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Understanding the Physical Health of Older Adults with Schizophrenia

by

Heather Leutwyler

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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by
Heather Leutwyler

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Understanding the physical health of older adults with schizophrenia

Heather Leutwyler

The portion of older adults with schizophrenia is growing and their physical health status is poor. Many factors contribute to poor physical health including unhealthy lifestyles, poorly managed chronic diseases, and socio-demographic factors. The purpose of this dissertation was to explore how older adults with schizophrenia understand their physical health

A quantitative secondary data analysis was conducted based on a randomized lifestyle intervention program for older persons with schizophrenia or schizoaffective disorder and diabetes mellitus recruited from board-and-care facilities and day treatment programs to explore the relationship between the symptoms of schizophrenia experienced and response to the intervention. The qualitative aspect was conducted using a grounded theory approach to guide interviews with 28 older adults with schizophrenia or schizoaffective disorder recruited from three mental health facilities to explore the individual understanding of physical health.

The quantitative study revealed a significant condition by symptom interaction for diabetes knowledge. The difference between change in knowledge for intervention and control groups depends on prevalence and severity of total, negative, and general symptoms. There was not a significant condition by positive symptom interaction for diabetes knowledge. A significant main effect was found between total, negative, positive, and general symptoms in the total sample for diabetes self-efficacy. Higher prevalence and severity of symptoms was negatively associated with improvement in diabetes self-efficacy.

The qualitative data revealed that while discussing conceptions of physical health, participants spoke about a sense of belonging as one of the key factors supporting feeling healthy. A sense of belonging could be derived from a sense of connection with others, a physical place, social relationships, and a sense of meaning and purpose. Also, the concept of trust between participants, health care providers, and the health care system emerged as a dynamic process that was built with factors of respect, caring, advocacy, and consistency and eroded through factors of disrespect, not being heard, lack of time, provider inaction, and stigmatization.

The symptoms and experience of schizophrenia, the health care system, and health care providers are critical factors to consider in the development of targeted interventions to improve the physical health of this population.

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Introduction

My interest in schizophrenia began during my undergraduate neuroscience education when I became fascinated by the biological and psychological aspects of the brain. When I later entered the nursing profession and completed my training as family nurse practitioner, I sought clinical work that would expose me to people struggling with serious mental illnesses. I began working as a family nurse practitioner in a residential facility for adults struggling with serious mental illness. My role was to provide primary care to the residents in the 89 bed facility. This showed me not only the multitude of acute and chronic physical diseases that this population struggles with but also the myriad of social challenges that make the management and promotion of health especially challenging. It became apparent that the older adult with schizophrenia in the facility often faced tremendous difficulty in reaching their optimal health status. When I was accepted into the doctoral program at the University of California, San Francisco, School of Nursing, I felt I was given a chance to help the older adult population with schizophrenia improve their health in ways that I could never accomplish with my clinical practice alone. My hope is that through my program of research, I may find avenues to improve the physical health of older adults with schizophrenia and continue to advance nursing as a science and profession.

Early on in my doctoral study, I began reviewing the literature to determine what was known about the poor physical health of older adults with schizophrenia. It became clear that the issue of poor physical for the older adult with schizophrenia is an important but neglected topic. First, this importance is underscored by the mere increase in the growth of this population. The number of people who struggle with schizophrenia living beyond the age of 55 is growing. This increase may be due to multiple factors, including

better psychiatric treatment options and response to these treatments and greater recognition of late onset cases as well as the general expansion of the older adult population (Mittal et al, 2006; Palmer, Heaton, & Jeste, 1999; Howard, Rabins, Seeman, Jeste, & the International Late Onset Schizophrenia Group, 2000). It is estimated that this growth will continue. By the year 2030, the number of severely mentally ill older adults is predicted to more than double to 15 million (Bartels, 2004).

Despite this increase in the population, less than 10% of published research in schizophrenia is done with older adults (Mittal et al., 2006). The data that has been gathered suggest that the health status of older adults living with schizophrenia is poor, supporting a need for further attention and intervention by researchers and clinicians. Common medical problems found in the population with schizophrenia include diabetes, hypertension, asthma, gastrointestinal disorders, skin infections, and respiratory disorders (Chafetz, White, Collins-Bride, & Nickens, 2005). Older persons with schizophrenia are more likely to be diagnosed with multiple medical problems as compared to the younger cohorts with schizophrenia (Kilbourne et al., 2005). This poor physical health status has been associated with decreased quality of well-being, depression, and decreased life satisfaction (McKibbin et al., 2006; Salokangas, Honkonen, Stengard, & Koivisto, 2006). In addition, physical health problems in the context of schizophrenia contribute to increased cost to the health care system. Annual per person cost of care for the person with schizophrenia over the age of 65 is suggested to amount to 40,000 dollars per year, or three times the amount to care for a patient with only a physical illness. (Bartels, Clark, Peacock, Dums, and Pratt, 2003). Contributions to this poor physical health status may be related to multiple difficulties with disease prevention, screening, and treatment

on both the part of patients and health care providers, such as unhealthy lifestyles and inadequate medical care (Bartels, 2004).

Few studies have assessed the reasons for poor health in this specific population and no studies to date have explored their understanding of physical health. This individual process of understanding may be impacted by multiple factors including health beliefs, health services use, and health behaviors. Furthermore, the symptoms of schizophrenia have the possibility to impact health beliefs, behaviors, and access to care. Evaluating the understanding of physical health among older adults with schizophrenia with both quantitative and qualitative methodologies may provide a better understanding of their health knowledge, needs, and communication differences.

Therefore, the purpose of this dissertation was to explore how older adults with schizophrenia understand their physical health with the ultimate goal of utilizing these data to develop targeted interventions to promote optimal functioning and minimize the negative impact of co-morbid conditions. The research question that has shaped this dissertation is: How does the older adult with schizophrenia understand their physical health? This question was approached through triangulating data from both quantitative and qualitative sources. Triangulation is way of approaching the same problem from different ways or different angles (Holloway and Wheeler, 2002) and this approach can yield different but complementary data on the same topic (Creswell and Clark, 2007). Thus, triangulating data was an ideal approach to evaluate the understanding of physical health among older adults with schizophrenia.

For the quantitative aspect of the dissertation, a secondary data analysis was conducted based on a lifestyle intervention program for persons over age 40 with

schizophrenia or schizoaffective disorder and diabetes mellitus recruited from board-and-care facilities and day treatment programs (McKibbin et al., 2006).

The qualitative aspect of the dissertation was conducted using a grounded theory approach to guide one-on-one open-ended interviews with 28 older adults with schizophrenia or schizoaffective disorder. Using a grounded theory approach embedded with the theoretical underpinnings of symbolic interactionism allowed for the creation of conceptually dense analyses and did not impose a predetermined framework on the person's experience which made this method ideal for exploring the individual understanding of health. Participants representing a range and variety of experiences were recruited from the following sites: a transitional residential and day treatment program, an intensive case management program, and a locked mental health rehabilitation center. The specific aims of the grounded theory study were:

1. To describe the health knowledge of the older adult with schizophrenia.
2. To describe the socio-cultural processes that contribute to this understanding of physical health.
3. To describe how older adults with schizophrenia talk about concurrent co-morbid conditions in the context of their understanding of their health.

