An exploratory study of barriers to psychotropic adherence from the client's perspective

Nicole Nanchy
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AN EXPLORATORY STUDY OF BARRIERS TO PSYCHOTROPIC ADHERENCE FROM THE CLIENT'S PERSPECTIVE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Nicole Nanchy
Michelle Sereese Green
June 2006
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ABSTRACT

Poor medication adherence among persons diagnosed with a severe and persistent mental illness causes repeated psychotic episodes that lead to rehospitalization, incarceration, adverse side effects, and suicide. This research study is exploratory in nature and utilized a methodology that elucidates the reasons for psychotropic nonadherence from the client’s perspective. This study included 16 participants diagnosed with a severe and persistent mental illness, who are currently receiving case management and psychiatric services from a community-based mental health agency. The survey instrument is a 10-item, one-to-one, semi-structured interview. Open-ended questions were designed to generate possible barriers to psychotropic adherence. At the conclusion of this study, researchers identified themes from the participants’ responses. Many of the same themes stated in current research were identified in the responses (i.e., side effects, relationship with mental health professionals, and insight). The responses derived from this study can be used to create new treatment interventions and recovery plans.
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DEDICATION

I would like to dedicate this project to my family, friends, and clients. To my family, thank you for not giving up on me. This journey began 11 years ago and with your unconditional love and support, my goal is accomplished, and now my work can begin. To my friends, thank you for being so understanding every time I turned down a dinner invitation or weekend away; those days of rejection are over! To my clients, you are amazing individuals. Continue to be yourselves and never give up hope.

Namaste - I honor the place in you, which is of love, of truth, of light, and of peace.

Nicole Nanchy
DEDICATION

I would like dedicate this to my family. To my husband Rick for tolerating the long hours and headache this research project commanded, thank you. To Jason and A.J., thank you for allowing me to go back to school to finish a dream. Thank you all for supporting me through this venture.

Michelle Sereese Green
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CHAPTER ONE

INTRODUCTION

This chapter provides an overview of the problems persons diagnosed with a severe and persistent mental illness experience as a result of nonadherence to psychotropic medication, the importance of studying nonadherence, the role of the mental health social worker, the methodology employed for this study, and its potential contributions to the field of social work.

Problem Statement

According to a study by the World Health Organization "mental illness (including depression, bipolar disorder, and schizophrenia) is the leading cause of disability worldwide, accounting for 25 percent of all disabilities across major industrialized countries" (New Freedom Commission on Mental Health, SMA-03-3832, 2003). Unfortunately, most people do not seek mental health treatment, which can lead to debilitating symptoms and diminished quality of life (Bond, Drake, Mueser, & Latimer, 2001). Medication nonadherence in individuals with a severe and persistent mental illness (SPMI) is
highly correlated with increased levels of symptomatology leading to relapse, adverse side effects, rehospitalization, incarceration, and suicide (Balon, 2002; Hewitt & Birchwood, 2002; Kopelowicz & Lieberman, 2003; Pinikahana, Happell, Taylor, & Keks, 2002; Trauer & Sacks, 1998; Wykes & Gournay, 2002).

In the U.S. alone, 22-23 percent of the adult population, 44 million people has a mental illness, of which, 2.6 percent—has a SPMI (U.S. Department of Health and Human Services [USDHHS], 1999). Furthermore, studies indicate that more than 50 percent of individuals taking psychotropics are nonadherent and at risk of relapse (Byrne, Deane, Lambert & Coombs, 2004; Dixon, Weiden, Torres & Lehman, 1997; Dodler, Lacro, Dunn & Jeste, 2002; Hogarty & Ulrich, 1998; Hughes & Hill, 1997).

Wykes and Gournay (2002) suggest that persons with a SPMI considered to be medication nonadherent have not taken their medication regimen as prescribed by a mental health professional. Although several attempts have been made to measure medication adherence through blood/urine tests, psychiatric assessments, pill counts, and self-reports, none of their methods were effective (Wykes & Gournay, 2002).
A study by Trauer and Sacks (1998) compared judgments concerning the medication adherence between the individual with the SPMI, the case manager, and the doctors, and found that "12.5 percent, or one in eight, of the clients thought by both clinicians to be compliant, rated themselves as noncompliant."

According to Hayward and Chan (1995), "...adherence to these drug regimes offers hope for a greatly increased quality of life for the long term mentally ill as well as an enormous saving of public money." Despite the hope pharmacotherapy brings to individuals with SPMI in the recovery process, many individuals continue to be nonadherent.

Under the rights-driven model, one of two approaches to treatment refusal, clients have the right to refuse medication regardless of the benefit (Kasper, Hoge, Feucht-Haviar, Cortina, & Cohen, 1997).

**Micro/Macro Policy.**

The National Association of Social Workers (NASW) Code of Ethics (1999) delineates ethical principles which guide both micro and macro practitioners. The ethical principle of social justice calls for social workers to pursue social change through advocacy and political
activism. Recently, social workers and mental health clients marched on California’s state capital advocating for increased mental health funding. Their advocacy was successful as California voters passed Proposition 63, the Mental Health Services Act, which will generate an estimated $650 million during the first fiscal year, 2005-2006 (California Department of Mental Health, 2005).

Currently, micro and macro level social workers are working on planning teams with other mental health professions creating a three-year plan for Proposition 63 funding expenditures. Once funding is awarded, macro practice social workers will collaborate on multidisciplinary teams, designing new mental health programs, and expanding existing programs to address such issues as treatment nonadherence with populations like those with SPMI. Without the advocacy of macro and micro practice social workers, community-based agencies will continue to be under staffed and under funded, making it difficult to initiate effective evidenced-based treatment that address nonadherence.

Social Work Roles

Mental health social workers play a multi-faceted role in the client/professional relationship, including
advocacy for reduced physical and psychological side effects of psychotropics, remaining client focused by bridging the gap between parallel treatment modalities, working on an inter-disciplinary teams applying a holistic treatment perspective, and educating clients about their medication regimen (Bentley & Walsh, 2001, p. 43). Social workers, committed to these roles, ethically fulfill their duties and responsibilities as change agents within the community.

Purpose of the Study

The purpose of this qualitative study was to identify barriers to psychotropic adherence regimens in clients with SPMI. Medication nonadherence perpetuates the cycle of psychotic episodes, which leads to rehospitalization, incarceration, and homeless nights. This series of events has been coined “the revolving door phenomenon” (Hewitt & Birchwood, 2002; Kopelowicz & Lieberman, 2003). Until mental health professionals listen to the population they serve and better understand the reasons for psychotropic nonadherence, treatment interventions will continue to be noneffective.
This study was conducted at the Mental Health Association of Orange County (MHAOC), a community-based nonprofit agency. This study is in keeping with the intent of the AB2034 Program, authorized in 1999, by the California State Legislature, to provide intensive recovery services to individuals diagnosed with a SPMI such as schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder, secondary diagnoses of substance disorders, and homelessness or being at risk of becoming homeless. These individuals are referred to the AB2034 program through Orange County Department of Behavioral Health, Homeless Outreach Program.

The AB2034 program serves adults over 18 years of age, both male and female, representing diverse cultural and religious backgrounds. With respect to individuals' cultural beliefs, practices, and personal goals, case managers link clients to practical services that promote recovery and social integration. These services include counseling, pharmacotherapy, housing, financial support through SSI, medical and dental benefits, food and clothing, detoxification, rehabilitation programs, and social skills training.
Studies identify numerous reasons for psychotropic nonadherence such as adverse side-effects (i.e. excessive weight gain, sexual dysfunction), client/clinician relationship, lack of insight, and complexity of medication regimen (Azrin & Teichner, 1998; Balon, 2002; Dixon et al., 1997; Edlund, Wang, Berglund, Katz, Lin & Kessler, 2002; Hewitt & Birchwood, 2002; Kane & Nemec, 2002; Love, 2002; Nasrallah & Korn, 2002; Rosenberg, Bleiberg, Koscis & Gross, 2003). Recent studies of psychotropic nonadherence indicate a significant correlation with the client/clinician relationship (Balon, 2002; Donnell, Lustig & Strauser, 2004; Gabbard & Kay, 2001; Kane & Nemec, 2002; Noordsy et al., 2002; Trauer & Sacks, 1998). Creating a positive, mutual working relationship is vital to adherence practices of those with SPMI, which essentially promotes recovery. Offering clients, especially those hard to reach, the opportunity to enhance their standard of living, guides this studies methodological rational.

Research Design

This research study is exploratory in nature and used a qualitative research methodology to elucidate the reasons for psychotropic nonadherence, from the SPMI
individual's perspective. The instrument used in this study was specifically designed to draw out participants' responses to psychotropic adherence questions based on their own experiences and perceptions. Due to limited research in this area no standardized measure was available. Data was collected through a semi-structured interview and recorded verbatim. Using a table of random numbers, researcher selected a random point on the table, reading across the rows, or down the columns, writing a list of the first 20 numbers found. These 20 numbers were used to identify the sample of this study.

A Licensed Family and Marriage Therapist administered the Mini Mental Status Exam (MMSE) to prospective participants to assess their current mental status. A minimum score of 21 was used to screen prospective participants into this study. After participating in the semi-structured qualitative interview, participants received an envelope containing $15 cash in return for their time and effort.

