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## DECISION-MAKING PROCESSES AND HEALTH BEHAVIORS AMONG ADULTS DIAGNOSED WITH SCHIZOPHRENIA

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DECISION-MAKING PROCESSES AND HEALTH BEHAVIORS AMONG ADULTS  
DIAGNOSED WITH SCHIZOPHRENIA

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DISSERTATION

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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  
Lillian J. Findlay

Lexington, Kentucky

Director: Dr. Patricia B. Howard, Professor of Nursing

Lexington, Kentucky

2012

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## ABSTRACT OF DISSERTATION

### DECISION-MAKING PROCESSES AND HEALTH BEHAVIORS AMONG ADULTS DIAGNOSED WITH SCHIZOPHRENIA

Individuals diagnosed with schizophrenia commonly experience problems with accurately assessing their health status due to cognitive deficits including impaired working memory, amotivation, and communication difficulties. Little is known about whether these deficiencies influence health behavior decision-making among individuals with schizophrenia. Individuals with schizophrenia die an average of 25 years earlier than those without a mental illness. Approximately 60% of premature deaths in this population are from medical comorbidities; mortality rates due to cardiovascular and pulmonary diseases are two to three times higher than the general population. In order to reduce morbidity and mortality, it is important to find effective ways to assist these individuals in modification of risky behaviors (e.g., smoking, poor dietary habits, and sedentary lifestyles) and to incorporate daily health promoting behaviors (e.g., balanced diet and regular exercise). This qualitative descriptive study was conducted to describe the decision-making processes used by adults with schizophrenia when making health behavior decisions, identify what it means to be healthy from the perspectives of adults with schizophrenia, and identify the perceived barriers and facilitators that affect health behavior decisions. Ten adults diagnosed with schizophrenia were interviewed for this study. Fifty-percent of participants were female, ages 28 to 59 years, and received treatment in a community mental health centers. Data were analyzed using content analysis. Methods included the use of field notes, open and axial coding, and development of a visual model. Trustworthiness of the findings was established through the qualifications and experience of the investigator, peer scrutiny, and member checks. Three phases of health behavior decision making were identified: Recognizing Complex Components of Health, Personalizing Components of Health, and Tracking Health Status. The main category that described health behavior decision making was "Tracking Health Behaviors," which resulted in the ability to maintain physical and mental health. Within each phase, specific actions associated with achieving and maintaining physical and mental health were identified and were displayed in a visual model. These findings provide a guide to clinicians in identifying health behavior decision making processes and may lead to the design of clinical interventions that improve the health status of adults with schizophrenia.

KEYWORDS: schizophrenia, health behaviors, health disparities, health promotion, decision-making.

Lillian J. Findlay  
Student's Signature

July 23, 2012  
Date

DECISION-MAKING PROCESSES AND HEALTH BEHAVIORS AMONG ADULTS  
DIAGNOSED WITH SCHIZOPHRENIA

By

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July 23, 2012

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*This dissertation is dedicated to my family and friends:  
my parents Jo Frances and Charles Findlay, my departed grandparents Ivel P. and Dr.  
James F. Caldwell and, Lillian A. and James Findlay, my siblings Jim, Steve, and Patti  
Findlay, and my many friends.*

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## CHAPTER ONE

### Introduction

According to the National Institute of Mental Health (NIMH; 2010), the 12-month prevalence of schizophrenia is approximately 1.1% of adults in the United States (US) or about 2.5 million people. The World Health Organization (WHO, 2012) estimates that the incidence of schizophrenia is about 3 per 10,000 people. Individuals diagnosed with schizophrenia, a serious mental illness (SMI), have more sedentary activity and unhealthy lifestyles than the general population (Faulkner et al., 2005). Also, individuals diagnosed with SMIs die an average of 25 years earlier than those without SMI (Parks, Svendsen, Singer, & Foti, 2006) perhaps in part due to unhealthy lifestyles. During any given two week period, those with SMIs participate in physical exercise at a rate of 12% of the time versus 35% among the general population (Faulkner et al., 2005). Poor dietary habits and high rates of smoking are also well documented in the SMI population; these behaviors contribute to chronic health problems. Up to 50% of persons with SMI are diagnosed with at least one co-morbid medical illness (Felker, Yazel, & Short, 1996; Howard, El-Mallakh, Rayens, & Clark, 2007). According to Parks et al. (2006), approximately 60% of premature deaths among those with SMIs are due to “natural causes,” (p. 11) “such as cardiovascular and pulmonary diseases” (p.11). These deaths result from illnesses seen in the general population but mortality rates are two to three times higher among those with SMIs (Parks et al., 2006).

The purpose of this qualitative study was to investigate the perspectives of adults with schizophrenia regarding what it means to be healthy, the barriers and facilitators to being healthy, and the cognitive processes used when making health behavior decisions. Specific aims were to: (1) describe what it means to be healthy from the perspectives of adults with schizophrenia; (2) identify the perceived barriers and facilitators that affect health behavior decisions among adults with schizophrenia; and (3) describe the decision-making processes used by adults with schizophrenia when making health behavior decisions. The findings of this study will lay the foundation for future research which will provide the basis for development and testing of clinical interventions to improve the health status of adults with schizophrenia.

## Significance of the Problem

Very little is known about how individuals with schizophrenia make decisions about health. Mental health clinicians do know that individuals with SMI commonly encounter difficulties that interfere with accurately assessing their health status. These include cognitive deficits involving memory and attention, information processing, abstract reasoning, difficulty with self-motivation, and communication difficulties (Lambert, Velakoulis, & Pantelis, 2003). These complicating factors suggest that there may be deficits in decision-making processes used by individuals with schizophrenia when they evaluate their ability to engage in health-promoting behaviors.

There is limited information on the subjective cognitive processes individuals with schizophrenia use when making health behavior decisions. Therefore, understanding factors that influence participation in health promoting behaviors such as diet, exercise, medication adherence and reduction of risky behaviors (e.g., smoking), is key to improving health outcomes (Faulkner et al., 2005).

The Substance Abuse and Mental Health Services Administration (SAMHSA, 2004) patient-centered recovery model seeks to close the 25-year mortality gap by 10 years within 10 years (Druss & Bornemann, 2010). SAMHSA's effort toward this goal encourages patient-centered self-determination, empowerment and personal responsibility for promoting one's own wellness. Assisting individuals with SMIs to achieve recovery should be the focus of current and future physical and mental health care services, and these must include partnerships between patients and clinicians in order to enhance efficacy. As SAMHSA (2004) asserts,

Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential. (SAMHSA, 2004, p.1)

Furthermore, health care delivery is increasingly moving toward evidence-based practice, a paradigm that encourages "the integration of best research evidence with clinical expertise and patient values" (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000, p.1). Healthcare providers know that health decision-making is an important

component of evidence-based practice, incorporates clinician recommendations and behavioral choices by patients, and requires effective collaboration between patients and clinicians (Spring, 2008). Therefore, it is imperative that mental healthcare providers seek to understand how to best assist individuals with SMIs to adopt and sustain health-promoting behaviors, avoid detrimental health habits, and gain and sustain access to quality physical and mental healthcare.

Research examining the subjective experiences of individuals with schizophrenia regarding what it means to be healthy, the barriers and facilitators of engaging in health-promoting behaviors, and the decision-making processes used when making health behavior decisions will lead to increased knowledge among mental healthcare providers and could be incorporated into techniques used in wellness and rehabilitation efforts.



## CHAPTER TWO

### Literature Review

Up to 50 % of persons with SMI are diagnosed with at least one co-morbid medical illness (Felker, Yazel, & Short, 1996; Howard, El-Mallakh, Rayens, & Clark, 2007). Howard et al. (2007) found that the top five medical illnesses experienced by individuals with schizophrenia were stomach problems, arthritis, hypertension, bronchitis, and spinal problems or migraine headaches. According to the Centers for Disease Control and Prevention (CDC, 2011), cardiovascular disease remains the leading cause of death in the US, and in 2010 the total costs of cardiovascular diseases were estimated to be \$444 billion. Treatment of heart disease accounts for about one of every six dollars spent on health care in the US (CDC, 2011). Furthermore, individuals diagnosed with schizophrenia or bipolar disorders have a cardiovascular death rate that is two to three times that of the general population (Morden, Mistler, Weeks, & Bartels, 2009). Among those with SMI, the prevalence of diabetes is estimated to be four times that of gender-and age-matched controls, and hypertension prevalence is two times that of the controls (Morden et al., 2009). Individuals with schizophrenia also have respiratory and infectious disease mortality rates over three times that of the general population (Parks et al., 2006). Clearly, having a SMI places one at considerable risk for mortality from cardiovascular disease, diabetes, hypertension, respiratory, and infectious diseases. High rates of substance use (40-70%) also negatively impact the health of those with SMI (Parks et al., 2006).

Although the prevalence of mental disorders for racial and ethnic minorities is similar to that of European Americans in the US, medical health disparities are greater (National Healthcare Disparities Report, 2009). For example, despite an overall decrease in death rates due to cardiovascular disease and stroke between 2000 and 2010 (in part due to improved treatments), this reduction was not met in the African American population or among men (Healthy People 2010). In 2006, the proportion of Coronary Heart Disease (CHD) deaths among individuals aged 45-74 was 37.9% among African American women compared to 19.4% among European American women, and African American men 61.5% versus 41.5% among European American men (CDC, 2010).

Among African American women, pre-mature death rates (before age 75) due to stroke were 39% compared to 17.3% among European American women, and 60.7% among African American men versus 31.1% among European American men (CDC, 2010). According to the Centers for Disease Control Morbidity and Mortality Report of 2011, among the African American population, the highest obesity prevalence was in women aged 40-59 and  $\geq 60$  and they were 52% and 55% respectively, compared to European American women at 37% and 32% (CDC, 2011). According to the American Diabetes Association (2012), the African American population is 1.8 times more likely to have diabetes compared to the non-Hispanic white population.

Undoubtedly, the dual factors of being African American and having a SMI places one in the highest risk groups for cardiovascular disease, hypertension, stroke, diabetes, obesity, and premature death. These chronic medical and mental illnesses require ongoing self-monitoring and treatment. Therefore, efforts must be made by healthcare providers to respectfully educate patients about the importance of their health behaviors. Specifically, clinicians should offer education in the areas of effective self-monitoring and self-administered treatment techniques with the ultimate goals of reducing morbidity and mortality and improving the quality of life.

While there are overlapping psychosocial models of health behavior, these merely predict the behaviors and do not describe how to change them (Bandura, 2004). Few studies describe the specific subjective experiences of individuals with schizophrenia regarding what it means to be healthy, the barriers and facilitators of engaging in health-promoting behaviors, and the decision-making processes used when making health behavior decisions. Understanding the decision-making processes used by individuals with schizophrenia when making health-behavior decisions will be beneficial to clinicians.

### **Comparisons of Health Behavior Decision-Making in Medical versus Mental Health Problems**

Among persons with chronic medical illnesses and those with SMI, there are similar patterns of accepting the chronic illness diagnosis and engaging in necessary

health behaviors required to manage symptoms adequately. Iversen et al. (2004) found that decision-making processes regarding participation in exercise among those diagnosed with rheumatoid arthritis (RA) were strongly predicted by prior participation in exercise, self-efficacy, level of social support, social norms (expectations and health behaviors of important others), and perceived barriers such as pain, medication side effects, depression, and stress. A qualitative study comparing responses of patients with schizophrenia and the chronic illnesses of asthma and epilepsy found that all three patient categories had similar dynamic decision-making processes regarding accepting the diagnosis of a chronic illness and adherence to medications (Marland & Cash, 2005). All three groups were able to discern, over time, that medications were needed in order to alleviate their respective symptoms and to avoid hospitalization. Individuals diagnosed with schizophrenia were more concerned about the negative social implications of re-hospitalization compared to those diagnosed with asthma or epilepsy. While groups were ultimately similar with respect to accepting a chronic illness diagnosis and subsequent treatments, individuals with schizophrenia who had relapsed as a result of stopping medications, had more prolonged delays in seeking assistance from clinicians primarily due to the fear of social stigma surrounding re-hospitalization; this may result in higher morbidity and mortality.

In contrast, among individuals with diabetes type II (DM-II), those with schizophrenia were more adherent to medications for the treatment of diabetes than those without schizophrenia (Kreyenbuhl et al., 2008). Among all participants, having more frequent contact with clinicians, prescriptions being delivered by mail, lower medication costs, and more complex medical regimens were related to better adherence (Kreyenbuhl et al., 2008). More research is needed to identify predictors of treatment adherence regarding other health behaviors among those diagnosed with SMIs and chronic comorbid medical conditions. A summary of studies comparing health behavior decision-making in medical versus mental health problems is located in Table 2.1.

### **Barriers to Health-Promoting Behaviors among Individuals with SMIs**

The combined barriers of stigma, marginalization by the medical community, low confidence to engage in self-care, psychiatric symptoms, and cognitive impairments may

negatively impact participation in health promoting behaviors. In addition to stigma, researchers have identified treatment delivery barriers. The National Alliance on Mental Illness Survey (2008) indicated that 49% of individuals with schizophrenia said they perceived that their doctors took their medical issues less seriously after learning about the presence of a mental health diagnosis. Lambert, Velakoulis, and Pantelis (2003) found that lack of referral resources, psychiatrists regarding physical complaints as psychosomatic, and reluctance of non-psychiatrists to treat people with SMIs were some of the barriers to early detection and treatment of medical conditions. Parks et al. (2006) stated that patient, provider, and systems factors contribute to increased morbidity and mortality among those with SMIs. According to Parks et al. (2006), patient factors included “amotivation, fearfulness, social instability, unemployment, and incarceration” (p. 16). Provider factors included “attitude and comfort levels with SMI population, coordination of care, and stigma” (Parks et al., 2006, p. 16). Finally, the “fragmentation between mental and general health care” (p.16), and lack of funding were noted as the primary systems problems (Parks, et al., 2006). Inadequate access to medical care also occurs due to underuse of preventive care by individuals with SMIs (Druss, 2002). One contributing factor is difficulty finding a primary care clinician who will accept the lower reimbursement rates offered by Medicaid and/or Medicare, the primary insurers of those with SMIs (Parks et al., 2006).

Inactivity, an additional factor to development of medical co-morbidity among those with SMIs is well documented among those with SMIs (Ussher, Stanbury, Cheeseman, & Faulkner, 2007). In a cross-sectional survey, Ussher et al. (2007) found that despite strong interest and recognition of the health benefits of exercise, adults with SMIs did not engage in physical activity due to the barriers of low confidence in their ability to exercise when experiencing sadness or stress, low social support, and fatigue or illness, when compared to non-ill adults. McDevitt, Snyder, Miller, and Wilbur (2006) conducted focus groups with individuals diagnosed with SMIs in a psychiatric rehabilitation program. Again, despite acknowledging the positive benefits of physical activity, the groups identified several perceived barriers to physical activity including mental illness symptoms, sedation from medications, weight gain, fear of unsafe places, fear of discrimination, and interpretations of program compliance which interfered with

their ability to be physically active. In a qualitative study, El-Mallakh (2006) examined evolving diabetic self-care among individuals with schizophrenia. Participants identified psychiatric symptoms as the primary barrier to diabetic self-care. The sedative effects of psychotropic medications, difficulty sustaining motivation, fear of pain, and feelings of lack of knowledge about exercise benefits also impeded participation in health promoting behaviors (Beebe, Tian, Morris, Goodwin, Allen, & Kuldau, 2005). Clearly, the barriers faced by those with SMI are challenging to patients and clinicians. Health behavior models are needed to guide researchers in efforts to determine predictors of health behaviors. A summary of studies examining the barriers to health promoting behaviors among individuals with SMI is located in Table 2.2.

### **Health Behavior Models**

The use of health behavior models to assist individuals toward achievement of optimal health is well documented. Existing models, including the Transtheoretical Model (TTM; Prochaska, DiClemente & Norcross, 1992), The Health Belief Model (HBM; Rosenstock, 1966), and the Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975), have primarily been used with individuals who have intact cognitive functioning. In addition, these models are used to guide strategies that change risky health behaviors such as smoking, substance addiction, resisting preventive health screenings, and sedentary lifestyles that lead to cardiovascular disease (DiClemente et al., 1991; Plotnikoff, Hotz, Birkett, & Courneya, 2001; Smith & Biddle, 1999; Bish, Sutton, & Golombok, 2000). These models have also been used in studies to identify factors influencing health behaviors and decision-making among individuals with SMI including those diagnosed with schizophrenia or schizoaffective disorder. For example, although the studies focused on outcomes of particular wellness or rehabilitation programs, they did not identify possible antecedents involved in the decision-making processes (Beebe, 2005; Camann, 2001; Faulkner et al., 2005; Holmberg & Kane, 1999).

The Transtheoretical Model (TTM) developed by Prochaska, DiClemente and Norcross (1992) is based on the theory that change in behavior is best accomplished when it is self-prompted. A visual representation of the TTM model is displayed in Appendix A. Prochaska et al. (1992) studied thousands of people who were successful

with self-change and were subsequently able to identify how to best assist individuals who find it difficult to make lifestyle changes such as smoking cessation. While important research has been conducted using the TTM, Plotnikoff, et al. (2001) noted that the TTM literature has not formally investigated the generalizability of the model in large community based samples. They also stated that the ability of the model to predict stage transitions has not been demonstrated.

Camann (2001) adapted the TTM to a wellness promotion program for outpatients in a psychiatric clinic. The pilot study included 55 individuals with SMIs, ages 18-59. Individual wellness reports were generated by objective assessment of health-promoting activity and health habits that could be addressed by changes in attitude or behavior. Subjective accounts of perceived participation in health-promoting behaviors were also obtained. All of the participants perceived themselves as taking better care of their physical health than they actually were. Nidecker, DiClemente, Bennett and Bellack (2008) tested the predictability of the model. They examined the psychometric properties of instruments associated with the TTM among individuals with schizophrenia, schizoaffective disorder or non-psychotic mood disorder, and current cocaine dependence or cocaine dependence in remission (Nidecker et al., 2008). The leading subscales associated with measurement of the TTM were valid and reliable in the total sample, expected patterns among the change stages emerged, and those with SMIs were found to use similar processes of change as non-ill persons (Nidecker et al., 2008). Replication of these data with regard to other needed health behavior changes (e.g., exercise and dietary habits) is needed.

The Health Belief Model (HBM; Rosenstock, 1966) was applied in health promotion studies among various populations, including individuals with SMIs. The HBM theorizes that three factors determine whether individuals take action regarding their health (Appendix B). These factors include: degree of health concern, perceived vulnerability, and reduction of the perceived threat if one accepts health recommendations, provided that they are within an acceptable cost range (Rosenstock, Strecher, & Becker, 1988).

In a prospective study of patients with a first-episode of psychosis, Perkins et al. (2006) found that the likelihood of becoming medication non-adherent for one week or longer was greater in those with a decreased belief in the need for treatment or who believed medications provided little benefit. The results of this study support the HBM hypothesis that perception of a significant threat or vulnerability must be present before health behaviors change. Perkins et al. concluded the primary targets for intervention to improve long-term medication adherence are beliefs about needing treatment and perceived benefits of treatment.

Fishbein and Ajzen (1975) developed the Theory of Reasoned Action (TRA) which assumes that humans prefer rational, systematic processes before deciding to engage in a particular behavior (Appendix C). These rational processes are value weighted before one makes a final decision to engage in a particular behavior. For example, one may believe that exercise is important for health reasons, but also believes that exercise takes too much time; one also values important others' opinion that exercise is worth engaging in, and a second important other's opinion that exercise is not worth engaging in (Miller, 2005). Thereafter, one balances his or her own beliefs or attitudes toward the importance of exercise with the subjective norm (opinions of important others about exercise) which leads to the intention to engage in exercise, and ultimately results in the actual behavior of exercising (Miller, 2005). This model may capture previously neglected areas regarding the promotion of healthy behaviors among the SMI in that it examines health behaviors in terms of the magnitude of relationships among attitudes, beliefs, behavioral intention, and actions regarding health behavior change. The TRA model is compelling because of its appropriateness in studying motivational factors involved in health promotion behaviors among persons with SMIs.

Holmberg and Kane (1999) investigated possible predictors of health-promotion lifestyle choices using the TRA in a pilot study of 22 outpatients diagnosed with SMI. Persons with SMI were less likely to engage in self-care practices compared to the general population despite similar scores on several scales of the Health Promoting Lifestyle Profile ([HPLP]; Walker, Sechrist, & Pender, 1987). These scales measure self-prompted activities and perceptions that contribute to the individual's ability to maintain behaviors which increase or preserve wellness and fulfillment (Holmberg & Kane, 1999).

Those with SMIs perceived less control of their health status, so clinicians may need to provide external influence on participation in health-promoting behaviors. Holmberg and Kane (1999) concluded that more robust studies are needed to identify predictors of healthy behaviors in the SMI population. Using the HPLPII, a revised version of the HPLP, may provide a more precise measure of the health promoting lifestyle; the revised version includes health responsibility, physical activity, nutrition, interpersonal relations, spiritual growth, and stress management (Walker & Hill-Polerecky, 1995).

Some research suggests that the neurophysiologic and anatomic abnormalities associated with schizophrenia can interfere with health care decision making. For example, van der Meer, Costafreda, Aleman, and David (2009) conducted a meta-analysis of neuroimaging studies, and reported that individuals with schizophrenia have abnormalities in the ventral and dorsal medial prefrontal cortex of the brain. Ventral deficiencies prohibit the internal processes required for self-reflection (van der Meer et al., 2009). Dorsal dysfunction interferes with reference to others and impairs decision-making (van der Meer et al., 2009). Therefore, self-prompted behavior change may not be possible regarding the ability to make adequate health decisions within the framework of the TRA or other models that require intact cognitive functioning.

Interviewing individuals with schizophrenia about illness beliefs led Kinderman, Setzu, Loban, and Salmon (2006) to suggest that individuals with schizophrenia who were psychotic did not believe they were ill (physically or mentally). These researchers concluded health models based on the intent of improving physical health needed adaptation. If long-term studies examining these models show weaknesses when used in the SMI population, modifications must be made, particularly in the areas of engaging in health promoting behaviors and perceived health status.

