DISSERTATION

Peggy El-Mallakh

The Graduate School
University of Kentucky
2005
Evolving Self-Care Among Individuals with Schizophrenia and Diabetes Mellitus

Dissertation

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing at the University of Kentucky

By

Peggy El-Mallakh

Lexington, Kentucky

Director: Dr. Patricia Byrd Howard, Associate Professor of Nursing

Lexington, Kentucky

2005

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Direcor of Graduate Studies

April 25, 2005

Date
ABSTRACT OF DISSERTATION

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EVOLVING SELF-CARE AMONG INDIVIDUALS WITH SCHIZOPHRENIA AND DIABETES MELLITUS

Diabetes mellitus is more common among individuals with schizophrenia compared to the general population, yet little is known about their diabetic self-care. This grounded theory study was conducted to identify the process by which individuals with schizophrenia and diabetes develop an understanding of the diagnosis of diabetes, identify the factors that influence the development of their diabetic self-care skills, and generate a theory that describes the antecedents and outcomes of their diabetic self-care. Twenty-six interviews were conducted among eleven respondents who were diagnosed with schizophrenia and diabetes. Four health care providers were also interviewed. Data were analyzed using the constant comparison method. Methods included open, axial, and selective coding, and the use of field notes and theoretical memos. Trustworthiness of the findings was enhanced through prolonged engagement, participant observation, member checks, and an audit trail. The core category that describes diabetic self-care among respondents is “Evolving Self-Care.” This is the process by which study respondents overcame the barriers that psychiatric symptoms presented as they engaged in diabetic self-care. The first major category is Mastering Schizophrenia, a stage in which respondents acknowledged their vulnerability to schizophrenia based on their experiences with psychosis and effectiveness of mental health treatment. Health beliefs developed during this stage focused on illness acceptance, understanding the serious negative consequences of psychosis, and understanding the need to adhere to mental health treatment. The second category, Accommodating Diabetes, occurred when respondents personalized their observations about diabetes and developed an understanding of diabetes based on their own experiences. This stage of self-care also involved acceptance of the diagnosis of diabetes, and application of acquired knowledge about schizophrenia to the care of diabetes. The third category of Evolving Self-Care is Striving for Health, in which respondents recognized their responsibility to care for both schizophrenia and diabetes to the best of their abilities, despite the challenges that both illnesses presented.
Providers are encouraged to take a holistic approach towards the education and treatment of their patients with schizophrenia and diabetes.

KEYWORDS: schizophrenia, diabetes, grounded theory, self-care, health beliefs
DEDICATION

To my husband, Rif, and my sons, James and Thomas

and

to the memory of Donna Marie Melby Wilson
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Many people helped and supported me throughout the years that I worked on this project. First, Pat Howard, my dissertation chair, was a source of inspiration to me due to her devotion to scholarship and integrity in research, and I want to thank her for all of the insights and encouragement she gave me throughout the process of data collection, theory development, and manuscript preparation. I also wish to thank the complete dissertation committee, Dr. Ann Peden, Dr. Sherry Warden, Dr. John Wilson, and Dr. Nancy Schoenberg. I greatly appreciate all of the insights and suggestions they gave me, which helped me stay focused throughout the study. Special thanks go to Ann Peden for serving as the external auditor for my audit trail. Jewel Begley was a great help in transcribing the taped interviews, and Robin Jones of the TASC Center created the graphics.

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"Hope is a big thing. When you're going through this disease and you're down on yourself and you're hearing voices, and you're doing all these crazy things, sometimes hope is the only thing you got going for you. You know, you either despair or you get over it. There are plenty of people in this place who have tried to commit suicide because of this disease, it can really overcome you, but you can't let that happen. You have to have hope that you can get better... sometimes, that hope can be just not having schizophrenia episodes. You know, it could be just a day of peace because you're troubled, and you're not at peace when you're going through schizophrenia."

--George, study respondent, 2004
CHAPTER ONE
PURPOSE, SPECIFIC AIMS, AND INTRODUCTION

Individuals with schizophrenia are more vulnerable to developing diabetes mellitus compared to the general population, but little is known about their diabetic self-care. The overall objective of this grounded theory study was to generate a theory about how individuals with co-morbid schizophrenia and diabetes mellitus incorporate diabetic self-care management into their lives. The specific aims were to:

1. identify the process by which individuals with schizophrenia and diabetes develop an understanding of the diagnosis of diabetes;
2. identify the factors that influence their adherence to diabetic self-care;
3. generate a theory that describes the relationships between the factors, antecedents, and outcomes of self-care for co-morbid schizophrenia and diabetes.

BACKGROUND

Individuals diagnosed with schizophrenia frequently have significant co-morbid medical illnesses (Cimpean, Torrey, & Green, 2005; Druss & Rosenheck, 1997; Goldman, 1999; Jeste, Gladsjo, Lindamer, & Lacro, 1996; Stroup, Gilmore, & Jarskog, 2000). In particular, schizophrenia is associated with diabetes mellitus; mental health professionals have observed that diabetes, impaired glucose tolerance, and insulin resistance occur more frequently among patients with schizophrenia compared to the general population (Dixon, Weiden, Delahanty, Goldberg, Postrado, & Lucksted et al., 2000; Goldman, 1999; Mukherjee, Decina, Bocola, Saraceni, & Scapicchio, 1996). Researchers estimate that rates of
diabetes in the general population are about 1.2% for people aged 18-44 years, and 6.3% for people aged 45 to 64 (Bushe & Holt, 2004). In contrast, Dixon and colleagues (2000) found a prevalence rate of 10.8% for diabetes among 719 individuals with schizophrenia. Ryan, Collins, and Thakore (2003) found that 15% of 26 patients (mean age: 33.6 years) with new onset schizophrenia had impaired fasting glucose tolerance, compared to none in a group of age-and-sex matched healthy comparison subjects. In Italy, Mukherjee and colleagues (1996) investigated the prevalence of diabetes among 95 patients between the ages of 45 and 74 who were diagnosed with schizophrenia. Findings indicated that the overall prevalence of diabetes was 15.8%. The Schizophrenia and Diabetes Expert Consensus Group (2004) concurs with these estimates, stating that the prevalence of diabetes among individuals with schizophrenia can be “reasonably” estimated to be 15-18%, and the prevalence of impaired glucose tolerance among individuals with schizophrenia “may be as high as 30%, depending upon age” (p. S112).

Much literature has been published in the last five years related to potential reasons for the increased association between schizophrenia and diabetes. The use of recently-developed “atypical” antipsychotic medications may play a large role; many clinicians have reported impaired glucose tolerance, new onset diabetes, and diabetic ketoacidosis in their patients after initiation of treatment with olanzapine and clozapine (Caro, Ward, Levinton, & Robinson, 2002; Haupt & Newcomer, 2001; Henderson, 2001; Koller, Schneider, Bennett, & Dubitsky, 2001; Melkersson, Hulting, & Brismar, 2000; Sernyak, Leslie, Alarcon, Losonczy, & Rosenheck, 2002). Meyer (2001) observes that the use of olanzapine and
clozapine has been associated with significant weight gain, which is a risk factor for non-insulin dependent diabetes.

Despite the recognized association between the use of atypical antipsychotic medications and diabetes, many clinicians and researchers emphasize that the use of these medications has contributed to great improvements in patients' cognitive functioning and negative symptoms. In particular, patients have experienced reduced apathy, depression, and social withdrawal; other gains include reduced hospitalization and improved functioning and quality of life. According to Meltzer (2001), the dilemma for the clinician is to weigh the risks of impaired glucose tolerance and diabetes against the benefits of reduced psychiatric symptoms and improved cognition and functioning. He further observes that in some studies, the patients who developed diabetes while taking clozapine were the same patients who experienced the best improvement in psychopathology and social functioning, and concludes that "of course, this type of patient should keep taking the drug" (Meltzer, 2001, p. 38).

Some researchers caution that the association between diabetes and the use of certain medications has only been observed in retrospective studies, in which other risk factors, such as age, weight, and previous use of antipsychotic medication, were unknown and therefore unable to be controlled in the research designs (Haddad, 2004; Thakore, 2004). They further note that early case reports describing the link between schizophrenia and diabetes were first published in the 1920s, about 30 years prior to the development of antipsychotic medications (Kohen, 2004; Mukherjee et al., 1996).
Rather than attributing the problem to antipsychotic medications, some researchers maintain that physiologic mechanisms related to schizophrenia are the sources of glucose dysregulation (Black, 2002; Dinan, 2004; Shiloah, Witz, Abramovitch, Cohen, Buchs, & Ramot et al., 2003; Thakore, 2004). Thakore (2004) and Dinan (2004a) suggest that the high rates of diabetes among individuals with schizophrenia result from chronic dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis. Patients can become very stressed by the emotional intensity associated with symptoms of paranoia, such as frightening hallucinations and delusions (Dinan, 2004a; Thakore, 2004; Vellenga & Christenson, 1994). Chronic psychological distress may cause chronic activation of the HPA axis, and consequent secretion of adrenaline, “a profoundly diabetogenic hormone... ...sustained hyperadrenalism produces sustained hyperglyaemia” (Dinan, 2004a, p. S72-S73). Based on these hypothesized physiologic mechanisms, some researchers and clinicians have suggested that schizophrenia could be considered an independent risk factor for developing diabetes (Bushe & Leonard, 2004; Dinan, 2004a; Ryan, Collins, & Thakore, 2003; Thakore, 2004).

Research also indicates that the severity of psychotic symptoms is related to the degree of glucose dysregulation in individuals with schizophrenia. In a study of 39 non-diabetic individuals diagnosed with schizophrenia, Shiloah and colleagues (2003) found that insulin sensitivity and pancreatic β-cell function were found to be inversely correlated (r = -0.38, p < 0.02) with scores of the Clinical Global Impression (CGI) Scale, which is used to measure severity of acute psychosis. Findings also indicated that subjects with highest levels of stress due
to symptoms of psychosis, as measured by the CGI, had significantly higher glucose levels compared to those with lower psychosis-related stress \((p = 0.01)\).

Other researchers attribute the high prevalence of diabetes among individuals with schizophrenia to lifestyle factors (Dixon et al., 2000; Peet, 2004). Individuals with schizophrenia engage in few health-promotion activities; they have lower levels of physical activity, and smoke twice as much, as the general population (Dixon et al., 2000; Murphy, Gass-Sternas, & Knight, 1995). Peet (2004) observes that in general, adolescents and young adults are sustained by a “particularly poor diet, consuming large quantities of burgers, fries, and full-sugar carbonated drinks” (p. S102). He further suggests that the diet of young individuals with schizophrenia is even worse; they consume substantially more saturated fat and sugar than age-matched non-mentally ill individuals (Peet, 2004). Obesity resulting from poor diet and physical inactivity places individuals with schizophrenia at risk for non-insulin dependent diabetes and the expression of the metabolic syndrome (Thakore, 2004).

**SIGNIFICANCE OF THE PROBLEM**

Diabetes mellitus, a serious and chronic endocrine disease, requires ongoing monitoring, lifestyle modifications, and life-long adherence to self-care. Successful treatment depends upon the willingness of the patient to be an active and consistent participant in treatment (Connelly, 1993). The health risks related to lack of adherence to diabetic self-care are numerous; these include retinopathy and blindness, renal failure, cardiac and peripheral vascular disease, skin ulcerations, and limb amputations.
According to McFarland and Thomas (1991), the ability to perform self-care depends on several individual and social factors, which can include age, gender, family support, level of development, overall health, cultural and socioeconomic factors, and characteristics of the health care system. Furthermore, adequate self-care requires the ability to seek medical assistance, understand the effects of illness, successfully perform self-care tasks, modify treatment to manage adverse effects, and adopt health lifestyle practices (Getty, Perese, & Knab, 1998). Getty and colleagues (1998) maintain that self-care for medical conditions such as diabetes may be compromised in individuals with schizophrenia due to poverty, lack of access to health care, and cognitive symptoms that prevent them from fully understanding the seriousness of medical illness and the need to engage in self-care.

Mental health professionals recognize that diabetes is a serious medical illness that is found with increasing frequency among patients with schizophrenia (Henderson & Ettinger, 2003). However, the majority of published literature related to co-morbid schizophrenia and diabetes focuses mostly on provider perspective of the problem. Current literature includes screening guidelines (Schizophrenia and Diabetes Expert Consensus Group, 2004; Green, Canuso, Brenner, & Wojcik, 2003; Haupt & Newcomer, 2001), assessment and ongoing monitoring for patients with schizophrenia and diabetes (Goldstein & Henderson, 2000; Henderson & Ettinger, 2003); guidelines for referring the patient to a primary care physician (Buse, 2002; Schizophrenia and Diabetes Expert Consensus Group, 2004), the role of antipsychotic medications in the development of diabetes (Buse, 2002; Bushe & Leonard, 2004; Caro et al., 2002;
Koller & Doraiswamy, 2002; Koller, Schneider, Bennett, & Dubitsky, 2001; Wirshing, Pierre, Erhart, & Boyd, 2003), and the cost-benefit ratio of continuing to prescribe medications that are associated with the development of diabetes (Meltzer, 2001).

To date, no literature has focused on the patient’s perspective of caring for co-morbid schizophrenia and diabetes. Few mental health clinicians have raised concerns about the long-term self-care issues and challenges in individuals with co-morbid schizophrenia and diabetes. Although Dixon and colleagues (2000) state that the use of pilot studies on exercise and dietary counseling could change health behaviors in individuals with schizophrenia and diabetes, they did not mention investigation of several other self-care activities common to diabetes, such as glucose monitoring, insulin administration, interpreting signs of hyper/hypoglycemia, and foot care. In addition, no researchers have encouraged investigation of factors that can influence the decision to adhere to treatment recommendations in this population.

Although the voices and stories of individuals with schizophrenia are beginning to be included in qualitative research on chronic illness, the subjective experience of living with chronic mental and physical illnesses has not been investigated. Nothing is currently known about the problems and processes of self-care among individuals with schizophrenia who have co-morbid diabetes. Research can lead to increased knowledge related to the ability of individuals with schizophrenia to adequately manage their diabetes, which can help health care providers identify patients at risk for poor self-care. Knowledge related to the processes through which patients with schizophrenia learn self-care and
incorporate it into their lives can help health care workers develop effective skills-
training interventions that address inadequate diabetic self-care, and thereby
contribute to improved health care and treatment outcomes for patients with
schizophrenia and diabetes.

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Overview of Schizophrenia

Schizophrenia is a chronic and debilitating psychiatric illness characterized by bizarre behavior and alterations in perception, ideation, and memory (American Psychiatric Association, 1997). Mental health clinicians view schizophrenia as a heterogeneous disorder with a wide variety of symptoms (Flaum, 1995); symptoms of schizophrenia are typically classified into positive or negative clusters (Maxmen & Ward, 1995; Nasrallah & Smeltzer, 2002). Positive symptoms include auditory and visual hallucinations (Maxmen & Ward, 1995), delusions (fixed false beliefs that are not supported by reality), disorganized speech and behavior (Nasrallah & Smeltzer, 2002), and abnormalities of logic and reasoning (Nasrallah & Smeltzer, 2002). The positive symptoms are associated with a better prognosis for long-term recovery, with better response to medications and less chronicity (Tandon, Jibson, Taylor, & DeGuardo, 1995).

In contrast, negative symptoms include reduced expression of emotions, social withdrawal, lack of motivation, slowness of thought and movement, under activity, and poverty of speech, also known as alogia (Maxmen & Ward, 1995; Hafner & Maurer, 1995; Nasrallah & Smeltzer, 2002). Compared to patients with positive symptoms, patients with negative symptoms show more evidence of cerebral atrophy and enlarged cerebral ventricles on computerized tomography (CT) scanning. In addition, patients with negative symptoms also exhibit higher levels of chronicity and cognitive impairment, and poorer social functioning (Tandon et al., 1995).
In addition to positive and negative symptoms, individuals with schizophrenia frequently exhibit global deficits in cognitive functioning (Pinals & Breier, 1997). These deficits frequently include problems with information processing, attention, concentration, verbal learning and fluency, and perceptual and motor functioning (Meltzer & McGurk, 1999; Nasrallah & Smeltzer, 2002; Pinals & Breier, 1998). Memory, particularly in the areas of encoding and retrieval of information, is also impaired. In addition, deficiencies occur in working memory, which is the ability to use information “directly after a short delay or to process or manipulate it mentally to solve cognitive and behavioral tasks” (Sharma & Antonova, 2003, p. 27); this cognitive skill is essential in the processes of reasoning, learning, and understanding. Nasrallah and Smeltzer (2002) state that individuals with schizophrenia also have deficits in “executive functioning” (p. 114), particularly with complex, goal-directed behaviors. The ability to adapt to environmental changes and demands is also deficient; impairments are frequently seen in anticipating problems, selecting goals, considering alternative ways of solving problems, planning, flexibility, and self-monitoring (Nasrallah & Smeltzer, 2002).

Problems with impaired reality perception, cognition, and motivation typically result in a progressive deterioration in functioning at school, work, and home (Keltner, Folks, Palmer & Powers, 1998). Flashman and Green (2004) maintain that schizophrenia is one of the most disabling mental illnesses. Nasrallah and Smeltzer (2002) concur, and estimate that about 75 % of individuals with schizophrenia will experience some degree of disability for most of their lives. The social consequences of the disability associated with
schizophrenia include poverty, substandard living conditions, homelessness, isolation, unemployment, marginalization, victimization, and increased rates of morbidity and mortality (Aro, Aro, & Keskimaki, 1995; Nasrallah & Smeltzer, 2002).

**Patient Adherence to Diabetic Self-Care**

Diabetes mellitus, a chronic illness that requires strict adherence to a treatment regimen to maintain normal blood glucose levels, is behaviorally complex (Jones, Edwards, Vallis, Ruggiero, Rossi, & Rossi et al., 2003) and demanding (Cox & Gonder-Frederick, 1992). Diabetic self-care includes the daily performance of 10 to 20 activities, such as medication administration, deciding when and what to eat, and “preventing, detecting, and treating high or low blood glucose levels” (Hurley, 1992, p. 29). Complex central nervous system functioning, particularly in the areas of planning and organization, is required to make adequate decisions about these tasks.

Effective diabetes self-care is patient-driven; Peterson and Hughes (2002) stress that “the patient is the most important provider of medical care” for diabetes (p. 266). Persons with diabetes deliver over 95% of their own care (Anderson, Fitzgerald, & Oh, 1993). Effective maintenance of normal blood sugar is crucial to prevent long-term complications (Fisher, Arfken, Heins, Houston, Jeffe, & Sykes, 1997; Institute of Medicine, 2001; Polly, 1992), which can include retinopathy and blindness, cardiac and peripheral vascular disorders, peripheral neuropathies, limb amputations, and renal failure (Fisher et al., 1997; Institute of Medicine, 2001; Whittemore, 2000). For this reason, factors that influence a patient’s decision to adhere to recommended diabetes treatment are a major...
concern for endocrinologists and behavioral scientists (Coates & Boore, 1998; Glasgow, Hampson, Strycker, & Ruggiero, 1997; Glasgow, Fisher, Anderson, LaGreca, Marrero, & Johnson et al., 1999; Peterson & Hughes, 2002; Whittemore, 2000).

Treatment adherence is the match between a patient’s behavior and the provider’s health care recommendations (Institute of Medicine, 2001). Researchers maintain that adherence to treatment recommendations in chronic illness is generally estimated to be 50%; consequently, optimum clinical benefit is not obtained (Dunbar-Jacob, Efen, Schlenk, Ryan, Sereika, & Doswell, 2000). Much research has found that adherence among individuals with diabetes is inadequate (Brownlee-Duffeck, Peterson, Simonds, Kilo, Goldstein, & Hoette, 1987; Fisher et al., 1997; Snoek, van der Ven, Lubach, Chatrou, Ader, & Heine et al., 2001). Several cognitive, behavioral, affective, and social factors influence a patient’s willingness and ability to adhere to recommended diabetes treatment (Brownlee-Duffeck et al., 1987; Cox & Gonder-Frederick, 1992; Fisher et al., 1997; Glasgow et al., 1997; Glasgow et al., 1999; Kavanaugh, Gooley, & Wilson, 1993; Wdowik, Kendall, Harris, & Auld, 2001; Whittemore, 2000). Glasgow and colleagues (1997) maintain that “personal models” (p. 556), or patients’ representations of their illness, are among the most important factors that influence diabetes self-care. These personal models generally encompass diabetes-related beliefs, attitudes, emotions, knowledge, and experiences (Glasgow et al., 1997). Specific elements of personal models can include perceived seriousness of, and susceptibility to, diabetes (Strecher, Champion, & Rosenstock, 1997), uncertainty about treatment (Fisher et al., 1997), perceptions
about self-care efficacy (Janz, Champion & Strecher, 2002; Kavanaugh et al., 1993), locus of control over the outcome of the illness (Bradley, 2001), motivation (Montano & Kasprzyk, 2002), coping and problem-solving skills (Wenzel, Glanz, & Lerman, 2002), and appraisal of social and environmental barriers to self-care (Glasgow, 2001). Glasgow and colleagues (1997) maintain that the beliefs and attitudes associated with personal models of diabetes ultimately guide the patient in making decisions about diabetes-related behaviors, such as self-care and patient-provider interactions.

**Treatment Adherence in Individuals with Schizophrenia**

To date, no research has been conducted to examine the factors that influence adherence to diabetes treatment in individuals with schizophrenia and diabetes. However, problems with adherence to mental health treatment among individuals with schizophrenia are well recognized among mental health providers and researchers. Much research has been conducted to identify factors that influence adherence and optimize interventions to promote treatment adherence in this population (Dolder, Lacro, Leckband, & Jeste, 2003; Fenton, Blyler, & Heinssen, 1997; Lacro, Dunn, Dolder, Leckband, & Jeste, 2002; Pinikahana, Happell, Taylor, & Keks, 2002; Weiden, Rapkin, Mott, Zygmunt, Goldman, Horvitz-Lennon, & Francis, 1994; Zygmunt, Olfson, Boyer, & Mechanic, 2002). Findings from this research can inform the identification of potential problems with adherence to diabetic care in individuals with schizophrenia and diabetes.

Researchers estimate that up to 50% of individuals with schizophrenia become non-adherent with medications within one year of being discharged from
an inpatient hospitalization, and up to 75% become non-adherent within two years of discharge (Weiden et al., 1994). Weiden and colleagues (1994) maintain that in individuals with schizophrenia, treatment adherence is often influenced by factors that are specific to the symptoms and impairments associated with the diagnosis. Substance abuse is strongly related to treatment non-adherence, and the Substance Abuse and Mental Health Services Administration (SAMHSA) (2002) estimates that approximately 47% of individuals with schizophrenia also have a substance abuse disorder. Negative symptoms, such as apathy, may prevent patients from maintaining the motivation needed to routinely take medications (Lacro et al., 2002). Cognitive impairments associated with schizophrenia have also been identified as barriers to treatment adherence; deficits in memory and problem solving skills often interfere with a patient’s ability to consistently follow a regular medication schedule and obtain medication refills on an ongoing basis. The side effects of psychopharmacologic treatment, too, can influence willingness to take medications (Dolder, Lacro, Dunn, & Jeste, 2002). Antipsychotic medications such as haloperidol, chlorpromazine, and trifluphenazine can cause severe restlessness, sedation, and dry mouth; these side effects can be very uncomfortable, and often interfere with daily functioning. Patients also object to the weight gain associated with the use of olanzapine, clozapine, quetiapine, and risperidone (Perkins, 1999). Meyer (2001) observes that obese patients with schizophrenia are three times as likely to be non-compliant with antipsychotic medications compared to non-obese patients.
Several researchers maintain that patients' perceptions, beliefs, and attitudes towards medications, and towards mental illness in general, influence willingness to adhere to treatment recommendations (Dolder et al., 2003; Fenton et al., 1997; Perkins, 1999; Weiden, Mott, & Curcio, 1995). Adherence can depend on the quality of the patient's relationship with his/her physician, fear of relapse and hospitalization, a perception of being "forced" or pressured to take medications, and the stigma associated with a diagnosis of a chronic mental illness (Weiden et al., 1994). Perceived benefits of treatment can also play a role; Fenton and colleagues (1997) suggest that compared to non-adherent patients, adherent patients are more likely to believe that medications prevent symptom relapse. They further suggest that patients who do not adhere to their medication regimen are more likely to believe that medications should be taken only when one feels sick, and that it is "unnatural to take medications" (p. 640).

According to Fenton and colleagues (1997), a subjective sense of well-being resulting from medications may function as a perceived immediate benefit. They suggest that "[p]atients who do not comply are likely to feel that their medications do not help, are of no benefit, or are ineffective and unnecessary" (p. 640). They further maintain that this immediate perception of well-being is a stronger motivator to taking medications compared to perceived susceptibility. In addition, insight—the patient's ability to recognize and understand symptoms and how they relate to an illness (Manschreck, Kopala, & Honer, 2003), and an awareness that the patient is at risk for developing symptoms—is crucial to the process of recognizing the link between medications and symptom reduction (Dolder et al., 2003; Fenton et al., 1997; Lacro et al., 2002; Perkins, 1999).
However, Perkins (1999) states that lack of insight is “characteristic of schizophrenia... and patients may be unaware of their symptoms, the risk of relapse, and illness-related impairment of functioning” (p. 26). Lacro and colleagues (2002) concur, stating that lack of insight into illness is consistently related to lack of medication adherence.