Significance of the Project for Social Work

This study is important to social work practice because it validates the principles of empowerment by
seeking a deeper understanding of the client's reasons for psychotropic nonadherence. Using a client-centered approach, researchers will engage clients with SPMI through personal interviews. Engagement is a powerful element of the working alliance supporting the ethical principles of social work practice. Furthermore, engaging clients and offering them the opportunity to discuss psychotropic regimen concerns, enhances the individual's inherent feelings of worth and self-determination. Findings from this client-centered study provide a unique insight into adherence issues that will inform both the design and implementation of new treatment approaches.

Furthermore, approaching nonadherence issues from the client's perspective helps mental health professionals move from the biological confines of the medical model that often perpetuates victimization to a more hopeful model of recovery that promotes quality of life (Ragins, 1994). Strategies which attempt to improve adherence through increased dosage, change in medication, or modifying the formulation (oral to depot) are typically unsuccessful (Ragins, 1994).

Effective community-based mental health agencies serving those with a SPMI use a dual-modality therapy
approach. Dual-modality is a combination of psychosocial rehabilitation (including psychotherapy) and pharmacological treatment. Crate (2003) notes that psychosocial rehabilitation is based on a number of psychological theories including: client-centered, rational emotive, and reality theory. Each of these theories promotes the ideal of client self-determination through conscious decision-making, an essential component of recovery.

Pharmacological treatment was ushered in the 1960’s, and played a central role in the early stages of deinstitutionalization (Heyscue, Levin & Merrick, 1998). Psychotropic medication is the single leading treatment modality in mental health care nation wide, offering quicker relief from psychotic symptoms than psychosocial rehabilitation. Both treatment modalities have a place in the field of mental health, however, combining these treatment modalities (i.e., psychosocial rehabilitation and pharmacotherapy) produces the best results.

Several studies of psychotropic nonadherence have called for further investigation of treatment adherence. With over one-half of persons’ with a SPMI nonadherent to psychotropic regimens, mental health social workers
continue to seek answers to address this crisis. The evaluation phase of this study is essential to the identification and implementation of effective interventions in the field of mental health social work.
CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will describe severe and persistent mental illness, determine costs involved in serving individuals with such illnesses, and the barriers to psychotropic adherence. It will also describe the different treatment modalities that are utilized with this population. For example, psychosocial therapy based interventions will be discussed in terms of improving medication adherence and insight into illness, and interventions based solely on pharmacotherapy. Dual-modality interventions that include psychosocial therapy and medication to assist severe and persistent mentally ill (SPMI) clients are also discussed. Finally, a discussion of the theories guiding this research project will conclude this chapter.

Severe and Persistent Mental Illness

Severe and persistent mental illness (SPMI) is determined by Federal regulations and "applies to mental disorders that interfere with some area of social functioning" (USDHHS, 1999). The areas of social
functioning include problems with primary support group, social environment, education, occupation, housing, economic stability, access to health care services, legal system/crime, and other psychosocial and environmental areas (DSM-IV TR, American Psychiatric Association, 2000).

Two components that warrant attention when addressing SPMI are the human and financial components. The human components are the problems that individuals with SPMI encounter, which include profound functional impairment in one or more of the above mention areas, and leads to loss of functioning in many different areas of life. The Advisory Mental Health Council estimated that nine percent of U.S. adults have mental disorders as well as deficits in functional abilities (as cited in USDHHS, 1999).

The financial component involves the direct and indirect costs involved in serving SPMI clients. The category of direct costs includes "mental health institutions, sheltered homes, drugs, support costs, and social welfare" (Lindstrom & Bingefors, 2000, p. 114). The indirect costs are computed as loss of productivity in the workplace, school, and home due to premature death
or disability (USDHHS, 1999). In 1996, the direct costs of mental health services totaled 69 billion dollars (USDHHS, 1999). Additional indirect costs were calculated in 1990 to exceed 78 billion dollars (USDHHS, 1999). In addition to these direct and indirect costs to humanity, overall reduction in the quality of life for the clients should also be included (Lindstrom & Bingefors, 2000).

Barriers to Psychotropic Adherence

Many different barriers to medication adherence have been discussed in the literature. Barriers to medication adherence include, but are not limited to the following: medication regime confusion, lack of insight (into mental illness), denial of diagnosis, cultural belief systems, self-medication with illicit drugs and alcohol, side effects, and relationship between client and clinician. Side effects and relationship between client and clinician appear to be the two most important factors in treatment adherence. In fact, Seedat, Stein, and Wilson (2002) examined the drop out rates of clients engaged in treatment (pharmacotherapy and psychotherapy), noting that almost one-half (45.6%) left treatment due to side effects.
Lack of Insight

Programs operating under the psychosocial model assist clients with psychotropic regime confusion, lack of insight, and denial of diagnosis. Lack of education was associated with medication nonadherence, discovering that clients were poorly informed of their diagnosis and treatment. Nearly one-half of those respondents discontinued medications due to side effects (Seedat et al., 2002). Louis-Simonet et al. (2004), on the other hand, utilized residents to perform a structured patient-centered discharge interview, concluding that patients exited the program with significantly increased knowledge about their medications. This study did not yield statistically significant results, most likely based on the lack of social support once clients were released from the hospital (Louis-Simonet et al., 2004).

Increased knowledge of medications in combination with social support has been shown to increase medication adherence (Ho et al., 1999). Hellwell (2002) also noted a link between insight into illness and medication adherence; in fact one out of five clients diagnosed with schizophrenia missed one week of medication during the first three months after hospitalization. Jordan,
Tunnicliffe, and Sykes (2002) developed the SPMI clients’ insight into illness and side effects of medication regimes by utilizing a checklist to assist clients to determine medication side effects. This checklist allowed clients to report unfavorable side effects in a timely manner to the psychiatrists once they understood that side effects were possible (Jordan et al., 2002).

Stawar and Allred (1999) discovered that the perceptions of the staff members and the clients differed considerably when concentrating on discontinuation of medication. They noted that very few staff members perceived confusion as a reason for medication nonadherence, whereas more than one-third of the residents did perceive it as such (Stawar & Allred, 1999).

Cultural Barriers

Cultural barriers can further complicate psychotropic adherence in many different populations. Minorities encounter many barriers to receiving mental health services. “Mistrust and fear of treatment; different cultural ideas about illnesses and health; differences in help-seeking behaviors, language, and
communication; racism; varying rates of being uninsured; and discrimination by individuals and institutions” are many of the cultural barriers faced by minorities in receiving mental health services (New Freedom Commission on Mental Health, SMA-03-3832, 2003). Stotland (2003) noted that unspoken fears, such as the barriers listed above, affect the treatment regime. These fears can manifest in cultural beliefs that prevent a client from receiving greatly needed services.

For example, Asian culture views the mind and body as “unitary” compared to the European ideal of “dualistic”. This belief tends to manifest in Asian patients as physical indicators, versus emotional symptoms (Lin & Cheung, 1999), as mental illness is viewed as shameful. This can be a barrier, as Asian clients might not seek mental health services, due to the belief that the problem is physical.

The National Institute on Mental Health (USDHHS, 1999) notes that the U.S. mental health system is not equipped to meet the needs of ethnic and racial minority populations. Cultural barriers (i.e., cultural beliefs) deter ethnic minorities from seeking treatment, and if
individuals seek treatment, their treatment plans may be inappropriate in nature (USDHHS, 1999).

Self-medicating Behaviors

Self-medicating (i.e., utilization of illicit drugs and/or alcohol) to reduce symptoms of SPMI clients is a direct barrier to medication adherence. Johnson, Brems, & Burke (2002) examined 104 clients in a substance abuse program, identifying 45 percent with an additional mental illness indicating that many times the two problems cannot be separated. Ho et al. (1999) adds that treating dually diagnosed individuals is increasingly difficult as clients face “increased morbidity from substance induced psychotic exacerbation, dysphoria, anxiety, insomnia, and agitation” (p. 1765).

Side Effects

Studies with SPMI clients have demonstrated side effects in drug treatment plans as a major cause of medication discontinuation. Side effects range from weight gain to sexual dysfunction. Green, Patel, Goisman, Allison, and Blackburn (2000) state that psychotropic drugs used to treat schizophrenia have been linked to substantial weight gain. Green et al., (2000) examined
obesity in schizophrenic clients, noting that these same clients are at risk for additional physical ailments such as Type II diabetes. Sexual side effects (i.e., sexual dysfunction, lack of desire, etc.) were reported by 62.5 percent of males and 38.5 percent of females in a study conducted by Rosenberg et al. (2003). Of particular interest is that 50 percent of the clients “never or infrequently” voiced these concerns to their clinicians (Rosenberg et al., 2003). These findings suggest that the relationship between the client and clinician needs to be open, honest, and safe, allowing clients to voice their symptoms/side effects with psychotropics.

Cognitive difficulties have been noted in previous studies as a result of psychotropic medication use. In fact, Hellwell (2002) noted that many clients experience problems with cognitive abilities such as rigidity or dullness of thinking. These cognitive difficulties can contribute to psychotropic medication nonadherence, as well as confusion of regimes.

