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## Caregiver Views on Medication Treatment for Persons with Schizophrenia in a Cultural Context

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# Caregiver Views on Medication Treatment for Persons with Schizophrenia in a Cultural Context

## Abstract

ABSTRACT

CAREGIVER VIEWS ON MEDICATION TREATMENT FOR PERSONS WITH SCHIZOPHRENIA IN A CULTURAL CONTEXT

Tracy Griffith

Roberta Sands Ph.D

Schizophrenia is a disabling, often persistent psychiatric disorder that poses numerous challenges in its management and consequences. The burden of care for persons with schizophrenia has shifted from hospitals to families, resulting in a significant cost for the caregiver as well as for the person with schizophrenia (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). Although there is no agreement on whether a specific cluster of psychotic symptoms has the most impact on a caregiver's burden of care, there is agreement that the severity of symptoms affects the caregiver. The more severe the symptoms, the larger the burden felt by the caregiver (Muhlbauer, 2008).

The cause of schizophrenia remains elusive and there is no known cure. The best practice model for treating the symptoms of schizophrenia is treatment with anti-psychotic medications and psychosocial supports for the person with schizophrenia and his or her caregiver (McDonald, Short, Berry & Dyck, 2003). Strong social supports, including family and community supports and a good relationship with the care team, reportedly exert a positive influence on medication adherence (Bentley & Walsh, 2006). A study by Drapalski, Leith and Dixon (2009) also has noted that when a family member acts as a caregiver, this has a positive effect on patient outcomes.

This qualitative study explored the views of African American caregivers on medication treatment for schizophrenia. It was guided by the following research questions: What are the views of African American caregivers toward the taking of medication for schizophrenia? How do the caregivers describe their role in relation to medication adherence? What kinds of strategies do the caregivers use to promote medication adherence? How do the caregivers describe their caregiving role in relation to activities outside medication adherence? How do African American caregivers incorporate cultural values into their caregiving role? How do caregivers view support, or lack thereof, provided by community mental health services?

The research used a modified grounded theory methodology. Semi-structured interviews were conducted with ten African American caregivers and two key informants. The major study findings were: (1) Monitoring of medication was a significant activity for caregivers. (2) Strategies to promote medication adherence varied among caregivers. (3) Non-medication adherence caregiver activities were around maintaining their loved one in the community. (4) The importance of family and church was a strong cultural value for the caregivers. (5) Supports and coping methods for the caregivers centered around a strong faith system and close family, friends and the relationship with the psychiatrist.

Two theories of explanation were used to interpret the findings, symbolic interactionism and a family life course developmental framework. Recommendations for social work intervention with caregivers were made.

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**CAREGIVER VIEWS ON MEDICATION TREATMENT FOR  
PERSONS WITH SCHIZOPHRENIA IN A CULTURAL CONTEXT**

Tracy Griffith

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## ABSTRACT

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Schizophrenia is a disabling, often persistent psychiatric disorder that poses numerous challenges in its management and consequences. The burden of care for persons with schizophrenia has shifted from hospitals to families, resulting in a significant cost for the caregiver as well as for the person with schizophrenia (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). Although there is no agreement on whether a specific cluster of psychotic symptoms has the most impact on a caregiver's burden of care, there is agreement that the severity of symptoms affects the caregiver. The more severe the symptoms, the larger the burden felt by the caregiver (Muhlbauer, 2008).

The cause of schizophrenia remains elusive and there is no known cure. The best practice model for treating the symptoms of schizophrenia is treatment with anti-psychotic medications and psychosocial supports for the person with schizophrenia and his or her caregiver (McDonald, Short, Berry & Dyck, 2003). Strong social supports, including family and community supports and a good relationship with the care team, reportedly exert a positive influence on medication adherence (Bentley & Walsh, 2006). A study by Drapalski, Leith and Dixon (2009) also has

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# **CHAPTER I**

## **INTRODUCTION**

The qualitative study presented here is about the attitudes and role of African American caregivers of persons with schizophrenia and related spectrum disorders in relation to the medication prescribed for their loved one. This chapter will discuss schizophrenia, its diagnosis and treatment; medication adherence; and cultural differences, as a way of providing a frame of reference for the research.

### **Schizophrenia**

It is important to have a frame of reference for schizophrenia and the person suffering from the illness, as this impacts the caregiver role. The number of people who have schizophrenia in the United States is widely debated; advocates for the mentally ill use higher numbers and those who are responsible for delivering services often use lower numbers. An NIMH-funded Epidemiologic Catchments Area (ECA) study carried out from 1980-1985 employed lay interviewers using a questionnaire to ascertain symptoms of mental illness among a sample of population at five sites. The ECA study reported that 1.5% of the US population 18 and over had schizophrenia over a one-year period, a prevalence approximately twice as high as previous studies have shown (Torrey, 2001). The 1999 Surgeon General's special report on mental health claimed that 1.3% of all individuals 18-54 have schizophrenia and Social Security Administration estimates from the same year show 2.7 million people with schizophrenia. The National Institute of Mental Health reports that these numbers continue to be accurate (NIMH, 2009).

## **The Diagnosis of Schizophrenia**

In 1980, the mental health profession adopted a revised system of diagnosis and nomenclature in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders*, also known as the *DSM-III*. This is a system that is continued in the more recently revised *DSM-IV-TR* (American Psychiatric Association [APA], 2000). Under this system, a diagnosis of schizophrenia can be made only when specific criteria have been fulfilled. The *DSM-IV-TR* criteria for schizophrenia have achieved wide acceptance in the United States.

The list of possible symptoms noted in the *DSM-IV-TR* can give the impression that schizophrenia is easily diagnosable. In its fully developed form it can be; but in the earlier stages of the disease, it can be difficult to diagnose with certainty. The symptoms may be intermittent or may be mild, and the affected individual may be able to mask some manifestations of the disease. It is therefore not uncommon for mental health professionals to write, “rule out schizophrenia” on their initial encounter with a patient. This means that their diagnosis is tentative until the clinical picture is clearer or they have more information.

The *DSM-IV-TR* also requires that symptoms be present for at least six months before schizophrenia can be diagnosed (APA, 2000). For people with schizophrenia-like symptoms of less than six months’ duration, the *DSM-IV-TR* recommends the use of schizophreniform disorder as a diagnosis. If the duration is less than one month, a diagnosis of brief psychotic disorder is used (APA, 2000).

Subtypes of schizophrenia have also been used to diagnose patients. Their differentiation is based exclusively on the symptoms of the illness. Thus, paranoid schizophrenia is characterized by delusions and/or hallucinations with a predominantly persecutory, or less

commonly, grandiose content. Disorganized-type schizophrenia has as its predominant symptoms disorganized speech, disorganized behavior and flat or inappropriate affect. Catatonic schizophrenia is diagnosed when the outstanding features of the disease are behavioral disturbances such as posturing, rigidity, stupor, and often autism. As Muhlbauer (2008) notes, caregivers find these subtype symptoms the most difficult to handle and can create misunderstanding and often anger among caregivers who believe they represent the personality qualities of the person who is ill rather than symptoms of schizophrenia.

Few patients fall clearly into one subtype or another, with most having a mixture of symptoms (NIMH, 2009). Also, it must be noted that people with schizophrenia often show a shift in their symptoms over time. Initially, a person may appear to be a catatonic subtype but a few years later may have symptoms of another subtype. For these reasons, there is an increasing tendency among mental health professionals to diagnose most patients as having the “undifferentiated type” which means that their symptoms are mixed or have symptoms from two or more subtypes (Mellor, 1970, NIMH, 2009).

Another method of categorizing schizophrenia that has been used is to divide patients into groups of those having predominantly “positive” symptoms and those with predominantly “negative” symptoms. Although the use of “positive” may seem odd for any symptom or seem like a contradiction of terms, it denotes more florid symptoms that are present but should be absent (e.g., delusions, hallucinations). “Negative” symptoms, on the other hand, describe the absence of characteristics that should be present (symptoms include apathy, social withdrawal, poverty of thoughts, blunting of emotions, slowness of movement, and lack of drive). Some researchers claim that these symptoms are actually different diseases. Their categories are Type I

for persons with predominantly “positive” symptoms. Type II is for persons with predominantly “negative” symptoms (APA, 2000). The negative symptoms often create the most problems for caregivers (Mulhauer, 2008).

### **Treatment of Schizophrenia**

Currently treatment for schizophrenia is focused on the elimination or reduction of the symptoms of the disease. Treatment also can include social support for the person with schizophrenia to live as independently as possible. This support includes interventions such as antipsychotic drug therapy, residential housing options, day programs, case management services, supportive therapy and support to caregivers.

The primary treatment modality is treatment with antipsychotic medications in conjunction with psychosocial interventions that provide education and support to patients, their families and other caregivers. These drugs can effectively alleviate the positive symptoms of the disease. As people react differently to medications, it is often necessary to try several medications before an effective one or a combination of efficacious drugs is found.

The medications typically start to improve the symptoms of agitation and hallucination within a few days of the beginning of treatment but take longer to improve other symptoms such as delusions. Patients with schizophrenia can anticipate overall improvement in symptoms within about six weeks; but this timeline is relative given the metabolic and other differences between patients.

The literature has shown that the rate of recurrence of positive psychotic episodes can be decreased in patients with schizophrenia if they take their medications (Ayuso-Gutierrez, & Vega, 1997). Without this consistency, patients will not be able to take advantage of other types

of interventions until their active symptoms are under control. Being able to take advantage of interventions for schizophrenia greatly increases the quality of life for both patients and their families.

### **Adherence and Non-Adherence to Medication**

What do we mean when we talk about medication adherence and non-adherence? Could it be that most people fall short of full adherence to any type of medication plan? On the other hand, it is unusual for there to be zero adherence to the prescribed regimen. Rather, some degree of non-adherence can be expected about half the time (Buckalew & Sallis, 1986). Non-adherence may be even lower among people with psychotic disorders than among those with physical disorders (Cramer & Rosenheck, 1999).

Non-adherence, that is, not having a prescription filled, not accepting medication at all, obtaining or accepting the medication but not taking it, or taking only part of it (not following the prescribed dosage) either by not taking the proper amount or by not taking it at the desired frequency, is a serious problem for patients with schizophrenia and their families, especially when the family member is also a caregiver. Franson and Smith (1998) note that 20% of all prescriptions are never filled and only 50% of those filled are taken correctly. Estimates of non-adherence among people with psychotic disorders are projected to be about 50% after one year and as much as 75% after two years (Weiden et al., 1994). Psychotropic drug therapy and psychosocial interventions for persons with schizophrenia together with interventions for their families is the cornerstone in the treatment of acute schizophrenic episodes and in the prevention of relapses (Rossler, Salize, & Riechler-Rossler, 2005). According to the literature, up to 72% of

patients with schizophrenia are non-adherent based on reports from patients, health professionals and family members (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002).

Among people with schizophrenia, failure to adhere to a prescribed regimen has enormous costs to those suffering from the illness and to their families and to the larger society as a whole. Non-adherence is associated with adverse consequences such as a higher probability of hospitalization and higher medical costs (Eaddy, Grogg, & Locklear, 2005). The shift of the burden of care away from hospitals and institutions onto families also has resulted in costs to the family. Since the 1950's, researchers have been investigating the effects of mental illness on patients' caregivers (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). Studies report a high degree of burden in caregivers (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). These studies explore how much family caregivers can provide assistance to the loved one with a severe mental illness before they become overburdened and require professional help.

Estimates by McDonell, Short, Berry and Dyck (2003) are that up to 80% of people with schizophrenia live with a family member or caregiver. Caregivers clearly play a major role in the life of a person with schizophrenia. They provide direct assistance, advocate for services and provide financial and emotional support. Caregivers can have enormous influence on the ability of persons with schizophrenia to live productive, integrated lives in their communities. Caregivers also play a key but relatively unexplored role in assisting their relatives in taking their medications and maintaining stability in the community (McDonell, Short, Berry, & Dyck, 2003). Strong social supports, including family and community supports and a good relationship with the care team, reportedly exert a positive influence on medication adherence. Studies also have shown that when a family member acts as a caregiver, this has a positive effect on patients

taking their medications (Bentley & Walsh, 2006). As medication adherence affects all parties involved to some degree, caregiver views on this issue warrant more exploration.

As suggested, research on caregiving in relation to medication adherence has been sparse. This is particularly so in relation to African American caregivers. In the next section, I will discuss racial and cultural differences and African American caregivers.

### **Racial and Cultural Differences**

We all come with distinct cultural backgrounds. Our personalities are shaped by culture, ethnicity, gender and socioeconomic status. Social factors such as poverty, discrimination and inequality can create undue stress on people who are ill. While these factors do not cause an illness such as schizophrenia, they can influence its development. Questions about bias in the diagnosis of minorities have been raised, as well as the role of discrimination and prejudice in creating stressors that might exacerbate genetic vulnerabilities in certain populations of people (Kohn, 1973). More research is needed in this area to identify the reasons for differences in the rate of diagnosis of schizophrenia.

Research is only beginning to focus on the area of racial variations in medication response. Perceived difference in mental disorders and treatment responses among racial and ethnic groups may occur because of differences in treatment-seeking behavior, differential presentation of symptoms, and the accuracy of diagnosis (Adebimpe, 1994). Further, it is difficult to claim that any sample is representative of a racial or ethnic group given the mixed lineage of participants and variable criteria used in self-identification. Cultural differences also exist in the ways individuals cope with stress, express emotions, and conceptualize and seek remedies for mental health problems (Adebimpe, 1994).

The demographics of the US population are changing dramatically. Overall, the percentage of the US population composed of ethnic minorities grew from 11% in 1960 to 28% in 2000 (Bentley & Walsh, 2006). There is a need to understand better how the members of these diverse groups will respond to psychotropic medications because they have historically been underrepresented in drug trials (Bentley & Walsh, 2006). What is known is that the range of bio-psychosocial factors that influence psychotropic drug metabolism and response among ethnic groups include the following: diet and nutritional factors; actions of certain enzymes; differences in consumption of cigarettes, caffeine, alcohol, herbs and other psychoactive substances; activity, rest, and sleep patterns; environmental exposure to toxins or pollutants; differences in exposure to psychological stress; prescribing practices among physicians; patterns of illness behavior among cultural groups; and cultural attitudes toward medication use (Jacobsen, 1994; Turner & Cooley-Quille, 1996).