**Current Theoretical Perspectives on Health Behavior**

Because the intent of this qualitative study was to generate theory, current theoretical perspectives were not used to guide the research questions, methods, and data analysis. However, Strauss and Corbin (1998) indicate that literature related to a particular qualitative research topic serves several functions: a.) it can sensitize the researcher to themes and concepts that could emerge from the literature; b.) it can serve as a secondary source of data; and c.) it can be used to confirm study findings. Following initial interactions with study participants, the decision was made to investigate the literature related to health beliefs to sensitize the researcher to current theoretical perspectives on why people engage in illness self-care. The literature reveals that attitudes and beliefs about health, illness, and medical treatment are a major determinant in adherence to treatment for a medical illness. Weinstein and Sandman (2002) contend that changes in health behavior require the patient to engage in a cognitive process of decision-making, in which the relative costs and benefits of a health behavior are compared. The concepts of health beliefs/attitudes and decision-making have been incorporated into several theories of health behavior to explain adherence to recommended medical treatment; these include the Health Belief Model and the Transtheoretical ("Stages of Change") Model. In addition, the Cognitive
Behavioral Model is frequently used in mental health to treat a wide variety of disorders, including depression, anxiety, obsessive-compulsive disorder, borderline personality disorder, and schizophrenia (Beck, 1979; Linehan, 1995; Wright et al., 1993; Kingdon & Turkington, 1994). These models will be summarized and critiqued within the context of adherence to self-care of medical illnesses among individuals with schizophrenia.

The Health Belief Model

The Health Belief Model (HBM), a widely used framework for health behavior research, endeavors to explain why people engage in health promotion and illness self-care activities (Janz, Champion, & Strecher, 2002). Janz and colleagues (2002) maintain that the HBM is influenced by social cognitive theory; it places an emphasis on the subjective value that people assign to a particular outcome, and the "expectation that a particular action will achieve that outcome" (Janz et al., 2002, p. 46.).

The major concepts of the HBM revolve around an individual’s perceptions of illness. A key concept is perceived threat of illness (Cohen & Welch, 2000), which relates to two variables: perceived susceptibility, the individual’s estimation of the chance of contracting an illness, and perceived severity, defined as the estimation of the seriousness of both the illness and the consequences of the illness (Janz et al., 2002). Motivation and concern about health must also exist to “make the health issues salient or relevant” (Cohen & Welch, 2000, p. 337) to the patient. In addition, cues to action, which include illness symptoms (Kelly, Mamon, & Scott, 1987), influence the decision to adhere to treatment recommendations.
The model also includes the patient’s perception of barriers to carrying out a health behavior (Janz & Becker, 1984; Janz et al., 2002). Barriers were originally conceptualized as negative aspects of a specific health behavior that interfere with the patient’s willingness to undertake the behavior; if patients view the behavior as expensive, painful, inconvenient, time-consuming, or associated with unpleasant side effects, they may conclude that the costs of treatment are higher than the benefits (Janz et al., 2002). More recently, however, some researchers have proposed that the construct of barriers should be expanded to include socioeconomic factors, such as social support, community resources, and the provider-patient relationship (Glasgow, 2001).

The HBM includes the concept of self-efficacy, which is the patient’s estimation of his or her ability and capacity to successfully carry out a health behavior and achieve the intended outcome (Cohen & Welch, 2000; Janz et al., 2002; Murdaugh & Vanderboom, 1997). A perception of low self-efficacy and lack of confidence in one’s ability to effectively perform a health-related behavior present further barriers to engaging in the behavior (Cohen & Welch, 2000).

Proponents of the HBM maintain that when deciding to engage in a particular health-related behavior, patients compare the perceived threat of illness and perceived barriers of a health care action to determine the benefits and costs of the health behavior. According to Cohen and Welch (2000), patients are more likely to engage in a health behavior if they perceive that the threat is high, the benefits of the behavior are high, and the costs of the behavior are low.
The Health Belief Model in schizophrenia. The utility of the HBM in schizophrenia research has been questioned by some mental health researchers. Zygmunt and colleagues (2002) suggest that “the highly rational assumptions of models such as the Health Belief Model are not helpful in understanding and predicting adherence in schizophrenia… ...patient schemas and coping plans may offer more potential for improving adherence in schizophrenia” (p. 1654). However, some research has found an association between health beliefs and the decision to adhere to treatment in individuals with schizophrenia (Adams & Scott, 2000; Dolder et al., 2003; Fenton et al., 1997; Kelly et al., 1987; Lacro et al., 2002; Perkins, 1999). Adams and Scott (2000) used the HBM to explain adherence in 39 inpatient participants with schizophrenia and schizoaffective disorder; findings indicated that two components of the HBM, perceived severity and perceived benefits of treatment, explained 43% of the variability in treatment adherence. Likewise, Kelly and colleagues (1987) examined the degree to which symptom-related health beliefs could predict adherence to medications among 107 veterans diagnosed with schizophrenia. Their findings indicated that 20% of the variability in adherence to medications could be explained by participants’ perceptions of susceptibility, illness severity, benefits, barriers, and cues to action (Kelly et al., 1987). Based on these findings, they suggested that health behaviors in individuals with schizophrenia are rationally motivated:

... ...there has been an inclination on the part of many researchers to view psychiatric patients as unreliable, incompetent, and unable
to hold rational views and beliefs concerning their illnesses and disabilities. Psychiatric outpatients do hold distinct and even realistic beliefs and perceptions regarding the extent of their illnesses. They also hold clear and identifiable beliefs about their treatment and its effects upon them (Kelly et al., 1987, p. 1209).

Although several researchers suggest that the HBM is applicable to schizophrenia research, they recommend that the model needs to be modified to address the unique issues associated with a diagnosis of schizophrenia. Lacro and colleagues (2002) and Perkins (1999) suggest that certain treatment barriers that are common among individuals with schizophrenia can be incorporated into the HBM; these include substance abuse, inadequate access to health care, lack of transportation, poor patient-provider alliance, inadequate hospital discharge planning and delayed follow-up outpatient care, complexity of medication regimen, and cognitive impairment. They further suggest that poor insight into illness can function as a risk factor modifier within the construct of perceived susceptibility to illness (Lacro et al., 2002; Perkins, 1999).

The Health Belief Model in diabetes. Behavioral health researchers have used the HBM as a theoretical framework to determine diabetes-related health beliefs in varying populations (Chapman, Ham, Liesen, & Winter, 1995; Coates & Boore, 1998; Polly, 1992; Wdowik et al., 2001). In one study of 48 elderly males, insulin-dependent respondents (n = 12) reported greater perceived barriers to control compared to non-insulin dependent (n = 36) respondents (Chapman et
al., 1995). Similarly, Polly (1992) examined the relationship between diabetes-related health beliefs and adherence to diabetes self-care; findings indicated that perceived barriers were significantly negative correlated ($r = -0.24, P = .02$) to self-reported dietary adherence.

**Transtheoretical/Stages of Change Theory**

The Transtheoretical Model, also known as the Stages of Change (SoC) Model, is a health belief model that incorporate a temporal dimension; this reflects researchers' observations that health beliefs change over time (Prochaska, Redding, & Evers, 2002). The theory postulates that when deciding to engage in a health or illness-related behavior, individuals move through five stages that reflect motivational readiness for change (Prochaska, Redding, Harlow, Rossi, & Velicer, 1994; Rollnick, Mason, & Butler, 2003). These include pre-contemplation, in which the individual is not aware of a health problem, and does not perceive a need to change; contemplation, in which the individual faces a growing awareness that a problem exists and that it needs to be addressed; preparation, in which the individual is ready for action and seriously considers change within the next month; action, in which overt modification of behaviors occurs; and maintenance, a time of continued action and relapse prevention (Prochaska et al., 2002).

According to SoC Theory, change involves a modification of cognitions, emotions, and behaviors over time; however, the specific interventions that address change vary depending on the individual's level of motivational readiness. For example, in the earlier stages of change, such as contemplation and preparation, interventions are mostly cognitive. The individual modifies
his/her beliefs and attitudes through “consciousness raising” (Prochaska et al., 2002, p. 103) which is the process of obtaining information to increase awareness about the problem behavior. An individual can also assess his/her self-image, both affectively and cognitively, “with and without the unhealthy behavior” (Prochaska et al., 2002, p. 103); this process is known as self-reevaluation. Later stages of change, such as action and maintenance, require more behavioral strategies, such as behavior modification, the use of counterconditioning behaviors, stimulus control, and contingency management. Finally, individuals who move through the stages also employ “decisional balance” (Prochaska et al., 1994, p. 478), in which individuals weigh the pros and cons of engaging in the health behavior.

Prochaska and colleagues (1994) maintain that the SoC Model is an appropriate framework to address both addictive and non-addictive behaviors; it is also suitable for both extinction of problem behaviors and acquisition of healthy behaviors. The behaviors that have been addressed by the Stages of Change Model include, among others, smoking cessation, quitting cocaine, weight control, and exercise acquisition (Prochaska, Velicer, Rossi, Goldstein, Marcus, & Rakowski et al., 1994). Miller and Rollnick (1991) have used the SoC Model in the treatment of alcohol abuse.

The Stages of Change Model in schizophrenia. The SoC model has been used infrequently to address adherence behaviors in individuals with schizophrenia. A randomized controlled trial compared a SoC-based intervention to usual treatment among 47 individuals with schizophrenia (Kemp, Hayward, Applewhaite, Everitt, & David, 1996). The intervention group (n = 25) worked with
a therapist in four to six sessions to explore ambivalence towards medications and to examine the costs and benefits of treatment adherence; the control group (n = 22) received supportive counseling in four to six sessions. Findings indicated that attitudes towards medications and illness, and insight into illness, were significantly improved in the intervention group. The authors reported that the intervention group was 5.2 times more likely to reach a “criterion level of adherence” compared to the control group (Kemp et al., 1996, p. 345). They further reported that these gains were sustained throughout an 18-month follow-up period (Kemp, Kirov, Everitt, Hayward, & David, 1998).

The Stages of Change Model in diabetes. The SoC model has been incorporated into diabetes educational programs (Jones et al., 2003; Peterson & Hughes, 2002). Jones and colleagues (2003) compared treatment as usual (TAU) to an educational intervention (SoC) designed to increase diabetes self-care and glycemic control among 1029 patients with diabetes. The SoC intervention targeted self-monitoring blood glucose, healthy eating, and smoking cessation; the interventions were personalized and matched to subjects’ stage of readiness for change. Findings indicated that subjects in the SoC intervention group moved more readily into action stages for the problem behaviors compared to the TAU subjects. Specifically, 33.2% of the SoC intervention group moved to the action stage in self-monitoring blood glucose, compared to 9.7% of the TAU group; 11.4% of the SoC group moved into the action stage for healthy eating, compared to 0% for TAU, and 5.5% of the SoC group moved into the action stage for smoking cessation, compared to 0% for the TAU group.
Cognitive-Behavioral Theory

Cognitive-behavioral theory (CBT), developed by Dr. Aaron Beck in the 1960s, focuses on the relationship between thought processes and psychiatric disorders. The theory postulates that an individual’s way of making sense of the self and environment can influence his or her mood and behavior (Turkington, Dudley, Warman, & Beck, 2004). A person’s views of self and environment are articulated through “automatic thoughts” (Thase & Beck, 1993, p. 5), which are typical human thought processes that can be viewed as internal dialogue, self-statements, or private thoughts. Persons with depression have been found to have particularly negative, pessimistic, or apprehensive automatic thoughts that are ruminative in nature, and these thoughts often interact with mood states: “the level of emotional distress is amplified by the frequency and intensity of negative automatic thoughts... and the probability of having such thoughts is increased by a dysphoric or anxious mood” (Thase & Beck, 1993, p. 5). The content of these thoughts typically relates to one or more elements of what Beck calls the “cognitive triad” (Thase & Beck, 1993, p. 4) of self, world, and future. In psychiatric disorders, these pessimistic automatic thoughts are distorted and inaccurate, yet the accuracy of these thoughts is almost never questioned. They are often extreme and absolute: “In order to be happy, everyone must always like me all the time;” “I must always put other peoples’ needs ahead of mine, otherwise I am a selfish and bad person;” “I failed this test—I can’t do anything right, I am a complete failure;” “I must hide my inner weaknesses from others in all circumstances” (Thase & Beck, 1993, p. 8). Interventions for cognitive distortions include interactive therapy, in which both the provider and patient
identify the patient's automatic negative thoughts, examine the thoughts to
determine their accuracy, and generate more realistic alternative statements that
explain the patient's perceptions (Beck, Rush, Shaw, & Emory, 1979).

In addition to illness-specific cognitions, the use of psychotropic
medications often results in negative and distorted thoughts (Wright, Thase, &
Sensky, 1993). According to Wright and colleagues (1993), erroneous cognitive
responses to treatment with medications include personal weakness (“I should
be able to make it on my own, without medications;” “Pills are just a crutch;”
“Pills mean you are not coping well”); fear about medication side effects (“I’ll
become an addict;” “I won’t be able to function if I take medications”); fear of the
opinions of others (“Everyone will think I’m crazy if they find out I’m taking
medications”); or misunderstanding about the illness (“I’m a miserable failure—
these pills are not going to change that;” “I’m feeling great, so I don’t need these
pills anymore—I’ll just stop taking them”).

**Cognitive-Behavioral Theory in schizophrenia.** Individuals with
schizophrenia often have dysfunctional and erroneous thoughts related to their
illness (Kingdon & Turkington, 1994; McQuaid, Granholm, McClure, Roepke,
Pedrelli, & Patterson et al., 2000; Scott, Byers, & Turkington, 1993; Turkington et
al., 2004); these beliefs often interfere with willingness to adhere to treatment
recommendations (McQuaid et al., 2000). For this reason, a growing number of
researchers are advocating for the use of the Cognitive-Behavioral Model as a
psychotherapeutic intervention for individuals with schizophrenia (Kingdon &
Turkington, 1994; McQuaid et al., 2000; Scott et al., 1993; Turkington et al.,
2004). For example, the diagnosis of schizophrenia can be very upsetting, which
may lead to denial of illness and lack of insight into the true nature of psychotic symptoms. In this instance, CBT is used to “decatastrophize” (Turkington et al., 2004, p. 10) the diagnosis and present a realistic picture of the long-term prognosis of the illness. Furthermore, medication adherence issues can be addressed using cognitive techniques (Heinssen, 2002); these include exploration of the patient’s views and beliefs about taking medications, examining the link between taking medication and symptom relief (Turkington et al., 2004), correct interpretation of side effects (Kingdon & Turkington, 1994), and linking the use of medications to the patient’s long-term personal goals (Heissenz, 2002).

To date, few studies have examined the effectiveness of CBT in the treatment of schizophrenia; in most cases, intervention studies have focused on the management of hallucinations and delusions in patients with chronic residual symptoms (Turkington et al., 2004). No research has been conducted on the use of CBT to enhance medication adherence.

**Cognitive-Behavioral Theory in diabetes.** Snoek and colleagues (2001) used a cognitive-behavioral model to intervene with 24 poorly-controlled adults with insulin-dependent diabetes. The intervention identified negative beliefs and attitudes towards diabetes (for example, “No matter what I do, diabetes-related complications will always develop, so I’m not going to bother with it”). A clinical psychologist and a diabetes nurse specialist jointly worked with subjects to challenge faulty beliefs and present a more accurate picture of glycemic control. The authors report that six months after the intervention, subjects’ mean glycated hemoglobin decreased by 0.8% (Snoek et al., 2001).
Critique of Theoretical Perspectives on Health Behaviors

The Health Belief Model, the Stages of Change Model, and the Cognitive-Behavioral Model have all been used in both diabetes and schizophrenia research. However, the majority of research has been conducted among individuals with a single illness. It is currently unclear whether the HBM model is adequate for individuals with multiple chronic illnesses; it does not provide a theoretical framework to help researchers understand and explain how people develop and act on the various beliefs and attitudes that can be associated with more than one chronic illness. In addition, the Health Belief Model does not explain the process by which individuals incorporate beliefs associated with two or more illnesses into a unified system of holistic health beliefs; no research has been conducted to determine how individuals compare perceived susceptibility and severity of two or more illnesses, and use their perceptions to assign relative importance to each illness. The process by which individuals prioritize and coordinate multiple tasks associated with the self-care of co-morbid chronic illnesses is not addressed in the HBM.

Although Prochaska and colleagues (2002) state that a person may become overwhelmed by an attempt to change several health-related behaviors simultaneously, Jones and colleagues (2003) demonstrated that several complex behaviors can be addressed by using a SoC Model. However, it has been used to address only one behavior—medication adherence—in individuals with schizophrenia. It is unclear whether a SoC intervention would be appropriate to address the multiple health-related behaviors in an individual who has
schizophrenia and diabetes, and may also be struggling to change smoking and substance abuse-related behaviors.

The Cognitive-Behavioral Model provides clinicians with an intervention to identify and modify faulty health-related beliefs. However, due to lack of research using CBT for medication adherence in individuals with schizophrenia, it is currently unclear whether it would be effective in improving adherence in this population. Furthermore, research needs to be conducted to determine its effectiveness in modifying faulty and dysfunctional beliefs associated with two or more chronic and complex illnesses.

The health-related issues of individuals with co-morbid chronic mental and physical illnesses are unique, complex, and challenging. Management of a chronic physical illness is complicated for individuals without mental illness; individuals with mental and physical illnesses are more disadvantaged because the symptoms of a mental illness can potentially interfere with the self-care of a physical illness. Problems with reality perception and cognitive impairments may prevent them from understanding the seriousness of a medical illness, monitoring symptoms, and planning and coordinating self-care.

Previous research indicates that individuals with schizophrenia develop reality-based, logical beliefs related to their mental illness and their need for treatment, yet nothing is known about how they develop beliefs related to self-care of physical illness. Continuing research is needed to address the increasingly complicated health care needs of this population.

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CHAPTER THREE

METHOD

Research Design

Qualitative research methods guided the design of this study. Researchers maintain that qualitative inquiry is an interpretive approach to the study of a particular subject (Denzin & Lincoln, 1998; Strauss & Corbin, 1998); it stresses the importance of "making sense of" (Denzin & Lincoln, 1998, p. 3) a phenomenon by articulating and interpreting the meaning that people assign to it. Qualitative research emphasizes the study of phenomena in their natural settings or contexts (Charmaz, 2000; Creswell, 1998; Lincoln & Guba, 1985). Although qualitative inquiry encompasses numerous methods, such as ethnography, case studies, participatory action research, phenomenology, and grounded theory, Denzin and Lincoln (1998) suggest that all qualitative methods include several similar features. These include an emphasis on the existence of multiple, constructed, and holistic realities among humans (Lincoln & Guba, 1985); multiple methods for gathering information, examination of the "constraints of everyday life" (Denzin & Lincoln, 1998, p. 10), and the acquisition of rich description that illuminates research participants' perspectives of a phenomenon.

A commonly used qualitative research approach is grounded theory, which provided the methodological basis for this study. Grounded theory research is based on the theory of symbolic interactionism, which maintains that human behavior results from interactions with one's surroundings (Blumer, 1969; Morse & Field, 1995; Morse & Richards, 2002). MacDonald and Schreiber (2001) suggest that individuals construct meaning and actions in response to
their life circumstances and the social contexts in which those circumstances occur. Grounded theorists, therefore, examine the actions and interactions between the person and society to understand how people construct their lives and the meanings they assign to their constructions.

Streubert and Carpenter (1995) maintain that a major goal of grounded theory is the identification of a core variable that summarizes “what is going on in the data” (p. 154); it essentially links and explains much of the variation found in the data. The core variable typically represents a basic social process that explains participants’ perspectives, actions, and responses to the studied phenomenon.

**Inclusion criteria for respondents**

Inclusion criteria for consumer respondents were: a.) a co-morbid diagnosis of schizophrenia or schizoaffective disorder, and Type 1 or Type 2 diabetes mellitus; b.) self-reported involvement in daily diabetic self-care activities (blood sugar monitoring, taking medications, adherence to a diabetic diet, following recommendations for foot care, and keeping appointments with providers); c.) willingness to participate in taped interviews, and d.) ages 18 to 72. Exclusion criteria for consumers were a.) any medical problem that prevented the client from participating in interviews, and b.) inability to understand the study purpose and procedures.

Criteria for inclusion of health care provider participants were: a licensed health care provider (advanced practice RN, dietician, licensed RN, physician, or physician’s assistant) who prescribed or taught diabetic care, or provided
counseling to patients on diabetic self-care management, and willingness to participate in taped interviews.

Institutional Review Board Procedures

A research proposal for the study was approved by the University of Kentucky Medical Institutional Review Board. The Institutional Review Boards associated with the proposed research sites, University of Louisville and Seven Counties Services (SCS), also approved the research proposal. Because the University of Louisville's Human Subjects Protection Office prohibited graduate students from functioning as Primary Investigators on research studies, a psychiatrist at the University of Louisville Department of Psychiatry and Behavioral Studies was the designated Primary Investigator for the study at the University of Louisville. The Medical Director of SCS functioned as the supervisor of research activities conducted at SCS sites. Continuation reviews were conducted in April, 2003, April, 2004, and February, 2005 at the University of Kentucky, University of Louisville, and SCS. Approval to continue research activities was given by the UK IRB and SCS IRBs. Letters of support to conduct research activities at the sites were obtained and submitted to the University of Kentucky Medical Institutional Review Board.

Respondent Recruitment

Following study approval by the University of Kentucky, University of Louisville, and SCS, the researcher initiated efforts to gain entry into the SCS Outpatient Community Mental Health Clinics. Research sites associated with SCS included the Center for Supported Living (CSL)-East, CSL-West, CSL-
Downtown, CSL-South, the Center for Rehabilitation and Recovery, and Artery House, a transitional living facility administered by SCS. An additional research site was the University of Louisville Ambulatory Care Psychiatric Service. One more site for recruitment of health care providers, Phoenix Health Center in Louisville, KY, was added during the second year of the research project.

The researcher contacted providers at each of the research sites to describe the study protocol, distribute flyers about the study (Appendix A), and request that they inform their eligible clients about the study. Providers requested permission from potential respondents to give the researcher their home phone numbers. When phone number were obtained, the eligible respondents were contacted and given a more detailed description of the study. At that time, arrangements were made to meet with the researcher at the outpatient sites from which they received mental health services.

Initial meetings with potential respondents began with the researcher and eligible respondents jointly reading the “Consent to Participate in a Research Study” form (Appendix B). The consent form provided details about the study purpose and procedures, participants’ roles in the research project, the risks and benefits associated with participation, the nature of voluntary participation, assurances of confidentiality, and their rights as research participants. The consent form also specified that the researcher would be obliged to report information that indicated that the participant was a danger to self or others.

Each consent form provided contact telephone numbers for the SCS IRB and the Office of Research Integrity at the University of Kentucky. Participants
were also given a contact telephone number for the researcher, with instructions
to call with any questions or concerns about the research project. Participants
enrolled after April, 2003 also signed the Permission to Disclose Protected
Health Information form, as required by the federal Health Insurance Portability
and Protection Act (HIPPA).

**Protection of Research Subjects**

In addition to compliance with HIPPA requirements, other strategies were
used to protect the confidentiality and anonymity of research subjects. All
identifying information was deleted from tapes and transcripts. All study records
were kept in a locked file cabinet, as required by the University of Kentucky
Medical IRB.

**Special Considerations in Research with Vulnerable Subjects**

Individuals diagnosed with serious and persistent psychiatric illnesses are
viewed as vulnerable research subjects by Institutional Review Boards. Roberts
(2002) maintains that research among individuals with mental illness poses
distinct ethical challenges to scientists. Cognitive limitations among individuals
with mental illness include impaired memory and judgment, which may interfere
with their ability to make sound decisions on their own behalf. In addition, these
impairments may prevent potential respondents from understanding complicated
research protocols, informed consent, volunteerism, confidentiality, and the risks
and benefits of participation in research.

As a result of their vulnerable status in medical research, individuals with
mental illness require special protections and safeguards throughout the
research process (Roberts, 2002; Wirshing, Sergi, & Mintz, 2005). Researchers emphasize that decisional capacity of vulnerable research subjects needs to be addressed throughout the research process. According to Roberts (2002), tools to assess potential participants' decisional capacity and understanding of research protocols can strengthen the "ethical rigor" (p. 539) of psychiatric research.

In this study, the research protocol included safeguards to assess potential respondents' ability to understand the research protocols, the nature of informed consent, and the nature of voluntary participation. First, the consent form was read aloud to potential participants by the researcher. Participants read the text while the consent form was being read aloud. All questions from participants were answered in understandable language, as required by the University of Kentucky Medical IRB. Following review of the consent form, a brief "Consent Confirmation" questionnaire was given to each participant. This involved the use of a 9-item, true-false quiz that tested participants' understanding of the study purpose and procedures, their rights as research participants, and the nature of voluntary participation (Appendix C). Comprehension of the study purpose and procedures was assumed to be accurate if all items on the questionnaire were answered correctly. All eleven participants correctly answered all of the questionnaire items.

Following the administration of the consent questionnaire, written permission was obtained from all study participants when they signed and dated the consent form. Copies of the consent form were given to each respondent, as
specified by the University of Kentucky IRB. Consumer respondents received $10 for each interview, which was intended to pay for their transportation costs to and from the interview sites.

Health care provider respondents also signed a Consent to Participate in a Research Study form prior to participation in the study (Appendix D). Health care providers did not receive renumeration for their participation in the study.