### **Facilitators or Predictors of Participation in Health-Promoting Behaviors among Individuals with Schizophrenia**

Despite evidence of dysfunction in the prefrontal cortex of the brain among individuals with schizophrenia, behavioral and thought pattern predictions associated with increased participation in health-promoting behaviors may be useful when



developing initial interventions aimed at improving health status. Only a few studies have identified predictors of participation and maintenance of health-promoting behaviors among individuals with schizophrenia.

Several researchers investigated factors associated with adherence to medication to identify predictors of engaging in health-promoting behaviors. Weiss, Smith, Hull, Piper, and Huppert (2002) found that individuals who were not medication adherent within two months of initiating treatment had decreased adherence as time progressed. A working alliance with the therapist was most consistently associated with adherence and predicted development and maintenance of active adherence better than global functioning (Weiss et al., 2002). Psychotic symptomatology was not related to antipsychotic medication adherence (Weiss et al., 2002). In another medication adherence study, conceptualization (an assessment of abstract concept formation and ability to identify differences in objects) and memory were the strongest patient-related predictors of ability to manage medications appropriately (Jeste et al., 2003).

Lee (2003) examined the relationships of illness cognition, optimism, and health locus of control with diabetes and overall health status among people with SMIs. They found that optimism and internal locus of control were significant predictors of general health. Optimism, internal locus of control, and illness cognitions were also significant predictors of the general physical health composite score on the SF-36 (Lee, 2003).

Leas and McCabe (2007) identified predictors of cardiovascular health behaviors among adults with schizophrenia and depression. Those included high levels of fear of cardiovascular disease, lack of knowledge regarding proper diet, lower self-efficacy, limited social support, and psychiatric symptoms (Leas & McCabe, 2007). A summary of studies examining the facilitators or predictors of participation in health-promoting behaviors among individuals with schizophrenia is displayed in Table 2.3

### **Cognitive Processes of Decision-Making**

Paulus and colleagues (2007) studied interactive affective and cognitive processes involved in decision-making. They found that if a homeostatic balance is not reached by an individual during interactive affective and cognitive processes, poor decisions may

result. In the review of research that examined neural-network and functional brain imaging studies conducted while decision-making tasks were being performed by a variety of subject populations, Paulus et al. reported that general decision-making processes are complex and dynamic homeostatic systems regulated by several areas of the brain. These processes are comprised of cognitive tasks that require individuals to select an action from available options; the choice selections that one makes results in an outcome that alters the psychological and physiological state of the decision-maker.

Optimal outcomes of decisions are dependent on the interplay of peripheral, central, sensory, and cognitive processes. Specifically, Paulus et al. (2007) stated that neuroimaging studies identified interactions of cortical and subcortical portions of the limbic system that aim to create a balance and produce the resultant exploitative and exploratory action plans of the decision-maker. These decisional strategies also rely on relative value assessments. Paulus et al. concluded that non-optimal decisions would be made if homeostatic balance was not reached as a result of dynamic affective and cognitive processes.

### **Cognitive Processes of Decision-Making among Individuals with Schizophrenia**

Individuals with SMIs have abnormalities in the prefrontal and emotional regulatory systems of the brain (Heerey, Bell-Warren., & Gold, 2008). These dysfunctions are known to result in faulty cognitions which negatively impact judgments/decisions (Heerey et al., 2008). Deficits in working memory and associated cognitive errors that result in an underestimation of the impact of losses and vulnerability to harm were noted by Heerey et al. These may be the most influential factors that impair general decision-making among individuals with schizophrenia.

Conversely, El-Mallakh (2006) found that individuals with diabetes and schizophrenia or schizoaffective disorder, who participated in individual interviews discussing diabetic self-care, made positive health decisions based on the need to avoid losses. Past losses experienced, due to non-adherence to psychiatric medications, included jobs, relationships, and independence (El-Mallakh, 2006). This suggests that

losses are considered in health behavior decision-making among those with schizophrenia. In addition, health knowledge was gained by observing family members with diabetes suffer negative health consequences due to poor control of diabetic symptoms (El-Mallakh, 2006). Because of these past experiences, participants were able to understand the importance of keeping mental illness and diabetic symptoms under control via medication adherence and other self-care measures such as consistent blood glucose monitoring.

Learning and complex decision-making are linked and are informed by prior experiences to produce new information (Newell & Bröder, 2008). Evans, Bowman, and Turnbull (2005) conducted a correlational study of individuals with schizophrenia where cognitive processes involved in general decision-making were examined in the context of performance on gambling tasks. Those tasks involved asking participants to choose between *good* and *bad* decks of cards based on the reward or punishment of either gaining or losing real money. The task also measured the subjective experience of how *good* or *bad* a deck was. Results indicated that behavioral learning between groups was roughly equal, and that subjective *gut-feelings* about whether a deck was *good* or *bad* were beyond chance for both groups (Evans et al., 2005). For individuals with schizophrenia, the subjective experience was a more powerful predictor than behavioral scores. This suggests that their decisions were more likely based on emotion versus logic.

Greig and colleagues (2007) conducted a year-long randomized controlled trial using a graduated cognitive remediation program based on learning, attention, language, executive function, and memory tasks (NET). Included in the sample were 72 individuals with schizophrenia or schizoaffective disorder. Subjects were either assigned to one of two treatment groups; the vocational services only group (VOC) or NET + VOC group. Both groups also had the benefit of staff-led work support and lifestyle sessions. Greig et al. (2007) found that frequent, systematic reinforcements and reminders of acquired skills might be important in overall vocational and memory function. One qualitative pilot study also found that individuals with SMI were able to actively engage in health-promoting behaviors with ongoing psychosocial support from treatment team members (Findlay, 2005).

Optimistic bias (the inaccurate belief that one's likelihood of experiencing a negative event is less than that of the average person), was investigated among individuals with schizophrenia and non-ill subjects, regarding how this may influence decision-making (Prentice, Gold, & Carpenter, 2005). Prentice et al. (2005) found that both groups had optimistic biases but non-ill subjects demonstrated a greater degree of optimistic bias, especially for events perceived as controllable. Individuals with schizophrenia perceived that they were less likely than others to experience an adverse life event but to a lesser degree than non-ill subjects. Thus, in patient education efforts regarding health risks, individuals with schizophrenia could possibly respond better than non-ill individuals, if provided with adequate support from the treatment team, family, peers, and others in the community.

Decision-making impairments, in the context of reward sensitivity among individuals with schizophrenia compared to non-ill individuals, were examined in a quantitative study (Heerey et al., 2008). This study tested reward sensitivity by introducing random visual representations of faces with different shaped mouths (short, long, or no mouth). Participants chose between two simultaneous gambles involving monetary rewards or penalties involving the faces. There was no detection of any group differences in development of bias which suggests intact sensitivity to reward among individuals with schizophrenia. Individuals with schizophrenia did place less influence on the potential losses when compared to the non-ill individuals suggesting there may be deficits in working memory. Researchers concluded that individuals with schizophrenia have intact implicit learning measures when coupled with reward; however, degraded working memory compromises their ability to weigh outcomes during affective (emotional) decision-making. Therefore, making rewards available in the immediate setting may mediate deficits in motivation among individuals with schizophrenia (Heerey et al., 2008). Following educational sessions, researchers have found that those diagnosed with psychosis were able to reach comprehension and understanding levels near to those in non-ill control groups on measures testing ability to provide informed consent, (Dunn et al., 2002; Carpenter et al., 2000). There is a lack of research regarding whether these cognitive problems affect health behavior decisions among individuals with schizophrenia.

In summary, the study findings of deficits in working memory, reduced estimates of the impact of losses, and having less optimistic bias than non-ill individuals, may be worth exploring in the context of how these factors affect decision-making processes regarding health behaviors as well as any associations with access to healthcare. The noted strengths of intact reward sensitivity and behavioral learning in decision-making could be incorporated into techniques used in wellness or rehabilitation efforts. A summary of studies examining the cognitive processes of decision-making among individuals with schizophrenia is displayed in Table 2.4.

Table 2.1 Comparisons of Health Behavior Decision-Making in Medical versus Mental Health Problems

Author	Purpose	Method	Sample	Findings
Iversen et al. (2004)	Identify predictors of exercise behavior at 6 months after clinic visit in moderately impaired patients with rheumatoid arthritis (RA).	Prospective, tested baseline vs. 6-month follow-up visit SF-36 short form, Lorig Self-Efficacy Other Scale, Arthritis Impact Measurement Scale (AIMS), Rheumatologist's attitudes/beliefs regarding physical therapy and own exercise habits, and if rheumatologist prescribed exercise.	25 rheumatologists and 132 patients, 20-94 years of age with RA.	<ul style="list-style-type: none"> <li>♦Significant decrease in exercise over the 6-months (37% vs. 27%). Patients 26% less likely to exercise if rheumatologist exercised possibly due to rheumatologist's assumptions exercise would be too strenuous for patients. These assumptions resulted in less patient education about exercise.</li> <li>♦No significant changes in any other scores.</li> <li>♦Decision-making regarding exercise among RA patients strongly predicted by: prior exercise behavior (patients seven times more likely to exercise if did before), physician's exercise behavior, self-efficacy, social norms and support, perceived barriers: pain, medication side effects, depression, and stress.</li> </ul>
Kreyenbuhl et al. (2008)	Measure medication adherence in Diabetes Mellitus type- II (DM) patients with and without schizophrenia or schizoaffective disorder.	Secondary analysis of Veteran's Affairs automated medication prescription record (MPR) data over fiscal year 2002.	454 patients with schizophrenia or schizoaffective disorder with DM vs. 560 patients without schizophrenia or schizoaffective disorder with DM, mean age 55 yrs.	<ul style="list-style-type: none"> <li>♦Poor adherence less in patients with schizophrenia (43%) vs. without (52%, <math>P &lt; .001</math>).</li> <li>♦Better adherence associated with more frequent contact with clinicians, prescriptions delivered by mail, lower medication costs, and more complex medical regimens.</li> </ul>

Table 2.1 (continued)

Author	Purpose	Method	Sample	Findings
Marland et al. (2005)	Compare prescription medication taking decisions of patients with schizophrenia, asthma, and epilepsy. Describe psychosocial processes associated with prescription medication taking decisions.	Qualitative-(Grounded Theory). Individual interviews.	16 diagnosed with schizophrenia, 13 asthma, 16 epilepsy and 11 caretakers (ages not specified).	<ul style="list-style-type: none"> <li>♦All patient types were able to discern, over time, that medications were needed in order to alleviate their symptoms and avoid hospitalization.</li> <li>♦Patients with schizophrenia were generally more concerned about the negative social implications of re-hospitalization vs. asthma or epilepsy patients.</li> <li>♦Patients with schizophrenia, who stopped medications and relapsed, had longer delays in seeking treatment-primarily due to fear of stigma.</li> </ul>
El-Mallakh (2006)	Identify factors associated with self-care health beliefs in individuals with schizophrenia, schizoaffective disorder, and diabetes mellitus. Develop a self-care theory.	Qualitative- (Grounded Theory) Individual interviews.	11 subjects, 18-72 years of age, diagnosed with schizophrenia, one with schizoaffective disorder.	<ul style="list-style-type: none"> <li>♦Theory of Evolving Self-Care-sequentially defined as mastering mental illness, accommodating diabetes, and striving for health (taking responsibility, doing my best, and hoping).</li> <li>♦Subjects' health beliefs developed over time.</li> <li>♦Positive health decisions based on the need to avoid losses.</li> <li>♦Important health knowledge was gained by observing family members with diabetes suffer negative health consequences due to poor control of diabetic symptoms.</li> </ul>

Table 2.2 Barriers to Health-Promoting Behaviors among Individuals with SMI

Author	Purpose	Method	Sample	Findings
Beebe (2005)	Compare physical and mental health parameters in a structured 16-week walking program in persons with schizophrenia.	Pilot study of 16-week outpatient walking program. Measures of six-minute walking distance, body mass index (BMI), % body fat, and severity of psychiatric symptoms (PANSS scores) taken at beginning and end of program & against non-intervention group.	Adults dx with schizophrenia (N=10), 8 = male and Caucasian, 2= female and African American.	<ul style="list-style-type: none"> <li>♦Post-intervention experimental group had significant reduction in body fat, greater aerobic fitness, lower BMI, and fewer psychiatric symptoms.</li> <li>♦No significant differences in baseline mean scores between groups.</li> <li>♦Aerobic exercise reduces depression and anxiety among persons with schizophrenia.</li> </ul>
Lambert et al. (2003)	Describe need for improved detection and treatment of medical illness among adults with schizophrenia.	Journal article/literature review.	Adults diagnosed with schizophrenia.	<ul style="list-style-type: none"> <li>♦Physical co-morbidity accounts for 60% of premature deaths (suicide excluded).</li> <li>♦Preventable risk factors higher in those diagnosed with schizophrenia or other mental illness.</li> </ul>
McDevitt et al. (2006)	Explore barriers and benefits of physical activity (PA) among persons in a psychiatric rehabilitation program.	Qualitative descriptive study: four focus groups from two agency sites, semi-structured interview guide, audiotapes transcribed and analyzed for themes/concepts.	34 adults, ages 18-50, with 62% of agency population dx schizophrenia or non-affective psychosis, mood disorder 29%, remainder diagnosed with anxiety.	<ul style="list-style-type: none"> <li>♦Significant barriers to physical activity: mental illness symptoms, medications, weight gain from meds, fear of discrimination and safety concerns.</li> <li>♦Patients were passive about exercise initiation due to their belief that they were being compliant if staff led exercise activities instead of themselves.</li> <li>♦Patients viewed PA positively and linked PA to improved mental health.</li> <li>♦Need to confront attitudes and barriers to PA.</li> <li>♦Need to define compliance to include self-initiation of PA.</li> </ul>



Table 2.2 (continued)

Author	Purpose	Method	Sample	Findings
Ussher et al. (2007)	Physical activity interests and perceived barriers among individuals with SMI.	Cross-sectional survey of adult inpatients and outpatients.	120 Adults with SMI: 35% schizophrenia, 58% male, 58% smokers, 68% Caucasian.	<ul style="list-style-type: none"> <li>♦70% prefer walking, 63% agreed or strongly agreed would exercise more if told needed to by doctor, 58% not at all or mildly confident about exercise when sad or stressed (self-efficacy measure), 68% would receive no help, very little help, or a little help with exercise, 20% too tired to exercise, 90% agreed that exercise important for physical health and 72% for mental health.</li> <li>♦Forced-entry regression: greater exercise self-efficacy was associated with being male, being an outpatient, and having a diagnosis of any mental illness other than depression.</li> <li>♦Prospective studies of preferences and barriers needed with larger sample size and exercise interventions need to be tailored to patient preferences.</li> <li>♦Exercise interventions need to maximize self-efficacy and social support must be provided.</li> </ul>

Table 2.3 Facilitators or Predictors of Participation in Health-Promoting Behaviors among Individuals with Schizophrenia

Author	Purpose	Method	Sample	Findings
Jeste et al. (2003)	Evaluation of cognitive predictors and performance-based measure of medication management (MMAA).	Patient scores on: Mattis' Dementia Rating Scale (DRS).  Drug Attitude Inventory (DAI).  Positive and Negative Syndrome Scale (PANSS).	110 middle-aged and older (45- ≥ 65 years) outpatients with schizophrenia or schizoaffective disorder.	<ul style="list-style-type: none"> <li>♦Older patients with increased cognitive impairment and increased negative symptoms on PANSS performed worse on MMAA.</li> <li>♦Patients with increased DAI scores performed better on MMAA.</li> <li>♦Subscale measures of cognitive performance with MMAA performance, best predictors are: memory impairment and difficulties with conceptualization.</li> <li>♦Teaching patients skills to enable taking medications correctly and addressing interventions addressing attitudes/beliefs are important.</li> <li>♦Interventions need to be designed to compensate for impaired memory functions.</li> </ul>

Table 2.3 (continued)

Author	Purpose	Method	Sample	Findings
Leas et al. (2007)	Evaluate the utility of Protection Motivation Theory (PMT)- proposes that individuals protect themselves based on four factors: Perceived severity of a threatening event. Perceived probability of occurrence of threatening event (vulnerability). Efficacy of the recommended preventive behavior. Perceived self-efficacy. The PMT was used to explain cardiovascular (CV) health behaviors among those with schizophrenia or depression (MDD).	Questionnaires adapted from Coalfield Heartbeat Study, Body and Mind Project.  Significant variables: Body Mass Index; perceived physical health; cardiovascular knowledge; social support; psychiatric symptoms; vulnerability to CV disease.	Total of 300 participants: Participants with mental illness (n=153): Schizophrenia (n= 83), ages 22-63 years (yrs), 60% male; Major Depressive Disorder, ages 22-70 yrs (n=70), 27% male; No history of mental illness (n=143), ages 18-77 yrs, 34% male.	<ul style="list-style-type: none"> <li>♦Partial support of the PMT in the prediction of health intentions and behaviors among those with mental illness.</li> <li>♦Comprehensive interventions are required targeting psychiatric symptoms, increasing social support, and alleviating fear among those with mental illness.</li> <li>♦Further research is needed regarding the role of social relationships in enhancing health behaviors for those with mental illness.</li> </ul>

Table 2.3 (continued)

Author	Purpose	Method	Sample	Findings
Lee (2003)	Investigate relationships and predictors between intra-individual variables (illness cognitions, optimism, health locus of control, and coping styles) and health related outcomes among those dually diagnosed with schizophrenia and diabetes.	Instruments: Global Assessment of Functioning (GAF), CAGE (alcohol screen); BPRS-A; FAS Verbal Fluency; WAIS-III (cognitive function); Life Orientation Test-LOT R (optimism); Multidimensional Health Locus of Control (MHLC); Ways of Coping Questionnaire (coping response to managing diabetes). Self-Report of Overall Health Status (Health status Questionnaire SF-36); Physical Functioning scale (presence and extent of physical limitations); Behavioral/Diabetes Self-Care (summary of diabetes self-care activities); GHb A1C. Implicit Models of Illness Questionnaire (IMIQ-illness cognitions).	77 adults (ages 31-79 yrs) with schizophrenia or schizoaffective disorder, 96% male and 86% African American.	<ul style="list-style-type: none"> <li>♦Optimism and internal health locus of control (IHLC) were associated with better general health status measure (Physical Health Composite score on SF-36).</li> <li>♦Illness cognitions are significant predictors of General Physical Health Component scores on SF-36.</li> <li>♦Self-reported outcome variables for general health status may be biased since being optimistic may lead to more positive self-evaluation.</li> <li>♦Patients with poorer metabolic control (of diabetes) used both emotion-focused and problem-focused coping strategies more than those with good metabolic control.</li> <li>♦Recommendations for future research: to longitudinally examine relationships between illness cognitions and physical disease and to test whether these cognitions are predictive of long-term health related behaviors.</li> </ul>

Table 2.3 (continued)

Author	Purpose	Method	Sample	Findings
Weiss et al. (2002)	Investigate medication adherence in those with psychotic illnesses.	<p>Cross-sectional, longitudinal prospective study (21-months).</p> <p>Clinical outcomes tracked using: Working Alliance Inventory (WAI).</p> <p>Treatment adherence rated by therapist on 4-point scale.</p> <p>Global Assessment of Functioning (GAF).</p> <p>The Basis-32 (psychosis and substance use).</p>	<p>162 individuals with schizophrenia (47.5%) or schizoaffective disorder (45%), ages 18-58 years, admitted to ambulatory psychotic disorders clinic.</p> <p>63% male, 78% Caucasian, average age of first hospitalization = age 23 years.</p>	<ul style="list-style-type: none"> <li>♦80% actively medication adherent on admission, 75% adherent at 5.2 months, 50 % adherent at 13.7 months.</li> <li>♦Working alliance with therapist most significant and consistent predictor of medication adherence.</li> <li>♦Being on Clozapine decreased risk of non-adherence by greater than half.</li> <li>♦Severity of positive psychotic symptoms (delusions and hallucinations) not found to be significantly related to medication adherence.</li> <li>♦Study replicates previous studies of association between adherence and global functioning, substance use, and working alliance with therapist.</li> </ul>

Table 2.4 Cognitive Processes of Decision-Making among Individuals with Schizophrenia

Author	Purpose	Method	Sample	Findings
Prentice et al. (2005)	Investigate whether optimistic bias (degree to which subjects rate their likelihood of experiencing an adverse life event) is similar between those with schizophrenia and non-ill subjects, and how this impacts decision-making.	<p>40-item Risk Perception Questionnaire (RPQ-7-point response-option that measures events: controllable, uncontrollable and neutral) administered (was read to patients).</p> <p>Group, event type, and interactions measured.</p> <p>Post hoc analysis on one-way, paired, and independent-sample t tests.</p> <p>Spearman's correlations calculated for Brief Psychiatric Rating Scale (BPRS-subscales for psychosis and anxiety) and with Scale for Assessment of Negative Symptoms (SANS).</p>	<p>22 outpatients with schizophrenia, 3 schizoaffective, 23 non-ill subjects.</p> <p>Patients had stable medication regimens and symptomatically stable for 4 weeks at time of study entry.</p>	<ul style="list-style-type: none"> <li>♦Both patients and non-ill subjects believed they were significantly less likely than others to experience adverse life events (non-ill felt less vulnerable to experience adverse events than patients for controllable life events).</li> <li>♦Correlational analysis of between patient BPRS depression scores and degree of optimism showed increased levels of depressed mood moderately associated with decreased optimism for all three event types but uncontrollable events significant.</li> <li>♦No relationship between psychosis and extent of optimistic bias.</li> </ul> <p>Patients feel less effective regarding their own ability to manage controllable life events than non-ill subjects-(this may result in patients having low confidence to engage in a variety of activities and needs to be tested).</p>

Table 2.4 (continued)

Author	Purpose	Method	Sample	Findings
Evans et al. (2005)	Investigate subjective experience (emotional learning and complex decision-making) on gambling tasks among those with schizophrenia compared to controls.	<p>Iowa Gambling Task (IGT) used to measure learning and complex decision-making (determined by choosing “good and bad decks” of cards while monetary rewards and punishments are simultaneously introduced).</p> <p>SANS used to measure psychiatric symptoms.</p> <p>Wechsler Abbreviated Scale of Intelligence (WASI).</p> <p>Modified Wisconsin Card Sorting Test (WCST) to measure executive functioning.</p> <p>Controlled Oral Word Association Test (COWAT) to measure executive functioning.</p>	38 subjects: 19 diagnosed with schizophrenia, 19 non-ill, case-matched for age and education).	<ul style="list-style-type: none"> <li>♦No main effect of group, no interaction between group and block in either group during advantageous card selections.</li> <li>♦Strong positive correlation between behavioral performance and subjective experiences for those with schizophrenia (<math>r = 0.66</math>, <math>p = .001</math>) and for controls (<math>r = 0.41</math>, <math>p = .042</math>)-the difference in magnitude of scores may suggest that patients are more likely to use emotion v. logic in decision-making.</li> <li>♦Patients tended to have more intuitive or “gut feelings” about whether a card deck was “good or bad”-- investigators stated they had never seen this before when testing the IGT with non-ill subjects.</li> <li>♦Emotion-based learning (emotional intelligence) on IGT comparable to non-ill controls and may be advantageous in some types of decision-making.</li> <li>♦Subjective (emotion-based) experience ratings remained higher than behavioral performance until later in the blocks-suggests greater awareness of nature of task than behavioral performance indicates.</li> </ul>

Table 2.4 (continued)

Author	Purpose	Method	Sample	Findings
Greig et al. (2007)	Evaluate the effect of Neurocognitive Enhancement Therapy (NET), a computer-based cognitive training program for remediating cognitive deficits in those with schizophrenia participating in a vocational program; (VOC)-included staff-led group about social and lifestyle concerns).	Instruments: WCST, Digit Span and Letter Number Sequencing subscales of WAIS-III, Logical Memory I and II and Visual Reproduction I and II subscales of the Wechsler Memory Scale III, trail 1-3 of 30 minute recall of scores on Hopkins Verbal Learning Test-Revised, Gorham's Proverbs Test rated for bizarreness. Social cognition measured with North American version of The Hinting Task and Bell-Lysaker Emotion Recognition Task.  Sci-Learn and CogRehab- (computerized cognitive remediation exercises)	72 stable outpatients diagnosed with schizophrenia or schizoaffective disorder.	After one year of treatment patients with NET + VOC had significantly greater improvements in executive functioning and working memory than VOC group only.  Continued development and evaluation of multifaceted cognitive remediation programs are needed.