Overview of papers

The dissertation is organized into four parts. The first paper presents a review of the literature about the contributing factors to poor physical health of the older adult with schizophrenia. Paper two presents the findings of the quantitative secondary data analysis. This paper explored the relationship between the symptoms of schizophrenia

experienced by older persons diagnosed with schizophrenia and type 2 diabetes mellitus and their response to a health promoting intervention. The next paper presents a key finding from the grounded theory study, finding a place to belong. Analyses revealed that while discussing conceptions of physical health, participants spoke about belonging as one of the key factors supporting feeling healthy. The final paper presents another key finding from the grounded theory study, the process of building and eroding trust. Analyses revealed a process of building and eroding trust between older adults with schizophrenia and their health care providers, the health care system, and within themselves. Trust was necessary for the older adult with schizophrenia to relate to, interact with, and open up to health care providers about their health concerns. The final paper is followed by a synthesis of the findings, implications for nursing research, and clinical practice.

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Paper 1

Literature Review: The Physical Health of Older Adults with Schizophrenia

Heather C. Leutwyler

Abstract

Background: Older adults with schizophrenia are a growing segment of the population yet their physical health is poor. **Objective:** To inform nurses about the current state of the science on factors that contribute to the poor physical health of older adults with schizophrenia. **Study design:** A review of the literature relevant to the physical health of older adults with schizophrenia. **Result:** Multiple factors contribute to poor health status such as the impact of schizophrenia symptoms, unhealthy lifestyles, poorly managed chronic diseases, and health care disparities. **Conclusions:** The literature reviewed revealed areas that nursing can focus on when caring for the physical health of older adults with schizophrenia.

The Physical Health of Older Adults with Schizophrenia

An estimated one in 17 people in the United States suffer from a serious mental illness (Kessler, Chiu, Demler, Merikangas, & Walters et al., 2005). Schizophrenia, one form of serious mental illness, affects approximately 2.4 million Americans (National Institute of Mental Health, 2008). Older adults with schizophrenia are a growing segment of the population (Howard, R., Rabins, P., Seeman, M., Jeste, D., & the International Late-Onset Schizophrenia Group. 2000; Mittal et al., 2006). Palmer, Heaton, and Jeste (1999) emphasize that in 2011, the first members of the baby boom generation will turn 65 bringing an increase in the number of elderly people within the general population. Furthermore, people with schizophrenia are the largest group of older people with severe mental health problems (Cohen et al., 2000). The number of severely mentally ill older adults is predicted to more than double to 15 million by the year 2030. (Bartels, 2004). This is attributable to multiple factors that may include better psychiatric treatment options and responses to these treatments and the increase in late onset schizophrenia diagnoses as well as the general expansion of the older adult population (Howard, R. , Rabins, P., Seeman, M., Jeste, D., & the International Late-Onset Schizophrenia Group, 2000; Mittal et al., 2006),

However, current data suggest that these older adults suffer from poor physical health as evidenced by the number of medical problems and increased rates of mortality. People with schizophrenia are reported to live, on average, 9-12 fewer years than persons not struggling with a severe, persistent mental illness (Copeland, Zeber, Rosenheck, & Miller, 2006). Common medical problems found in the population with schizophrenia

include diabetes, hypertension, asthma, gastrointestinal disorders, skin infections, and respiratory disorders (Chafetz, White, Collins-Bride, & Nickens, 2005).

Researchers have demonstrated that the prevalence of certain diseases are higher in the population with mental illness than the general population (Carney, Jones, & Woolson, 2006; Himelhoch, McCarthy et al., 2009; Dixon, Postrado, Delahanty, Fischer, & Lehman, 1999). In a study analyzing longitudinal claims data documenting the comorbidities of people with schizophrenia, 33% had three or more comorbidities and an increased odds ratio for conditions spanning nearly every organ system including diabetes, hypothyroidism, hepatitis C, liver disease, pancreatitis, renal failure, and fluid/electrolyte disorders (Carney, Jones, & Woolson, 2006). Additional research has confirmed the higher rates of hepatitis C in people with schizophrenia (Himelhoch, McCarthy et al., 2009). Furthermore, rates of diabetes and hypertension exceed rates found in the general population (Dixon et al., 1999). The older patient with mental illness is even more likely to be diagnosed with multiple medical problems (three on average) when compared to the younger cohorts (Kilbourne et al., 2005).

Providing patient centered care to this population may be a way to optimize physical health. Cumbie, Conley, and Burman (2004) define patient centered care as care that involves a respect for and integration of individual differences, taking into account the patient's beliefs, goals, and resources. In order to provide client centered care, nurses need to know the individual needs, preferences, and expectations of those with whom they work (Cumbie et al., 2004). Therefore, it is imperative that nurses become aware of the challenges to maintaining and achieving optimal physical health for the older adult with schizophrenia.

The purpose of this article is to inform nurses about the current state of the science on factors that contribute to the poor physical health of older adults with schizophrenia in order to begin to guide client centered care to meet the individual and collective needs of this vulnerable population.

Physical Health Problems Across the Lifespan

The literature reviewed in this section is not limited to older adults because of a lack of data on this cohort. Clearly this is a limitation, yet also supports the importance of studying the unique needs of older adults with schizophrenia.

Influence of Psychiatric Symptoms

The literature indicated an association between greater numbers of psychiatric symptoms and poor physical health status, less effective disease management, and lower levels of health services use. For instance, research has shown that a greater number of medical problems are independently associated with worse perceived physical health status and more severe psychosis (Dixon et al., 1999). Also, worse physical functioning, as measured by the physical component summary subscale on the 12-item Medical Outcomes Study short form, has been associated with a greater total number of symptoms across the continuum of schizophrenia symptoms assessed (Chwastiak et al., 2006).

Disease management is impacted by schizophrenia symptoms as well. Dickerson et al. (2005) illustrated this point with their findings that total psychiatric symptoms were significantly associated with reported barriers to diabetes care. El-Mallakh (2006) elaborated on this in a grounded theory study of self-care behaviors in individuals with schizophrenia and diabetes mellitus. One of El-Mallakh's (2006) conclusions was that

despite varying degrees of self-care, most participants believed that engaging in effective diabetes self-care was not possible when psychotic symptoms became overwhelming.

Schizophrenia symptoms may also impact service use because they may limit insight into illness, possibly leading to missed opportunities to participate in activities to prevent and screen for diseases (Jeste, Gladsjo, Lindamer, & Lacro, 1996). Paranoia can impact the patient's ability to participate in medical testing or treatment and poverty of speech may limit the individual's expression of symptoms (Copeland et al., 2006). Less than adequate medication treatment for comorbid physical conditions has been associated with higher depression scores and higher amounts of positive symptoms (Vahia et al., 2008). Schizophrenia symptoms may also play a role in the delay of diagnosis and treatment of cancer. For example, Inagaki et al. (2006) found a correlation between more severe negative symptoms and difficulty understanding and cooperating with cancer treatment. When cancer was eventually discovered, the disease was already advanced to stage IV in four of the patients in the untreated group. The literature showed that psychiatric symptomatology appears to have an association with medical comorbidity that is in need of further research. The research that has looked at this intersection was not done with methodology that would allow for interpretations of causality.