Sample Selection

Theoretical sampling guided the selection of respondents for the study. According to Glaser and Strauss (1967), theoretical sampling facilitates the generation of new theory by selecting respondents according to their "theoretical relevance" (p. 49) to the emerging themes of the theory. They recommend maximizing the differences between respondents by selecting them from the widest range of types, degrees, conditions, uniformities and variations, "all necessary for elaboration of the theory" (p. 57).

In this study, the first two respondents were European-American males who lived in a personal care home; both of them had type 2 diabetes and thus took oral hypoglycemic agents to control their blood sugars. Subsequent recruitment efforts sought female respondents who were either African-American or European-American ethnicity. As themes began to emerge from the data, participants with different types of diabetes were selected. For example, potential respondents who had Type 1 diabetes were sought to obtain information related to the use of insulin and management of more severe levels of hypo/hyperglycemia. Interviews with these participants promoted further
investigation of several emerging themes, including “problem-solving,” “self-monitoring symptoms,” and “motivation.” Respondents who lived independently in the community were also sought to gain perspectives on how they managed their own food selection and preparation; this was intended to expand on the emerging themes of “finances.” Respondents who lived with their families were sought to obtain information related to the emerging theme “family involvement” by exploring the various roles that family members took in the diabetic care of respondents.

**Data Collection**

Data for the study were collected between January, 2002 and May, 2004. Data collection included interviews with consumers and health care providers, observation of consumers’ blood sugar monitoring techniques, and diaries of blood sugar monitoring by select consumer respondents. Additional data were collected through observation of a Diabetic Support Group at one of the outpatient sites. Field notes comprised an additional source of data; these notes consisted of observations and impressions of the interviews, emerging themes, and ideas for additional interview questions.

**Consumer interviews.** A total of 26 interviews were conducted among 11 respondents. Each interview began with the collection of respondents’ demographic information (Appendix E). Demographic information included age, gender, ethnicity, marital status and number of children, living situation, educational background, employment status, medications, age of diagnosis of schizophrenia, and age of diagnosis of diabetes mellitus. Furthermore, a Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975) was
administered to obtain a general measure of respondents’ attention, concentration, and ability to understand directions (Appendix F). The MMSE, a screening tool for cognitive loss (McDowell & Newell, 1996) contains 11 items that are verbally administered; it assesses orientation, memory, attention, reading and writing skills, ability to name objects, follow verbal and written commands, and copy complicated shapes. The scale is scored by summing correct responses. The maximum score is 30, and scores of 23-24 indicate cognitive deficits. Reports of internal consistency range from .68 to .96 (McDowell & Newell, 1996).

Narrative data were collected in up to three taped, semi-structured interviews with respondents. Each interview lasted approximately 45-60 minutes. Initial interviews focused solely on respondents’ diabetic self-care; subsequent interviews concentrated more on self-care for schizophrenia. The first interviews were guided by the following general questions and statements (Appendix G):

- Tell me everything you do to take care of your diabetes.
- How did you learn to do these things?
- What are your concerns about having diabetes?
- What are the things that help you the most in caring for your diabetes?
- What are the things that are hardest in caring for your diabetes?

Additional questions were asked during each interview to clarify, probe and explore information provided by respondents.

At the end of each initial interview, respondents were asked to demonstrate their technique for checking their blood sugar using the researcher’s “One-Touch” glucometer. This demonstration allowed respondents’ techniques
to be assessed for correct use of the glucometer, alcohol wipes, and test strips. Furthermore, the results of the glucometer test served as a prompt to encourage discussion about how respondents interpreted the meaning and seriousness of their blood sugars, and how they would adjust their diet according to the results.

**Question evolution.** Analysis of initial interviews revealed several consistent themes. For example, the first three respondents revealed that family involvement and motivation to stay healthy were important factors in their self-care. In addition, respondents spoke at length about the challenges that limited incomes presented to their diabetes care. Therefore, interviews with subsequent respondents included the following questions:

- What has helped you make a commitment to your diabetic care? What keeps you motivated to continue doing it?
- What role does your family play in your diabetes care?
- What are your goals in life?
- Tell me about any issues you may have had in paying for your diabetes supplies and food.
- If you were to meet a person with schizophrenia who just found out he had diabetes, what advice would you give him?

Data analysis and question evolution continued throughout the process of interviewing consumers. Additional questions that were added as a result of emerging themes in the data included:

- How did you find out you had diabetes? What was your reaction when you found out you had diabetes?
- Do you use drugs and alcohol? How does that affect your diabetes care?
• What do you want from your health care provider to help you do this successfully?

During the interview process, the research proposal was reviewed by the Research Council of the International Society of Psychiatric-Mental Health Nurses; based on the committee’s recommendations, additional questions were added to the interviews:

• What is diabetes? What causes it?
• What does it do to people’s health?

The final interviews with respondents focused specifically on the issue of self-care for schizophrenia. Analysis of earlier interviews revealed that varying levels of commitment to diabetes self-care were apparent among the respondents. More importantly, however, respondents were also committed to their mental health care, and some were far more committed to maintaining their mental health than to maintaining a stable blood sugar. Therefore, the final interviews focused primarily on sources of commitment to mental health, and how the care of the mental illness influenced the care of the physical illness:

• What motivates you to take care of your schizophrenia?
• Some people live only with schizophrenia, and some people live with only diabetes, but you have both of these illnesses. What is it like to manage both of these illnesses?
• Tell me about how your mental illness has affected your ability to care for your diabetes.
Health care provider interviews. Four interviews were conducted with health care providers who treat individuals with diabetes mellitus and schizophrenia. Interviews were organized around five general questions (Appendix H):

- Tell me about your experiences in caring for diabetic patients with schizophrenia.
- How well, in your opinion, have they been able to learn self-care skills?
- What skills do you think have been the easiest for your patients to learn and master?
- What skills and interventions have been more difficult for your patients to learn and master?
- What do you think needs to be done to improve the care of your diabetic patients with schizophrenia?

As with the consumer interviews, additional questions were asked to probe, clarify and explore the responses from health care providers.

Participant observation. In addition to taped interviews with consumer and provider respondents, data were also collected during observation of a Diabetic Support Group conducted at a SCS outpatient site. A total of 10 group sessions were observed by the researcher. The group consisted of about seven individuals diagnosed with chronic mental illness and diabetes mellitus. The group was led by a mental health consumer and a mental health professional with a non-medical degree.

Data saturation. Interviews with consumers and health care providers were conducted until data analysis indicated that the categories were saturated.
Qualitative researchers define saturation as the point at which no new themes are identified in the data (Creswell, 1998; Strauss & Corbin, 1998).

Data Analysis

Data analysis was conducted over a period of two years, beginning with the first interview. First, impressions of the interviews were written in field notes and memos, including words or phrases from study respondents that appeared to reflect important issues and potential emerging themes. Second, transcripts of interviews were read and reviewed several times for initial impressions of emerging themes. Third, open, axial, and selective coding guided the formation of categories and subcategories from the emerging themes.

Open coding. Open coding and microanalysis of the narrative data were initially done by hand with the use of color codes to distinguish emerging themes, as recommended by Patton (2002). Microanalysis, referred to as “line-by-line coding” by Charmaz (2000, p. 515), promoted the identification of the characteristics, properties and dimensions of the emerging themes (Strauss & Corbin, 1998). The identification of characteristics of the emerging themes facilitated the process of constant comparison of data (Charmaz, 2000; Strauss & Corbin, 1998) in which every piece of data was compared to every other piece of data. For example, the theme “connecting two illnesses” emerged as an important theme very early in the study. Properties and dimensions of this theme included respondents’ perceptions about the permanence of each illness, the negative consequences of each illness, and the need for consistent, daily attention to self-care. Further open coding revealed that respondents were aware that maintenance of their mental health was a crucial precursor to
adequate diabetic self-care. This insight led to the identification of the basic social problem, psychiatric barriers to diabetic self-care.

**Axial coding.** Axial coding, the process of relating categories to their subcategories, involves "reassembling data that were fractured during open coding" (Strauss & Corbin, 1998, p.124). Strauss and Corbin (1998) suggest that axial coding requires a search for "repeated patterns of happenings, events, or actions/interactions that represent what people do or say, alone or together, in response to problems and situations in which they find themselves" (p. 130).

Several recurrent themes and patterns were found in respondents' narratives of diabetic self-care. A consistent theme in all narratives was family influence. Respondents learned much of what they knew about diabetes by observing their family members' experiences with the illness; based on these observations, they were able to fully understand the implications and potential negative consequences of a diagnosis of diabetes. Axial coding led to the development of this theme into "Personalizing Observations" about diabetes. Further axial coding revealed that respondents' commitment to self-care depended on their ability to understand the consequences of each illness on their own health and functioning. These insights led to the creation of the subcategory "Acknowledging Vulnerability" to both schizophrenia and diabetes.

Development of the theme "connecting two illnesses" led to further refinement of categories and subcategories of the model. Respondents connected their understandings of the two illnesses by realizing that there were many similarities between schizophrenia and diabetes, particularly related to consequences of lack of adherence to self-care. In addition, respondents
connected the two illnesses through their awareness that an exacerbation of symptoms of psychosis could interfere with their ability to perform diabetic self-care activities. Axial coding revealed that the majority of respondents used their experiences with schizophrenia to make decisions about the care of their diabetes. These themes led to the development of the subcategory "Applying Acquired Knowledge of Schizophrenia to Diabetes Care." The three subcategories of "Personalizing Observations," "Acknowledging Vulnerability to Diabetes," and "Applying Acquired Knowledge of Schizophrenia to Diabetes Care" were consolidated into the major category of "Accommodating Diabetes."

Selective coding. Selective coding relates to the refinement and integration of a theory (Strauss & Corbin, 1998). During this stage, the central, or core, category is selected; this category is intended to "pull the other categories together to form an explanatory whole" (Strauss & Corbin, 1998, p. 146). In this study, selection of the core category was facilitated by examining the temporal dimensions of each respondent's experiences with schizophrenia and diabetes. Data analysis revealed that respondents had several years of experience with managing schizophrenia prior to receiving a diagnosis of diabetes. During the time in which they lived with only schizophrenia, they developed health beliefs about self-care for psychosis that would eventually inform the development of their beliefs about diabetes self-care. The process of developing increasingly mature and complex ideas about self-care over time was identified as the core category, "Evolving Self-Care for Schizophrenia and Diabetes." This core category serves as an explanation for the entire model. It describes the process by which respondents first developed self-care beliefs about schizophrenia, then
developed self-care beliefs about diabetes, and then developed complex, integrated self-care beliefs about both illnesses. The core category further encompasses the outcome of respondents' integrated, holistic views of self-care; it incorporates respondents' decisions about self, health, commitment, obligation, and future.

Qualitative software. Following comprehensive sorting of the data by hand, coding was facilitated by the use of N6, a software package for qualitative data development, support and management. All data that had been coded by hand was transferred to the N6 program. The use of N6 allowed all narrative data that was relevant to a particular code to be compiled and stored in one file.

Data Trustworthiness

Several techniques recommended by Lincoln and Guba (1985) were used to enhance data trustworthiness. Credibility of the study findings was enhanced through prolonged engagement in the field; multiple interviews with consumer and provider respondents were conducted over a period of 18 months. In addition, a Diabetic Support Group was observed in 10 group sessions over a period of four months.

Persistent observation, another technique suggested by Lincoln and Guba (1985) was conducted through the use of extensive field notes written after each interview and during observations of Diabetic Support Group sessions. Member checks were conducted with respondents continuously throughout the study, as recommended by Lincoln and Guba (1985). Second and third interviews with each respondent were used, in part, as an opportunity to summarize and confirm information obtained in earlier interviews. Upon completion of data collection and
category identification, final member checks were conducted with four of the respondents in the study. A diagram of the study categories was given to respondents; they were asked to comment on the findings and discuss whether the categories reflected their actual experiences of simultaneously caring for their schizophrenia and their diabetes mellitus. All respondents who were asked to comment confirmed that the categories were an accurate reflection of their experiences.

A detailed audit trail was started immediately following the initial interview with the first respondent of the study. As the study progressed, all documentation of study procedures, field notes, theoretical memos, and coding notes were incorporated into the audit trail, as suggested by Lincoln and Guba (1985). An external auditor from the University of Kentucky College of Nursing reviewed the audit trail and attested to the trustworthiness of the study findings (Appendix I).

Study Limitations

In this study, respondents represented a variety of ages, ethnicity, severity of diabetes, length of time of diagnosis, and living situations. However, it is important to emphasize that all respondents' symptoms of psychosis were relatively stable, and respondents were therefore able to provide meaningful and insightful narratives about their experiences with self-care for dual illnesses. These respondents' stories do not reflect the issues of individuals who experience severe and recurring residual symptoms of psychosis despite adherence to recommended treatment.
In some cases, recommended data collection procedures for qualitative research needed to be modified based on respondents’ interactions with the researcher. Qualitative researchers typically recommend broad, open-ended questions to give respondents an opportunity to guide the interview with their narratives (Creswell, 1998); details are confirmed and clarified with the use of more specific probing questions. A few respondents who exhibited paucity of speech related to their psychiatric illness were unable to provide many details related to their self-care of schizophrenia and diabetes. In these cases, specific probing questions were used more frequently than recommended in qualitative research. This strategy is consistent with Creswell’s (1998) recommendation to “[match] the ‘level’ of the questions to the ability of informants” (p. 131). Despite the limited details from some respondents, their narratives reflected their unique perceptions, opinions and interpretations of the experience of caring for dual illnesses.

SUMMARY

Qualitative methods guided the process of data collection and analysis. The respondents were recruited and interviewed at five research sites over the course of 17 months. Participant observation was conducted during 10 group sessions over a period of four months at one of the research sites. Data analysis was conducted through hand coding and the use of N6 Qualitative Software. Data analysis began with the first interview and took place over a period of two years. Saturation of data occurred after 26 interviews with consumer respondents and four interviews with provider respondents. Several recommended strategies were used to ensure trustworthiness of the data, including persistent observation,
prolonged engagement in the field, an audit trail, and the use of field notes and memos.

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CHAPTER FOUR

DESCRIPTION OF RESPONDENTS

A total of 11 individuals diagnosed with schizophrenia or schizoaffective disorder and diabetes mellitus participated in the study. Their demographic characteristics are displayed in Table 1.

Respondents' demographic characteristics are summarized in Table 2. As indicated, six of the 11 respondents (55%) were male; 55% were European-Americans, and the remaining respondents were African-Americans. Male respondents were predominantly European-American, and female respondents were predominantly African-American. Eight respondents (73%) had never been married, one respondent (9%) was divorced, one (9%) was separated, and one (9%) was widowed. Respondents' ages ranged from 42 to 70; the mean age was 50.3 years (SD = 9.5). The majority of respondents (n = 7, 64%) were unemployed; of those who were employed, all worked less than 20 hours per week. Six respondents (55%) lived with a family member, three respondents (27%) lived in a personal care home, and two respondents (19%) lived alone. The mean Mini-Mental Status Exam score was 28.4 (SD = 1.7). Eight respondents (73%) were treated with an atypical antipsychotic medication for their symptoms of schizophrenia, two (18%) were treated with a typical antipsychotic medication, and one respondent (9%) was treated with both an atypical and typical antipsychotic medication. Six respondents (55%) were treated with an oral hypoglycemic agent for their diabetes; two respondents
<table>
<thead>
<tr>
<th>Respondent pseudonym</th>
<th>Interviews</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Marital status</th>
<th>Living Arrangement</th>
<th>Employment</th>
<th>Diabetic Medication</th>
<th>Antipsychotic medication</th>
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<td>Unemployed</td>
<td>Humulin 70/30 Insulin &amp; Metformin</td>
<td>Clozapine</td>
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aEA: European-American  
bAA: African-American
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<th>Interviews</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Marital status</th>
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<th>Employment</th>
<th>Diabetic Medication</th>
<th>Antipsychotic medication</th>
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<td>Unemployed</td>
<td>Glyburide</td>
<td>Quetiapine &amp; Olanzapine</td>
</tr>
<tr>
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<td>70</td>
<td>Female</td>
<td>AA</td>
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<td>Lives with son</td>
<td>Part-time</td>
<td>Glyburide &amp; Metformin</td>
<td>Fluphenazine &amp; Risperidone</td>
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<td>Quetiapine &amp; Aripiprazole</td>
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<tr>
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<td>Lives with brother</td>
<td>Unemployed</td>
<td>Metformin</td>
<td>Quetiapine</td>
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</table>
(18%) were treated with insulin. In addition, three respondents (27%) were treated with both insulin and an oral hypoglycemic agent. Whereas the majority of respondents were diagnosed with schizophrenia in their late 20s, most were in their late 30s or early 40s when they were diagnosed with DM. Most respondents, therefore, lived with the single diagnosis of schizophrenia for about 7 to 25 years before being diagnosed with diabetes.

### TABLE 2. SUMMARY OF RESPONDENT CHARACTERISTICS

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<th>Characteristic</th>
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<table>
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<tr>
<td>Ethnicity</td>
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<td>African-American</td>
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<tr>
<td>Marital status</td>
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<tr>
<td>Separated</td>
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<tr>
<td>Widowed</td>
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<tr>
<td>Living arrangements</td>
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<tr>
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<td>55</td>
</tr>
<tr>
<td>Both</td>
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<td>27</td>
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</tbody>
</table>
Consumer Respondent Profiles

The following descriptions include more details about the respondents' lives and perspectives related to the management of a chronic mental illness and a chronic physical illness. Some impressions and thoughts that I developed during their interviews are also provided in each respondent's description. All respondents are identified with pseudonyms.

George was a 42-year-old European-American male who lived in a personal care home at the time of the study. He had never been married and worked part-time at a restaurant. He took metformin for his diabetes, and was treated with quetiapine for his symptoms of psychosis. His symptoms consisted of mostly religious delusions and ideas of reference (the people on television communicated with him). He was distracted and tentative during the first interview, and he appeared to be struggling to concentrate on the questions that I asked him. It ended after about 30 minutes. After that first interview, I observed him as he tested his blood sugar; his hand tremors were so severe that I doubted whether he would be able to steady them long enough to get a drop of blood on the test strip. But he made a valiant effort, holding his fingers steady with his other hand, and was able to complete the blood test.

During the second interview, he told me that he had stopped taking his medications at the time of the first interview, which probably accounted for his distracted demeanor and poor concentration. He was taking them as prescribed at the time of the second and third interviews. The change in his behavior between the first and second interviews was striking; he was attentive, thoughtful, and eager to share his insights about his diabetes. He talked at
length about his strategies for self-care, his motivations for taking care of himself, and the help and support he received from his mother in diabetic self-care. George proved to be a crucial respondent in many ways. He was the first to identify several of the themes that were later confirmed through other interviews: commitment to diabetic self-care, family involvement, motivation, and connecting and prioritizing the self-care of schizophrenia and diabetes—the notion that you have to take care of schizophrenia in order to take care of diabetes. His narrative account of his experiences led to the development of the in vivo code of “hoping.”

Henry, a 65-year-old divorced male, was George’s roommate at the personal care home. His religious preoccupations were apparent during his interviews, but he stayed focused on my questions and talked at length about several of his diabetic issues. His interviews were important in that he expanded on some of the themes that George had raised. He told me that he prioritized his schizophrenia and diabetes care, but his diabetes was of little concern to him, “on the back burner.” He had been strict with the diet when he was first diagnosed with diabetes, but as he got tired of it and “cheated,” he discovered that his blood sugar never went above 150 mg/dl. His conclusion: it never got out of control, and “I just don’t worry about it.” His schizophrenia and mental health were far more important to him; he would never let himself slide with that.

During his second interview, Henry spoke at length about his college days and young adulthood. He had been diagnosed with schizophrenia as an adolescent, and his psychiatrist advised his parents to not expect much from him. Nevertheless, he had graduated from college, and had been employed for many
years. He had abused alcohol in the past, but was abstinent at the time of the study. In his later years, he struggled with depression and religious delusions, and was unable to live independently.

At one point during his third interview, Henry's memories appeared to discourage him: he paused for a little while and stared at the floor with a vacant look, apparently reflecting on everything he had told me about his life. He then shook his head and sighed. Who would have thought it would turn out like this? But then he rallied and spoke of his hopes and dreams. "When I came here, I had three goals: to regain my mental health, to get married again, and I forgot what the third thing was."

Adam was a 46-year-old unmarried European-American male, and was the first insulin-dependent respondent that I interviewed. He took haloperidol for his symptoms of psychosis. He exhibited the paucity of speech characteristic of individuals diagnosed with schizophrenia; despite my efforts try to ask open-ended questions, his responses were mostly "yup", "nope", and "I don't know". In any case, he did provide some valuable insights about the role of family in diabetic care in this population; he was dependent upon his mother to provide food and make decisions about blood sugar testing and how much insulin to take.

Steve was a 51-year-old, unmarried European-American male who lived at home with his elderly parents. His medications were haloperidol and Lantis insulin. He was, without question, the respondent with the most expertise in diabetic self-care; he clearly was comfortable with the monitoring and problem-solving required of individuals with diabetes. More than once I got the impression
that his motivation for participating in the study was to make an impression about his expert knowledge related to diabetes. He was a connoisseur of the various types of insulin available to diabetics: "I never liked the Humulin, it comes on too strong, the highs and lows are too severe... but the Lantis—now that is a godsend. You don’t have those strong highs and lows you get with the Humulin, it comes on much smoother.” He knew exactly what a 20 minute walk to the bus stop would do to his blood sugar. He knew from experience what a banana would do his blood sugar, and what a chocolate candy bar would do, and spoke at length about why bananas are better than chocolate: the banana would keep his blood sugar more stable for a longer period of time.

Despite his expertise, he overdid the self-monitoring at times. I asked him to keep a diary of his blood sugars, and when I reviewed it during the third interview, I found that he had checked his blood sugar over 20 times the previous day. “My doctor says I don’t have to do it that often.” Why check it so much? “Well, when it’s running high I don’t want to guess what it is, I want to know for sure.” Biggest concern about having diabetes? “Not having the money to pay for glucose testing strips.”

Despite his expertise at his diabetic self-care, he had some issues related to substance abuse. He drank beer a few times a week, but always adjusted his insulin to cover the increased caloric intake. He also used crack cocaine about every three weeks, and readily acknowledged that it interfered with his diabetic self care. “I don’t eat when I’m using cocaine.”

Kathy was a 44-year-old, unmarried African-American female who lived at home with her mother. She was unemployed and attended groups at Seven
Counties three days per week. She took clozapine for her psychotic symptoms, and was treated with Humulin 70/30 insulin for her diabetes. She was definitely the most humorous respondent in the study. She would sit with me in an office at Seven Counties, wearing a hat knitted in gold yarn, and she would make some ironic comment with a sly smile and a sideways glance at me to see if I got it. She referred to people with diabetes, herself included, as "sugarplums". Her humor was laced with touches of resignation: "My diabetes? Well, I guess I'm not really scared of it, you know, because I've got to die anyways... ...and why not die a sugarplum?" "I want to get a husband, wear pretty clothes, get a good job, but I'll probably just come to Seven Counties every day until I die." She made it clear throughout the interviews that she knew her commitment to diabetes self-care was minimal; she frequently made comments like "I need to be pushed... ...I could be doing better... ...I'm not ready to do it yet... ...I'm enjoying being big and fat too much."

Kathy was somewhat tangential during her interviews. When responding to a question, she would usually provide one or two sentences as a direct response, and then she would immediately shift to a detailed description of her mother's recipe for Punch Bowl Cake, and then to a description of her favorite "ritual" foods: Sugar Frosted Flakes and sweetened lemonade. She would invariably conclude her narratives with the question, "Now what were you asking me again?" Early in her interviews, it became immediately apparent that she really loved food. However, I discovered that she was stuck in a bind that is all too familiar to many obese people; her mother, with whom she lived, frequently berated and criticized her for being overweight. "She tells me, 'you look like a
freak, you are so fat, you look like you're nine months pregnant.' And I just say, 'okay, fine....'" Simultaneously, however, her mother baked sweets in large quantities for her church group, which she left sitting around their home: chess squares, jam cakes, sweet potato pies, brownies, cookies, and punch bowl cake. She was surrounded by high-sugar, high-fat food most of the time, and expressed resentment that she wasn't supposed to eat it.

Sheila, a 42-year-old African-American female, was different from the other respondents. Although I did not have access to any of the respondents’ charts, it became fairly easy to determine their subtype diagnoses of schizophrenia after talking with them for a few minutes. The majority of respondents described hallucinations and/or delusions as their predominant symptoms—the people on television talking directly to them, usually by sending secret messages, people following them, or talking about them behind their backs. It was clear that their predominant symptom profile was paranoia. Sheila, however, did not talk about any thoughts that reflected a disordered perception of reality. Instead, she exhibited symptoms of disorganized thinking, and consequently had a difficult time getting her point across. Her speech exhibited some communication problems common among people with a disorganized type of schizophrenia. For example, she used neologisms to convey her ideas; when I asked her about problems that diabetic patients usually experience, she replied, "They get deadness, and headaches, and deadness." She also had two abnormal speech patterns; she was tangential, a speech pattern in which people stray so far from their original point that the original point is often forgotten. Her other speech pattern is referred to as perseveration, in
which a phrase is repeated when it is no longer necessary: "I used to hear, I used to go see, I used to, when the church bell rings, the church bell rang, like the church bell rang you gotta say well, that means mama's going to be okay, you know, because when the church bell rang when I get to the hospital and then my birthday will be on a Sunday."