Physical ailments are identified in studies describing side effects of psychotropic medication use. Fincke, Miller, and Spiro (1998) note that clients reported an increase in physical illness while on
psychotropic medications, including, "nausea, indigestion, headache, blurred vision, dizziness, dry mouth, and itchy skin" (p. 184). Additional physical ailments discussed in the literature include psoriasis, acne, and hair loss. These side effects have been found among 45 percent of clients on a Lithium regime (Yeung & Chan, 2004). Hair loss has also been identified in studies of antidepressant use in adolescent quality of life (Cheung, Levitt, & Szalai, 2003).

Relationship between Client and Clinician

Another barrier to medication adherence is the relationship between clients and their clinicians. Lindstrom and Bingefors (2000) noted that the attitudes of clinicians towards clients affects clients' adherence. Other factors that reduced medication adherence were the clinicians' "authoritarian attitude, aloofness, passive behavior, indifference, anger, denial, cynicism, hopelessness, and ignorance" (Lindstrom & Bingefors, 2000, p. 113). Kerse et al. (2004) studied medication adherence in comparison with physician/patient relationship and discovered that "trust and physician/patient concordance were significantly related
These findings suggest that improving the relationship between clients and their clinicians can have long-term effects on medication compliance (Kerse et al., 2004).

Treatment

The treatment of SPMI includes psychosocial therapy, pharmacotherapy, and dual-modality services (i.e., a combination of the two) for clients. Evidence-based practice finds that a dual-modality approach to SPMI clients increases psychotropic adherence (Bentley, Rosenson, & Zito, 1990). Pharmacotherapy includes oral and intramuscular psychotropic medications. Psychotherapy utilizes individual and group therapy typically psychoeducational in nature to promote insight. Smith, Birchwood, and Haddrell (1992) noted that many SPMI clients lack knowledge about psychotropics, which can lead to lowered adherence rates.

Psychosocial Rehabilitation

Psychosocial rehabilitation (i.e., psychoeducation) targeted to SPMI clients regarding drug regimes, illness, and side effects can help increase insight. Yet, mixed findings exist. Increased insight can improve clients'
medication adherence. However, studies that base interventions in psychosocial rehabilitation, without utilizing additional facets to assist clients, fall short of the goal of increased psychotropic adherence (Hayward & Chan, 1995; Kavanagh, Duncan-McConnell, Greenwood, Trivedi, & Wykes, 2003; Smith et al., 1992).

Assertive Community Treatment (ACT) is an "intense mental health program model in which a multidisciplinary team of professionals serves patients who do not readily use clinic-based services, but who are often at high risk for psychiatric hospitalization" (Bond et al., 2001). ACT has been found to increase medication adherence among the homeless population. Dixon et al. (1997) studied a group of homeless individuals who voluntarily received services from a clinical team that employed the ACT program. The results of this treatment modality included rapid increase in medication adherence among the homeless population, as well as fewer psychiatric symptoms (Dixon et al., 1997).

Pharmacotherapy

Many interventions targeted for SPMI clients include pharmacotherapy. Psychotropic adherence is a main concern
for many clinicians working with SPMI clients, as re-hospitalizations are costly to the public. Many studies analyze tactics for increasing psychotropic adherence. Love (2002) investigated the strategies employed to increase medication adherence and noted that depot psychotropic medications (i.e., intramuscular injection of a psychotropic medication) utilized with non-adherent clients were more effective when combined with social support. He also found that atypical psychotropics (i.e., second-generation anti-psychotics) with improved efficacy and tolerability, increased adherence and reduced hospitalizations compared to the depot and oral medications (Love, 2002). Love’s (2002) findings should be heeded as a significant number of hospitals and community mental health centers are being sued for incompetence, neglect, and even abuse in relation to clients’ adherence to psychotropic medication (Gerhart & Brooks, 1983).

Dual-modality Interventions

Programs that utilize a combination of psychosocial rehabilitation and pharmacotherapy have significant results in regards to increased psychotropic adherence.
Ho et al. (1999) utilized psychoeducational groups to increase clients’ insights into their illness and psychotropics, employing the ACT program that "enhanced the engagement process by maximizing patients’ access to social and rehabilitative resources" (p. 1768). The results of Ho et al. (1999) included increased engagement rates, fewer hospitalizations after entering the ACT program, and abstinence from illicit drugs (measured by urine toxicology).

Utilization of dual-modality treatment markedly increased rates of psychotropic adherence for clients with chronic mental illness. Azrin and Teichner (1998) utilized family support and psychoeducation to increase adherence rates. They utilized a control group and an experimental group, where the control group received information based solely on the medication, and the experimental group received an in-depth educational program that included the client and the family receiving information about the drug regime. The program increased adherence to 94 percent in the experimental group, whereas the control group’s rate of adherence was 73 percent (Azrin & Teichner, 1998).
Skinner (2005) worked with the mentally ill homeless population by employing psychoeducation and a program that he termed Modified Therapeutic Community (MTC). MTC is similar to ACT, where clients’ individual treatment plans revolve around psychosocial rehabilitation, support, and pharmacotherapy. Skinner (2005) utilized a quasi-experimental design and compared the MTC group to a group of homeless individuals at a general shelter. The general shelter did not incorporate all the needs of the client, only housing. The MTC experimental group had a significantly lower percentage of individuals hospitalized and/or transferred to a high level of care facility when compared to the population in the general shelter. Skinner’s (2005) MTC group also had higher rates of medication adherence compared to the control group (81.4% versus 64.7%, respectively).

Theories Guiding Conceptualization

There are several theories discussed in the literature regarding medication adherence. Social learning theory is based on behavioral theories that focus on observable behaviors, rather than internal motivations, needs, and perceptions of individuals.
(Zastrow & Kirst-Ashman, 2004). Social learning theory focuses on behaviors and how these are learned. It assumes that behaviors can be changed with positive reinforcement (Zastrow & Kirst-Ashman, 2004). Social learning theory includes a "positive orientation to treatment that attempts to build patients' self-awareness, awareness of others, and coping skills" (Bedell, Hunter & Corrigan, 1997). Studies that utilize any form of psychosocial education to increase clients' insight are employing social learning theory (Hayward & Chan, 1995; Kavanagh et al., 2003; Smith et al., 1992).

Another theory that has guided research in this area of study is compliance theory. Compliance theory is a health-belief model asserting that:

- individuals will take action, seek care and comply with health regimes if they regard themselves as being susceptible to the condition in question, if the condition has serious consequences, if the action would be beneficial and if they feel that the barriers to action are outweighed by the benefits (Lindstrom & Bingefors, 2000).
This model utilizes sociodemographic factors, particularly education, when describing behaviors (Lindstrom & Bingefors (2000). Behaviors are influenced by the perceived severity of illness and benefits of medication, as well as barriers. Rietveld and Koomen (2002) describe the health belief model in terms of seven determinants of compliance behaviors: "when pain would remit, the cause of pain, the mysterious nature of pain, how pain alters life style, personal control of pain, regarding blame for pain, and whether pain is experienced constantly of intermittently" (p. 625). Psychosocial rehabilitation addresses self-determination through social skills group training, which can lead to increased adherence, the ultimate goal of many research projects.

The theory guiding this research project is client-centered theory. Carl Rogers developed this theory from his self-theory describing a person as the result of his/her experiences and how he/she perceives those experiences (Zastrow & Kirst-Ashman, 2004). This theory focuses on the "way of being" with the client, as opposed to the "way of doing" things for the client (Corey, 2000). Corey describes the sense of trust that enables
the client to move forward and grow (2000). Faith in the person is one of the basic premises of this theory, the faith that each person can be trusted (Corey, 2000). This research project aims to understand client nonadherence to medication while increasing trust between clinicians and clients. The conceptual framework of the client-centered theory is that clients will become more honest with clinicians once they feel that they are understood and respected by those same clinicians (Thorne, as cited in Corey, 2000).

Summary

This chapter discussed severe and persistent mental illness, as well as outlines the costs (direct and indirect) involved in serving individuals with SPMI. Barriers to medication adherence are discussed in detail as well as the different treatment modalities utilized with this population. Psychosocial therapy based interventions are discussed in terms of improving medication adherence and insight into illness. Interventions based solely on pharmacotherapy and dual-modality interventions, those that combine psychosocial therapy and medication to assist SPMI
clients is discussed. Finally, the theories guiding this research project concludes this chapter.
CHAPTER THREE

METHODS

Introduction
This exploratory study was conducted using both a qualitative and quantitative measurement method to explore, from the clients' perspective, barriers to psychotropic medication adherence. This chapter will discuss the study design, sample from which data was collected, method and instrument used for data collection, data analysis, and procedures taken to protect confidentiality and anonymity for human subjects in this study.

Study Design
The purpose of this study was to explore the barriers that cause psychotropic nonadherence in individuals with severe and persistent mental illness (SPMI). Clients were encouraged to share information in relation to their experiences with psychotropic medication regimes during a semi-structured, one-on-one interview. The interviewer administered the study questionnaire that included both a quantitative and a qualitative component. The demographic component
contained information such as; age, gender, number of hospitalizations, diagnosis, etc., while the qualitative portion explored barriers to psychotropic adherence from the client’s perspective, through open-ended questions.