An important perspective that the social work profession brings to cultural and ethnic differences is its appreciation for such differences and how they can play out in the area of health care delivery. Different ethnic groups and cultures have diverse perspectives on treating illness, especially mental illness and what it means to be sick. Western notions of individuality and self-autonomy can be very different for those in African, Asian and Latin cultures, for instance. Within a given culture there are also different attitudes and perspectives that need to be taken into consideration. Ethnicity and culture are the starting points to understanding a person in context but they do not give one the whole story. The multi-layered aspect of individuals needs to be acknowledged and the social work mantra to “start where the client is” continues to be the best approach in understanding people and their constructed lives. Within the diverse tapestry

that makes up the United States, a person suffering from a severe mental illness might be Asian, African, South or Central American or Caribbean in background. Sensitivity to different cultural backgrounds and awareness of different cultural norms are important areas of consideration when planning health care delivery system as well as designing individual treatment plans. It is important for health care professionals to understand the different attitudes regarding taking medications as this will impact adherence. Also the role of what it means to be a caregiver can be very different in different cultural and ethnic groups. Different racial and ethnic responses to medications also must be considered for the medications to be effective.

### **African Americans**

Most of the studies examining differences in medication response among racial and ethnic groups have been done on African Americans. Differences have been noted in how African Americans are diagnosed. African Americans are more likely to be diagnosed with schizophrenia than Caucasians or any other ethnic group and less likely to be diagnosed with an affective disorder (Lawson, 2000). The seeming over diagnosis of schizophrenia may be related to a higher prevalence of positive—as opposed to negative—symptoms of mental disorders in African Americans. Cohen and Magai (1999) found that this trend held among 240 older adults with dementia; African Americans were more likely to present symptoms of psychosis than depression. Also, African Americans may not receive thorough assessments of mental status. Segal (1996) found in a large study of 18,543 clients in New York State, that Caucasian emergency room physicians spent less time assessing African Americans than members of their own race. It has been noted that African Americans are less inclined to self-disclosure than Caucasians (Adebimpe, 1994) which may affect the process of diagnosis. Further, African

American families are less likely to seek help from mental health professionals for their children, and individuals of all ages are less likely to perceive themselves as having a mental illness (McMiller & Weisz, 1996). It has been consistently found that African Americans with mental illness are prescribed more medications and at higher dosages than Caucasians; and they are more likely to receive antipsychotic medications and are more at risk for tardive dyskinesia and other adverse physical effects (Lawson, 2000). On the positive side, African American clients with schizophrenia typically respond better than Caucasian clients to phenothiazines and to the newer drug olanzapine (Evans & Johnson, 2001).

### **Research Questions**

The qualitative study described in this document explored the views of African American caregivers on medication treatment for schizophrenia and schizophrenia-spectrum disorders. The aim of the study was to understand how these views might influence medication adherence on the part of the person with schizophrenia. It explored the following research questions:

- What are the views of African American caregivers toward the taking of medication for schizophrenia?
- How do the caregivers describe their role in relation to medication adherence?
- What kinds of strategies do the caregivers use to promote medication adherence?
- How do the caregivers describe their caregiving role in relation to activities besides medication adherence?
- How do African American caregivers incorporate cultural values into their caregiving role?

- How do caregivers view support, or lack thereof, by community mental health services?

## **CHAPTER II**

### **LITERATURE REVIEW**

This study explored the role of the caregivers in the taking of medication by their loved ones. In order to understand the challenges facing the person with schizophrenia and his or her caregiver it is important to have some background on medication adherence as it pertains to schizophrenia. This chapter begins with a discussion of issues related to non-adherence. It also treats the topics of patient and family education and educational programs and describes theories relevant to this study.

#### **Reasons for Non-Adherence**

Non-adherence of prescribed medication and scheduled dosage among individuals with schizophrenia is a major source of frustration for families and other caregivers. It is also the single biggest cause of relapse and rehospitalization (Lacro, Dunn, Dolder, Leckband & Jeste, 2002). Torrey (2001) notes some possible reasons for non-adherence by persons with schizophrenia. One significant reason is anosognosia, the lack of awareness that one is sick. Such lack of insight is biological in origin; it is caused by damage to the frontal lobe. If people do not think they are sick, they see no need for medications (Torrey, 2001).

Denial is another reason people with schizophrenia do not take their medications. In denial, the person is aware that he/she is sick but wishes not to be. Taking medication is a daily reminder of one's illness; not taking medication is therefore an attempt to refute that the illness exists. Denial is often temporarily effective until symptoms of the illness recur. Whereas anosognosia is biological in origin, denial is psychological in origin.

A third major reason for non-adherence among individuals with schizophrenia is the side effects of the medications. Antipsychotic medications often have serious side effects that also must be addressed in order for patients to be comfortable enough to take the medications. These side effects include weight gain, loss of sexual desire and performance, and in some cases diabetes, and can be difficult for patients to cope with.

Another factor in non-adherence is the symptoms of schizophrenia. For example, delusions may be present and this delusion may lead the patient to believe the medication is poison. Some patients do not take their medications due to confusion, disorganization or other cognitive deficits associated with schizophrenia. Here, the caregiver will need to play an important role in helping the person with schizophrenia remain on their medicines by providing support and encouragement to take the medications. A few people do not comply with medication protocols out of fear that they will become dependent on or addicted to the drug(s) (Bentley & Walsh, 2006).

### **What We Know About How to Improve Adherence**

What can be done about these issues of non-adherence? It is important for families and mental health professionals to recognize how common non-adherence is, including the suspected high frequency of unknown non-adherence that occurs when others erroneously think patients are taking their medications. It is also important to ascertain the reasons for non-adherence because solutions to the problems noted above—lack of awareness of illness, denial, medication side effects, and other reasons such as delusional thinking—are quite different (Bentley & Walsh, 2006). It is difficult to address the concerns of patients if we do not understand the

dynamics of their reasons for not taking medications. The caregiver also will have an opinion about medications and this will need to be explored if they are in the role of assisting the patient to take the medications.

Researchers have explored many areas of medication non-adherence (Rocca et al., 2008). They have looked at antipsychotic medication effectiveness, family supports, community supports, symptom management, and other aspects. However, given that patients with schizophrenia are heavily reliant on their caregivers, the role of caregivers has not been thoroughly explored as a possible avenue for better understanding of the entire process and meaning-making that occur with any long-term illness and its management. The issue has a great impact on treatment outcomes for persons with schizophrenia and their quality of life.

Medication effectiveness is one of the most important issues when prescribing any medication. Thomas (2007) looked at antipsychotic medication effectiveness and adherence. Thomas (2007) found that long-term symptom control, tolerability and hence adherence to treatment can all be improved using atypical or second-generation antipsychotic agents compared with typical antipsychotic drugs. He also noted that antipsychotic treatment for schizophrenia should focus on improving real-world outcomes, including functional capacity and health-related quality of life because these factors are important from the patients' perspective and influence medication adherence.

Gianfrancesco, Rajagopalan, Sajatovic, and Wang (2006) also looked at adherence from the perspective of typical antipsychotic drugs versus atypical ones and found that each of the atypicals studied demonstrated a significantly higher adherence intensity rate than all of the typicals combined. These studies are important because the more effective the medication in

treatment is, the more likely the patient is to see positive reasons to take the medications. Also with symptom alleviation, quality of life improves as persons with schizophrenia are able to participate in family and community activities. These studies of the effectiveness of medications are also significant as one explores the role of caregivers and medication adherence and non-adherence. It is clear that the more the effective the medication, the greater the adherence. More research needs to investigate how medication effectiveness impacts the caregiver role in medication adherence.

Another area of adherence that has been studied is the concept of both adherent and non-adherent behaviors with clients with a mental health diagnosis (Lowry (1998). Lowry highlights out that attempting to define patient characteristics to explain noncompliance, primarily as a way to reduce such behaviors—with the added benefit of reducing both the incidence and the cost to the health service—is too narrow an approach to the problem. The author proposes that a new approach to non-adherence in the psychiatric setting is required. This approach is dependent upon the willing cooperation and participation of the patient in his own health care and the willingness of health professionals to let go of some of their traditional roles and personal prejudices (Lowry, 1998). Caregivers also need to be involved in this process of participation because they play a much larger role in the lives of persons with schizophrenia than the medical team and often have the ability to more directly impact the quality of life of the person with schizophrenia.

### **Relapse**

Relapse can be a serious issue for people with schizophrenia. The term relapse refers to a deterioration or reoccurrence of positive rather than negative features of the disease and appears

to increase the severity of the course of the illness. Almost all severely mentally ill patients with schizophrenia depend on a maintenance regimen of psychotropic medication along with social and family support to remain out of the hospital. Effective neuroleptic drugs have been available for the past 40 years, but over 50% of schizophrenic patients, under normal treatment conditions, relapse within one year after their latest episode (Ayuso-Gutierrez & Vega, 1997). Post-hospital discharge noncompliance rates in community settings are estimated to be 7.6% per month (Weiden & Olfson, 1995). There are obviously enormous quality of life issues for patient to staying out of the hospital and stable in the community. There also appears to be an enormous financial incentive to keeping patients out of the hospital when possible and medication adherence appears to play a large part in this, but it is not the total picture. The interplay of family/caregiver and other community supports is also important in order for people with schizophrenia to maintain themselves in the community. The Schizophrenia Patient Outcomes Research Team (PORT) recommends family education as one way to cut relapse rates. The study notes that other studies have shown a decrease of up to 50% in relapse when family members have participated in a family psychoeducation program of at least 9 months duration (Lehman, Kreyenbuhl, Buchanan, Dickerson et al., 2004)

### **The Caregiver Role**

Caregivers are an important national health care resource. Families often are a primary source of home care and support for older relatives and people with serious mental illness. They contribute services that would cost hundreds of billions of dollars annually if purchased independently (Shultz & Sherwood, 2008).

Schultz and Sherwood (2008) note that assuming a caregiving role can be stressful and burdensome. They noted that caregiving has all the features of a chronic stress experience. It creates physical and psychological strain over extended time periods. The authors noted that performing this function is accompanied by high levels of unpredictability and uncontrollability and has the capacity to create secondary stress in multiple life areas such as work and family relationships. They further stated that measures of psychological well being, such as depression and stress, have been the most frequently studied consequences of caregiving. Older caregivers, people of low socioeconomic status, and those with limited support systems report poorer psychological and physical health than caregivers who are younger and have more economic and interpersonal resources (Pinquart, 2001; Schulz et al., 1995; Vitaliano et al., 2003). Considering the important role they play in the lives of their loved ones, we need to better understand the needs and concerns of caregivers. It is hoped that this study helps illuminate caregivers' contributions to their relatives' mental health and increases understanding of the role of the caregiver of someone with a severe mental illness such as schizophrenia.

Unfortunately, more than half of the patients are in settings with families and caregivers who lack information about mental illness or the medications used to treat the condition and often lack management and coping skills (Bentley, Rosenson & Zito, 1990). This conclusion corroborates my own experience working with caregivers. Families and caregivers are not often provided with even one educational session about their family member's illness. If it is a newly diagnosed patient, one 30 minute family meeting is not enough time to prepare patients, families and caregivers fully for the skills they will need to keep the patient functioning and out of the hospital.

Non-adherence with medication regimens is pervasive among this population of the mentally ill and thus a major source of frustration and tension for families. Families and caregivers report that apathy is often a problem for the family member with schizophrenia. Apathy is a common negative symptom in schizophrenia that has been associated with poor medication compliance and treatment outcome (Roth et al., 2008). This is a concept I explored in my study.

Other studies have evaluated patient-related and treatment-related factors associated with medication compliance for inpatients with a diagnosis of schizophrenia. A study by Jansen et al. (2006) took place in seven psychiatric hospitals. Individuals with a psychotic disorder were assessed weekly on mental state, social functioning, side effects and medication compliance. A logistic regression analysis was performed to assess patient and clinical predictors of adherence to medication protocols. The authors found a significant association between lower medication adherence and substance abuse, involuntary admissions, history of aggressive behavior and no high school graduation. Individuals with pronounced paranoia or negative symptoms were also less adherent in taking their medications (Jansen et al., 2006). Not surprisingly, the authors also found that patient-related factors and family supports, and not just disease-related factors, influence adherence to instructions for taking medication.

Fenton, Blyler, and Heinssen (1997) found that clinical correlates of compliance that have been studied include: patient socio-demographic features, illness characteristics, medication features (including side effects, route and frequency of administration), family/social supports and quality of the physician-patient relationship. The authors reviewed the substantive literature on medication adherence in schizophrenia. They focused on empirical studies that identified

current or predictive correlates of adherence/non-adherence and assessed interventions targeted to improve adherence. Interventions studied were reinforcement, education, skills training, and memory enhancement (Fenton, et al., 1997). Additionally, they also looked at the issues of compliance and designed an experiment using the principles of Medication Self-Management (MSM). This technique uses motivational interviewing principles. The authors found no statistical significance in the difference between those who received this intervention and the control group. This study seemed to suggest that MSM was not effective in increasing adherence in patients with a severe mental illness. This needs further study but is an interesting starting point for possible effective interventions with this population.

Other studies have found that with schizophrenia, health care workers should take into account social supportive factors such as instrumental or directive hands-on assistance from family caregivers (Garcia, Chang, Young, Lopez & Jenkins, 2006). Another area that must be taken into consideration is the cultural context of families of people with severe mental illness. Finley (1998) suggested that the needs of families from different ethnic and cultural backgrounds coping with a member who is mentally ill are often neglected. She discusses obstacles encountered by families and attitudes concerning adherence to taking medications possessed by those of different cultural backgrounds; she also addresses their attitudes toward the mental health professionals in general. Patients return to their unique cultural backgrounds when discharged from hospitals and the attitudes of their culture toward their illness needs to be considered when addressing the issues of adherence.

With regard to cultural difference, Anglin, Alberti, Link and Phelan (2008) note that racial/ethnic minority groups are less likely than Caucasians to access mental health services, despite

recent evidence of more favorable attitudes regarding treatment effectiveness. They point out that while African Americans were more likely than Caucasians to believe that mental health professionals could help individuals with schizophrenia, they were also more likely to believe mental health problems would improve on their own. Their findings suggest that a belief in treatment effectiveness may not increase service utilization among African Americans who are more likely to believe treatment is unnecessary. They note also that mental health services offered through community churches might improve utilization of services since churches have become a primary source of support for many African Americans.