Table 2.4 (continued)

Author	Purpose	Method	Sample	Findings
Heerey et al. (2008)	Determine how decision-making difficulties among those with schizophrenia affect their ability to assign subjective value to potential outcomes and not reward sensitivity.	Instruments: HVLT, Wechsler Test of Adult Reading,  Simultaneous gambles involving hypothetical monetary rewards/penalties used to measure probabilistic decision-making.	66 subjects; 40 diagnosed with schizophrenia, 26 non-ill.	Individuals with schizophrenia have intact reward sensitivity in decision-making.  Working memory entirely accounted for group differences in participants' subjective valuations of potential outcomes.  Individuals with schizophrenia give significantly less weight to potential losses.  Results suggest that deficits in motivated behavior among those with schizophrenia may arise as rewards become increasingly remote or require integration of cognition and affect.  Conversely, when rewards are immediate, behavioral deficits decrease and motivated behavior increases. Consistent and tangible reinforcements may shape motivated behavior more so than temporally remote rewards.

## CHAPTER THREE

### Methodology

#### Design

Qualitative descriptive research methodology guided the design of this study. This methodology emphasizes a straightforward description of the content of data that is derived from a natural setting and is summarized in a manner that best fits the data (Sandelowski, 2000). The central goal of qualitative descriptive research is to gain understanding of the experiences and perspectives of the research participants within the contexts of their daily lives. It is considered naturalistic inquiry and does not require a pre-determined theoretical framework (Sandelowski, 2000; Miles & Huberman, 1994; Lincoln & Guba, 1985) Qualitative descriptive methodology was chosen for this study because there is lack of basic information about how adults diagnosed with schizophrenia make health behavior decisions and this methodology facilitated the study of individuals with schizophrenia in their most natural state.

Qualitative description does not require the researcher “to move as far from or as into their data” (Sandelowski, 2000, p.335) as Thorne, Kirkham, and MacDonald-Emes’ (1997) interpretive description suggests. Rather, interpretive description assumes a more structured understanding of clinical phenomenon. Despite attempts to describe the data in its most basic form, the researcher will influence the final analysis because “descriptions always depend on the perceptions, inclinations, sensitivities, and sensibilities of the describer” (Sandelowski, 2000, p. 335). However, in order to reduce the subjectivity of the researcher’s descriptions, Sandelowski suggests it is important that investigators using qualitative descriptive methodology reach a consensus that the results are accurate even if they view the same observation in slightly different ways. This can be accomplished by producing summaries that have descriptive and interpretive validity which convey accurate sequencing and meanings of events described by the participants (Maxwell, 1992). Unlike phenomenological, ethnographic, narrative, and grounded theory methods, qualitative description does not require formation of theories or abstract concepts but may contain elements of these techniques (Sandelowski, 2000). Although

the intent of this study was to remain as close to the data as possible, following content analysis, the outcome did result in categories with some conceptual ordering and linkages. In addition, a core category or theme was derived from an *in vivo* quote which represents the tone of a grounded theory methodology (Streubert-Speziale & Carpenter, 2003). Streubert-Speziale and Carpenter (2003) described the emergence of a core variable as a category that accounts for the majority of patterns of behavior via integration of preceding categories, and can ultimately result in theoretical codes used in grounded theory methodology.

In this study, a semi-structured topical interview guide was used to generate a qualitative description of perspectives of adults with schizophrenia regarding what it means to be healthy, the cognitive processes used when making health behavior decisions, and the barriers and facilitators to being healthy. Interview probes were used when participants gave short answers or experienced difficulty verbalizing their thoughts. A copy of the interview guide is located in Appendix D.

### **Inclusion criteria for participants**

Inclusion criteria for participants were: a.) adults 18 years or older who have a diagnosis of schizophrenia b.) individuals who speak English c.) individuals with no major communication difficulties such as deafness or muteness d.) average intelligence determined by participant's psychiatrist or psychologist e.) willingness to talk about their health f.) willingness to participate in taped interviews. Exclusion criteria for participants were: a.) any medical condition that prevents the individual from participating b.) inability to understand the study purposes and procedures and c.) inability to meet inclusion criteria.

### **Institutional Review Board Procedures**

The study was approved by the University of Kentucky Medical Institutional Review Board as well as the Institutional Review Boards associated with the research sites: Seven Counties Services (SCS) and Bluegrass Mental Health and Mental Retardation Board (BGMH-MR). The Vice President of Adult Mental Health Services supervised research activities conducted at SCS sites. The Chief Clinical Officer

supervised research activities at BGMH-MR. Letters of support to conduct research at each site were obtained and submitted to the University of Kentucky Medical Institutional Review Board (Appendix E).

### **Participant Recruitment**

Participants were recruited at the Institutional Review Board approved sites. SCS study sites included Center One, Center One West, Center One Downtown, and Pyramid House. The BGMH-MR site was the Newtown Pike Community Mental Health Center.

Clinicians facilitated recruitment procedures. For example, the researcher contacted clinicians at each study site to describe the study protocol and to request that they distribute study flyers in the clinics and to potential participants (Appendix F). Once clinicians confirmed the diagnosis of schizophrenia a “Consent for Contact” release of information was signed by clients if they verbalized an interest in being in the study (Appendix G). The release provided permission for the researcher to have knowledge of the potential participant’s diagnosis and to have their home phone numbers so that they could be contacted to see if they met study criteria. Participants were then contacted by the researcher via telephone to determine if they met study criteria, further describe the study, and make arrangements to meet those who were eligible at the outpatient clinic or day treatment center where they received their usual care. Recruitment interviews were conducted in clinic or day treatment center rooms or offices considered to be confidential settings.

The recruitment interview began with the researcher reading aloud the “Consent to Participate in a Research Study” form while the potential participant read along to themselves (Appendix H). Rights as a research participant were emphasized and participants were given the opportunity to ask questions following the interview. The form was then signed and dated by the participant indicating agreement to volunteer for the study. Because individuals diagnosed with schizophrenia are considered a vulnerable population regarding the ability to provide informed consent (Roberts, 2002; Wirshing, 2005) further protection was given by assessing the participant’s ability to understand the research protocol. This was accomplished by administering the “Consent Confirmation”

questionnaire, a 9-item true-false quiz (El-Mallakh, 2005) that tested the information contained in the informed consent regarding the study procedures, rights as a research participant, and their status as a volunteer in the study (Appendix I). Participant's ability to answer all 9-items correctly indicated an understanding of the study procedures and their rights as a research participant. Therefore, they were eligible to participate in the study. Demographic information was then collected and participants received \$5 for transportation costs (Appendix J). Copies of the signed informed consent were given to each participant.

The audio-taped individual interview was conducted during the second meeting with those who were enrolled in the study. During this meeting, the topical interview guide questions were asked. Similarly, the third meeting was held to clarify answers provided by participants and to obtain answers to any inadvertently omitted questions. Participants received \$10 for the lengthier second interview and \$5 for the final interview. The fourth and final member-check meeting was conducted over the telephone and participants were not reimbursed.

### **Protection of Research Subjects**

Confidentiality and anonymity of study participants was assured by adhering to HIPPA requirements, keeping study records in locked files, and erasing all identifying information from transcripts and audio taped interviews. Statistical analysis performed on the computer did not contain any identifying information as the participants were assigned a number instead.

### **Sample Selection**

Once inclusion criteria were confirmed, purposive, criterion sampling guided the overall selection of participants for this study. This form of sampling is useful when individuals have all experienced the phenomenon being studied (Creswell, 1998). In addition, criterion sampling provides an opportunity to gain an in-depth understanding of the phenomenon and produces information-rich cases (Sandelowski & Barroso, 2003).

In this study, participants were selected based on the criteria of being adults diagnosed with schizophrenia and having a willingness to describe how they make health behavior decisions. It was estimated that a sample size of ten would be needed to be considered an adequate representation of a homogeneous group (Sandelowski, 1995). A sample size of ten was ultimately determined once similar concepts and themes emerged between the individual interviews, satisfying informational redundancy (Sandelowski, 1995).

The sample consisted of 10 adults diagnosed with schizophrenia between the ages of 28 and 59 years. Although length of time since diagnosis was not formally investigated, most participants stated that they had been diagnosed with schizophrenia since their late teens or by mid to late twenties. According to Sham, MacLean, and Kendler (1994), the average age of onset of schizophrenia in men is 18 years and women 25 years. The average age of this sample was 45.4 years, indicating that participants had experienced a considerable adjustment period regarding acceptance of the diagnosis of schizophrenia and had perhaps responded to the therapeutic effects of antipsychotic medications and/or other treatments such as support groups and day program activities. This provided an opportunity to examine individuals who could provide rich and meaningful descriptions of their decisions related to health behaviors that have developed over time.

### **Data Collection**

Study data were collected between December 2011 and May 2012. The data included audio-taped individual interviews and field notes of general observations about the participant or setting. Once themes were identified, additional data were collected through short follow-up interviews to clarify answers provided by participants when needed.

Participants engaged in three interviews each for a total of 27 interviews. Three of the third interviews were lost to follow-up (one due to loss of cell phone service, one due to transfer of care, and the third because of failure to show up for the interview). The first interview lasted about 30-45 minutes to obtain written informed consent. Demographic

data included age, race, gender, employment status, annual income, disability status, marital status, household characteristics, housing type, education level, and number of children. Medical history data included: (1.) ability to name psychiatric medications, dosage and frequency, and adherence, (2.) ability to name medical illnesses, medical medications, dosage and frequency, and adherence; medical treatments and frequency of treatment, (3.) frequency of participation in day treatment programs per week, and primary contact for emotional support or encouragement, and (4.) history of tobacco, illicit drug or alcohol use.

The audio-taped interview during the second meeting lasted about 30-45 minutes. During this interview, the topical interview guide was used. The topical interview guide was comprised of seven broad statements or questions:

1. "Tell me your definition of what it is to be healthy."
2. "Tell me about what things you do each day to be healthy."
3. "Talk to me about any difficulties that you may have with trying to be healthy."
4. "Tell me how you know that you are healthy."
5. "Tell me about what helps you to be healthy."
6. "Tell me about how your mental illness (or symptoms of schizophrenia) has affected your ability to be healthy."
7. "Tell me what you can do if something makes it difficult for you to be healthy."

After the first two participants completed the individual interview, the interview guide was modified to probe more deeply into short answers. For example, the primary interview question designed to explore barriers to health behaviors, ("talk to me about difficulties that you may have with trying to be healthy") was expanded to include sub-questions that successively incorporated the original question within the separate contexts of exercising, taking medications, and following health instructions given by their nurse, doctor, or other clinicians (e.g., "talk to me about difficulties that you have with exercising, taking your medications, and following health instructions"). Similarly, questions exploring facilitators to health behaviors were modified. Additional sub-questions added in this category probed for descriptions about what participants thought

might happen if they did or did not exercise, take all medications, or follow health instructions (Appendix D). The changes to the interview guide resulted in participants providing greater detail in their responses and descriptions.

The third meeting was held for clarification and confirmation purposes and to obtain answers to any inadvertently omitted questions. Following data analysis, a de-identified summary of study findings was electronically mailed to each participant's mental healthcare clinician to distribute. Finally, a member check was conducted over the telephone after each participant reviewed the study findings with their mental health care provider.

### **Data Analysis**

As recommended, (Sandelowski, 2000), content analysis was the method of data analysis in this exploratory descriptive study and it was used to guide data analysis. This method of dynamically incorporating a variety of data sources (visual and verbal) resulted in a straightforward summary derived from the combined information. For example, analysis began with several readings and interpretations of the audio-taped individual interview transcripts that had been transcribed verbatim by an independent transcriptionist. Accuracy was assured by listening to the tapes while reading the transcripts twice. During and following each interview, field notes were taken to provide observational details about the participant and setting (e.g., whether the participant had difficulty answering questions or if they seemed comfortable in the research setting). These notes were taken into account and incorporated into the data analysis when indicated. As suggested by Glaser & Strauss (1967), constant comparison analysis was also performed throughout the data collection process to determine the accuracy of emerging themes or categories and their properties or dimensions across cases. For example, during the first interview, the response to "tell me your definition of what it is to be healthy," the first participant described that having a good heart and lungs, being able to wash clothes, cook, clean house, and having good personal hygiene, was a definition of being healthy. These descriptors of health were initially labeled as factors that affect the body, including appearance and ability to engage in activities of daily living. This response prompted exploration of whether having a healthy body and being



able to perform activities of daily living would be defined as components of health when examining subsequent cases. Ultimately, the following categories emerged: “recognizing the complex components of health,” and included the dimensions of “body, mind, and spirit,” as areas of health that must be attended to in order to be healthy.

In addition, a conceptual matrix was constructed to aid in ordering participant’s answers to interview guide questions with the initial categories highlighted with color codes within each segment across cases (Miles & Huberman, 1994). “Here the analyst is blending inferences drawn directly from the displayed data (tactics: **seeing patterns**, **themes**; and **factoring**-that is, seeing a few general variables underlying many specifics), with illustrative comments drawn from elsewhere in the case” (Miles & Huberman, 1994, p. 131-133).

Open coding (Strauss & Corbin, 1998) was used to identify the initial seven categories found in the content of the transcripts. Glaser (1978) suggests the initial themes or categories are needed to supply the researcher with informative leads that direct the study toward more developed themes or categories. In this study, Patton’s (2002) strategy for manually coding and color highlighting categories was used. Initial categories were: appearance, motivation, responsibility, de-stressing, co-morbidities, transportation, and routines/schedules.

Subsequently, axial coding (Strauss & Corbin, 1998) was conducted to allow for the reduction of the initial categories into three main or overarching categories. These categories represented three dynamic phases of health behavior decision-making: recognizing complex components of health, personalizing components of health, and tracking health status (Figure 5.1). In addition, eight specific subcategories or actions emerged that were associated with achieving and maintaining physical and mental health.

Qualitative descriptive research demands only that a descriptive summary of a phenomenon be organized in a manner that best encompasses the collected data (Sandelowski, 2000). Accordingly, the summary does not have to produce theoretical renderings but may contain concepts or themes for future grounded theory study (Sandelowski, 2000). In this study, an *in vivo* quote, “maintaining physical and mental stability,” influenced the formation of a central theme, “tracking health behaviors.” This

theme was not intended to serve as a selective code that would provide a theoretical explanation of all categories (Strauss & Corbin, 1998). Rather, the central theme was meant to simply anchor the three interconnected phases of health behavior decision-making and described how participants were able to make active, comprehensive health behavior decisions by systematically “tracking” or monitoring their daily health behaviors.

### **Scientific Rigor**

Data verification and trustworthiness was assured by using techniques associated with the concepts of credibility, dependability, and confirmability (Lincoln & Guba, 1985). Credibility and dependability, to establish confidence in the truth of the study findings, was enhanced by taking field notes during and after individual interviews and having meetings with each participant to clarify unclear statements or answers to study questions (Lincoln & Guba, 1985). Confirmability is determined by evaluating the degree to which study findings are a result of information provided by participants (Lincoln & Guba, 1985). Confirmability was fostered by an audit trail initiated with the first interview that included documentation of all study procedures, field notes, and coding notes, and continued until study completion. The audit trail and coding was verified as accurate by a researcher with expertise in qualitative methods. In addition, participants were provided with a summary of study findings and main categories related to health behavior decision-making. After participants had an opportunity to review these summaries, “member checks” (or participants review of the model) were conducted with seven participants to verify accuracy of the study findings and to confirm that the main categories described their definition of health and health behavior decision-making processes. All seven participants agreed that the categories accurately reflected their definitions of health and health behavior decision-making processes. Confirmability can also be established by stating the assumptions or biases of the researcher that may have been present prior to data collection (Lincoln & Guba, 1985). Assumptions of this study were based on the clinical experience of the researcher, review of the literature, and included:

1. Individuals use cognitive processes when making health behavior decisions.

2. There are facilitators to health behaviors such as social support, self-efficacy, and positive relationships with health care providers or others that influence health behavior decision-making and encourage participation in health-promoting behaviors.
3. There are barriers to health behaviors such as cognitive deficits, treatment side effects, psychiatric symptoms, lack of access to treatment, and social stigma associated with a mental health diagnosis that interfere with health behavior decision-making and participation in health-promoting behaviors.

Because of having 21 years of clinical experience as a psychiatric nurse assisting patients diagnosed with schizophrenia with their mental healthcare needs, observations were made during this time that could have influenced the researcher's interpretation of study findings. For example, the researcher previously noted that patients had problems gaining timely access to care and experienced cognitive difficulties that interfered with their ability to make adequate health behavior decisions. These deficiencies led to poorer general health outcomes. However, if individuals with schizophrenia were provided with adequate support from their treatment teams and others in the community, they had better physical and mental health outcomes.

These conclusions were made as a result of working in a variety of settings, some which had greater support for patients in their wellness and health education programs, when compared to others. Among those settings in which there was frequent contact with treatment team members, individuals with schizophrenia seemed to have better states of physical and mental health and were more actively engaged in treatment. In addition, prior to study conduction, the researcher reviewed information in the literature regarding the health behaviors and cognitive processes used by adults with schizophrenia. These prior clinical experiences and the review of the literature may have biased observations made by the researcher during the conduction of this study.

## CHAPTER FOUR

### Description of Participants

#### **Demographic Characteristics**

A total of 10 adults diagnosed with schizophrenia participated in the study. Eight participants were diagnosed with paranoid schizophrenia (80%) and two were diagnosed with undifferentiated schizophrenia (20%). As noted in the table 4.1 display of select social demographics, pseudonyms are used in descriptions of study participants. As indicated, there were an equal number of male and female participants. 100% were African Americans (AA) and ages ranged from 28 to 59 years with an average of 45.4 years of age. Six participants had never been married (60%), one was currently married (10%), two were divorced (20%), and one was partnered (10%). All participants were unemployed (100%), and were considered disabled (100%). Eight participants had annual incomes of less than \$10,000 (80%), one female participant had an annual income of \$10,000-\$20,999 (10%), and another female participant had an annual income of \$21,000-\$30,999. Although both females in the highest income brackets had completed 12<sup>th</sup> grade, half did not have a high school education. Other education levels ranged from 8<sup>th</sup> grade to Master's degree. Four participants lived alone (40%), three lived with parents (30%), two lived with roommates (20%), and one lived with a marital spouse (10%). Half of all those who participated lived in apartment housing, two lived in a group home (20%), two lived in a parent's house (20%), and one lived in a rental house (10%). Four participants did not have children (40%), two had two children (20%), one had three children (10%), and three had more than six children (30%).

Forty-percent of participants smoked tobacco daily or several times per week (three female, one male), one participant endorsed using illicit drugs intermittently, and all participants denied alcohol use (100%). All participants were treated with atypical antipsychotic medications and were able to name the medications (100%). Eighty-percent of participants had medical co-morbidities. Five females had type II diabetes, and three were diagnosed with hypertension (two also had co-morbid high total cholesterol). One male (10%) experienced chronic back pain, one male (10%) was diagnosed with type II

diabetes and hypertension, and one male (10%) had prostate cancer. The majority of participants with medical co-morbidities were able to state the names and indications of their medical medications. Thirty-percent of participants attended day a treatment program once per week, 40% two to four times per week, 20% five to seven times per week, and one participant (10%) did not attend. A summary of the demographic characteristics are displayed in Table 4.2. Select medical demographics of participants are displayed in Table 4.3 and current psychiatric medications taken by participants are displayed in Table 4.4.

## **Participant Profiles**

### **Ann**

The first participant was Ann. Ann was a 56-year-old female living with her parents in their rental home at the time of the study. She smoked tobacco daily. Ann had the co-morbid illnesses of emphysema and type II DM. She reported that she took all of her daily medical and psychiatric medications as prescribed including daily insulin, an antipsychotic medication (did not state the name), trihexyphenidyl for antipsychotic medication side effects, and the mood stabilizer divalproex sodium. She had never been married but had 11 children, the majority of whom were raised by their fathers because of her symptoms of schizophrenia. Her sister raised two of her children. Ann felt that she developed of a distrust of others because they essentially took away her parenting opportunities. She was able to have a relationship with most of her children once they became adults and stated that maintaining this connection with them was the primary motivating factor to adhering to her psychiatric treatment.