The most she could say about her diet was that she stayed "on the light side." Her discussion of other issues was somewhat clearer; she related that her deceased mother had diabetes and died due to complications from cardiovascular surgery. "They cut her here (indicating sternum) and here (indicating legs) and she died. I'm so scared of the diabetes." Despite her disorganized communication, however, her input was valuable; she was the first respondent to relate that financial considerations were a major barrier to diabetic care in this population: "I don't take the medicine because I don't have four dollars a month to pay for it."

Mary was a 70-year-old widowed African-American female; she worked two days weekly as a housekeeper for an elderly man. Her medications for schizophrenia included fluphenazine and risperidone; her diabetic medication was Glucovance, a combination of glyburide and metformin. During her first interview, she repeatedly emphasized that "doing the right thing" was the philosophy that guided her life and everything she did: her diabetes care, her care for her mental illness, her care of her family, her work, and her service to others as a volunteer. She accepted the fact that diabetes was just a part of her life; she believed everyone has some type of problem that they need to deal with, and this was her problem, and she knew that she just had to accept it and get on
with life. She was meticulous with her diabetes care; she described how she took the time to calculate fat and carbohydrate grams of the foods that she prepared. She ate only sugar-free candy and ice cream, and absolutely would not touch any type of food that was not allowed on her diabetic diet.

Dave was a 47-year-old African-American male who was separated from his wife; he lived alone in his own apartment. His medication for schizophrenia was olanzapine, and his diabetic medications included Humulin 70/30 insulin and metformin. Although he was not very articulate, he provided some very valuable information about the need to commit to diabetes self-care and never, ever quit doing it. He told me that his sister had suspected that he was diabetic for several months before he was diagnosed, but he had ignored her warnings. After months of showing the classic signs of hyperglycemia, he ended up being rushed to the hospital in a diabetic coma. This acute medical crisis convinced him that not only did he have diabetes, but that he needed to take it very seriously and make a serious commitment to diabetes care. And he said this often during his interviews: “You can’t mess around with it, you have to take care of it, you could die from this disease.” He lived alone and cooking was an issue for him—he didn’t really know how to cook, but his wife visited him frequently and cooked for him. To him, diabetes was an isolating experience; no one but his sister understood what it was like to live like this; the people in his church, well, “they said they understand, but they don’t understand, because they don’t have it.” Fortunately, he was very close to his sister, who also had diabetes, and she was a valuable resource and a source of reassurance to him.
Pamela was a 51-year-old unmarried European-American female. Her medication for schizophrenia was olanzapine, and she took metformin for her diabetes. At the time of the interview, she lived in a group home; however, she was finalizing plans to move to her own apartment and live independently. This was her first chance to live independently, and a recurrent theme during her interview was independence, going it alone, being self-sufficient, “you just have to do it.” She acknowledged, however, that family support was crucial and that she could depend on her sister to help her with her diabetes if she ever became unable to do it herself.

Barbara was an African-American female who could not remember exactly how old she was at the time of her interviews, but she guessed that she was about 42 years old. She took aripiprazole for her symptoms of psychosis, and Lantis insulin for her diabetes. She was the only respondent in the study who was diagnosed with diabetes before she was diagnosed with schizophrenia. She was about seven years old when she developed diabetes, and found out about it when she lost consciousness on the street one day. “Some woman found me and brought me to the hospital… …they told me I had diabetes.” She lived with her father, who sexually and physically abused her for many years. During that time, she refused to accept her diagnosis of diabetes, and would often eat sugary and high-calorie foods. Consequently, she recalls frequently waking up in a hospital emergency room, surrounded by hospital staff who were “poking me with needles.” During her adolescence, she became anorexic, and abused laxatives to lose weight. She ultimately accepted that she had diabetes when she was a young adult, but much damage had been done by that time. She developed
severe peripheral neuropathy, and had to use a wheelchair. Her neuropathy was so severe that she repeatedly broke one toe by bumping it against her furniture. She was completely blind in one eye, with only 20% vision in the other eye. She was committed to her diabetes care just to save what little remained of her eyesight.

Compared with other respondents, Barbara had more of a struggle with diabetic self-care. She told me that her limited income was a major barrier to care; because she took so many medications, she couldn’t afford the co-payments that Medicaid required; consequently, she had to pick and choose which medications she could pay for each month. It wasn’t unusual for her to go for a month or so without taking her psychiatric medication, or her cardiac or blood pressure medication. “Oh my God, it is awful.” In addition, she had a more difficult time accepting and coping with her diabetes. She related that her symptoms of paranoia interfered with her diabetic care; her fiancée helped her take care of her diabetes, and she frequently suspected that he put too much insulin in the syringes. She felt depressed and hopeless at times, and conveyed this during an interview. “I wish I would die, I wish I would accidentally overdose on insulin and die in my sleep, and it wouldn’t be a sin because it would be an accident.” As a mental health clinician, I became very concerned when I heard this, and had to stop the interview to assess her for her potential for suicide. She convinced me that she would not commit suicide, but to better assure for her safety, I let her outpatient clinician know about my concerns.

Matthew was a 52-year-old European-American male who lived with his brother. His psychiatric medication was quetiapine, and he was treated with
metformin for his diabetes. Diabetes and its consequences terrified him; his mother had died of diabetes-related complications and he told me that her doctors “didn’t do nothing for her, they just let her die.” He was distressed during his first interview, relating that he was constantly hearing voices that told him he was “no good” to his body. His psychiatric symptoms caused him to be completely dependent upon his brother for all his diabetic care: “I couldn’t do it without him, that’s all there is to it, I just couldn’t do it because of the voices.” Finances were a severe stressor to him, and he went to the local food banks whenever he ran out of money, about twice a week. Like Barbara, he told me that his life circumstances left him hopeless, and that at times he saw no point in continuing to go on with his life. Again, I stopped the interview to check this out further, and he assured me that he would not commit suicide. Nevertheless, I told his clinician, who replied, “Yes, he’s been like that for awhile.”

The second interview with Matthew was a very different story; he was relaxed, smiling, and friendly throughout the whole interview. He looked so different that I initially was not absolutely sure that this was the same man that I had interviewed earlier and found to be hopeless. He told me that he had recently started a volunteer job at a local personal care home. Most of his co-volunteers were also diabetic, and they all decided together what they could and could not eat for lunch. He talked at length about their support and how much he loved volunteering at the personal care home. In addition, he told me that he had moved in with his sister and was currently independent with his diabetic care. The change from the first interview was so remarkable that I finally had to say, “You really are doing so much better compared to when I last saw you. What do
you think caused this change?" "Oh, that's easy: I started getting some veteran's benefits, and my income has almost doubled, and now I don't have to worry about where my next meal is coming from." He said that he continued to hear voices, despite his adherence to his medications, but he didn't let them bother him anymore. He just accepted them and went on with his life.

Health Care Provider Profiles

Additional interviews were conducted with four nurses who practiced in the Louisville metropolitan area. Two of these were Advanced Practice Psychiatric Nurses; because of their advanced training and licensure, they had their own caseloads of patients and prescribed medications according to protocols developed with a psychiatrist. The third provider respondent had a Bachelor's Degree in nursing; her job responsibilities included educating and monitoring patients with schizophrenia at one of the research sites. The fourth provider respondent was an Advanced Practice Nurse who treated patients at a primary care clinic for homeless individuals in Louisville.

The Diabetes Support Group

Data collection procedures included observation of a Diabetes Support group conducted at one of the outpatient mental health clinics in Louisville. A mental health professional with a non-medical degree led the group because some of the nurses had been laid off by the clinic earlier in the year. The remaining nurses had very large caseloads, and no time to conduct groups.

About six or seven women attended the group every week. Of these attendees, four had a diagnosis of schizophrenia. The process of the group was the same from week to week: the group leader asked each member how they
had managed their diabetes the previous week, and how their blood sugars were that morning. Group members would discuss issues and challenges about sticking with the diet. The group also served as a forum for asking questions and sharing important information. Does Medicaid pay for those special shoes for diabetics? (Yes, one pair per year.) Was everyone aware that this grocery store over on the corner was having a sale on canned vegetables? Six for a dollar, people, be sure to get over there and buy some!

When all the questions and issues were settled, the group leader would hand out copies of diabetes educational material that focused on specific tasks, such as foot care, monitoring symptoms of hypoglycemia, cooking diabetic food, the effect of exercise on blood sugar, what to do when you get the flu, and complications that people with diabetes needed to watch out for. She read the text of the handout out loud while the group members followed along with their handouts. The group would then have a short discussion about the content and its implications, and many questions were raised. There were times when the group leader was unable to answer certain questions—arteriosclerosis? Oh, man, that doesn't sound good, what is that? Because of her limited knowledge about medical terminology, I found myself stepping in and answering the medical questions with increasing frequency. I was gradually changing my role from an observer to a co-leader. At that point, I decided it was best to end my observations, because I was no longer able to be objective. The group experience was valuable, however—it illuminated the difficulties and challenges that this group faced when trying to go through the daily routine of diabetic self-care. The group members weren't employed, and they all received monthly
disability payments. Paying for everything they needed was a problem, and many of them just couldn't make ends meet.

SUMMARY

In summary, respondents possessed a wide variety of demographic characteristics, which contributed to the maximum variation sampling recommended in qualitative research. In general, males and females were equally represented, as were African-Americans and European Americans. Respondents lived in a variety of residences, and had varying levels of family involvement. In addition, respondents varied in the seriousness of their diabetes and treatment they received to stabilize blood sugars. This variation among respondents led to some variation in the properties and dimensions of the themes that emerged from narrative data analysis. Variations in their approaches to self-care will be discussed in the Findings Chapter.

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CHAPTER FIVE

INTRODUCTION OF THE THEORETICAL MODEL

The process of data collection, constant comparative analysis, writing theoretical memos, and coding led to the development of a model that describes the self-care of individuals with schizophrenia and diabetes mellitus. This chapter presents an overview of the core category and subcategories of the model.

Overview of the Theoretical Model

The Theoretical Model that emerged from the data is Evolving Self-Care for Schizophrenia and Diabetes. The model addresses the basic social psychological problem of psychiatric barriers to diabetic self-care, which the majority of study respondents recognized as the most important problem that they faced when engaging in self-care. The basic social process depicted in the model is the evolution of self-care for schizophrenia and diabetes.

Evolving Self-Care

The core category, Evolving Self-Care, describes the process by which respondents’ rationales for self-care developed over time to help them manage two illnesses. Shawler (2003) suggests that the concept of “evolution” involves continuous growth and development from a simple state to a more complex, improved state. The evolution of respondents’ self-care occurred throughout the process of experiencing, observing, and adjusting to the management of dual illnesses. Throughout this process, they formed separate beliefs about each illness; these health beliefs revolved around their perceptions of their own
personal vulnerability, the seriousness of each illness, and the personal consequences of lack of adherence to recommended treatment for each illness.

The unique aspect about these respondents is that they combined their beliefs about schizophrenia and their beliefs about diabetes to form integrated beliefs about having dual illnesses. As they experienced the symptoms and the consequences of both illnesses, they developed a set of complex beliefs that linked the consequences of acute psychosis with the consequences of poorly controlled diabetes. Subsequently, these complex, integrated beliefs caused them to ultimately reflect on the value of health and self-care, and to articulate their commitment to move forward with their self-care activities to the best of their abilities. These health beliefs reflected their perceptions of their personal obligation and commitment to continuous care for both illnesses.

Specific Concepts in the Model

The major concepts of the theoretical model are depicted in Figure 1. A summary of health beliefs associated with each of the major concepts is depicted in Figure 2.

Mastering Schizophrenia. The process of Evolving Self-Care began during Stage One, depicted in the model as Mastering Schizophrenia. In this stage, respondents acquired the initial diagnosis of schizophrenia and learned to successfully manage a single illness. Respondents developed important health beliefs about schizophrenia during this stage, including:

- I have schizophrenia.
- My symptoms of psychosis result in serious negative consequences for me.
Evolution of Self-Care for Schizophrenia and Diabetes Mellitus

Mastering Schizophrenia
- Acknowledging vulnerability
- Maintaining stability

Accommodating Diabetes
- Personalizing observations
- Acknowledging vulnerability
- Applying acquired knowledge of schizophrenia to diabetes care

Striving for Health
- Taking responsibility
- Doing my best
- Hoping
Progression of Self-Care Health Beliefs

- **Mastering Schizophrenia**
  - I have schizophrenia
  - Psychosis has serious consequences
  - Treatment results in stability

- **Accommodating Diabetes**
  - I have diabetes
  - Poorly controlled diabetes causes complications
  - Psychosis results in poorly controlled diabetes, which causes complications

- **Striving for Health**
  - I need to take care of both illnesses
  - I need to do the best that I can
  - I'm doing it for my future
• Treatment for psychosis results in symptom stability.

The first subcategory is Acknowledging Vulnerability; this describes the process by which respondents learned the implications of their untreated symptoms on their ability to function. The second subcategory, Maintaining Stability, describes the commitment to adhere to treatment for symptoms of schizophrenia. It also describes respondents’ ability to recognize the relationships between antipsychotic medications, eliminations of symptoms, and improvement in functioning.

Accommodating Diabetes. During Stage Two, Accommodating Diabetes, respondents acquired a second diagnosis of diabetes. The term “accommodating”, in the case of study respondents, can be viewed as the process by which they learned the meaning of diabetes for them, proceeded to adjust to the diagnosis of diabetes, and learned to fit diabetic self-care activities into their lives. When accommodating diabetes, they “made a place” for diabetes in their lives. Three crucial health beliefs developed during this stage:

• I have diabetes.
• Poorly controlled diabetes has the potential to cause serious health problems for me.
• Psychosis results in poorly managed diabetes, which results in complications that can ruin my health.

The first subcategory is Personalizing Observations, the process by which respondents learned about the seriousness of diabetes by observing the trajectory of diabetes in family members and significant others. Through
observation of others, respondents came to understand that they were vulnerable to the potential complications of poorly controlled diabetes.

The second subcategory of Accommodating Diabetes is Acknowledging Vulnerability. This describes respondents' reactions to their personal experiences with diabetes. Through their personal experiences, they recognized the need for consistent self-care and monitoring to avoid the potential consequences of poorly controlled blood sugar.

The subcategory Applying Acquired Knowledge of Schizophrenia to Diabetes Care is the stage in which respondents incorporated the insights and knowledge gained from the self-care of schizophrenia to the self-care of diabetes. This consolidation of health beliefs into an integrated system enabled respondents to successfully manage both illnesses. They developed new understandings and beliefs about the relationships between the illnesses, the impact that each illness had on the other, and how they needed to proceed as they engaged in simultaneous self-care for schizophrenia and diabetes.

**Striving for Health.** Stage Three, Striving for Health, describes the culmination of the health beliefs developed during the first two stages; it represents the logical conclusion of all of their experiences, knowledge, and insights related to both illnesses. The health beliefs that respondents developed during the phase of Striving for Health include:

- I owe it to myself to take care of both of my illnesses.
- I need to do the best I can in taking care of myself.
- I'm doing it for my future.
Subcategories include Taking Responsibility, Doing my Best, and Hoping. Taking responsibility describes respondents' sense of obligation to consistently engage in self-care. Doing my Best, a category that was developed from an in vivo code, describes the degree of commitment and effort that respondents were willing to devote to the self-care of dual illnesses; it also reflects respondents' knowledge that optimal self-care needed to be consistently performed, despite the frequent challenges and frustrations presented by psychotic symptoms and social factors. The final subcategory associated with Striving for Health is Hoping, an in vivo code that describes respondents' anticipation of positive outcomes resulting from commitment to self-care.

SUMMARY

An overview of the theoretical model described the social problem that respondents faced when caring for their diabetes: psychiatric barriers to diabetic self-care. The model depicted the basic social process of Evolving Self-Care for Schizophrenia and Diabetes; this process enabled respondents to successfully manage the care of dual illnesses. These concepts will be discussed in depth in the Findings Chapter, in which narrative quotes from respondents will be used to support the concepts of the theory.

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CHAPTER SIX
FINDINGS

The categories described here are extrapolated from extensive narratives of consumer and mental health provider respondents. Strategies of grounded theory data analysis, such as constant comparison of data, open, axial, and selective coding, and writing theoretical memos, facilitated the identification of categories. In the following discussion, narrative quotes from respondents will be used to illustrate the categories of the theory. When applicable, variations in health beliefs of respondents will be presented.

During the data collection process, respondents devoted much time to discussions of the experience of living with dual illnesses, and how schizophrenia often complicated their diabetic self-care. From these interviews, the issue of psychiatric barriers emerged and became the central focus of respondents’ narratives. The major categories that summarize their stories include Mastering Schizophrenia, Accommodating Diabetes, and Striving for Health.

Mastering Schizophrenia

The category Mastering Schizophrenia represents the stage in which respondents were diagnosed with schizophrenia, learned what it meant and how it affected their lives, and made decisions about how they were going to take care of it. The subcategories include Acknowledging Vulnerability to Schizophrenia and Maintaining Stability.
Acknowledging Vulnerability to Schizophrenia

At the time of their interviews for this study, most respondents had been living with schizophrenia for about 25 to 30 years. They were generally diagnosed with schizophrenia when they were in their mid 20s; at that time, most respondents were finishing school, starting careers, and establishing a life independent of their parents. In the case of these respondents, the acute symptoms of psychosis, and the consequent deterioration in functioning, interrupted this movement towards independence.

When discussing their experiences with schizophrenia, the respondents described them mostly in terms of losses that occurred early in the course of the illness. Kathy “had a nervous breakdown” while in college. “I was hearing voices and I’d sleep a lot” and had to drop out of classes. “My mother was so mad because she put a whole lot of money into it.” During the early years of her illness, she struggled with paranoia and stated that she heard voices telling her to kill herself. Her mother became her main source of support.

When I had my nervous breakdown about 20 years ago, I was so sick that I didn’t want her out of my presence. I wanted her around me constantly... ...she’s have to go to work and I’d say, ‘Mama, stay here today, I don’t feel well,’ I was paranoid, you know... ... For the next 20 years, Kathy received treatment at several facilities throughout the state. She learned basic living skills at long-term rehabilitation facilities, such as Wellspring, Bridgehaven, Unity House, and Pyramid House. She was able to live by herself for 14 months when she was about 35 years old. Ultimately, however, her symptoms caused a deterioration in her functioning and
in her ability to live alone; she moved back home with her mother and has been living with her ever since.

Henry was diagnosed with schizophrenia at the age of 15. His diagnosis came in the 1950s, considered by many to be the early years of psychiatry; very few medications had been developed, and treatment at the time consisted mostly of insulin shock therapy. “Well, during that time I saw horrible things, things I would not wish on Saddam Hussein himself.” His psychiatrist told his parents not to expect too much from him. “I was in and out of the hospital since I was 15 years old and, well, they said I was a hopeless case.” His parents had difficulty accepting his illness, and did not provide support to him during the early years of his illness. Despite their lack of support and involvement, he was able to achieve independence by getting an education.

... ...the psychiatrist that treated me first time said I was not only a hopeless case but he told my parents, ‘why don’t you forget about him,’ and all through my life my mother said to me I was bad, she said ‘now Dr. so and so, he said that we should forget about you so we’re not going to fool with you’ but I graduated from (a local university) and got a degree.

During the early years of illness, his ability to function was erratic. He was employed for a few years at a brewery and as a welder, but was unable to maintain employment. He also married and divorced during the early years of his illness. He was eventually hospitalized for three years at a state psychiatric hospital. After discharge from the hospital, he moved to a personal care home near a local state hospital, and has been living there ever since.
Steve stated that schizophrenia created chaos in his life, particularly when he was first diagnosed. His symptoms of psychosis, and lack of adherence to treatment, caused him to be hospitalized frequently.

... ...when I was first seeing the doctor, I was in and out of the hospital maybe two dozen times. Early 80s, I was about 25... ...I was in and out of the hospital because I didn't take my (haloperidol)... ...I would just get into fights and start throwing things.

Likewise, Mary stated that her symptoms of schizophrenia would cause her to be hospitalized frequently.

I would go to hearing voices because I would be under a lot of stress, you know... ...my husband would bring me in. I didn't know what was wrong with me, I was just screaming and you know things like that, just raging, things like that.

In Mary's case, acknowledging vulnerability came after many years of living with symptoms of psychosis; she stated that her physician did not tell her that she had schizophrenia when she was first hospitalized. For years, she had no idea why she acted the way she did. Finally, receiving an official diagnosis convinced her that she had a mental illness that needed treatment.

It was 15 years before I got a diagnosis of schizophrenia... ...they didn't tell me what was wrong with me. Finally they told me, and it didn't bother me, it cleared up a lot of questions... ...I finally understood what was wrong with me... ...it just made me know what was wrong, that's what it did.

For most respondents, acknowledging vulnerability included an awareness and acceptance that they had a chronic and permanent mental illness that needed continuous monitoring and treatment in order to avoid symptoms and loss of functioning. Acceptance allowed them to reconcile themselves to the presence of the illness in their lives, incorporate self-care into their daily routine,
and move on with the task of living. They saw the need to view it as only one part of their lives, and not let it become the main focus of their existence. Matthew emphasized: “It (schizophrenia) don’t bother me, it’s just there and I just have to live with it.” Kathy felt the need to pursue stability and go on with her life despite the presence of a chronic mental illness.

... ...you just deal with it because the medications they give me help me make it through that (psychiatric symptoms)... ...this is a thing that will probably go on for the rest of my life, but I'm trying to maintain, and act like a normal human being, you know... ...since they do let people with mental problems not be in the hospital, you know... ...
schizophrenia that caused me to get to the point that I don't want anymore.

The recognition that antipsychotic medications were effective in eliminating the symptoms of schizophrenia was critical to their recovery and ongoing stability. For George, adhering to treatment—in other words, taking his medications regularly—helped him avoid chaos and disorganization in his life:

I've gotten off the medication (quetiapine) before since I've been here, and it's always ended up being a disaster... ...even when I've taken it I've had problems, but in the last three or four months I've been doing really good.

He told me that he often stopped taking his medications when he felt stable enough to think clearly; during those times, he doubted that he had a mental illness. But he admitted that this was a frequent pattern with him. "I have a tendency to stop my medications... ...the people around here know that about me.” He was aware that this was a problem that he needed to change:

The last time I saw you I was having trouble and when I saw you was probably a couple of months ago, wasn't it?... ...yeah, I was still having some really bad problems in regards to my schizophrenia ... ...and since that time, I have been on a roll, I'm doing really good... ...I stopped my medications one day because I was fed up with it, I said, 'I'm still having difficulties, and I'm still on the medication. I want to find out what would happen if I'm off the medication, maybe I can pinpoint why I do the things I do.' Well I was off of it (quetiapine) for about a day... ...and then the next day I started taking them again because you can't get off of it, there's just no way... ...it's too hard, really, your mind goes... ...

Steve was adherent to his medications because he knew that his behaviors were a serious problem for him; treatment prevented the emergence of unstable, violent behaviors that could cause him to be continuously admitted and readmitted to the hospital.
I always remember to take my (haloperidol)... you feel better when you take your medicine. I mean, you're not depressed, you're not talking out of your mind, you're not getting hot, you know, throwing things, or whatever, you're just controlled. It controls me, I mean I know I need my medicine, I can't live without it.

He further stated that he adhered to treatment for many positive reasons, not just to avoid hospitalization. Treatment and its consequent stability allowed him to work, go on dates, and develop a social life with friends that he cared about.

"I've got a good hold on my mental health, you know, I do good, I do good... it (haloperidol) has given me a life instead of a mental condition."

Several issues convinced Kathy to adhere to her psychiatric treatment.

She hated the idea of hospitalization, and the thought of homelessness and unrelenting psychosis was a significant fear for her.

When they assign me pills from here (outpatient clinic) I take it... I don't want to think about getting institutionalized... I figure if they've got a medicine for whatever is wrong with me, I'm going to take it. I'm trying to do the right thing, and I want to get, feel better. I don't want to get worse, you know... I'll take all the medicine I can while I can, I mean I don't want to get to a place where I ain't taking no medicine and walking the streets talking to myself... I have a fear of being locked up. I feel like I like being free... I don't want to have to be institutionalized because that would be awful. I could see myself now, locked up. 'She lost her mind, and they had to lock her up!!'... and then the next stage, there ain't nothing you can do but die, you know... that's all you can do, is just die... 

Not all respondents were motivated by fear; some told me that symptoms would interfere with their day-to-day routines, and they didn't have time for an exacerbation of psychosis. Dave was active in his church, and Matthew did volunteer work every day. Pamela was occupied with transitioning from a group home to her own apartment; she was also attended a therapeutic rehabilitation facility several days per week. Mary lived a very full life, and was occupied with
her job, her church activities, her volunteer work, and caring for her grandchildren. She realized that stopping her medications would be a mistake; too many people depended on her to stay stable and be able to function.

I just depend on it (fluphenazine and risperidone)... ...I don’t think I could go off of it because I have a lot of problems with the grandkids and different things, and I think I would have to just take it... ...I got off the medicine two nights ago, and I didn’t sleep like I was supposed to sleep, I feel the effects, if I stay off I would lose a lot of sleep and go to hearing voices, you know, I figure that might happen and I don’t want that to happen.