Other studies (e.g., Roick, Heider, Toumi, & Angermeyer, 2006) looked at the impact of caregivers' characteristics and patients' conditions and found that negative symptoms of the disease impact caregivers' burden with respect to differences in both interpersonal and intrapersonal changes over time. Positive symptoms only predicted burden in the intrapersonal comparison. They also found that caregivers who cope better with their family member's behavior over time have less of a sense of burden.

Veltman, Cameron and Stewart (2002) conducted a qualitative study looking at caregivers' perspectives on both the negative and positive aspects of caregiving. They conducted twenty in-depth, audiotaped, semi-structured interviews focusing on caregivers' positive and negative personal experiences of caregivers toward a relative with mental illness. Caregivers reported common negative impacts but also beneficial effects, such as feelings of gratification, love and pride. They discovered common themes of stigma, systems issues, life lessons learned and love and caring for the ill relative. This study counterbalances the predominately negative consequences previously reported and adds to the emerging literature on positive aspects of

caregiving. The authors note that professionals need to help caregivers' families make choices to improve their difficult situations. They need to help caregivers identify the rewards of caregiving and to advocate for increased community support.

Andrews, Farhall, Ong and Waddell (2009) looked at the perceptions of mental health professionals and family caregivers and their collaborative relationship with one another. The results of the study suggested that relatively simple collaboration models can describe routine professional-caregiver interactions, although professionals possess a more differentiated concept of collaboration than family caregivers. Unexpectedly, both professionals and caregivers trended to attribute responsibility for collaboration to the other group. They recommended that training programs in which mental health professionals and caregivers jointly learn the best ways to work together may be valuable. Jungbauer, Stelling, Dietrich and Angermeyer (2003) examined the problem of spatial separation in families. They noted that in the past, family relationships of people with schizophrenia have been investigated mainly from a clinical viewpoint. The perspective of family development has generally been overlooked in this area of research. They conducted 51 in-depth interviews with parents of people with schizophrenia. They explored their living situations and relationships with patients. The study noted that spatial separation from the family home was often complicated with patients permanently living in their parents' households or in the same neighborhood. Many patients remained dependent on their parents' emotional, practical and financial support. They noted that the parent-child relationship was re-intensified, often with a concurrent loss of social contacts outside the family. From a biographical point of view, schizophrenia often caused problems for families by making parenthood permanent and

lifelong parental support necessary. Parents often have to revise their expectations of both their ill child's development and their own personal plans.

### **Patient, Family and Caregiver Education**

Patient, family and caregiver education is an important area of intervention and study. Reibschleger et al. (2008) examined medical educational curricula and found they have insufficient content about families that include people who suffer from mental illness. They stated that the curricula do not adequately prepare physicians for working with family members of patients with a mental illness. This is the case despite the fact that many patients rely on family members to assist with adhering to their treatment plans.

A study by Stengard, Honkonen, Kovivisto and Salokangas (2000) looked at the satisfaction of caregivers of patients with schizophrenia. They noted two dimensions of satisfaction. First, caregivers need to be accepted and treated as active partners in the patient's care and rehabilitation. Second, the burden on the caregivers of people with mental illness can be alleviated with long term rehabilitation and care to help patients gain a high functional state of wellness. This is logical given that the more independent the person with a severe mental illness is, the less the burden is imposed on the caregiver. Medications often play a significant role in regaining a functioning role in families. Ricard, Bonin, and Ezer (1999) examined factors associated with the burden faced by primary caregivers of mentally ill patients. They found that the most difficult behaviors to cope with were specific behaviors related to disturbances. Those that generated the greatest burden on caregivers were ones associated with a threat both to the security of the caregiver and the patient. Patients who are actively psychotic and not taking their

antipsychotic medication or see no response in symptom alleviation can be the most threatening to caregivers.

Similarly, Lauber, Eichenberger, Luginbuhl, Keller and Rossler (2003) looked at determinants of burden for caregivers of patients with exacerbating schizophrenia. They found that family members/caregivers are most concerned about threats from their severely mentally ill family member. The authors stated that families should be included in the decision to determine if an affected person should be hospitalized. Szmukler et al. (1996) examined caring for relatives with serious mental illness and found that the data indicate the experience of caregivers is multidimensional. They determined that negative behaviors affected satisfaction with the caregiver's role and sense of burden and identified threatening behavior as a serious precursor to feelings of burden.

Caregivers are often a lifeline to the community for a person suffering from schizophrenia. They assist patients with normalizing their lives and are often responsible for helping with medication adherence. Their attitudes toward treatment with antipsychotic medications and beliefs about schizophrenia in general are important factors in determining how effective any treatment plan will be. Piat, Ricard, Sabetti and Beauvais (2007) note this in their qualitative study that examined the values and qualities of being a good caregiver to the seriously mentally ill in a group home setting. They found that caregivers are often highly motivated and should be recognized as full participants in the mental health system at all levels. Shultz and Sherwood (2008) also notes that we need a better understanding of the different types of caregiving experiences and their effects on health. Providing help that fails to enhance the quality of the patient's life may lead to frustration, resignation and negative effects for the

caregiver. The authors believe that it is also likely that providing help that significantly addresses the needs and desires of a patient is uplifting to the caregiver and contributes to positive health effects. They note that research on positive aspects of caregiving is relatively new and that we know little about how these good experiences moderate the stress response and affect health.

Noting a similar finding, Lakeman (2008), in her study on family and caregiver participation in mental health care, states that for caregivers and patients, any demarcation between mental health and other care makes little sense since their responsibilities and relationships persist regardless of whether or not someone is involved with mental health services. For this reason she notes that mental health services need to recognize both the family and the patient as the natural source of support for service users, not just the patient. Families, caregivers and patients have different but related informational and support needs, which vary depending on their familiarity with mental health services, the acuity of problems, the presence of crisis and the context in which care takes place.

Psychoeducational programs appear to help alleviate some of the sense of burden often felt by caregivers. Grandon, Jenaro, and Lemos (2007) examined the sense of burden felt by primary caregivers of persons with schizophrenia who were outpatients and found that psychological education interventions were effective in making the family caregivers feel less burdened with their caregiving responsibilities. Their study of 101 schizophrenic outpatients and their caregivers found that higher frequencies of relapse combined with lower self-control attributed to the patient, a decrease in social interest, and less effective support were predictors of an increased sense of burden in the caregiver. Relapse was more common in patients who were

non-adherent with taking medications. The authors recommended psychoeducational programs as a possible intervention modality for caregivers in this situation.

In another study of caregiver and burden, Onwumere et al. (2008) looked at caregivers and illness beliefs in the course of psychotic illness. They conducted a cross-sectional study with a sample of 146 caregivers. They found that caregivers' cognitive representations of psychosis appear to play an important role in the appraisals they make about their caregiving experiences, even during the early phases of the illness. Negative caregiving appraisals are persistent and directly related to psychiatric morbidity in caregivers. Such negative caregiving appraisals (and distress) may be modified by individual attention to caregivers' illness beliefs as part of routine clinical work. They note that it is important to identify beliefs about psychosis in the process of offering interventions to caregivers. Further, they note, the specific relations between appraisal and illness beliefs among caregivers of patients with early psychosis suggest that intervention at this stage may be particularly helpful in reducing negative appraisal and distress. They note that there is some encouraging evidence from the physical health literature that interventions specifically aimed at modifying aspects of an individual's illness models can be successful.

Looking at the caregiving role from a different perspective, Gray, Robinson, Seddon and Roberts (2009) explored the emotions of family caregivers from the perspective of health care professionals. They interviewed 65 health care professionals. The respondents were encouraged to talk in detail about their understanding of the emotions of family caregivers. They noted a clear lack of emotional support for family caregivers, with accompanying feelings of marginalization. These were particularly evident during transition periods especially those involving young caregivers and ethnic minorities. They emphasized the importance of

psychological education for family caregivers and support groups as potentially holistic, effective and economical ways of meeting caregivers' emotional needs.

Finally, Muhlbauer (2008) looked at caregiver perceptions and needs regarding symptom attenuation in severe and persistent mental illness. This qualitative study used the symbolic interaction paradigm of dramaturgical interviewing. There were 35 caregivers in the study who participated in one to two hour semi-structured interviews. The study found that lack of understanding about negative symptom expression was a significant issue for caregivers. It led to substantial participant misinterpretation of patients' behavior and resulted in an atmosphere of increased anger and hostility. The author noted that although information about negative symptoms has not been a primary focus of psychological education, data from this study strongly support the need for its inclusion. The author also advocated clear and direct conversation with patients and caregivers when patients are not in severe psychotic distress on possible actions and needs for the caregiver.

### **Educational Programs for Individuals with Severe Mental Illness and Their Families about Medication Management**

Several comprehensive medication education programs are used with the severely mentally ill population and their families. Falloon (1984) developed the first such program about two decades ago. In his team's comprehensive psychological educational program designed for people with schizophrenia and their families, family members and clients participate together in sessions that take place in the family home. Following a session on the nature of the illness, the second educational session is completely devoted to medication (Bentley & Walsh, 2006).

Bentley and Walsh (2006) describe a medication session with individuals with mental illness as follows. After reviewing the previous sessions' main points and answering any questions the participants might have, the leader begins medication education by discussing the underlying rationale for medication. Medication is explained as a way of managing the chemical imbalance in the brain. Using clear and simple graphs, the leader highlights the reduced symptoms and relapse rates of those individuals who regularly take their prescribed medications. The leader asks participants to discuss their own experiences with medications and presents information on relapse. The leader then asks if the participant had ever relapsed due to not taking medication (Bentley & Walsh, 2006).

Since publication of the original Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations in 1998, scientific advances have occurred in the knowledge about how to help persons with schizophrenia and their families (Lehman et al., 2004). Lehman and his colleagues (2004) note that PORT recommendations for family intervention are for a family psychoeducation program that includes a duration of a least 9 months, illness education, crisis intervention, emotional support and training in how to cope with illness symptoms and related problems. They note that, in a review of more than 20 controlled studies, family programs have typically halved relapse rates. Meta-analyses pooling data across studies have consistently shown reductions in relapse rates and also reduced family burden (Falloon et al., 1985; Pilling et al. 2002).

### **Possible Theories that Inform Adherence Behavior Issues**

In this study I explored two theories that inform human behavior, symbolic interactionism and the family life course development framework. These were used initially in a

provisional way to determine whether and how they fit the data. Each of these theories has proved to have something to offer in the consideration of individual actions within the context of the family and adherence to a medication protocol.

### **Symbolic Interactionism**

Symbolic interactionism is one of the interpretive perspectives used in qualitative research and is the theory and approach for the study of individuals' social action/interaction in search of portraying and understanding the process of meaning-making. The goal is to understand the complex world of lived experience from the point of view of those who live it (Jeon, 2004). Blumer (1969) proposed the methodological position for symbolic interactionism. He maintained that to understand the world one must analyze it in terms of the participants' actions and interactions. He stated that the researcher must be able to actively interact with the persons being researched and see things from their point of view and in their natural context. When adopting the symbolic interactionist approach, the researcher needs to be actively engaged in the world of the study, for example, by using participant observation. Blumer (1969) described the researcher's activity as:

...lifting the veil that obscures or hides what is going on. The task of scientific study is to lift the veils that cover the area of group life that one proposes to study. The veils are not lifted by substituting, in whatever degree, preformed images for firsthand knowledge. The veils are lifted by getting close to the area and by digging deep into it through careful study. (p. 20)

The basic research assumption of my study is consistent with this view. If one wants to understand the interaction between the caregiver and the cared for person, one needs to

comprehend their experience as they see it. I hope to discern this from the caregiver interviews. The inquirer needs to observe what the caregiver and their family member take into account and identify how they interpret their individual experiences and shared situations, what alternatives they use when acting in different situations and under what conditions alternative actions are chosen (Jeon, 2004). Although I did not plan to do any direct observation (except if a family member's relative happened to appear during any of my caregiver interviews), I listened for narratives about caregiver-cared for person interactions.

The symbolic interactionist perspective can provide the researcher with a guiding framework to explore how caregivers define the sick role of their family member and vice versa. The task of my study in using symbolic interactionism would be to discover what is happening in the processes through which the caregiver interacts with the person with a severe mental illness. This theoretical perspective could provide insight into the relationship to be studied.

### **The Family Life Course Developmental Framework**

The family life course developmental framework theory contains three complementary theoretical approaches (White & Klein, 2008). The first is the individual life span theory, which focuses on the ontogenetic development of the individual and factors that affect that development. Because many of these factors affecting individuals are found in families, this individual approach cannot avoid the family as the context of individual development. The second theoretical approach within this framework is family development theory. This theory focuses on the systemic and patterned changes experienced by families as they move through stages and events of their family life course. Although family development theorists acknowledge the importance of individual development, the development of the family as a

group of interacting individuals and organized by social norms is their major focus. The third major theoretical approach encompassed within this framework is life course theory. Life course theory examines the event history of an individual and how earlier events influence later outcomes, such as divorce or fertility. Although life course theory originally emerged from studies of the individual life course, White and Klein (2008) suggest that this approach could be used on the family as a unit of analysis.

Family development theory relies on basic assumptions about the family. These assumptions are not restricted to the family group but extend to the broader fabric of the social institution of the family. These assumptions are that developmental processes are inevitable and important in understanding families. The changing roles and expectations for different stages of the family are viewed as essential to an understanding of the family. All levels of analysis affect family groups including the social norms of the larger society and the social norms of clusters such as social class (White & Klein, 2008). For example, the norms about techniques of child discipline are related to social class as well as to the codifications of the larger social system. Another assumption within family development is that time is multidimensional. This challenges the assumption that time moves at a uniform state, as measured by gears in a wristwatch, to use an example supplied by White and Klein (2008). The authors point out that this is counter to much of our experience. Most of us have experienced an hour spent in an enjoyable pursuit as “flying by” or an hour spent in a dull and boring activity as “dragging out.” In other words, our experience of time is perhaps not as regimented as a wristwatch would lead us to believe. This alternative concept of time is called social process time (White & Klein, 2008). For family life course development theory, the family process dimension of time is critical to understanding and

explaining family change because it provides the marker events (birth, death, marriage) for analysis. Important propositions are that family development is a group process regulated by societal timing and sequencing norms. Another is that if a family or individual is “out of sequence” with the normative ordering of family events, the probability of later life disruptions is increased. Within families, family members create internal family norms. These are a few examples that can be used to inform the researcher’s process of trying to understand and evaluate family behavior.