Ann had been unemployed and on disability for many years but stated that she worked as a nurse for four years in the past. She quit her job as a nurse at the age of 27 years because of the symptoms of schizophrenia. She reported that when she was able to maintain good personal hygiene this helped her know that she was in a healthy state. In addition, she stated that listening to health advice from doctors helps her to adhere to recommended treatments, and that this helps her “turn out pretty healthy,” and avoid psychiatric re-hospitalization. She attended a day treatment program two to four times

each week and felt a sense of emotional support or encouragement from peers and staff at the program. The primary barriers to her health were lack of consistent transportation to get to exercise classes, difficulty ambulating because of being overweight, shortness of breath, and at times having long toenails (waits to have toenails cut at doctor's office to avoid potential infection associated with diabetes), and a fear of falling.

### **Betty**

Another female participant, Betty, was a 39-year old female living in a group home with a roommate at the time of the study. She had the co-morbid illnesses of hypertension (HTN) and high cholesterol but was unable to state what the illnesses were. Her thoughts were disorganized but she was eager to talk about the topic of health. Despite being unable to name her medical illnesses she was able to state that her medications were for her "health." Betty reported that she took all of her daily medical and psychiatric medications as prescribed. She used a list of medications that she kept in her purse to prompt her in naming her medications. The medications that she took suggested that she was being treated for high cholesterol (atorvastatin), HTN (propranolol), psychosis (ziprasidone), and depression (trazodone and duloxetine). Betty never married and had no children.

Her primary source of emotional support included peers and staff at the psychiatric day treatment program that she attended at least five days per week. She was on disability and unemployed. Betty used changes in her weight as a gauge as to whether she was healthy and indicated that she tries to lose weight through exercise and "eating the right foods." She reported that the things that help facilitate her health were taking her medications at the same time daily and having them with her wherever she goes, weighing herself regularly, and de-stressing by "having fun or relaxing at home."

Betty stated that the main difficulty with trying to be healthy was lack of consistent transportation to get to doctor's appointments. She also explained that when she does not understand medication instructions given by her doctor or nurse she has difficulty taking her medications correctly. Betty considered the ability to work as a sign of being healthy and emphasized that her symptoms of schizophrenia have negatively

affected her ability to maintain employment. Because of Betty's thought disorganization and short answers to interview questions, interview probes and sub-questions were incorporated into subsequent participant interviews (Appendix D).

### **Cathy**

Characteristics of a third female participant differed from others. Cathy was a 36-year-old female who lived in an apartment with her husband whom she had met at a psychiatric day treatment program. She was one of the most articulate and well-informed participants regarding health behaviors. Cathy had the co-morbid illness type II DM. She smoked tobacco daily. Cathy reported that she took her daily medical and psychiatric medications as prescribed and was able to state the medication names. Due to moderate thought disorganization, she had difficulty spelling the names of her medications and filling out some answers on the demographic form without assistance from the principal investigator (PI). However, Cathy self-administered daily insulin injections and finger stick blood glucose monitoring each morning and night. She took the oral antipsychotic medications haloperidol and aripiprazole, the mood stabilizer divalproex sodium, and benztropine for the side effects caused by the antipsychotic medications. Cathy had no difficulty with medication adherence and stated that she knew it was because of recognizing that if she doesn't take her psychiatric medications "she gets real sick," and it results in psychiatric re-hospitalization. She was unemployed, on disability, and had two children.

When asked about her definition of what it is to be healthy, Cathy stated "just really taking care of yourself," indicating that taking personal responsibility was a key factor in achieving a healthy state. She was physically active and fit and described specific behaviors that she engaged in that helped her to be healthy. The primary health behaviors Cathy participated in were "eating the right foods, not too much grease or too much starch," Yoga exercises, walking with her husband, and meditation. She enjoyed participating in exercise classes provided by a physical trainer at the psychiatric day treatment program she attended. When the instructor was not available, she used exercise videos at home such as the "Jane Fonda tapes," and participated in deep breathing, and meditation that included visualization of relaxing places and listening to soft music. She

liked imagining that she was “in a field playing a piano and floating,” in order to relax or de-stress. Cathy adapted her dietary habits to eat proper portions of salads and fruit and fewer sweets based on health instructions from her doctor once she was diagnosed with type II DM. She recognized the connection between elevated blood glucose levels and improper diet and commented that “every time you eat the wrong things, your sugar goes up.” In addition, Cathy was motivated to eat a diabetic diet and continue exercising to avoid possible complications associated with diabetes, such as poor circulation, that could possibly lead to leg amputations, strokes, and feeling faint.

She stated that “feeling really great after a walk,” gave her the desire to walk again in the near future. Cathy felt the main barriers to her health included getting off track with her diet by eating fatty or greasy foods and that this led to weight gain, feeling lazy and unmotivated, and caused her to stop exercising. If she became unmotivated, she re-motivated herself to exercise and keep her weight within normal range by using promises to self and memories from her great grandmother telling her that she could do whatever she needed to do in life if she made up her mind. Cathy also felt that one should give a positive affirmation to self or “a pat on the back” for getting back on track with health behaviors. Typical of the affective flatness seen among many with schizophrenia, after the individual interview ended, she told me without an outward expression of sadness, that her brother had died from a heart attack that morning. I expressed my deep sympathy and she stated “I’m okay, I’m strong,” then asked for and received a supportive hug from me. She indicated that she would get the needed emotional support to cope with her brother’s death from her usual sources, her father and husband.

### **Dave**

One of the males who participated in the study was perhaps the most articulate of all in descriptions of health behavior decision-making processes and health behaviors. Dave was a 35-year-old single male, father of seven children, who lived with his parents. Dave no longer attended the psychiatric day treatment program associated with his mental health clinic because he felt that he was psychiatrically stable and only needed to check in with his psychiatrist periodically for medication refills. Dave graduated from high school and had some college credits in accounting and business courses. He



attempted to enter the military in his late twenties but was unable to because he began hearing voices and having loss of control of physical aggression two days prior to leaving for basic training. However, he stated that he was not diagnosed with schizophrenia until he was 31 years of age while in prison. Dave reported that he wound up in prison because of failure to pay child support after losing his warehouse job because of symptoms of psychosis. Over time, Dave developed a distrust of law enforcement officials as a result of being imprisoned when he was experiencing psychotic symptoms and a past experience of witnessing a man with psychotic symptoms die outside of a restaurant after being shocked excessively with a Taser gun used by police. He felt that “law enforcement officials did not have an adequate understanding of people with mental illnesses or proper training in how to approach individuals in the community with psychotic symptoms.”

Dave had a girlfriend at the time of the study: he said that “she is a good source of emotional support and encouragement” and that he enjoyed spending time with her. He was unemployed because he was told by potential employers that being on psychotropic medications could negatively affect his ability to remain alert on the job and that this was a liability. At the time of the interview, Dave was expecting to be granted disability due to his mental illness. He had a co-morbid medical problem of chronic back pain. Dave stated that he took his daily antipsychotic medication, Seroquel XR <sup>TM</sup>, as prescribed to reduce symptoms of paranoia and auditory hallucinations (hearing voices).

His definition of what it is to be healthy was “to maintain physical and mental stability.” His ability to articulate and explain his abstract thoughts led to the *in vivo* category of “tracking health behaviors results in the ability to maintain physical and mental health.” He stated that understanding the symptoms of his mental illness, having a daily regimen of “eating healthy, taking prescribed medications,” and making sure that his weight was within normal limits helped him achieve his health goal of “maintaining physical and mental stability.” Dave engaged in a variety of activities to achieve a healthy state and some of them included physical exercise to relieve stress when he was not experiencing back pain, use of reading or listening to music through his MP3 player headphones to “block out the voices,” and consistently having the support of trusted people in his life who understand his mental illness. He stated that “keeping a circle around me that’s real positive, really helps me if I lose focus or get frustrated” because of

being distracted by hearing voices or feeling paranoid. Dave was most appreciative of his sister, a nurse, who had been able to attend some of his mental clinic appointments to gain an in-depth understanding of his mental illness and recommended treatments. He stated that his sister was able to determine when he was experiencing symptoms of psychosis and had a unique ability to distract him by spending time with him or playing board games “long enough to alleviate the voices.” He used note taking as a reminder to assist him with staying on a daily schedule and to recall important health instructions from his clinicians when he felt he may be experiencing difficulty with short-term memory. Dave stated that the primary barrier to his health was break-through psychotic symptoms (hearing voices) despite adherence to treatment that interfered with his ability to have employment so that he could support his children, caused loss of sleep, and reduced his appetite. He said that once he had experienced significant sleep deprivation and weight loss he knew that he was not in an ideal state of health. When faced with health barriers, Dave used reaching out to others for needed support and prayer as a means of coping.

### **Earl**

The youngest participant was a 28-year-old single male who lived alone in an apartment. Earl said that when he was first diagnosed with schizophrenia, around 18 to 19 years of age, that “he felt miserable and just wanted people to leave him alone.” He stated that he felt socially awkward because one of his symptoms of schizophrenia was the inability to have appropriate facial expressions and this resulted in avoidance of others. Consequently, his psychiatrist taught him to practice smiling while looking in the mirror so that he could incorporate this expression appropriately when in social settings. He was not in a relationship with a significant other and did not have children. His mother and sister were the primary people in his life who provided him with emotional support and encouragement. When compared to descriptions of other participants, Earl expressed the most disillusionment with having the diagnosis of schizophrenia due to the symptoms occurring “in the prime of his life.” He stated that he felt as though he had “graduated” from a psychiatric day treatment program that he previously attended three to five days per week but no longer attended. Other than being mildly overweight, he was healthy

physically. Earl stated that he took his daily psychiatric medications as prescribed and was able to name the medications correctly. He took the antipsychotic medication paliperidone and the antidepressant paroxetine. Earl was unemployed and disabled. He completed ninth grade and reported obtaining a high school equivalent degree (GED) a few years ago.

When asked about how he decided to be healthy he stated that he would “think and plan throughout the week about things he could do to be healthier” but that he experienced particular difficulty staying on track with a healthy diet because he was tempted to purchase snack foods when he went grocery shopping. He stated that he struggled with healthy eating the most when he was feeling unmotivated and recognized that this led to eating convenient snack foods instead of cooking healthy foods and resulted in weight gain. Earl stated that having a “good body weight” was the main signal that let him know that he was healthy. He recognized that regular exercise was the most effective way to lose weight but that his ability to exercise was hampered in winter months because of cold weather which prevented him from walking outdoors and at other times due to long bus commutes just to get to a gym a few miles away. When asked what health advice he would give someone who was newly diagnosed with schizophrenia he stated that he would tell them to “get hobbies” or find a distraction to reduce negative thoughts and would recommend at least 30 minutes of daily exercise to reduce stress and improve energy levels. He stated that he used these same behaviors to improve his health and reduce stress. Earl was most animated when talking about his hobby of playing guitar and added that he was currently trying to learn how to play some Jimmy Hendrix tunes.

He reported frequent difficulties with short-term memory, concentration, and verbal and/or emotional expression of his thoughts. Earl emphasized that getting adequate sleep and exercise improved his cognitive abilities and, like other participants, he was able to compensate for these cognitive deficits by keeping the same daily schedules or routines and by using a pill organizer to assist to help him to remember to take his medications. One of his most intriguing adaptive behaviors was the use of texting to communicate with others and aid him in emotional expression; “it’s easier to text than to say to my mother how I’m doing right now or to tell her I love her and I attach a smiley face.”

## **Frank**

Frank was a 59-year-old partnered male who lived at home with his parents. He completed twelfth grade, was unemployed and disabled. Frank attended a psychiatric day treatment program once per week. He did not have children. He had a moderate amount of thought disorganization and had occasional difficulty spelling on the demographic form which prompted intermittent assistance from me. Frank had co-morbid illnesses including type II DM, HTN, and high cholesterol. He reported that he took his daily medical and psychiatric medications as prescribed and self-administered daily finger stick blood glucose monitoring. Frank was unable to recall the names of his medical medications despite being able to state his medical diagnoses. He said that he took the antipsychotic medication aripiprazole. He stated that he did not have any difficulty adhering to any of his medications and used a pill organizer to help him remember to take them. Despite Frank's thought disorganization and short answers to questions, he was able to provide valuable insights regarding what constitutes a healthy diet including the importance of eating proper portions, adhering to a diabetic diet, and avoidance of poor food choices such as greasy and processed foods. He recognized that if he ate the wrong foods that his blood pressure and glucose levels would become elevated and that this could lead to a heart attack or stroke. Even though he recognized the health benefits of exercise, he stated that he struggled with lack of motivation to engage in it because it bored him and therefore, he felt it wasn't worth doing. When emotionally upset he de-stressed by doing yard work or household chores and talking or praying with his girlfriend or neighbors. Frank also stated that he felt healthier when he reads on the computer and that this helped "sharpen his mind."

At times, Frank stated that he experienced paranoid delusions that the devil was trying to control his head or tell him what to do. He felt that his mother, girlfriend, and neighbors provided him with emotional support and encouragement when he wasn't feeling good or was experiencing paranoia. He was noted to be somewhat hyper-religious and said a quick prayer for me after the individual interview ended.

## Gail

Interestingly, one of the female participants had participated in a research study conducted by a nurse in the past; she stated that she liked being able to contribute information that would be helpful to others. Gail was a 57-year-old divorced female who was disabled and lived alone in an apartment. She completed a Master of Arts degree in education and taught school in special education for several years prior to becoming disabled. Gail stated that she had two children and that she was diagnosed with schizophrenia following the birth of her second child at 29 years of age. She was articulate and had well-organized thoughts and verbal communication. Gail was able to name her co-morbid illnesses and they were HTN, high cholesterol, overactive bladder, and an unspecified skin problem. She stated that she took all of her daily medical and psychiatric medications as prescribed and was able to correctly name them and dosages. Gail took atenolol and triamterene/hydrochlorothiazide for HTN, rosuvastatin for high cholesterol, and solifenacin and trimethoprim/sulfamethoxazole for her bladder disease. She took the antipsychotic medications Invega Sustenna™ (a once per month intramuscular injection) and perphenazine, and diphenhydramine for side effects from the antipsychotic medications.

Gail participated in a psychiatric day treatment program two to four times per week. She described the importance of taking personal responsibility for achieving a healthy state and said that in order to be healthy that one needs to eat a balanced diet, maintain an ideal body weight, take all medications as prescribed, and exercise regularly. Gail felt that a significant barrier to her health was lack of transportation to attend exercise programs. She had been regularly attending a water aerobics and chair exercise class until her sister could no longer provide her with a ride; “I was doing exercise about four days a week and now I don’t do anything; I’m so mad at myself.” Gail also described a pressure feeling in her head that caused her to stop exercising at times and attributed this to being a symptom of schizophrenia; “it feels like a ton of bricks on my head, makes me immovable, and causes me to just sit and stare.”

When asked what helped her get back on track after experiencing the pressure feeling in her head she stated that most of the time she was able to “pep herself up,” by

using mind over matter and that it was also helpful if people believed her when she told them she was experiencing psychotic symptoms. She also felt frustrated when her mental health clinicians did not listen to her. Gail cited one example of a nurse who administered her antipsychotic medication injection not taking her seriously when she told the nurse the injection site was sore and the nurse kept giving the shot in the same location. Another health barrier that greatly concerned Gail was weight gain associated with her psychiatric medications.

Gail was sensitive to the stigma of mental illness and paid close attention to the way people looked at or reacted to her in public. She said that if she perceived that others have decided that she is mentally ill, she tried to mimic past behaviors of being more “gregarious” so that she seemed more socially appropriate. Gail stated that she usually doesn’t have difficulty with engaging in healthy behaviors such as eating a balanced diet, taking medications, and exercising, but that what is missing from feeling an ideal state of health is a sense of emotional connection and community since her parents died a few years ago; “I used to enjoy getting together with my family for dinners, it’s different now and it makes me sad.” She also indicated that she had stopped communicating with several close friends over the last few years and attributed this to having symptoms of schizophrenia. When asked what health advice she would give to someone who was recently diagnosed with schizophrenia she stated that she would tell them “not to isolate yourself from society or your family” and “don’t skip your medicine.”

## **Henry**

Although Henry exhibited the characteristic symptoms of paucity of speech and disorganized thoughts associated with schizophrenia, he contributed to study content and themes. Henry was 45-year-old single male who lived in a boarding home with a roommate. He completed ninth grade, was unemployed and disabled due to his mental illness. Henry did not have children. He had poor personal hygiene and cleanliness and his clothing was soiled. Sadly, these characteristics are not always uncommon among members of this vulnerable population who often have lack of access to assistance in daily care skills. Regardless, Henry offered some useful information regarding his definition of what it is to be healthy. He stated that in order to be healthy one should “eat

the right foods, take medicine and vitamins, and exercise.” He stated that when he was 11 years of age he was struck by a vehicle when crossing the street and that this collision caused severe injuries to his legs. Henry was able to participate in physical rehabilitation and this left an impression on him about the importance of using regular exercise, primarily walking, to build and maintain muscle strength in his legs. He stated that his ability to walk for exercise had been reduced recently due to years of smoking cigarettes, but that he was able to perform some calisthenics while watching exercise programs on television. Henry stated that he did not have any current difficulty with adherence to his antipsychotic medication, Risperdal Consta™ bi-weekly intramuscular injections. Despite adherence to his antipsychotic medication, Henry appeared to have residual psychotic symptoms. For example, as I arrived at the clinic for his second interview, he was in the parking lot yelling loudly and angrily pointing his index finger into the air, which is a sign that he was responding to internal stimuli or hallucinating.

### **Ida**

Ida was a 34-year-old single female who lived alone in an apartment. She completed eighth grade. Ida had the comorbid illness of HTN and she smoked tobacco daily. She was well-groomed and articulate. She stated that she took her medical and psychiatric medications as prescribed, and took hydrochlorothiazide for HTN, and the antipsychotic medication olanzapine for symptoms of psychosis (hearing voices). Ida did express concern that taking antipsychotic medications for a long period could lead to medical problems or that she may develop unwanted side effects.

Ida emphasized that her general definition of being healthy was “being able to function in everyday life.” She stated that she decides to be healthy by planning ahead and is able to tell that she is functioning well if she is able to adhere to a daily schedule of keeping good personal hygiene, eating a balanced diet, follow through with daily plans, and is able to distract herself when hearing voices. Ida said that when she hears voices “it throws her completely off track” from being able to complete her daily routines. She was able to get back on track with her routines by getting back into exercise via walking and going for a massage to release tension. Typical daily plans for Ida included keeping a daily planner, taking medications, eating a healthy diet, communicating with supportive

people (friends, family, and church members), keeping appointments, and de-stressing by having daily prayer or meditation. Ida also felt that being in frequent contact with her therapist, doctor, and psychiatric support group members facilitated her health. She stated that if she allows herself to become unorganized that she “feels out of her zone” and that this causes her to feel unhealthy.”

When first diagnosed with schizophrenia, Ida was unable to accept the diagnosis of schizophrenia for “a long time” because of the associated social stigma. She was very concerned, that when her children become older and learn of her diagnosis of schizophrenia, they would be less accepting of her or that people would tell them “your mom is crazy.” She stated that having the diagnosis of schizophrenia caused rejection by some family members and others “who I thought loved me.”

When asked what health advice she would give to someone newly diagnosed with schizophrenia, she stated that she would tell them to “take one day at a time, pray, and talk with people who have had schizophrenia for a while for support.” She emphasized the health benefits and importance of individuals with schizophrenia providing emotional support and encouragement to each other. Ida was hopeful that she would recover from the symptoms of schizophrenia because of the support she received from peers, some family members, friends, and clinicians.

## **James**

James was a 55-year-old divorced male who lived alone in an apartment. He completed tenth grade and was the father of three children. James was physically healthy except for receiving the recent diagnosis of prostate cancer. He was able to correctly name his antipsychotic medication, quetiapine, but was unable to recall the dosage. James stated that he did not have any difficulty with taking his medication as prescribed but that he was not consistent with keeping his mental health clinic appointments. He provided short answers to most questions and was somewhat hyper-religious. James was wearing a large cross necklace during the individual interview and tended to state that the answer to being healthy was getting closer to God or prayer in several portions of the interview. James’ religious beliefs seemed to provide a daily structure that kept him from “hanging



around the wrong people,” drinking alcohol or using drugs, or from engaging in antisocial behaviors such as extorting money from others.

When asked what it is to be healthy he stated it was being free of pain but did not describe what type of pain. He stated that he knew he was healthy if he was “thinking better, not hallucinating that much.” James indicated that even when he is feeling healthy that he still struggles with paranoia. He was able to outline his daily health routine that included meditating and praying upon awakening, reading the Bible, taking medication, doing calisthenics, and reducing stress by “avoiding people who don’t have his best interest in mind.” James stated he “gets off balance” with his health when he feels stressed, doesn’t eat the right diet, and when he allows himself to “think about doing things I know is wrong,” such as trying to illegally get money from people or fighting. He stated that when he gets “off balance” that he stops caring for himself, eating (due to fear his food has been poisoned), and bathing, and loses his spiritual awareness. James emphasized that being able to see his grandchildren and keeping his independent living arrangements were the primary motivators to psychiatric treatment adherence.

### **Summary**

The participants of this study were adults diagnosed with schizophrenia who were willing to describe how they defined health and made health behavior decisions. These two qualities fulfilled criterion sampling in qualitative descriptive research. All participants were unemployed and disabled because of the symptoms of schizophrenia. Males and females were equally represented. There was an unintentional lack of racial and ethnic diversity due to all participants being African-American. In addition, participants had varying levels of education, types of living arrangements, and social support networks, and they provided rich and meaningful descriptions of their decision-making processes regarding health behaviors that developed over time. The descriptions of their narratives regarding what it means to be healthy, the cognitive processes used when making health behavior decisions, and the barriers and facilitators to being healthy will be discussed in Chapter Five (Findings).

