: I didn't take the pill last night and I'm tired today. I didn't take it because I had a bad taste in my mouth and I thought the pill wouldn't digest.

Several participants mentioned that the medications were either affected by or not to be taken with alcohol. Their response to this knowledge was to not drink alcohol at all, to drink alcohol with what they considered to be due caution, or to miss their medication.

S: I can't have alcohol, any alcoholic beverages.

R: So, if you ever have a drink, how do you manage that with the medications?

S: I just don't take medications. I might have a glass of wine or something, and still take the medication.

R: Uh-hmm.

S: But hard liquor, I'm not supposed to have at all, because of the medication.

R: So if you ever have a glass of hard liquor, then you --?

S: I don't take the medication.

Other deliberate variations were "test" experiences, where one or several doses of medication were missed to assess the effects. These "test" experiences were differentiated from medication stoppages as the intention was to continue on medications following the test. Similar, but of a more impulsive nature, were situations in which a dose may be thrown away in anger, but medications resumed again.

S: I think once I did, a long, long time ago, I forgot to take one pill.

R: Uh-hmm.

S: Oh no, that's not true, actually, I flushed that pill down the toilet, because I didn't want to take it.

S: I think one day I went without anything, for one whole day.

R: Uh-huh.

S: And I got through the day. I just wanted to see if I could do it. But I wouldn't be able to do it for any length of time, I don't think.

Some participants had also stopped their medications in the past -- all participants expressed that they were currently taking medications.

This discussion of medication-taking practises has considered everyday patterns and variations to these patterns. There were some practise guidelines mentioned in addition to these which should be included. These practises will be discussed under the general heading of safety precautions.

C. Safety Precautions.

Participants mentioned an assortment of practises which can be included in this category. The dangers of having excess medication around because of children were mentioned (as well as the relative futility of the safety container as the participant could not open it, but the child could). One participant stressed the importance of informing the family doctor and "the clinic" of one another's actions in regards to medication; another mentioned not taking pills which dropped on the floor.

Several participants mentioned the dangers of "pill-popping" which appeared to be taking more medication than prescribed or unprescribed medication. For example, such practises as taking other persons' medications or combining excess medication and alcohol were mentioned disparagingly

as "pill-popping."

S: But that's, that's pill-popping, you know.

R: Ya?

S: Pill-popping, and that's no good for anybody. They, they want -- they think, they can get a high on, high on somebody else's pills, so they'll trade pills, or something like that, you know, which isn't good for them.

As mentioned previously in regards to scheduling practises, participants were concerned about the effects of too much medication -- "I never take more. That's a no-no." One participant stated that taking the daily dose of four pills at one time, instead of throughout the day "may just ruin the uh, the idea of taking medications, you know."

"Over-use" was a concern as well. This notion implied being on the same medication for too long a period of time. Both "after-effects" from over-use and loss of effectiveness of the medication were mentioned as complications of this practise. Thus some participants felt medications should be changed periodically.

D. Prescribed Medication Changes

To this point, this section on medication-taking practises has described the variations in medication-taking which participants initiated, although these may be based on knowledge and suggestions from others. In addition to these self-initiated variations, several participants experienced prescribed medication changes in the course of the study, changes which gave rise to variations in their medication schedules and hence their everyday lives. Prescribed medication changes will be further discussed in the sections of this thesis describing the participants' past experiences with medication; the participants' understanding, and lack of understanding, of the reasons for the changes; and the therapist-patient

relationship. Although the participants expressed uncertainty as to the therapists' reasons for the changes, their own active sense making and evaluation of the changes was evident in their discussion.

CURRENT PERSPECTIVES TOWARDS MEDICATION-TAKING

The participants' current ideas about medications and medication-taking will be presented. These ideas are organized under three general headings: the participants' notions about medications, the reasons why participants need medication, and expectations concerning medication-taking.

A. The Participants' Notions About Medications

The participants' conceptions or notions about medications themselves will be discussed. The contributing sources or origins of these understandings are other persons such as therapists, fellow patients, and families; their own observations of such things as hospital practises; and their own sense making. These notions are not static as learning about medications is an on-going process.

When initiating discussion concerning medication-taking, the researcher asked the participants what medications they were currently taking. The majority of the participants could not answer this question and sought out their pills which they gave to the researcher to check the name. The pronunciation of the names appeared a major difficulty in their communication concerning the medication.

S: It's just up here -- I can never pronounce it.

S: The names are so hard to pronounce.

R: Ya.

S: I couldn't begin to spell them, let alone pronounce them.

Once the researcher pronounced the name, some participants would attempt to use the names.

S: Two "trifluozine" in the morning and one -- Benz -- what do you call it?

R: Benztropine.

This participant immediately switched to using the colors rather than the names, which was often the way that others identified the pills. Some participants were of the understanding that the dosage number indicated the strength of the medication, regardless of type of medication, thus Chlorpromazine 25 mgm. would be a greater dose than Trifluoperazine 20 mgm. As well, some participants used the notion of "a heavy" tranquilizer, which was considered a strong tranquilizer.

The general understanding of the medications were that they were "tranquilizers" "to calm you down.". Participants were asked about their notions of how the medication works. Some stated that, although they had thought about it, they could not explain it. Others were able to give explanations: "it controls your thought patterns, it uh helps you think things slowly and uh helps you"; "slowed me down -- you have to do all the work, it just does the chemical balance that, that you have to work with"; "my brain gets rested"; and "it's for my mind -- so I won't get, start feeling, um, what do you call it -- suspicious and all that." These understandings are related to the individuals' understandings of their illness and their reasons for taking medication.

Some participants discussed the specific actions of the different medications.

S: And what is affected is your hemioglands, the color, the color glands, by chlorpromazine, and your skin turns brown or purple.

R: Uh-hmm.

S: And there's women and men out there -- mostly women -- with their purple and brown skin because people didn't know that.

S: Well, uh, each pill, no matter what it is, it's to correct some, something or other.

R: Uh-hmm.

S: And, each pill is for a different reason, I guess, or maybe there's two or three kinds by different companies with the same purpose more or less. Each company would call their pill a different name, I guess, but maybe it's more or less supposed to do the same thing. I don't know --. Oh, to calm you down.

S: Somebody's told me once about haloperidol, I'm not sure I remember really, it's for psychosis. It's for social withdrawal, it's for tension, it's for eh, I don't know. Anyway, I'm not worried about all that -- I don't know, I just take it as a tranquilizer.

Another participant described what it was like to be on medication:

S: But when, when you're taking pills like this, even though they're affecting more than any drinks you can have.

R: Uh-huh.

S: But you don't feel it that way, you do not go out of uh, out of your circle, to feel the medication. The medication is always, already just there.

Certain features of the medication, namely side effects, addictions and withdrawals were frequently mentioned.

1. Side Effects

Participants were familiar with the term "side effects" although some could not relate any specific side effects. They used the term spontaneously in the interviews. Participants discussed the side effects which they were currently experiencing, tiredness being the most common. Some participants expressed having no side effects. The importance of the side effect to that person, including the way in which the side effect influences

the person's life, were important aspects in understanding the significance of side effects.

R: What would your, your preference be, _____, how would you like to see it?

S: Well, I think I'd like to go back on two again, because, uh, I don't know, it's not as restricting, uh, uh, being able to do things, you know, I mean four makes me very tired.

S: Like even right now I'm getting a little bit of dry mouth.

R: Uh-huh.

S: And uh, about two weeks before it was a lot more drier, like I couldn't talk at all, if I was talking to any stranger, for five-ten minutes, it would get so that I couldn't even speak anymore words.

The participants' difficulties in determining what physical phenomena are associated with the medication, thus might be considered side effects, were evident in their comments.

S: Well, I do get side effects.

R: I see. So, could you tell me about those, the side effects.

S: Well, I start, I don't know if they're side effects, but I think they are.

R: Uh-hmm.

S: Like I have pains in my side and that.

S: Oh, I've been noticing that I'm getting cramps, pains, and everything, in my back and my legs. I'm wondering, perhaps, if that's something to do with medications, I don't know.

S: Maybe the doctor was concerned, although he^{*} said he didn't think that they (the medication) were to blame for the nose-

* As mentioned previously, masculine pronouns will be used for therapists and doctors, and feminine pronouns will be used for participants.

bleeds. And now that I've been on the new pills for awhile with no nosebleeds, it looks like it definitely must be the pills. Although the nosebleeds are not great hardship, it's definitely something that shouldn't be. Yes, it's definitely something that should be -- maybe they don't agree with my body or something.

2. Addiction and Withdrawal.

Some participants expressed the notions of becoming, or fear of becoming, addicted to the medication, as well as the belief that when stopping the medication, they would experience withdrawal. Addiction was related to the length of time one was on the medication, that is, the longer on the drug, the greater the chance of addiction. Addiction was also described in the way of a dependency or a need for the drug.

R: Can you tell me about that, when you say the medication is addictive, how is it addictive?

S: Well, you don't feel right without it.

R: Uh-huh.

S: You don't feel...you've got used to the drug.

Withdrawal appeared to be an adjustment process to being without medication.

S: Each pill has a different withdrawal, like with Stelazine, it leaves me slow.

R: Uh-hmm.

S: Like without energy, like I don't feel like talking, and um, and I don't feel like um, I have strength to talk. I think I have to rest until I get over the withdrawal period.

B. The Reasons Why The Participants Need Medication

The reasons why the participants took and/or needed medication were explored. Ambivalence and uncertainty towards medication-taking was a theme in these discussions. Participants presented these feelings despite articulating reasons for medication taking.

S: I don't know for how much longer I'll be needing my (medication) -- if uh, I'm, I don't know, unstable is the right word for it. I can't tell whether I really need it, or whether I could do without it.

R: How long, how, how long ago was that, that change took place?

S: Well, I guess I could say when I started doing it, when I started taking them, even though I talked about it and didn't like to take them, I guess, ten years ago. But when I became more positive myself, sometimes I still doubt it.

S: I mean the reason I've been taking it regularly.

R: Right.

S: Is because I'm not confident of what will happen if I did not take the medicine.

Some participants expressed strong commitment towards taking their medications. However, it appeared they too had some feelings of ambivalence and uncertainty, as displayed by what have been described as testing behaviors, such as stopping medications for short periods of time or missing doses on occasion.

The reasons why the participants felt they took and/or needed medication were grouped into five categories: physiological reasons; the symptoms in relation to past or present sickness; the avoidance of past treatment experiences; the influence of others; and support and dependency. Participants stated reasons in more than one category.

1. *Physiological Reasons*

These explanations related the participants' sickness and their need for medication to an organic condition: their "system working with the pills"; their "body chemistry"; or "a chemical missing in the system." Several invoked the analogy of a diabetic needing insulin.

S: I know I need them (the medications), just like a diabetic would need insulin.

2. *The 'Symptom' Approach*

Reasons for taking medication were predominantly in this category. The researcher chose the word "symptom" to signify those reasons for taking medication related to the participants' descriptions of the illness or features of the illness.