Methodology implications for this study are based on the guiding principles of the psychosocial rehabilitation and recovery model. These principles promote self-determination by supporting persons with SPMI, encouraging them to make their own choices, and involving clients in their own treatment planning. By providing individuals with the opportunity to express their own needs and desires, mental health workers minimize professional distance and create empowering adult-to adult relationships (Ragins, 1994).

Clients may have benefited from participation in this study by learning the importance of self-advocacy, enhancing self-esteem, and understanding the importance of mutual working relationships with mental health professionals. This project was an exploratory study of barriers to psychotropic adherence from the client’s perspective. By inviting individuals to voice their mental health concerns, this study supported the consumer
movement motto: "Nothing about us without us" (National Mental Health Association, 2005).

Limitations

There are several limitations of this study. Social desirability, answering questions in the direction of the interviewers perceived needs or wants, is unavoidable in this study due to the design. Nancarrow and Brace (2000) examined the causes of social desirability bias (SDR), ways of detecting bias, and techniques used to reduce the problem. They concluded that there is no way to reduce or eliminate social desirability because establishing that it actually took place is difficult.

A second limitation is use of a non-standardized instrument. A standardized instrument addressing medication nonadherence from the participant's perspective could not be located. Researchers designed a questionnaire (Appendix A), specific to this research, for the interview process. To ensure content validity, researchers conducted a two-phase pretest.

Phase one, employed mental health professionals (i.e., case managers), serving individuals with SPMI, to review the interview questionnaire and provide critical feedback. This segment of the pretest identified poorly
worded interview questions, questions revealing the researcher's bias, and culturally sensitive wording. Phase-two tested the interviewer's ability to deliver the study instrument effectively. Case managers were given a questionnaire to score the wording of questions, the interviewer's ability to communicate clearly, and the interviewer's approach to the interview process (Berg, 2004, p. 90). Additionally, the pretest provided researchers with the opportunity to test the interview environment and determine the duration of the interview and debriefing process.

The final limitation in this study is a result of purposeful sampling. Because this study addresses a specific problem, within a distinct population, purposive sampling requires that participants have certain characteristics in common in order to be selected for an interview. The selection criteria for this study included persons' with a SPMI, receiving mental health treatment from the AB2034 program, male and female, and a minimum of 18 years of age. Furthermore, external validity is limited because the participants are from one agency; making it difficult to generalize study findings. Notwithstanding these limitations, this exploratory study
provided valuable insight to psychotropic nonadherence from the most reliable source, individuals diagnosed with a SPMI.

Sampling

A simple random sampling of participants consisting of, males and females at least 18 years of age, diagnosed with a SPMI or co-occurring disorder (COD), i.e., mental disorder and substance use was employed (DHHS Publication No. [SMA] 05-3992, 2005). These individuals are currently receiving intensive recovery services through the AB2034 program at the Mental Health Association of Orange County, California. Of the 99 clients currently enrolled in the AB2034 program, this study included 16 individuals as participants.

To select a sample of 16 individuals, each client was first assigned a number between 1 and 99. Using a table of random numbers (Appendix B), researcher will picked any point on the table, reading across the rows, or down the columns, writing a list of the first 16 numbers found. These 16 numbers identified the 16 participants that made-up the sample for this study. Each person selected for the study was provided with a
recruitment flyer, hand delivered by his or her case manager, which provided information such as the time, date, and possible benefits for participating in the study (Appendix C). Next, identified participants were then phoned by the researchers and asked if interested in participating in this study.

Permission to conduct this study was granted after review of the project proposal by Keith Parker LMFT, AB2034 Program Director for the Mental Health Association of Orange County, California.

Data Collection and Instruments

The survey instrument was a 10-item, one-to-one, semi-structured interview. Open-ended questions were designed to generate possible reasons for psychotropic nonadherence. Examples of interview questions included, "Can you tell me why you take medications?"; "Do you believe it is your decision alone to take medications? Who do you believe makes this decision?" and "How have medications helped you". Examples of demographic questions included, "What is your currently living situation?"; "What is your diagnosis?" and "Including all mental health agencies, how long have you been receiving
mental services?” Both components of this study, demographics and qualitative interview, use a nominal level of measurement.

Due to the lack of qualitative studies on psychotropic adherence, this questionnaire was uniquely designed to explore possible barriers to adherence, from the participant’s perceptive. To ensure content validity, this study instrument was designed based upon previous studies cited in the literature review.

Procedures

Data collection took place on Fridays between the hours of 8:00 a.m. and 3:00 p.m., over a period of two-weeks. Interviews were held at one of the Mental Health Associations of Orange County’s clinics. To ensure confidentiality, interviews were conducted in a private office. Interview sessions range from 15 - 40 minutes.

A Mini Mental Status Exam (MMSE) (Appendix D) was administered to individuals interested in participating in this study. The AB2034 Program Director, a Licensed Marriage and Family Therapist (LMFT), agreed to perform the MMSE on each person wishing to participate. This measure was taken to ensure the individuals’ cognitive
appropriateness to participate in the study at this particular time.

The LMFT administering the MMSE followed Folstein & Folstein’s, suggested guidelines for scoring as noted at the bottom for the MMSE form. Participants scoring more than 21 points out of the maximum 30 point were invited to participate in the study. Participants scoring less than 21 points were not eligible to participate in the study due to mild-moderate cognitive impairments. Fortunately, no participants were turned away due to scores under 21 points. Participants received an envelope containing $15 cash in return for their time and effort. Upon receipt of the $15 cash gift for participating, participants were asked to sign a receipt form by placing an “X” in the box. This method of signature for receipt of funds was instituted to maintain the participant’s privacy and to keep their information confidential.

All data and client information, MMSE, interview questionnaires, and interviewers’ notes was contained in a locked file cabinet within the locked office of the program director.
Protection of Human Subjects

Several measures were taken to protect the confidentiality of the participants in this study. All participants in this study were voluntary. The questionnaires used during the interview utilized an identification number rather than the participant's names. Informed consent (Appendix E) was obtained by using forms and procedures approved by the institutional review board. Documentation of informed consent was read aloud and explained to each participant. Participants agreeing to the study were asked to place an “X” in the box on the consent form labeled “YES”. This method of identification and signature of consent was instituted to maintain the participant’s privacy and to keep their information confidential. To maintain confidentiality, any documents containing participant information were only accessible to the researchers and their research advisor.

Participants were informed at the beginning of the interview that they did not have to answer any questions they believe to be too personal. Furthermore they were informed that they had the right to refuse answering any/or all questions without explanation or penalty. The
interviewer informed participants that the study was voluntary and that they could discontinue the interview and leave at anytime. Participants were informed of the confidential nature of their responses. At the end of the interview, researchers provided participants with a debriefing statement (Appendix F), which was read aloud and explained. Participants were informed of how they obtain study results and were provided with names and numbers of mental health agencies on the debriefing statement, in case participants became distressed.

Data Analysis

Qualitative data analysis was used for participant’s responses to open-ended questions during a one-to-one semi-structured interview. Researchers identified cultural domains for participants’ responses to all open-ended questions based on underlying association of content. The responses derived from this study could be used to create new treatment interventions and recovery planning.

Summary

This exploratory study used both a qualitative and quantitative measurement method to explore, from the
client's perspective, barriers to psychotropic adherence. This chapter discussed the study design, sample from which data will be collected, method and instrument used for data collection, data analysis, and procedures taken to protect confidentiality and anonymity for human subjects in this study.
CHAPTER FOUR
RESULTS

Introduction

This chapter describes the demographics for the study group using a quantitative method of data collection and the major themes that emerged using a qualitative method, open-ended questions, concerning reasons for psychotropic medication nonadherence. Verbatim responses from participants as recorded in one-on-one interviews are provided allowing consumers of mental health services a chance to be heard.

Presentation of Findings

Demographics for eligible participants consisted of 16 adults receiving mental health services from the Mental Health Association of Orange County, AB2034 Program. In terms of gender, 62.5% of the participants were female and 37.5% of the participants were male (Table 1). The mean age was 42.3 years old (Table 2). The sample was composed of 50% Caucasian, 18.8% Black or African American, 18.8% other of which one participant sincerely replied, "I am capital, NEGRO, Negro," and 12.5% of participants refused to answer the
question (Table 3). Of the 16 participants involved in the study, 50% were single/never married, 6.3% were separated, 37.5% reported being divorced, and 6.3% were widowed (Table 4). A majority of the participants 93.8% reported being unemployed (Table 5), while 31.3% reported having a high school diploma or the equivalent, and 37.5% reported having some college or a two-year college degree (Table 6).

Within the past 12 months of administering the questionnaire, 12.5% of the participants stated that they had been hospitalized for psychiatric care, and 12.5% were incarcerated. Another 12.5% were both incarcerated and admitted to a psychiatric hospital, 6.3% were both incarcerated and received detoxification treatment for substance abuse, 6.3% received detoxification treatment for substance abuse only, and 50% reported no hospitalization, incarcerations, or substance use treatment (Table 7).