Table 4.1 Select Demographic Descriptions of Participants

Participant pseudonym	Age	Gender	Marital status	Living arrangement	Number of children
Ann	56	Female	Single <sup>a</sup>	Rental house with parents	> 6
Betty	39	Female	Single <sup>a</sup>	Group home with roommate	None
Cathy	36	Female	Married	Apartment with husband	2
Dave	35	Male	Single <sup>a</sup>	House with parents	> 6
Earl	28	Male	Single <sup>a</sup>	Apartment alone	None
Frank	59	Male	Partnered	House with parents	None
Gail	57	Female	Divorced	Apartment alone	2
Henry	45	Male	Single <sup>a</sup>	Group home with roommate	None
Ida	34	Female	Single <sup>a</sup>	Apartment alone	> 6
James	55	Male	Divorced	Apartment alone	1

<sup>a</sup>Single: never married

Table 4.2 Summary of Demographic Characteristics

Characteristic	<i>N</i>	%
<b>Gender</b>		
Male	5	50
Female	5	50
<b>Ethnicity</b>		
African-American	10	100
<b>Marital status</b>		
Married	1	10
Single	6	60
Divorced	2	20
Partnered	1	10
<b>Lives with</b>		
Marital spouse	1	10
Roommate	2	20
Alone	4	40
Parents	3	30
<b>Employment</b>		
Unemployed	10	100
<b>Number of children</b>		
None	4	40
Two	2	20
Three	1	10
Greater than six	3	30
<b>Disability status</b>		
Disabled	10	100

Table 4.3 Select Medical Demographics of Participants

Participant pseudonym	Medical illnesses	Medical medications	Smokes tobacco	Current alcohol use	Current illicit drug use
Ann	emphysema type II DM obese	insulin	Yes	No	No
Betty	HTN obese high cholesterol	atorvastatin propranolol	No	No	No
Cathy	type II DM	insulin “diabetic pills”	Yes	No	No
Dave	“bad back”	None	No	No	No
Earl	None	None	No	No	No
Frank	type II DM, HTN high cholesterol	“sugar pill” “blood pressure pill” “cholesterol pill”	No	No	No
Gail	HTN high cholesterol overactive bladder unspecified skin problem mildly obese	atenolol triamterene/hydrochlorot hiazide rosuvastatin solifenacin trimethoprim/sulfametho xazole	No	No	No
Henry	None	None	Yes	No	No
Ida	HTN	hydrochlorothiazide	Yes	No	No
James	prostate cancer	None	No	No	No

Table 4.4 Current Psychiatric Medications of Participants

Participant pseudonym	Psychiatric medication/s
Ann	“an antipsychotic” trihexyphenidyl divalproex sodium
Betty	trazodone duloxetine ziprasidone
Cathy	haloperidol aripiprazole divalproex sodium benztropine
Dave	Seroquel XR <sup>TM</sup>
Earl	paliperidone paroxetine
Frank	aripiprazole
Gail	Invega Sustenna <sup>TM</sup>
Henry	Risperdal Consta <sup>TM</sup>
Ida	olanzapine
James	quetiapine

## CHAPTER FIVE

### Findings

The process of collecting data included audio-taped individual interviews, field notes, and coding. When these sources of information were combined, three categories emerged that described the phases of health behavior decision-making. A final category was developed as a means of encompassing the three interconnected descriptive categories about the phases of health behavior decision-making. Collectively the descriptive themes depicted how participants were able to make active, comprehensive health behavior decisions by systematically “tracking” or monitoring their daily health behaviors. This chapter describes the three phases, the subcategories, and a final central category about health behavior decision-making.

#### **Overview of the Model of Three Phases of Health Behavior Decision-Making**

Three phases of health behavior decision-making emerged that from the individual interviews were: Recognizing Complex Components of Health, Personalizing Components of Health, and Tracking Health Status. The central category that encompasses the three interconnected phases of health behavior decision-making- Tracking Health Behaviors results in the Ability to Maintain Physical and Mental Health, The model, depicted in Figure 5.1, illustrates the three dynamic phases of health behavior decision-making, eight subcategories with specific actions associated with achieving and maintaining physical and mental health, and shows the central category.

#### **Three Phases of Health Behavior Decision-Making**

##### **Recognizing Complex Components of Health**

The first phase of health behavior decision-making is- Recognizing Complex Components of Health. Recognizing Complex Components of Health involved an intellectual awareness or recognition of the intricate components of health and included the elements of body, mind, and spirit. Participants stated that throughout their lives, they gained knowledge about what constitutes a healthy state through a variety of sources of

information including advice from healthcare providers, peer discussions, and health media (graphs, posters, books, magazines, and television).

### ***Body***

Participants identified several factors that affected or determined whether their body was healthy. Factors were:

- maintaining a normal body weight;
- maintaining healthy body systems: heart, lungs and extremities;
- maintaining normal blood glucose levels, blood pressure, and pulse rate;
- getting regular exercise;
- eating healthy foods;
- taking vitamins;
- taking prescribed medications;
- maintaining good personal hygiene;
- getting adequate sleep; and
- reducing emotional stress or de-stressing.

### ***Mind***

Having a healthy mind was generally described as having a “peace of mind,” and was achieved by various methods of stress reduction/de-stressing that included

- taking psychiatric medications;
- listening to soothing music (classical or “soft”);
- keeping a schedule or routine (compensated for poor memory and provided a feeling of structure and self-control);
- having a social support network (reduced fear of stigma, enhanced feelings of acceptance and encouragement);

- maintaining adequate sleep (improved cognitive functioning);
- participating in relaxation exercises (visual imagery, deep breathing, meditation, massage, Yoga, calisthenics, and aerobic exercise);
- having fun with friends or family (playing board games); and
- using distractions or hobbies (playing a musical instrument or listening to music via headphones to “block voices”).

### *Spirit*

Having a healthy spirit was described as a way to have hope or internal strength. Participants indicated they maintained a healthy spirit by:

- praying;
- meditating;
- singing (in church choir);
- reading the Bible; and
- exercising

James said that when he exercised he was “feeling closer to God”. Although, two participants had delusions or false beliefs that evil forces were controlling their minds, the majority of them described common spiritual practices that were reality based or non-delusional.

### **Personalizing Components of Health**

The second phase of health behavior decision-making, Personalizing Components of Health, involved a sense of ownership or responsibility for one’s health status. There were four subcategories that affected health behavior decision-making in the second phase: Recognizing barriers, Recognizing facilitators, Recognizing strategies for staying on track, and Recognizing that participation in healthy behaviors results in maintaining a balance of physical and mental health.



## ***Recognizing Barriers***

Participants identified several obstacles and circumstances that interfered with being healthy. These barriers were divided into four areas: (a) physical, (b) psychiatric, (c) social, and (d) environmental.

***Physical barriers.*** The most often cited physical barriers included being under or overweight, side effects of psychiatric medications, and symptoms from medical co-morbidities. Other significant physical barriers were pain, sleep deprivation, and eating a poor diet. A few participants stated that negative effects of tobacco, alcohol, or illicit drugs interfered with their physical health.

Henry said that smoking cigarettes reduced his ability to exercise. When asked what got in the way of being healthy, he emphasized the negative impact of smoking by stating, “Do not smoke cigarettes!” Similarly, Ann discussed smoking. She said she smoked tobacco daily and was diagnosed with emphysema and diabetes. As a result, Ann experienced the most difficulty from medical co-morbidities. When asked what difficulties she had with trying to be healthy, Ann stated that it was hard to breathe due to the symptoms of emphysema associated with smoking tobacco daily. She also commented about her weight: “I have an overweight problem and my arms are heavy and my knees are too heavy, so that’s my main problem.” Ann elaborated that not only does her shortness of breath reduce her ability to exercise, but that because of seemingly simple complications of diabetes she also avoids exercise: “I have to wait on the doctor to trim my toenails, so when they get long it causes me to feel like I might lose my balance and fall.”

Betty and several other participants stated that the side effect of drowsiness from the psychiatric medications kept them from exercising on a regular basis at times. Betty mentioned an additional barrier to exercise was “it makes you real sore when you get finished exercising. Makes you real [*sic*] sore...and sometimes you might not wanna [*sic*] do it on every single day.” Dave experienced back pain from an old injury that sometimes interfered with his ability to engage in daily calisthenics. When asked what things got in the way of his being healthy, James stated:

I'm off balance (with physical and mental health) I stop doing a little bit of everything. I stop taking care of myself. I stop eating. I stop bathing. I stop having my spiritual awareness...I'm thinking about doing things that I know is wrong...like I would go in the parking lot and I would charge people to park there...and start hanging around the wrong people and I start drinking (alcohol) and stuff like that.

Cathy linked eating a poor diet to lower motivation to exercise. When asked what got in the way of exercising Cathy stated: "Uh, basically not eating the right food. Cuz [sic] at first, I was eating fried food with lots of grease, and they say that a lot of fat and grease is not good for you, it clogs your arteries up." An indication that erratic eating patterns was a barrier to exercise was highlighted by Ann following being asked what she could do if she found it difficult to exercise. Ann stated:

Uh, cut out certain foods because sometimes, like one week I'll be a heavy eater, no matter what's there. A week or two later, I might go light, you know soup and sandwich [sic] for like the first part of the week, then the last part, I'll eat nothing but fish.

Two participants received antipsychotic medication by intramuscular injection and this generally helped with medication adherence, but Gail experienced physical pain from receiving injections and at times this caused her to want to avoid taking her psychiatric medication despite its efficacy: "I have a knot on my arm and it hurts where I got the injection and I'm... I'm concerned about that. I'm getting fed up with it." Psychiatric medication side effects or inefficacy caused several participants to have difficulty with motivation to remain medication adherent. Betty stated "sometimes my medicine can get [sic] me drowsy," but she recognized that she should take them despite the side effects in order to avoid re-hospitalization. Other participants struggled more with medication inefficacy; they not only experienced drowsiness as a side effect but continued to have auditory hallucinations (voices). Ida described how this phenomenon caused her to feel:

I'm really, really upset, I get upset and I'm just feeling the medication, but not, it's not taking away nothing [sic], but I can feel the...like if I take it, I can feel the effect...I'm having the side effects that it say [sic] I have but then I can also feel the medication kicking in to where my body starts reacting off of it, but I'm dealing with the voices. Then I don't want to take it (medication).

The effects of sleep deprivation caused several participants to experience a worsening of psychiatric symptoms and Dave described this concisely:

Uh just the voices and then by me [sic] getting frustrated when the voices are not going away; that it causes me to have lack of sleep, and uh, a lack of appetite. If I ain't [sic] gettin' the proper rest, then my appetite's not good and if I ain't [sic] got no [sic] appetite, then I'm losin' [sic] weight. Then everything intensifies as far as the voices.

Similarly, Ida commented that when she felt rested that she awakened "feeling good," but when tired she felt unhealthy: "I don't wake up feeling good. I don't want to do nothing [sic]. I'm just real upset. I don't eat. I don't want to go nowhere [sic], don't want to be around nobody [sic]."

**Psychiatric barriers.** Most participants described experiencing the psychiatric barriers of emotional stress, feelings of hopelessness, difficulty with communication, poor memory/cognitive function, lack of motivation, and auditory hallucinations or paranoid delusions. Earl gave a precise summary of how cognitive deficits, lack of motivation, and treatment side effects associated with schizophrenia can lead to an inability to participate in health promoting behaviors:

I just wasn't motivated to do anything anymore and I don't remember everything but I remember I just used to lay in bed and eat and I just got bigger and bigger. First, they said I wasn't eating enough so they got these vanilla shakes and chocolate shakes and I kept eatin' [sic] them, I mean drinkin' [sic] them and I think the medicine I was on, Abilify, the kind that makes you gain weight, so I gained a lot of weight and I wasn't getting no [sic] exercise like I was when I was just a kid running around.

Earl articulated that when he was initially diagnosed with schizophrenia, at about 18 or 19 years of age, that he recalled feeling "miserable," was socially isolated, and had significant memory deficits:

I was just wantin' [sic] everybody to leave me alone even when nobody's bothering me, wantin' [sic] to do stuff but I know I don't know how, forgettin' [sic] how to do...conversatin' [sic] with people like I did when I was probably a year or two younger and just forgettin' [sic] all of the stuff that I knew how to do that was easy.

Furthermore, Earl was aware that part of the symptomatology of schizophrenia that he experienced affected his ability to have appropriate facial expressions and this contributed to his urge to socially isolate:

I might um, go like that (he demonstrated a blank stare) or have a blank stare or something. Just try to smile. And I don't um, say anything inappropriate; I guess...yes, practice smiling into the mirror because with some people it's easier, but for me it's kind of difficult.

When asked what made him decided not to take actions that would help toward being healthy, Dave stated that interference was “primarily the voices.” Gail emphasized that a pressure feeling in her head caused her to stop exercising at times and attributed this to being a symptom of schizophrenia; “it feels like a ton of bricks on my head, makes me immovable, and causes me to just sit and stare...that's my biggest obstacle.” Like many other participants, Frank stated that lack of motivation interfered with his ability to exercise at times: “Sometimes I don't wanna [sic] do nothin' [sic] but just sit around and lay, look at T.V.”

**Social barriers.** Social barriers included the stigma of having a mental illness and subsequent feelings of isolation and rejection by others. For example, Ida stated that she was concerned that she may have to take her psychiatric medications long-term despite the fact that they were not fully effective. She feared the day when her children would become aware that she was taking a medication for schizophrenia:

I have growing children, you know, and whenever they start being able to be amongst [sic] everybody else, and start, you know, having these thoughts and hearing about different medications and mental illnesses...I don't want nothing [sic] to change...which I don't kind of feel like it will if I'm teaching them right, but I don't want them to get this idea like my mom is crazy or somebody else can tell them that and they have a reaction or something like that.

All participants were unemployed and considered disabled, but Betty and Dave were the only participants who stated that having the side effect of drowsiness from medications taken for schizophrenia precluded them from being able to maintain employment. Dave did not think that his current symptoms of schizophrenia would interfere with his ability to work. However, prior to receiving treatment for schizophrenia

he was having difficulty adequately functioning on the job because of feeling “extremely paranoid.” During that time he was also physically unhealthy:

I had dramatic weight loss, had problems associating with people, as far as, I was working and then trying to work and then the voices kickin' [sic] in, and I ain't [sic] know it, it was really affecting me, cause' I ain't [sic] want people to look at me the wrong way but I ain't [sic] wanna lash out because they understand what was goin' [sic] on. That was real stressful because if a person understands your illness, they'll understand exactly what you're goin' [sic] through.

**Environmental barriers.** Environmental barriers included lack of or cumbersome transportation services and inclement weather. Earl articulated that long bus commutes reduced his motivation to exercise:

I got [sic] a thing to the gym, the Y (YMCA) but I don't, I have to talk to my mom to see if she paid it, but it's so far out. Sometimes it takes like an hour to get there. Then I work out for 30 minutes or an hour. Then I get on the bus and it takes me about an hour to get back home.

In addition, Earl stated that his exercise routine included walking in his neighborhood and “was easier in the summer” but that recent cold weather interfered. Gail stated that not having her own vehicle was a major barrier to exercise: “I was taking water aerobics this summer but my sister couldn't go anymore, so she was driving, so I had to stop- Lack of transportation puts me in a bind.” Betty agreed that one of her greatest barriers to health was not having consistent transportation and that this interfered because it caused “having difficulty getting to the doctor.”

### **Recognizing Facilitators**

Participants described a variety of supports and behaviors that enhanced their health. These facilitators were divided into five areas: (a) physical, (b) psychiatric, (c) social, (d) environmental, and (e) personal.

**Physical facilitators.** Physical facilitators included maintenance of ideal body weight, eating a healthy diet, good personal hygiene, and regular physical exercise. Four participants specifically stated that having an ideal body weight was the primary measure they used to determine whether they were physically healthy and that they weighed regularly. The majority of participants named several types of foods commonly

considered to be healthy and commented that if they incorporated them into their diet it would lead to being healthy. One participant, Ann, stated that she decided to be healthy by including a daily routine and that an important part of this regimen was to have good personal hygiene: “I wash up. Put on clean clothes. Uh, try to be um, as neat as possible. I try to keep the outfit as good as I can. I don’t want to look too tacky. That’s it.” All but one participant described the important contribution of daily exercise to their physical and mental health.

Ida stated that regular exercise was a key facilitator to her health:

If I don’t exercise I can act out. If I don’t do my exercise daily, or you know, if I get too caught up in not doing it, I can suddenly start fading away from other things that will help me be healthy.

**Psychiatric facilitators.** Psychiatric facilitators included getting adequate sleep, de-stressing, and adherence to psychiatric medications to reduce or prevent symptoms of psychosis. Earl stated that he knows that he’s healthy when he gets adequate sleep:

If I can get enough sleep, I can think clearer. I’m more, I can focus more and I can concentrate good. And um, I just don’t get caught in thinking in my mind, like my mom says and think outside that and be [*sic*] lively, and um, carry myself so I’m not offending anyone or something like that...

The majority of participants stated that they de-stressed with various forms of relaxation and that this reduced the frequency and intensity of psychiatric symptoms. Cathy stated that she experienced lasting positive effects following Yoga, deep breathing, and visual imagery exercises led by an exercise instructor at her day program:

Well, it actually made me start going home, just turn the TV off, the radio off, and basically just sit back and relax, listen to some soft music if I wanted to, to turn the radio on, it’s soft music.

Likewise, Earl used soothing music to reduce the intensity of negative thoughts and aid relaxation:

I listen to um, like um, orchestra music or something, something that’s not...I like listening to rock n’ roll, but it always gets me in a um, it doesn’t make me angry or anything, but I just listen to it and say the words and release that way [*sic*].

Dave agreed that music helps reduce his psychiatric symptoms:

I just try to uh, alleviate the voices and maybe listen to a CD player or iPod just to listen to music to block out, because the only thing about havin' [sic] this disorder is it's an unpredictable disorder; if you're naturally aggressive and you don't have an understanding of what's goin' [sic] on, it can turn real turbulent before you know it. Then, you can wind up in a whole lot of serious trouble and the legal system don't understand that.

All participants stated that they had no difficulty with adherence to psychiatric medications and that it was an important part of maintaining their daily health.

**Social facilitators.** Having an adequate support network (family, friends, neighbors, support groups, clinicians, and church members), and communication with others were among the most mentioned facilitators to health. Earl stated that when he was first involved in group therapy he refused to participate, but that he felt that he “had to do something to get his life back,” However, by continuing to go to the groups he eventually realized that his peers and the group leader were “nice and I started to like it there,” and this made him feel accepted. Furthermore, Earl specifically benefitted by his peers' use of humor: “some of the stuff they said was funny...sometimes they'd say stuff just to say stuff, tell jokes. It made me laugh. Even though I wasn't laughing out loud, it made me feel good and motivated me to do something.” Dave stated that: “if it weren't for the medications and luckily, God done [sic] blessed me with lovely people here at Seven Counties (mental health clinic) I really don't know what would go on.” Frank found his girlfriend and neighbors to be sources of support if he was struggling with feeling emotionally upset: “I like my people; they alright [sic]. We sit down and talk; talk it over, talk on the phone, you know, pray with one another.” Earl struggled with verbalizing his feelings most of the time but interestingly, enhanced his communication, especially with his mother, by using cell phone texting:

It's easier to text than say it...I just say it and put in the letters in different ways or something like that and put a picture attached to it, like a smiley face is easier than trying to write out words.

**Environmental facilitators.** Environmental facilitators included maintaining a daily schedule/routine, and external reminders (use of pill organizers, educational media, and reminders from clinicians, family, or friends). The majority of participants used a daily routine to assure participation in healthy behaviors. For example, Betty stated that

in order to have a sense of stability it was necessary for her to adhere to a daily health routine: “I get up, eat breakfast, lunch, and dinner. I try to exercise if my back will allow me to and just read just to take away the voices I be [sic] hearing, to make me stay stable.” Similarly, when Cathy was asked how she knew that she was healthy she described that her ability to engage in a daily routine assured her that she was in a healthy state: “well, I walk every day. I eat healthy food, like salad, fruit. I drink plenty of water, and sometimes me [sic] and my husband go for a 20 mile walk.”

**Personal facilitators.** Personal facilitators included use of internal motivation to take responsibility for setting and adhering to realistic health goals. Cathy stated that she was able to achieve this by making a promise to self or “sticking to my guns.” Dave was better able to adhere to health instructions given by healthcare professionals by following a daily to-do list:

What helps me out...I normally keep uh, notes of everything in case I happen to forget. My memory is pretty good but I normally would get up in the morning and write notes, medicines at such-and-such a time at night.

### ***Recognizing Strategies for Staying on Track***

Most participants developed health strategies to assure maintenance of social or family ties and avoid the reoccurrence of psychotic symptoms or medical complications from co-morbid illnesses. Two primary methods of remaining healthy included seeking guidance and setting goals.

**Guidance.** Guidance was sought from respected others such as healthcare professionals, crisis hotline operators, and friends or family members, when participants experienced a recurrence of psychotic symptoms, or were unclear on health instructions or found them difficult to follow. For example, Ida stated that part of her decision-making regarding maintenance of a healthy state included “speaking with people that keeps [sic] me on track like friends, family, and church members; they are very positive and encourage me.” Earl agreed that if something was making it difficult to remain healthy that he would:

Call up my mom, talk to her, um, have a conversation with my sisters or something and um, I know if I don't feel good, I don't know what the hotline



(phone number) is, but I could call this place and at one point it would turn in to a hotline where you could just conversate [*sic*] with somebody.

When unclear about medications or health instructions Betty indicated that: “I call my doctor, pharmacy, or the crisis line if I have questions.” Likewise, James stated that when he was uncertain about health instructions, “I just keep asking them (doctor or nurse) until they break it down in layman’s terms.” When asked what he would do if he found it difficult to take his psychiatric medication or if he was hearing voices (auditory hallucinations), Henry stated “I tell my social worker, he tell [*sic*] my nurse to give me a shot for it.”

**Goal setting.** Setting goals was used by participants to assist them with maintaining a sense of well-being and avoiding reoccurring psychiatric symptoms, medical complications, or losses. The process of setting personal health goals varied among participants but generally included self-motivation and planning ahead in terms of taking daily medications or treatments, exercise, and eating a balanced diet.

When questioned about how she defined health and accomplished daily health goals Ida stated: “I decide to be healthy by planning ahead and keeping...you know, staying away from things that will make me upset...keeping a planner, also taking my medications, eating healthy, speaking with people that keeps [*sic*] me on track and that’s it.” Cathy had a co-morbid diagnosis of diabetes which required being on a diabetic diet. She set her dietary goals based on advice from her doctor and fear of developing medical complications:

Well since I became a diabetic, my doctor told me that I couldn’t eat a lot of sweets...(because if does eat sweets) they may have to amputate my leg or I might have a stroke, get shaky, nervous, and I might faint.