Smoking and Substance Use

Various unhealthy behavior patterns were documented that may negatively impact the physical health of the older adult with schizophrenia such as higher rates of smoking and the prevalence of alcohol use. Dickerson, Pater, and Origoni (2002) revealed that in a sample of 43 women with schizophrenia (between the ages of 40-70), 63% smoked and

were more likely than smokers in the age matched reference sample to smoke greater than 20 cigarettes a day. Chafetz, White, Collins-Bride, Nickens, and Cooper et al. (2006) illustrated the impact of smoking in describing the physical functioning of 309 adults (between the ages of 18-60) with severe mental illness. Lifetime years of smoking significantly impacted physical functioning which included activities such as walking, lifting, and physical activity (Chafetz et al., 2006).

Morbidity studies alluded to the impact of long years of smoking on the health of this population. Adults over the age of 60 in a sample of 8,083 diagnosed with serious mental illness were more likely than younger cohorts with similar diagnoses to have comorbid pulmonary diseases (Kilbourne et al., 2005). Deaths due to respiratory diseases were found to be more common in long stay psychiatric patients in Finland when compared to the non mentally ill population and that circulatory system diseases were the most common single cause of death in this sample at rates exceeding the mortality of the general population by a factor of 3.5 (Rasanen, Hakko, Viilo, Meyer-Rochow, & Moring, 2003).

It has been indicated that substance use is an issue for the older adult with schizophrenia as well (Kilbourne et al., 2005; Sajatovic, Friedman, Sabharwal, & Bingham, 2004). Alcohol use in early life may impact physical health in later years. Chafetz et al. (2005) found that alcohol was the number one substance abused in a sample of 781 individuals with severe mental illness (between the ages of 18-64). Almost half of the subgroup with schizophrenia (271) in this sample reported some alcohol use.

Sociodemographic Factors

The literature reviewed revealed that conditions associated with urban life, poor living conditions, and inadequate health role models and settings may contribute to this poor health. Chafetz et al. (2005) indicated that health problems associated with the urban poor such as allergies, asthma, injuries, bronchitis, and skin problems are found frequently in the population with severe mental illness. The onset of these diseases may be partially accounted for by homelessness, shelter living, or use of short-term hotels. Schizophrenia is approximately 10 times more common in the homeless population in comparison to the general population (Folsom et al., 2002). Older adults living in shelters may face further burden through exposure to respiratory and skin infections due to close living quarters and inadequate hygiene (Chafetz et al., 2005). Group homes may promote positive healthy living aspects such as access to health care and socialization yet may reinforce negative health behaviors through incorporation of sedentary living and diets that are not ideal in the management of weight (Chafetz et al., 2005).

A few studies indicated that the population with schizophrenia is more likely to have health insurance (most likely Medicare/Medicaid) than other subgroups of those diagnosed with mental illness (Chafetz et al., 2005; Dixon et al., 1999). Yet, this does not ensure comprehensive access to care. Patients are frequently being evaluated for their physical health needs by primary care providers without specialized psychiatric training, not by individuals in psychiatric settings. A cross sectional survey of outpatient visits from 1993-1998, captured in a national ambulatory medical care survey, documented 2,397 physician visits by patients diagnosed with schizophrenia or bipolar disorders with almost one quarter of the sample cared for in the primary care sector (Daumit, Pratt, Crum, Powe, & Ford, 2002). Copeland et al. (2006) studied mortality reports during

fiscal year 2002 in a sample of patients with schizophrenia within the Veterans Administration system and found a two-fold increased risk of unforeseen death. Unforeseen death was defined as deaths not preceded by a record of treatment for life-threatening diseases as would ordinarily be the case with most chronic diseases. These patients seemed to have become significantly disengaged from the system as evidenced by limited inpatient and out-patient visits (Copeland et al., 2006).

Contributing Factors Specific to the Older Adult

Self management of many chronic conditions experienced by older adults is shown to positively influence physical health. Thus, the common chronic diseases that involve self-care management and that especially affect older persons with schizophrenia will be reviewed first. The section will conclude with a review of the literature on the impact of the physiological aspects of aging and medication side effects in the population of aging people with schizophrenia.

Diabetes Mellitus Type II

Diabetes mellitus type II is common in the older adult with schizophrenia (McKibbin et al., 2006). Contributing factors to the onset are multi-factorial and possibly include genetics, side effects of antipsychotic medication and lifestyle (McKibbin et al., 2006). Regardless of the etiology, successful management of diabetes is dependent on ongoing medical monitoring as well as self-monitoring by the patient (McKibbin et al., 2006). Few interventions have targeted the health promotion of the older adult with schizophrenia. However, a study conducted by McKibbin et al. (2006) investigated the efficacy of a 24-week lifestyle to reduce obesity in middle aged and older adults with

schizophrenia and type II diabetes mellitus. A pre-test post-test quasi-experimental design was used to test the feasibility and efficacy of the intervention, Diabetes Awareness and Rehabilitation Training (DART). The intervention included diabetes education, lifestyle exercise, and nutrition counseling. Participants were further counseled on how to talk with their providers about diabetes management. The total sample was comprised of 64 subjects, ranging in age from 40 to 81, from board and care, day treatment programs, and community clubhouses that were randomly assigned to treatment (DART) and control groups (UCI) (McKibbin et al., 2006).

About 90% of the sample completed the study and results showed significant reductions in body mass index and body weight for the DART group. The DART group also had greater reductions in waist circumference, in plasma triglyceride levels, and number of fat servings consumed in daily dietary intake. Diabetes knowledge was significantly improved in the DART group with further improvement seen in those who attended all 24 sessions. Additionally, physical activity scores improved for the DART group. Significant correlations were found between diabetes self-efficacy and improved diabetes knowledge yet differences in glycosylated hemoglobin scores were not statistically significant. This study showed that an intervention can improve self management of diabetes in older people with schizophrenia. However McKibbin et al. (2006) suggest that additional intervention with one-on-one reinforcement of skills and information may be necessary to achieve better health outcomes.

Hypertension

Hypertension is another common comorbidity among the general population as

well as the person with schizophrenia and from the review of literature it appears that frequency of blood pressure control is lower among older adults with schizophrenia. An estimated fifty million individuals in the US are diagnosed with hypertension and a relatively small proportion of these people have adequate blood pressure control (Dolder, Furtek, Lacro, & Jeste, 2005). Non-adherence to antihypertensive therapy is thought to be a common cause of uncontrolled high blood pressure (Dolder et al., 2005). Hypertension management may be more complex within the population of people with schizophrenia. Cardiovascular morbidity has been identified as one of the most common causes for increased mortality within the population with schizophrenia (Dolder et al., 2005). The aging process further complicates the issue of hypertension in part because older adults may be taking multiple medications (adding a range of side effects to the mix) and is made even more difficult when this aging person is also struggling with a mental illness (Dolder et al., 2005).

This aspect of poorly controlled hypertension was evaluated by Dolder et al. (2005) by analyzing the relationship between antihypertensive medication adherence and blood pressure control among 89 patients with schizophrenia or related psychotic disorders compared to 89 age matched comparison patients. Both groups were hypertensive, at least 45 years old, were receiving care at the Veterans Administration, and had a minimum of two antihypertensive prescriptions filled during the 12-month period. There was no significant difference found between the groups regarding the number of prescriptions given, the dose, or class of antihypertensive prescribed.