These descriptions could be loosely placed on two dimensions, past and present, and positive and negative. The past dimension describes those reasons which relate to past experiences without medication and the participants' taking medication to avoid "being sick again." The present dimension characterizes those reasons related to current action of the medication, "slowed down," "more content," "not so jittery," etc. The medication is seen as actively influencing the present, not just preventing the past.

The positive and negative dimensions of these explanations characterized whether the medication promotes health, "function better" and "be more myself," the positive approach, or counteracts the features of the illness, the negative approach. Examples of reasons for medication-taking with the negative dimension are "helping with voices," preventing "symbolism," and "so I don't smash my brains against the wall." The majority of the reasons given could be characterized as "present" and "negative."

S: It (the medication) seems to be doing what it's supposed to do. I'm calmer, not losing my temper, not crying, not depressed.

S: The only thing it does is slow me down. It's uh, tranquilizer. And I'm over-active, the doctor says. So, it just needs a little, a little bit, two pills a day, just to keep me sort-of on a level keel.

- R: But there's something that you want to get out of that pill, and that's what I was trying to, uh, find out.
- S: Well, as long as I don't go, don't go "foot in the air" and I sleep at night. Uh, I'm hoping that, uh, I've been bothered by voices from time to time and I'm hoping that it'll, it'll all clear up and uh, that I can stay healthier and get healthier and that sort of thing.

Participants sometimes differentiated why they needed certain medications.

- R: Can you tell me a bit about that, like why you think Chlorpromazine has been the best?
- S: Well, I, I sleep right through the whole night, when I take one, and also I'm much more calmer during the day.
- R: Uh-hmm.
- S: I think it's the one that keeps me calm, better than any of the others.

-
- S: Um, the trifluoperazine, or stelazine, it, it gives me a pick up, energizes me.

3. *Avoidance of Past Treatment*

Avoidance of hospitalization, as opposed to avoidance of illness which was described in the previous category, the symptom approach, was a powerful influence on some participants' medication-taking.

- S: And uh, they (medication) don't strike me that much, so I feel that, you know, I don't need any more medication. But even though, I just carry, carry through with it, because uh, I don't want to go back to the hospital again, right.

-
- R: Can you see other ways that the medication has helped you?

- S: Well, it's kept me out of hospital, like I haven't uh, I mean maybe it's just a coincidence, but when I was on four a day, I never went in to the hospital.

- R: Uh-hmm.

- S: And I would do anything to stay out of hospital because that's, you know, a terrifying experience.

The difficulty in differentiating between avoidance of past treatment and the prevention of illness is clearly shown in the following participant's explanation.

R: You had mentioned that the doctor used the expression --

S: 'Going back to the hospital.'

R: 'Going back to the hospital' -- that had been kind of the reason for taking the medication, eh?

S: It's the reason I take it regularly. That I don't want to get sick again and I don't want to go back to the hospital.

R: Right, ya, you had said that, he, you felt that he used that expression, going back to the hospital to describe --

S: Ya, getting sick, getting sick again.

Hence, this category may be interpreted in two ways. Firstly, it may be a category expressing avoidance of treatment as a reason for taking medication, or secondly, this category may not exist as avoidance of treatment may be another way of expressing their wish to avoid illness.

4. *The Influence of Others*

Some participants, who also stated other reasons for being on medication, placed great emphasis on the role of others, especially their doctor/therapist, in their medication-taking. Ambivalence and uncertainty were mentioned as features of the participants' accounts of their reasons for taking medication. The role of the doctor/therapist appeared to be related to these themes: the involvement of another, who can be seen as an authority, in the closure of a very difficult decision.

R: If you weren't seeing (therapist) would you?

S: No, I don't think I'd be on the pills now.

R: So now you're feeling you're ready to be off of it (medication) again?

S: Yes.

R: Is that what you mean?

S: Uh-hmm.

R: Um -- so, um, would you stop it again now then?

S: No, I wouldn't stop them until the doctor says.

5. *Support and Dependency*

The themes, ambivalence and uncertainty, are linked with this final category, support and dependency. In the face of uncertainty, the participants have come to rely on the medications.

S: Well, if I wasn't taking medication, I'd feel not secure.

S: I have it in my mind if I take a pill, I'll be better.

R: Uh-huh.

S: So, um, like I take, don't take a pill in the morning, and then go out, I'm really shaky until I've taken my pill.

R: Uh-huh.

S: Because I think it's just a psychological thing that I have to have a pill.

In concluding the reasons why participants feel they need and take medication, it is emphasized that all of the reasons mentioned are enhanced by an understanding of the clients' perspective of their illness and/or treatment, which will be discussed later.

C. *The Participants' Expectations Concerning Medication Taking*

Participants' expectations concerning medication-taking could also be categorized; three categories were developed and will be described shortly. As in the reasons for medication-taking, themes were apparent, regardless of the category (or categories) of expectation. One theme, which can be

considered similar to the ambivalence and uncertainty expressed in the previous section, was concern about "how things would go" if they were to be off medication. Would they have to go back on them?

S: Well, I feel I can come off them, and just forget about it, but uh, would worries pile up on me, and --

R: Uh-hmm.

S: Would I be back on the pills again? Like I'd like to get off them and never have to touch the pills again.

S: Oh, I've been taking it for so long -- uh -- I don't know if I could ever get right off them.

R: Uh-hmm.

S: I might get off them for a short time, but I think I'd probably end up back on them again.

R: Do you anticipate in the future ever having to go back on them again, or what do you think about that?

S: Yes, I've always wondered if I'd have to go back on them after I've finished taking them.

A second theme was that they would like to be off the medication. Even those who accepted medications "for life" expressed the desirability of being off medication if it were possible. Congruent with this theme is the notion that a medication reduction is significant of progress; medication reductions were seen as good.

R: What makes you wonder if you need it?

S: Because I want to get off them.

R: Uh-hmm.

S: I don't want to have uh any more pills.

S: If you can do without them, it's better to be without them.

The third theme was that expectations for medication-taking were considered in conjunction with other aspects of the individual's life plan. That is, the participants considered other aspects of their life situation in determining the need for medication. The following comment illustrates both the wish to be off medication and the consideration of other life events.

R: So some people equate progress with medication?

S: Ya, without taking it.

R: Do you, how do you feel, say, when the medication's reduced, do you, do you like that, do you feel that's kind of progress?

S: Ya, ya, I, I think that, you know, that's great, and I think that's not only the medication that, mind you, maybe that could be, but I think things happen to me in my life.

Some participants expressed different expectations at different times, in their efforts to sort out the place of medications in their lives. The three categories of expectations represent different points in the 'on medication--off medication' continuum: expect to be on them for life; maybe could/will come off sometime in the future; and expect to be off medication in the near future.

1. *Expect. to be on them for life*

Although this expectation involves medication-taking for life, participants expressed goals for medication-taking in the form of reductions and going off them on occasion etc., indicating their desire to be on as little medication as possible.

S: I'd like to cut out one set, like in the afternoon, gradually cut down. I'll probably have to take them the rest of my life, they tell me.

S: But I don't think I'll ever be able to go off them altogether, but I think I could cut the dosage down.

2. *Maybe could come off medication*

This expectation was very much associated with a future life situation which would be conducive to their ceasing medication, perhaps, as stated by one participant, "a religious miracle." Medication-taking at present was accepted.

R: What would you like to see happen as a result of your being on medication?

S: Well, I wish I could get straightened out and be able to cope fine again. And to be taken off the meds -- feel fine -- I think that's a long time in the future -- I can feel like a human being, even without taking pills, you know, without getting upset, being able to cope.

S: So I think I still need the medication. But once I'm emotionally happy, and I'm there, I think I can try again and just do without.

R: What about being on no medication, whatsoever, what, what would you think about that idea?

S: It's been a long time since I've been on no medication, you know.

R: Uh-huh.

S: It would mean that I'd have to have a well-organized life, you know, and follow a pattern everyday.

S: And uh, maybe, maybe one day I'll be, you know, well enough that I'll not have any; but it doesn't, I don't even think about it, I don't even question it.

3. *Expect to be off medication in the near future*

These participants questioned their need of medication more strongly than the previous categories and expressed some expectation of the medication being stopped soon. As these expectations of medication stoppages were often based on their expectations of the doctors' prescribing

actions, the influences of the doctors/therapists were apparent in their reasons for taking medication.

S: Taking medication now and a month ago, I just feel the same way about it. Every time I take medication, I feel that'll be the last two weeks now, eh.

R: Ya.

S: But then, the doctor reduces it down a little more, and gives it to me the same, uh, less dosage, but uh, I have to keep on with the medication again.

S: And, uh, through the years, they're cutting me down, you know, too.

R: Uh-hmm.

S: Hoping I'll be able to go off them in a few months.

R: What are your expectations now in regards to the medication?

S: Well, I have to take them now.

R: Uh-huh.

S: For a little while longer.

R: Uh-hmm.

S: And then they'll decrease it, and then every time they'll keep lowering it, and then I'll finally go off.

Both of the "short-term" participants expressed expectations only in this later category; both expected to be off medication in the near future. Thus their expectations appeared to be more in common with an acute illness paradigm -- sickness, treatment, cure, restored health -- than a chronic illness paradigm in which management is a long-term issue. It was this perspective towards medication-taking that differentiated the "short-term" participant in the first group of interviews and led the researcher to seek out other such participants for the study.

THE CONTEXT OF MEDICATION-TAKING

Participants presented their descriptions of present medication-taking within an historical context, inferring that medication-taking cannot be understood as an isolated action. Thus, participants would state:

S: So -- but to tell you about my medication. I started,
I started on medication when I was 16.

R: Did anything come to your mind in terms of taking medication, what it was like for you to take medication?

S: To take medication is not bad.

R: Uh-huh.

S: Like uh, I think of improving right from the day I started with the Team.

As demonstrated by these examples, the historical introduction would occasionally be accompanied by an evaluative statement as to whether being on medication was "good" or "bad." Past and present experience, specifically in relation to illness and treatment, was presented by the participants, forming the basis for their current perspectives towards medication-taking.

A. The Illness Experience

Participants described their illness, or "sickness" which was their usual term, as a past occurrence, although none of them felt that they were "completely well" at this point in time. The descriptions of their sickness were individualized, for example: "feeling very high or very low"; being "speedy" which was described as "talking fast and being anxious"; "losing control"; "I felt like I was dying"; "went crazy"; "blanking out completely"; "feeling depressed and crying"; "thinking in symbols and colors"; "hearing voices"; "thinking overtime"; and being "emotionally

distressed." Sometimes psychiatric terminology was used to describe the illness, "being paranoid" and "hallucinating." The term "nervous breakdown" was often used to describe the experience in a general way.