The theory also uses family stages. A family stage is an interval of time in which the structure and inactions of role relationships are noticeably distinct from other periods of time. Transitions are also important events in the theory. Transitions are shifts from one family stage to another. A family career is composed of many such transitions between stages. The concept that has emerged is that family transitions viewed over time consist of paths taken and not taken. An example of this would be divorce in a family that creates a new direction or transition to another stage.

There are many applications for family life course development theory. One example is looking at resiliency and stress in families. The study of stress in family development theory has emphasized significant events in the individual and family history as areas that increase family stress. This is an area that lends itself to my study, that is, the stress involved in being a caregiver and the transition from a parent, sibling, or partner to that of a caregiver.

## **CHAPTER III**

### **METHODOLOGY**

This qualitative study used modified constructivist grounded theory as the research methodology. I relied on the work of Charmaz (1990) as the foundation for the type of grounded theory I used for my analysis. Charmaz (1990) notes that grounded theory is a way to explore social constructions by people or, in my case, caregivers. She describes the term social constructionist as:

...people's creation of taken-for-granted interactions, emotions, definitions, ideas and knowledge about illness and about self and also the researcher's sociological constructions which they develop, in turn, by studying peoples (caregiver in my study) constructions. (p.130)

Charmaz (1990) also notes that people "...experience their constructions as reality; their constructions are neither convenient fabrications nor idiosyncratic interventions" (p.130).

I am calling this a "modified" constructivist grounded theory methodology because I did not use all the methods associated with this tradition. I did not use theoretical sampling or the constant comparative method.

#### **Concepts and Operational Definitions**

For this study, I defined *medication adherence* as the consistent taking of prescribed antipsychotic medications. Non-adherence is described as consistently not taking prescribed medications. Consistency is defined as often enough for the drug to have a therapeutic effect on the symptoms for which the drugs are prescribed.

I defined a *caregiver* as a person who provides direct assistance to a person with a diagnosis of schizophrenia on at least a weekly basis. Caregiver and the cared for person do not necessarily live in the same residence.

I defined a *person with schizophrenia* as someone who has been diagnosed with this illness or other schizophrenia-spectrum disorders (e.g., schizoaffective disorder) by a psychiatrist and is currently being treated for the illness. The person is currently on antipsychotic medications for symptoms related to the illness.

My primary method of data collection was interviewing. The study used two sets of interviewees—caregivers and key informants.

### **Caregiver Interviews**

For this study, 10 African American caregivers of persons with schizophrenia were interviewed. The inclusion criteria were as follows:

1. Must have a family member or loved one who has a diagnosis of schizophrenia or a schizophrenia spectrum disorder (e.g., schizoaffective disorder). They do not have to be related by blood or a legal marriage.
2. Must provide ongoing care for their family member or loved one. They do not have to live together but must have weekly contact and provide some assistance to the person with schizophrenia.
3. The person with schizophrenia must have been ill for at least 1 year.
4. The caregivers must be African American.

5. The person with schizophrenia must be taking one or more medications to treat his or her illness.

All caregivers were prescreened by phone, when necessary, to ensure they met the inclusion criteria.

The caregiver interviews were face-to-face using a semi-structured format. A guide was developed for this purpose (see discussion below and Appendix B). The interviews were audiotaped for evaluation at a later time. Each interview lasted about one hour. All the interviews took place in a quiet private location at an urban hospital. The interviews were transcribed for analysis by the researcher and a second person, also a social worker with experience working with persons with schizophrenia and their families, once all of the interviews were completed. Institutional Review Board (IRB) approval from the University of Pennsylvania was obtained prior to the interviews. Consent forms were signed before any interview and approval was obtained from the caregiver prior to the interview. Each participant was reimbursed \$20 for the interview.

### **Recruitment Strategy**

I recruited caregivers from the Outpatient Neuropsychiatry Clinic at an urban hospital and from study flyers posted at the same hospital. IRB (Protocol #812132) approval was obtained prior to recruitment. It was requested that the staff obtain permission from the caregiver for me to contact them directly. Once approval was obtained, I contacted the caregiver and discussed the research project. If the caregiver gave verbal permission for the interview, I arranged a time to meet them at whatever location best suited their needs. Before we met, I

informed the caregiver that the interview would be audiotaped and later transcribed for the study. From the posted flyers in the hospital I received calls directly from the caregiver and discussed the study and explained that the interview would be audiotaped and that there was a \$20 reimbursement for their involvement. I also obtained a signed consent before the interview was conducted.

### **Description of Interview Sample**

Six African American caregivers were recruited from an outpatient neuropsychiatry clinic. They included five female and one male caregiver. From the posted flyers, two males and two female caregivers were recruited. The total interviews completed were ten. They included one father, five mothers, one sibling and three partners (one married and two not married but together over 2 years). All persons with schizophrenia were less than 50 years of age, were from the Philadelphia area, and were born in the USA. All the caregivers' loved ones had at least one hospitalization in the last 5 years. Demographic information was collected in a special form at the time of the interview. Table 1, below, was added to illustrate the caregiver demographic information.

Table 1  
*Caregiver Demographic Information*

Age	Race	Sex	Relationship	Years as caregiver	Live together	Native to Philadelphia area and a citizen of the USA
65	AA	M	Father	5 plus	yes	yes
29	AA	F	Partner	5 plus	yes	yes
47	AA	M	Partner	5 plus	yes	yes
32	AA	M	Partner	2 plus	yes	yes
45	AA	F	Sister	5 plus	yes	yes
44	AA	F	Mother	5 plus	yes	yes
49	AA	F	Mother	5 plus	yes	yes
60	AA	F	Mother	5 plus	no	yes
48	AA	F	Mother	5 plus	yes	yes
52	AA	F	Mother	5 plus	yes	yes

## **Interview Guide**

I used a self-designed semi-structured interview guide. The interview guide is included in Appendix B. The interview guide consisted primarily of open-ended questions to make it possible for me to get a better sense of the caregiver's role, attitudes and involvement in medication management. I also tried to incorporate trends noted in the literature review about the importance of cultural attitudes about mental illness and taking medications (e.g., Horwitz, & Reinhard, 1995). In addition, the questions attempted to explore what strategies have been used that were effective.

## **Key Informants**

Two key informant interviews with mental health experts were conducted. One was a psychiatrist and the other was a psychiatric social worker. I did not electronically record these interviews but took notes, which I subsequently wrote up in a narrative form. The following questions were asked of the key informants:

1. What do you see as the role of the caregiver in the area of medication adherence?
2. What are the challenges facing your patients and families in this area?
3. How do you see culture and ethnicity impacting patients taking antipsychotic medications?
4. How does the system support caregivers? How does the system impede caregivers?

## **Data Analysis**

As mentioned, this study used modified grounded theory methods as described by Charmaz (2009) for constructivist grounded theory analysis. The data analysis process included memo writing and coding to include initial, in vivo and focused coding procedures. In addition, the researcher conducted ongoing reflexivity writing about preconceived ideas regarding caregivers, caregiving and the research process.

**Memo writing.** I wrote memos about my emerging ideas during the data collection (Charmaz, 2006). This was done after each interview. Charmaz (1999) describes memo writing as the pivotal intermediate step between coding data and writing the first draft of the analysis

**Initial coding.** The study involved initial coding. This involved word-by-word, line-by-line, incident-by-incident coding to meet the criteria for completing a grounded theory analysis:

fit and relevance (Charmaz, 2006). According to Charmaz, the study fits the empirical world when you have constructed codes and developed them into categories that crystallize participants' experience. This helps makes relationships between processes and structures visible.

**In vivo coding.** In vivo coding refers to codes of participant's special terms (Charmaz, 2006). In vivo codes help us to preserve participants' meanings of their views and actions in the coding itself. In vivo codes serve as symbolic markers of participants' speech and meanings. In vivo codes do not stand on their own in a robust grounded theory; these codes need to be integrated into the theory. Charmaz (2006) states that there are three kinds of in vivo codes that prove useful: "Those general terms everyone 'knows' that flag condensed but significant meaning. A participant's innovative term that captures meaning or experience and insider shorthand terms specific to a particular group that reflect their perspective " (p.55).

She goes on to say that in each study one conducts, participants will use words or write things in a way that crystallize and condense meaning. Hearing and seeing their words anew allows one to explore their meanings and to understand their actions through coding and subsequent data collection.

**Focused coding.** This is the second major phase in coding. These codes are more directed, selective and conceptual than word-by-word and line-by-line and incident-by-incident coding. After I have established some strong analytic directions through my initial line-by-line coding, I began focused coding to synthesize and explain larger segments of data. Focused coding means using the most significant and/ or frequent earlier codes to sift through large amounts of data. The goal is to determine the adequacy of those codes. Focused coding requires

decisions about which initial codes make the most analytic sense to categorize my data incisively and completely.

### **Reflexivity Journal**

During the interview process I kept a journal of my thoughts and experiences. Since most of the caregivers elected to come to the hospital for the interview, I tried to be sensitive to the fact that the caregiver was not a client I was working with during my regularly scheduled job at the hospital as a social worker. This was not easy because the psychosocial stressors that the caregivers often shared with me were in some ways similar to issues I work with everyday. It was difficult not to give advice. The interview could have easily turned into a counseling session. Another area that I journaled about was my own experience as a caregiver and attempted not to conflate this experience with that of the one the caregiver was experiencing. Again, this is harder than it might seem. Since my education and training are as a social worker, I use a strengths based approach in my work. It was difficult to remain neutral at times and not get the caregiver to focus on the positive aspects of caregiving. The journaling helped me stay clear about my role in this process. My current attitudes about caregiving responsibilities for my mother were also an area that I tried to be aware of and its impact on my interpretation of the data.

### **Reflexivity Statement**

Caregiving can be a wonderfully rewarding experience as well as an incredibly draining and stressful one. I was a caregiver for my grandmother while I was a senior in high school. She lived next door to me and could not be alone at night and needed assistance with cooking, running errands and occasionally with bathing.

At the time, I resented this responsibility. It was difficult to manage my own feelings of resentment. Of course I knew she was sick and needed the help and I knew that I loved her and wanted to help, but it was time-consuming and at times, draining. There was setting up pills boxes every week, shopping, cleaning and having to get up in the middle of the night to assist my grandmother with getting out of the bed to go to the bathroom.

I now realize what a great honor it was to care for her and how much love and support she gave me. In time I came to realize that it was one of the most important things I have done in my life. It was an experience I will never forget and one that now means more to me than anything else I have ever done in my life.

While conducting this study I have also been a caregiver of sorts from a distance for my mother. She has had multiple health issues over the last year and they reached a crisis over the last month. This necessitated my traveling to Arkansas to help my stepfather manage some of her care needs. This very difficult time period also brought home to me the more negative aspects of the role of a caregiver. My mother has cognitive deficits that can make her difficult to be with and impede her getting the care she needs. I have seen first hand the frustration of family members who distance themselves from the person needing help because they cannot cope with the illness and the caregiving needs. I have also been forced to deal with the fragmented health care system and the frustration and anger it can engender in families and caregivers.

I also have worked for many years as a social worker working with families in the role of a caregiver for persons with mental illness. I have sat for hours listening to their stories of the difficulties involved in caring for someone with delusions, for example, a relative's belief that the caregiver was trying to "kill" them by "forcing" medications on them. The loved ones at

times are off their medications and floridly psychotic and a danger to themselves and threatening to others. I have heard the stories of caregivers trying to get help from the community mental health system and getting nowhere. I have listened to the caregivers' difficulties in getting information from doctors, nurses and social workers about their loved ones and the medications they are taking and the possible side effects that they often have to deal with at home. It is tragic to watch a daughter, son, or spouse decompensate before your eyes and feel powerless to help them and then to have the "professional" deaf to your pleas for help. Suicide is certainly a possibility with a person with schizophrenia who is psychotic and not receiving services to assist him or her to stay well.

Through these times of listening and trying to help, I would remember my own experience and the eventual satisfaction the role provided me in hindsight. This is not to say that my experience will be that of others, only that for some people caregiving is not only a burden but also an act of love.

I also have personal experience with a family member who has a severe mental illness. My brother has been diagnosed and treated for a severe mental illness for many years and I have firsthand experience with his and my family's struggle to cope with the illness. While I am not a direct caregiver for my brother, I am aware of his condition and circumstance and how they have impacted my mother who has been a caregiver to him on and off for over twenty years.

During the process of conducting the interviews, it was apparent how much time and energy went into helping loved ones remain stable and out of the hospital. Caregivers discussed their difficulties and the behavior of their family member when they were not in treatment but continued to support and encourage their loved one to resume treatment and get better. They

expressed gratitude to their families for the support they received and they often would thank God for the strength to carry on in often difficult circumstance. I often wondered if I would be able to “manage” with a family member living with me who was not in treatment and possibly acutely psychotic. Caregivers often had to contend with bizarre behavior and somehow not lose hope and keep going.

The actual coding of the interviews was an arduous process and required putting aside my own notions about what caregivers should and should not do. It was difficult not to read into their behavior more than might be there or to portray their responsibility as heavier than they imagined them to be because of my own sense of discomfort with the behaviors described. I have worked hard to keep my own biases out of the study as much as possible and allow the caregiver participants to tell their own story.

## CHAPTER IV

### FINDINGS

The study findings crystallized around five core areas of interest. They are (a) the centrality of monitoring medication adherence, (b) strategies to promote medication adherence, (c) non-medication adherence caregiver activities, (d) cultural values and religion, and (e) supports and coping methods. The views of key informants on caregiving difficulties around medication adherence are also described. This chapter begins with a discussion of the five core areas with corresponding caregiver comments to illuminate the findings.

#### **Centrality of Monitoring Medication Adherence in Caregiver Role**

All the caregivers expressed a basic understanding of why the medications were necessary and what they did to facilitate improved mental health for their family member. They had all met with the psychiatrist for their family member and appeared to have acquired an understanding of the symptoms of schizophrenia and that while there was no cure, the medications did minimize the negative aspects of the symptoms and improve the overall functioning of their loved one. Ms. P gave an example of her sister's behavior when she is not taking her medication. While her example is dramatic, it is not unusual.

Well, I think the medicine they're giving her really helps her, a lot. Because when she's off of it, like one time she was off her medicine and wouldn't let nobody take her to the hospital, wouldn't let nobody do nothing for her--this was awhile back, like years back--then one day I came home from work and I was looking at her and she had washed her face with bleach! She told me something like, "I couldn't get the dirt off." I was like, "What?" I mean her whole skin was like.....