These results indicated that patients with schizophrenia had significantly lower frequency of blood pressure control despite similar antihypertensive medication

adherence when compared to age matched comparison patients (Dolder et al., 2005). Medication adherence was measured with the cumulative mean gap ratio. This was done by dividing the number of days of medication that were unavailable for consumption (due to delayed refills) by the total number of days during that same time interval. Dolder et al. (2005) postulated the difference between groups could be due to factors not specifically analyzed such as higher rates of smoking and lower rates of health promoting behaviors.

Weight management

Weight management is another aspect of physical health involving self-care. Multiple studies illustrate the prevalence of obesity among the older population with schizophrenia. Dickerson et al. (2002) reported that the majority of women in their sample of 43 women with schizophrenia (between the ages of 40-70) were obese or overweight. Bhat, Chiu, and Jeste (2005) reviewed nutrition literature in geriatric psychiatry suggesting that adults with schizophrenia may have diets higher in fat and lower in fiber when compared to others of equal socioeconomic status. Obesity can also be attributed to the side effects of antipsychotic medication (Allison et al., 2009).

Less involvement in physical activity has also been documented in the population with schizophrenia and may contribute to the increased weight (Bhat et al., 2005). Studies evaluating the physical activity of the person with schizophrenia were located yet related only to the younger than 55 population. Barriers to activity discussed were the impact of psychiatric symptoms, a schizophrenia diagnosis, and sociodemographic factors (McDevitt, Snyder, Miller, & Wilburn, 2006). Living in urban neighborhoods, feeling unsafe to walk around, or fear of being identified as mentally ill were listed as

additional barriers to exercise (McDevitt et al., 2006). For example, one participant noted hearing comments about her physical size while riding the bus. Benefits to activity, such as involvement in life and a positive sense of self, were also discussed (Fogarty & Happell, 2005; McDevitt et al., 2006). An expert committee reported on obesity among people with serious mental illness suggesting that obesity in this population has not been adequately studied and deserves further attention (Allison et al., 2009).

Aging Process

Age associated changes in metabolism, physiology, and cognitive functioning pose a threat to achieving improved physical health (Bartels, 2004; Bhat et al., 2005). Higher rates of sensory impairment were found in the older person with schizophrenia, such as hearing impairment (Rodriguez-Ferrera, Vassilas, & Haque, 2004; Dixon et al., 1999). Hearing impairment may contribute multiple difficulties in communicating thus adding further burden to achieving optimal health status. Furthermore, older adults are at risk for normal cognitive slowing and functional decline related to the aging process (Sudore, Mehta, et al., 2006). This impaired cognition can also contribute to impaired communication in the health care environment and inability to independently care for physical health needs.

Medication Side Effects

Symptoms associated with schizophrenia often necessitate treatment with antipsychotic medication. Treatment with antipsychotic agents has been associated with an array of extra pyramidal symptoms, including tardive dyskinesia, dystonia, and akathisia (Ren et al., 2004). More recently, comorbidity has been attributed to the

increased use of novel antipsychotic medications, specifically clozapine and olanzapine, because of their potential to result in weight gain and the development of diabetes (Allison et al., 2009; Henderson et al., 2000). Lambert, Copeland, Sampson, and Duffy (2006) found an association with initiation of olanzapine treatment and new onset diabetes within the first year of treatment upon reviewing 412 charts of middle-aged veterans within the Veteran's Administration. Tovey, Rampes, and Livingstone (2005) also found increasing blood sugar levels in case studies of patients initiated on clozapine therapy. Furthermore, an increased risk of sudden cardiac death has been associated with both typical and atypical antipsychotic medications (Ray, Chung, Murray, Hall, & Stein, 2009). Hyperlipidemia has been associated with the newer antipsychotic medications as well as dry mouth, abdominal pain, and dyspepsia (Bartels, 2004; Ren et al., 2004).

Older age individuals are at a higher risk for development of adverse effects due to alterations in pharmacokinetic responses resulting in an increased sensitivity to medication (Le Couteur, Hilmer, Glasgow, Naganathan, & Cumming et al., 2004). Furthermore, second generation anti-psychotic polypharmacy has been common in older adults with schizophrenia and can impact side effect profiles further (Gilmer et al., 2007)

Health Care System Factors

This final section addresses potential contributing factors impacting physical health for the adult with schizophrenia within the health care system. First, health care disparities will be described, then there will be a brief discussion on what is known regarding the perspective of patient and provider on the health care system.

Health Care Disparities

Comprehensive quality health care is dependent on preventing, screening for and treating disease, yet screening differences are apparent in the population with schizophrenia. The literature reviewed revealed that older adults with schizophrenia are often not provided with health screening tests and medications or procedures that may be helpful in preventing future health complications.

Studies showed that people with schizophrenia are under diagnosed, under treated, and less likely to be admitted during early, less severe stages of a physical illness (Folsom et al., 2002). Lindamer et al. (2003) illustrated screening and prevention differences. The authors indicated that despite higher potential for gynecological diseases in the female population with schizophrenia, many may go undetected. A convenience sample of 65 older women with schizophrenia (between the ages of 50-79) was recruited from an ongoing study of late life psychosis (Lindamer et al., 2003). Gynecologic service use was compared to a control group of 51 older women with no known psychiatric diagnosis. The women with schizophrenia were less likely to receive mammograms, pelvic examinations, pap smears, or to have used hormone replacement therapy when compared to women without a psychiatric diagnosis.

Similar findings are seen with significantly lower utilization of osteoporosis drugs and hormone replacement therapy for indicators of osteoporosis in a sample of 46 women with schizophrenia when compared to age matched controls. (Bishop, Alexander, Lund, & Klepser, 2004). The 65 and older women in the control group were 2.2 times more likely to receive osteoporosis drugs (Bishop et al., 2004).

Folsom et al. (2002) add to these findings by documenting fewer preventive care visits. Their study of homeless older patients with schizophrenia receiving care at a shelter revealed lower rates of cholesterol and colon cancer screening when compared to depressed patients. The group with schizophrenia was also less likely to receive a detailed physical exam. Preventive care services were offered only 11% of the time in a national survey of outpatient visits (Daumit, Crum, Guallar, & Ford, 2002). Preventive care was more likely to be offered if a nurse was present during the visit. Furthermore, when compared with age matched peers in the general community, the older adult with schizophrenia may receive less adequate medication treatment for certain chronic conditions (Vahia et al., 2008). Nasrallah et al. (2006) highlight this disparity when they found that 88% of participants with dislipidemia in the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study were not receiving lipid lowering medication.

Acute care differences are also apparent. An analysis of a national cohort showed patients with schizophrenia differed in the care received post myocardial infarction in that they were less likely to undergo cardiac catheterization and had a greater one year mortality rate than non mentally ill patients (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001). Himelhoch, Leith et al. (2009) also showed that adults with schizophrenia and type 2 diabetes who smoke were less likely to receive services and treatments known to improve cardiovascular outcomes, such as cardioprotective pharmacotherapy, when compared to non-mentally ill smokers with type 2 diabetes.

Petersen, Normand, Druss, and Rosenheck (2003) looked at similar outcome measures in 4,340 veterans discharged after an acute myocardial infarction. Patients with mental illness (including schizophrenia, other psychoses, bipolar, major depression, or

post traumatic stress disorder for a total of 859 subjects) were marginally less likely to receive angiography yet no significant difference was found in regards to receipt of coronary artery bypass graft or medications known to be of benefit post myocardial infarction. Furthermore, no difference in one-year mortality rate was found. Providers caring for patients outside of this coordinated care setting, however, may experience difficulties (Simon, Lauber, Ludewig, Braun-Scharm, & Umbricht, 2005; Bazemore, Gitlin, & Soreff, 2005).