Earl had the goal of keeping his weight within normal limits and used exercise to keep his weight down. He also used exercise to generate feelings of well-being: “If I exercise I feel more confident, like a more well-balanced person...I feel better about myself and I feel more alive, not sluggish and slow.” When asked what he thought would happen should he stop exercising, Earl stated “I would relapse with weight gain and would become depressed.”

Gail stated that “making decisions for yourself that affect you,” is the first step that must be taken when forming health goals. James indicated that he reaches his health goals by maintaining a daily regimen of health behaviors that includes meditation, prayer, reading the Bible, taking medications, exercising, eating good foods, and stress reduction. He stated that by keeping his daily health routines he is able to maintain his goal of “feeling balanced,” but that if stressed, he stops engaging in healthy behaviors and subsequently feels “off balance.” When asked what he could do if he found it difficult to maintain healthy behaviors such as taking his psychiatric medication, James stated that he would remind himself of past negative consequences such as winding up in “jail or homeless.” In addition, James kept his goal of adherence to psychiatric medications to prevent several potential losses: “I have an apartment now and I got [sic] things and I’m seeing my grandkids, so that keeps me in contact with taking my medicine.”

### ***Recognizing Healthy Behaviors and Balancing Physical and Mental Health***

Participants’ past physical and mental health treatment experiences aided them in acquiring health knowledge and resulted in the recognition that maintaining physical and mental health is mutually beneficial. Moreover, the majority of participants stated that they needed to motivate themselves to participate in daily health behaviors so that they could successfully achieve a balance of physical and mental health. Gail stated that she decided to take personal responsibility for being healthy “because no one else is going to take care of me, but me.” Cathy described her sense of personal responsibility for her health as “walking and eating the right food...and really just basically, really taking care of yourself [sic].” When asked to describe his definition of health, Dave stated: “my definition to be [sic] healthy is to maintain physical and mental stability,” indicating a sense of personal responsibility for his health outcomes. This *in vivo* quote resulted in the final category, Tracking Health Behaviors Results in the Ability to Maintain Physical and Mental Health.

Early in the course of illness with schizophrenia, the majority of participants learned that central to being able to maintain their mental health was adherence to psychiatric medications. Most participants stated that it only took one or two attempts of going without the psychiatric medications before they realized that this would have the

catastrophic effects of psychiatric re-hospitalization and the likelihood of loss of employment, independence, and relationships with friends and family. One participant, Earl, never tested going without his antipsychotic medication because of ongoing encouragement from his mother: “I never stopped taking the medicines...but if I did I would conversate [*sic*] with my mom and tell her exactly what was going on and she would motivate me to get back on it.”

Dave experienced imprisonment as a result of his initial symptoms of psychosis. He was working in a warehouse and began hearing voices (auditory hallucinations) telling him that people were talking about him while on the job. Dave continued to hear the voices for several days which caused him to be unable to sleep and ultimately he became verbally aggressive toward others at work and led to loss of employment. Following his job loss, he was imprisoned twice due to being unable to pay child support. While in prison, Dave was diagnosed with schizophrenia and began initial treatment with antipsychotic medication. After being on the antipsychotic medication for a while, he learned quickly that most of his symptoms of psychosis were alleviated. Dave was hopeful that since he became psychiatrically stable he would find employment again in the near future. Unfortunately, potential employers refused to hire Dave because of fear that the psychiatric medications he was taking could cause him to be unsteady around machinery and this posed a potential liability.

When I got out of prison, my whole plan was to go get help, but I got [*sic*] children. I got [*sic*] a whole bunch of children and child support wasn't really hearing me at that point so I had to work just to stay out (of prison) but, I couldn't take no [*sic*] medicine and be around machinery. So if I was to take my medicine, I couldn't work and I was back in prison. But once I was laid off that was the perfect opportunity for me to receive help and I took full advantage of it...Since I've been gettin' [*sic*] the medicine as of late it [voices and paranoia] hasn't really bothered me.

Despite the trauma of imprisonment and loss of employment, Dave was motivated to remain adherent to the antipsychotic medication in order to avoid additional losses such as the ability to be a good son, brother, and father to his children should he become psychiatrically ill again:

It's just knowing that the medication (psychiatric) is really a big key with me...cause [*sic*] since I've been taking the medicine, I can see my daily regiment

[sic] becoming continuous where I could stick to my daily goals but before, it was real difficult (when did not take medicines consistently). If I don't exercise and take my medications it would be my demise...just not bein' [sic] able to be the father I should towards my children, the son I should toward my parents, not bein' [sic] the brother I should toward my sister, or the friend I should towards my friends.

Most participants recognized that physical and mental health could be maintained by adhering to treatment recommendations, a healthy diet, and regular exercise. For example, when asked what she thought would happen if she followed general health instructions given by her doctor or nurse Ann stated: "I just turn out pretty healthy." In contrast, James described a more universal outcome: "I would be able to live a lifetime and be a productive citizen."

### **Tracking Health Status**

The third phase of health behavior decision-making, Tracking Health Status, occurred within the context of implementing daily health promoting behaviors. Once they were engaged in health promoting behaviors, participants recognized that they needed a systematic way of determining whether they were indeed healthy or were making good decisions regarding their health. This phase contained four subcategories: Daily health promoting behaviors, Getting off track, Getting back on track, and Staying on track.

### ***Daily Health Promoting Behaviors***

Participation in daily health promoting behaviors required personal responsibility, incorporation of facilitators to health, and avoidance of barriers. When asked what participants did on a daily basis to be healthy they all stated that they followed a daily routine that included taking care of personal hygiene, taking medications on the same schedule (usually timed around sleep-wake cycles or at meal times), some form of exercise, and de-stressing primarily by listening to music. Participants stated that eating a healthy diet, engaging in spiritual activities (reading the Bible, prayer, meditation, singing in choir at church), and getting support from others were also activities they engaged in to improve their overall daily health.

### ***Getting Off Track***

Several of the barriers to health caused the majority of participants to feel that they had been derailed or thrown off track from being able to maintain a healthy balance of physical and mental health. However, the barrier most often cited was symptoms of schizophrenia. When asked how the symptoms of schizophrenia affected his health Frank stated:

Well, I try to stay on the right track but sometimes when I wake up, I get all mental [*sic*] ill, you know, cause you're just wakin' [*sic*] up out of bed and you know, you don't like just rushin' [*sic*] right in to what you need to do.

Others stated that hearing voices interfered with their ability to concentrate, caused frustration or agitation, insomnia, lack of motivation, and an urge to isolate themselves. Many factors associated with having a mental illness disrupted participants' sense of balanced health; some included weight gain due to psychiatric medication side effects, fear that long term use of antipsychotic medication could cause medical co-morbidities, feeling stressed, and social stigma.

Other barriers that made it difficult to maintain healthy routines included symptoms from medical co-morbidities, lack of exercise (many participants stopped exercising when they gained weight or felt unmotivated), getting out of sync with daily routines (lack of structure), and transportation difficulties. Financial limitations associated with unemployment and disability status caused difficulty with purchasing enough food and providing for their families to the extent desired.

### ***Getting Back on Track***

Once participants detected that they were not on a healthy trajectory with the maintenance of physical and mental health, they recognized that the use of effective strategies would be needed to restore their health. They used several techniques to get back on track with their health habits, which included the prior successful behaviors of using internal and external motivation, de-stressing, getting back on a schedule/routine, and practicing spirituality.

Although the definition of motivation is beyond the scope of this study, it is useful to describe the general concept of motivation in terms of its influence on health behaviors. According to Huitt (2011), the general consensus among behavioral theorists is that, “motivation is an internal state or condition (sometimes described as a need, desire, or want) that serves to activate or energize behavior and give it direction.” In addition, Rakich, Longest, and O’Donovan (1977) stated that

The concept of motivation...is simple because the behavior of individuals is goal-directed and either externally or internally induced. It is complex because the mechanism which induces behavior consists of the individual’s needs, wants, and desires and these are shaped, affected, and satisfied in many different ways.  
(p. 262)

Participants in this study used both internal and external sources of motivation to return to previous successful health behaviors. For example, one participant, Cathy, was able to internally motivate herself to get back into healthy habits by recalling past encouragement from her deceased great-grandmother: “you know, if you want to do something in life, do it. Nobody can stop you.” Several participants were able to motivate themselves by making positive affirmations that they could get back into healthy routines. Another portrayal was when Frank stated that what helped him remember to exercise and take his medications was by simply to “just get up and do it,” and that if he found it difficult to maintain these habits that he knew “somebody else would remind me of it; if they’re around me, they’ll remind me to take it (medications),” particularly his mother. Cathy stated that self-monitoring of weight gain is the motivator that she uses to begin exercising again: “I just basically tell myself that I need to be more motivated. You understand what I’m saying? Basically just doing the right things to keep my weight down.” In addition, Cathy stated that: “a promise to myself” was all that was needed to adhere to her exercise goals. When experiencing re-occurring psychiatric symptoms described as “a pressure feeling in my head...that makes me unable to do anything,” Gail stated that she regains the ability to function again with a pep-talk; “I talk to myself. I talk myself into it, pep myself up and say ‘get up, get up, do this, do that,’” and that she has used the philosophy of “mind over matter for 25 years...and that most of the time it works.” Ida agreed with the concept of self-motivation and stated that she motivates herself to take her psychiatric medications so that she can hopefully avoid “long-term”

psychiatric illness: “I eventually motivate myself to go on and take it. I might wait for a while...an hour, two hours, three hours, but then I say, you know, I need to take it.”

External motivators were needed primarily to prompt medication and exercise adherence and many participants used reminders from others (usually family members or healthcare professionals), daily planners or to-do lists, and pill organizers as mechanisms of assistance. Participants also paid close attention to health media such as food and weight charts in medical clinics, exercise programs on television, and books about exercise techniques to enhance their health.

### *Staying on Track*

In this study participants were able to maintain physical and mental health by using internal and external motivation. Being able to recall that they felt good, were less stressed, and had fewer psychotic symptoms when they participated in health promoting behaviors enhanced their sense of well-being and reinforced their desire to continue engaging in healthy behaviors. In addition, they felt that it was their personal responsibility to stay healthy and used this as a mechanism to stay on track with healthy behaviors.

### **Tracking Health Behaviors Results in the Ability to Maintain Physical and Mental Health**

The central category, Tracking Health Behaviors Results in the Ability to Maintain Physical and Mental Health, encompasses the three interconnected phases of health behavior decision-making and describes the process of how participants were able to make active, comprehensive health behavior decisions by systematically “tracking” or monitoring their daily health behaviors.

First, participants had to have a cognitive awareness that the body, mind, and spirit were important aspects of health that could be affected by their behaviors and choices. They also had to incorporate health information acquired through a variety of sources, including advice from clinicians, in decisions regarding their health behaviors.

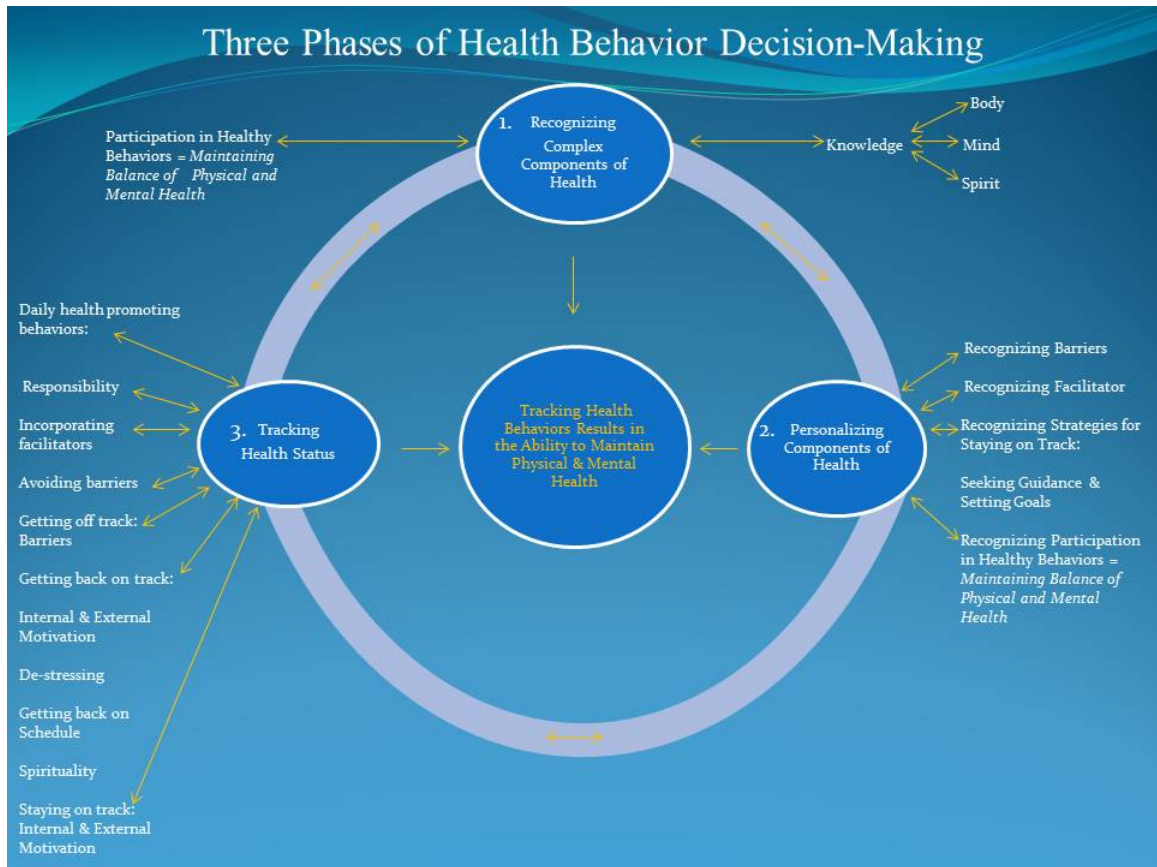
Second, participants were able to adopt daily health behaviors by identifying barriers and facilitators to health. After making personal observations about what detracted from or enhanced their health, participants developed strategies for maintaining a healthy state and those included seeking guidance and setting reasonable health goals.

Lastly, participants described a process of monitoring whether they were in a healthy state and this practice included a series of dynamic actions: taking personal responsibility for participation in daily health promoting behaviors, getting back on track when perceived to be unhealthy or after stopping participation in healthy behaviors, and staying on a healthy track by using internal and external motivation. The culmination of the three phases of health behavior decision-making: Recognizing the complex components of health, Personalizing components of health, and Tracking health status resulted in the ability to maintain a balance of physical and mental health.



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Figure 5.1 Three Phases of Health Behavior Decision-Making



## CHAPTER SIX

### Discussion

This qualitative study explored how adults diagnosed with schizophrenia make health behavior decisions. Ten adults were interviewed and provided a description of what it means to be healthy, the barriers and facilitators to being healthy, and the cognitive processes used when making health behavior decisions. Information that emanated from the interviews led to the development of a model that depicts dynamic phases of health behavior decision-making and incorporates the effects of barriers and facilitators to health. This model is meant to portray the logical and systematic processes used when applying health knowledge to daily health promoting behaviors. This chapter will focus on how key aspects of the model are similar to or different from previous research about health behavior decision-making processes among adults diagnosed with SMIs.

The majority of participants in this study had been diagnosed with schizophrenia for greater than 10 years and acquired health knowledge throughout the course of their illness. In addition, 80% of participants were diagnosed with medical co-morbidities that required successful self-care and their health knowledge was enhanced as a result of having to manage both a medical illness and symptoms of schizophrenia. Participants decided whether they were in good health based on knowledge of physiological parameters such as ideal body weight, normal serum glucose levels, blood pressure, and pulse rates. They also engaged in a dynamic process of self-evaluation that enabled them to determine when they had lapsed into poor health habits and when to return to previously successful health promoting practices. They used internal and external motivation to maintain healthy behaviors such as medication adherence, regular exercise, and eating healthy foods. Many maintained healthy behaviors because they feared negative health outcomes, loss of relationships, or psychiatric re-hospitalization. Participants also learned from past experiences that they preferred to avoid psychological or emotional suffering experienced when they discontinued psychiatric medications, and that medication adherence (psychiatric and medical medications) played a pivotal role in health maintenance. This finding is contrary to the conclusions of Heerey, Bell-Warren,

and Gold (2008), who found that the deficits in working memory resulted in an underestimation of the impact of losses and vulnerability to harm among those diagnosed with schizophrenia. Furthermore, in my study, not all of participant's health behavior decisions were based on fear; the majority also described a desire to have a sense of well-being or wholeness, similar to what most experience in the general population, and recognized that in order to achieve this state that they needed to maintain a balance of physical and mental health.

Participants engaged in health promoting behaviors and demonstrated an ability to make appropriate health behavior decisions based on acquired health knowledge. In addition, participants used current technological devices such as cell phones and computers to enhance health knowledge and to increase communication with others.

Although this study did not specifically examine health literacy, it is useful to describe this concept within the context of health behavior decision-making because participants in this study demonstrated the ability to use their health knowledge.

According to the US Department of Health and Human Services (2000), health literacy "is the degree to which individuals have the capacity to obtain, process, and understand basic health information." In 2003, researchers examined health literacy among 19,000 adults ("ages 16 and older") among those in households or prisons using the National Assessment of Adult Literacy ([NAAL]; Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C., 2006). Although it was not specified whether those with SMI's were included in this study, many racial and ethnic groups were represented including African Americans, Asian/Pacific Islander Americans, American Indians or Alaskan Natives, Caucasian Americans, and Multiracial Americans (Kutner et al., 2006). In the study, ability of patients to perform health tasks involving reading comprehension, use of information read, and performance of computations was measured across three domains of "health, healthcare information, and services: clinical, prevention, and navigation of the health system" (Kutner et al., 2006). Findings indicated that 14% of subjects had below basic health literacy (Kutner et al., 2006). However, health literacy increased with higher education levels (Kutner et al., 2006).

Little is known about health literacy levels and the impact on participation in health behaviors among those with a SMI. Galletly, Neaves, Burton, Liu, and Denson (2012) concluded that health literacy was understudied among those with mental illnesses and this led to their evaluation of the health literacy of Australian adults diagnosed with depression or schizophrenia. Galletly et al. (2012) measured whether low literacy correlated with medication non-adherence and lower education levels using the Test of Functional Health Literacy in Adults (TOLFA), which has concurrent validity of 0.74 with the Wide Range Achievement Test-Revised and 0.84 with the Rapid Estimate of Adult Literacy. The TOLFA score categories include adequate, marginal, and inadequate health literacy. Galletly et al. (2012) found that 93% in the depressed group and 97% schizophrenia group scored within the “adequate” health literacy category, health literacy was positively correlated with years of education ( $r = 0.29$ ,  $n = 60$ ,  $P = .023$ ), and there was no association between health literacy and medication adherence ( $r = -0.05$ ,  $n = 60$ ,  $P = .697$ ). In a study of health literacy using the TOLFA among the general population in Australia, Barber et al. (2009) found that 93.2% scored in the “adequate” health literacy category. The results of health literacy scores in Australian samples were similar between those with and without mental illness. In addition, Galletly et al. (2012) stated that they believed that they were the first to examine health literacy among those with depression or schizophrenia using the TOLFA. Although medication adherence was not associated with health literacy in one prior study (Galletly et al., 2012), replication of studies that measure the impact of health literacy regarding engagement in health behaviors such as medication adherence, exercise and healthy dietary habits among those diagnosed with schizophrenia is needed.

### **Phases of Health Behavior Decision-Making and Concepts of Existing Health Behavior Models**

In this study, some of the cognitive processes involved in the three phases of health behavior decision-making were consistent with concepts found in existing health behavior models: Health Belief Model, Theory of Reasoned Action, and The Transtheoretical Model. Therefore, from the study findings, it is beneficial to provide a comparison of strengths and weaknesses of the models and whether these could possibly

be applied to future wellness and rehabilitation efforts aimed at improving the health of individuals with schizophrenia.

### **Health Belief Model**

The Health Belief Model theorizes that three factors determine whether individuals take action regarding their health: the degree of health concern, perceived vulnerability, and reduction of the perceived threat if one accepts health recommendations, provided that they are worth the costs or efforts to overcome perceived barriers (Rosenstock, Strecher, & Becker, 1988). Findings of my study support the hypothesis that perceptions of vulnerability and a threat must be present before health behaviors change and that it must be worth the investment to engage in the behavior change. All participants stated that they needed treatment with psychiatric medications and medical treatments or medications when diagnosed with a medical co-morbidity because they indeed felt vulnerable to the symptoms of schizophrenia and/or medical illnesses, and wished to avoid the negative health consequences associated with non-adherence to treatment. Most participants also stated that it only took about two occasions of trying to go without taking their psychiatric medications before recognizing that they were more mentally and emotionally stable as a result of treatment adherence, and that they were able to reduce the likelihood of experiencing potential losses. Furthermore, most participants valued feeling physically and mentally balanced or having a sense of well-being as a result of participating in the health promoting behaviors of eating a healthy diet, relaxation, and daily exercise. Only one participant stated that exercising regularly was not worth the effort required to achieve a better state of physical health.

Replication of studies is needed to measure beliefs about needing to participate in the health promoting behaviors of eating a healthy diet and daily exercise and whether the perceived benefits of participation influence long-term adherence. Another factor that influences belief systems is the presence of optimistic bias or the inaccurate belief that one's likelihood of experiencing a negative event is less than that of the average person (Prentice, Gold, & Carpenter, 2005). Optimistic bias has been found to be present among adults with schizophrenia but to a lesser extent than non-ill individuals (Prentice et al.,

2005). In future studies examining health behaviors among individuals with schizophrenia, it is important to address acknowledgement of vulnerability to potential health threats and whether this may influence improved health behavior decision-making. In addition, a comparison with non-ill individuals would be worth further study.

Personal beliefs about vulnerability to harm are not the only cognitive factors that affect health behavior decision-making. As noted in the Theory of Reasoned Action, the value placed on specific health behaviors and subsequent potential outcomes occurs in a logical manner, while taking into account the opinions of others, and also plays an important role in how one makes health decisions.