Participants were asked, "Including all mental health agencies, how long have you been receiving mental health services?" Findings declared that 6.3% had been receiving services for less than 2 years, 25% stated 2 - 5 years, 12.5% fell between 5 - 7 years, 12.5% claimed 7
- 10 years, and 43.8% said they had received services for more than 10 years (Table 8).

Finding permanent housing for persons with a severe and persistent mental illness can be challenging. However, this study revealed that 56.3% of the participants live independently, meaning, they rent an apartment in the community. Furthermore, 12.5% reside in sober living facilities, 6.3% live with family members, 6.3% stated other living arrangements (possibly a hotel room), and unfortunately 18.8% remain homeless (Table 9).

All participants in this study are diagnosed with a severe and persistent mental illness (SPMI) and diagnostic types were not reported. Self-reported diagnosis included 31.3% Schizophrenia, 31.3% Bipolar Disorder, 12.5% Schizoaffective Disorder, 6.3% Major Depressive Disorder, and 18.6% reported multiple diagnosis with conflicting diagnostic criteria (Table 10).

Using the most recent clinical documentation reported by the clients' attending psychiatrist and participants' self-reports, 31.3% of the client/psychiatrist diagnoses matched, 31.3% did not match, and 37.4% matched part of the reported diagnosis,
but not the complete diagnosis. These findings lead to a comparative analysis of clients' self-reported medication regimen versus the psychiatrists' documentation of prescribed psychotropic regimens.

The comparison of clients' self-reported psychotropic regimens versus psychiatric records revealed that 31.3% of the clients had accurately stated their prescribed medication, of which 31.3% reported completely different psychotropic medications than documented by their psychiatrist; 31.3% reported some of the same medications as were documented, but not all; and 6.1% reported taking psychotropic medications while their records indicated that they were no longer receiving pharmacotherapy treatment.

Participants were asked the same questions, in the same order. Each set of questions were designed to illicit reasons for adherence/nonadherence to psychotropic medication regimes from the participants' perspective. Several content categories emerged from the participants' verbatim responses, some of which will be provided to illustrate the nature of their concerns.

The first set of questions explored current use of psychotropic medications and their perceived benefits, if
any. "Are you currently taking medications for a mental illness?" Which was followed by one prompt, "Pills or shot?" All participants said they were currently taking medications, of which 93.7% stated they were taking their medication in pill form and 6.3% said by shot. Given the severity of the participant's mental illnesses, and the high rate of psychotropic nonadherence within this population, researchers suspect some level of social desirability effect.

The next was, "Can you tell me why you take medication?" Nearly 70% (68.8%) of the participants stated that they took psychotropic medications to address symptoms caused by a mental illness, while 31.2% simply stated that they took the prescribed medication because they were diagnosed with a mental illness. One of the participants responded to this question by saying, "Because I have racing thoughts, unable to sleep, massive mood swings, violent, quite the shopper when not on medications." Another participant responded by saying, "Because I have been diagnosed with schizophrenia in 1990."

This question was followed by one prompt: "How have medications helped you?" Once again the majority, 68.4%,
stated that medications helped to reduce symptoms, 21% reported increase ability to function in daily activities, 1% found the medications non-effective, and 1% did not have an understandable response. A participant that believed medications helped reduce symptoms said, "Helps me to sleep, helps me when I hear voices, when I do not take them I get depressed, it stabilizes my mood." A participant that reported an increase in functioning stated, "Helps a great deal, helps me function, even though I do not have a job or anything constructive, I can get the basic needs: food, not afraid to deal with social environment." The participant that found psychotropic medications ineffective responded by saying, "I do not really feel a difference, but I do not feel mentally ill either."

When asked, "Tell me reasons why you do not like taking your medication?" 72.7% of the participants stated they did not like taking psychotropic medications due negative side effects, 9.1% identified feelings of depersonalization, 9.1% found psychotropics inconvenient, and 9.1% said the medications were ineffective. One of the clients concerned with negative side effects stated that the medication, "Make me feel sick and very sleepy
or worse than I am feeling." The participant expressing feelings of depersonalization replied, "Makes me feel
different at times, different than other people, I feel
ok and if I continue the medications it might induce
something to make it worse." Another participant stated
that taking medications were inconvenient, "Cuz it’s a
hassle to take them, remembering to take them."
Ineffectiveness was expressed as, "One reason, it doesn’t
help much. I am kind of scared of them too, they may hurt
my body."

The following prompt was asked after the previous
question to evaluate participants’ willingness and/or
opportunity to seek help to manage medication regimens:
"Have you talked to anyone about this?" Most of the
participants (66.7%) said that they had talked to
someone, 25% stated they had not talked to anyone, and
8.3% stated that they attempted to talk with someone. One
of the participants said, "Yes, I talk to other clients
and doctor." Another client attempted addressing
medication concerns stated, "Try to talk to doctor about
it, yet we do not have anytime. But I would like to."

The next set of questions deal with the
participants’ environment, relationships, illicit drug
use, and mental health services they may have received or would like to receive.

The first question was, “Can you remember a time when you decided not to take your medications?” The response was almost split evenly: 56% replied, “yes”, while 43.7% relied “no.” The follow-up probing question was then asked of all participants: “Can you tell me what was going on in your life at this time?” Active psychiatric symptoms were reported by 75% of the participants. One participant stated, “I was religiously preoccupied, had the desire to be functionable without medication. Spiritually I felt I had to be off medications, I don’t feel that way now, voices were being crafty, evil voices telling me to take the medications, anyone would be scared.” Furthermore, 12.5% reported physical ailments, and 12.5% reported being in denial of having a mental illness.

The following question asked participants to discuss their opinion of their psychiatrist: “How do you feel about your psychiatrist?” The vast majority, 72.2%, had a positive response such as, “I like him, able to communicate. He has respect for me.” While 27.8% had a negative response such as, “He does not say too much. He
prescribes meds, get therapy elsewhere. Pretty much in-and-out."

Seeking concreteness, the following probing question was asked of all participants: "How do you expect your psychiatrist to treat you?" An appraisal of the participants' responses resulted in 40% stating that they wanted to be treated professionally, as interpreted by one participant's reply, "With a firm hand, he is very good." Another 25% said that they expected to be treated respectfully by their psychiatrist: "With respect, just as I respect him." Furthermore, 25% wanted their psychiatrist to engage in active listening: "Be a bit more flexible about lowering the dosage or not taking certain medications. He wants me to take more to get rid of the voices. I do not want to take Zyprexa because of the side effects." Finally, 10% of the respondents said that they wanted to be treated compassionately, simply stated as, "Kindly."

The following questions were asked to explore the possibility of participants engaging in self-medication practices using illegal drugs. When asked, "Was there ever a time in your life when you used substances such as; alcohol, cocaine, marijuana, methamphetamines,
heroin, etc., instead of your medications?” About (43.7%) said, “Yes” and 56.3% said, “No.” Once again, researchers believe there to be some element of social desirability in the participants’ responses because most of the clients enrolled in the program surveyed have co-occurring disorders.

Of the participants who stated they had used illegal drugs, a probing question was asked: “Can you tell me why you decided to do illegal drugs instead of taking your medication?” 38.6% said they took psychotropic drugs to reduce psychiatric symptoms: one participant said they used illegal drugs due to, “Depression.” Furthermore, 23.1% replied similarly stating they wanted to feel different: “I wanted to a different feeling over my body and mental status.” Another 23.1% stated other reasons for using such as concurrent use: “I used cocaine and meth and marijuana but not instead of [my prescribed medication].” In addition, 7.6% faulted their current living situation for taking illegal drugs instead of their prescribed medications: “Partly environment, homeless....” Lastly, 7.6% stated boredom as a reason for using illegal substances, “... bored, being poor you have.
nothing to do, so you take drugs offered to you for free."

The next question attempted to identify the mental health services that participants believed to improve their quality of life: "Thinking about the mental health services you have received, what services do you believe have most improved your quality of life?" The participants' responses were diverse for example, 22.7% said that their relationship with their mental health worker improved their quality of life: "... I have a really good counselor." Another 18.2% stated that psychotropic medications played an important part of their recovery. One participant provided a powerful illustration of their perceived benefits of psychotropic medications: "Medications, without it I would be starving myself out on the street, cold, voices tell me to leave even if I had a home, don't wear warm clothes, don't eat, don't move, keep walking forever." Several other services were mentioned: group therapy (18.2%), individual therapy (13.6%), educational services (9.1%), food (9.1%), and housing (9.1%). The following statements further exemplify services the participants found useful: "The food, housing, computer room for school and stuff,
"therapy women's group." "Having my own place at an affordable rate, Section 8 housing way below monthly rate of rent. Inspections to help get our place more organized." And, "Therapy, talking and the medications, having a place to come to, to focus on staying healthy mentally."

The final question, followed by two probing questions, revealed from the participants' perspective who they believed controls their decision to take psychotropic medications or not. Beginning with: "Do you believe it is your decision alone to take medications?" Of the 16 participants, 62.5% answered, "No," while 37.5% answered, "Yes."