Tsay et al. (2007) analyzed National Health Insurance hospital discharge data in Taiwan from 1997-2001 to compare the likelihood of perforated appendix in 97,589 adults over the age of 15 hospitalized for acute appendicitis. After adjusting for age, sex, ethnicity, socioeconomic status, and hospital characteristics, the presence of a schizophrenia diagnosis was associated with 2.83 times higher risk of rupture. The presence of other mental disorders was not a significant predictor of rupture. Patients with no mental disorder had the lowest rupture rate. Increasing age and being male were also associated with higher risk of rupture.

The use of emergency services has been documented to be higher among people with schizophrenia in comparison to the person without a mental illness as well as to a person with a mental illness other than schizophrenia (Mausbach, Cardenas, McKibbin, Jeste, & Patterson, 2008). Mausbach et al. (2008) suggest this use of emergency services may be deterred by teaching the older adult with schizophrenia life skills through psychosocial interventions. The researchers utilized a previously tested behavioral skills intervention, the Functional Adaptation and Skills Training (FAST), for improving functional skills in a sample of 240 older adults with psychotic disorders. Control participants were twice as

likely to use any emergency services during the active phase of the intervention. The long term benefits of the FAST intervention were not as clear as a total of 78 participants used services in the maintenance phase (FAST=37 and control=41) with no significant difference found between groups. The authors conclude that the intervention appears efficacious at reducing the short-term use of emergency services but that long-term efficacy is not clear.

Patient and Provider Views on Primary care

Through conducting focus groups, Lester, Tritter, and Sorohan (2005) showed that some providers' views on caring for the adult with serious mental illness involve a level of hesitancy contrasted with a desire to treat diseases more effectively. Providers often did not feel they had the sufficient training and skills to treat severe mental health problems. Meanwhile, the patients indicated a preference for continuity of care and ease in the process of navigating the health care system. Patients preferred seeing their primary care provider for both physical and mental health issues attributing this to the already established trusting relationship with the provider. Patients also expressed concern about waiting rooms and the benefit of having an advocate to help make or attend the appointment.

Health Information

Persons with schizophrenia may be limited in the breadth of information they take in regarding their physical health (Dickerson et al., 2005). Yet people with schizophrenia were interested in improving their health. MacHaffie (2002) interviewed 41 persons over the age of 18 diagnosed with schizophrenia, schizoaffective or bipolar disorders to

determine who provided the patients with health information and the perceived reliability of the information given. Patients deemed health professionals as most reliable sources of information, preferred interpersonal communication over written methods, reported a desire to be healthier, and had contemplated making behavior changes during the past year, such as smoking cessation, but did not know how to begin. Auslander and Jeste (2002) confirmed the patients' desire to improve personal health status on a survey of 72 older stable outpatients with schizophrenia and related psychotic disorders about their perceived specific health needs and knowledge. The patients also placed a high priority on improved physical health.

Discussion

Limitations to generalizing these findings relate to the fact that much of the literature reviewed excluded the older adult with schizophrenia and often the sample sizes were small. Less than 10 percent of published research in schizophrenia focuses on older adults (Mittal et al., 2006). Samples were also biased towards participants that had access to care and were engaged with the health care system. Finally, none of the studies adequately explored the individual perspective of the older adult with schizophrenia regarding physical health. This perspective may be important as Cumbie et al. (2004) suggest that clients must make personal sense of health information in order to obtain meaning and sustain desired health outcomes.

Key factors were identified as contributing to poor physical health including the impact of schizophrenia and schizophrenia symptoms, higher rates of smoking and alcohol use, and sociodemographic factors. Contributing factors specific to the older

adult with schizophrenia were identified as issues relating to chronic disease management, the physiological impact of aging as well as iatrogenic effects of treatment. Finally, factors in health care services were identified as health care disparities, provider difficulties in caring for the patient with schizophrenia, the patients' reported desire for advocacy and continuity of care that may not be met, as well as issues relating to delivery and receipt of health information. A consistent finding across all sections of this literature review was the potential for schizophrenia and schizophrenia symptoms to interact with physical health as evidenced by associations with: greater numbers of comorbidities, physical functioning, altered self care management, living environments, altered activity involvement, increased numbers of medications and side effects, and altered interactions within the health care system.

Recommendations for Clinical Practice

Critical information was uncovered in the literature review that can guide patient centered care for the older adult with schizophrenia. Providing comprehensive care that includes both caring for the mental as well as physical health care needs is imperative. Collaborating with other members of the health care team, such as social services and psychiatry, may begin to improve the physical health of the older adult with schizophrenia. In addition, providing patient centered education, including discussions about identifying patient goals, addressing challenges and frustrations of self care and exploring the meanings that patients place on self-care were also emphasized (El-Mallakh, 2006; Auslander & Jeste, 2002; MacHaffie, 2002; MckKibbin et al., 2006, Mausbach et al, 2008)

Key areas for future research surround the need to include the older adult with schizophrenia in research studies. Additionally, gathering the individual perspective on physical health is necessary. This review has illustrated that psychiatric symptoms have an influence on physical symptom recognition, health management, and self-care, yet no studies were identified that specifically evaluate the influence of schizophrenia on health meaning and understanding in the older adult. Gathering this health understanding may provide the background for developing programs for improving physical health, supporting the patient's engagement in care, and diminishing the health care disparities among older adults with schizophrenia.

The future challenges of caring for the growing aging population must be addressed in the present. Attention to older adults with schizophrenia must be a research and clinical priority in order to evolve scientifically supported interventions that will allow these individuals to live healthy and satisfied lives into their later years.

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Paper 2

The Impact of Symptomatology on Response to a Health Promoting Intervention among
Older Adults with Schizophrenia

Heather Leutwyler

Heather C. Leutwyler, PhD (c), FNP, CNS¹, Margaret Wallhagen, PhD, GNP-BC,

AGSF, FAAN¹, Christine McKibbin, PhD²

1. University of California San Francisco, School of Nursing
2. University of Wyoming, Department of Psychology

Abstract to be presented at the 162nd annual meeting of the American Psychiatric Association, San Francisco, CA, May, 2009 and the 61st annual meeting of the Institute on Psychiatric Services, New York City, NY, October 2009.

Abstract

Objectives: To explore the relationship between the symptoms of schizophrenia experienced by older persons diagnosed with schizophrenia and type 2 diabetes mellitus (DM) and their response to a health promoting intervention. **Design:** Secondary data analysis. **Setting:** Participants recruited from board-and-care facilities and day treatment programs. **Participants:** Persons over age 40 with schizophrenia or schizoaffective disorder and DM. **Intervention:** The original study was a lifestyle intervention program. Participants were randomly assigned to a 24-week Diabetes Awareness and Rehabilitation Training (DART; n=32) or Usual Care plus Information (UCI; n=32) comparison group. **Measurements:** Baseline and 6-month (intervention completion) assessments included a diabetes knowledge test (DKT), diabetes empowerment scale (DES), and symptomatology defined by the Positive and Negative Syndrome Scale (PANSS). Hierarchical regression models were used to analyze the data. **Results:** A significant condition by symptom interaction was found for DKT. The difference between change in knowledge for DART and UCI groups depends on prevalence and severity of total, negative, and general symptoms. There was no significant condition by positive symptom interaction for DKT. A significant main effect was found between total, negative, positive, and general symptoms in the total sample for improvement in DES. Higher prevalence and severity of symptoms was negatively associated with improvement in DES. **Conclusion:** Research is needed on larger samples, those with greater severity of symptoms, and using measures that more completely capture the individual experience of symptoms. Researchers need to consider the impact of schizophrenia symptoms on response to health promoting interventions.