The sickness was alternatively referred to as difficulties within their lives, demonstrating the difficulty of conceptually separating their illness and their lives. The sickness was described as having both internal and external origins. Internal origins were such things as an inferiority complex, exhaustion, and withdrawal. External origins were such things as foreign substances like a drug, accidents, family problems, and acts of God. Oftentimes, both external and internal origins would be considered as possible causes.

During the interviews, participants were involved in evaluating and reconstructing these past illnesses.

- S: They might not have known about my past, and I was in the shape, I was, condition I was, they might have thought I was just plain sick, but I wasn't just plain sick.
- R: Uh-huh, what do you think if they had known about your past would have made sense to them about the way that you were?
- S: Well, they might have realized that um, I wasn't crazy, that it's a natural outcome from being neglected, from being abused.

-
- S: And I didn't, I don't sound all that crazy right through the whole thing. I, I could remember what happened and how it happened, right.

These reconstructions appear to represent the participants' work in resolving the questions of "how sick was I," "how did I come to be this way," and "was I crazy?" One subject, who had been informed of diagnosis, questioned the meaning of the diagnosis:

- S: I watched um, a program about madness, or something, and it was a -- boy who, say like he was a schizophrenic.

R: Uh-hmm.

S: And they showed him walking and hearing these voices in him.

R: Uh-hmm.

S: I never had that. I think things, but I know it's myself thinking. But I never have heard voices. So I don't know, I don't know really what a schizophrenic is.

Differences in how the participants and care-givers define "what is sickness" were apparent:

S: I dig my privacy. I dig being alone, you know. And when people tell me that's too much for me, "you're doing too much of that, it's no good for you, it's unhealthy," and all this business -- and "you shouldn't be doing it"; and "don't do it," and lock you out of your room and everything, I can't take that, I hate it!

Another aspect of the illness experience is their current assessment of their health and the way in which their life is currently influenced by the illness.

R: If you had to say how you feel right now in terms of being well or being ill, how would you classify yourself?

S: In the middle.

S: And I haven't had too bad reaction since then.

R: Uh-hmm.

S: Matter-of-fact, now, I think I'm thinking more normally. I'm planning on going back to work again steady.

R: If you don't call yourself well now, how do you see how you are now?

S: Well, I just see myself as normal, you know, I'm just normal. But I'm not, I think anybody who's just normal is not exceptional.

R: Ya.

S: You know, and I feel like I'm sort of special in a way, like uh, like uh I need care, I need to see a doctor, and um, I

have to be looked after. I have to look after myself.

S: When I first got sick, it was such an overwhelming thing that it, you know, you didn't, you thought about it constantly.

R: Uh-hmm.

S: But uh, I haven't had a relapse now for two years, so therefore it's not part of my life.

Wellness can also be defined in terms of how much medication one takes, or being off of the medication.

R: How, how do you think you would be if you were to be well?

S: Well, I think I, maybe I'd be able to take a little bit less medication than I'm taking now -- I'm not really as good as I'd like to be.

S: It -- it never struck me that "Gee, now," I should have told myself "Now they've taken me off the pills, now I'm well." I never felt that way for some stupid reason. This might have worked on me, with his consent, you know, what I mean, but it, it never struck me, you know what I mean?

The participants' perspective on their illness, both past and present, is an important feature in understanding medication-taking, as is their perspective on treatment.

B. Treatment Experience

"Treatment experience" is the researcher's term for the participants' descriptions of their past contacts with the mental health system as well as experiences classified by participants as related to "getting better."

The long-term client population vividly described what might be termed "the old mental health system," which was contrasted with "the new system." The "old system" can be characterized by the themes of hospitalization as a punitive experience, dehumanization, and the injustice of their situation.

The descriptions of hospitalization illustrate their sense of imprisonment: "they had you under their thumb"; "the way he (father) misrepresented me when I was imprisoned must have been all wrong"; and "I thought I was in jail." Dehumanization was conveyed in their statements "you're like a vegetable and they experiment on you," and "they don't have any feelings, they treat you like animals." The injustice of their situation is portrayed in statements: "I needed human therapy, not shock therapy"; "the inflictions and pain and the insults"; and "It used to be considered a miracle when anybody got released from that hospital." Their sense of injustice was heightened by seeing themselves as different from the other patients: "all those people being so sick. And I felt I wasn't sick. I felt they were all crazy" and "they used to lock the doors and they had these old women with these forked dog's teeth hanging out, you know." One participant described strategies for survival in the hospital amongst what were described as undesirable fellow patients -- "never had a fear. Mind my own business, kept my mouth shut."

Negative treatment experiences were not reserved for the hospital, as one participant described the community as "all they were interested in was getting money." More positive descriptions of the hospital were as a place providing "reconditioning" and where one subject "learned to work."

In contrast to the past, the "new system" was presented as superior in both attitude towards the patient and knowledge of mental illness, including medication.

S: They're starting the philosophy now where the patient has a mind of his own, and he can recuperate on his own, more, better than being forced into thinking the way of the psychiatrist. I find that that's the difference in the way they treat mental illness now, is that the person who is affected, mentally, by the situation, can work their way out themselves, you know, which gives them a certain amount of self-respect, in a way.

S: Well, I think they know a lot more than they knew then, too, about side effects, for example.

R: Uh-hmm.

S: I think everything's just, they're finding out, doing more research, and that, on drugs, and they're finding out more things and that, than they did maybe 20 years ago.

Other significant themes in participants' discussions concerning "what makes them better" were their efforts to manage their lives, leading to beliefs in a wide variety of things which have been helpful to them. These themes clearly demonstrate the intertwining of "life," "illness," and "treatment," and how they are lived as one by the patient.

Life management included the participants' learning experiences about themselves, particularly learning those things which contributed to the "sickness."

S: And I think I've gotten to know myself better and so I'm much more aware. Like I would do things like worrying about myself, and really being stressful, and whether it's the medication that slows you down, um, now whether that's helped or the therapy's helped, I don't know, or just getting older and getting wiser, I would say I'm really a lot better than what I used to be.

S: I can't take a lot of pressure.

R: Uh-huh, is that your own idea, or is this been something that you've been told or how have you come up with that conclusion?

S: No, it's just something I've learned over the years about myself.

Participants' beliefs about those things which contributed to wellness varied widely. Lifestyle was considered important by some: exercise, general activity level, a routine, good diet, sufficient sleep, and good health in general. Some emphasized religion and faith. Interpersonal relationships were seen of significant help: "a strong family"; "having

responsibility"; "settling marriage problems"; "support"; "therapy"; "affection"; "nice warm people to talk to"; and patient organizations such as Mental Patients' Association ("M.P.A.") and the Coast Foundation. Negative influences on their lives/wellness were mentioned, such as lack of money and loneliness.

Participants were asked to compare medication with other factors contributing to wellness. Medication was seen as significant in how they were feeling, sometimes the most important thing. However, other factors were seen as most important by some.

R: What might be more important than the medication?

S: Oh, getting support, maybe.

R: Uh-huh, support, like what kind of support?

S: Just that I'm normal, I'm going to be O.K. without medication, like I'm functioning O.K. I'm doing well. Maybe I'm mature now.

R: Uh-huh.

S: And uh, that my decisions aren't all crazy.

The impression conveyed by the consideration of medication vis à vis other aspects of the patients' lives illustrated again the pervading nature of the illness/treatment experience on people's lives. What for others may simply be living becomes illness management for the person with schizophrenia. Illness management is an on-going process during which treatments, such as medication, are evaluated.

The way in which the long-term group perceived the "old mental health system" has been discussed. Participants' descriptions of other previous treatment experiences also illustrate the way in which clients' perceptions of treatment will differ from therapists. Clients can be aware of the way in which their actions will be viewed by health professionals, and

may modify their behavior accordingly.

S: And then, I, he let me out, the doctor let me out and I went. I didn't tell him I was going (on a trip) because I thought he thought I might be fantasizing or something.

As discussed in Chapter Three, accounts change and participants also acknowledged changes in their evaluation of previous treatment.

R: Uh-hmm. What I'm wondering is, uh, when did you sort of start to see things in terms of the past the way that you do now?

S: I think, uh, gaining more responsibility. I really got started getting better, the hospital was right.

R: Uh-huh.

S: They were right, except that, I needed, I needed uh -- well, I don't know what I needed (laughs).

Subjects presented a considerable amount of information related to their past experiences with medication: the types of medications which they have been on in the past; medication changes including type and dosage; their assessments of these experiences; and various other episodes in their medication-taking history. An example of such information is:

S: I said to, to the nurse one time, I said "I don't really need that much medication." I said something like that, and I said "I think I'd be O.K. without so much medication." She said "Prove it." I said "Well, how can I prove it if I'm on all that medication, you know."

Three categories of past experience bear particular mention because of the content emphasis placed on these categories in the participants' accounts. These categories are: experiences concerning stopping the medication; experiences with side effects or "bad reactions" to medication; and times when the medication worked remarkably well.

1. Stopping the medication

Cessation of medication occurred in several ways. The doctor might discontinue the medication, frequently in response to the person's requests

for reduction or cessation. Participants discontinued medications, often done in situations where there was not regular contact with an agency or doctor. One participant described deliberately not returning to a doctor who had not responded to concerns about the medication -- "I finally decided I wasn't going back to see him...because he wouldn't listen, to take me off and put me back on pills." These medication stoppages were temporary as participants resumed taking medication, sometimes via the route of hospitalization. In retrospect, they commented on their possible lack of wisdom with these stoppages, assuming some responsibility for doctor-induced stoppages due to their active promotion of the stoppage.

S: I shouldn't have gone off it when that doctor told me, when I could. I think I got my own way there.

S: And I think I was a little bit sick then, too, because I wasn't taking my medication and, and that (Hospital), they should have followed up on me.

R: Uh-hmm.

S: They should have, but they never...and they said that if you stop taking your medication, then you'll, you'll run into trouble, but I never believed them.

2. *Side effects*

Current side effects have been discussed. In discussing past side effects, the participants described such problems as sunburn, constipation, blurred vision, shakiness, and restlessness. An important aspect of the side effect experiences was the action taken by the therapist to help the patient obtain relief: side-effect pills or injections, dosage reductions, or medication changes. Lack of attention to these problems could lead to an angry patient and drug stoppage. Some of the untoward reactions to medications were termed "bad reactions," "adverse effects," or similar

terms, rather than side effects. The most frequently mentioned traumatic experiences in relation to medication side effects were their experiences on injectable drugs.

S: ...a lot of them get injections. And I was on injections once and I didn't do too well on them. I guess they didn't agree with me or I, I was so nervous and I tore holes in my clothes and I was always picking.

3. *Positive experiences with medication*

The kinds of positive experiences recounted included medication changes which prevented hospitalization and rapid response to increased medication. These episodes reflected confidence in the medication, often in the particular medication involved, "because it's done me the best." This confidence in medication was reinforced by the care-givers.

S: My doctor wrote a letter, and he was saying, well, giving me the benefit of the doubt, he was saying "well as long as S keeps on medication."