Respondents stated that avoidance of symptoms such as hallucinations and delusions was crucial step towards stability. Despite adherence to antipsychotic medications, however, respondents related that they still experienced symptoms during times of stress. For some respondents, self-monitoring and preventing these symptoms presented a significant challenge. George spoke of the difficulty he sometimes experienced in being able to distinguish reality from delusions:

Well, schizophrenia is a tough disease to have, it’s full of disillusionments... ...you can be disillusioned in any type of thing, it can be harmful thinking, it can be productive thinking but normally it’s an adverse type of idea and that’s what’s hard, it’s hard to cope with, because you have to know what’s reality and what isn’t.

Despite being adherent to their medication regimens, many respondents continued to experience residual symptoms of psychosis. To manage these symptoms, respondents relied on self-management skills such as reality-based self-talk and stress management. According to Mary, “it’s a mind thing, you know, you have to keep telling yourself, ‘this isn’t real’, and you have to keep praying about it.” Mary told me that her self-management skills developed over
time. "At first I wasn’t dealing with it, but I done grew, and I know how to deal with it better than when I first had it."

Matthew told me that despite his adherence to taking antipsychotic medications, he still heard voices almost continuously. During his first interview, they had caused him noticeable distress. However, during his second interview, he appeared much less stressed; he attributed this to the additional VA benefits he had begun to receive the previous month. These additional resources enabled him to rent an apartment and buy food. He told me that because he was much less stressed, his auditory hallucinations were much more manageable and tolerable, and he was able to cope quite well with them. Shortly after he began receiving benefits, he started volunteering at a supported living facility near his home.

I just take the medicine like she (prescriber) wants me to, and I'm doing ok now... ...I mean, I hear voices all the time, but I just don't let it bother me anymore... ...I just decided to go on with my life and do what I have to do, and let the rest of it take care of itself.

Other respondents had more difficulty with symptom management. Barbara related that managing auditory hallucinations was her biggest challenge, and admitted that despite her attempts, she was not completely successful with it.

... ...when I'm out on the street I'm thinking everyone is talking about me and that's why I wear the headphones when I'm out in my wheelchair, because the headphones keep the voices out, you know, and keep some of the paranoia down when I'm out. It is awful, it is so awful. I try to fight this paranoia but it's not working......

Although Barbara frequently experienced symptoms, she devoted much effort towards maintaining stability to the best of her abilities. She took her
medications when she was able to pay for them, participated in her mental health clinic’s diabetic support group, and attended appointments with her therapist and physician.

Respondents’ symptoms of psychosis were mostly stable at the time of the study; despite this, all respondents experienced the long-term social and functional consequences typical of individuals with schizophrenia. The issues of independence, housing, finances, employment, transportation, and social interaction presented significant challenges for them. During their interviews, they told me about their wishes for a “normal life,” in which they would live in their own apartments and support themselves with no help—not only would they not have to worry about where their next meal was coming from, they would also have cars and nice clothes to wear.

Respondents knew that they lived in a world in which desires and reality did not always match. They desired independence and wanted to make it on their own, but symptoms and social factors often interfered with self-reliance and self-sufficiency. Dave related that he wanted to work, but described himself as a “loner;” his need for privacy and isolation prevented him from seeking employment.

Financial problems, too, contributed to respondents’ inability to live independently. Four respondents—George, Henry, Steve, and Mary—were employed, but they only worked about two days per week in minimum-wage jobs. The rest received disability and Social Security Insurance (SSI) payments. Because respondents were either unemployed or employed part-time, finances were a continuous source of stress for them. Complete independence was not
feasible for most respondents, because they could not afford to pay rent on their
disability and SSI incomes. Only two respondents, Mary and Leonard, lived
alone; the others lived with parents or siblings, or in personal care homes. Most
relied on their families to make ends meet; parents often provided food, housing,
and transportation.

Respondents noticed, however, that their parents were aging, and
understood that their reliance on parents would end someday. Steve received
regular reminders from his parents:

Mom and Dad help me, and that's definite, they'll help me, if I can't
buy the food they'll buy it for me, they've already said, 'We'd help
you if you don't make it, you know, but try and make it, because
we're not going to be around all the time' . . . and they're 78 and 77
years old right now. . . .

Likewise, Kathy was often reminded about her reliance on her mother.

[My mother] said, 'I'm 76. . . . I'm overdue, I should've been gone. . . .
I should've died six years ago, God is just sparing me to take
care of you'. . . . she said 'I must be here to take care of you,
because I should've been dead six years ago. . . .'

In some cases, brothers and sisters were involved with respondents.

Dave relied on his sister, a diabetic herself, for advice and support in managing
his illnesses. However, about half of the respondents had siblings who didn't
want to help. Steve stated, "My sister doesn't want to have much to do with me."
Likewise, Henry had no family other than one nephew who didn't contact him.

The future loomed before these respondents, and many were
apprehensive about it. They expressed concern about making it on their own,
and the potential for homelessness was always there. They knew that the only
thing preventing them from becoming homeless was support from aging parents.
What will happen to me when my parents are gone and my brothers and sisters turn me away? How will I ever have enough money to survive? Kathy feared being incarcerated or needing to rely on homeless shelters; the potential inability to access psychiatric care and necessary medications also concerned her. “I don’t want to end up wandering the streets talking to myself.” Henry shared his concerns:

... ...you know, I’m 65 years old, I’ve had this all my life, I know it what it does.... ...living alone and buying medicine would cost $1200 a month, and I don’t have $1200 a month, my God, I only make $800 a month on Social Security, so you don’t have to be a mathematical genius to figure it out...

The respondents planned for the future; they would budget, save money, and buy only what was necessary. Steve told me that he had applied for Section Eight housing, and there were two people on the list ahead of him, so it wouldn’t be long before he could move towards his dream of independence. “I’ll have to watch what I buy, but I should be able to make it on my income.”

**Summary of Mastering Schizophrenia**

Respondents’ narratives indicated that they developed critical health beliefs during the stage of Mastering Schizophrenia. They recognized that they had a diagnosis of schizophrenia, and consequently had symptoms that could cause a severe loss of functioning. They further realized that treatment adherence was crucial in maintaining stability. These health beliefs provided a rationale for adherence to taking medications, and facilitated their ongoing commitment to maintaining their mental health.

Respondents faced the challenges of schizophrenia and succeeded in overcoming many of them. These challenges influenced the health beliefs of
respondents as they matured and made decisions about how to proceed with self-care. In later stages of the model, respondents’ narratives will demonstrate that they refused to give up on taking care of themselves, even though they knew that this was the easiest route to take. Instead, they came to the decision to make a commitment to self-care and proceed with the difficult task of managing two illnesses.

**Accommodating Diabetes**

The category Accommodating Diabetes represents the stage in which respondents were diagnosed with diabetes and the process by which they adjusted to the new self-care activities of a medical illness. Major subcategories include Personalizing Observations, Acknowledging Vulnerability to Diabetes, and Applying Acquired Knowledge of Schizophrenia to Diabetes Care.

**Personalizing Observations**

The majority of respondents stated that they had some knowledge about diabetes and its consequences before they developed the illness; in general, they came to understand the diagnosis of diabetes from their observations of family members. Most respondents stated that several of their close relatives, particularly siblings and parents, had lived with diabetes for several years.

Positive role modeling. Respondents’ observations of relatives’ experiences with diabetes were both positive and negative. George related that whereas his blood sugar was adequately controlled with metformin, his mother had to take insulin injections to stabilize her blood sugar. She taught him the essentials of a diabetic diet, how to manage abnormal blood sugars, and how to use a glucometer. He stated that his mother served as a positive role model for
him, she was a "gold standard" for excellent diabetic care, and a guide to how life as a diabetic should ideally be lived:

... ...with all the things that could go wrong, she seems to be healthy to me, you know. She tries to work out and exercise and she tries to live a healthy life... ... she wants to live as long as she can. I think her ultimate goal is to stay healthy and live, she doesn’t want to die and she doesn’t want to have problems that diabetics sometimes have, you know, the eyesight can go bad, you can lose some limbs, you know, you can lose your feet... ...there’s so many complications with diabetes... ...

**Observing complications.** Several respondents became aware of the problems associated with diabetes by observing their relatives’ problems with managing blood sugars and experiencing diabetes-related complications. Although George was aware that his mother was an expert at diabetes self-care and a positive role model for him, she also served as a warning about future problems that could happen to him:

My mom has it (diabetes) worse than me and she has a tougher life than I have... ... just seeing what she has to do every day, which is take shots, and it’s just something I don’t want to do, I don’t want to go there, I don’t want to be on insulin, and she’s tried to influence me to diet so that I don’t have to go through what she goes through... ...she sometimes gets a low blood sugar and she has to eat a candy bar or take some orange juice to get it back up... ...it’s a danger, she lives a little bit more dangerous of a life than I do.

For other respondents, their relatives’ complications from diabetes included peripheral neuropathies, limb amputations, myocardial infarctions, and cerebral vascular accidents. Steve said, “I saw an aunt die with it... ...she lost her knee and leg up to here, and my girlfriend lost her knee up to there, you know, with diabetes, you can have your leg amputated.” Kathy observed the consequences of diabetes among several relatives, which helped her realize the hereditary nature of diabetes:
I had an aunt on my mother's side that had it so bad they had to amputate her legs from being a diabetic and eating sweets, they cut both her legs off. Then I had another great auntie and see, they cut her legs off, and they cut my cousin's daddy's legs off and I got a cousin here in Louisville that's got a toe missing... we're big people, you know, and it's just hereditary it seem like to me, more hereditary than it is to be sitting there eating a whole cake at one time. Of course I'd like to do that sometime, get me a jug of milk and eat a whole cake, but I don't.

The issue of diabetes-related complications was a significant concern to most respondents. Dave identified strongly with his sister, who taught him everything he knew about diabetes. He watched her as she experienced vascular complications, and was concerned about sharing the same problem in the future.

...my sister got a problem with her feet, she got an infection and she's gotta take some of that (terbinafine) plus something else that her doctor give her, costs two hundred something dollars... and I pray for her that she'll be all right, but if she let it sit a little longer she could have an amputation. You're faced with all that stuff.

Kathy related that her life at the present time would not accommodate the addition of a diabetes-related physical disability.

I just don't want to die with both my legs cut off like my aunt... having my legs amputated and not being able to walk... I don't have nobody but my mother and there ain't no way in heck we can live in that house and not to move my legs and feet and things and not be able to go to anywhere, we don't have no ramp or nothing for me, if I was in a wheelchair, to get down on or nothing...

Watching a parent or grandparent die from diabetes-related complications was very traumatic for some respondents. Although Sheila had much difficulty articulating the influence of diabetes on her own life, she was very clear about what it had done to her mother: "She had, she lost her leg, really just lost her leg
and then because she lost her leg, she just died.” She was apprehensive about self-care because of her mother’s experiences:

... ...that stuff (glucometer and syringes) is scary, that stuff is scary though, that stuff is scary... ...I practically seen my mom do it, I practically seen my mom do it all her, do it all her life, all her life, like all her life. But I never would ask her what was the name of nothing, I would never ask her what was the name of nothing.

Matthew related that when he was first diagnosed with diabetes, “I thought it was something that would shorten my life.” He acknowledged that the source of his fears was his mother’s experiences with diabetes; she had developed several diabetes-related vascular complications, which resulted in her death.

... ...my mom had diabetes... ...she died from it, they weren’t treating it... ...she was real sick. Her legs gave out on her and she wasn’t able to sit up, she wasn’t able to stand, she wasn’t able to walk... ...they didn’t treat her for it and she was too far gone, they just let her waste away... ...they wouldn’t help my mom, they just let her die... ...They put her in the hospital and she lasted two weeks and that was it. I just hope I don’t ever get in that situation but I don’t know. I still worry about these strokes and stuff because sometimes my arm, my leg will get numb and I’m scared to death of having a stroke, but I don’t know... ...

Because of their observations of family members’ diabetes-related complications, respondents became aware of their own risk for complications and increased mortality due to poorly controlled diabetes. When discussing their family members’ problems, a recurrent theme was, “this could happen to me if I don’t take care of it.” Kathy watched her grandfather and aunt lose their legs; her aunt died of gangrene two weeks after her surgery. She learned that diabetes is fatal; “I could die from it, it’s a silent killer... ...I just don’t want to die with both my legs cut off.” Henry stated, “Oh, gee Willy, I’ve heard it’s a horrible death if you
don’t take care of it.” Likewise, Sheila conveyed what she learned from her mother’s experiences: “You get deadness... and headaches, and deadness.”

Steve agreed:

> Diabetes is a slow death, you know, I’ve heard it called that. Well, it’s not if you keep it up. If you don’t manage it, sure it’s going to kill you, but if you manage it you can live a long life and that’s one reason I do, because I don’t want to die from diabetes, I’d rather die from something other than diabetes.

**Acknowledging Vulnerability to Diabetes**

The category of Acknowledging Vulnerability to Diabetes has many similarities to the category of Acknowledging Vulnerability to Schizophrenia. As a result of their experiences with diabetes, respondents developed an awareness of the permanence and chronic nature of the illness, the need for consistent daily monitoring, the need to adhere to treatment recommendations to avoid problems, and potential consequences of lack of adherence to treatment.

**Getting a diagnosis.** Respondents had varying experiences with diabetic symptoms; whereas some found out they were diabetic during routine physical exams, others experienced a medical crisis that led to the diagnosis. For Henry, the classic symptoms of polyuria, polyphasia, and polydipsia came on suddenly:

> I remember that I went to the doctor, I was drinking two big liters of diet soda, and all of a sudden, I wanted more and more of them. And I knew there was something wrong with that system... so when I went to see the doctor, he put me in the hospital for three days.

Similarly, Steve related that he was “skinny, losing weight, the weight was falling off of me.” He was admitted to the hospital and found that his blood sugar was 800 mg/dl, which far exceeded the normal range of 70 to 120 mg/dl (Semb, 2004).
For these respondents, the early symptoms of diabetes were enough to convince them that they had an illness that they needed to pay attention to. In contrast, Dave initially had much more difficulty acknowledging a problem when faced with diabetic symptoms. He initially ignored the warnings of his sister, who had many years of experience living with diabetes and was able to guess what was wrong with him. Finally, an acute medical crisis served as his “wake-up call” to the problem:

I noticed some feelings back in 1997, my sister and I were together, and I started itching.... ...then all of a sudden I was getting weak, didn't pay no attention.... ...kept using the restroom.... ...and my sister said, 'you better get yourself checked, I believe you have the same thing I have,' and I said, 'oh, I ain't got it' .... ...and she noticed I was getting nervous and agitated easy sometimes, and she said, 'your blood sugar must be up,' and I just wasn't paying no attention to her, and then in 2000 it showed up.... ...I got sick, cramps and bloating, and then I started losing weight, itching, getting weak, my blood sugar went up to around 500 or 800.... ...I was weak and barely able to call 911, and they came and got me... ...they said I was almost dead in a coma.

Unlike the majority of respondents in the study, Barbara developed diabetes as a child, at least 20 years before being diagnosed with schizophrenia. She related that her experiences with a medical crisis prior to diagnosis did not convince her family that she had diabetes:

I was about six or seven years old and I was on my way to school and I passed out and some lady picked me up and, it was in California and she asked me, did I have diabetes. I didn't know what diabetes was, I was only about seven years old and she gave me a pop and it brought me around.... ...Well I was just living with my dad then and my brother and sister, and they didn't believe anything was wrong with me.... ...we came to Louisville, Kentucky, and I passed out again when I was at school.... ...and when I came to I was in the hospital, I was real thin, I was like 60 some odd pounds, I was real thirsty all the time, I was drinking lots and lots and lots of water, I mean the more I ate the thinner I got, you know all the symptoms.
Experiencing complications. Several respondents related that the experience of subjective symptoms helped them to fully understand the nature of diabetes. In particular, symptoms of hyperglycemia were problematic for respondents. Mary could tell when her blood sugar was high, because it made her eyes hurt. Steve was also aware of subjective symptoms of hyperglycemia, and the effect it had on his ability to self-monitor his symptoms.

... when your blood sugar is 300 or 400, you get tired and groggy... I get nervous and groggy and upset, you know, it's not good. When I'm around 120 I'm more healthier altogether, mentally and physically... it does have an effect on my mental condition.

Other respondents stated that complications resulting from diabetes continually reinforced their understanding of diabetes and its implications for them. Several respondents reported slow healing of sores and cuts, particularly on their feet. Dave had been told by his physician that he had "gallstones"; she was concerned about a gall bladder infection, which would be much more serious in a patient with diabetes compared to a non-diabetic patient.

Barbara experienced severe complications as a result of her diabetes. She stated that she refused to take insulin shots when she was a child; "I just wouldn't do it... I hated it then and I hate it now." In addition, she refused to adhere to a diabetic diet. "I used to eat a lot of sweets and stuff... That was through my little kid years, like 10-11-12-13, teenage years and stuff." Due to her resistance to diabetic self-care at an early age, she developed vascular complications during her adolescence:

About 17-18 years old, my eyesight started going away and I noticed that I was passing out a lot, you know, and waking up in the hospital a lot, a lot of times I wasn't eating and I had became
anorexic, I was anorexic and I was taking like two boxes of laxatives every day...... most of the time I didn’t eat, or there were times that I overate, and I would pass out all over, I mean, all over Louisville, in stores and everywhere, from not eating...... because I felt that the insulin was making me fat...... and I just felt real big so I just stopped eating, became anorexic.

As an adult, Barbara experienced two myocardial infarctions and developed several vascular-related complications:

The neuropathy from my diabetes, it made my legs numb and my feet tingle and hurt and I mean I tried to walk, I tried to stand and my legs would go out from underneath me and I’d fall, I had pain in my lower back, and then I still got pain in my hands...... I have retinal neuropathy and all this stuff, my whole body has been affected, all of it has been affected by diabetes, every bit of my body’s been affected. You know, my heart, my kidneys, my liver even, my lungs, I’m supposed to be on oxygen you know, my skin you know, all that stuff. It just scares me and I’m petrified you know...

As a result of respondents’ experiences with symptoms and complications, they developed an awareness of the seriousness of diabetes and a sense of their own personal vulnerability to the consequences of inadequate diabetic self-care. Dave stated that the memory of the acute medical crisis was a constant reminder to him that he needed to stay vigilant with self-care. Throughout his interviews, he frequently stated, “it’s so serious, you can’t mess with it.”

... ...you gotta be serious about it, you gotta be because like the doctor said, doctor said it’s a serious disease so you better watch out, she tell me because amputation, or what is that, you have stroke, heart trouble, kidney failure, amputations and blindness, most of all blindness, that scares you too.

Barbara’s experiences with complications also served as a wake-up call, but she acknowledged that this understanding of the seriousness of diabetes came too late:
I’m losing my vision, most of it, I don’t want to get to the point where everything is completely black, you know, completely dark, I don’t want that and right now I’m at the point where I’d do anything to keep the rest of my vision… …if you take care of it the way you should, you might end up with a few complications but they won’t be as severe as if you don’t take care of it, you know… …I didn’t take care of mine and I have all the complications from it.

Accepting the Diagnosis. Similarly to schizophrenia, acknowledging vulnerability to diabetes required respondents to recognize and accept that they had a chronic illness and needed to incorporate diabetic self-care into their lives in order to avoid serious consequences. Illness acceptance was facilitated by the conviction of the permanence and chronic nature of diabetes; respondents essentially told themselves, “I have it, it’s there, and it isn’t going away.” The health beliefs expressed by respondents regarding acceptance of diabetes varied, depending on their attitudes towards diabetes, emotional reactions to the diagnosis, and the degree to which they were willing to make a commitment to diabetic self-care.

At times, respondents suggested that acceptance involved some degree of resignation; they wished they didn’t have it, but they had no choice. Steve spoke of the difficulties associated with a commitment to self-care.

… …it’s a burden to be a diabetic, it’s not something that helps you, it’s hard to manage you know, it takes a lot of money, time and effort, you know, and you gotta always check your blood and see where you are during the day, you know… …

Kathy made it clear that she resented her diagnosis of diabetes:

I get mad and upset because I’m a diabetic, I get mad at myself and say, well, if I wasn’t a diabetic, look at what I could have--a jam cake at Christmas time, we used to make when we have a family gathering. I’d see my mother make chess squares and take that to the church, you know, donate to the church that we go to and she’d make them and I’d say, ‘oh Lord I can’t have none of that.'
Sometimes I would sneak but I'd say, I can't have none of this because I'm a diabetic and I wished I wasn't a diabetic so I could have some.

Adam regarded his diabetes as a nuisance; despite this, he had to deal with it:

"The only advice I could give someone is to accept their diabetes daily and check your diabetes daily, and try to cope with it." Steve concurred; he stated that he would "rather not have to deal with it." Some respondents were ambivalent for several months before accepting the diagnosis. This was a problem early in the course of Dave's illness:

(When I was first diagnosed) I couldn't take it, couldn't accept it, because I wanted to be like I used to be when I wasn't taking nothing (medications)... I said, 'I ain't gonna pay no attention to them doctors.' I didn't pay no attention. I said, "I ain't got it", but I did... I couldn't face it. But then they was telling me, 'you better take care, it's a serious illness'... and I was in a coma... and taking care of it since then, you know, it's a wake up call, you don't play with diabetes. I started taking (my psych meds), and I started taking my insulin.

Barbara also had extreme difficulty with acceptance, and still is ambivalent about it. Her emotional reaction to having diabetes, and the complications she experienced, strongly influenced her ability to accept the illness. Despite her anger at having diabetes, she knew she had to take care of it:

... I've had it for 33 years, and I've never been able to accept it, I hate it with a passion....it's not something that goes casually by, it's something you have to deal with and something that I've had to deal with my entire life.

Other respondents had less severe emotional reactions to the illness.

Mary and Pamela decided that diabetes was a part of life; they both believed that they were capable of fitting it into their lives and managing it successfully.
Pamela was able to accept it because she recognized the hereditary nature of diabetes.

Well, diabetes is just something you have to live with, and I'm trying to live with it, and I'm trying to be on my own with it, too.... it's inherited, and can't be helped, that's the reason I ended up having it, and my brother too.

Mary also accepted the fact that diabetes was part of her life, but she was clear that it was one small part. She had so many other things that occupied her, such as her church, her job, her children, and her grandchildren. Although she had to pay attention to her diabetes, she would not allow it to interfere with the rest of her life: "I control the diabetes, it doesn't control me... I don't let it get in my way, because I haven't let it get in my way." She took a philosophical approach to acceptance of her diabetes. In her view, problems in life could not be avoided by anyone, and the best approach to coping and adjusting to an illness was to acknowledge it, fit it into life along with the other problems, and move on with living:

Well, just try to accept it, that's what I'm trying to do, I'm trying to accept it... it's just a problem, you know, it's just like any other thing... everybody has a different complaint, different illness, and whatever you have, you just have to do what the doctor says, and just do the best you can with it... it doesn't control me... yeah, I know I got diabetes, and I have to accept it, I'm not going to let it get in my way......I just do what I have to do.

**Applying Acquired Knowledge about Schizophrenia to Diabetes Care**

The third major subcategory in Accommodating Diabetes, Applying Acquired Knowledge of Schizophrenia to Diabetes Care, represents a consolidation of respondents' core beliefs about schizophrenia and diabetes. In general, respondents had been living with schizophrenia for about 7 to 25 years...
before being diagnosed with diabetes. Their experiences with the multiple losses that occurred during episodes of untreated psychosis, and with complications of diabetes, served to inform the development of the consolidated health beliefs about having dual illnesses. When living with only schizophrenia, they had learned from experience that lack of adherence to antipsychotic medications had caused them to lose their independence, their careers, and their relationships with others; in this stage, they came to the realization that lack of adherence to antipsychotic medications, and consequent poorly controlled blood sugars, would place them at high risk for losing their limbs, their eyesight, and their lives.

The influence of psychotic symptoms. At times, the respondents spoke of the two illnesses as if they were intertwined and almost inseparable; they knew that the outcome of the mental illness strongly influenced the outcome of the physical illness. Respondents consistently conveyed their awareness that acute psychosis presented a major barrier to their ability to engage in diabetic self-care. They related that psychotic symptoms, particularly delusions and hallucinations, were overwhelming at times and became a distraction that prevented them from focusing on anything else. Dave found that his delusional symptoms, particularly paranoia, prevented him from routinely adhering to treatment. “The paranoia, thinking people are after me, and stuff, you know, it gets in the way (of my diabetes care).” Barbara found that her symptoms of paranoia made her question the actions of the people she relied on for support, including her fiancée and her visiting nurse. “Sometimes I think that my fiancée took (the syringe) and put more insulin in it, hoping I’d take the insulin and die.” Matthew experienced similar problems. At the time of his first interview, he stated that his hallucinations
interfered with his ability and willingness to take care of his diabetes. He was unable to do anything, including eat, because of his psychosis. His family assumed responsibility for his diabetic care when he was unable to take care of himself independently:

I can't, I can't do it, that's all there is to it....I wouldn't eat right, that's all there is to it.... I can't because of the voices. I would go without eating for two or three days because of the voices. I moved in with my brother and he took care of me. I couldn't do it without him.

Most respondents conveyed the belief that taking antipsychotic medications was the most important thing they could do to stay stable enough to engage in diabetic self-care. Steve's advice was to “take the medication both ways (for schizophrenia and diabetes), and try to gain control of the diabetes, you control it, it doesn't control you, and or course, stay stable mentally.”

According to Dave,

When you're off your (psychiatric) medication, you don't take care of yourself the way you should....but all of a sudden you get back to yourself and take the medicine, and you think about this, 'I can't let myself go.'