Her example illustrates why so many caregiver try to anticipate non-adherence in their loved one and strive to circumvent it. The danger to their loved one and the constant feeling of having to be on guard can be overwhelming at times for the caregiver.

All caregivers were involved in some capacity in helping their family members take their medications. This was expressed in caregivers' overseeing their taking of their medication, obtaining the medications, administering the medication, storing the medications, arranging a psychiatrist visit, and/or encouraging the family member to take his or her medication.

In the following example, Mr. F talked about his monitoring role with his wife. Several of the caregiver used this word, *monitoring*, and it appears to be an anticipatory strategy to avert a problem later on. He described his role as follows: "Well, I like monitor her to make sure that she takes the medicine, but sometimes she doesn't like to take her medication. But I do reassure that like, 'this is for you and your well-being, so it's necessary that you take your medicine.' And sometimes....I get it, I go to the pharmacy, refills it, all of that."

All the interviewees conveyed that monitoring the behavior of their loved one was a primary function they provided as caregivers. In fact, many family members appear to have internalized the monitoring role so much that looking for signs that the family member is not taking his or her medications has almost become second nature. It is something they do without realizing it and appears to define the role of caregiver. Here is how Ms. T spoke about her husband and her role as a caregiver to him:

I look out for the predictors. Like I know if something isn't going right, because his behavior changes, and he doesn't notice it right away, and I'm the one who notices. So I

notice a change in appetite, or the way he's interacting with us at home, or whether or not he's getting the amount of sleep he needs, things that he doesn't notice right away.

This quotation illustrates how the caretaker tunes into the family member's behavior, looking for signs that he is not taking his medication.

A caregiver with a daughter with schizophrenia, Ms. W, describes her experience in this way: "I see the medication as making her more like herself, more kind, understanding and approachable. When she is not taking her medication she would lock herself in her bedroom, stay in bed all day and sometimes not even eat... I have to constantly remind her to take her medications." Another caregiver, Ms. G, talked about how she prevents her son from not taking his medications for long periods of time and thereby, increases his medication adherence. As she explains, "It's only hard if he hasn't taken his medicine in a really long time, like in a month, but I won't let that happen. If I have to bring him 10 pills and he threw them all away, but the 11<sup>th</sup> one he took, it's worth the 10 he threw away." Both of these mothers are also having to contend with the role of caring for an adult child who, according to life course development theory, should normatively be independent and starting his or her life. This appeared to cause great sadness for both mothers. They had professional and personal hopes for their children which they now knew would probably not happen. The caregiver's life course, too, had been interrupted and perhaps forever. This is something that all caregivers have to cope with, changed expectations for their loved one who may not have a "normal" life trajectory.

The symptoms of schizophrenia can be so severe and disruptive not only to the loved one but also to the family. Averting an "episode," as several of the family members call them, can be a 24/7 job and becomes part of the monitoring role. Ms. P talked about caring for her sister. Like

all the family members, she seems to have a great deal of love and devotion for her sister, but also we get a sense of the challenges she faces:

Well I'm her older sister, and I'm the sibling who takes care of everyone in my family, for real. But talking of her, you know, 'cause she gets out of hand sometimes, you know she goes through her tantrums, and I have to tell her to go comb her hair, or take a shower. You know, she fusses with all three of us (her two teenage daughters who also live in the house), but we love her. I love my sister and they love their aunt.

Um well basically it's just the three of us with her. So we all help each other. And I mean she helps us, too, because when she's on her medication, I can ask her to do things and she'll do it. But if she's not on her medication, she ain't gonna...Do you want me to cuss? (Interviewer: Sure go ahead) .....She'll say, "I'm not doing a f\*\*\*ing thing! I don't know who you think y'all is, I ain't doing nothing!" It's like she's a whole different person, it's like, what the heck happened to her? And then she's in the back yard, cussing, and you're like who is she cussing out?

Ms. P went on to say there was no one there. Her sister was cursing at an imaginary person that she thought was there. Ms. P has learned about schizophrenia and knows this can be a warning sign of an episode.

All the caregivers saw the medication adherence as not only supporting independence in their family member but also allowing for more "normal" family life at home. The monitoring role further helps to achieve normalcy at home. This is not surprising since having a psychotic loved one living with a caregiver can be alarming and disruptive to everyone involved. All of

the caregivers whose family members lived with them talked about this experience. Typically they would redirect their loved one or explain to them that what they were experiencing was part of the illness and could be lessened by taking their medication. There was a clear connection between active psychosis and medication non-adherence for the caregivers.

Part of the monitoring role also seemed to involve recognizing when a psychotic loved one required more than medication treatment at home. Many of the caregivers had to involuntarily commit (what is known as taking out a “302” in Philadelphia) their loved one to a psychiatric hospital for observation and treatment. Here two family members speak about what a difficult process this is for them. First, Ms. G explains how her son’s landlord lets her know when things have gotten out of control. Again note the monitoring process, this time involving someone other than the family caregiver:

But before he was working, I’d stop by either on Friday night or Sunday and it’s hit or miss. So I usually assess by looking in his room, you know, if he was just there or not. Now he has his landlord, (and) she told us at the time that he was getting really bad, that he needed a 302. So she’ll text me or when there was a period of time where I didn’t see him for about two weeks.

The second example is from Ms. T. She describes how she monitors her husband and the challenges they faced before marriage when she had to commit him involuntarily:

But prior to that, in the beginning he always says, “I’m okay”... and I try to tell him, not convince him, but I try to let him see just telling him what I notice differently. So I compare the two-what he’s doing now compared to what it is you usually do....

Yeah, when he first got sick, I had a hard time 302 him, because of course at that time I was his girlfriend, and they don't take things like that lightly, because they say they don't know if it's malice.

The legal system does not recognize a girlfriend the same way it would a wife. The legal status of a wife is different and holds more authority. Although many people live in committed relationships and are partners in the same way a married person might be, this can be a hurdle as caregivers monitor and obtain treatment for their loved one.

To summarize, monitoring medication adherence appears to be the central activity around which all other activities seem to rotate. This is so because schizophrenia can be hugely disruptive and make the other activities of caring for a person much more challenging. It is difficult to provide support, carry on a conversation, and assist with daily tasks if the person one is trying to help is so impaired that he or she refuses all assistance or refuses to even see the need for assistance.

### **Strategies to Promote Medication Adherence**

All caregivers were involved in promoting medication adherence and most developed one or more strategies to do this. They provided encouragement and support around the taking of medications. They were also involved in filling prescriptions, storing and administering medications. The caregivers described a variety of strategies that they used. One of them, *encouragement*, was a common strategy described by the caregivers. One caregiver, Ms. C, talked about how important providing encouragement has been when things are particularly challenging for her son:

I could say a typical day with T when things aren't going well, is me having to keep putting encouragement in him, talk with him, letting him know that he can do anything he wants to do, to not care about what other people say about him, that he's still just as good as anybody else, you know?

She also drew on her own life experience to encourage her son, "Well I try to plant things in my kids I've learned from my lifetime, 'cause I've really, really, really been through a lot. So things I've been through in my lifetime, I got through it, so I let them know they can get through it too."

Another caregiver, Mr. F, also talked about providing encouragement. Here he talks about his wife at a time when she would speak of wanting to give up:

Just by doing what I do now, just keep encouraging her, you know. And I always, I don't know if it's right, but I always use her kids as an example, I say, "What would they do without you? If you were to do some harm, or something to yourself?" 'Cause sometimes she'll say she don't want to live, sometimes she do say that.

Another strategy utilized by caregivers was *storing and administering medications*. This was also a common activity for the caregivers. Many reported the need to store medications or they would be lost or misplaced. Ms. G spoke about administering her son's medications:

So I give him his pill every night, and I usually say, "Here you go, babe." But It took me three years for him to accept that A, something was wrong with him, and B, he had a problem with the diagnosis, which I understand, nobody wants to be diagnosed that, and C, he had a problem believing that it was his medication. I had to prove to him that it was his medicine.

One family member talked about using a special bowl. He left the medication in this “special place” every day he had to work early. Mr. L said the following: “Now, well if I have to go to work real early, I’ve got a dish, a little small Asian dish, and I’ve got him trained. I put the medication in there and something there for him to drink ‘cause he dehydrates a lot with his medication.”

Another strategy used was *modeling behavior*, taking medication in front of the family member and giving them their medication. One particularly vivid illustration of this is the case of Ms. G with her son:

What I started doing, when he wouldn’t take his medicine, was taking my blood pressure medicine, which I probably need to up now, and I’d take it in front of him... I’d say, “Oh it’s a good thing I take this because my blood pressure would be through the roof, and I’d have a heart attack. I’ve got to take it every day.” I’d be nonchalant, no big deal. I’d point out his dad takes a lot of different medicines and his insulin for his diabetes and say “You and me, we’re lucky we just have to take one pill.” I started doing that everyday, I still do it.

Ms. G modeled the behavior she desired from her son. She also provided encouragement, and compared their “lucky” situation with other people who have to take a lot of different medications:

So with the medicine, what I’ve been saying lately is, “if you take your medicine every day, it’s possible you may go in remission...so we’re not there yet, but that’s my newest thing, because I want him to take his medicine every day. I give it to him in trust, but really, I want to throw the medicine down his throat and make him swallow!

Another caregiver, Ms. T, used a different approach. She *compared her husband's behavior from day to day*. She attempted to help him gain insight into what he was doing that might be a problem. Here is an example from Ms. T in relation to her husband:

Well yeah, just communication. I know that J, he doesn't like to be told that something is wrong with him when you notice a change, so I always have to make it to be positive. I'll say, "Oh J, I noticed today you just ate oatmeal, but yesterday you had your breakfast, you had your nuts and your fruit and your this and your that" and it'll make him think, "Oh, I didn't even notice that." Instead of me saying, "J something is wrong with you, I think you're getting sick again."

*Communicating with the family member* to ensure he or she was taking the medication was also a common strategy. This description by Ms. T, talking about her husband, is a good example of this type of caregiver role:

We have a good system in place. A lot of it has to do with communication. A lot of it has to do with that now he accepts that he has the illness; he understands more about it, he's willing to go to the doctor and all that other stuff. He doesn't mind me being on top of him, you know, just kind of like his reminder person, so the communication is good and we just have a good system.

Another example of the lengths some caregivers go to improve medication adherence in their loved one is the case of Ms. C. She describes below how she initially managed with her son's medication non-adherence by putting the medication in his food. He was not agreeable to treatment and did not believe he had schizophrenia:

So when he didn't want to take his medication, I had to ground it up and putting it in their food, I had to start doing that.....then they got hip to that and I had to find another way to try to make them take their medication. Then I had to start putting it into their juice or their soda until it dissolved, and that's what really kind of helped me out. I mean, it's a lot going through it with somebody with schizophrenia.

Another area of assistance provided was *logistical support*. The caregivers were involved in taking their loved one to see the psychiatrist, confirming appointments, dropping off medication prescriptions and picking the medications up at the pharmacy. These were all areas of assistance to their loved ones that the caregivers mentioned, as areas of help they provided to their loved one. Ms. D describes her role in this area:

Um, well he allows me, at this time, to take him to the doctor, now that he is willing to go see the doctor. I pick up his medication for him. Um, I just, you know, wanted to make sure to ask him how he's doing, you know, is he sleeping, is he eating? And I try to, I guess, challenge him during the times where he feels like he's not going to take his medications.

The *advocacy* role was also important to many caregivers. All the study participants' loved ones had been hospitalized at some point and due to their functional impairment were not always able to advocate for their care needs. Ms. C discussed her role as an advocate when her son was in the hospital after an acute psychotic episode:

When he was in the hospital, I sort of challenged the doctors to say, you know, "If you're going to give him medications against his will anyway, then why don't you make the decision to do a shot if you feel the shot is really going to help him?" And so, I'm

sure that they had discussed it while he was in there and so luckily he followed through on it...It's time-released in the body over the month. So he tells me when the appointments are, and I contact the secretary just to make sure he had an appointment and when he comes, and that's pretty much it.

Ms. C felt that the monthly shot was a better option for her son. Her intervention appears to have made the difference in her son's treatment. She reported that he functioned much better with the monthly shot. His issues with medication adherence also decreased since there was no daily medication required to control the symptoms. She also established a good working relationship with her son's psychiatrist which also improved her son's adherence and quality of life.

#### **Non-Medication Adherence Caregiver Activity**

All caregivers were involved in activities outside medication management. These included providing encouraging activity, taking charge of the household, and staying aware of new and current treatment options. Ms. T spoke of *encouraging her husband to get active* by making sure that he gets up in the morning and by checking in on him later in the day. She stated:

We kind of encourage him to try to get up in the morning, but I know he really needs his sleep. Some morning he'll say he'll take the kids to school for me, and then he'll go to the gym, and that's basically it. And then I don't see him until the next morning...I talk to him on the phone throughout the day, just to see how things are going and vice versa, but he works at night and I work during the day.

At this point Ms. T reports that her husband is doing well. He is taking his medications and she reports they are very effective in controlling the symptoms of his illness. She was aware that apathy is a negative symptom of the illness. It is also one that she finds difficult to cope with as it seems merely a lack of interest in something that we all feel. The connection with his illness was not always an easy “bridge to cross.” Her comments describe a normal give and take in their relationship. This was not always the case. Her husband has been hospitalized several times and had difficulty taking medication in the past. Ms. T has persevered through it all.

Another caregiver, Ms. G, spoke about how she *encourages her son’s artistic side*. “I tell him that I’m always in his corner, that I’ve always got his back, and I always do positive things. Like I bought him a piano for his birthday, a used piano, ‘cause he wanted to learn how to play.”

Mr. F, whose wife has schizophrenia, said that he *takes charge* by assuming full responsibility for the household at times while providing emotional support. Here, in his own words, is a description of the things he does for his family:

You know it’s like basically, emotionally, and sometimes just doing everything around the house; like the cooking, the cleaning, the laundry, and all that type of stuff. So that’s basically my role mostly every day. And just trying to be there for her when she needs someone, a shoulder to cry on, or just someone to talk to. I try to keep her positive as much as I can, you know, on the outcomes of life.

Mr. L spoke of his concern for his son and how he takes charge by keeping him safe. “And then, the non-working hours, I just take him with me. That’s all, just drive around, keep an eye on him more or less.”