R: Uh-hmm.

S: "Until the time comes when she can be taken off, she will never have another nervous breakdown," because he knew that, you know.

C. The Process of Deciding About Medications

The clients' conceptualizations of illness and treatment provide a context for current medication-taking. The linkages between their past experiences and their current perspectives will now be examined. Participants expressed changes over time in their perspectives towards medication-taking, although the complexity of sorting out what has been helpful to them is evident. Uncertainty, expressed as self-doubt and lack of confidence, was displayed in their conclusions of what is their best course of action and also increased the influence which health professionals

had on their decisions. They assessed how the medication has helped, a major consideration being how they are doing now while on medications vis à vis how they have done in the past, both off and on medications.

S: I have thrown my pills out in the past too. I've learned from that, I've learned that that's not the way to get well, you know.

S: Well actually my attitude has changed, even though I said to the nurse one time, "I'm not takin' no anti-schizoid shit," you know, but still I did, I did manage to, you know, accept it more, you know.

R: What, what kinds of experiences do you think were really important in learning that?

S: Well, just the way I feel, I'm taking my (medication) and, um, the experience of what happened when I threw away my pills, and once when the doctor took me off, and the last time they took me off when I should have been on them, I think.

S: I know I wouldn't, I wouldn't have said this when I was first taking pills. This is, it's a learning process. It's, it's just trying, you, you sort of like start from 1 to 10. And then, when you get past 5, you can start to talk about it. But I'm at about 8.

S: But I had to stay in the hospital. And I thought that would be all right, as long as I could be off medication, because I hated it so much.

R: Uh-huh.

S: I didn't think I'd ever willingly take it, outside of the hospital.

These participants express a learning experience which has changed their attitude in a positive direction towards taking medication. Other attitude and behavioral changes were expressed, for example, a change towards greater self-determination on the part of the individual towards

medication-taking.

R: That say 20 years ago, you might have taken them exactly?

S: As I was told, but now I'm experimenting myself.

R: Uh-huh.

S: To see what I can do, uh, I can do with less of this, or less of that.

R: Uh-hmm.

S: I'm doing the experimenting myself.

R: Uh-hmm. How do you feel about that?

S: Good.

Both the long-term and short-term groups expressed attitude change based on experience, although the time span of this process was much greater for the long-term group. These attitude and behavioral changes based on experience with their illness, treatment, and medications were features of the accounts.

THE MORAL IMPLICATIONS OF MEDICATION-TAKING

The participants described medication-taking as having what will be termed "moral implications." In the context of this thesis, moral means a value judgment, imparting either goodness or badness to the person, in this case by virtue of their illness, treatment, and taking the medications in question. The previous discussion of medication-taking, has emphasized the cognitive dimension, the participants' beliefs and understandings concerning medication-taking.

Thus far, moral implications have only been suggested. For example, in the discussion of the context of medication-taking, it was stated that, in introducing medication-taking, evaluative statements were made. However, these evaluative statements could refer to the technical "goodness,"

as in effectiveness, or the moral "goodness" of the medication. The "old system" of treatment, characterized by dehumanization, was portrayed by the participants as a morally degrading experience.

S: I had a bit of a complex, that I wasn't as good as other people, you know, from being in the hospital.

This section further develops the moral implications of medication-taking. The moral value which the participants attributed to themselves was influenced both positively and negatively by the illness, the treatment, and medication-taking. Participants expressed awareness of the public's attitudes towards illness and treatment. In their experiences with others, or from their perception of the public at large, they expressed that mental illness has been equated with "laziness," "weakness," "dirtiness," and "being unkept," as well as "craziness."

S: I don't know much about the stigma, except that people think you're still crazy and all this.

R: O.K., is uh --

S: People think you're crazy and they don't like it, they think you're crazy, they laugh at you, and they put you down.

Because of their knowledge of these attitudes, the participants stated they used judgment in whom to tell about their illness and treatment experiences, "I'm careful with each person." Several mentioned difficulties finding and keeping jobs due to their hospitalization histories. Participants attributed these attitudes to a lack of knowledge on the part of the public.

S: I think a lot of quote "normal's" really don't know what they're talking about because there comes a time that you just don't have any control.

S: Because a lot of people do have a lack of understanding, they don't understand, you know, and people aren't capable.

A participant also expressed that public opinion was improving:

S: I think people are becoming more educated and it's more common these days. I don't think it's so much of a problem as it was before, when I had it, you know.

The participants expressed their sense of the abnormality of their lives, vis à vis the "average person." This sense of abnormality was conveyed by phrases such as "working their (patients') way back into citizens," "as if I'm the one down below," "even a normal person," "it seems that I turned out a Black Sheep," "I feel like my whole life's been a waste," and "I was just born lazy." Participants perceived their illness as morally degrading.

S: Like when you're put in a cell (at the hospital), nobody talks to you, nobody wants to talk to you, and simply you're just full of uh, you know, considered as uh, as anybody that, that be crazy, right.

S: Like everybody, I thought I was going to be mental. Well, I guess you can call it mental, but anyways, I ended up what I am anyhow, and um, so it was nice then.

R: Uh-hmm.

S: To finally find out that somebody knows what you were talking about.

R: Uh-hmm.

S: And to find other people who had the same thing.

The above excerpt conveys that the participant preferred to have "something" defined, rather than being grouped in the large category "mental" and that it was meaningful to meet others with that "something."

Experiences with the illness, and trying to make their way in life, did not always lead to the participants' perceiving themselves as having lowered moral standing. One participant, due to religious affiliation, saw the experience as imbuing a sense of "pride" and "accomplishment,"

for having overcome the "struggles" and temptations."

S: I think everybody is placed on this earth, not by accident, there's a purpose, everybody has a mission to fulfill.

Others adopted a morally neutral stance: "it wasn't such a bad thing, having a nervous breakdown."

Medication-taking has moral implications. Participants talked about the difficulty accepting the notion of taking medication. Medication-taking was described as "not normal."

S: It doesn't seem normal to take it.

R: What do you, you laugh when you say "as normal as I'll ever be," what do you mean by that?

S: Well, that's just me, that's my little joke about myself.

R: Uh-huh.

S: I don't think I'll ever be able to go without drugs at all, but maybe I'll be able to go with less of them.

R: If you were off of the pills, you'd just be normal, just like everybody else?

S: Um.

R: Does being on pills make you feel that you're not?

S: Uh, yes, it does.

R: Uh-huh.

S: Because I wouldn't be taking them.

R: Can you, you know, tell me a little more about that, what --

S: Well, the other people are not taking them, and they're getting along fine in this world and doing the best they can, and I think I can do the same thing.

- S: I don't know, maybe it gave me an inferiority complex, because I used to think that I wasn't as good as other people, but uh,
- R: Related to being on medication? Because you were on medications?
- S: Ya -- because I was on medication.
- R: Uh-huh.
- S: My sister would tell me I had to be on medication for the rest of my life.

Other descriptions of medication-taking contributed to the overall impression that being on medication was morally inferior: use of the term "pride" in being able to do without medication, and referring to medication as a crutch. As mentioned previously in regard to participants' expectations of medication-taking, to be off medication was seen as desirable, "it's better for us, maybe, if we can get along without it." A male participant expressed that it was more difficult for a man to be on medication, which was related to his ideas concerning masculinity and men having greater strength and responsibility than women.

Some participants acknowledged but challenged the moral implications of medication-taking.

- S: What's taking a few pills a day?
- R: Uh-hmm.
- S: As I say, I don't think a diabetic's ashamed of taking insulin, why should we be ashamed of taking our medication?

Although one participant denied feeling badly about being on medication, self-descriptions and descriptions of interactions with others indicated awareness and acceptance of the negative moral implications.

The moral implications of medication-taking influence the participants' practices in regard to medication-taking, including influencing

whether the participants take medication at all. The two most discussed aspects were the management of taking medication away from home and the management of information to such persons as friends and employers.

One participant never took the medication along when going out, to avoid being identified as taking medication. Others expressed embarrassment at taking pills in public, although stating "probably people would never know what they're for anyway." Participants also expressed concern that people might think they were taking dope or that they were drug addicts. Taking the medication in front of people presents an opportunity for persons to ask questions, such as what type of medication and why is the person taking it -- subjects that would not ordinarily come up in conversation. The participants then had to manage what to say in such a situation.

Management of information about medication to friends, employers, etc. was of concern to the participants.

S: I don't think anybody needs to know. I think it's something between you and the doctor.

R: Uh-huh.

S: And I think, uh, you should be given a chance. The people now don't know I'm on medication.

S: Different ones will ask me what drugs are you on, _____, and I'll just say "Well, they're all tranquilizers" and I drop the subject.

R: Uh-hmm. So I get a sense that, of a very strong feeling of privacy, towards the topic of medication, eh?

S: Uh-hmm.

R: Is it you're concerned what your friends might think of, of you, if they were to know more, or why do you think that sense of privacy is there?

S: Well, some of them may just drop me as a friend, I think, and want nothing to do with me.

These comments illustrate the participants' management of information, questions of who should be told and what should they be told. Some participants stated that they did not discuss medication with anyone but their therapists. Some mentioned speaking about medications more freely in the past, but gradually becoming more closed due to the reactions they encountered. Some participants felt they were generally fairly open about being on medication, although they also cited individuals with whom they chose not to discuss medication.

S: This one in particular. She had not got, she had stopped taking medication and, um, she had pulled herself out of it. And had no reason, wasn't, you know, didn't realized, couldn't see why I couldn't do the same. Wasn't the least bit sympathetic, just that you shouldn't have got sick, you shouldn't have gone into the hospital, you shouldn't be taking medication.

R: Uh-hmm.

S: "I didn't have to so therefore," you know, and nobody was any worse off than she. So it was mainly for this one person that I, you know, I didn't say anything.

Participants explained their pattern of information control in a variety of ways, that is, why it is necessary to control information: their friends' lack of information about medication caused their negative attitude, or that "most people don't know anything about it so aren't interested" and therefore don't want much information. Some participants acknowledged the possible stigmatization due to medication-taking and responded to it in a direct manner.

S: I say it doesn't bother me being on medication. If I was, I keep using this diabetic because the doctor told it to me and it was good, and as I said, I don't mind if I'm on it.

S: Because people don't understand, they don't have that same understanding so, but, but I'm above that, you know, above their lack of understanding. I can teach otherwise.

R: So they look at you and you can look at them, and they can think what they want and you'll think --

S: I never had a stigma or a prejudice or anything, sort of thing, so I'll damn well look right back at them.

R: What do you think that they would think about the medications?

S: I don't give a darn.

One group of people with whom participants could freely discuss medication were those persons who have taken or are also taking these medications.

R: So what kinds of things would you talk about with her?

S: Oh, how people think.

R: Uh-huh.

S: If you think, you know, if they're talking about us or something.

S: You're not being, um, what you call, um, you know that they've been on medications, they're not, uh, oh, high and mighty with someone.