Like Dave, Steve recognized a direct link between his adherence to psychiatric medications and his ability to perform his routine, day-to-day care: “If I don't take my (haloperidol) I tend to skip meals and things....it doesn't happen very often because I'm pretty good about taking my insulin and (haloperidol).”

Well if I don't take my (haloperidol) I get depressed you know, mixed up feelings and things, you know, and it controls what I eat, I don't eat as good as I should because I pass food up, you know. And today I had lunch and breakfast and I feel pretty good.
When asked what would happen to his diabetes if he experienced an acute exacerbation of psychotic symptoms, Steve reacted with genuine surprise, stating that he had never thought about that scenario.

You mean, like, skipping both the [haloperidol] and the insulin? I can't imagine not taking both of them, you could get really messed up, you know... ...I don’t know, I can’t imagine not taking both. You know, I might forget one but I never have forgotten both.

His conclusion was that he would never allow it to happen. “There is no way I could take care of my diabetes unless my schizophrenia is stable.” Furthermore, Steve was convinced that his symptom stability over the course of several years played a key role in his ability to develop diabetic self-care skills.

I've been stable mentally, for 15 or 20 years I've been stable mentally, so I had a good jump on diabetes when it started happening. I could take the medicine and remember to take it, and watch my sugar, and it'd be ok.

For George, the symptoms of psychosis were only one aspect of schizophrenia that interfered with his self-care. He knew that his delusions presented a barrier to his diabetic self-care, which threatened his health, and possibly his life. “You can die from this disease, you know.” However, he also stated that throughout his adult life, he intermittently reacted to his diagnosis of schizophrenia with distress, depression, lack of motivation, and low self-esteem. Overcoming the depression and hopelessness that resulted from a diagnosis of schizophrenia was as important to him as overcoming the symptoms of psychosis. Adherence to his antipsychotic medications was one small but important part of diabetic self-care. However, George also believed that constant vigilance in self-monitoring his thoughts, mood, and self-esteem was crucial to maintain his mental health, and as a result, his physical health:
... ...you despair sometimes, and that's probably something I
would say to somebody, when you get down, be sure and pick
yourself back up, don't stay down too long because you can
really get hurt. I've despaired a few times, just like I don't care
and all, you know, I'm just going to do what I want to do, da,
da, da, da, but it doesn't last very long... ...we're only human, we
have weak points and we have strong points, some days are
better than others, and I think that's what I would try to tell
somebody about schizophrenia and diabetes, that you're
going to have your ups and downs, and you gotta be ready for
both... ...if you're ever in a euphoria about yourself, you know,
don't get illusions of grandeur, thinking that it's going last
without maintenance, you know... ... It is a highly
maintenance type of disease, diabetes is, and so is
schizophrenia.

He further stated that making a conscientious effort to consistently adhere
to treatment recommendations gave him a sense of accomplishment and
success.

It's a day-to day-commitment. I think once you get into the
habit of taking care of yourself, you feel better about
yourself, you feel more confident and self-esteem and stuff.
It's just like anything else, if you do it and you do it wrong,
you know, are you going to feel good about yourself?

The influence of substance abuse. In addition to symptoms of psychosis,
respondents were aware that substance abuse could interfere with the self-care
of both their illnesses. Dave knew that alcohol could cause an acute
exacerbation of his psychotic symptoms, and could also cause hyperglycemia, so
he quit drinking when he decided to make a firm commitment to self-care. "I
don't need to go messing with that alcohol stuff."

Some respondents used alcohol and illicit drugs, despite their awareness
of the consequences for their mental and physical health. George related that
his alcohol use concerned him; although he had been abstinent for a month prior
to his interviews, the risk of relapse was frequently on his mind. "I don't know, I'm
not convinced that I don't have another drink in me, I'm just staying away from it, you know, kind of like the people at Alcoholics Anonymous do.” He knew he had to abstain for the sake of both of his illnesses.

Self-medication, drinking alcohol and stuff... the schizophrenia can really make you want to self-medicate. I mean, if you are an alcoholic, which I am, it can make you want to drink, and you can't. Now if you drink it's just going to be worse, it doesn't go away and you're just killing yourself with two things there, you're not treating your mental illness right and you're not treating your diabetes right because of the sugar in the alcohol... that's what I worry about the most, those are the things that I really gotta watch out for.

Similarly, Steve knew the impact that alcohol could have on his diabetes and was able to compensate for alcohol intake in his daily self-care. He took about two extra units of insulin before he drank alcohol, which prevented a spike in his blood sugar. His real problem, he confessed, was his cocaine use, which diminished his conscientiousness and vigilance in self-care. “When I use cocaine it makes me not want to eat, but I eat anyways.” His skills in self-monitoring the signs and symptoms of hypoglycemia were also impaired by cocaine use: “I don’t realize it’s low because I’ve been using cocaine... that happens about once a month.”

Some respondents used nicotine, which had severe consequences for their vascular status. Kathy smoked five packs of cigarettes a day. “I’m sitting here craving one while I’m talking to you.” Despite her vascular problems, Barbara smoked two packs per day. She knew the consequences of smoking on her health and had made several unsuccessful attempts to quit.

Well, the thing that concerns me is, when I had my first heart attack, I was smoking three packs a day and right after the heart
attack I went down to one pack and then gradually I started, I ended up right back at two packs again.... what I don't understand is that I can be in the hospital for a week or two and then come out and start back smoking again.... ....I was trying to convince myself to not smoke last night. I told myself, Barbara, think, pretend you're in the hospital, imagine you're in the hospital and you can't smoke.... ....but it didn't work. You know, I'm in trouble. It just really bothers me about me smoking, I need to quit because it's causing damage in my veins in my legs and my eyes and it's messing with my heart and my lungs.... ....

Prioritizing illnesses. Most respondents compared their perceptions about the relative severity of schizophrenia and diabetes. In some cases, this comparison led respondents to believe that both illnesses were equally severe and equally important to take care of. Dave related that the illnesses were equally important because consequences of lack of adherence for both illnesses were equally serious. "I'm going to tell you the truth, they are both equal.... ....you can't let one go, and you can't let the other go." Adam agreed:

They are equally important to watch, because you can get depressed and do something to yourself.... ....you might try to overeat sweets to try to kill yourself. So you need your depression pills and your schizophrenia pills.... ....I'm all right just as long as I take care of my diabetes and my schizophrenia.

Others stated that the illnesses were equally demanding of concentration, attention, planning, self-monitoring, and problem-solving. Kathy told me that the care of her mental illness meant constantly monitoring her thoughts, deciding whether they were accurate and reality-based, taking her medications, attending medical appointments and groups three days a week at the outpatient clinic. She took clozapine for symptoms of psychosis, which required a lab test every other week to measure her white blood cell count. The care of her diabetes involved measuring her blood sugar twice a day, drawing up and injecting herself with
insulin, planning her meals, and paying attention to signs of hyperglycemia and hypoglycemia. “Most of my attention has to be paid on those two illnesses.”

For most respondents, care of schizophrenia was recognized as their priority. Schizophrenia demanded more of their attention and more self-monitoring to determine whether their thoughts were reality-based or moving towards delusions. For Mary, schizophrenia self-care required ongoing “self-talk” as a reminder to stay connected with reality. George related that symptoms of schizophrenia could overwhelm any of his efforts to engage in diabetic self-care. Stability of his schizophrenia was a priority with him:

I think one good thing leads to another… ...If you are doing well with your schizophrenia or your mental illness, you have a hell of a lot better chance of maintenance in your diabetes… ...there’s no possible way you can take care of yourself properly, having those symptoms of schizophrenia, and having diabetes at the same time… ...you just wouldn’t be able to take care of yourself, and I think a lot of it is, you just wouldn’t give a damn, you know, you would just give up… …it’s just too hard to deal with…. …the first thing you have to do is take care of your schizophrenia, then you can concentrate on your diabetes, because concentrating on your diabetes is not going to make you well mentally.

Similarly, Dave recognized that while both illnesses required attention and commitment, stability with schizophrenia was a crucial precursor to diabetic self-care. Psychosis had the potential to interfere with the care of an illness that had left him in a coma and almost resulted in his death.

Well it’s true, you gotta be stable… ...in order to take care of any kind of illness… …you gotta take your medicine for schizophrenia because, well then you’d be hearing them voices and getting paranoid… …you’d be worried about that hearing voices so much you ain’t got time to care of yourself, diabetes or nothing else.
Henry compared the seriousness of both illnesses and had come to the conclusion that schizophrenia was a far more serious illness compared to diabetes. During his interviews, he made it clear several times that he didn’t regard his diabetes as being worth much effort: “I don’t do much to take care of it.” The only thing he really did was drink diet soda; he admitted that he ate ice cream frequently at work, and liked to go to a nearby bar to drink a few non-alcohol beers. He had observed, however, that no matter what he ate, his blood sugar never went above 150 or 155 mg/dl. The complications of diabetes, if they ever did occur, were far off in the future. Schizophrenia, however, was a different story; for him, the functional consequences of untreated schizophrenia were more immediate, more severe, and more devastating compared to the consequences of diabetes. Schizophrenia had caused him to lose his job and his marriage, and took away his ability to live independently in the community. It could cause him to become homeless in the future.

To be quite frank with you, I never really did think that it (diabetes) was something that I had to take care of....I take care of it but... ...I don’t feel that it’s as bad as my schizophrenia....I definitely have to take care of my schizophrenia....but as far as the diabetes is concerned, I feel it’s on the back burner.

He further stated that his approach would definitely change if his blood sugar was in the range of 300 to 400 mg/dl, but as for right now, “it doesn’t get out of control, and I don’t worry about it.”

Provider perspectives. Health care provider respondents supported consumer respondents’ observations about the degree to which psychiatric symptoms interfered with diabetic self-care. They all told me that their stable patients had medical appointments at the clinics about every three months;
because they were not experiencing acute psychotic symptoms, they didn't need to be seen more often. Instead, they saw unstable patients more frequently, and were very concerned that ongoing symptoms of psychosis in these patients interfered with their diabetes care. Denise, an Advanced Practice Psychiatric Nurse, offered her perspectives regarding the degree to which psychiatric symptoms could present a barrier to accessing necessary medical care.

... ...many of these folks can become paranoid to the point that they're afraid to leave their apartments. They're actually afraid to go to their doctor's appointments--or if they get there, they can't tolerate the sitting and the waiting (in the waiting room) because of their paranoia. So that's a difficult part of this population to manage... ...just helping them overcome the paranoia enough to be able to go where they need to go in order to manage any illness, you know, including diabetes.

Monica, a Bachelor's degree nurse at the same clinic, agreed with respondents that symptoms of psychosis presented a significant barrier to self-care. She described her experiences with patients who could not care for their diabetes due to devastating hallucinations and delusions.

Oh, they can't even take care of their mental illness or take care of the symptoms that are causing them so much distress... ...how in the world would you be able to prepare meals, shop right, exercise? A person needs to be 'with it' to do those things, not hearing voices and not seeing violent things on the sidewalk... ... Adrienne, an Advanced Practice Psychiatric Nurse who prescribed medications for patients at one of the research sites, provided insights about her own patients who struggled with caring for both illnesses. She stated that the patients who did not understand diabetes, and did not see the relationships between schizophrenia and diabetes, were at risk for serious problems.

... ...it's really dicey because I'm dealing with people with a severe mental illness who have problems taking the (antipsychotic)
medications I'm prescribing for them, and then they are also supposed to be taking their own blood sugars and deciding how much insulin they're supposed to take, or how they need to modify their diets.... I would say 50% of (my patients) learn it and do well with it, but then I have 50% who don't learn any of it and do very poorly with it.... the one group (that does poorly) is much sicker mentally than the other group.

The group that did poorly with diabetic care was a major source of concern for Adrienne; her patients with cognitive impairments were often unable to grasp the significance of diabetic symptoms. She described the case of one of her patients, an elderly woman with schizophrenia who was newly diagnosed with diabetes; she couldn't make an association between a low glucometer reading and hypoglycemia.

I've got this one elderly lady that just got diagnosed with diabetes, and she thought that when her blood sugar was 30, that was normal.... I'm afraid this lady isn't going to make it. She almost died when I diagnosed her with diabetes.... I'm amazed she lived because she was in a coma and on life support with hyperglycemia, but now that she's medicated (her blood sugar) keeps bottoming out.... she's so confused right now that she comes in here (the outpatient clinic) and she doesn't remember who she's supposed to see, and doesn't know who to ask for, and it's just a mess.... I'm afraid she's going to end up in the hospital again.

Adrienne further suggested that existing services for patients with schizophrenia were inadequate to address her patient's unique learning needs.

The Visiting Nurses Association (VNA) had made a few home visits to teach her patient about diabetes self-care, but she was unable to retain the information.

They've already taken the VNA out of her home, they said that all they were there for was to teach, and that they had done their part, and they're gone.... then her case manager went to the doctor with her, and told the doctor, 'She doesn't know how to use the (glucometer), she doesn't understand the numbers, and you know, I'm not a nurse and I don't know these things'.... well, they just sent her on her way. They said, 'Well, you know, she's gotten all
she can out of us, and that's all we can do,' which is just horrifying to me.

Monica further supported the degree to which psychiatric barriers prevented her patients from successfully caring for their diabetes. This knowledge guided her approach to patient care and education; she maintained that continuously stressing the link between schizophrenia and diabetes was the most successful way to help patients recognize the need for treatment of both illnesses. When providing patient education, she attempted to help patients understand their vulnerability to the negative consequences of acute psychosis and poorly controlled diabetes.

Validate their feelings from the get go, then begin to stress the importance of taking care of yourself and compare it to the mental illness. ‘If you don't do this for your mental illness, if you don't come here and make the appointments and see the doctor or if you don't take your medicine, this is what happens to you’, and then roll it around to the same thing with the diabetes and talk to what could happen if you're not managing your diabetes and what are the long term effects of that, same as with mental illness and then compare those.

**Summary of Accommodating Diabetes**

Respondents accommodated diabetes in their lives by understanding and accepting the implications of their diagnosis. In addition, respondents developed critical insights and beliefs about the relationships between diabetes and schizophrenia as they learned to simultaneously manage both illnesses. Their evolving health beliefs reflected their ability to take a holistic approach when engaging in the self-care of dual illnesses. Respondents emerged from this stage with the knowledge that they needed to continuously care for their schizophrenia in order to adequately care for their diabetes. Respondents compared and
connected everything they knew about their individual illnesses to create more complex rationales for caring for dual illnesses. These complex health beliefs led them to solidify their commitment to taking care of dual illnesses during the final stage of evolving self-care.

**Striving for Health**

The final stage in the evolution of self-care is Striving for Health; this category represents the logical conclusion of the first two stages. Respondents used their experiences, observations, and insights to make decisions about how they would proceed with self-care of both illnesses. The subcategories of this stage include Taking Responsibility, Doing my Best, and Hoping.

**Taking Responsibility**

When taking responsibility for their illnesses, respondents recognized the need to continuously engage in consistent self-care. They made it clear that they would have preferred not to do it; they described diabetes as a “pain,” a “hassle,” a “nuisance,” something that “gets in the way.” Regardless of their attitudes towards the illnesses, they conveyed a sense of obligation and commitment towards self-care; they did it for the sake of things that were most important to them, including their health and their future. Mary approached self-care in the same way she approached all other aspects of her life: “It’s the right thing to do.” Likewise, George made a commitment because of the things he valued: “I owe to myself and my family to stay healthy.” He acknowledged that this commitment to self-care was not an easy decision, but his sense of obligation to himself and his health left him no choice. “You know, it’s easy to give up on yourself, but you
can't.” For Dave, consistent attention to self-care for dual illnesses was a part of a lifestyle that embraced health. His commitment to health was all-inclusive:

... ...take care of yourself, follow the doctor's orders, eat right and exercise, do what the doctor say, don't smoke, or drink, or fool around and get AIDS or sexually transmitted diseases... ...lead a clean life, you know, a positive clean life, do things positive and just take care of yourself.

Other respondents stated that they made a commitment to self-care out of necessity. They had weighed all the risks and all the benefits, and reviewed all the problems that they had experienced in the past and could experience in the future. They came to the conclusion that whether they liked it or not, they were going to do it. They believed they had no choice. "I have to" was a frequent theme. George stated, “I don’t like it but I have to do it.” Likewise, Steve, the expert in self-care among all the respondents, stated, “Yeah, it’s a hassle to take a needle and put it in your stomach you know, it’s a hassle but it’s something you gotta do and I didn’t have any problem doing it from day one, you know.” Other respondents agreed:

Dave: It’s tough but you just have to deal with it... ...I wish I didn’t have nothing, for real I wish I was like anybody else you know, but some people are just blessed and some ain’t blessed more than others..... I just have to deal with it the best I can. I just have to.

Matthew: You just have to keep going... ...stay ahead of the diabetes. You have to stay ahead of it to keep from having problems with your kidneys and liver and stuff like that.

Kathy: I have to realize that to keep from going to jail, or penitentiary or getting put out of the house, or winding up dead, I have to take my nerve medicine to keep me at a norm... ...and then with the diabetes, I’m watching it more since they told me I could die from it... ...now, I know you’ve got to die from something, but I always thought that I’d try to go natural, you know?
In addition to a strong sense of obligation, many respondents stated that their ultimate goal with self-care was complete self-sufficiency. They had come to rely on their parents when they were learning to live with and successfully manage schizophrenia. Although they appreciated the support they received from others, respondents were aware that taking full responsibility for the self-care of both illnesses meant relying on themselves, solving their own problems, and finding their own resources. Dave’s goal was to reduce his reliance on his health care worker. “She can’t do everything, she can’t beat you up and make you (take your medications), because it’s up to you.” Pamela was planning to move to her own apartment and live by herself for the first time in thirty years, and self-reliance was a priority with her. “I want to be independent with it.” George was aware that independence was crucial to his success in managing dual illnesses when his parents could no longer help him:

I could sink or swim (when I move to an apartment), you know, because you’re on your own. My parents are up there in their late 60s, I mean it’s my time now, it’s my time to take care of myself and that’s what I’m going to have to do and I have the tools to get it done. I have AA, I have knowledge about both my illnesses, and it’s just a matter of treating them both with respect for their specific needs.

Steve agreed:

….for the last four or five years, mom and dad have been helping me and it’s time to get on my own and manage my diabetes….I think it’s time that I managed by diabetes on my own, you know, I’ve had enough time to break it in, see what it’s like, you know, see how to do it. I think it’s time for me to be on my own.

**Doing my Best**

The subcategory Doing my Best represents respondents’ awareness of the efforts required to conduct adequate self-care despite the challenges and
frustrations they experienced. Doing my Best is an in vivo category that emerged from the narrative data; the majority of respondents said it in one form or another during their interviews:

Adam: I’d tell someone (with diabetes and schizophrenia) to accept his illness daily and do the best he can.

Steve: Do the best you can... ...I think about it a lot and I try to do right... ...I try, I try, I could do better but I do pretty good now.

Mary: I’m doing the best I can... ...just don’t give up, just keep going and do the best you can.

Dave: Well, I’m trying to do the best I can, I ain’t got no way better than that... ...I think I’m trying to do OK, it ain’t bad as what you think, it’s just how you take care of yourself, it’s just how you take care of it.

Pamela: I’ve managed to keep away from it [sugar] the best I can... I’m not supposed to have sugar and I try to stay away from it the best I can.

Matthew: I just try to do what they tell me to do, and go on, and I know I got it, and you know, I just take care of it as best I can.

Respondents spoke at length about their diligence in performing self-care activities. They were comfortable with counting calories and calculating the fat and carbohydrate grams of the foods they ate. The majority of respondents also had a regular schedule for using their glucometers; many kept records of their blood sugar readings to show their primary care physicians during medical appointments. In addition, the majority of respondents were aware of trends in their glycated hemoglobin levels that were measured by their primary care physicians. They were equally conscientious about foot care; they inspected their feet for sores several times per week, wore special shoes designed for diabetics, and applied special creams to prevent their skin from cracking.
Exercise fit easily into their lifestyle; they did not own cars, and if they wanted to go somewhere, they had to walk several blocks to the bus stop. Pamela counted her eight-block walks to her therapeutic rehabilitation center as her exercise. Mary had an exercise bicycle that she used three times per week; she also did strength and conditioning exercises for her arms every day. George went to the gym and ran around the track several times per week, and Henry attended an aerobics class for senior citizens.

Respondents were aware of the many challenges that could interfere with their self-care; many told me that they were in the process of formulating practical plans for managing in the future. They knew they needed to learn basic living skills, such as food purchasing and preparation. Many respondents, especially the men, told me that they were aware of their shortcomings as cooks and housekeepers. Life without a microwave oven and frozen food was inconceivable to them; however, they were taking small steps towards learning how to prepare simple and nutritious meals for themselves. They listed foods that they knew they could easily prepare: salads, sandwiches, turkey, tuna, low-fat roast beef, small baked potatoes with no butter, canned green beans—Dave emphasized that the salt needs to rinsed off if it isn’t that special low-sodium kind of green beans. Several respondents told me that they could use those boxes of prepared rice and noodles as long as they counted the carbohydrate and fat grams for each serving.

The social consequences of living with schizophrenia created several barriers to respondents’ ability to adequately care for their diabetes. Sheila was unable to purchase her diabetes medication because she didn’t have the money
to pay for it. Transportation to her health clinic was also difficult for her; her primary care physician had an office all the way across town, and occasionally she could not go to her medical appointments because she didn’t have a ride.

Some respondents told me that they often didn’t eat enough because they had no money for food, and were consequently at risk for hypoglycemia. Adam skipped meals when he ran out of money, and Dave revealed that he ate breakfast only three or four times a week. “You gotta stretch it, you know.” As with all their other barriers, however, they persevered and overcame them when they needed to. Many respondents were very aware of sales at the grocery stores and bought only low-priced food in bulk quantities to stretch their food budget. When they didn’t have enough money to purchase food, they managed by finding other resources in the community. Barbara used several church-based food banks regularly. “I’ve been going to these churches usually twice a month, and I go to another church every three months. I get food and clothes there.”

The staff at Pamela’s group home used a food bank regularly for all the residents, and she appreciated the fact that they had food available for people with diabetes. “We go to Dare to Care, that’s a good place to go to get the sugar-free stuff, if they have it.” Before receiving veteran’s benefits, Matthew and his brother regularly used food banks.

We (my brother and I) pay all of our bills, we pay them together and then we worry about food. And sometimes we don’t have enough for food. We just do what we can…we go to the help centers and places like that and get food, canned goods. We do that about like once a month…you get enough for three meals. Most of the help centers have a dietitian, and they give out certain foods. They don’t give out fattening foods and stuff like that. They don’t give out just anything…we go to the help centers, they are run by the federal...
government. We go to Sister Visitors, it’s a Catholic place, and we go to Dare to Care.

Barbara had serious financial issues, which influenced her ability to access adequate care for her illnesses:

Oh my God it’s awful. When I’m charged through Passport (Medicaid managed care plan), they charge one dollar for each prescription, and I take like 20-25 medications… …plus the Lantis (insulin) and humalog (insulin) and the syringes, the needles, you know, the sticks, that’s an extra $5 on top of the $25 I already take. I don’t have to pay for my own medications, but that’s $30 per month, and I cannot afford that, and because of that, I’m having to pick and choose which medication to take and which medication to leave because I can’t afford to buy it, and it’s causing a lot of health problems… …you know, people don’t think a dollar is very much but when you take as many medications as I do, that is a lot.

Barbara was aware of the unfairness of having financial problems due to the ongoing expenses of a chronic illness:

… …we didn’t wish this on ourselves, we did not wish this diabetes on ourselves. Some people kind of help it by not living right… …but then there are the ones that are born with it. It wasn’t (our) fault, and now we have to pay for our illness, we have to pay for our insulin, syringes, sticks.

Despite the severe distress this financial difficulty caused her, she persevered in exploring options for obtaining extra benefits; she considered applying to Social Security for additional benefits that are available to people with visual impairments. “I might have to call the Social Security people and let them know what’s going on. I might be able to increase my food stamps… …the money I spend on food could go towards the co-payments.”

The risk of relapse of psychiatric symptoms was always a concern for respondents. George stated that “the biggest worry I have is managing both my mental illness and my diabetes, I want to do good at both of them.” Steve stated
that his biggest challenge was just getting tired of the whole thing. “There are times when I just say ‘the heck with it,’ and eat some cake on my job.” Apathy sometimes challenged Kathy. “Sometimes my glucometer is across the room and I just don’t feel like walking across the room to get it.”

Two respondents, Henry and Kathy, made the decision to make a stronger commitment to the care of their schizophrenia rather than their diabetes. They made it clear that they knew they weren’t doing their best with their diabetes self-care. Henry didn’t worry about it just because he didn’t think his diabetes was serious enough to warrant attention. Kathy accepted the fact that she had diabetes, and knew the potential consequences of diabetes for her. But she had difficulty following through with self-care. “I could be doing better... ...I don’t feel like it, I don’t want to,” she said several times during her interviews. The lure of her mother’s chess pies, jam cakes, brownies, and cookies was too much for her to withstand: “I’m not ready to diet yet. I’m enjoying being big and fat too much... ...I figure, you have to die someday, you may as well die a sugarplum.” She said similar things about other aspects of self-care. “I’m just not ready to exercise yet... ...I need to be pushed more, made to do things, because I don’t take care of my diabetes as well as I should.” She was much more committed to her schizophrenia self-care, because she feared the consequences of psychosis—hospitalization, incarceration, and homelessness--more than the consequences of diabetes. “I have always taken my medications for schizophrenia.”