Another caregiver, Ms. G, commented on how she tries to *stay current on treatment options*. Hoping that soon she will hear about a treatment or program that can improve the life of her son, she explained, “I am the ‘interceptor.’ For care, to see if there’s any up-to-date, or revised or better research or programs so he can get it. I make sure he gets his meds. Sort of I guess the middle person, the middleman.”

### **Cultural Values and the African American Community and Church**

Many of the caregivers spoke of the role of faith in their lives and how important it was. Not all the caregivers went to a church regularly, but they all mentioned God and prayer as supports.

Ms. G spoke eloquently about her experience and the difficulty she had accepting the diagnosis for her son. She also spoke of an understanding pastor at her church who was receptive to education around mental illness at the church she attends. Ms. C in particular spoke about her strong faith:

I keep telling him, that he has a good heart, he’s a real good person, T will go out of his way for anyone, just anybody, he don’t care who it is....I get up every morning and thank God for waking me up, for my children and sometimes I need that time just for me to just read my Bible. I put that in my children’s hearts, you know, no matter what you go through, trust in God because God don’t lie. I lean on Him each and every day no matter what situation I go through and He always carries me through.

Another caregiver, Ms. W discussed the first time she knew her daughter was really sick:

I thought she went to bed but no; she was up in same clothes, in the kitchen and had torn my kitchen up. She had on rubber gloves and had dumped my toaster oven unto the table,

talking crazy...accusing me of why my dad died, belittling me and I called my mother and she came over and then my youngest brother came over who is a pastor. We prayed for her, but she started sticking her tongue out and was like looking through you. My brother said we can't leave her here like this so...we took her to Einstein...they admitted her. She talked non-stop for ten hours!

Some of the caregivers did comment on the *negative view of mental illness in some of the churches* they were familiar with. Ms. G, who has a son with schizophrenia, spoke about the attitude in some churches and she also spoke about the support she has received from the NAMI support group, Family-to-Family:

Well yeah (when asked about cultural background attitudes), I think there's a definite taboo regarding mental illness. And I think that's, you know, part of the problem, too, especially when someone's so young, and you don't want to be different, what have you. And I think that our culture also, as we're Christians, you know some Christians feel that it's just something you can pray about, it's either a demon or something that was a result of some sinful act that you did or whatever. SO you get a lot of that, too, when it comes to mental illness. Um, I think that our pastor, I think Family-to-Family has been really great because they provided training to our counselors at our church and to our pastor who has distributed the flyers for Family-to-Family...so I think that it's very good as far as going into the Black churches educating the group there, that can then reach out to communities and things like that.

Ms. G spoke specifically about attitudes in the African American community. She talked of the stigma of mental illness in general but also in her own community. She explained:

Sometimes in the Black community, there's such a stigma, that they won't go to someone...I worked in a hospital so I have a different view, and I've worked with psychiatrist so I have a different view. But, even if you work in a hospital, in African American culture and in Spanish culture and maybe Asian culture, they believe that if someone's mentally ill or something, that you just kind of keep that from the community, because you're ashamed, and you don't tell anyone. Or everybody has that crazy uncle or aunt...but nobody really discusses it. So, by asking around, I found out that two people in Ronald's family had something, but no one really told me what that was...I told my sister-in-law, me and her are pretty close, what A diagnosis was and I'm sorry I did. I was very frustrated that day and I needed someone to talk to, and I told her it was confidential information and not to tell anyone...but I could tell when we went to a wedding, from how everyone was treating A, that she had and that hurt...It's bad enough when people know you're kind of strange, you know, but that could be anything. What I tell my son, and what we tell people now is A was in the army, and when he came out he had post-traumatic stress or bipolar. But we don't tell them schizophrenia, because it just seems, when you say that word...

Other study participants shared their thoughts on the attitude of mental illness in the church, for example:

I have to reassure her that it's alright to be on medication. Sometimes she feels like...an outcast 'cause she's on medication, maybe. It's due to her family a lot, because they don't understand. I know they've known her longer than I have, but they don't understand medication. They're like, I don't want to put this the wrong way, they're like church

people, and they think God should do everything, without medications, and stuff like that. They're religious like that... They think God, just pray and God will heal it and make everything right. But I guess they don't understand, some things, God put these here for you, too.

Thus, even though the church and God provided support to some caregivers, for others, the influence was negative.

*Hopefulness* was also another common cultural theme that, based on their own reports, characterized the caregivers. All expressed hope for the future and they all shared a common belief that their loved one could get better and lead a productive and valuable life. They all saw the illness as something to overcome or work around, but not so debilitating that they could not have hope for the future. Ms. T's views were common among the caregivers, who refused to see schizophrenia as the defining characteristic of their loved one. Here she talks about her husband:

Just that besides having schizophrenia, he is an excellent man, an excellent father, and excellent provider, I couldn't have asked for a better mate, a better partner, a better father for my children. You can see past, that's the stuff that I see. I don't see the illness; I see all the good things. There are people, who don't suffer from mental illness, and they do a lot worse, you know what I mean?

Self-reliance, rather than reliance on outside programs, was a cultural value the caregivers cherished. The caregivers saw the value of educational programs and community support but only a few of them had ever taken advantage of these services for themselves. The exception was Ms. G, who attended the NAMI sponsored program, Family-to-Family. The underutilization of community support programs for caregivers was most often because of lack

of time or scheduling difficulties due to other obligations. Most caregivers received their information about the illness from their loved one's psychiatrist or from staff at hospitals during times of hospitalization. The family members with schizophrenia had all refused participation in day programs and client support groups. The most common reason the person with schizophrenia declined participation because they did not feel comfortable in such groups.

### **Support and Coping Methods for the Caregiver**

Most caregivers expressed the *importance of the family* in the caregiver's life. Although this sometimes involved conflict, it was a shared value. All the family members relied on their family for some level of support. This was primarily around taking medication but also included a strong emotional bond to family. Typical of the responses were Mr. F's comments on his parents as a strong support: "I usually talk to, my parents helps us out a lot, and then my best girlfriend, we've been friends for 10 years, and we talk a lot. She still lives in North Carolina so we talk over the phone a lot. You know you need a venting person, just to hear you out and let you get it out."

Another caregiver specifically mentioned his mother as a strong support. As he said, "I talk to my mom a lot, you know, and she has to tell me lots of the time that if I love her then these are the things I have to help her with, you know, in order for the relationship to work."

Other caregivers spoke of close friends who they would turn to as support or as a diversion for the responsibility of caring for someone with schizophrenia. One caregiver said:

Um, sometimes, I have one close girlfriend, we're like sisters now, and maybe I might get out and go around to her house and sit with her for a minute, but it's not a thing like,

you know how sometimes you just need to get away just to be by yourself, to get your thoughts together, just to think?

While almost all of the caregivers spoke about having family supports, one expressed a feeling of having lack of support at times from some extended family members. Ms. G talked about the stigma associated with schizophrenia:

(Interviewer: Do you feel supported?) No. Because you can't tell everybody, because it's such a stigma. I'll give you a for instance. My husband R has a large family. And I think in his family there may be schizophrenia or bipolar.... but I'm the in-law, so no one's directly told me that, and I wouldn't directly bring that up. Because, first of all, when we found out that A was diagnosed with schizophrenia, I was in denial, I really was. Everybody was, 'cause it was like, where did that come from?

(Referring to people with schizophrenia) I don't see enough of that, like people who have it, talking about their illness. I would love to see that, we need that.... I think it would help with the stigma, too. Not that they may be perfect, (but) you may be able to tell they're, whatever, you know, with their meds. I know there was that one professor; you know the story, the movie that they made? (Interviewer: "Beautiful Mind.")

Faith in God and prayer were also strong supports. They talked about their faith as a source of strength. This allowed some to do what they had to do on a daily basis. None of the caregivers used religion as an explanation for the illness. Several of them did however discuss how some people in their families attended churches where taking medications for mental illness was not the answer to getting better and told stories of family members telling them prayer was

the only answer. The caregivers did not reject prayer as an adjunct to medication but used it more for support.

The relationship with healthcare providers was also a source of support. Several expressed their gratitude for having a caring, understanding psychiatrist. Mr. F specifically spoke of this support. He said (referring to meeting with psychiatrist), “It was very helpful, he gave me a little more insight about the schizophrenia, helped me understand a little better. ‘Cause for real I didn’t know what actually was going on. Without the help of him then I might still have been in the dark a little more than I am, but it was very helpful talking to him.”

Ms. G spoke of a social worker who was particularly helpful. Her comment shows the role a health care professional can have on easing the sense of burden a caregiver often feels. She said (regarding a social worker in her county):

She was a huge support to me. She would help as far as helping A understand what was available to him, another person he could call for whatever reason if he couldn’t get hold of me. You know he never really agreed to do the group therapy or anything like that, he always felt that, and it was true, that it was more for older people, so he couldn’t really relate with the people who were in those groups.

The social worker was someone who contributed to her a peace of mind and demonstrated that someone else cared. Also important was that she felt her son had another person to turn to if he was in need. This feeling of not being alone was very strong for Ms. G. She needed to feel that her son would be protected if she were not around. While Ms. G was in good health, she was older and worried about who would care for her adult son if her health declined or if she died.

As mentioned earlier, one caregiver had participated in the NAMI-sponsored family education program, Family-to-Family. Participation in the educational workshop and the follow-up support group appeared to add another layer of support for this caregiver outside of family and friends. In regard to this program, she said:

We have my Family-to-Family support group, so the families, I guess there's maybe seven or eight of us, um, who went through the workshop together and then we meet maybe every quarter, or twice a year, what have you or we're on email too if something gets too bad we'll reach out to each other.

She indicated here that the members of the support group continued to help each other after the family educational workshop ended.

Two caregivers mentioned their loved ones' work as a source of support. They were still able to work because they worked in an environment that took into consideration family needs and allowed flexibility to the caregiver and, in some cases, to the person with schizophrenia. Here are a caregiver's comments on a particular caring boss: "You know, I feel it's a blessing that his boss, you know, still allows him to come to work and A must, you know, try to control it as much as he does. He's pretty good at controlling [the symptoms]." Another caregiver expressed a similar appreciation for his employer. He said:

Yeah. And my boss, we come from another job together. So, he pretty much knows what's going on, so if I get a phone call and I have to leave, he understands. Sometimes he might make me punch out, sometimes he might not....I miss her working, but it is what it is. I love her...she's still a good partner.

One caregiver mentioned writing as a way to cope. He, at times, felt overwhelmed with his ill family member's behavior and had difficulty controlling his emotions. At these times, he would write down his thoughts and then read them back to himself when he became frustrated with the ill family member instead of responding to them in a negative manner. This is how he explained about what he does after a bad "episode":

After I think it's safe enough, sometimes I go, I take walks, and I do have family that I sit and I talk to a lot. Sometimes I just sit and write and write, sometimes I do, just sit and write, write, write, letters to myself sometimes. Some things that I probably wouldn't say to her I'll write out on paper, you know.... Then if I read it, and I look at it, and I think about it, I'll say yeah, it's good you wrote this on paper!

In summary, all the caregivers who participated in this study had a role in medication management for their loved one. They all experienced a loved one in an acute psychotic episode and at least one hospitalization related to this episode. They saw a clear improvement in their loved ones' functional status with proper medication adherence; and hence the centrality of their caregiving role around taking medications.

Caregivers also named a host of supports. Family and faith in God were the primary supports. The relationship with their psychiatrist was also mentioned as an important support. Two caregivers benefited from formal educational programs or support groups though most did not. They all were aware of the stigma associated with a diagnosis of schizophrenia for their loved one but refused to have their loved one defined by the illness. They all expressed hope for the future even if this hope was guarded.

## **Key Informants' Views on Caregiver Difficulties around Medication Adherence**

The study also included two key informants who gave their views on medication non-adherence in persons with schizophrenia. One was a social worker who has worked for over 10 years in the area on mental health and has experience in the community and acute hospital setting. The other informant was a psychiatrist familiar with the illness and challenges faced by patients and caregivers. They described five areas of challenge for the caregiver. They were: (a) monitoring and advocacy role for the caregiver with the treatment team, (b) the difficulty of taking medications in general over a long period of time and when the client does not believe he or she is sick, (c) the often severe side effects of psychotic medications, (d) an unresponsive mental health system, and (e) privacy laws (i.e. HIPAA) that hinder inclusion the caregiver in the treatment process (HIPAA).

They discussed the important roles of *monitoring medication adherence in the home and advocating* to the treatment team when necessary on behalf of the patient. They explained that the caregiver is often in the position of having to daily remind the patient to take their medication. They also are responsible for storing and administering the medication in many cases. They, more than anyone on the team, know when the patient is not adhering to their treatment plan. This monitoring role helps the treatment team evaluate the effectiveness of the treatment. They are also acutely aware of return of symptoms when the patient is not taking their medications. The caregiver also must at times advocate for changes in the medication treatment plan when they see adverse side effects or non-therapeutic responses to the medications.

The key informants also discussed the *difficulty in taking medications for undefined periods of time*. Patients often require medications for years or decades. Medication effectiveness

changes over time when tolerance to the dose increases and reevaluation is necessary. The ongoing time commitment to treatment is difficult for any patient, let alone one with an illness where a side effect may be that you do not feel you are ill.

The often severe *side effects* are another barrier to medication adherence in this population. The side effects can include weight gain, diabetes, decreased sexual desire or ability and increased blood pressure. The patients often report feeling "drugged" or having "blunted" emotions. Patients often described these feelings as feeling less, being less aware of their surroundings and decreased ability to participate in daily activities. These side effects must be managed with a supportive treatment team since finding the appropriate dosing can be challenging and time consuming.

Finally, the key informants talked about *the mental health care system* and its lack of responsiveness to patient and caregiver needs at times. The system often appears to only respond to crisis situations; therefore caregivers who are trying to maintain a sense of normalcy in their loved ones are often not prioritized for care. One example of this is the wife of a patient who could see her husband slowly decompensate from not taking his medication regularly. She tried to have him committed for treatment in the hospital but the system does not allow proactive admissions to hospitals. Instead, they want families to wait until the situation is so severe that the patient is a danger to himself or others. As one can imagine, by that time the caregiver is at her wit's end and desperate for help. If the system was more proactive and truly community based, perhaps more caregivers would have a place to turn before medication adherence became a much larger issue for them and the patient.