### **Theory of Reasoned Action**

The Theory of Reasoned Action assumes that humans prefer rational, systematic processes before deciding to engage in a particular behavior (Fishbein & Ajzen, 1975). These processes are influenced by the value one places on their own beliefs and the opinions of respected others. Consistent with the basic tenants of the Theory of Reasoned Action, all participants in my study engaged in a system of rational systematic decision-making regarding their health behaviors. They were best able to make rational decisions when they were not experiencing symptoms of psychosis (hallucinations, delusions, or disorganized thinking), or feeling stressed. Moreover, most participants were able to make good health decisions despite occasionally experiencing residual psychotic symptoms by seeking guidance from clinicians, particularly regarding medication inefficacy or side effects. This finding supports research by Weiss et al. (2002) who found that a working alliance with the therapist was most consistently associated with psychiatric medication adherence and predicted development and maintenance of active adherence better than measures of global functioning. In addition, there was consistency with the findings of Holmberg and Kane (1999), in that participants felt less control of their health status, and subsequently did not meet the assumptions of the model, when they experienced emotional stress, sedating side effects of psychiatric medications, or residual symptoms of schizophrenia such as feeling unmotivated or when the amplitude of auditory hallucinations (voices) was so severe that they felt agitated and unable to focus or concentrate.

## The Transtheoretical Model

The readiness of an individual to change to healthier behaviors has been studied. As noted in the Transtheoretical Model, readiness to change can be assessed based on stages of pre-contemplation, contemplation, preparation, action, and maintenance (Prochaska, DiClemente, & Norcross, 1992). Interestingly, the majority of participants in this study engaged in expected patterns of the stages of change outlined by Prochaska, DiClemente, and Norcross, (1992). Furthermore, findings were consistent with those of Nidecker et al. (2008) who found that those with SMI's use processes of change that are similar to those of non-ill persons. Another similarity was found with those of El-Mallakh (2006), because like her findings, the majority of participants specifically described health beliefs and behaviors that developed over time and were based on losses experienced as a result of their recurrent psychotic symptoms. Early in the course of illness with schizophrenia, and prior to accepting that they truly had a mental illness, many participants were resistant to psychiatric medication adherence despite being told by their clinicians that in order to achieve the best health outcome they needed consistent treatment with antipsychotic medications; this reflected the 'pre-contemplation' stage of change. However, most participants quickly adapted their health beliefs and behaviors based on personal and socioeconomic losses associated with remaining psychiatrically ill, and this led to their decision to adhere to psychiatric medications.

The "contemplation" stage of change was noted when participants realized that if they became non-adherent to their psychiatric medications that they would be re-hospitalized on the psychiatric unit. Two participants also recognized the possibility of being placed in jail due to unpredictable or aggressive behaviors that occurred when experiencing an exacerbation of the symptoms of schizophrenia. Thus, in order to avoid these outcomes, participants moved into the "action" and "maintenance" stages whereby they agreed that they needed treatment and adhered to their psychiatric medications. Those with medical co-morbidities more readily accepted that they needed to adhere to medical treatments because of fear of negative health outcomes such as leg amputations or stroke as in the cases of those who were also diagnosed with diabetes. All participants described having no difficulty with adherence to psychiatric medications or medical



treatments associated with chronic co-morbidities, such as performing daily blood glucose monitoring for those with diabetes, which suggests that they were in the latter part of the “maintenance” stage known as “termination.”

However, when it came to exercise and adherence to a healthy diet, most participants admitted that they occasionally struggled with the “maintenance” stage regarding these health behaviors. Replication of findings by Nidecker et al. (2008), that those with SMI’s are found to use similar processes of change as non-ill persons, is needed. In addition, identification of predictors of participation in healthy lifestyles is needed to determine whether those with schizophrenia can engage in and maintain self-prompted health behaviors that preserve wellness and fulfillment.

### **Application to Clinical Practice**

The findings of this study offer a greater understanding to clinicians regarding how adults with schizophrenia make health behavior decisions. Study results should remind clinicians that individuals diagnosed with schizophrenia accumulate and synthesize health information. Assumptions to the contrary should not be made by healthcare providers based solely on the facts that cognitive deficits, communication difficulties, and intermittent lack of motivation exist among those diagnosed with schizophrenia. Therefore, clinicians must not dismiss the importance of providing health education and encouragement of participation in health promoting behaviors when opportunities arise. This course of treatment may contribute to the reduction of significant health disparities in this vulnerable population. In addition, clinicians must make a concerted effort to develop an early recognition of difficulties with adherence to health promoting behaviors among individuals with schizophrenia and how to best assist them in regaining healthy daily habits.

Because health behavior decision-making incorporates clinician recommendations and behavioral choices by patients, as well as effective collaboration between patients and clinicians (Spring, 2008), it is imperative that mental health providers seek to understand how to best assist individuals with SMIs adopt and sustain health-promoting behaviors, avoid detrimental health habits, and also gain and sustain access to quality

physical and mental healthcare. Toward these efforts, as SAMHSA (2004) has noted, clinicians should form partnerships with patients and encourage them to be self-determined and empowered in taking personal responsibility for promoting their own wellness. Furthermore, the focus of current and future physical and mental health care services should not only aim to reduce health disparities, it should also promote the recovery process among individuals with SMIs. In this study, all participants described a need to take personal responsibility for their physical and mental health and considered this to be a key determinate of their health behavior decision-making.

However, leaving the full responsibility of seeking optimal health outcomes should not be left only to patients. It is well documented that among those with SMIs the cardiovascular mortality is two to three times the general population, the prevalence of diabetes is estimated to be four times that of gender and age matched controls, and hypertension prevalence is two times that of controls (Morden et al., 2009). This strongly suggests that there are significant barriers to health among those with SMI's. Little is known about how to best meet the medical healthcare needs of individuals with schizophrenia. Morden et al. (2009) proposed a recent model of integrative care that could be useful in helping those with physical and mental health needs. This model recommends building integrated care into healthcare practices through collaboration with psychiatrists and addresses the complex medical needs of those with SMIs by encouraging family medical physicians to increase their understanding of psychopharmacologic treatments and associated medication monitoring guidelines (Morden et al., 2009). Recommendations of other integrated care models included having on site medical consultants at mental health clinics, encouragement of increased communication between medical and mental health teams to increase referrals, and using nurse case managers to assist patients with making medical decisions, gaining access to care, and provide patient education (Morden et al., 2009). Advanced practice psychiatric nurses provide mental health care in a variety of inpatient and outpatient settings and are positioned to be powerful advocates in terms of assisting patients to reach their health goals. While El-Mallakh (2005) has pointed out that it remains unclear whether advanced practice psychiatric nurses should engage in dual roles as primary care and mental health clinicians, they can provide interdisciplinary collaboration in an effort to improve the

health outcomes of those diagnosed with schizophrenia. However, perhaps the time has come that a new paradigm in advanced practice nursing, that includes the dual roles of primary medical care (family practice) and mental health nursing, should be considered in an effort to reduce the morbidity and mortality of those with SMIs who have medical co-morbidities.

Finally, since patients take into consideration health advice from respected others, including healthcare professionals, nurses and other clinicians should consider the importance of achieving a healthy balance of their own physical and mental health in order to be considered well-regarded role models.

### **Study Limitations**

Several limitations of this study are acknowledged. The majority of participants were relatively high functioning in regard to their daily health behaviors, and their psychiatric symptoms were considered stable for 10 years or longer from the perspectives of their clinicians. This lengthy period of treatment provided participants time to learn and adapt their health behaviors due to multiple encounters with the healthcare system and therefore may not represent those who are newly diagnosed or with residual or intractable symptoms of schizophrenia. The small sample size and lack of variance since time of diagnosis hinders extension of the proposed model beyond this particular group.

Another possible study constraint could be associated with the investigator self-identifying as a nurse at the beginning of study recruitment. Acknowledgement of being a nurse could have influenced participants to offer answers that they thought would sound acceptable to a healthcare professional rather than reflecting health behaviors with which they were actually engaged.

This study described participants' perceptions about the complex components of health, barriers and facilitators to health, and factors involved in health behavior decision-making. Absent from this analysis was the perspectives of others in the participant's support network such as their clinicians, families, and friends regarding their observations of how participants make health behavior decisions, overcome health barriers, and incorporate facilitators to health. Future study designs could include

observations made by those in the participant's support network regarding health behavior decision-making and participation in health promoting behaviors.

Qualitative studies rely on perceptions of participants and this may only provide a snapshot of their views at the time of study. Therefore, there is a need to study the model's strength for longer periods with larger samples to determine if it holds up across diverse groups of adults diagnosed with schizophrenia at various time points of the illness spectrum. Finally, the model only provides a general description or outline of phases of health behavior decision-making and needs further study to test possible theoretical implications.

### **Implications for Future Research**

The identification of three phases of health behavior decision-making described in this study adds support to previous models about health beliefs including the Health Belief Model (Rosenstock, Strecher, & Becker, 1988), Theory of Reasoned Action (Fishbein & Ajzen, 1975), and The Transtheoretical Model (Prochaska, DiClemente, & Norcross, 1992). Further examination of whether the findings from this study can be more robustly linked to these existing models is needed.

Previous study findings that individuals with schizophrenia have deficits in working memory and reduced estimates of the impact of losses (Heerey et al., 2008) may be worth further exploration within the context of whether these factors affect health behavior decision-making processes and if they influence access to healthcare. To further test the Health Belief Model, future studies could examine whether patients with schizophrenia underestimate the impact of losses and vulnerability to harm involving health behaviors such as dietary and exercise habits. In this study, all participants were able to recognize potential negative future outcomes if they failed to adhere to a healthy diet, regular exercise, and psychiatric and medical treatment recommendations.

In this study, all participants used daily routines and reminder notes-to-self and many used daily planners and/or pill organizers to compensate for memory deficits and assure treatment and exercise adherence. This suggests that they preferred a systematic logical approach while carrying-out their daily health routines. Since the Theory of

Reasoned Action assumes that logical processes are used when making decisions, future studies could be designed to examine whether the skills required to acquire health literacy affect health behavior decision-making and levels of participation in the health promoting behaviors of exercise, eating a healthy diet, and adherence to medical treatments, among those diagnosed with schizophrenia. Furthermore, studies should examine whether thought processes associated with health behavior decisions among those with schizophrenia are faulty due to known deficits in working memory. Researchers must test whether exposure to frequent systematic reinforcements and reminders of acquired skills helps with overall memory function and ability to adhere to healthy behaviors. When designing methods to assist those with schizophrenia to reconnect with healthy routines, clinicians' use of immediate rewards and frequent reminders could play important roles since intact reward sensitivity and behavioral learning in decision-making exists (Heerey et al., 2008) and would be worthy of further study.

In addition, since working memory, a neurocognitive process involved in self-evaluation, has been found to be degraded among those diagnosed with schizophrenia (Heerey et al., 2008), it is important to determine whether this affects the ability to successfully engage in health promoting behaviors. Future studies that are guided by the Transtheoretical Model of change could investigate the capacity for self-reflection and the degree to which this affects self-prompted health behavior change in exercise and dietary habits among individuals diagnosed with schizophrenia.

Most participants in this study stated, that at some point during their illness with schizophrenia, they were unable to concentrate or organize thoughts due to interference from auditory hallucinations and/or experienced intermittent lack of motivation that impeded participation in healthy behaviors. Thus, in future studies, it would be useful to examine whether individuals with schizophrenia need more external motivation or encouragement from others to participate in health promoting behaviors when experiencing these residual psychotic symptoms or cognitive deficiencies. Knowing more specifically what the role of nurses and other clinicians should be in guiding health behavior decision-making processes and how to best support individuals with schizophrenia when they meet difficult health challenges would be a valuable outcome of

longitudinal studies examining cognitive factors associated with medication, diet and exercise adherence.

## Conclusion

Participants in this study used systematic cognitive processes when making health behavior decisions in spite of barriers such as cognitive deficits, treatment side effects, psychiatric symptoms, lack of access to treatment, and social stigma associated with a mental health diagnosis. Participants were able to overcome these barriers by using facilitators such as social support networks that included positive relationships with health care providers or others who encourage participation in health-promoting behaviors and self-efficacy (taking personal responsibility). Other health facilitators included the use of support groups, access to exercise facilities, reliable transportation, and internal/external motivators. Participants maintained a balance of physical and mental health, the majority of the time, by incorporating health facilitators, avoiding barriers, and tracking their health behaviors.

The value of this study can be found in what the participants had to say regarding their health behavior decision-making. Overall, Ida summarized what it meant to make health behavior decisions that enabled the achievement and maintenance of a balanced state of physical and mental health:

My definition of being healthy is being able to function in everyday life...When I wake up, I get dressed properly, eat breakfast, be [*sic*] able to know what I have to do for that day and proceed on...I decide to be healthy by planning ahead and keeping...you know, staying away from things that will make me upset (emotionally)...keeping a planner, also taking my medications, eating healthy, speaking with people that keeps [*sic*] me on track and that's it.

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## APPENDICES

### Appendix A

#### Stages of Transtheoretical Change Model

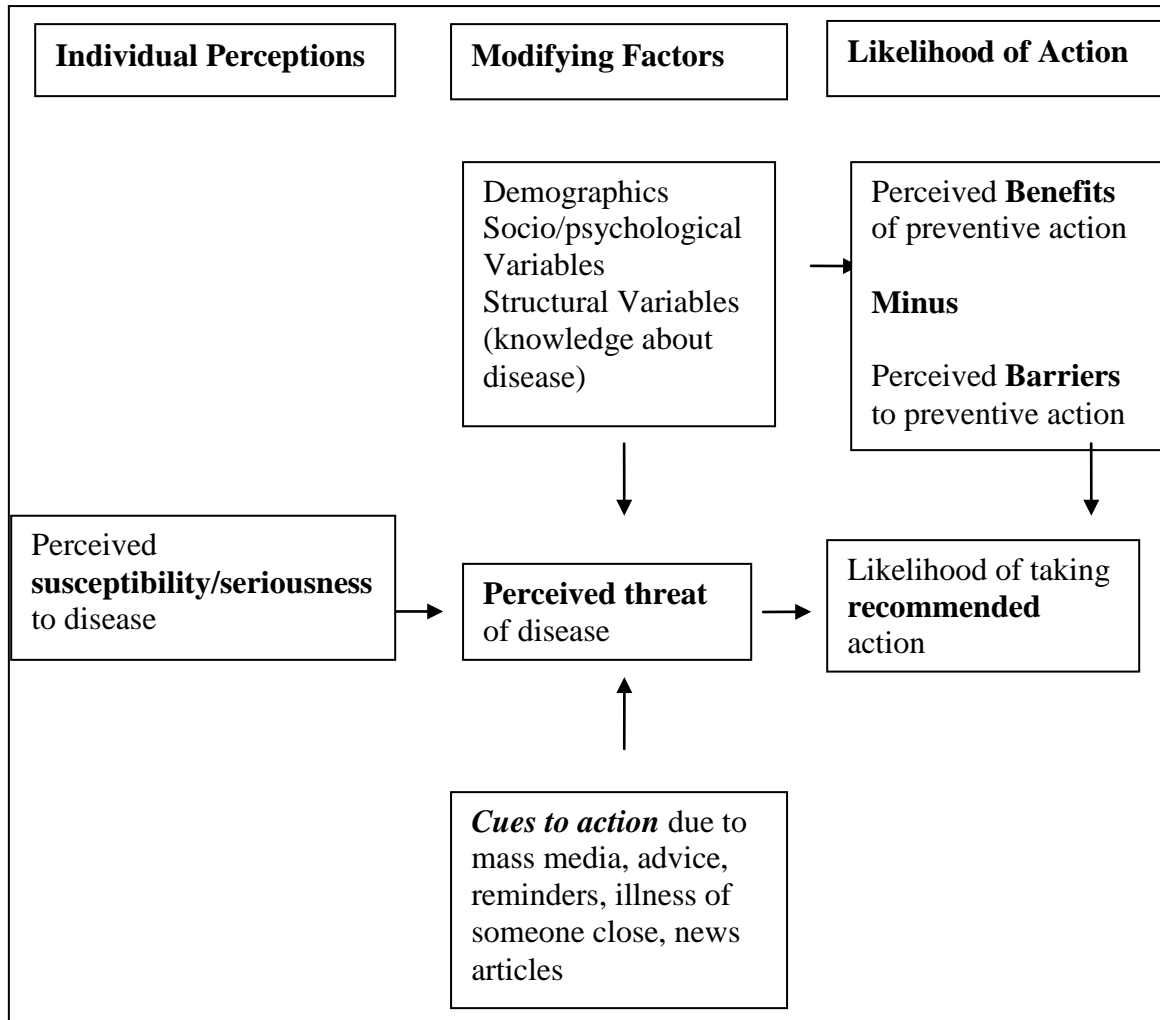


(Prochaska, DiClemente, & Norcross, 1992)



Appendix B

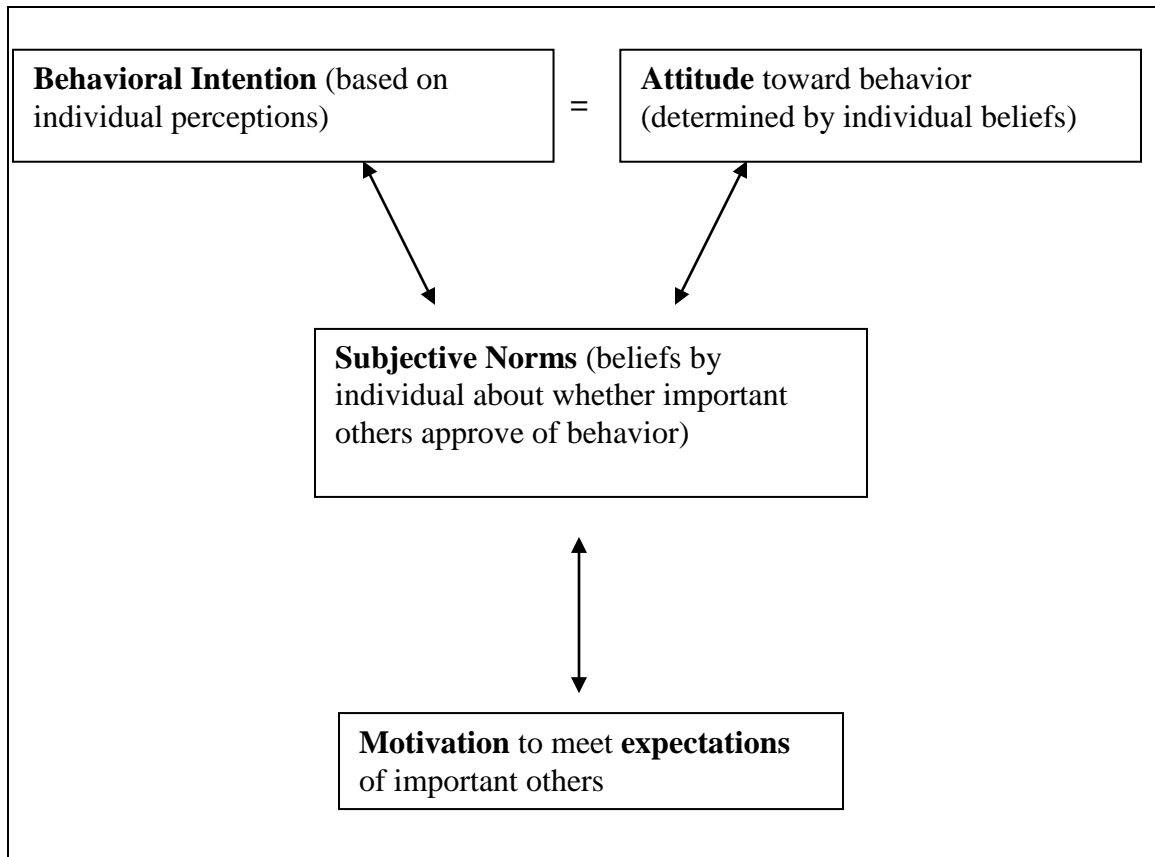
**Health Belief Model**



(Becker, Drachman, & Kirscht, 1974)

Appendix C

Theory of Reasoned Action Model



(Fishbein, 1975)

## Appendix D

### Interview Guide

1. Tell me your definition of what it is to be healthy.
  - Describe how you decide to be healthy.
2. Tell me how you know that you are healthy.
3. Describe what things you do each day to be healthy.
4. Talk about any difficulties that you may have with trying to be healthy.
  - Tell me what makes you decide not to take actions that you know will help you be healthy.
  - Talk to me about any difficulties you may have with taking your medicine.
  - Talk to me about any difficulties you may have with exercising.
  - Talk to me about any difficulties you may have with following instructions about daily treatments needed for your health conditions (such as controlling diabetes, high blood pressure, weight management, or diet).
5. Describe to me what helps you to be healthy.
  - Tell me about what helps you to exercise.
  - Tell me about what helps you to take your medicine.
  - Tell me about what helps you to follow instructions about daily treatments needed for your health conditions (such as controlling diabetes, high blood pressure, weight management, or diet).
6. Talk to me about how your mental illness has affected your ability to be healthy.
  - Describe to me how your mental illness has affected your ability to exercise.

### Appendix D (continued)

- Describe to me about how your mental illness has affected your ability to take medications as directed by your nurse, doctor, or other medical clinician.
  - Tell me what you think will happen if you do not exercise
  - Tell me what you think will happen if you do not take your medications.
  - Tell me what you think will happen if you do not follow health instructions given to you by your nurse, doctor, or other clinicians.
  - Tell me what you think will happen if you do exercise.
  - Tell me what you think will happen if you do take your medications.
  - Tell me what you think will happen if you do follow health instructions given to you by your nurse, doctor, or other clinicians.
7. Describe to me what you can do if something makes it difficult for you to be healthy.
- Talk to me about what you can do if something makes it difficult for you to exercise.
  - Tell me what you can do if something makes it difficult for you take your medications.
  - Tell me what you can do if something makes it difficult for you follow health instructions given to you by your nurse, doctor, or other clinicians.