Of those participants who believed it was not their decision alone whether or not to take medications, the following probing questions were asked: "who do you believe makes this decision?" followed by, "Can you tell me more about that?" Sixty-percent of the respondents believed it to be the doctors' decision alone whether or not they needed to take psychotropic medications, while 20% stated it was their choice together with their doctor, and 20% said it was a combination of themselves, their doctor, and society.
Whether or not participants believed it was their decision to take medications, the doctors, or society, they were given the opportunity to explain their responses when asked, “Can you tell me more about that?” Participants’ verbatim responses were as follows:

- “I feel he knows the best about the medications and what it can do for my mental illness.”
- “It needs to be a joint decision, they have the knowledge, I have the job of giving approval so I can get better.”
- “I don’t know how to elaborate.”
- “My mind is not ready to make decisions on my own about medications.”
- “Too little time in the office, I would like a half-hour to lye on couch.”
- “I take it. I stay on my path of education and a good job. If I don’t take it, I relapse. I do not want to go through that again. I am thankful for the chance.”
- “Because in order to receive SSI you must be following a plan, not taking meds can take you
off SSI. The doctor can put you in the hospital to get you regulated when you do not comply.”

- “Because I tell him the medicine is too strong, he tells me to take it anyway. I will reduce the dose, pill down to 4 to 6 parts.”

- “I need medication. I went for a physical they told me to see a psychologist. Then they sent me to a psychiatrist for medication. That is why I think that.”

- “Society can interfere by telling doctors, people, the law, we are being out of control and give me a diagnosis.”

- “He knows what I need for my mental problems, what type of medication.”

- “I have struggled with mental illness 4 years and voices off and on medications. Off meds I talk to myself, yelling, relationship with society strained, people think I’m crazy. I regret what I have said during times I am off medication and behavior. Experiencing time without meds make me understand that I need it and helps me set the right dosages. I used to
sleep all day, eat all day, get fat, state of incapacitation. It was torture, so I went off.”

Summary

This chapter reviewed the results of this research project derived from participant’s verbatim responses conducted through one-to-one interviews. Data was obtained from individuals diagnosed with a severe and persistent mental illness and substance use disorder in an attempt explain barriers to psychotropic adherence from the client’s perspective. Three themes were found that might cause barriers to psychotropic adherence; negative side effects, relationship with mental health professionals, and insight.
CHAPTER FIVE

DISCUSSION

Introduction

This chapter will discuss the results of this study and how they are essential to the understanding of clients and their adherence or nonadherence to a medication regime. It will also discuss the limitations of the study. This chapter will also provide recommendations for social work practice. This chapter will close with a final conclusion of the section.

Discussion

Due to the nature of this exploratory study and the use of a non-standardized instrument, the researchers utilized frequencies to identify significant results. The percentages were calculated for each question. The calculations were utilized to identify any relevant themes noted in the participant responses.

All participants revealed that they were in fact taking psychotropics for a mental illness. Over 90 percent of the participants were taking pills, leaving less than 10 percent currently taking a shot to deal with a mental illness. Even this first question leaves the
researchers in a quandary. Social desirability was believed to affect at least one participant in how they answered because they recently had their psychotropics revoked to determine if the identified symptoms were in fact from a mental illness or due to illicit drug use. The reasoning behind most of the participants having pills prescribed is cost. It has been noted to the researchers that for a client to have monthly injections, the cost would soar to over $2000.00. The pills are cheaper and do not require a doctor visit to administer the medications.

In this study, several themes were found to affect adherence to a psychotropic regime. Insight, side effects, and relationship between client and clinician are a few of the themes identified during the one-on-one interviews with clients suffering from SPMI.

**Insight**

In response to the question of “Why do you take medication?” 68.8 percent of the participants described reduction of symptoms from the mental illness (i.e., voices lessened, less racing thoughts, etc.). The researchers accepted these types of responses as an indication of client insight into their mental illness.
and symptomotology. The remaining 31.2 percent of participants taking psychotropics do so due to a diagnosis of a mental illness. The participants appeared to understand why they take psychotropics, yet they did not altogether understand their diagnosis or psychotropic regime.

Less than one-third (31.3%) of the clients surveyed were aware of their diagnosis. This means that 68.7 percent of the clients surveyed were unaware of their current diagnosis. This statistic suggests lack of client insight which can affect their adherence/nonadherence to a medication regime. If the clients do not know their diagnosis, how can they possibly understand what they need to do to help themselves recover? Seedat et al. (2002) noted that lack of education is associated with medication nonadherence. In fact, these authors stated that clients are poorly informed of their diagnosis and treatment.

Another question that identifies lack of insight is the medication regime identified by the participant. The researchers, after conducting the interviews, reviewed the clients' files to ascertain whether they had answered these two questions correctly. Again, less than one-third
(31.3%) of the clients reported the correct medication regime that they were currently prescribed. This leaves 68.7 percent of participants unaware of their current medication regime. The participants do not understand what they had been prescribed or their current diagnosis. This can be seen as the lack of insight into mental illness and/or denial of diagnosis. Yet it can be also seem as a problem with the doctors and how they discuss the mental health diagnoses and how medication can help. Clients need to be informed about their illness and medication regime to increase psychotropic adherence.

As the interviews continued, it was noted that clients claimed to continue taking medications despite effective elimination of symptoms. Many clients reported decreased symptoms, but increased side effects (i.e., sleepy, not hungry, too hungry, etc.). Most (72.7%) of the participants reported talking to friends and family about their side effects, 25 percent reported not talking to anyone, and only 8.3 percent of participants who attempted to talk to their doctor. If participants are getting information about side effects, mental illness, and medication from friends and family, they are overlooking the one individual that has the knowledge and
ability to help them: the clinician. If clients are seeking information from the clinician, insight into their mental illness, symptoms, side effects, and alternative treatments can be discussed in detail.

**Side Effects**

When the participants were asked why they did not like taking their medications, almost three quarters (72.7%) noted side effects. Another 9.1 percent noted feelings of depersonalization as the reason for not taking the medications. Other responses included inconvenience and ineffectiveness.

The next question was posed to have the participants speculate on why they might not want to take medications. When the same participants were asked why they might not want to take the medications, many answered side effects (50%). Another 20 percent noted increased symptoms as the sole reason. The last 10 percent of participants demonstrated increased insight into psychotropic regimes when noting a fear of addiction. Due to the design of this study, the exact side effects were not identified. Many clients may have felt embarrassment and chose not to describe the sexual side effects as a reason for nonadherence. Many clients noted the sleep side effects
(whether too much or too little) and the weight gain. Green et al. (2000) stated that psychotropics used to treat schizophrenia have been linked to weight gain. Clients appear well aware of these side effects. In the future, the researchers would design the next questionnaire to more fully identify the exact side effects experienced by each participant.

**Relationship between Client and Clinician**

A close working relationship between client and clinician is helpful in addressing adherence/nonadherence to treatment plans utilizing psychotropics. The participants were asked if they had talked to anyone regarding the reasons why they do not like taking medications. This question not only suggested clients’ insight into their mental illness, but also the quality of their relationship with their clinician. As stated before, over one-half (66.7%) of the participants stated that they talk to their family and friends, another 25 percent revealed they do not talk to anyone, and only 8.3 percent of the participants reported attempting to talk to their doctor. Participants felt that their clinician did not listen to their concerns, telling them to continue on the same path. The responses to this question
are telling in that participants would prefer to talk to friends and family versus talking to the doctor. Rosenberg et al. (2003) found that 50 percent of clients "never or infrequently" voiced concerns of side effects to their doctors. This suggests the importance of an open, honest, and egalitarian relationship between client and clinician.

The participants were also asked how they felt about their psychiatrist. Almost three quarters (72.2%) had positive feelings regarding their psychiatrist. The rest of the participants (27.8%) had negative feelings regarding their psychiatrist. Participants stated that they felt their psychiatrist was doing his/her job, yet the psychiatrist would not listen to the participants' concerns. Some examples of responses to this question include, "He doesn't listen," "He prescribes medications, get therapy elsewhere," and "I don't know if he really listens."

Many participants felt that they were not given enough time to talk to the psychiatrist. This could be due to the overwhelming case load that the doctors are currently managing. The doctors do not have the time to go over each detail in a client's life. Yet, if the
client is to be involved in their own treatment plan, the doctors must divide time equally for clients so they have time to explain what they are feeling. Kerse et al. (2004) noted that "trust" was significantly related to adherence. Improving the relationship between client and clinician can have long-term affects on medication adherence (Kerse et al., 2004).

The researchers then asked the participants how they expected their psychiatrist to treat them. Almost one-half (40%) wanted to be treated "professionally" by their psychiatrist. Being treated "respectfully" and using active listening skills were each represented by 25 percent of the participants (i.e., 50% of total responses when added together). Another 10 percent wanted their psychiatrist to demonstrate compassion. Many participants feel they are not being treated as they should. If one of the precipitating factors in client adherence to a psychotropic regime is the quality of the relationship with their clinician, then we as a mental health field are failing to create an adequate, therapeutic and trusting working relationship with these clients.