The Impact of Symptomatology on Response to a Health Promoting Intervention among Older Adults with Schizophrenia

An estimated 1 in 17 people in the United States suffer from a serious mental illness (Kessler, Chiu, Demler, Merikangas, & Walters et al., 2005) such as schizophrenia, a condition that affects approximately 2.4 million Americans (National Institute of Mental Health (NIMH), 2008). The number of people who struggle with schizophrenia living beyond the age of 55 is growing. By the year 2030, the number of severely mentally ill older adults is predicted to more than double to 15 million (Bartels, 2004).

The effects of schizophrenia on older individuals are multi-faceted. Current data suggests that their physical health status is poor (Kilbourne et al., 2005), possibly because of difficulties with disease prevention (Bishop, Alexander, Lund, & Klepser, 2004; Folsom et al., 2002; Daumit, Crum, Guallar, & Ford, 2002), screening (Lindamer et al., 2003), and treatment (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001; Vahia et al., 2008). In order to improve the physical health status of these older adults, researchers and clinicians need interventions to prevent, screen for and manage physical comorbidities. Yet before interventions can be designed, the factors that influence the individual's response to interventions, such as the symptoms experienced by persons with schizophrenia, must be understood.

The purpose of this paper is to explore the relationship between the symptoms of schizophrenia experienced by older persons diagnosed with schizophrenia and their response to a health promoting intervention. First, a brief overview of schizophrenia and the symptoms experienced by individuals with schizophrenia will be presented along

with current research perspectives about how these symptoms may influence health status. Then, the Symptom Management Model (Dodd et al., 2001) will be discussed as a theoretical standpoint from which to explore the relationship between symptoms and physical health. Next, a secondary analysis of data from a lifestyle intervention program for persons with schizophrenia and diabetes will be presented to illustrate the potential influence of symptoms on health through their effect on the response to a health promoting intervention. The discussion will focus on the need for further attention to the impact of symptoms on physical health and the need for further research to enhance our understanding of the underlying mechanisms involved.

Background and Significance

Schizophrenia is a chronic, severe, and disabling brain disorder (National Institute of Mental Health (NIMH), 2007). People with schizophrenia may hear voices that other people do not hear, may believe that others are controlling their mind and thoughts, or believe that others are trying to harm them (NIMH,2007). These experiences are often frightening, usually chronic, and have the potential to impact all aspects of an individual's life including physical health. The symptoms experienced by the person with schizophrenia are often categorized as positive, negative, and general. Positive symptoms refer to thoughts, perceptions, and behaviors such as hallucinations, delusions, and paranoia (NIMH, 2007). Negative symptoms refer to the absence of specific thoughts, perceptions or behaviors and include symptoms such as apathy, anhedonia, and poverty of speech (NIMH, 2007). General symptoms refer to general psychopathology and include problems with attention, certain types of memory, and executive functioning (NIMH, 2007). These varying symptoms can be problematic for the person, significantly

impacting their daily lives. Management is thus imperative. Treatment may consist of a multi-tiered approach that includes medication along with psychosocial interventions such as the development of illness management skills, self-help groups, and cognitive behavioral therapy (NIMH, 2007).

Literature Review

Current literature conducted among people with schizophrenia and schizophrenia spectrum disorders allude to the association between higher numbers of psychiatric symptoms and poorer physical health status, less effective disease management, and lower levels of health services use. For example, research has shown that a greater number of medical problems are independently associated with worse perceived physical health status and more severe psychosis (Dixon, Postrado, Delahanty, Fischer, & Lehman, 1999). Further, worse physical functioning, as measured by the physical component summary subscale on the 12-item Medical Outcomes Study short form, has been associated with a greater total number of symptoms across the continuum of schizophrenia symptoms assessed (Chwastiak et al., 2006).

Symptoms experienced by individuals with schizophrenia impact disease management as well. Dickerson et al. (2005) illustrate this with their findings that total psychiatric symptoms were significantly associated with reported barriers to diabetes care. El-Mallakh (2006) elaborates on this diabetes specific understanding through developing a theory of evolving self care in individuals with schizophrenia and diabetes mellitus in a grounded theory study. One of El-Mallakh's (2006) conclusions is that despite varying degrees of self-care, most respondents believed that engaging in effective diabetes self-care was not possible when psychotic symptoms became overwhelming.

Schizophrenia symptoms may also impact service use because psychiatric symptoms may limit insight into illness, thus leading to the possibility of missed opportunities to participate in activities to prevent, and screen for diseases (Jeste, Gladsjo, Lindamer, & Lacro, 1996). Paranoia can impact the patient's ability to participate in or accept medical testing or treatment, and poverty of speech may limit the individual's expression of symptoms (Copeland, Zeber, Rosenheck, & Miller, 2006). Schizophrenia symptoms also have been suggested as playing a role in delay of diagnosis and treatment of cancer as well as the understanding of the disease (Inagaki et al., 2006). Inagaki et al. (2006) found a correlation between more severe negative symptoms and difficulty understanding and cooperating with treatment. When cancer was discovered, the disease was already advanced to stage IV in four of the patients in the untreated group.

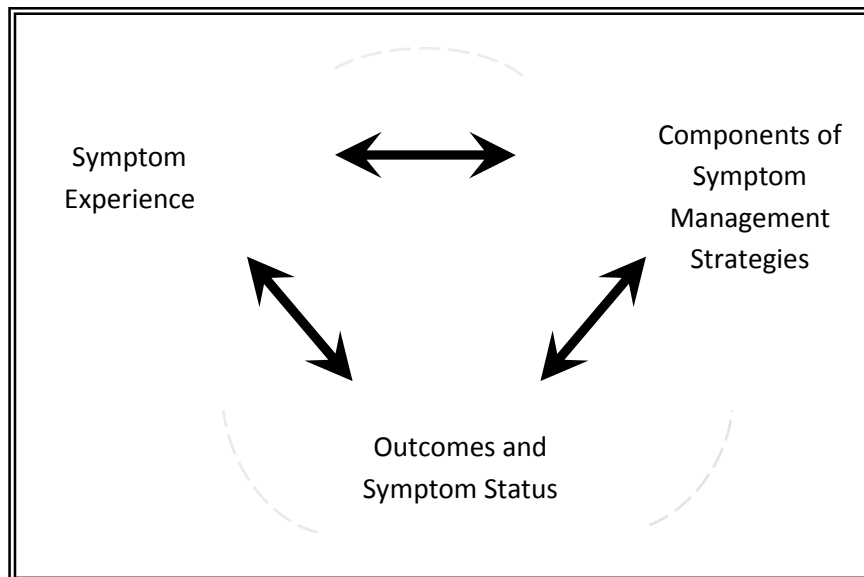
The literature reviewed here on the relationship between psychiatric symptoms and physical health was not limited to only older adults because of a lack of data on this particularly vulnerable cohort. Clearly, this is a limitation, yet also supports the importance of studying the unique needs of older adults with schizophrenia. In addition, multiple symptom measurement scales are utilized throughout the studies cited thus further limiting generalizability. At the same time, the literature does indicate that the continuum of schizophrenia symptoms are associated with greater medical comorbidity as well as poorer understanding of and cooperation with treatment, lower service use, and perceived barriers to care. One framework which may facilitate an understanding of the relationship between symptoms and physical health status is the Symptom Management Model (Dodd et al., 2001).