In addition to sharing concerns about the moral implications of being on medication and providing a morally neutral territory, this group provided opportunities for information-sharing about medication-taking. Organizations such as the MPA and the Coast Foundation provided opportunities for participants to be with, and share with, others who are also on medication. As well, both organizations have sponsored occasional formal discussions, with invited professionals such as psychiatrists and nurses, for learning about medication.

THE INFLUENCE OF OTHERS ON MEDICATION-TAKING

A. The Family's Influence on Medication-Taking

The role of individuals and organizations was discussed in terms of information management. The participants discussed their family's role in terms of support. Families were seen as either supporting the participant's point of view or holding a perspective contrary to the participant. Thus, the same stance on the part of a family, either encouraging or discouraging the taking of medication, was seen as either supportive or non-supportive, dependent on the participant's point of view.

Supportive actions by families were described as reminding the participant to take medication, reinforcing the therapist's point of view in regard to treatment, and encouraging the individual's ability to cope without medications. An interesting example of family support is portrayed in the following participant's comments:

S: My Mom and Dad were so disappointed in me. They said, "Well, I thought you would just talk to them, not admit yourself, there's nothing wrong with you." They kept sticking up for me. And I said, "Well, I'll just get, you know, a little help."

Although the family in the above excerpt expressed disappointment at the participant's action, the participant saw their stance as supportive of her -- "sticking up for me." It seems that they were supportive of her normalcy, and the ability to manage on her own, perhaps reflecting her own ambivalence during a crisis period.

Non-supportive actions by families were described as families' questioning of the medication and expressing that the individuals should not be on medications, contradicting the individuals who think they should be on medication at this point in time. Conversely, another participant felt his family's emphasis on medication-taking was silly:

S: The advice is always this, you know, like don't forget to take medication and keep on with it.

R: Uh-huh. What do you think about that?

S: I think it's silly. I should have stopped.

In another situation, a man whose wife took an active role in administering the medication expressed that her dominant role increased his sense of shame in having to take medication.

Families also related in relatively neutral roles towards the medication-taking. As well, some close friends who were taken into confidence by the participants also acted in these supportive, non-supportive, or neutral stances.

Although participants did not always comply with family or others' wishes, these wishes did influence their medication-taking practises.

R: Uh-huh, so it sounds like you're finding a happy medium, between --

S: Between the clinic and my Mom and Dad, I'm finding a happy medium.

R: And if you weren't on the medication?

S: Uh, she's very leary, leary of me.

R: Uh-huh, so, um, do you think if you weren't on them, she would not be around, is that?

S: Ya -- um, I'd be shown the door.

Other actions such as reminding the participant to take medication have been mentioned previously.

B. Therapist-Patient Relationship and Medication-Taking

Families and friends influence medication-taking. However, the therapist's role is even more important, as medication-taking is not a self-initiated activity, but is a course of action emanating from the

therapist. The role of their doctor/therapist has been mentioned previously, for example, in conjunction with the reasons for taking medication.

Participants expressed that currently their therapist and the "clinic" doctor were the primary persons with whom they discussed medication. As well, doctors, nurses, social workers, and other mental health professionals have been major sources of information in the past. These health professionals were seen as legitimate sources of information, that is, the persons with whom they should discuss medications.

R: It sounds like you've received information from (therapist)?

S: Well, and other people.

R: And other people too? That's what I was wondering about.

S: Doctors.

R: Ya?

S: Not anybody who doesn't know.

However, participants also felt health professionals did not know everything about medication; there was a recognition that the client and the therapist would have different perspectives on medication-taking.

R: You had mentioned you wanted them (doctors) to "level" with you, and I'm wondering if there's any specific information that you would like to know about the medications?

S: Well, I think they don't understand, because a person with an experience is worth a thousand without.

R: Uh-huh.

S: And uh, they just tell me, they just read out of books what the books say about them.

R: Uh-huh.

S: And I go by, by what I know, through, through, through, uh, like they don't tell me anything about the medication, I have to go and find out myself.

R: Through your own experience, is that what you mean?

S: Not only that, through um, through talking to other patients and, and other people.

Another participant commented on the fixed nature of the professionals' viewpoints.

R: What about, um, have you learned much about medication from say the doctors and, and therapists that you've seen at the Care Team, or?

S: Yes, but uh, I've found that they're not really as, con -- not conscientious, that's not the word, uh, but uh, understanding in so many ways, uh, they feel that they're correct in what they're doing. And you can't change their attitudes and their beliefs as far as that's concerned.

The notion of health professionals "not levelling" with them was mentioned by participants, as suggested by a previous quotation. Participants expressed wishing more medication information on such questions as: why are medications changed, what the medication was meant to do, how long will they need to keep taking medication, the effects of the medication as one ages, and what is an average dose.

R: Would you like to know more or different things about it (the medication)?

S: I would like to know more about it.

R: Uh-huh.

S: Uh, what it's supposed to -- how long it will take to, for me to keep taking them?

One participant complained that the answer to questions was inevitably "take your medication," with no other information forthcoming. Participants liked "them to give it to me right on the level."

R: Can you think of anything in particular that Dr. _____ does that you feel is helpful?

S: Well he tells me right out things. If he wants to say something, he says it right out, he doesn't keep it from me.

The importance of the therapist's attitude has already been mentioned, for example, in the discussion of treatment experiences, the general importance of support, and in conjunction with reasons for medication-taking. Participants placed considerable emphasis on the therapist's attitude..

S: But, uh, there has to be some sort of humane attitude between the patient and the doctor, I believe, before they can really come to a serious discussion on how medications are affecting you, and uh, and other things besides that, socializing.

S: (Doctor) helped me by, he's helped me change my attitude towards medication just, just by liking me especially for being myself, sort of, more or less.

R: What are your expectations of, you know, whoever you work with, be it (therapist) or the doctor, in terms of your medication?

S: Have a good, have a good understanding of me.

R: Uh-huh.

S: And knowing what pills can do what, or are better for what person.

Similar to the desire to be "levelled with" is the expectation that the therapist/doctor will present their point of view.

S: But I didn't want him to leave it up to me, because, because, uh, after all I'm, I'm, I'm supervised, you know, with the medication.

It appears that participants valued their own experience and ideas, and wished professional recognition of these, but also valued the knowledge of the professionals.

One participant, who placed great trust in the therapist, stated the therapist had concerns about this trust:

S: (Therapist) sometimes doesn't like me to trust him at all.

R: Can you tell me a bit more about that, that it sounds -- that he sometimes thinks you shouldn't trust him, is that how it goes?

S: Uh, y'm, because I'm doing the help myself towards my body and my --

R: Uh-hmm. So, uh, I'm still not too clear on that, can you tell me a bit more?

S: Well, uh, I, I'm making him into a God.

Participants described their pattern of interaction with therapists, particularly doctors, in regards to medications. The pattern appeared to be one of the patient giving information and the doctor making a decision based on that information.

R: You mentioned that you didn't know what the doctor would do? Do you influence the doctor in any way, and if so, how?

S: I just tell him my problems, like how I've been sleeping, and then leave it up to him and let him decide.

R: What do you think about that system?

S: Well, I don't know anything about medicine. I'm not a nurse or a druggist.

R: How might you influence what they (Care Team) give you, in terms of medication?

S: Uh, well, you tell them your reactions to pills, that's all they ask for, seeing if they suit you, you know. And uh, well, uh, what, you, you let them more or less tell you too. You know, they have to know the effects of the pills you've been on.

R: Uh-hmm.

S: And uh, it's really, different doctors are different in their, in their perspective of how people should take medications, you know.

R: Uh-huh.

S: Some doctors believe in keeping you on a minimum dosage for a long time, and then they decide to go to, either take you off them, or if they think you're not well enough, they give you more I suppose, I don't know.

Participants described themselves as assuming a passive role in these interactions. As mentioned in Chapter Three, this content area was difficult for participants to discuss, probably due to feelings of loyalty towards their care givers and concerns about "incriminating" themselves. Participants described feeling leary or uneasy about changes to another medication, medication increases, and medication decreases, but did not discuss these concerns with the doctors. Questions such as "how long am I to be on medication" or what therapists meant by certain remarks would go unasked.

R: It sounds to, to me that uh, you have some reservations about how much you can, say, disagree with the doctor about the medication?

S: Uh-hmm.

R: Like if he says this is the way it's going to be, I don't think that you --

S: I don't say anything back.

R: Uh-huh?

S: No.

R: How, why do you think that's the case?

S: I don't know.

The passivity of the participants was also displayed in their descriptions of being on medication: "he's just trying me out on something else," "he'd keep me on it," "they took me off that," and other phrases which emphasize the active role of the care-givers and the participants' passivity. An aspect of this passivity is the participants' beliefs that therapists will understand the meaning of their indirect communication and they likewise attach meaning to therapists' actions which have not been explained to them.

S: He's seen me with the car and he doesn't say anything at all (the subject thus assumes the therapist approves of driving the car while on medication).

R: How are they aware (that the participant didn't want to be on medication)?

S: Well, because I stopped them before.

(R then asked why S didn't ask directly.)

S: Well, I don't feel direct all the time.

R: Uh-huh.

S: Because they'll be thinking "Well, why does she keep asking me about being off the pills."

S: But he increased them and I don't know what his reason was, he didn't say, I don't think he gave a reason. Uh I don't know, I don't know what, unless, I don't really know, no. Unless he wanted to see if I was trustworthy in taking them all the time.

The reasons for the passive stance on the part of the participants seemed related to the rational power they attributed to the therapists, based on the therapists' knowledge, and partly based on historical patterns of interacting with their mental health care-givers. One can infer that treatment experiences, particularly experiences with the "old system," would contribute to this passive stance. However, the short-term group, without this historical basis, also assumed this passive stance, so that past experience is not sufficient. As mentioned earlier in regards to participants' expectations, participants valued the "doctor's" judgment and wished to work with the doctor. As well, the relationship between the decision-making and the influence of health professionals has been mentioned, and this relationship is consistent with the participants' stance as well. One participant acknowledged that perhaps "they're wait-

ing for me to say something"; her silence was not attributed to fear but to history, "I've been seeing doctors and psychiatrists ever since I was 17 years old."

Finally, although participants may not engage in active negotiations concerning their medication, their passivity in the interaction is not significant of a totally passive stance in regards to medication-taking. The choice to take medication or not rests with the participant.

R: When I was talking about this, I was meaning you feel like they uh, they really expect you to take them that way, and that it's very difficult for you to disagree, and say "Oh no, I'm not going to," eh?

S: I never have done that.

R: You've never done that?

S: But I've al, always decided what pill I'd take.

T: Uh-huh.

S: If I didn't like it, I just never took it.

Another participant expressed exercising this choice by refusing to return to the psychiatrist.

SUMMARY

This chapter has presented the participants' accounts of their medication-taking, organized within a framework developed by the researcher using categories, themes, and concepts arising from the data, and thus reflective of the group's perspective. The purpose of the chapter has been to describe the participants' medication-taking behaviors and their explanations for those behaviors within the context of their everyday life.