Participants were also asked if it was their decision alone to take medications. About 63 percent
(62.5 %) stated “no,” and only 37.5 percent of respondents thought that it was their decision. The large percentage of participants stating that it is not their decision may suggest that many clients feel that they must take psychotropics to receive services for their mental illness, and they will take them even if the psychotropics appear to do nothing in terms of managing their symptoms.

Of the 62.5 percent who stated “no” to the above question, 60 percent believe that the doctor makes the decision to take medications, 20 percent believe that society makes that decision, and another 20 percent believe that they bear some of the decision making responsibility. This finding is troublesome as participants feel that it is not their choice to either take the medications or refuse them for a different treatment plan (i.e., alternative treatment plans that do not involve psychotropics). This finding may result in clients feeling disempowered, and perhaps even as if they are subjects of social control, and thus less apt to comply with their medication regimen.
Self-medicating Behaviors

The researchers attempted to discover whether the participants had, in the past, utilized illegal substances instead of taking their prescribed psychotropic medications. Over one-half (56.3%) stated that they had never utilized substances instead of their psychotropics. This is another question for which responses may be influenced social desirability. Of the 43.7 percent that stated that they had used illegal drugs instead of their psychotropics, over one third (38.6%) of the participants stated that the reason was to reduce symptoms. The other answers ranged from feel different (23.1%), environment (7.6%), and boredom (7.6%). Another 23.1 percent of the responses were categorized as “other” as the respondents stated concurrent usage of drugs and psychotropics. Johnson, Brems, and Burke (2002) noted that 45 percent of substance abuse clients also had a mental disorder indicating the difficulty of separating these two issues.

The researchers have working relationships with most of the participants in this study as interns at the AB2034 program. The researchers believe that the participants may have wanted to keep their drug use
private so that they would not lose services of the program. This seemed apparent in many answers to survey questions. The researchers needed to address confidentiality several times during interviews as clients struggled with telling their whole story. For example, when a participant was asked what type of medications s/he was currently taking, s/he asked “Who is going to see this research?” The researcher assured the participant that s/he would not be identified as there were no names included in the study results. In fact, the doctors would not know who had participated in the study.

Limitations

The first and foremost limitation of this study is its sample size. Due to the nature of this exploratory study, the researchers limited the participants to fewer than 20. The researchers conducted one-on-one interviews with each participant. Before the interview could begin, the participants were required to pass a mini-mental status exam performed by the program manager. If the study had been given unlimited time and resources, all 100 clients in the AB2034 would have been interviewed.
Due to the limited size of the sample, generalizing the findings to the rest of this population is difficult.

The second limitation concerns the nature of this exploratory study. There are limitations in terms of the participants self-reporting. In many cases participants will not report honest answers to the researchers for several different reasons. One, despite numerous assurances of confidentiality, the respondents may have been concerned that some of their responses could be later traced back to them, and their continued participation in the AB program would have been jeopardized.

This aspect may have led at least some participants to answering some questions in a social desirable fashion. Participants may also have been concerned with telling everything to the researchers due to the researchers and respondents having a current working relationship. And, some participants may have been concerned with the embarrassment, shame, and stigma attached to reporting certain behaviors, such as illicit drug use.

Another limitation to this study was the design of the questionnaire. This study is unique as the
researchers wanted to tap into the participants’ reasons for psychotropic adherence/nonadherence. The lack of a standardized questionnaire led the researchers to create the questionnaire based on their ideas gathered from existing research. Once the interviews began, the researchers identified several questions that they would either change or eliminate altogether. Some questions were designed to elicit a particular response, yet the question was unfortunately designed to be answered with a yes/no response. This limited the data collected on several respondents. An example of this is the question, “Can you tell me what was going on in your life at that time?” Many respondents answered that question with a “no”.

The final limitation to this study was noted by the researchers, in that all the participants were recruited from the same agency. This fact makes generalizing the findings to other similar agencies difficult, as well as to the entire population of clients with SPMI.

Recommendations for Social Work Practice, Policy and Research

The available research that is written on adherence/nonadherence to psychotropic regimes is based
solely on quantitative data collection and analysis. This qualitative project solicited responses from the participants' viewpoints, asking them exactly what they felt instead of having them select their responses from a list of answer options. This gave the participants the opportunity to voice their concerns in their own words. This study is unique in that the participants were permitted to state anything that they saw necessary to further explain their answers. The answers were written verbatim during each interview. The use of a tape recorder may have helped reduce the time of each interview as the researcher had to ask the participants to give them additional time to record their responses. This may have altered the results, as the participants may have lost their train of thought, however to what degree we cannot be certain.

Clear explanations could have been useful to the participants in terms of the guidelines for accepting services from the AB2034 program. Many participants may have altered their answers to cover up any undesirable behaviors that could eliminate them from the program in their perception (i.e., illegal drug use, nonadherence to treatment plan, and negative thoughts about the program).
The study would have been best performed if no one working in the agency knew which respondents participated, attempted to participate, or were asked questions about the study. The study could have been performed in the privacy of the participants' home, utilizing personnel to perform the mini-mental status exam that had no knowledge of the participant or history. This may have helped the participants to answer questions in a safer environment, as no one knew them or could affect the services they receive from the program.

Another conclusion drawn from this study is that clients must be better informed about their diagnosis and medication regimes. This idea supports the psychosocial model of rehabilitation. If a client understands what they have been diagnosed with and how the psychotropics affect their body, the client will have more insight into their illness. Client insight provides for more effective self-determination. If the doctor and case managers spent more time educating the client about his/her illness, this would conceivably produce a more informed consumer and foster a more positive working relationship between client and clinician, which is integral to a client's
adherence to a treatment plan, which many times rely on psychotropics.

The client would also have the requisite knowledge to decide which medication they would like to try based on more than just rumors from other clients in the program. Perhaps then, clients may attain the type of egalitarian relationship with their doctor that will promote more equal decision making power, respect, and client self-determination. This egalitarian relationship is the key to recovery (Kerse et al., 2004).

Our recommendations based on our findings are to include more psychoeducational training in the following areas: building more egalitarian clinician-client working relationships, disseminating information and ensuring clients' understanding of their diagnosis, mental illness, symptoms, symptom management, with clinicians striving to reduce the stigma associated with mental illness, and better educate clients about their medications, specifically how they work and why each they need them, and exploring alternative treatments to psychotropics with clients.
Conclusions

The purpose of this study was to examine barriers to psychotropic adherence/nonadherence from the client’s perspective. This study examined the similarities between data collected utilizing quantitative measures and the data collected using the qualitative measures of this study. Interesting, the participants described many of the same barriers to psychotropic adherence as the current scholarly research. Participants described side effects, insight, self medicating behaviors, and relationship between client and clinician as the barriers they face while attempting to be psychotropic adherent.

Each of these factors are important to future studies, particularly from the client’s perspective, as the latest model of recovery includes the clients as the experts into their own illness and recovery. The Mental Health Services Act (MHSA) is currently changing the face of mental health services to become more client and family centered. This study was a first attempt at starting the conversation about the need to create a more egalitarian working relationship between clients and clinicians to assist in the former’s recovery.
Additional studies should be conducted to replicate the findings of this project and be informed by these researchers' suggestions for an improved methodology.

When researchers asked the participants what has worked and did not work for them in recovery, new interventions can be created that can address the very barriers that each client with SPMI faces each day on the road to recovery.
APPENDIX A

QUESTIONNAIRE
Survey

Instructions: (read aloud)
This study was designed to give you, the participant, an opportunity to share your experiences with mental health services. I will read each question just as it is written, I can re-read the question if you do not understand it the first time. If you still do not understand the question, or you do not want to answer the question, for any reason, I will go onto the next question. Please take your time answering the questions. You may stop this interview at anytime. Are you ready for me to begin?

1. Are you currently taking psychiatric medications to address symptoms related to a mental illness?
   If yes,
   a. What type?
   b. Pills or a shot?

2. Can you tell me why you take medication?

   (a) Probing: How have medications helped you?

3. Tell me the reasons why you do not like taking your medication.

   (a) Probing: Have you talked to anyone about this?

4. Can you remember a time when you decided not to take your medications? If yes,

   (a) Probing: Can you tell me what was going on in your life at that time?

5. How would you feel about your psychiatrist?

   (a) Probing: How do you expect your psychiatrist to treat you?
6. Was there ever a time in your life when you used substance such as; alcohol, cocaine, marijuana, methamphetamines, heroin, etc., instead of your medication? If yes,

   (a) Probing: Can you tell me why you decided to do illegal drugs instead of taking your medication?

7. Can you tell me some reasons you might not want to take medications?

8. Thinking about the mental health services you have received: What services do you believe have most improved your quality of life?

9. What services do you believe would help people with mental illness have a better life?

10. Do you believe it is your decision alone, to take medication? Yes or No  
    (a) Who do you believe makes this decision?

    (b) Probing: Can you tell me more about that?
## DEMOGRAPHICS

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<td>IN THE PAST 12 MONTHS HAVE YOU BEEN/RECEIVED: (circle all that apply)</td>
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<tr>
<td>7= Other _______________</td>
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<td>CURRENT DIAGNOSIS: (circle all that apply)</td>
<td>INCLUDING ALL MENTAL HEALTH AGENCIES, HOW LONG HAVE YOU BEEN RECEIVING MENTAL HEALTH SERVICES: (circle one)</td>
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<tr>
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<tr>
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<td>7= other _______________</td>
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APPENDIX C

RECRUITMENT FLYER
YOU ARE INVITED TO PARTICIPATE IN A STUDY INTERVIEW

As a participant in this study, you would be asked to complete a Mini Mental Status Exam followed by a short interview.