Hoping

The subcategory of Hoping represents respondents’ goals for the future
and reasons for engaging in self-care for dual illnesses. When reviewing the implications of having a diagnosis of schizophrenia, respondents spoke of their concerns about independence and self-sufficiency; respondents wanted to avoid homelessness, incarceration and unrelenting psychosis resulting from an inability to access needed psychiatric care. Likewise, when reviewing the implications of diabetes, respondents had mentioned rationales for self-care that were fear and loss-oriented; I don’t want to lose my legs, I don’t want to lose my eyesight, I don’t want to die, period.

Despite being motivated by fear-oriented concerns, respondents spoke at length about their value-oriented goals and their desires for a “normal” life in which they could have the same things everyone else does. These value-oriented goals were additional rationales for making a commitment to, and taking responsibility for, self-care. They anticipated good outcomes for both mental and physical health in return for their commitment and effort. They realized that stability with psychosis and with diabetes was crucial to achieving their goals. All respondents talked about their hopes for a better future. Steve desired a more comfortable life and avoidance of health problems. “I want to have my own car, live on my own, I want to live till I’m 80 or more… …I don’t want to die from diabetes, I’d rather die from something other than diabetes.” Similarly, Matthew stated, “I want to stay as healthy as I can.” Henry desired companionship and ongoing stability of his mental health. “I had three goals when I came here: regain my mental health, get married again, and I forgot what the third thing was.” Kathy hoped for a successful career: “I want to see a better day. I want to be able to do something, you know, and be successful at it, that’s what I want.”
Mary was the only respondent who just wanted to continue doing exactly what she always did. "I want to be healthy and do what I can for others and just help, do whatever I can to help others and help myself. That's what I'd like to do."

Respondents varied in how they intended to improve their lives. For some, a better future meant going to school and learning new skills. Dave said that he would not let his age interfere with what he wanted to do:

You take care of yourself so you can live to strive for your goals, you know, and that fits right in with it, without that I couldn't do it, couldn't do it, trying the best I can... ...I'm thinking about going back to school and get my GED. Yeah I got goals at an older age.... ...you never too old, I seen a lady at 90 years old on television who went back to school.... ...Some people might even get halfway to middle-aged, you might get ashamed sometime, going back to school, but I just gotta do it, just gotta do it, you know, let them laugh or whatever because it's a goal I want to accomplish.

Similarly, Kathy hoped to return to school to learn new job skills; as with everything she said, her articulation of her goals contained just a small amount of resignation that she may not achieve the things she wanted.

I want to be able to handle my diabetes and live a normal life if I could, if I can, taking up on academic courses, maybe going to the public library, learning how to work the computer by myself.... ...and buy me a computer and work on that.... ...I want a boyfriend, and get a good job, and wear pretty clothes.... ...but I'll probably just come to Seven Counties every day until I die.

Other respondents hoped for career opportunities; Barbara talked about her desire to open a restaurant for diabetic people. George wanted better insurance benefits and a chance to advance:

I'm not in a place where I want to be in, which is here.... ...I want to eventually prosper and do well in life and have life insurance and better medical insurance than what I have.... ...my future is what I live for.... ...I'm well aware of what it costs to stay healthy and if something goes wrong, where I'm going to be, up the creek, you know.
Like "Doing my Best," Hoping is an in vivo code. George used the word “hope” when describing the things he wanted as a result of his self-care, and when dreaming about his future. Stability of his symptoms of psychosis instilled a sense of hope in him:

Hope is a big thing. When you’re going through this disease and you’re down on yourself and you’re hearing voices, and you’re doing all these crazy things, sometimes hope is the only thing you got going for you. You know, you either despair or you get over it. There are plenty of people in this place who have tried to commit suicide because of this disease, it can really overcome you, but you can’t let that happen. You have to have hope that you can get better.... sometimes, that hope can be just not having schizophrenia episodes. You know, it could be just a day of peace because you’re troubled, and you’re not at peace when you’re going through schizophrenia.

Summary of Striving for Health

During the final phase of Evolving Self-Care, respondents consolidated their commitments to the care of dual illnesses. The health beliefs developed during this stage reflected the value of health, and more importantly, the value of self; self-care was worthwhile because they were worth the commitment and effort. The future was worthwhile also, despite challenges of psychosis, potential complications, isolation, financial difficulties, and dependence on others for support. Individuals with schizophrenia are often stigmatized in a society that misunderstands the diagnosis and its implications. Depression, despair, and hopelessness are common among individuals diagnosed with schizophrenia due to a sense of "entrapment" (McCann & Clark, 2004, p. 793) by the illness, symptom relapse, chronic residual symptoms, and hospitalization. Chronic functional impairments, and associated marginalization, isolation, poverty, and lack of opportunities, also create hopelessness. Researchers estimate that
suicide is 20 to 50 times higher among individuals with schizophrenia compared to the general population (Pinikahana, Happell, & Keks, 2003). Up to 50% of individuals with schizophrenia attempt suicide (Sadock & Sadock, 2001); an estimated 10 to 15% of people diagnosed with schizophrenia actually succeed in their suicide attempts (Sadock & Sadock, 2001; Nasrallah & Smeltzer, 2002; Pinikahana et al., 2003). Indeed, some of these respondents told me that they had considered suicide as an option for them. However, they persevered with caring for dual illnesses, and did well with their self-care, despite the numerous obstacles that their illnesses and society placed in their ways.

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CHAPTER SEVEN

SUMMARY, DISCUSSION, IMPLICATIONS, AND CONCLUSION

Summary

The purpose of this study was to develop a theory of how individuals with schizophrenia and diabetes incorporate diabetic self-care into their lives. The specific aims were to a). identify the process by which individuals with schizophrenia develop an understanding of their diagnosis of diabetes; b). identify the factors that influence their adherence to diabetic self-care; and c). generate a theory that describes the relationships between the factors, their antecedents, and outcomes of self-care among individuals with co-morbid schizophrenia and diabetes.

Analysis of respondents’ narratives provided a framework that describes some crucial elements of diabetic self-care for study respondents who were diagnosed with schizophrenia. The theory described respondents’ health beliefs about schizophrenia, diabetes, and the relationship between the two illnesses; these health beliefs functioned as rationales for engaging in consistent self-care of dual illnesses. Findings suggest that insight, or the ability to recognize the presence of an illness and judge the seriousness of the consequences of untreated illness, played a critical role in the development of health beliefs. In addition, contributing factors such as commitment, responsibility, motivation, and hope guided the development of health beliefs in respondents.
Discussion

The experience of chronic illness has been the focus of much research in the past decade (Charmaz, 2003; Corbin & Strauss, 1988; McCann & Clark, 2004; Thorne & Paterson, 2000). Qualitative research, and resulting illness narratives about living with chronic illnesses, have contributed to greater understanding about the role of individuals as active agents of self-care and "analysts of their circumstances" (Thorne & Paterson, 2000, p. 4). The study findings reported here contribute to further knowledge development about chronic physical and mental illnesses, particularly related to the interplay between self-care, health beliefs, attitudes towards illness, and complex contextual factors, such as social factors and interpersonal relationships. In addition, it contributes to further knowledge development about the influence of multiple chronic illnesses on other aspects of life. This discussion will compare and contrast study findings to previous research about chronic illness.

Health Belief Models

The major concepts of the Evolving Self-Care Model have been illustrated through the use of respondents' health beliefs about schizophrenia, diabetes, the relationships between the two, and their own responsibility and rationales for self-care for dual illnesses. For this reason, it is useful to compare the study findings with current models about health beliefs. Many of the concepts in the Evolving Self-Care Model are consistent with Health Belief Model and Stages of Change (SoC) Model. In their personal narratives about illness and health, respondents expressed knowledge about perceived severity and vulnerability to both illnesses, the benefits of self-care, and perceived barriers to engaging in self-
care. Findings support Kelly and colleagues' (1987) contention that individuals with schizophrenia are capable of rationally motivated health behaviors. Respondents' health behaviors were motivated by logical and accurate perceptions about their own vulnerability to both diabetes and schizophrenia and the consequences of not adhering to treatment for both illnesses.

The Health Belief Model suggests that perceived barriers to self-care influence the willingness to engage in self-care behaviors. Janz and colleagues (2002) state that the construct of perception of barriers is "the most powerful single predictor" (p. 52) of self-care behavior in several studies that investigated a wide variety of health behaviors. Findings of the study lend support to the construct of perceived barriers to care; respondents' narratives focused repeatedly on the many barriers that mental illness and social contextual factors presented as they engaged in self-care. In particular, symptoms of psychosis and lack of adherence to mental health treatment emerged as significant barriers to diabetic care. Substance abuse, hopelessness, and poverty, common problems among individuals with schizophrenia, were also identified as perceived barriers. Provider respondents identified lack of insight into illness as an additional barrier. These findings emphasize the need to include mental illness-specific barriers to care in models of health beliefs and health behaviors, as recommended by Lacro and colleagues (2002) and Perkins (1999).

Transtheoretical/Stages of Change Model

The Evolving Self-Care Model has some similarities to the Stages of Change (SoC) Model due to the temporal nature of both models. In their illness narratives, respondents described changes in beliefs over time that could reflect
some of the stages of the SoC model. Most respondents appear to have experienced what the SoC model refers to as the “pre-contemplation” and “contemplation” phases. Early in their illness courses, they experienced numerous negative outcomes, mostly losses resulting from psychosis and erratic behavior; these outcomes enabled them to reach the decision that they had a chronic illness that they needed to address through treatment adherence.

Progression through the remaining stages of the SoC model is more difficult to determine from respondents’ narratives; memory may have been selective, and respondents’ narratives did not contain enough depth and description to determine the various stages of change. However, at the time of their interviews, most appeared to be in a maintenance phase of both their schizophrenia and diabetes self-care, given the reported consistency of their routine day-to-day self-care. Longitudinal research is needed to determine the process by which individuals with mental and physical illnesses proceed through the stages of change and identity intervening variables that influence that progression.

Cognitive-Behavioral Theory

The respondents verbalized mostly accurate beliefs about the nature of schizophrenia and diabetes, the relationships between the two illnesses, their own personal vulnerability to illness, and their roles and responsibilities in self-care. Although CBT was not applicable to these study findings, it has the potential to be a very useful guide in assessing the accuracy of patients’ health beliefs. Observation of serious complications in family members could cause patients to “catastrophize” the illness and erroneously magnify their own risks for complications due to diabetes. The intent of CBT in these cases would be to
identify a patient’s tendency to elevate or minimize risk beyond what is reasonable, work with the patient to help him or her develop accurate and realistic health beliefs about vulnerability to illness, and help the patient develop accurate perceptions about the effectiveness of treatment.

**Diabetes-Specific Health Belief Models**

Glasgow and colleagues (1997) maintain that a patient's personal illness model is a crucial variable in diabetes self-care. Personal illness models address beliefs related to symptoms, disease course, consequences of diabetes, and treatment effectiveness. In a study of older individuals with diabetes, beliefs about the seriousness of diabetes and treatment effectiveness were predictive of dietary intake and frequency of physical activity (Hampson, Glasgow, & Foster, 1995). In addition, health beliefs that reflected treatment effectiveness predicted glycated hemoglobin levels (Hampson et al., 1995). Similarly, Skinner and Hampson (2001) found that beliefs about treatment effectiveness predicted self-care activities among adolescents with diabetes.

In a meta-analysis of qualitative studies about diabetes, Paterson, Thorne, and Dewis (1998) described findings that focus on respondents' desire to control diabetes, rather than having the illness control them; additional constructs include being independent and assuming responsibility for diabetes care. Likewise, Hörnsten, Sandström and Lundman (2004) identified several health belief constructs among individuals with Type 2 diabetes, including taking responsibility and creating plans for the future. However, they reported that few respondents incorporated the negative consequences of diabetes when discussing their plans for the future (Hörnsten et al., 2004).
In this study, respondents expressed self-care beliefs that are consistent with other diabetes-related health belief models. They developed beliefs about their own vulnerability to diabetic complications, treatment effectiveness, and responsibility for self-care; furthermore, they applied these health beliefs in the process of making decisions about treatment adherence and the level of commitment they were willing to make to diabetic self-care. They also developed future-oriented health beliefs about anticipated outcomes and desire to achieve their goals. However, whereas Hörnsten and colleagues' (2004) respondents envisioned futures with few problems and complications, respondents in this study were equally aware of potential negative and positive consequences of dual illnesses. This further reinforces Kelly and colleagues' (1987) contention that individuals with schizophrenia develop rationale health beliefs; in addition, findings demonstrate that they are able to realistically consider and plan for a wide variety of potential future outcomes.

**Schizophrenia**

The findings add to the knowledge base related to mental health consumers' perceptions about living with schizophrenia. Issues such as insight, illness acceptance, family care-giving, and hope have previously been described in the mental health literature (Hatfield & Lefley, 2000; Howard, 1994; Landeen, Pawlick, Woodside, Kirkpatrick & Byrne, 2000; Littrell, Herth, & Hinten, 1996; Saunders, 2003; Rinkelman, 2004. Although insight is recognized as a crucial factor in treatment adherence among individuals with schizophrenia, researchers caution that insight into illness is not common in this population. Rinkelman (2004) estimates that up to 60% of individuals with schizophrenia lack insight into
their symptoms and the presence of a mental illness. Unawareness of illness in individuals with schizophrenia is known as anosognosia, a medical condition associated with diffuse impairments in the non-dominant hemisphere and frontal lobe (Rinkelman, 2004). Lack of insight into illness has been associated with suspiciousness and paranoia; it is also common in individuals with cognitive deficits such as conceptual disorganization, poor information processing, poor abstract thinking, and emotional withdrawal (Rinkelman, 2004).

In this study, respondents possessed insight into the severity of schizophrenia; awareness of symptoms and their consequences was identified by respondents as an important factor in Mastering Schizophrenia. Insight allowed respondents to develop accurate health beliefs about the perceived seriousness of schizophrenia and their own personal vulnerability to the negative consequences of lack of treatment adherence. Respondents' symptoms of psychosis were generally adequately stabilized due to their insight and consequent adherence to treatment. However, it must be emphasized that because of the study methods, these respondents are not representative of the entire population of people diagnosed with schizophrenia. Up to 50% of individuals with schizophrenia do not regularly adhere to treatment due to lack of insight, and many experience chronic residual symptoms despite adherence to medications. For many individuals, ongoing symptoms of schizophrenia that are resistant to treatment may present serious barriers to self-care for both mental and physical illnesses. More research is needed to determine the influence of ongoing psychotic symptoms on health outcomes in this population.
Illness Careers

Self-care of a chronic illness requires work (Corbin & Strauss, 1988; Hörnsten et al., 2004; Price, 1996). Hörnsten and colleagues (2004) refer to the work of chronic illness as “making space” for the illness; it involves assigning priorities to self-care activities. Through the process of making space, ill individuals evaluate the importance of the illness to determine the effort needed to devote to self-care. Making space also involves devoting time in the course of the day to specific self-care activities and the work of coping with the illness. The impact of a demanding self-care regimen can have a permanent effect on an individual’s life course (Price, 1996); relationships and roles are altered to accommodate the numerous activities required in the care of a chronic illness. According to Hörsten and colleagues (1996), the demands of self-care compete with, and interrupt, other activities of living. Corbin and Strauss (1988) concur, stating that self-care for chronic illness takes precedent over several other types of work of the ill individual. These include biographical work, or the work of defining and maintaining an identity within the context of a chronic illness, and work of “everyday lives” (p.10), such as running a household and maintaining employment. “Articulation work” (Corbin & Strauss, 1988, p.11), the organization and coordination of the many tasks of self-care, further consumes time and energy. According to Corbin and Strauss (1988), the work of self-care affects all aspects on one’s life. One respondent in their study stated, “it impacts money, friendship networks, work; it impacts the quality of your quiet time….how relaxed you are, everything! I can’t think of a single thing it does not affect” (p.7). Corbin and Strauss (1988) refer to the work of self-care as “unending” (p.1):
chronically ill individuals never get a day off from the work of caring for their illnesses.

In this study, respondents provided insight about the day-to-day work of caring for dual illnesses. These respondents defined the "space" for illness in the context of two illnesses; many spoke of the priorities that they assigned to the illnesses, and their efforts to accommodate the care of two illnesses into their lives. Some reported that the work of dual illnesses consumed much time, effort and attention. Self-care demands may have several implications for the quality of life of individuals with dual illnesses; if self-care activities consume an excessive amount of time and attention, little time may be left for employment, socialization, recreation, and other tasks necessary in routine daily life. Supported employment is available to accommodate the special needs of individuals with schizophrenia (Substance Abuse and Mental Health Administration, 2003) but it is unknown whether any employers have made arrangements to accommodate individuals with schizophrenia who need to adhere to a consistent diabetic self-care routine on the job.

Family Caregiving

In this study, respondents suggested that reliance on family was an important factor in their self-care. Although some respondents assumed responsibility for the tasks of diabetes care, others reported that their families provided significant amounts of supervision and support for their mental health and diabetes care. Even when respondents were independent with self-care, their parents provided food, housing, money, and transportation; these resources served to mitigate some of the social stressors related to unemployment, low
disability income, and consequent insufficient financial resources among respondents. Parents protected their adult children from poverty and homelessness.

These findings support much research about the role of the family in the care of relatives with schizophrenia. Previous research suggests that family caregivers, particularly parents, assume much responsibility for the mental health care of adult children with schizophrenia (Hatfield & Lefley, 2000; Howard, 1994; Saunders, 2003). As indicated previously, the work of self-care for chronic illnesses is constant (Corbin & Strauss, 1988); when individuals with schizophrenia are unable to independently care for themselves due to ongoing symptoms and cognitive impairments, parents take on the "physical and mental tasks" (Howard, 1994, p. 110) of care.

Many researchers have observed that problems in the care-giving role can occur as parents grow older (Hatfield & Lefley, 2000; Teschinsky, 2000); according to Hatfield and Lefley (2000), the care of an adult child with schizophrenia can be overwhelming for parents who are experiencing a decline in physical capabilities and age-related health problems. In addition, aging parents often express concern that their adult children with schizophrenia will not be adequately cared for after their deaths (Teschinsky, 2000); parental fears of homelessness, lack of emotional support, and suicide of the ill child are common. In this study, the mean age of respondents was 50.3 years, and they reported that their parents' ages were about 70-80. They expressed much concern about the ages of their parents and their own future welfare; they coped with the stress
of potential loss of caregiving parents by planning for independence and assuming responsibility for self-care.

Assuming responsibility for the care of a chronic medical illness in an adult child with schizophrenia is an additional burden for caregiving parents. Care of dual illnesses includes the provision of mental health care, which requires monitoring for psychotic symptoms, monitoring adherence to medications, and coping with exacerbations of psychotic symptoms that could result in unpredictable and frightening behavior. Additional problems facing family caregivers of adult children with schizophrenia include legal problems due to ill relatives' erratic behaviors, lack of support from friends, other family members, and health care providers, negative emotional responses to the care-giving role, particularly depression and anxiety, and the stigma of having a relative with a severe and persistent mental illness. In addition to mental health care, parental responsibilities would include the provision of diabetic care, including the purchasing and preparation of food, monitoring glucose levels, drawing up and injecting insulin, intervening for hypoglycemia, and monitoring for foot ulcerations and infections. No research has investigated this issue; however, it is likely that for aging, frail parents, the stress associated with the caregiving role of dual illnesses of an adult child may be very high.

Social Considerations

The relationship between social factors and self-care is an important study finding. A growing body of research in social epidemiology has investigated the relationships between social factors and health; unemployment, inadequate housing, and racism have been linked to inequities in health and high mortality.
rates (Adler & Newman, 2002; Deaton, 2002; Farmer, 2003; Feachem, 2000; Marmot, 2002; Mechanic, 2002). Poverty, defined as lacking or being denied adequate resources to participate meaningfully in society, also contributes to poor health (Krieger, 2001). However, the construct of poverty is complex, and multiple dimensions of poverty play a role in poor health outcomes (Krieger, 2001). According to Krieger (2001), the World Health Organization (WHO) makes a distinction between human poverty and income poverty; human poverty is defined as “impoverishment in multiple dimensions—deprivations in a long and healthy life, in knowledge, in a decent standard of living, in participation” (p. 695). In contrast, WHO maintains that income poverty is deprivation in the single dimension of income. “From this perspective, income poverty constitutes a critical (but not exclusive) determinant of human poverty, including the latter’s expression of compromised health status” (Krieger, 2001, p. 695). Other psychosocial risk factors for poor health include chronic and acute stress resulting from chronic material deprivation, marginalization, perceived inability to control life circumstances, and lack of social support (Berkman & Glass, 2000; House & Williams, 2003; Krieger, 2003; Lynch & Kaplan, 2000).

Individuals with schizophrenia are at risk for health disparities due to many sociodemographic characteristics and psychosocial stressors. According to Eaton and Muntaner (1999), a diagnosis of schizophrenia is strongly associated with low socioeconomic status because it impairs ability to obtain an education and employment. The Substance Abuse and Mental Health Administration (SAMHA) (2003) estimates that only 15% of individuals with severe and persistent mental illnesses are employed. Consequently, individuals with
schizophrenia frequently experience “social drift” (Aro et al., 1995, p. 759), a progressive downward social mobility that results in poverty and social marginalization. Thus, according to WHO’s definition of poverty, this population is at risk for both income poverty and human poverty, due to material deprivation, limited participation in society, and lack of a decent standard of living. Financial difficulties create a barrier to obtaining adequate housing; individuals with schizophrenia, when they are able to live independently, often live in substandard houses in deteriorating neighborhoods, which creates an additional risk for poor health (Hofrichter, 2003). For some individuals with schizophrenia, adequate housing is unattainable: SAMHSA (2003) reports that 20 to 25% of homeless individuals have a severe and persistent mental illness, including schizophrenia and schizoaffective disorder. Social exclusion, lack of education, unemployment, poor housing, homelessness, and material deprivation can contribute to health inequities among individuals with schizophrenia. Furthermore, individuals with schizophrenia experience the stress of social stigma and isolation due to their diagnosis; McCann and Clark (2004) have observed that a diagnosis of schizophrenia is a “mediator” of social relationships that can alienate family and damage or end important friendships.

Respondents’ narratives indicated that they were members of a vulnerable population, and were consequently at risk for health problems. Respondents spoke of low levels of employment, financial difficulties, and acute distress resulting from their difficult living situations. Many respondents stated that poverty was a major barrier to self-care; they went without food and medications
when they couldn’t purchase them, and frequently used food banks or relied on family members to access needed resources.

A growing body of social research has illuminated the relationships between health and social factors such as gender, race, ethnicity, and socioeconomic status. However, no research has been conducted to determine the relationships between social factors, mental health, and physical health among individuals with chronic and persistent mental illnesses such as schizophrenia. More research is needed to investigate the influence of social inequality, poverty and unemployment on morbidity and mortality among individuals with schizophrenia, and how social factors influence their ability to adhere to treatment for multiple illnesses.

**Hope in Chronic Illness**

Hope is recognized as a crucial factor in coping with chronic illness (Adams & Jenkins-Partee, 1998; Farran, Herth, & Popovich, 1995; Henderson, 2004; Littrell et al., 1996; Morse & Doberneck, 1995; Morse & Penrod, 1999). Researchers maintain that hope in chronically ill individuals possesses several distinct and critical attributes, including an anticipation of a desired event or condition (Adams & Jenkins-Partee, 1998), a future orientation, an “energized action orientation” (Kirkpatrick, Landeen, Woodside, & Byrne, 2001, p. 47), and having a general or specific goal. Hopeful individuals have a sense of direction and optimism; they believe that life has “value and worth” (Littrell et al., 1996, p. 64).

Hope has been investigated in individuals with schizophrenia. Landeen and colleagues (2001) conducted a qualitative study of 10 individuals with
schizophrenia to determine the factors that facilitated hope. Findings indicate that experiencing success and having control over their symptoms and lives contributed to their sense of hopefulness. In a longitudinal study of 44 adults with schizophrenia, Littrell and colleagues (1996) found that levels of hope depended on the effectiveness of psychopharmacologic treatment. Hope increased as symptoms of psychosis improved, and subjects who were treated with clozapine and psychotherapy had the greatest increases in hope over a 12-month period. In another study of 55 individuals with schizophrenia, hope was significantly related to measures of quality of life ($r = 0.62$). In addition, findings indicate that global quality of life accounted for 35% ($p < .001$) of the variability in hopefulness (Landeen et al., 2000).

In this study, hope was a major factor in respondents’ self-care. Despite the challenges they experienced as they attempted to perform the multiple tasks necessary in the care of their schizophrenia and diabetes, they remained optimistic about their futures. They expected their efforts in self-care for dual illnesses to have good outcomes, and their expectations motivated them to consistently strive to achieve the best health possible. Hope was articulated through their goals and dreams for the future. Mental and physical wellness was required to achieve these goals, and their goals provided them with strong rationales for treatment adherence. Their experiences helped them realize that health and stability were crucial to the achievement of their goals.
Implications

Nursing Practice

Individuals with schizophrenia and diabetes have multiple, complex health care needs that can be addressed by psychiatric nurses. The Evolving Self-Care Model can provide a framework for approaching the nursing care of individuals with dual illnesses. Psychiatric nurses can use the Model to assist patients in recognizing the relationships between negative consequences of psychosis, treatment adherence, and symptom stability. In addition, the issues of potential negative consequences of psychosis on diabetes self-care can be incorporated into the education and counseling of patients with dual illnesses. Articulation of goals, working with patients to address the challenges and frustrations of self-care, and exploration of meanings that the patients assign to the concepts of responsibility, motivation, and commitment can also be incorporated into patient counseling.