Symptom Management Model

A symptom has been defined as “a subjective experience reflecting changes in bio-psychosocial functioning, sensations, or cognition of an individual” (Dodd et al., 2001). Symptoms are an important cue to bring problems to the attention of both patients and their clinicians. The UCSF Symptom Management Model comes from the belief that effective management of a symptom or group of symptoms demands that the symptom experience, symptom management strategy, and outcomes all be considered (Dodd et al., 2001). Thus, one of the key assumptions of the model is that the gold standard for the study of symptoms is the perception of the individual experiencing the symptoms and the person’s self report. Further, symptom management is viewed as a dynamic process that is modifiable by both individual outcomes and the influences of the nursing domains of person, health/illness, or environment (Dodd et al., 2001).

The conceptualized relationships between the dimensions depicted in the adapted revised model can be found in figure 1.

Figure 1. Symptom Management Model, Adapted from Dodd et al., 2001



Dimensions of the Model

The symptom management model provides direction for selecting clinical interventions, informing research, and bridging a variety of symptoms associated with numerous diseases and conditions, including physical and mental. The first dimension of the model discussed here is the symptom experience. This experience includes the individual's perception of a symptom, meaning of a symptom, and response to the symptom (Dodd et al., 2001). The perception of a symptom refers to whether an individual notices a change from the way they usually feel or behave (Dodd et al., 2001). Responses to the symptoms can be physiological, psychological, socio-cultural, and behavioral (Dodd et al., 2001). There are bi-directional relationships among the components of the symptom experience, such as the potential for evaluation, and response to modify the symptom perception. These are conceived to be iterative processes and can occur simultaneously (Dodd et al., 2001). For the older adult with schizophrenia, the iterative nature of the experience could include symptom responses to a variety of things in the person's life, such as engagement or lack of engagement in a diabetes educational intervention. This multilevel impact may allow for the possibility of the illness to impact other illnesses, such as schizophrenia impacting diabetes.

A second dimension of the model is symptom management. The goal of symptom management is to circumvent a negative outcome through biomedical, professional, and self care strategies (Dodd et al., 2001). This management begins with assessment, followed by identifying a focus for intervention, and is a dynamic process that requires changes in strategies over time. The symptom management model includes management specifications of what, when, where, why, how much, to whom, and how. For the older

adult with schizophrenia, this symptom management may include activities such as a medication regimen and involvement in psychosocial treatment.

The outcomes dimension focuses on eight factors: functional status, self-care, costs, quality of life, morbidity and co-morbidity, mortality, and emotional status (Dodd et al., 2001). The older adult with schizophrenia is known to experience significantly higher rates of morbidity and mortality as well as declining quality of well-being associated with increased disability (McKibbin, Patterson, & Jeste, 2004). The factors in the outcome dimension, such as morbidity and functional status, provide an illustration of the factors relatedness to one another as well as to symptom status. When a symptom is treated and resolved, Dodd et al. (2001) suggest the model is no longer needed. However, complete symptom resolution is often not the case with the older adult with schizophrenia because the illness is chronic and symptoms usually remain even if in remission. Therefore the symptom management model may remain applicable over the long term.

The symptom management model provides a theoretical foundation for exploring the relationship between physical health and schizophrenia symptoms. As the discussion about the conceptual model illustrates, symptom experiences, symptom management strategies, and symptom outcomes are key factors to consider when evaluating the relationship of schizophrenia to physical health status. These dimensions can help clinicians and researchers better understand how the individual's needs and subjective experience interact with and are influenced by interventions or management strategies. Understanding these experiences and needs may be necessary to design physical health interventions and treatment plans that are tailored specifically for the older adult with schizophrenia. The results of a secondary analysis of data from a study designed to test a

diabetes education intervention among a sample of older adults with schizophrenia and co-morbid diabetes will elaborate on the link between schizophrenia symptom experience, management and outcomes and the person's physical health status and response to the educational intervention.

Original Study

Few interventions have been developed and tested for the health promotion of the older adult with schizophrenia. However, a study conducted by McKibbin et al. (2006) investigated the efficacy of a 24-week lifestyle intervention based on social cognitive theory to reduce obesity in middle aged and older adults with schizophrenia and type II diabetes mellitus (DMII). The hypothesis for this study was that the intervention group receiving the Diabetes Awareness and Rehabilitation Training (DART) would demonstrate greater reductions in body mass index (BMI) in comparison to the usual care plus information group. A pre-test post-test quasi-experimental design was used to test feasibility and efficacy of DART. The intervention consisted of diabetes education, nutrition counseling, and lifestyle exercise. Participants were also counseled on how to talk with their providers about diabetes management.

The total sample was comprised of 64 subjects from board and care, day treatment programs, and community clubhouses that were randomly assigned to treatment (DART) and control groups (UCI) (McKibbin et al., 2006). All participants were taking neuroleptic medications. Participants ranged in age from 40 to 81 and carried the diagnosis of DMII for less than ten years.

Approximately 90% of the sample completed the study and results showed

significant reductions in BMI and body weight for the DART group. DART group participants also had greater reductions in waist circumference, in plasma triglyceride levels, and number of fat servings consumed in daily dietary intake. Diabetes knowledge was significantly improved in the DART group and further improvement was also seen with those who attended all 24 sessions. Physical activity scores improved for the DART group as well. Significant correlations were found between diabetes self-efficacy and improved diabetes knowledge. Differences in glycosylated hemoglobin scores were not statistically significant.

Symptom Experience and Health Outcomes

The current study explored whether the symptoms experienced by older adults with both schizophrenia and co-morbid diabetes influenced the response to a diabetes education program.

Methods

For the purpose of this secondary data analysis, the variables of interest are schizophrenia symptoms, diabetes knowledge (DK), and diabetes self-efficacy. These variables were chosen with the theoretical guidance of the Symptom Management Model (Dodd et al., 2001). Exploring the amount, type, and severity of symptoms in relation to diabetes knowledge and self-efficacy may help to further understand the relationship between schizophrenia symptoms and physical health status.

The 23-item diabetes knowledge test (DKT) designed to measure diabetes knowledge in type 1 and type 2 diabetes patients (Fitzgerald et al., 1998) was used to assess diabetes knowledge. Prior psychometric testing supports the validity and reliability

of the DKT (Fitzgerald et al., 1998). Internal consistency reliability (Cronbach's alpha) was greater than .70. The test takes approximately 15 minutes to complete and the reading level as assessed by the Flesch-Kincaid is at the 6th grade level. Fitzgerald et al. (1998) conclude that the DKT is an effective and efficient way to evaluate patients' diabetes knowledge. For the purposes of the current study, the percent correct was calculated for the first 14 items (i.e., items appropriate for people who do not use insulin). Higher scores reflect greater DK.