They also discussed *privacy laws* and their impact on the treatment process. While privacy laws are in place to protect us all from having our medical information disclosed without our permission, they can be problematic when a caregiver is involved and needs crucial information to continue effectively in that role. Individuals with schizophrenia who do not feel they are sick or in need of care may refuse disclosure of information on their treatment plans but they may be dependent on a caregiver to maintain themselves in the community. Also as the social worker explained, in a busy outpatient practice it is often easy for staff to say they cannot speak to a caregiver of family member because of privacy laws but in fact they just do not want to take the time to do so. Rather, they can explain the parameters of the privacy laws and obtain consent from the patient. This would be of great benefit to the caregiver and patient.

To conclude the findings chapter, the caregiver participants discussed their experiences around medication adherence for their family member with schizophrenia. They shared intimate stories about their struggles to assist their family member with staying out of the hospital and “well.” In addition, the key informants identified issues around medication that were salient to them. Themes that were common to caregiver and key informant participants were identified and illustrated with quotations from their interviews.

## CHAPTER V

### DISCUSSION, IMPLICATIONS, AND CONCLUSIONS

This study revolved around the following questions about the role of the caregiver: (1) What are the views of African American caregivers toward the taking of medication for schizophrenia? (2) How did the caregivers describe their role in relation to medication adherence? (3) What kinds of strategies did the caregivers use to promote medication adherence? (4) How did the caregivers describe their care giving role in relation to activities besides medication adherence? (5) How did African American caregivers incorporate cultural values into their care giving role? (6) How did caregivers view support provided to them by the community mental health system? In this concluding chapter, I will address each of these research questions, based on the participants' and my own interpretation of the meaning of the findings.

It is important to note the caregiver /cared for family relationship. All of the study participants were caregivers for a family member, whether a spouse, sibling or child. The study did not screen for this traditional definition of family but that is who volunteered to participate. It does, however, show the strong family ties that exist in the African American family and the belief that "family take care of family." This also has been shown in other studies to be characteristic of the African American family (Gerdner, Tripp-Reimer & Simpson, 2007)

#### **Discussion**

The caregivers discussed the importance of taking medication for management of the disease. They all felt the medications made a difference in the quality of life of there loved ones. The most commonly used phrase was that the medication allowed their loved one to live "normally." By normal they seem to mean the ability to interact in a socially defined appropriate

manner and included the ability to work, have a meaningful relationship with the caregiver and pursue daily activities that were enjoyable for the loved one. The caregivers often expressed frustration at seeing their loved one struggle in social situations and they noted it made their role more difficult when the family member was not in treatment. They felt it was their responsibility to care for their loved one. This is of course very difficult when the person you are caring for is in an active psychotic state and possibly a danger to themselves or others.

Several study participants noted their concern for the safety of the loved one when they were off their medications and appeared disorganized and were making threatening statements. Going off medication is also the single biggest cause of relapse and rehospitalization (Lacro, Dunn, Dolder, Leckband & Jeste, 2002). All the caregivers discussed their role of vigilance in trying to keep their loved one out of the hospital and well and again saw taking medications as the current best approach to this.

None were opposed to the taking of medication for treatment of the illness. They saw schizophrenia as similar to any other illness that benefited from medication therapy. This attempt on their part to make the illness like any other physical illness was interesting, given that they often spoke of the stigma of the mental illness and, in particular, a diagnosis of schizophrenia. Perhaps it was a way for them to reframe the illness in a way that made the caregiver more comfortable with their own loved one's mental illness. Several caregivers, as noted in the previous chapter, would not share the loved one's diagnosis with even close family and certainly not strangers they knew. They seem to believe that not only was it safer to be vague about their loved ones illness but also there was nothing to be gained, for the loved one, by sharing this information too liberally with others. This was not a universal feeling among the

caregivers, but all expressed reservations about sharing information about their loved one's illness to some degree. I also wonder if they did not feel adequately prepared/ educated about the illness enough to feel that they could have a meaningful conversation about what schizophrenia is and how it impacts their loved one. Bentley, Rosenson, and Zito (1990) explored this issue and found that often the caregivers do not have adequate information about the illness, symptoms and strategies for coping.

**Symbolic role of medications.** One way to decipher the meaning of medication to the caregiver is to examine it through the lens of symbolic interactionism. The daily interactions with the cared for person and the outer world that make meaning of the experience for the caregiver are important to understand the needs and expectations of the caregiver. The meaning of the caregiving role and the meaning of the illness, schizophrenia in this case, can be unique to each family and caregiver.

The caregivers in this study were all African American and native born. All were from the Philadelphia area with most having family roots in the southern part of the USA. This study illuminated the power of medications in the imagination of the caregivers. They all held the belief that medication for schizophrenia was the best hope for a normal life experience for their loved one. It appeared that the taking of medication became the central focus of their duties as caregivers. Medication adherence became a symbol of wellness of sorts. It was something they could grab hold of in a fight against a terrible illness of unknown etiology and an illness that often stigmatizes those you have it. The medications were the one concrete "weapon" for the caregivers to use to hold the illness at bay. They all knew the medications are not a cure for the illness but the medications were a symbolic of hope for normalcy. The other "weapon" was

prayer. This is an interesting finding in that there is a whole subculture movement against psychiatry and the taking of medications for mental illness. For these caregivers the medications were not some larger pharmaceutical money-making project that victimized the patient but a symbolic of hope for a normal life.

The medications seemed to be the one concrete thing that made the illness more manageable and that they could do something about that made a difference. It was not that they did not think psychosocial interventions were unnecessary or did not work. The consensus appeared to be that these types of interventions were helpful and necessary but it was the medications that were the main treatment option that they knew and could see made some difference in the quality of life of their loved one. As mentioned earlier, the medications also help medicalize the illness in a way that made it seem to be less threatening to them and others.

While all the caregivers expressed gratitude for having the medications, they recognized that the medications are not a cure for schizophrenia and that the so-called “normalizing” effect of the medications comes at some cost in side effects to the patient. While the caregivers did not minimize the negative side effects of the medications, they thought that in most cases the side effects could be managed and that the benefits outweighed the negatives. It is important to remember that the caregivers had all observed close up severe episodes of illness in their loved ones, some requiring court commitment to psychiatric facilities. Many also had the day to day experience of living with someone out of touch with reality and at times belligerent and hostile to the caregiver and others in their surroundings. In light of this experience, I think it is understandable that they would be so readily willing to minimize the negative side effects of taking medications in their loved ones. Many were responsible for the daily care needs of their

family member. This is of course their own perspective but one that is important for a full understanding of the issue of adherence. They saw the medications as the best treatment option for their loved one. The literature also bears out their view. Thomas (2007) looked at antipsychotic medication effectiveness and adherence. He notes that adherence to taking medication is an important factor in the effective management of schizophrenia, and poor adherence has been linked directly with impaired long-term outcomes. The caregivers did not directly state this connection, but they did note that taking the medications was important for their loved one to remain out of the hospital.

The caregivers saw themselves in a supportive role to their loved one. Their involvement varied but their commitment to keeping their family member well did not. They would remind their loved one to take their medication and often had a more involved role in this process. While they had different strategies for doing this, their central concern was the well being of their loved one. The centrality of the caregiver role was around the taking of medications and monitoring this process and their loved ones behavior for signs they were getting ill and that they were not taking the medication. One has to imagine the amount of stress the caregivers must have felt at times in this monitoring role. There was a constant sense that they were responsible for helping their loved one stay well. No matter how much they loved their family member, it was a strain at times, characterized by a sense of burden. Studies that have looked at burden and stress in caregivers have noted that severe symptoms in their loved one increase the sense of burden in the caregiver (Lauber, Eichenberger, Luginbuhl, Keller & Rossler, 2003). The key informants also touched on this issue and the difficulty of long-term adherence to medication treatment. It

requires constant diligence and the development of a routine to life that is difficult to sustain over long periods of time.

**Family life course developmental framework.** Assumptions taken from family life course development theory can also help us understand the experience of the caregivers in this study.

Schizophrenia is a serious mental illness that often affects persons in their late teens and early twenties. This is a developmental period for young adults, who are separating from their parents and family and beginning to embark on a more independent life. They are preparing to leave secondary school and enter the work force and/or perhaps attend college. Young adults are forming emotional and intimate relationships with significant others in their lives outside the family. The illness can make it more difficult to sustain relationships, obtain regular employment or attend college. These “hallmark” events in a young person’s life can become much more difficult and for some unobtainable. The illness can impede or delay this transition.

It is not only the person with schizophrenia who is affected by the disruption. The entire family is affected by the changes in the normative stages of development. Adult children who are not able to attend college or enter the work force become a source of concern and continued financial burden for their family. They are not able to do the expected transition from dependence on family to independent and autonomy. This can include not just financial but also emotional and psychological independence. Several of our caregivers spoke about coping with children who were not able to transition to a more independent life. These young people still required the support of their families. While all expressed a desire to help, it was still not what they expected at this stage of their lives with their children.

The families are also in a position of not being able to move on with their lives. With their children grown and out of the house, their plans for a “new” phase in their lives are changed. They are often in a position of having to delay their own plans or alter their plans based on the needs of their children. Similarly, a sister who is caring for her adult sister in her home spoke of the household adjustments required for this situation to work. She had young children of her own at home who were now required to help care for her sister in various ways. Another caregiver spoke of her second marriage and the impact of her daughter’s illness on her relationship with this man. She related the stress and strain caused by their different views on mental illness and her need to devote so much time to her daughter’s care. This caused resentment in her husband who did not really understand what her daughter was going through and did not understand the manifestations of the illness in her behavior.

Often the illness changes the dynamics of the family relationship. One mother spoke of the impact of her son’s illness on her involvement with other family members and her relationship with her husband. She was no longer able to feel close to some family members as she felt they held negative attitudes about mental illness. She felt the need to not reveal too much information about her son and to often lie about his illness. This naturally affected how close she could feel with these family members. Accommodations have to be made, such as the father who now has to change his schedule to regularly check on his son or the mother who has to spend time worrying about and assisting her son in taking his medications, often at the expense of her other children. Hopes and dreams for their loved one have to be re-envisioned or at times scrapped totally. One mother spoke of her desire for her son to finish college but now she doubted that could happen and instead hoped that he would be able to remain “stable” and not ill or in a

hospital. The new reality of their lives is altered by the illness and future events clouded by the new responsibilities.

At times the families' shared beliefs are challenged by the illness and sometimes new ways of viewing mental illness are formed. Negative beliefs about mental illness are confronted and replaced with new ones. Priorities are changed by the illness. Career and personal hopes and dreams for the loved one are changed to hoping for stability and normalcy. Religious beliefs are often challenged and sometime strengthened which we saw in many of our caregivers. New alliances and relationships are formed that would not have seemed possible in the past.

In conclusion of this discussion on the family life course developmental framework, family life courses are altered by the illness and new attitudes and beliefs accepted. Transitional periods are delayed or missed and new priorities set for the entire family. This aspect of family life provides a context for a discussion of medication management.

**Medication issues.** The most common strategy, as mentioned earlier, utilized by the caregiver was monitoring the loved one to see that he or she was taking the prescribed medications. This often involved providing encouragement that the medications was helping the loved one to remain well. The caregiver would often remind the loved one of "what happened last time" they stopped taking the medication. This may appear to be a small role but in actuality I think it makes a great deal of difference in the loved one remaining on their medications. This encouragement is a daily level of support that appears to make a difference to the loved ones sense that things are ok and that someone cares. This is an important strategy for caregiver as Franson and Smith (1998) note that 20% of all prescriptions are never filled and only 50% of those filled are taken correctly. Estimates of non-adherence among people with psychotic

disorders are projected to be about 50% after one year and as much as 75% after two years (Weiden et al., 1994).

Modeling behavior was also utilized by caregivers. One caregiver stated that she would purposely take her blood pressure medication in front of her son and verbalize how important it was for her to take her medication as prescribed. She would then say to her son that they were in the “ same situation” and attempt to normalized the daily routine as something many people have to contend with in their lives and that they were fortunate to have a drug available to help them stay healthy. Finally, adding stability and routine to the lives of their loved one was an important strategy to keeping them well and out of the hospital. A safe place to live with regular meals and activities of interest while seemingly mundane, were important to the stability of the loved one. Several caregivers noted that when their loved ones tried to live on their own, they had increased episodes of illness and decompensation often leading to rehospitalization. As was mentioned in the previous chapter, providing a safe and stable living environment was a concern to the caregiver. They wondered what would happen to their loved one if they were no longer alive or sick and no longer able to provide a home and daily supervision. Even when the loved one was high functioning and able to work, the caregiver would note that they still felt their role as partner and monitor was important to the loved one being able to work and function on a daily basis.

The African American caregivers discussed the importance of their faith in God in helping them get through the day-to-day struggles associated with caring for a love one. They voiced this faith as their primary support, along with family and close friends. For a few of the caregiver, their church was a major support. While not all of the caregivers attended a church

regularly, they did mention the role of the church in the African American community as a strong force. While several mentioned that they had a family member who believed prayer alone heals, this was not the attitude of any of the caregivers. Prayer was an adjunct to medical treatment. The two could not be separated so easily and they saw no contradiction in believing that faith and prayer were important to healing and their loved one getting better. One caregiver noted that her pastor often told her son that taking medications was also important and encouraged him to stay on his medications. There was a general sense that more education was needed around mental illness in the African American community, and every other community for that matter. Several mentioned how their faith in God gave them hope that things could get better for their loved one. There has historically been a significant role for religiosity in the lives and culture of African Americans (Holt & MClue, 2006).

All the caregivers expressed a belief that it was their responsibility to care for a family member and that with God's help, their loved one could get better. The caregivers tended to view their role as a caregiver as an expression of love and devotion to their family member. While they verbalized frustration with their loved one and families at times they did not describe them as a burden. The situation might be burdensome at times but the loved one was not the burden. The centrality of spirituality was noted in all the caregiver stories. This attitude has also been validated in numerous studies on faith and the African American family (Gerdner, Tripp-Reimer, & Simpson, 2007). Johnson, Elbert-Avila and Tulskey (2005) noted that for African Americans spiritual beliefs and practices are often a source of comfort, coping and support and many believe they are the most effective way to influence healing. All the caregiver stated they

prayed regularly for their loved ones to get better. They viewed medications as helping with the day-to-day management of their loved one but God was the one who heals the spirit.