The profession of Advanced Practice Psychiatric Nurses (APPN) is currently divided regarding how to best approach the complex health care needs of individuals with mental illness. Some practitioners suggest that APPNs are in the best position to provide both mental and primary health care to this population. They maintain that mental health providers are often the only health care providers for patients with schizophrenia (Chafetz, Collins-Bride, & Lego, 1998; McDevitt, 2004), and further observe that primary health care providers are often reluctant to treat the medical problems of patients with schizophrenia due to fear and poor understanding of psychotic symptoms. For these reasons, some practitioners and nurse educators maintain that APPNs need to be competent to
address a wide variety of co-morbid illnesses in individuals with schizophrenia (Chafetz et al., 1998). However, some practitioners express concern about “role strain” that may occur when practitioners attempt to “do it all”; they point to the voluminous amount of knowledge that a practitioner would require, and speculate that the pursuit of new knowledge in primary care would prevent the practitioner from having the time to actually practice in a clinical setting (Chafetz et al., 1998). Others suggest that a collaborative care model, in which APPNs and primary care practitioners work together in a single treatment setting, is the most feasible option for addressing the mental and physical health needs of patients (Chafetz et al., 1998; Controneo, Outlaw, King, & Brince, 1997). However, little research has been done to evaluate the effectiveness of collaborative practice models between disciplines. The issue of access to health care for vulnerable populations needs to move beyond the debate about scope of practice and roles for advanced practice nurses, and focus more on the development of adequate models that will ensure optimal health outcomes for individuals with multiple mental and physical health needs.

Findings suggest that the diabetic education for individuals with dual illnesses is inadequate. The American Association of Diabetes Educators (2002) has issued a policy statement specifying that a disability such as serious mental illness “does not necessarily preclude effective diabetes self-management” (p. 917). In addition, the Association (2002) states that diabetes education is an integral part of diabetes care, and individuals with diabetes who have disabilities should receive diabetic education that is equivalent to that received by people without disabilities. The policy statement further recommends that diabetes...
education needs to be consistent with patients' cognitive and learning abilities. When necessary, educators should assess the effect of a disability on the ability of the patient to learn and perform diabetic self-care skills. Teaching approaches should be tailored to accommodate the patient's learning abilities. Advanced practice psychiatric nurses can play a pivotal role in assisting diabetes educators to identify cognitive deficits common among individuals with schizophrenia, and help them adapt their teaching strategies so that patients may retain information more effectively.

**Research**

More research needs to be conducted to investigate the multiple issues of complex care for co-morbid schizophrenia and diabetes. Research needs to investigate the relationships between self-care and other factors such as symptom severity, overall functioning, quality of life, and social support. Many of the concepts that are salient to diabetic self-care, including self-efficacy, perceived control, diabetes knowledge, well-being, and psychosocial adjustment (Bradley, 2003) can be investigated in the context of a co-morbid diagnosis of schizophrenia. Furthermore, little is known about the diabetes-related health outcomes in individuals who are unable to engage in diabetic self-care due to cognitive impairments and symptoms that are resistant to treatment. Research can lead to the development of specialized treatment interventions that can improve the self-care and treatment outcomes in these individuals.

Little is known about family issues in the care of relatives with schizophrenia and diabetes. Many psychological and social issues need to be investigated, including the financial impact of care for relatives' multiple illnesses,
and the various ways that family members may negotiate, manage, and cope with the multiple demands of caring for ill relatives with schizophrenia and chronic medical illnesses such as diabetes. In addition, researchers need to investigate the diabetes-related knowledge of family caregivers to determine whether they possess sufficient information to provide adequate diabetic care to their ill relatives.

**Conclusion**

Study respondents developed accurate and realistic health beliefs that reflected their experiences with schizophrenia and diabetes. They engaged in self-care for dual chronic illnesses in the face of challenges, difficulties, and frustrations, yet they maintained their determination, their sense of responsibility, and their hope. They created a system of holistic health beliefs that supported them through the difficulties and barriers to care.

In the past, qualitative researchers have generally overlooked the voices and stories of individuals with schizophrenia, to the detriment of knowledge development in mental health research. Some nurse researchers are beginning to include individuals with schizophrenia in qualitative research, but the totality of the lived experience of schizophrenia has yet to be determined. This study illuminates their capacity and desire to tell their own stories, and thereby strengthen the knowledge base about the subjective experience of schizophrenia. In addition, it illuminates the experiences and processes of self-care for individuals with multiple illnesses. Findings can be used to enhance clinicians' understandings of the subjective experience of mental illness and of chronic illnesses in general. In addition, findings can be used to improve the
treatment of individuals with schizophrenia and diabetes, and thereby improve mental and physical health and quality of life for this population.

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RESEARCH STUDY

FOR PEOPLE WHO HAVE BOTH SCHIZOPHRENIA AND DIABETES MELLITUS

• Take part in 1-3 taped interviews
• Talk about how you take care of your diabetes
• Participants will get $10 for each interview

Please contact:

Peggy El-Mallakh, MSN, RN
University of Kentucky
College of Nursing
Phone: [Redacted]
Appendix B
Consent to Participate in a Research Study
Consumer Form

DIABETIC SELF-CARE MANAGEMENT IN INDIVIDUALS WITH CO-MORBID SCHIZOPHRENIA AND DIABETES MELLITUS

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to participate in this research study about diabetic self-care in people with schizophrenia because you have been diagnosed with both diabetes mellitus and schizophrenia. If you volunteer to participate in this study, you will be one of about 15 health care consumers to do so. About 6 health care providers who treat patients with diabetes and schizophrenia will also participate in this study.

WHO IS DOING THE STUDY?

The person in charge of this study is Peggy El-Mallakh, MSN, RN, a doctoral student at the University of Kentucky College of Nursing. She is being guided in this research by Patricia B. Howard, PhD, RN, her faculty advisor at the University of Kentucky College of Nursing. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to find out how you have learned to take care of your diabetes, talk about all the things you do to take care of your diabetes, and to hear your ideas about the things that help you take care of your diabetes.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The research will be conducted in the outpatient clinic where you see your doctor. You will need to meet with Ms. El-Mallakh three times. Each of those meetings will take about 60 to 90 minutes. The total amount of time you will be asked to volunteer for this study is about 5 hours over the next two weeks.

After Ms. El-Mallakh interviews the other people in the study, she will meet with you again for about 60 minutes to let you know what she thinks about the information and to see if you agree with her. She will have this last meeting with you in the spring of 2003.
WHAT WILL I BE ASKED TO DO?

You will be asked to meet with Ms. El-Mallakh three times to talk about how you care for your diabetes. Ms. El-Mallakh will also ask you some questions about your memory. She will tape record these meetings. Also, Ms El-Mallakh will ask you to show her how you check your blood sugar with a glucometer.

ARE THERE ANY REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?

You should not take part in this study if you have any medical problems that would make it hard for you to be in the study. You should also not take part in the study if you are not sure what the study is about and what you will need to do in this study.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

The only risks are some discomfort and bleeding from your finger when you test your blood sugar with the glucometer. There is a slight chance of infection in that finger. These discomforts and risks are no greater than what you get when you do your daily, routine diabetic self-care.

WILL I BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. However, some people have had good feelings about helping health care workers figure out how to better take care of people who have an illness. We cannot and do not guarantee that you will receive any benefits from taking part in this study.

DO I HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

IF I DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except to not take part in the study.

WHAT WILL IT COST ME TO PARTICIPATE?

You and/or your insurance company, Medicare or Medicaid will be responsible for the cost of all care and treatment you receive during this study that you would
normally receive for your condition. These are costs that are considered medically reasonable and necessary and will be part of the care you receive if you do not take part in this study.

The University of Kentucky is not allowed to bill your insurance company, Medicare or Medicaid for the medical costs of procedures done strictly for research. Therefore, these costs will be your responsibility.

**WHO WILL SEE THE INFORMATION THAT I GIVE?**

We will keep private all research records that identify you to the extent allowed by law.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials. We may publish the result of this study; however, we will keep your name and other identifying information private.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information that you give, and these two things will be stored in different places under lock and key. You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you pose a danger to yourself or someone else.

Someone from the University of Kentucky may look at or copy pertinent portions of records that identify you.

**CAN MY TAKING PART IN THE STUDY END EARLY?**

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to withdraw you from the study. This may occur if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency financing the study decides to stop the study early for a variety of scientific reasons.

**WHAT HAPPENS IF I GET HURT OR SICK DURING THE STUDY?**

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Peggy El-Mallakh at [contact information] immediately.
It is important for you to understand that the University of Kentucky will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, the University of Kentucky will not pay for any wage you may lose if you are harmed by this study.

Medical costs that result from research-related harm cannot be included as regular medical costs. The University of Kentucky is not allowed to bill your insurance company, Medicare, or Medicaid for these costs. You should ask your insurer if you have any questions about your insurer’s willingness to pay under these circumstances. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility.

WILL I RECEIVE ANY REWARDS FOR TAKING PART IN THE STUDY?

You will receive $10 for each interview with Ms. El-Mallakh.

WHAT IF I HAVE QUESTIONS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Peggy El-Mallakh, at [contact information]. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity at the University of Kentucky at [contact information]. You can also call the Office of Research Integrity at a toll-free number, [phone number]. We will give you a copy of this consent form to take with you.

WHAT ELSE DO I NEED TO KNOW?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in the study.

________________________________________  __________________________
Signature of person agreeing to take part in the study  Date

________________________________________
Printed name of person agreeing to take part in the study

________________________________________  __________________________
Name of person providing information to subject  Date

________________________________________
Signature of Investigator
Appendix C
Consent Confirmation Questionnaire

Participant name: ___________________________ Date ______________

Directions: Please circle the best answer (TRUE or FALSE) to each question.

1. The purpose of this study is to find out how I take care of my diabetes.
   TRUE   FALSE

2. I will take part in up to three interviews.
   TRUE   FALSE

3. The interviews will not be tape-recorded.
   TRUE   FALSE

4. I will be asked to show the researcher how I use a glucometer.
   TRUE   FALSE

5. Taking part in this study is voluntary and I can stop taking part in the study at any time.
   TRUE   FALSE

6. The records of this study are not confidential and can be given to anyone.
   TRUE   FALSE

7. I can call the Office of Research Integrity if I have any questions about my rights as a participant.
   TRUE   FALSE

8. There are no risks at all from taking part in this study.
   TRUE   FALSE

9. I will be given a copy of the consent form.
   TRUE   FALSE

______________________________  _________________________
Signature of Participant             Date

______________________________  _________________________
Signature of person obtaining consent  Date
Appendix D
Consent to Participate in a Research Study
Health Care Provider Form

DIABETIC SELF-CARE MANAGEMENT IN INDIVIDUALS WITH CO-MORBID SCHIZOPHRENIA AND DIABETES MELLITUS

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in this study because you are a health care provider who treats, teaches, or counsels patients who have diabetes mellitus and schizophrenia. If you take part in this study, you will be one of about 6 health care providers to do so. About 15 individuals diagnosed with diabetes mellitus and schizophrenia will also participate in this study.

WHO IS DOING THE STUDY?

The person in charge of the study is Peggy El-Mallakh, MSN, RN, a doctoral student from the University of Kentucky College of Nursing. She is being guided in this research by Patricia B Howard, PhD, RN, her faculty advisor at the University of Kentucky College of Nursing. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THE STUDY?

The purposes of this study are to: a.) determine how people who have been diagnosed with both diabetes mellitus and schizophrenia learn diabetic self-care; b.) describe participants’ diabetic self-care practices; and c.) describe the factors that influence the development of self-care skills in individuals with diabetes mellitus and schizophrenia.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The study will take place in outpatient psychiatric and endocrine clinics in Lexington and Louisville. You will need to come to your clinic office 3 times during the study for the study interviews. The total amount of time you will be asked to volunteer is about 5 hours over the next two weeks.

WHAT WILL I BE ASKED TO DO?

You will be asked to talk about your experiences in providing care to people with diabetes mellitus and schizophrenia during three interviews with Ms. El-Mallakh. Each interview will last about 60 to 90 minutes. The interviews will be tape-recorded and transcribed.
After the study is finished, Ms. El-Mallakh will contact you to provide you with a summary of all of the interviews and conclusions about the themes and important issues that were identified by the health care provider participants. You will be asked to comment on the degree to which the conclusions are an accurate account of your care-giving experiences.

ARE THERE ANY REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?

You should not participate in the study if you object to the interviews being tape recorded and transcribed.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no known discomforts that will result from participating in this study. The only risk is loss of time from participating in the interviews.

WILL I BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. We cannot and do not guarantee that you will receive any benefits from taking part in this study.

DO I HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

IF I DON’T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST ME TO PARTICIPATE?

You and/or your insurance company, Medicare, or Medicaid will be responsible for the costs of all care and treatment you receive during this study that you would normally receive for your condition. These are costs that are considered medically reasonable and necessary and will be part of the care you receive if you do not take part in this study.

The University of Kentucky is usually not allowed to bill your insurance company, Medicare or Medicaid for the medical costs of procedures done strictly for research. Therefore, these costs will be your responsibility.
WHO WILL SEE THE INFORMATION THAT I GIVE?

We will keep private all research records that identify you to the extent allowed by law.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.

We will make every effort to prevent anyone who is not on the research team from knowing that you have information or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key. You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court.

Someone from the University of Kentucky may look at or copy pertinent portions of records that identify you.

CAN MY TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to withdraw you from the study. This may occur if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

WHAT HAPPENS IF I GET HURT OR SICK DURING THE STUDY?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Peggy El-Mallakh at immediately. It is important for you to understand that the University of Kentucky will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, the University of Kentucky will not pay for any wage you may lose if you are harmed by this study.

Medical costs that result from research-related harm cannot be included as regular medical costs. The University of Kentucky is not allowed to bill your insurance company, Medicare, or Medicaid for these costs. You should ask your
insurer if you have any questions about your insurer's willingness to pay under these circumstances. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility.

WILL I RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will not receive any rewards or payment for taking part in this study. Your willingness to take part, however, may, in the future, help doctors better understand and/or treat patients with diabetes and schizophrenia.

WHAT IF I HAVE QUESTIONS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Peggy El-Mallakh, at [ pulvera@lumc.edu]. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity at the University of Kentucky at [384-1100]. You can also call the Office of Research Integrity at a toll-free number, 1-888-397-5699. We will give you a copy of this consent form to take with you.

WHAT ELSE DO I NEED TO KNOW?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in the study.

Signature of person agreeing to take part in the study  

Date

Printed name of person agreeing to take part in the study

Name of person providing information to subject  

Date

Signature of Investigator
### Appendix E

**Demographic Interview Form**

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>________________________________</td>
</tr>
<tr>
<td>Identifying number</td>
<td>________________________________</td>
</tr>
<tr>
<td>Address</td>
<td>________________________________</td>
</tr>
<tr>
<td>C/S/Z</td>
<td>________________________________</td>
</tr>
<tr>
<td>Telephone</td>
<td>________________________________</td>
</tr>
<tr>
<td>Age</td>
<td>________________________________</td>
</tr>
<tr>
<td>DOB</td>
<td>________________________________</td>
</tr>
<tr>
<td>Sex</td>
<td>________________________________</td>
</tr>
<tr>
<td>Marital Status</td>
<td>________________________________</td>
</tr>
<tr>
<td>Number of children</td>
<td>________________________________</td>
</tr>
<tr>
<td>Highest grade completed in school</td>
<td>________________________________</td>
</tr>
<tr>
<td>Employment</td>
<td>________________________________</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>________________________________</td>
</tr>
<tr>
<td>Age of dx of mental illness</td>
<td>________________________________</td>
</tr>
<tr>
<td>Age at dx of diabetes</td>
<td>________________________________</td>
</tr>
<tr>
<td>Type of diabetes</td>
<td>________________________________</td>
</tr>
<tr>
<td>Medications</td>
<td>________________________________</td>
</tr>
</tbody>
</table>

**Mini-Mental Exam Score:** ____________________
Appendix F
Mini-Mental Status Exam

Patient ........................................
Examiner ......................................
Date ...........................................

"MINI-MENTAL STATE"

<table>
<thead>
<tr>
<th>Maximum Score</th>
<th>Score</th>
</tr>
</thead>
</table>

**ORIENTATION**
5 ( ) What is the (year) (season) (date) (day) (month)?
5 ( ) Where are we: (state) (county) (town) (hospital) (floor).

**REGISTRATION**
3 ( ) Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record.

**ATTENTION AND CALCULATION**
5 ( ) Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively spell "world" backwards.

**RECALL**
3 ( ) Ask for the 3 objects repeated above. Give 1 point for each correct.

**LANGUAGE**
9 ( ) Name a pencil, and watch (2 points)
Repeat the following "No ifs, ands or buts." (1 point)
Follow a 3-stage command:
  "Take a paper in your right hand, fold it in half, and put it on the floor" (3 points)
Read and obey the following:
  CLOSE YOUR EYES (1 point)
Write a sentence (1 point)
Copy design (1 point)

Total score

ASSESS level of consciousness along a continuum:

Alert  Drowsy  Stupor  Coma

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INSTRUCTIONS FOR ADMINISTRATION OF MINI-MENTAL STATE EXAMINATION

ORIENTATION

(1) Ask for the date. Then ask specifically for parts omitted, e.g., "Can you also tell me what season it is?" One point for each correct.
(2) Ask in turn "Can you tell me the name of this hospital?" (town, county, etc.). One point for each correct.

REGISTRATION

Ask the patient if you may test his memory. Then say the names of 3 unrelated objects, clearly and slowly, about one second for each. After you have said all 3, ask him to repeat them. This first repetition determines his score (0–3) but keep saying them until he can repeat all 3, up to 6 trials. If he does not eventually learn all 3, recall cannot be meaningfully tested.

ATTENTION AND CALCULATION

Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers.
If the patient cannot or will not perform this task, ask him to spell the word "world" backwards. The score is the number of letters in correct order. E.g. dlrow = 5, dlrow = 3.

RECALL

Ask the patient if he can recall the 3 words you previously asked him to remember. Score 0–3.

LANGUAGE

Naming: Show the patient a wrist watch and ask him what it is. Repeat for pencil. Score 0–2.
Repetition: Ask the patient to repeat the sentence after you. Allow only one trial. Score 0 or 1.
3-Stage command: Give the patient a piece of plain blank paper and repeat the command. Score 1 point for each part correctly executed.

Reading: On a blank piece of paper print the sentence "Close your eyes", in letters large enough for the patient to see clearly. Ask him to read it and do what it says. Score 1 point only if he actually closes his eyes.

Writing: Give the patient a blank piece of paper and ask him to write a sentence for you. Do not dictate a sentence, let it be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

Copying: On a clean piece of paper, draw intersecting pentagons, each side about 1 in., and ask him to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Estimate the patient's level of sensorium along a continuum, from alert on the left to coma on the right.
Appendix G
Consumer Interview Questions

Tell me everything you do to take care of your diabetes.
How did you learn to do these things?
What are your concerns about having diabetes?
What are the things that help you the most in taking care of your diabetes?
What are the things that are least helpful to you in taking care of your diabetes?
Can you show me how you test your blood sugar using this glucometer?

Added questions: (after first 5 interviews)

What was it that helped you make a commitment to following your diabetic care?
What keeps you motivated to continue doing it?
What are your goals in life?
Where does your diabetes care fit into your life goals?
If you were to meet someone with schizophrenia who just found out he had diabetes, what advice would you give him?

Added questions: (after interviews with participants 6 & 7)

Tell me about any issues you have had in paying for your diabetic supplies and care.
What helps you remember to do your diabetes care?

Added questions: After #8:

What is diabetes? What causes it?
How did you find out you had it? What was your reaction to hearing that you were diabetic?
Added questions for final interviews:

What motivates you to take care of your schizophrenia?

Some people live only with schizophrenia, and some people live with only diabetes, but you have both of these illnesses. What is it like to manage both of these illnesses?

Tell me about how your mental illness has affected your ability to care for your diabetes.
Appendix H
Provider Interview Questions

1. Tell me about your experiences in caring for diabetic patients with schizophrenia.

2. How well, in your opinion, have they been able to learn self-care skills?

3. What skills do you think have been the easiest for your patients to learn and master?

4. What skills and interventions have been more difficult for your patients to learn or grasp?

5. What do you think needs to be done to improve the care of your patients with schizophrenia?
Appendix I
Attestation of Trustworthiness of Study Findings
February 25, 2005

Dr. Ann Peden, DSN, ARNP, BC
University of Kentucky
Lexington, KY

Dear Ms. El-Mallakh:

Thank you for the opportunity to serve as an external auditor of the research records for the project, “Evolving Self-Care in Individuals with Schizophrenia and Diabetes Mellitus.” The purpose of this audit was to determine the transferability and confirmability of the research findings. I have reviewed the raw data, coding notes, and theoretical memos that were developed throughout the process of data analysis.

As a result of the audit, I have determined that the findings of the study are confirmable; the categories of the theory are logically connected to the raw data obtained during interviews with study respondents. I believe that the categories fit with the data and explain the data. I have also determined that the categories are dependable; the categories of the resulting model account for the majority of data collected during the study.

In summary, I attest to the confirmability and dependability of the study findings of “Evolving Self-Care in Individuals with Schizophrenia and Diabetes Mellitus.”

Sincerely,

Ann Peden
Professor
REFERENCES


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Behavior Research I: Personal and Social Determinants (pp. 71-91). New York: Plenum Press.


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VITA

Peggy Louise El-Mallakh
Date of birth: June 18, 1
Place of birth: Chicago, Illinois

Education

<table>
<thead>
<tr>
<th>Date</th>
<th>Degree</th>
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<tbody>
<tr>
<td>August, 1988</td>
<td>BSN</td>
<td>Central Connecticut State University</td>
</tr>
<tr>
<td></td>
<td></td>
<td>New Britain, CT</td>
</tr>
<tr>
<td>May, 1998</td>
<td>MSN</td>
<td>University of Kentucky</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lexington, KY</td>
</tr>
</tbody>
</table>

Employment

June 1982—May 1984: Staff RN
St. Francis Hospital
Peoria, IL

June 1984—May 1988: Staff RN
Hartford Hospital
Hartford, CT

August 1988—May 1989: Staff RN
Connecticut Mental Health Center
New Haven, CT

June 1989—December 1991: Staff RN
Psychiatric Institute of Washington, D.C.
Washington, D.C.

January 1993—Nov. 1995: Staff RN
Norton Hospital
Louisville, KY

January 1998—Present: Research Assistant
University of Kentucky College of Nursing
Lexington, KY

August 2002-May 2004: Lecturer
University of Louisville School of Nursing
Louisville, KY

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Publications

"Treatment Models For Clients with Co-occurring Addictive and Mental Disorders," Archives of Psychiatric Nursing (1998), April, 12(2), pp. 71-80


"Consumer Perspectives on Quality of Inpatient Mental Health Services," with Patricia B. Howard, Mary Kay Rayens, and James J. Clark, Archives of Psychiatric Nursing, (2003), 17, 205-217.

"Patient Satisfaction and Treatment Outcomes as Quality Indicators for Mental Health Services," with Patricia B. Howard, Mary Kay Rayens, and James J. Clark, International Psychiatry (2004), July, issue 5, pp. 5-6

Executive Reports

"Assessment of Kentucky Behavioral Health Satisfaction: Summary Report on the Adult Medicaid Population", with Howard, P. B., Rayens, M. K., Clark, J. J., and Coyle, W. R., at the University of Kentucky Research and Data Management Center/Kentucky Department of Mental Health/Mental Retardation Services.

Paper Presentations

"Hope in Chronic Illness: Implications for Clients with Chronic Mental Illness", Presented at the Society for Education and Research in Psychiatric-Mental Health Nursing Conference, November, 1998, in Chicago, IL

"The Role of Consumers in Data Collection: Promoting Trustworthiness of Mental Health Services Research on Satisfaction", Presented at the International Society for Psychiatric-Mental Health Nursing Conference, April, 2000, in Miami, FL

"Consumer Satisfaction with Mental Health Services in an Adult Medicaid Population," presented with Patricia B. Howard, PhD, RN, at the International Society for Psychiatric-Mental Health Nursing, April, 2001, in Phoenix, AZ

"Using Fidelity Measures in an Evidence-Based Protocol to Evaluate Adherence to Medication Algorithms," presented with Patricia B. Howard, PhD, RN, at the International Society for Psychiatric-Mental Health Nurses, April 7, 2005, in Pittsburgh, PA
“Diabetic Self-Care in Individuals with Schizophrenia and Diabetes Mellitus, International Society for Psychiatric Mental-Health Nurses, April 8, 2005, in Pittsburgh, PA

Poster Presentations

“Satisfaction with Inpatient Services at Two State Psychiatric Hospitals”, presented at Sigma Theta Tau International Biennial Conference, Nov. 15, 2001, Indianapolis, IN

“Using Fidelity Measures in an Evidence-Based Protocol to Evaluate Adherence to Medication Algorithms,” presented with Patricia B. Howard, PhD, RN, at the Sigma Theta Tau International Biennial Conference, July, 2005, Kona, Hawaii

Research Grants

Research Grant from the International for Psychiatric Mental-Health Nursing, $1000, for dissertation project, “Diabetic Self-Care Management in Individuals with Co-Morbid Schizophrenia and Diabetes Mellitus,” Awarded April 7, 2003