Participation in this study is voluntary and confidential.

In appreciation of your time you will receive $15 cash.

Your participation would involve coming to The MHA drop-in center in Santa Ana On January 27th for approximately one hour.

For more information about this study, or to Volunteer for this study, please contact:

Nicole Nanchy or Michelle Green, Social Work Graduate Students or your PSC at (714) 668-8498.

This study has been approved by the Institutional Review Board for California State University San Bernardino
APPENDIX D

MINI MENTAL STATUS EXAM
Mini Mental Status Exam (MMSE)
ID# __________________________ Date: ____________________

<table>
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<tr>
<th>MAXIMUM SCORE</th>
<th>SCORE</th>
<th>(1 point per right answer)</th>
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<tbody>
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<td>Orienation 5</td>
<td>What is the? (year) (season) (date) (day) (month)</td>
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</tr>
<tr>
<td></td>
<td>Where are we? (state) (county) (city) (hospital) (floor)</td>
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</tr>
<tr>
<td>Registration 3</td>
<td>Name 3 common objects (e.g. apple, table, penny). Take 1 second to pronounce each word. The ask the patient to repeat all 3 words. Give one point for each correct answer.</td>
<td></td>
</tr>
<tr>
<td>Attention and Calculation 5</td>
<td>Ask the patient to spell &quot;WORLD&quot; backwards. The score is the number of letters in correct order (D_L_R_O_W_).</td>
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<tr>
<td>Recall 3</td>
<td>Ask the patient for the three objects repeated above. Give 1 point for each correct answer. (Note: Recall cannot be tested if all 3 objects were not remembered during registration.)</td>
<td></td>
</tr>
<tr>
<td>Language 2</td>
<td>Show the patient a &quot;pencil&quot; and a &quot;watch&quot; and ask him/her to name them.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ask patient to repeat the following: [ No ifs, ands or buts]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ask patient to follow a 3-stage command: [ take a paper in your right hand, fold it in half, and put it on the floor]</td>
<td></td>
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</tbody>
</table>
|               | Ask the patient to read and obey the following:  
|               | • Close your eyes.  
|               | • Write a sentence.  
|               | • Copy the following design. |

Maximum Total Score 30

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Mild: MMSE ≥ 21</th>
<th>Moderate: MMSE 10-20</th>
<th>Severe: MMSE ≤ 9</th>
</tr>
</thead>
</table>

Based on this assessment, is this individual cognitively capable to participate in this study? (circle one) YES / NO
Mini Mental Status Exam (MMSE)
ID# ___________________________ Date: ____________________________

This paper is to be used for MMSE participants to respond to written questions. Please attach this sheet to MMSE test instrument.
APPENDIX E

CONSENT FORM
Informed Consent for Participation in the Interview

Title of Research: An Exploratory Study of Barriers to Psychotropic Adherence from the Client’s Perspective.

Name of Researchers: Nicole Nanchy and Michelle Green, Social Work Graduate Students

You are invited to participate in a research study exploring barriers to treatment adherence. First, you will be asked to participate in a Mini Mental Status Exam. Next, you may be asked to participate in an interview lasting approximately one hour. Participation is this study is voluntary and confidential. You are free to withdraw from this study or decline answering any questions at anytime without being asked why you have made this decision.

There are no foreseen risks beyond those of everyday life. The benefit you may receive for your participation in this study is the opportunity to share your experiences with mental health services, specifically, your experience taking psychotropic medication. Your involvement in this study will help identify barriers to treatment, which may lead to better mental health practices. You will receive a Visa gift certificate for $15 in return for your time and effort.

This study has been approved by the Institutional Review Board for California State University, San Bernardino.

If you have any questions or concerns please contact research advisor, Herbert Shon, Ph.D., L.C.S.W. at (909) 537-5532.

Please check the box below to indicate that you have read this informed consent and choose to participate in this interview. By checking this box you are also verifying that you are 18-years of age or older.

Please place a checkmark here □  Today's Date: ____________
APPENDIX F

DEBRIEFING STATEMENT
Debriefing Statement

Title of Research: An Exploratory Study of Barriers to Psychotropic Adherence from the Client’s Perspective.

Name of Researchers: Nicole Nanchy and Michelle Green, Social Work Graduate Students

We would like to take this time to thank you for your participation in this study. You have participated in a research study that explored people’s opinions and beliefs about psychiatric medications. You were asked to participate in a Mini Mental Status Exam and a one-to-one interview. Participation in this study was anonymous and confidential.

We ask all participants to avoid discussing the nature of this study with other participants as it may influence their responses. A copy of the study results will be provided and available to you through the Mental Health Association of Orange County, AB2034 Program by September 15, 2006.

If you have any concerns about having participated in this research study, contact Herbert Shon, Ph.D., L.C.S.W. at (909) 537-5532.
APPENDIX G

DEFINITION OF TERMS
DEFINITION OF TERMS

empowerment In social work practice, the process of helping individuals, families, groups, and communities increase their personal, socioeconomic, and political strength, and develop influence toward improving their circumstances (Barker, 2003).

evidenced-based practice (EBP) The use of the best available scientific knowledge derived from randomized controlled outcome studies, and meta-analysis of existing outcome studies, as one basis for guiding professional interventions and effective therapies, combined with professional ethical standards, clinical judgment, and practice wisdom (Barker, 2003).

macro practice Social work practice aimed at bringing about improvements and changes in the general society. Such activities include some types of political action, community organizations, public education campaigning, and the administration of broad-based social services agencies or public welfare departments (Barker, 2003).

medical model An approach to helping people that is patterned after the orientation used by many physicians. This includes looking at the clients as an individual with an illness to be treated, giving relatively less attention to factors in the clients environment, diagnosing the condition with fairly specific labels, and treating the problems through regular clinical appointments (Barker, 2003).

mental status exam mini A systematic evaluation of a patients level of psychosocial, intellectual, and emotional functioning (Barker, 2003).

micro practice The term used by social workers to identify professional activities that are designed to help solve the problems faced primarily by individuals, families, and small groups. Usually micro practice focuses on direct interventions on a case-by-case basis or in a clinical setting (Barker, 2003).

pharmacotherapy The administration of medications to help maximize the physical or mental health potential of a patient. This includes educating the patient about the need for the drug and its proper use, monitoring, and taking efforts to modify the prescription as needed. Counseling support are also important (Barker, 2003).
DEFINITION OF TERMS

**psychoeducation** The process of teaching clients with a mental illness and their family members about the nature of the illness, including its etiology, progression, consequences, prognosis, treatment, and alternatives (Baker, 2003).

**psychopharmacology** The study and use of drugs to bring about changes in behavior and personality (Barker, 2003).

**psychosis** *Psychotic episode* A serious and frequently incapacitating mental disorder that may be of organic or psychological origin. These disorders are characterized by some or all of the following symptoms: impaired thinking and reasoning ability, perceptual distortions, inappropriate emotional responses, inappropriate affect, regressive behavior, reduced impulse control, impaired reality testing, ideas of reference, hallucinations, and delusions (Barker, 2003).

**psychotropic** Drugs used by psychiatrists to help their patients achieve psychological or emotional changes (Barker, 2003). Classifications:

1. Antipsychotics (such as; Thorazine, Haldol, Prolixin).
2. Antidepressents (such as; Prozac, Elavil, Norpramin).
3. Antimanics (Lithium carbonate—that is, Eskalith, Lithane, or Lithonate).
4. Antianxiety agents (such as; Valium, Ativan & various barbiturates). (Barker, 2003).

**rational emotive therapy** A psychotherapeutic method based on the cognitive theory of psychologist Albert Ellis, in which the client is encouraged to make distinctions between what is objective fact in the environment and the inaccurate, negative, and self-limiting interpretations made of one's own behavior and life (Barker, 2003).

**reality theory** Psychosocial and behavioral intervention, developed by William Glasser, that focuses on the clients' behavior rather than the past. Therapists encourage working out alternative solutions to problems. They do not accept client excuses, rarely ask "why," and place little emphasis on taking case histories (Barker, 2003).
APPENDIX H

TABLES
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Table 6

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### Table 7

#### History

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<tbody>
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<td>Valid</td>
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</tr>
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### Table 8

#### Tx Duration

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### Table 9

#### Housing

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REFERENCES


This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:
   Assigned Leader: Michelle Green
   Assisted By: Nicole Nanchy

2. Data Entry and Analysis:
   Team Effort: Michelle and Nicole

3. Writing Report and Presentation of Findings:
   a. Introduction and Literature
      Assigned Chapter 1: Nicole Nanchy
      Assigned Chapter 2: Michelle Green
   b. Methods
      Assigned Chapter 3: Nicole Nanchy
   c. Results
      Assigned Chapter 4: Nicole Nanchy
   d. Discussion
      Assigned Chapter 5: Michelle Green