In general, the primary supports for the caregivers were their faith and family. Family was often mentioned as a strong support, which is consistent with the literature on caregiver and coping (Gonzales, 1996). A few mentioned the strong supportive relationship they had with their loved one's psychiatrist as very helpful to them feeling they could cope with the situation. It appears this relationship is very important to the health of the loved one. One caregiver mentioned a social worker that was very helpful to her in keeping her son well. This was in another county and she had not experience the same level of involvement and support from the mental health system in Philadelphia. No other caregiver mentioned a supportive and helping relationship with a professional in the mental health system. Only one of the participants was involved with NAMI and she mentioned this as a source of much support. She had attended the family psychoeducation program they provide to families of persons with a mental illness. She found the people she met through this organization to be a great resource for her. There appears to be an under utilization of NAMI by African American caregivers. This is an area where more outreach into the African American community might be helpful. None of the other study participants had attended any community support groups or was actively involved with any community organization. A few had involvement with the mental health court system but it was not a positive experience for them. They had involuntarily committed their loved ones after they had stopped taking their medications and had become acutely psychotic and ill. Their feeling was that the system does not intervene soon enough to actually help keep their loved one out of the hospital. The system appears to respond to crisis situations but is not so responsive to assisting

in ongoing recovery in the community. Not specifically mentioned by the caregivers but mentioned by the key informants were the privacy laws around divulging patient care information. The caregiver can often be left out of the planning process because of too stringent interpretations of HIPPA. The busy staff at an outpatient clinic can use the law as a way to limit access and involvement in the treatment plans for families and caregivers.

This lack of involvement in the community mental health system by the caregivers and their loved ones in the study is interesting, given the availability of services in the city. Considering that each area of the city has a community mental health system, one wonders why there is not more linkage and utilization of these services by this group. One explanation might be that these centers are utilized by older, more chronically ill clients with fewer family/ community supports. Having visited a few of these programs, I believe that this is the case. Perhaps there is an interplay of race and socio-economic class distinctions also in who utilizes these services, with more economically disadvantaged groups who have limited family supports utilizing these services more often. It might be the case that African Americans who are middle or upper class socio-economically use other types of informal supports such as family and friends and the services of private clinics for psychiatric care.

Studies have shown a lack of utilization by African Americans in general in the community mental health system. Anglin, Alberti, Link, and Phelan (2008) note that racial/ethnic minority groups are less likely than Caucasians to access mental health services, despite recent evidence of more favorable attitudes regarding treatment effectiveness. They point out that while African Americans were more likely than Caucasians to believe that mental health professionals could help individuals with schizophrenia, they were also more likely to believe mental health

problems would improve on their own. McMiller and Weiz, (1996) had a similar finding that African American families are less likely to seek help from mental health professionals for their children and persons of all ages.

### **Implications for Social Work Practice**

Social workers are in the unique position in the mental health system to be able to intervene on behalf of caregivers. They also bring a holistic, person-in-environment perspective to the care of persons with schizophrenia and their caregivers. They are a part of the treatment team in hospital inpatient psychiatric units where they are usually responsible for coordinating the aftercare plans for patients going home. Social workers also work in community mental health centers and outpatient clinics associated with teaching hospital. Social workers have various roles in these settings. They interact with caregivers and their loved ones on a micro and macro levels. For example, they conduct intake evaluations along with the psychiatrist; they provide supportive counseling services and more concrete case management services. They are also often involved in leading or making referrals to family/ caregiver support groups at the centers and in the community. Social workers are also involved in developing policies and practice guidelines in the area of mental health and often are in positions of leadership. I am thinking of Philadelphia's Community Behavioral Health in this regard. In summation, social workers are in positions to make a real difference in the lives of caregivers and clients.

One possible area for social work intervention with caregivers is around the issue of caregiver support and advocacy. Caregiving can be a difficult, stressful job, and caregivers are at danger of burnout and disengagement from the loved one. This is especially true when they are caring for a loved one who can be threatening and hostile to help. Lauber, Eichenberger,

Luginbuhl, Keller, and Rossler (2003) looked at determinants of burden for caregivers of patients with exacerbating schizophrenia. The study found that family members/caregivers are concerned about threats from their severely mentally ill family member. This is a difficult area for caregivers to address on their own. They need to support of the mental health system if and when these situations arise. The authors noted that the family should be included in the decision to determine if an affected person should be hospitalized. Unfortunately this does not always happen. Families are often left pleading for help from the professionals in the system but only to be blocked by issues around patient privacy laws and a reimbursement system for care that does not allow admissions to inpatient psychiatric unit often until the situation is at a dangerous point for the ill person (Szmukler et al., 1996). Noting a similar finding, Lakewood (2008), in her study on family and caregiver participation in mental health care, states that for caregivers and patients, any demarcation between mental health and other care makes little sense since their responsibilities and relationships persist regardless of whether or not someone is involved with mental health services. For this reason she notes that mental health services need to recognize both the family and the patient as the natural sources of support to each other.

The study findings indicate the need for caregiver's involvement in the treatment planning process. Whatever plan is initiated by the treatment team will often depend on the involvement of the caregiver to be successful. Every opportunity should be used to include the caregiver in the decision making process and for feedback on what is going on with the patient. This is a necessary step to ensure the patient's ability to adhere to any outpatient treatment plan.

Family and caregiver education is an important area of intervention. Reibschleger et al. (2008) examined medical educational curricula and found they have insufficient content about

families that include people who suffer from mental illness. They stated they do not adequately prepare physicians for working with family members of patients with a mental illness. While not referring to psychiatrist training programs, it must be remembered that patients with mental illnesses are often treated by general practitioners as well. The role of the social worker in health care setting as well as mental health setting becomes all the more important in educating the care team and caregiver about possible psychosocial stressors and adherence issues.

Based on the findings of this study, I offer the following recommendations to social workers in the mental health area:

1. Psychoeducational counseling for caregivers on schizophrenia and the role of medication therapy in controlling the symptoms of the illness. This could include information on the medications being prescribed, how they work and possible side effects.
2. Education on medication adherence strategies tailored to the individual needs of the caregiver's social situation. Address any psychosocial factors the caregiver may be experiencing that could impede adherence and the ability of the caregiver to assist the loved one. This could include a discussion of their role in caregiving and any anticipatory problems they feel might arise from caregiving.
3. An understanding of the mental health system and the commitment process could be included in the educational process. Discussion can include the benefits of referral to a community mental health support system such as NAMI or a local community mental health center.
4. Finally, social workers should advocate for the caregiver to be involved as much as possible in the decision making process for their loved one's care.

## **Conclusions**

This study explored the views of caregivers as well as a couple of providers on medication treatment for persons with schizophrenia. The study validated prior studies on the importance of psychoeducation and support for caregivers of a person with a chronic mental illness. The study also mirrored earlier findings that African Americans underutilized mental health services. Auslander and Freedenthal (2005) have shown that African Americans are less likely than other groups to seek out community support when they have a loved one with a serious mental illness. In addition, African American families are less likely to seek help from mental health professionals for their children and individuals of all ages are less likely to perceive themselves as having a mental illness (McMiller & Weisz, 1996). The study found medication management to be central to the caregiving role, with monitoring behaviors the key to the role and definition of what it means to be a caregiver. This is a new and interesting finding about what it means to be a caregiver for a person with schizophrenia. Also all the caregivers in the study expressed the belief that the medications made a difference in the quality of the lives of their loved ones. As mentioned earlier in the study, this finding is also consistent with studies on effectiveness of antipsychotic medication for the treatment of the illness.

The African American caregivers expressed a belief and hope that their loved ones could get better. They saw the medications as a way to manage the illness but not a cure. They used prayer and family as their primary supports and were not involved in the community mental health system to any large degree, NAMI being the only organization mentioned and by only one caregiver. While some turned to the church, others expressed deep spiritual beliefs but were not part of any organized faith congregation for support. A positive relationship with their

psychiatrist was also noted as important to them. They acknowledged the stigma of mental illness in their community but did not see this as unique to the African American community. Some worried about the future of their loved one when they were gone and others took it one day at a time. Their attempts to normalize the everyday lives of their loved one are a testament to their love and devotion.

This study was limited by its small sample size. The study included ten African American caregivers who were interviewed about their experiences. While the caregivers all had a common ethnic/racial background and all were from the same geographic area, the study cannot be generalized to the larger African American population of caregivers for persons with schizophrenia. Another limitation of the study is the racial difference of the interviewer and the participants. It is possible that an African American interviewer would have gotten different or more in-depth responses from the caregivers about the role of culture and the church in their lives and attitudes toward mental illness. The study did, however, support other studies by African American researchers in the area of caregiving on the importance of faith, family and church in their coping with an illness and the role of being a caregiver (Johnson, Elbert & Tulskey, 2005). Caregivers play a key but relatively unexplored role in assisting their relatives in taking their medications and maintaining stability in the community (McDonnell, Short, Berry, & Dyck, 2003). This strategy appears to make a major difference in adherence

### **Implications for Future Research**

This study highlighted the important role that caregivers play in medication adherence for persons with schizophrenia. The study identified the primary role of the caregiver around

medication monitoring activities. From the findings, future studies, with a larger sample of African American caregiver, could explore this issue in more detail. Perhaps a quantitative study examining the amount of time spent with each activity and its possible impact on medication adherence.

Other areas of exploration might be around increasing utilization of community mental health services in the African American community. A study exploring barriers to utilization of community mental health services and possible strategies to increase participation by caregivers would also be beneficial. Also the caregivers identified their relationship with their psychiatrist as very important to taking care of their loved one. This area also could use further exploration. What are the aspects of the relationship that seem to create positive outcomes for the person with schizophrenia and their caregiver.

Finally, given the importance of taking medications for this population, additional study of possible ways to involve caregivers in the treatment planning process in psychiatric hospitals and community mental health centers would appear to offer benefit in improving medication adherence.

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## APPENDIX A: Consent Form

### **Consent for Interview**

#### **Introduction and Purpose of Interview/Focus Group**

I am a graduate student in the DSW program at the University of Pennsylvania School of Social Policy and Practice. As part of the requirements for my program dissertation I will be conducting and analyzing intensive semi-structured interviews with caregivers of persons with schizophrenia.

Please ask any questions that you have about participating in this project at any time. I want you to have the information you need to make a decision that is best for you.

#### **What is involved?**

The interview will last about an hour to an hour and a half. I will make an audio recording of the interview and may take written notes.

I am exploring the reasons patients with schizophrenia do not take their medications. I want to interview a family member for any personal insight into this issue. I am also interested in knowing what the patients' families think about medication as the primary treatment for schizophrenia and their perception of the difficulties in taking medications on a consistent basis.

#### **Confidentiality:**

The information you share will be kept confidential. I will not share your specific information about whether or not you participate in this project or what you say with anyone.

Anything with your name on it, such as signed consent forms, and any other documents that could be used to identify you, will be kept in a locked file cabinet, separate from your interview tapes and transcripts of those tapes. I am the only person who will be able to listen to the tape. Once I have analyzed the interview and written my final paper for this project, I will destroy any audio recordings, interview notes, interview transcripts, and any other materials related to this project. The final paper, including the transcript, will only be viewed by my dissertation committee.

#### **Benefits of participating:**

Although being interviewed will not help you directly, your answers will assist me in developing, performing, and analyzing an intensive interview/focus group. You may also find it interesting to share your own story.

**Risks of participating:**

There are no known risks of participating. If answering some of the questions makes you uncomfortable, please let me know. We can stop the interview for a few moments, or you can decide to stop participating entirely. Should you continue to feel upset in the next few days, please be in touch with me and I will provide some suggestions about resources for talking about your concerns.

**Compensation:**

If you decide to participate, you will be given \$25 in cash after the interview is completed. You will also be reimbursed for any money you spend to travel to the interview site.

**If you have questions about the project, please feel free to contact me:**

Tracy Griffith  
Hospital of the University of Pennsylvania  
3400 Spruce Street  
1 Gibson Building  
Philadelphia, PA 19104

**Your participation is completely voluntary:**

You do not have to participate in this project. There will be no negative consequences if you decide not to participate. No one will know whether you participate or not.

If you do decide to be interviewed today, you can stop the interview at any time. You can also refuse to answer any questions that you don't want to answer.

By signing this consent form, I am indicating that I have had all of my questions about this project answered to my satisfaction and that I have been given a copy of this consent form.

Participant signature: \_\_\_\_\_

Participant printed name: \_\_\_\_\_

Date: \_\_\_\_\_

Patient Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Interviewer signature: \_\_\_\_\_

Interviewer printed name: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX B: Interview Questions

### Interview Questions

I am a Doctor of Social Work student at the University of Pennsylvania in Philadelphia, PA. I plan to use this information from this interview in my dissertation, which is about the experiences of caregivers of persons with schizophrenia. Do you have any questions or concerns about the study and the use of this information? Now I would like to ask you some questions that will help me understand your experience as a caregiver of a person with schizophrenia.

#### Relationship and Role Questions related to Medication Management

1. What is your relationship to\_\_\_\_\_ (the person with schizophrenia)?
2. What is your role in helping care for him/her?
3. How long has he/she has been diagnosed with schizophrenia?
4. Tell me what it is like to live with this person. Take me through a particular day when this person is not using medication.
5. Whom do you turn to for support?
6. What does it mean to you to be a caregiver of someone with a severe mental illness?
7. Describe for me your feelings about being a caregiver? What are the challenges for you to the role?
8. What about your background affects this role for you?
9. What are your attitudes in general about mental illness and treatment?
10. What type of information on their medication did you receive? Side effects?

11. Who provided you with this information? Can you describe what that meeting was like for you?
12. How long has he/she been on medication? When does he/she take the medications?
13. How can you tell when he/she is taking the medications?
14. What are some of the signs you look for?
15. What type of help do they ask for with taking medications?
16. When have you had to remind him/her to take medications? Is there a strategy you use to get him/her to take medication? Does he/she have one? If he/she does, can you describe it to me?
17. What type of feelings do they express to you about taking medications?
18. How does he/she talk about the medications?
19. What sorts of things happen that might make it difficult for him/her to take medications?
20. How do you think the medication helps him/her? How do the drugs make it difficult for her/him?
21. What would help him/her at this time in taking medications? Education? Counseling? Problem solving skills training?
22. What type of interventions have he/she ever had to help him/her with taking medications?

#### Cultural and System Attitude Questions

23. What is your attitude about the medications he/she takes?

24. Are there any particular attitudes about mental illness and taking medications that you feel are unique to your cultural background? If so, could you tell me about what these different attitudes are?

25. How do you feel about the mental health system in this city? Do you feel the system is sensitive to the needs of people with a severe mental illness such as schizophrenia?  
African Americans?

#### Closing Question

26. Thank you for taking the time to help me with this project. Is there anything else you would like to add?