This chapter has presented medication-taking as a complex behavior, with many varied influences at work in determining that behavior. It was not the purpose of this study to present a rigorous theory for predicting

why schizophrenic clients do or do not take medication. The value of the descriptive data presented in this chapter lies in demonstrating the importance of understanding a client's perspective towards his/her medication-taking. The data presented in this chapter also provides a basis for the discussion of compliance theories in the following chapter.

CHAPTER V: DISCUSSION OF RESEARCH FINDINGS

INTRODUCTION

This chapter will discuss the compliance literature reviewed in Chapter Two, vis à vis the participants' accounts presented in Chapter Four. As stated in Chapter One, the study's intent is to approach the existing research and literature concerning non-compliance in an explanatory way; supporting or questioning the various proposed factors assumed relevant to schizophrenic clients' medication-taking.

This study is not intended to develop a theory of compliance by quantifying or organizing relationships amongst variables to predict compliance. Although comparisons will be drawn between the research data and existing studies, this discussion of research findings cannot directly support or refute existing theories of compliance. These theories must be tested on the basis of studies designed for that purpose. This research is intended to provide another perspective, that of the client, which would be useful in conceptualizing the phenomenon "compliance." What research will lead to the "best" understanding of compliance? Rist (1979) states in his discussion of quantitative and qualitative research "if each approach does provide a perspective which is the mirror-opposite of the other, the creative effort becomes one of trying to find ways of taking these partial images of reality and piecing them into a new orientation or perspective" (Rist 1979, p. 21). In the spirit of such creative efforts, this chapter is aimed at providing a greater understanding of compliance.

DISCUSSION OF THE COMPLIANCE LITERATURE

The first question to be raised is whether the terms "compliance" and "non-compliance" are in fact meaningful and useful. These terms represent the reality of medication-taking as something that some patients do and others do not. It is assumed in many compliance theories that those who take medication may be separated from those who do not on the basis of certain factors, such as the illness, the regime, their health beliefs, or the interaction with the physician. Those studies which adopted the client's perspective did not necessarily share this perspective towards medication-taking.

Based on the data gathered in this study, the usefulness of categorizing those clients on medication as compliers or non-compliers is questionable. Although all of the study participants were currently taking medication (hence compliers), all had stopped or altered medications in the past (hence non-compliers). Thus, in order to incorporate this data, one would have to see compliance as situational, not an enduring characteristic. But what of the various alterations in medication-taking practises dependent on daily circumstances? Depending on the operationalization of compliance, for example, whether it is defined as taking all or some of the prescribed medication, the same clients might alternate daily between compliance and non-compliance. As well, these patients, adjusting their medications according to what they think to be proper medication-taking procedures, might be bewildered at the possible insinuation that they are not taking medication as prescribed.

The concept "compliance" does not accurately represent the medication-taking process for these clients, nor probably others, who are living with medication-taking on an on-going basis. The participants experienced

changes over time in their perspectives towards medication-taking. Some became more committed to taking medication and others did more experimentation. Regardless of the commitment to medication, some alterations occurred. The word "compliance" can be seen as representing an on-going process, involving uncertainty and decision-making, in which medications are stopped, started, forgotten, and altered, as well as taken as prescribed.

As well, the term "compliance," defined previously as the extent to which a patient's behavior coincides with medical or health advice (Haynes, Taylor, and Sackett 1979, p. 2) emphasizes the practitioner-patient relationship in medication-taking behavior. The study data supports the importance of this relationship and recognizes that prescribed medication-taking by necessity must involve that relationship. However, medication-taking is presented as a complex behavior. The emphasis on compliance tends to emphasize one feature of medication-taking, while overlooking other important aspects, thus altering our perception of the phenomenon "medication-taking."

The literature on compliance will now be discussed following the same organization as that used in Chapter Two: a) studies determining rates and factors associated with compliance, b) the Health Belief Model, c) the clinician-patient relationship, d) the client's perspective, and e) combined approaches to compliance.

A. Studies Determining Rates and Factors Associated with Compliance

The previous comments about the nature of compliance indicated that compliance is a process which is misrepresented by the categorizing of individuals as compliant and non-compliant. This understanding helps

to account for the variance in rates and the lack of utility of such variables as demographic characteristics.

The patient's living situation -- living alone, poverty, unemployment, and family instability -- has been related to compliance. The influence of the family, both positively and negatively, was a feature of the participants' accounts of their medication-taking. Another feature of the accounts, also related to the patient's living situation, was the evaluation of treatment, including medication, in the context of "how life is going." If the medications are perceived to have contributed towards a better life, they will be more favorably evaluated than if life is seen to be going poorly. Life circumstance, such as poverty, may be seen by the medication-taker as having more impact on the life situation than the medication, reducing the significance of the medication.

Chronic illness, especially when treatment is prolonged, prophylactic, or suppressive in nature, and when the consequences of stopping therapy may be delayed, is associated with higher non-compliance rates (Blackwell 1973a). The research data presented in this study provides some interesting relationships to the above statement. Firstly, in comparing the short-term and long-term client groups, there was the implication that long-term medication required a shift in expectations concerning the nature and the time-frame associated with medication-taking. Time on medication could increase the commitment on the part of the participants as well as increase self-regulation. Secondly, it appeared that many participants did see the medication as prophylactic or suppressive, as in preventing a recurrence of the illness, but still took the medications. Regardless of how participants saw their need for medication, they approached medication-taking with ambivalence and uncertainty, expressing the wish to

do without medication if possible. Thirdly, many participants did acknowledge the "longer-acting" nature of the anti-psychotic medications and this knowledge did seem directly related to "test" stoppages and missing or forgetting doses with less concern, but not necessarily medication stoppage.

The finding that psychiatric illness is associated with higher non-compliance is difficult to address as this study included only psychiatric clients. Without addressing the clinical features of mental illness, one possible factor might be that the moral implications of mental illness and the psychotropic medications are more devaluing than those of other illnesses and medications.

The complexity of the regimen appeared to be a factor for participants as the middle of the day doses were most often missed due to other activities. As participants referred to medication-taking as a habit or system within their lives, the less change and the least complex medication-taking patterns seemed to be adhered to most easily. Participants expressed the wish for the least medication possible -- a desire seen to be based on both practical and moral reasons.

The health care setting is said to influence compliance. As all the participants were involved in basically the same type of health care delivery system, comparative data is not available. The notion that extended supervision increases compliance is consistent with the participants' accounts. Some participants stopped medication when in infrequent contact with a doctor or an agency. However, considering the importance of the nature of the relationship with the therapist, the quality as well as the quantity of contact must be considered.

The previous discussion relates to general compliance research.

Those studies concerned with medication-taking in schizophrenic client populations will now be examined.

Psychiatric symptoms, such as paranoid ideation, lack of motivation, and the presence of grandiosity versus depression and anxiety have been invoked as explanations for non-compliance. This study did not categorize participants in terms of symptomatology and the participants rarely used these concepts in explaining the variations in their medication-taking. Thus it is difficult to comment on the importance of these symptoms. The researcher recognizes that there could be considerable debate around this issue as many clinicians might think it imperative to consider these symptoms.

The side effects of medication are frequently related to non-compliance (Michaux 1961; Van Putten 1974). Experiences with side effects of medication were presented in the participants' accounts. The therapist's reaction to the side effect in helping the patient obtain relief was an important aspect of these experiences. The meaning of the side effect to the participant was also important -- the significance of the particular side effect to the participant's daily life and how the side effect is interpreted. For example, side effects were seen as an indication that the medication "doesn't agree with me." Participants continued to take medications despite both past and present side effects. Emphasizing one particular variable, such as side effects, seems to be a distortion of the reality presented by the participants. Medication-taking is a complex behavior with no simplistic answers, such as side effects, to explain patterns.

The final explanations of compliance behavior to be discussed in this section are those cited by Serban and Thomas (1974). Their study

states: "further questioning in order to determine if the attitude was due to failure to understand the importance of medication revealed that both acute and chronic patients would discontinue medication if: they felt they no longer needed it, taking medications interfered with their activities, taking medication made them feel different from others, and they felt no difference in their condition after forgetting to take medication" (Serban and Thomas 1974, p. 992). The wording of the above statement, using the word "if," raises doubt as to how this information was obtained. That is, were the patients asked "why" they discontinued their medications or "if" they would discontinue medications under the above mentioned circumstances? Logically, patients would discontinue medications "if they felt they no longer needed them," as well as "if taking medications interfered with their activities." The word "interfere" implies hinder or obstruct (Webster 1976, p. 602). The study participants acknowledged that medication-taking was something that was adjusted and integrated within one's daily life, including the special circumstances which were managed. Perhaps "interfere" connoted problems which could not be solved by such adjustment and thus would lead to discontinuation of medication.

The notion that taking medication made them feel different from others is a theme cited by the participants in this study. This theme influenced medication-taking behavior. The participants in this study continued to take medication despite their concerns about "normality." Similarly, participants in this study noted both the preventative and long-acting nature of medication and probably would acknowledge that "they felt no difference in their condition after forgetting to take medication" (Serban and Thomas 1974, p. 992). Although this knowledge appeared

to contribute to the self-regulation efforts of the participants, the participants were taking medication on an on-going basis despite this knowledge.

B. The Health Belief Model

The Health Belief Model is based on the presumed relationship between the individual's subjective state and health behavior. Hence, one might expect to identify similarities in the participants' accounts of medication-taking and the proposed variables in the Health Belief Model. There is correspondence between such variables as perceived susceptibility and perceived seriousness and the participants' notions concerning their illness. Likewise correspondence is apparent between the perceived benefits of taking action and the participants' evaluations of the reasons why they need medication, their concerns about stopping medication et cetera. In fact, it might be possible to translate all of the participants' accounts into the variables mentioned in this model. However, the researcher questions the usefulness of this task, and in so doing, highlights the problems of such "subjective" models as the Health Belief Model.

The ideal of "translating" from the participants' accounts to the Health Belief Model is important. Although the Health Belief Model is concerned with patient's subjective world, the model uses "scientific" concepts and terminology to represent the patient's world. Thus the categories are not meaningful to patients without "translation" and one questions the way that the patients' perceptions would be obtained.

Further, these categories have been quantified in order that values could be assigned to the categories to use for the prediction of health behavior and testing of the theory. This quantification represents

further distortion of the clients' perceptions, which, as presented in the participants' accounts, do not exist in the form of "yes" and "no" categories for quantification. If, as suggested by the participants' accounts, the process of taking medication is characterized by uncertainty, ambivalence, and continued decision-making, the Health Belief Model would capture only one moment in time, thus not accurately representing the clients' changing ideas.