# Appendix E

## Approval Letters

BLUEGRASS REGIONAL MH-MR  
BOARD, INC.  
IRB APPROVAL

### Bluegrass Regional MH/MR Board, Inc Institutional Review Board IRB Action Report

VALID  
IRB No: 11-03

Principal Investigator: Lillian J. Findlay, MSN, APRN Research Sponsor: Rose Douglass, LCSW  
Proposal Title: Decision Making Processes & Health Behaviors Among Adults Diagnosed with Schizophrenia

#### Application Types:

<input type="checkbox"/> Exempted	<input type="checkbox"/> Expedited	<input checked="" type="checkbox"/> Full Review	<input type="checkbox"/> Continuation
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#### IRB Action:

<input type="checkbox"/> Exemption Certified	<input checked="" type="checkbox"/> Approved	<input type="checkbox"/> Conditionally Approved
<input type="checkbox"/> Revisions	<input type="checkbox"/> Additional Information Required	
<input type="checkbox"/> Expedited Review Required	<input type="checkbox"/> Full Review Required	<input type="checkbox"/> Disapproved

#### Review Comments or Conditions:

Changes suggested on June 3, 2011 have all been made. A second review has been conducted by Institutional Review Board chair, David E. Hanna, PhD.

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(use other side of this form for additional comments)

Research will begin June 30, 2011 and end Dec. 30, 2011 Continuation Review Date \_\_\_\_\_

PRC Chairperson \_\_\_\_\_ Date: 6/27/2011

IRB Chairperson David E. Hanna Date: 6/27/2011

The Principal Investigator (PI) agrees to adhere to any of the conditions which are appended to the submitted research protocol. The PI also agrees to comply with the Regional Board's policies and procedures in all matters and to place the confidentiality and safety of research subjects above the research procedure. The PI agrees to immediately report to the sponsor and to the IRB any injury or unforeseen risk to subjects during implementation of the research, and to report any changes made in the protocol. Further, the PI assumes primary responsibility for the decisions and actions of the assisting or co-investigators listed in the Review Application. It is understood that these assurances constitute a contractual agreement between the PI and the Bluegrass Regional MH-MR Board, Inc. A signed copy of this contract must be on file with the IRB prior to implementation of the research study.

Principal Investigator: [Signature] Date: 6/28/2011

Appendix E (Continued)



**Seven Counties Services, Inc.**

**School-Based Services**

4710 Champions Trace; Suite 107  
Louisville, KY 40218  
(502) 454-6343

June 21, 2011

Dear Ms. Lillian Findlay,

Congratulations, the IRB of Seven Counties Services, Inc., has approved your research proposal entitled:

*Decision-Making Processes and Health Behaviors Among Adults Diagnosed with Schizophrenia*

Is approved by the IRB of Seven Counties Services, Inc.

Attached, please find our general Agreement, obtained from all researchers who conduct their investigations at Seven Counties Services, Inc. The Agreement simply acknowledges that you will abide by the terms of your proposal, submit any revisions to the IRB in a timely manner, and provide the IRB with a summary of your results upon completion of your research.

We wish you well in your investigation. Please feel free to contact the IRB if you have any questions regarding your project.

Sincerely,

Ron Van Treuren, Ph.D.  
Chair, IRB Seven Counties Services, Inc.  
[rvantreu@sevencounties.org](mailto:rvantreu@sevencounties.org)

## Appendix E (Continued)



Office of Research Integrity  
IRB, IACUC, RDRC  
315 Kinkead Hall  
Lexington, KY 40506-0  
859 257-9428  
fax 859 257-8995  
www.research.uky.edu

Initial Review

Approval Ends  
August 27, 2012

IRB Number  
11-0578-F1V

TO: Lillian Findlay  
210 Albany Road  
Lexington, KY 40503  
(859)608-4240

FROM: Chairperson/Vice Chairperson  
Medical Institutional Review Board (IRB)

SUBJECT: Approval of Protocol Number 11-0578-F1V

DATE: September 22, 2011

On September 20, 2011, the Medical Institutional Review Board approved minor revisions requested at the convened meeting on August 29, 2011 for your protocol entitled:

*Decision Making Processes and Health Behaviors among Adults  
Diagnosed with Schizophrenia*

Approval is effective from August 29, 2011 until August 27, 2012 and extends to any consent/assent form, cover letter, and/or phone script. If applicable, attached is the IRB approved consent/assent document(s) to be used when enrolling subjects. **[Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.]** Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and returned to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigator's responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after IRB approval has been obtained, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's Guidance/Policy Documents web page [<http://www.research.uky.edu/ori/human/guidance.htm#PIresp>]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [<http://www.research.uky.edu/ori/>]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.

A handwritten signature in black ink that reads "Terry Malone, Ed.D., P.T., /ark".  
Chairperson/Vice Chairperson

Appendix F  
Recruitment Flyer

UNIVERSITY OF KENTUCKY RESEARCH



## Do you have Schizophrenia?

Researchers at the University of Kentucky College of Nursing are conducting a research study with individuals who have been diagnosed with Schizophrenia and want to help nurses understand what it means to be healthy.

**You may be eligible to participate if you:**

- are willing to participate in 1-3 taped interviews; and
- are willing to talk about what it means to be healthy.

Participants will be given \$5 for the 1st interview, \$10 for the 2nd interview and \$5 for the 3rd interview.

Interviews will be held in a private setting at your usual clinic location.

**To participate in this study, please contact:**

Lillian Findlay, MSN, RN  
Phone: 859-608-4240



*An Equal Opportunity University*

[www.UKclinicalresearch.com](http://www.UKclinicalresearch.com)

NURS-049\_flyer #



## Appendix G

### Permission to be Contacted

I, \_\_\_\_\_ am interested in finding out from nurse  
(printed name)

Findlay if I qualify to participate in the research study, *Decision-Making Processes and Health Behaviors Among Adults Diagnosed with Schizophrenia*, being conducted by Lillian Findlay, MSN, APRN. Because I am interested in participating in this study, clinic staff has my permission to contact Ms. Findlay, and Ms. Findlay may contact me at my telephone number: \_\_\_\_\_ to see if I qualify to participate.

I understand that this form is *only* giving permission to clinic staff to share my phone number with nurse Findlay so that she may call me to see if I qualify to participate.

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

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

Witness Signature: \_\_\_\_\_

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

## Appendix H

### Consent to Participate in Research

#### **Decision-Making Processes and Health Behaviors Among Adults Diagnosed with Schizophrenia**

##### **WHY ARE YOU BEING ASKED TO TAKE PART IN THIS RESEARCH?**

You are being invited to take part in a research study about what you think it means to be healthy and how you make decisions about your health. You are being invited to participate in this study because you are diagnosed with schizophrenia and are 18 years of age or older. If you decide to take part in this study, you will be one of about 10 adults from several different counties to do so. "I, \_\_\_\_\_, agree to participate in the research study under the direction of Nurse Lillian Findlay."

##### **WHO IS DOING THIS STUDY?**

The person in charge of this study is Lillian Findlay, 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, FAAN, RN, her faculty advisor at the University of Kentucky College of Nursing. Other people on the College of Nursing research team may assist at different times during the study.

##### **WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study is to learn about your definition of what it means to be healthy and how you make decisions about your health.

##### **WHERE IS THE STUDY GOING TO TAKE PLACE?**

You will be interviewed by the study nurse Ms. Lillian Findlay, and this interview will be with only you and the nurse for about three times. Each of those meetings will last about 30 to 90 minutes. The interviews will take place at your outpatient mental health treatment center where you see your doctor, during regular office hours.

After Ms. Findlay interviews the other study participants, she will talk with you again for the last time by telephone and will be about five minutes in length, to let you know what she thinks about the information gathered and to see if you agree with her. This last talk will occur by the summer of 2012.

##### **WHAT WILL I BE ASKED TO DO?**

You will be asked to meet with Ms. Findlay three times. The first meeting is to hear about the study and decide if you want to participate, the second will be to talk about how you define what it means to be healthy and how you make decisions about your health, and the third will be to add anything that you may have forgotten to say in earlier meetings or for Ms. Findlay to clarify answers that you gave her. Ms. Findlay will also ask you questions about your memory. She will tape record these meetings and take written notes. To assure your confidentiality, audio taped sessions and written notes will

## **Appendix H (continued)**

not contain any identifying information or names. In addition, the audio taped sessions and all study files will be destroyed following completion of the study. Ms. Findlay will mail the study results to your therapist, who will give the results to you to read. After you have read the study results, Ms. Findlay will call you by telephone to review the study results to let you know what she thinks about the information gathered and to see if you agree with her and this will take about five minutes to discuss. The study results being mailed to your therapist will not contain your name or other identifying information. This last talk will occur by the summer of 2012.

### **ARE THERE ANY REASONS 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. If you are not sure what the study is about and what you will need to do in the study, you should not take part in the study.

### **WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

The primary risk to you is emotional discomfort. Some people find it difficult to talk about their health habits. Ms. Findlay will make every effort to make you feel at ease when talking with her. You will not be forced to talk about anything you do not wish to discuss. While participating in this research study, there may be a risk that the privacy of your records could be unintentionally broken, and if this occurred, it could possibly affect your social relationships or employability. However, every possible effort will be made to maintain your confidentiality and this will be done by keeping your records in a secure locked file and by assigning you a study number rather than using your name or other personal information. In addition, your research files will be destroyed following the end of this study. You will be free to leave the study at any time.

### **WILL I BENEFIT FROM TAKING PART IN THIS STUDY?**

There is no guarantee that you will get any benefit from being in the study. However, some people have had good feelings about helping health care workers learn how to take better care of individuals with an illness. We cannot and do not guarantee that you will receive any benefits from being in the 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 can stop at any time during the study. If you choose to stop participating in the study you will not lose any benefits or rights that you normally had before volunteering.

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

If you do not want to take part 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 cost of all

## **Appendix H (continued)**

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. There are no costs to you to participate in this research.

### **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 that 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.

Officials of the University of Kentucky, and the research team at the University of Kentucky College of Nursing, 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 a 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 SICK OF HURT 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 Lillian Findlay at 859-608-4240 immediately.

It is important that you 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

**Appendix H (continued)**

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 \$5.00 for the initial interview with Ms. Findlay, explaining the details of the study. You will receive another \$10.00 for the second interview and \$5.00 for the third interview. The last talk with Ms. Findlay will take about five minutes by telephone and you will not receive compensation for this discussion.

If you decide to leave or have to leave the study for any reason, you will only receive compensation for the interviews that you actually participated in and you will not receive any further compensation once you leave the study.

**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, Lillian Findlay, at 859-608-4240. 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 859-257-9428. You can also call the Office of Research Integrity at a toll-free number, 1-866-400-9428. 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 this 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

"I have explained and defined in detail the research procedure in which the subject has consented to participate."

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

## Appendix I

### 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 define what it means to me to be healthy.  
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 by the researcher what I do to be healthy.  
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 confidential and my information will be kept private.  
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 participating in this study.  
TRUE FALSE
9. I will be given a copy of the consent form.  
TRUE FALSE

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Signature of Participant

Date

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Signature of person obtaining consent

Date

(El-Mallakh, 2005)

## Appendix J

### Demographics Form

**Directions: Fill in blank lines with your written answers and for questions with check boxes, check the box to the right of your answer choice.**

1. Your age is \_\_\_\_\_.
2. Race: African-American  Hispanic  Caucasian  Asian  Native-American   
Other
3. Gender: Male  Female
4. Are you employed? Yes  No
5. If you are employed, what type of job/career do you have? \_\_\_\_\_  
\_\_\_\_\_
6. What is your annual income? Less than \$10,000 per year  \$10,000-\$20,999   
\$21,000-30,999  \$31,000-40,999  \$41,000-50,999  \$51,000-60,999   
\$61,000-70,999  \$71,000-80,999  \$81,000-90,999  \$91,000-100,999   
\$101,000 or greater
7. Are you considered disabled (do you receive financial disability support from the state of KY)?  
Yes  No
8. What is your current marital status? Married  Single  Divorced  Separated   
Partnered  Widowed
9. Who do you live with? Wife  Husband  Partner  Friend/s  Room-mate   
Live Alone  Parents  Brother  Sister  Other Relatives
10. What type of housing do you have? Own my home  Apartment  Rental House   
Group Home  Other

**Appendix J (continued)**

11. How far have you gone in school (what grade level/how much college or vocational training)?

Less than eighth grade  Eighth grade  Ninth grade  Tenth grade

Eleventh grade  Twelfth grade  Some college  Associates degree

Bachelors degree  Masters degree  Doctoral degree  Post-doctoral degree

12. Do you currently smoke tobacco on a regular basis (meaning daily or several times per week)? Yes  No

13. Do you use any illicit drugs or street drugs? Yes  No

If yes, how many times per week \_\_\_\_\_

14. Do you drink alcohol Yes  No

If yes, how many drinks per week \_\_\_\_\_

15. How many children do you have? None  One  Two  Three  Four   
Five  Six  Greater than six

16. How many medications do you take daily to treat your symptoms of schizophrenia?  
None  One  Two  Three  Four  Five  Six  Greater than six

17. What are the names of your mental health or psychiatric medications, what dosage do you take, and how many times per day do you take the medication/s?

\_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_



**Appendix J (continued)**

18. Do you take your psychiatric medications every day as directed by your nurse or doctor? Yes  No

19. How many prescription medications do you take daily for medical conditions? None   
One  Two  Three  Four  Five  Six  Greater than six

20. What are the names of your medical medications and what dosage do you take?

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21. Do you take your medical medications every day as directed by your nurse or doctor?

Yes  No

22. What are the names of the medical illnesses your nurse or doctor has diagnosed you with?

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23. What type of medical treatments do you have and how often do you have them each day or week?

### Appendix J (continued)

24. How often do you participate in day treatment programs each week? None
- Once per week  Two-Four times per week  Five-seven times per week
- Eight-ten times per week  Greater than ten times per week
25. Who provides emotional support or encouragement to you? Mother  Father
- Sister  Brother  Aunt  Uncle  Grandmother  Grandfather
- Other family members  Friends  Nurse  Doctor  Social Worker
- Psychologist  Case Worker  Other

## VITA

### Lillian Jeannette Findlay

#### EDUCATION

- Summer 1983-May 1988 Bachelor of Science in Nursing, Capstone College of Nursing, the University of Alabama, Tuscaloosa, AL
- August 1993-August 1995 Master of Science in Advanced Practice of Psychiatric Mental-Health Nursing of Adults, University of Alabama at Birmingham (UAB), AL
- October 1999 Imago Relationship/Couples Therapy Training, Miami, Florida

#### LICENSURE & CERTIFICATION

- July 1988-present National Council Licensure for Registered Nurses. Initial licensure in Alabama; current licensure in Kentucky RN # 1100891, APRN # 3004037
- October 1998-present American Nurses Credentialing Center (ANCC) Certification in Psychiatric Mental-Health Nursing of Adults, Clinical Nurse Specialist # 0326014
- October 1999-present Certified in Imago Relationship/Couples Psychotherapy

#### INTELLECTUAL PROPERTIES

- August 2010-present Co-developer of: Kentucky Disability Determination Consultative Examination (All Rights Reserved); a database and electronic medical record software application for psychiatric disability determination evaluations; Lillian Findlay, Incorporated, Lexington, KY and co-developer Charlie Shanks, LLC (computer systems analyst); contact @ phone# 859-533-8874 [Charlie@myoldkyhomepage.com](mailto:Charlie@myoldkyhomepage.com)

#### HONORS & AWARDS

- 1982 Performance-Dedication Award, Cross-Country State Competitor, Lettered in Cross-Country, Holt High School, Tuscaloosa, AL
- 1983 Member of the University of Alabama Cross-Country Track Team, Tuscaloosa, AL

1985	Member of sixth-ranked Sunbelt Conference Cross-Country Track Team, the University of South Alabama, Mobile, AL
1995	Nominated for the UAB MSN Outstanding Student Award
1996	UAB Mental Health System Respect Award
2000-2002	Elected as an Eli Lilly Neuroscience Treatment Team Partner, with three speaking engagements
February 2010-present	Sigma Theta Tau International Honor Society of Nursing, Delta Psi Chapter Member

## **PROFESSIONAL EXPERIENCE: PRACTICE, RESEARCH & TEACHING**

### **Practice**

July 1988-1991	Staff Nurse, Medical Intensive Care Unit, Veterans Administration Medical Center, Tuscaloosa, AL
1991-1994	Charge Nurse, Inpatient Acute Adult Psychiatry, Veterans Administration Medical Center, Tuscaloosa, AL
August-October 1994	Staff Nurse, Inpatient Geropsychiatry, Veterans Administration Medical Center, Tuscaloosa, AL
September 1995-Nov. 1998	Acute Psychiatric Adult Inpatient Clinical Nurse Specialist. UAB, Birmingham, AL
November 1998-Aug. 1999	Geriatric Psychiatric Inpatient Clinical Nurse Specialist. UAB, Birmingham, AL
November 1998-July 2002	Clinical Research Study Coordinator, Data Collection, IRB Document Preparation at UAB Department of Psychiatric Research, Birmingham, AL
January 2003-August 2003	Advanced Practice Registered Nurse-Adult Psychiatric Mental Health Clinical Nurse Specialist, Outpatients, Parkview Psychiatric Services, Jeffersonville, IN
August 2003-March 2006	Advanced Practice Registered Nurse-Adult Psychiatric Mental Health- Clinical Nurse Specialist. Bluegrass Regional Mental Health and Mental Retardation Board, Nicholas, Harrison and Jessamine Counties, Lexington, KY
November 2006-Oct. 2009	Advanced Practice Registered Nurse (Adult Psychiatric Mental Health Clinical Nurse Specialist). Central Kentucky Behavioral Health, Lexington, KY

May 2010-present	Psychiatric Disability Determination Evaluations Assistant to Psychiatrist, Dr. David Atcher, MD; Psychiatric History/Evaluations
February 2011-Feb. 2012	Advanced Practice Registered Nurse (Adult Psychiatric Mental Health Clinical Nurse Specialist). Psychiatric Associates, PSC, Lexington, KY
February 2012-present	Advanced Practice Registered Nurse (Adult Psychiatric Mental Health Clinical Nurse Specialist). Behavioral Health and Wellness Center, PSC (formerly Psychiatric Associates, PSC), Lexington, KY

### **Research**

November 1998-July 2002 Clinical Research Study Coordinator, Data Collection, IRB Document Preparation at UAB Department of Psychiatric Research, Birmingham, AL:

#### **Biovail Corporation Clinical Drug Trial:**

Drug delivery system study for generalized anxiety disorder

#### **Eli Lilly, Four Clinical Trials:**

- Weight gain in patients treated with olanzapine: A retrospective survey
- A double-blind randomized comparison of the efficacy and safety of short-acting intramuscular (IM) olanzapine, short-acting IM lorazepam and IM placebo in acute agitated patients diagnosed with mania associated with bipolar disorder
- Olanzapine versus divalproex in the treatment of acute mania
- A randomized, double-blind placebo-controlled trial of the efficacy of olanzapine in the treatment of motor, psychological, and cognitive abnormalities in outpatients with Huntington's disease

#### **Ortho-McNeil-Janssen Pharmaceuticals, Inc. Drug Trial:**

A placebo-controlled 21-day study of the safety and efficacy of topiramate for the treatment of treatment-resistant bipolar I disorder with an optional open-label extension

#### **UAB Department of Psychiatry and Behavioral Neurobiology Study:**

Compliance in patients with schizophrenia and comorbid medical illness

- June 2003-August 2004      Advanced Practice Registered Nurse (Adult Psychiatric Mental Health Clinical Nurse Specialist)-*Psychiatric Nurse Research Assistant* to Dr. Ann Peden, DSN. University of Kentucky College of Nursing, Lexington, KY
- 2010      Data collection for A. Fallin, University of Kentucky College of Nursing: Implementation effectiveness of campus tobacco-free policies, (2011), Lexington, KY

### **Teaching**

- 1995-2001      UAB Center for Psychiatric Medicine inpatient clinical mentor to nursing and medical students
- 1998-2000      Provided continuing education units for the UAB Center for Psychiatric Medicine psychiatric staff nurses teaching neurophysiology, neuropathophysiology and psychopharmacology
- November 2006-Oct. 2009      Clinical Instructor for Eastern Kentucky University Psychiatric Nurse Practitioner Students, Lexington, KY

### **PUBLICATIONS**

- Winter 2002      Co-author of the study (abstract published): Compliance in patients with schizophrenia and co-morbid medical illness; Munoz, C., Jackson, W.T., Savage, R.M., Feldman, J.F., Ryan, W.G., **Findlay, J.**, et al., *Journal of Neuropsychiatry Clinical Neuroscience*, 14(1), Winter 2006
- 2008      Co-author of the Publication: Teen smokers' perceptions of tobacco purchase, use, and possession laws; Hahn, E.J., Hoehne, A., Riker, C.A., Hickman, A., Butler, K.M, **Findlay, J.** (2008). *Kentucky Journal of Communication*, 27(2), 95-10

### **PRESENTATIONS**

- February 2001      **Findlay, J.** (2001). Poster presentation: Weight gain in patients treated with olanzapine: A retrospective survey (study funded by Eli Lilly). Eli Lilly Investigator Initiated Trials, Dallas, TX
- September 2001      **Findlay, J.** (2001). Paper presentation: Weight gain in patients treated with olanzapine: A retrospective survey. Southeastern Conference of Clinical Nurse Specialists and Nurse Practitioners 23<sup>rd</sup> Annual Conference, Asheville, North Carolina

May 2001 **Findlay, J.** (2001). Poster presentation: Weight gain in patients treated with olanzapine: A retrospective survey. American Psychiatric Association Annual Conference, New Orleans, Louisiana

#### **MEMBERSHIP IN PROFESSIONAL SOCIETIES & ORGANIZATIONS**

October 1999-2001 Clinical Member of The Institute for Imago Relationship Therapy

1995-present American Psychiatric Nurses Association

February 2010-present Sigma Theta Tau International Honor Society of Nursing, Delta Psi Chapter Member

December 2010-present International Society of Psychiatric-Mental Health Nurses-Member

#### **SERVICE**

2008-present Support Fuller Center for Housing (founders of Habitat for Humanity), Americus, GA

Summer 2010 Volunteer at Cedar Hill Retreat Center-*assisted with planting organic vegetable crops and taught agricultural methods to youth groups from North Carolina, Carlisle, KY*

2010-2011 Volunteer for B.U.I.L.D. (Building a United Interfaith Lexington through Direct-Action); *a justice ministry network aimed at resolving inequities in education (restorative justice), housing, and health care at the local level*

## REFERENCES

Dr. Lynne Hall, Dr. PH  
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