Similar concerns to those discussed above would also apply to the study conducted by Lin, Spiga, and Fortsch (1979) which related insight and adherence to medication-taking in chronic schizophrenia. The difficulties inherent in the way these models have used subjective data may account for their lack of success in demonstrating significant correlations between the variables and adherence.

Kasl (1974) proposed modifications to the Health Belief Model to account for chronic illness. He suggested that chronic illness is consistent with an "at-risk" status, rather than the sick-role. The research data in this study supports this reconsideration of chronic illness. The participants described themselves as neither sick nor well, and they tended to endorse medication-taking as preventing recurrences of illness rather than as active treatment. Illness management and life management became so intertwined that sick-role does not appear to be the appropriate concept. Kasl also suggested enlargement of the Health Belief Model to include the concepts of lay referral systems; social support; the influence of the doctor-patient relationship; and socioculturally determined expectations of pain and symptoms, health and illness, and the sick-role. The participants' accounts included the influence of others: fellow patients on medications, friends, and family, as well as the therapist-

patient relationship. Clients' perceptions of such things as their illness and their social role have to be seen within a sociocultural context.

In summary, although supporting Kasl's proposed modifications to the Health Belief Model, the researcher questioned the present form and method of using this model, for the reasons which were discussed.

C. The Clinician-Patient Relationship

The literature review identified several perspectives which have been used in the study of compliance and the clinician-patient relationship: role expectations and role fulfillment in the management of the problem-solving interaction (Davis 1968 and 1971); patient satisfaction and the physician's ability to communicate in a personalized way with patients (Korsch, Gozzi, and Vida 1978; Freemon, Negrete, Davis, and Korsch 1971); the physician's instructional and motivational effort (Svarstad 1977); and the physician's ability to negotiate a treatment plan suitable to the client (Eisenthal et al 1979). The above approaches will be discussed in relation to the research data gathered in this study.

The notion that clients have role expectations of both their own and the therapist's behavior is supported by the study data. The patient's role was described as predominantly passive with expectations that the doctor/therapist would be active in terms of giving information and making decisions. However, the participants' passivity was also accompanied by an expectation that their concerns would be heard and acted upon. Participants valued both their own and others' experiences in making decisions about medications. Thus, although authority was invested in the doctor/therapist, there were both limitations and obligations attached to this authority. The complementary nature of role expectations requires further

study of both the clients' and the therapists' perceptions.

The participants' comments about the doctor's attitude support previous research concerning the importance of both patient satisfaction and the ability of the physician to communicate in a personalized way.

The physician's instructional effort is of particular interest, due to the present emphasis on patient education. The study participants acknowledged desires for more information about medication, although the kind of information desired varied among participants. The importance of the participants' knowledge base in the formation of their medication-taking practises is also clear. For example, notions re the proper scheduling of medication will influence medication-taking patterns.

Some inferences about the usefulness of patient teaching can be drawn: the client needs to be actively involved in determining the instructional content, and actual practises or behaviors need to be discussed rather than didactic presentation of information as information can be used by the client in unpredictable ways. It must also be recognized that clients will have their own perspectives on their medication-taking, both on an individual level and on a cultural level. Although valuing professional knowledge, clients will make their own decisions in regards to medication-taking.

Health teaching programs tend to focus on the clients' knowledge of medication, what might be termed the technical aspects of medication. Such issues as the moral implications might not be acknowledged, or if acknowledged, dispelled by the professional ideology towards mental illness. For example, professional ideology might claim that mental illness is like any other illness, which contradicts the clients' perceived social reality. Broadened course content to include such issues as moral impli-

cations would be more reflective of the clients' perspective on medication-taking.

The negotiated approach in clinician-patient relationships assumes that patients have a distinct perspective regarding their problems and treatment. This study identified the participants' perspectives in relation to their medication-taking behavior and therefore supports the basis of the negotiated approach. As well, the study data supports the need for the therapist and patient to work together in developing the pattern of medication-taking.

In summary, it appears that all of the research perspectives used in understanding the clinician-patient relationship and compliance have some validity in terms of this study's findings. A conceptualization of the therapist-patient relationship to include all of these perspectives would be useful. Although this relationship is important to compliance, the study data indicated other aspects of the participants' perspective toward medication-taking which should also be considered in understanding compliance. Compliance is a complex behavior which cannot be conceptualized in terms of one variable such as the therapist-patient relationship.

In considering the study data and the previous research concerning the clinician-patient relationship, several questions became apparent to the researcher.

1. Is there a difference in the effect of the doctor-patient relationship versus the non-physician therapist-patient relationship on medication-taking? Most of the reported research studied physicians. This study did not differentiate the participants' comments as related to doctors or other therapists; the comments were grouped into the therapist-patient relationship. The study participants were involved with both a

non-physician therapist and a doctor. How these participants, and patients in other settings, perceive these two groups in relation to their medication-taking needs further study.

2. Is there a difference in the clinician-patient relationship in acute versus chronic illness? Research has tended to use acute illness situations for the study of relationships and compliance. This study included both short-term and long-term illness participants. There was some evidence to indicate that as patients' perspectives towards their illness and treatment change, their perspectives towards the care-givers also change.

3. Are there unique features of illness and treatment experiences which lead to unique patient-therapist relationships? In particular, are there unique features of schizophrenia which contributed to the therapist-patient relationship described in this study? For example, it appeared that the importance of professionals as sources of information and advice might be related to less information-sharing with others such as friends than would be the case with more common and/or less stigmatized illnesses.

D. The Client's Perspective

The previously reviewed research which had adopted the client's perspective illustrated several ways in which this perspective could be used in understanding health behaviors, including medication-taking. This study is a further example of the usefulness of this approach. Rather than compare this study to other studies within this perspective, it would seem beneficial to briefly describe how the researcher has come to understand schizophrenic clients' medication-taking, as presented by this study's participants.

The medication-taking pattern is determined by the client's under-

standing of the prescribed pattern, as well as the actualities of everyday living such as forgetting, and going out. Variations in everyday practise are based on the participants' notions about the medications and proper medication-taking. These notions are based on information from a variety of sources: therapists, other medication-takers, the participants' observations of practises such as hospital practices, and their own sense making based on their own experiences, and interpreted within their own socio-cultural framework.

The therapist-patient relationship contributes to the medication-taking pattern, as do the moral implications of being on medication. Medication-taking is constantly under review, as clients are not certain about what is their best course of action for their situation. Their continuing evaluations of illness and treatment, as experienced in their everyday life, include evaluation of the relationship between medication and their illness. Illness management is a social process in which behaviors, such as taking medications, are evaluated.

This understanding of medication-taking is generally consistent with that of the other "client perspective" studies reviewed. The notions that scientific medicine and patients represent two distinct ideological systems will be explored further.

Psychiatric theory provides a framework for viewing mental illness, specifically schizophrenia. In so doing, this theory describes ways of organizing the clients' accounts, for example, psychiatric assessments. Likewise, psychiatric theory provides explanations of client behavior, including medication-taking. As shown by the study participants, clients have their own frameworks for organizing their accounts, as well as explanations for their own behavior. These frameworks can be seen as competing

ways of organizing data and are also reflective of different value systems of health and illness, etc. (Kleinman 1977). The degree of correspondence between these two systems can vary greatly. These ideological differences are true of other areas of medical practice as well as psychiatry, but the issues of client rationality and competency make these issues even more difficult in psychiatry. How are these ideological differences resolved? This question presents questions at both practical and broader ethical levels.

The practical questions relate to the nature of the patient-therapist relationship, such as the valuing of information and the sharing of decision-making. The broader ethical issues relate to the fact that the scientific medical ideology reflects the value system of the dominant culture in our society and thus is more powerful than the patients' ideological system (Kleinman 1977). This raises questions about the rights of a dominant culture to impose itself on another culture, and the danger of scientific medicine acting upon its ideology as if it was "eternally right" and not a construction of the world. As both scientific medicine and patients offer useful perspectives, there is a need to recognize and utilize both perspectives.

E. Combined Approaches to Compliance

The combined approaches to compliance recognize the complexity of a health behavior such as medication-taking. The research data gathered in this study lends support to two combined approaches in particular, although this support is not to be interpreted as total endorsement of these two approaches.

Christensen's (1978) model is supported for its recognition of the process involved in compliant behavior. "A major distinction of the above

model is the explicit recognition of compliance behavior as a dynamic process in which change occurs as a result of new information and experience gained by the patient" (Christensen 1978, p. 184). Jenkins' (1979) model is the broadest conceptual model and thus includes the many aspects of health behavior which were identified within this study. However, the aim of the Jenkins' model is to provide a diagnosis and treatment approach to "unhealthy" behavior, not to understand compliance as a process, as does the Christensen model. Both of these models have incorporated the health belief models, the patient-physician relationship, and relationships with others as factors influencing compliance and health-related behavior.

DISCUSSION OF DRUG THERAPY IN SCHIZOPHRENIA

Although the purpose of this study was to compare the participants' accounts with the compliance literature, the content presented in drug therapy in schizophrenia will be briefly discussed in relation to the accounts. This discussion provides further understanding of the phenomenon "compliance" as well as presenting some considerations for psychiatric clinicians.

The idea that clients and therapists differ in their perspectives towards medication-taking has been previously discussed. Some of these differences will be highlighted. Firstly, the value attached to medication in terms of its contribution towards the client's "doing better" may differ. Participants identified aspects other than medications which they saw as contributing to their health status. Medications are currently highly valued by therapists (Soskis and Jaffe 1979) who may place more emphasis on medications than their clients. In addition to their belief

in the efficacy of medication, therapists' valuing of medication might be related to the fact that therapists have more control over medication (or at least feel they have more control) than over factors such as the client's finances, nutritional status, family situation, or other such life situation circumstances.

Secondly, practitioners' enthusiasm for injectable medications was not shared by the participants in this study, as was mentioned in their past experiences with medication. It would seem useful to investigate the use of injectable medications both from the perspective of practitioners and clients, especially considering the greater choice available in oral medications. Thirdly, this study suggested that short-term and long-term clients varied in their perspective towards illness and treatment. If this is the case, do practitioners appreciate this difference, or do practitioners see one schizophrenic episode as the beginning of a chronic illness (although this may or may not be justified)? Such different perspectives lead to greater divergence in the client's and practitioner's view of reality in terms of illness and treatment.

Although there are differences in the clients' and therapists' perspectives, there are similarities in their perspectives as well. The participants' uncertainty concerning medication-taking and their beliefs about individual differences in response to medication are paralleled by uncertainty on the part of the clinician who must decide on the efficacy of medication in general and which specific medication at what dosage. From both perspectives, medication-taking necessitates continual decision-making. How much of this uncertainty do practitioners feel comfortable expressing, as well as how much uncertainty do participants feel comfortable accepting from practitioners? These are questions for exploration.

tion in understanding the patient-therapist relationship.

Many of the participants' notions in regard to desired medication-taking, such as once-a-day dosages and trial periods without medication, are in accordance with current medical notions about desired practices. The extent to which clinical prescribing practises and the information given to patients are in accord with scientific thinking in regard to drug therapy in schizophrenia is not known.

Another consideration in comparing the participants' accounts to scientific medicine is the impact of various models of etiology and treatment. The biological model, adopted by some participants, appeared to reduce the negative moral implications of the illness. The comparison to diabetes appeared to reduce the shame of both the illness and the medication. The interaction between professional, patient, and public ideologies concerning an illness and treatment are important aspects in understanding health behavior.

This brief discussion of similarities and differences in perspectives towards medication-taking highlighted some of the questions to be explored in relation to our understanding of medication-taking in schizophrenia. Many other comparisons to previous research can be made by the reader. Although recognizing the need to work with the differences in perspectives between therapists and clients, the basis for a therapeutic alliance appears to be present, both on the part of the participants and from the standpoint of scientific medicine.

SUMMARY

This chapter has discussed "compliance" as presented by both relevant literature and the participants' accounts. The participants' perspec-

tive as developed in this study brings into question the assumptions and conclusions operative in some compliance research and theorizing, while lending support to others. In so doing, implications for the delivery of health care and further research have been identified, for example, in relation to patient education programs.

The researcher wishes to emphasize that there are many perspectives towards a phenomenon such as compliance. No perspective can be seen as "the only reality" as "reality" is socially constructed. It is hoped that the perspective presented by this study has led to a greater understanding of the phenomenon "compliance."

CHAPTER VI: SUMMARY AND CONCLUSIONS

SUMMARY OF THIS STUDY

This study presented a qualitative approach to the understanding of patient health behaviors, specifically, the medication-taking behavior of schizophrenic clients. This study differed from previous research by focussing on the clients' perspectives towards their medication-taking. Previous research had concerned itself with compliance, the extent to which patient behavior coincides with health advice.

Using interview data obtained from the study participants, a client's perspective was constructed which described both the medication-taking behavior of schizophrenic clients and their explanations for that behavior. This construction was then compared to the conceptualizations and theories concerning compliance presented in previous research. In so doing, new perspectives towards compliance and health behavior were suggested.

The nature of qualitative research does not lend itself to definitive statements concerning the nature of social behavior. However, implications for health care and suggestions for future research can be drawn from this study. This study's contribution to the development of theory in relation to health behavior and compliance is in demonstrating an alternative approach from which data was gathered and to which previous research was compared. As this perspective itself is an essential feature of this study's contribution, the discussion of the implications for health care and further research is not limited to the medication-taking of schizophrenic clients, but also extends to patient health behavior and compliance in general.

IMPLICATIONS FOR HEALTH CARE

Both the terms "compliance" and "medication-taking" have been used throughout this study to refer to patient behavior in regards to medication. The use of "compliance" to describe this behavior denotes a particular perspective towards that behavior, and thus it influences the way in which both clinicians and researchers approach patients' medication-taking. Even newer terms such as therapeutic alliance emphasize the patient-therapist relationship in medication-taking. This study's data demonstrates the complexity of patient behavior which may not be identified by focussing on compliance or the patient-therapist relationship in general. Terms which describe the patient behavior, such as medication-taking, appear to be more useful starting points for clinicians and researchers in conceptualizing such behavior.

Support for some of the factors which have been suggested in previous compliance research was given, for example, the complexity of the regime, and the frequency of contact with the care-giver (supervision). However, this study emphasizes there are no simplistic answers to be found.

The study identifies the need for greater understanding of patient behavior and chronic illness. It has been suggested that patients experience changes in their perspectives, with accompanying changes in their behavior, as they live with their illnesses.

The study suggested considerations for patient education programs. The assumption that patient education leads to greater compliance had previously been challenged. This study suggests additional notions concerning patient education: that patients value information and experience from sources in addition to professionals; that knowledge can be implemented unpredictably, therefore actual behaviors need to be discussed;

and many facets of living with the illness affect the particular health behavior and therefore should be considered in patient education programs.

The notion that clients and health care professionals may not share the same ideological basis in regard to the illness and treatment has considerable implications for health care. There is a need for the health professional to elicit and attend to the client's ideology in order to provide optimal health care.

Although the previous comments apply to many health professions, specific implications for nursing will now be discussed. There is a need to examine the similarities and differences in the ways in which nurses, as compared to other health professionals, influence patients' health behaviors, both from the nurses' and patients' perspectives. As nurses assume more expanded roles as primary care givers, there is greater need for nurses to understand the clients' perspectives on health behavior and the impact of these perspectives on the determination of patient behavior. Hogue (1979) makes three suggestions to nurses who wish to improve compliance: "think about the regimen from the patient's point of view; use the power of natural support systems; and collaborate with others interested in the patient's progress" (Hogue 1979, p. 257-258). The organization of the participants' accounts indicated some major categories which might be helpful to nurses in obtaining client perspectives toward medication-taking.

This study was not guided by a theoretical framework for nursing. However, the empirical data presented in this study can be used in relation to theory development in nursing: what guidance does a particular framework offer for the understanding of this data? For example, the concept "self-care" has been identified as a key concept for nursing (Orem 1971)

and the data gathered in this study could prove useful in the validation and further development of this concept.

SUGGESTIONS FOR FURTHER RESEARCH

The introduction to this discussion indicated that, due to the importance of the perspective adopted by this study, findings would be generalized to patient health behaviors. However, further research with other patient groups is suggested and will be discussed.

The participants in this study were schizophrenic clients who have been categorized into two groups, short-term and long-term clients, based on the length of their treatment and illness. The participant group shared distinct features compared with the schizophrenic population in general: their community living arrangements and their use of oral medications. Is their perspective representative of this client population in total? Further research including clients on injectable medications is indicated. In order to explore the different perspectives of short-term and long-term patients, the most desirable designs for further research are longitudinal studies. Such studies could describe the process of taking medications more fully. These studies would also include patients with diversities of outcomes in terms of contact with the mental health system, types of living arrangements, and types of medications.

Longitudinal studies should focus on the illness and treatment experience in general, considering patient behaviors other than medication-taking. In order to enhance our understanding of the patient-therapist relationship, both the clients' and the health care professionals' perspectives should be studied, as well as the interaction between these perspectives. The need to differentiate the influence of the various professional roles on patient behavior has been discussed previously.

Although this and other studies have been applied to compliance research in general, there is a need to understand client perspectives for various illnesses. In what way is illness, particularly chronic illness, a similar experience? In what ways do the unique features of the disease and treatment contribute to different illness experiences? Further research is suggested to answer these questions.

Previously it was emphasized that the regime must be efficacious before concern about compliance was warranted. The final suggestion for research relates to the need to link the process of health care with outcomes. What behaviors on the part of the patient and the care-givers lead to improved health outcomes, recognizing that a variety of measures have been used in judging health?

The value of this study rests in its contribution toward the understanding of patient health behavior, specifically the medication-taking of schizophrenic clients. It is hoped that this understanding will be beneficial in the continuing development of co-operative and productive relationships between nurses and their clients.

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A P P E N D I X

Appendix A

Sample: Introductory Letter

Dear _____:

This letter is to ask you to participate in a study which I am doing as a student at the University of British Columbia, taking my Masters in Nursing. Although (Team Name) has helped me to contact you, I do not work for G.V.M.H.S.

I am interested in how persons like yourself deal with your medication on a day to day basis. There is very little information about clients' views of medication and I think it is important to know more about what you think about medication.

If you are willing to participate in the study, I would like to meet with you twice, at your residence, once in April or May and once in June. A third meeting may be requested; this will be discussed at the completion of the second interview. You will be free to withdraw from the study at any time. You would not be identified by name in the study. I will tape record the interviews, rather than write as we talk - the tape recordings would be for my use only.

If you are willing to participate in the study, I will contact you by phone the week of _____ to arrange an interview time. If you should decide not to participate, your refusal to participate will not affect your contact with (Care Team Name) in any way. If you decide to participate, you will be informed of the final results of the study.

Sincerely yours,

Pat Porterfield

Appendix B

GREATER VANCOUVER MENTAL HEALTH SERVICECONSENT

I, _____, do hereby give my consent to participate in the study on medication-taking behavior which is being conducted by the School of Nursing of the University of British Columbia.

- I understand a) that participation in the study involves no risks or discomforts;
- b) that my participation is voluntary and that I may withdraw at any time;
- c) that refusal to participate in the study or withdrawal from the study will in no way interfere with the treatment which I will receive, and
- d) that any information personally identifying me as a participant in this study will remain strictly confidential.

Client, or person authorizing consent if
other than client.

Date

Relationship

Therapist

Date

Position

Appendix C

GREATER VANCOUVER MENTAL HEALTH SERVICE

USE OF AUDIO/VISUAL EQUIPMENT

The use of an audio/visual tape recorder to record my therapy sessions/ interviews has been discussed with me, and I agree to this. They may be used by the following:

	YES	NO
The Therapist	<input type="checkbox"/>	<input type="checkbox"/>
The Student placed at this Community Care Team	<input type="checkbox"/>	<input type="checkbox"/>
The Student's External Supervisor	<input type="checkbox"/>	<input type="checkbox"/>
Authorized Personnel of the Greater Vancouver Mental Health Service	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>

with the provision that:

- a) The need for confidentiality shall be explained prior to each showing.
- b) The student's field supervisor shall be responsible for the safe-keeping and erasing of all tapes at the end of the student's placement, unless otherwise agreed upon.
- c) I have the right to revoke this permission at any time.

I hereby give my consent for the tapes to be retained for the following purpose:

YES NO

☐ ☐

_____ Date	_____ Client	
_____ Date	G.V.M.H.S. Field Supervisor	_____ Position
_____ Date	Student	_____ C.C.T.

Appendix D

Interview GuideA Description of Content to be Discussed in Initial Interview

1. Medication-taking behavior within client's daily life:
 - (a) Identification of medication in question.
 - (b) Description of current medication-taking pattern (what, how much, when, where, how, how much variation).
 - (c) How client determines daily pattern of medication-taking.
 - (d) What influences client to alter pattern of medication-taking.
 - (e) How medication-taking fits into daily pattern of activities.
 - (f) With whom client discusses medication-taking.
 - (g) Who influences client's medication-taking.
 - (h) How client discusses medication-taking with health professionals (doctors, nurses, etc.).
 - (i) Any thoughts and concerns about medication/medication-taking.
2. The aims and intent of medication-taking; the client's:
 - (a) Goal/aim in regards to medication-taking.
 - (b) Expectations concerning future medication-taking (for how long/ until when).
 - (c) Expectations of future if not currently taking medication.
 - (d) Explanation of how medication works.
 - (e) Sources of information concerning medication.
3. Past Experiences with medication-taking:
 - (a) Length of time client has been taking medication.
 - (b) Comparison of current pattern to previous patterns of medication-taking.
 - (c) How changes in the medication-taking pattern came about.
 - (d) Past experience related to medication-taking.
 - (e) Influence of any previous experiences on present medication-taking.