Participants rated their diabetes self-efficacy on the 28-item Diabetes Empowerment Scale (DES) (Anderson et al., 2000). Internal consistency reliability (Cronbach's alpha) was .96 and the three factor solution accounts for 56% of the total variance (Anderson et al., 2000) The scale has a test-retest correlation of .79 (Anderson et al., 2000). Items were rated on a 5-point likert-type scale from 1 (strongly agree) to 5 (strongly disagree). A mean score was calculated for each of the three subscales: managing psychosocial aspects of diabetes (MPAD), dissatisfaction and readiness to change (DRFC), and setting and achieving goals (SADG). Higher scores reflect higher self-efficacy.

Psychiatric symptom severity was measured with the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein, & Opler, 1987). Kay et al. (1987) developed the PANSS which consists of three subscales measuring seven positive, seven negative, and 16 general psychopathology symptoms. Lindenmayer, Harvey, Khan, and Kirkpatrick (2007) describe the 30-item scale to have demonstrated reliable psychometric properties in assessing symptoms and their change during the course of treatment in clinical trials with participants diagnosed with schizophrenia.

The PANSS is designed to be administered by personnel trained in psychiatric interview techniques and with experience working with persons with schizophrenia (Lindenmayer et al., 2007). The scale takes approximately 40 minutes to administer and was developed with a comprehensive anchoring system with the intention of improving reliability of ratings (Lindenmayer et al., 2007). The three subscales contain the items listed in Table 1.

The time frame for rating the PANSS is typically within the past week before the rating (Lindenmayer et al., 2007). A semi-structured interview for the PANSS, called the SCI-PANSS, guides interviewers with specific questions to gather information required to evaluate the presence and severity of symptoms. The items on the PANSS are summed to determine the scores on the three subscales and the total score (the sum of all three subscales). Items are scored from one (absent) to seven (extreme) (Lindenmayer et al., 2007). The potential range of scores for the positive and negative subscales is 7 to 49, with a total score of 7 indicating no symptoms. The potential range of scores on the general psychopathology symptom subscale ranges from 16 to 112 (Lindenmayer et al., 2007).

Lindameyer et al. (2007) support the psychometric strength of the PANSS indicating that a number of studies have established good-to-excellent reliability. For example, Bell et al. (1990) established inter-rater reliability with a sample of 56 patients diagnosed with schizophrenia or schizoaffective disorder. Intraclass Correlation Coefficients (ICCs) ranged from .81 to .93 for positive symptom sub scales. The ICCs ranged from .63 to .90 for the negative symptom sub scale and from .54 to .92 for the general psychopathology symptom subscale. Lindameyer et al. (2007) indicate that most

other psychometric studies of the PANSS confirm these findings. Furthermore, reviewing other psychometric studies provides evidence of the PANSS criterion-related validity, its predictive validity, and drug sensitivity (Lindameyer et al (2007)).

Statistical Analyses

Distributions of all variables were examined in the original study. Square root transformations were utilized for the PANSS scores to approximate a more normal distribution. Alpha was set to $p < .05$. In the current study, two models were explored. In the first model, change in diabetes knowledge at 6 months was the dependent variable and in the second model change in diabetes self-efficacy at 6 months was the dependent variable. Change scores were derived by controlling for baseline measures in each model. The independent variables in each model were schizophrenia symptoms as measured by the PANSS and condition (DART/intervention group versus UCI/Usual care group).

To explore the relationship between schizophrenia symptoms and diabetes knowledge and diabetes self-efficacy, we used hierarchical regression and included all participants who completed the baseline and 6-month evaluations regardless of attendance. In the first step, baseline knowledge was entered as a control. In the second step, the main effects of condition (DART versus UCI) and total schizophrenia symptoms at time two (intervention completion) were entered. In the final step, an interaction product term was entered to assess for condition by symptom interaction.

Results

A total of 58 participants (UCI=29 and DART=29) were included in the analyses. Sociodemographic and clinical characteristics for all subjects included in the secondary analysis are presented in Table 2.

For change in diabetes knowledge there was a significant interaction between condition and total symptoms; that is, the difference in change in knowledge between the DART and UCI groups depended on the prevalence and severity of schizophrenia symptoms (Table 3). When the total schizophrenia symptom score was low, change in diabetes knowledge was significantly higher in the treatment group than the control group. However, when the total schizophrenia symptom score was high there was no difference in change in diabetes knowledge between the treatment group and the control group.

When each subscale was evaluated, there were significant interactions between condition and both greater negative and general symptom scores (Table 3). When either negative or general symptom scores were low, the treatment group did better than the control group. However, when the negative and general symptom scores were high, the treatment group was not different than the control group. However, there was no interaction found between group condition and positive symptom scores.

For change in diabetes self-efficacy, there was not a significant interaction between condition and total symptoms. A significant main effect was found between total, negative, positive, and general symptoms in the total sample for diabetes self-efficacy. Higher prevalence and severity of symptoms was negatively associated with diabetes self-efficacy improvement (Tables 4,5,& 6).

To summarize, the results reveal that the impact of treatment with the DART intervention was moderated by higher levels of total schizophrenia symptoms. In addition the impact of treatment on DKT was moderated by higher general and negative symptoms. However, treatment on DKT was not moderated by the impact of greater positive symptoms. For the total sample, change in diabetes self-efficacy was moderated by total, positive, negative and general symptoms.

Discussion

The relationship of symptoms to physical health outcomes has been largely ignored in the literature and is in need of further exploration. Dixon et al. (1999) indicated in one of the initial studies on physical health status that there is a need to better understand this relationship between mental health status and medical comorbidity. Dixon et al. (1999) suggested the importance for future research to attempt to tease apart how medical illness and psychiatric status interact. These data begin to shed light on medical illness and psychiatric status by suggesting that symptoms may impact disease management. Patients with lower diabetes knowledge and lower levels of self-efficacy to manage diabetes may be more susceptible to difficulty with self-care and at risk for additional co-morbidities as well as death related to unmanaged diabetes.

Consistent with the literature reviewed, these data suggest the importance of symptoms influence on disease management. Although the positive symptom scores were not significant in terms of the interaction testing, it may be important to further explore the impact of positive symptoms on health as well. The lack of positive symptoms moderating effect on DKT may be related to positive symptom severity that

was under rated by the clinician completing the PANSS scale. All PANSS raters in the study were highly trained and reliable in their ratings of participant psychiatric symptoms. However, when studies have explored patient self rating of schizophrenia symptoms, it appears that patient versus an observer reported rating of symptoms hold different meanings therefore the perceptions may not be assumed to be equal (Biancosino et al., 2007; Preston & Harrison, 2003). Biancosino et al. (2007) point out that a few studies have indicated a lack of congruence between patients and clinicians when evaluating psychotic experiences. Biancosino et al. (2007) suggest that the patient's perception of psychopathology provides an additional dimension that should be incorporated into the process of making decisions and in the evaluation of effectiveness of interventions.

Dodd et al. (2001) state that the source of report of the symptom is complex when thought of in the context of multiple perceivers, such as the patient and the health care provider. This may be the case when evaluating symptoms with the PANSS scale. The patient may or may not report symptom experiences to the rater. Excellent psychometric properties of a scale, such as high inter-rater reliability, does not necessarily equate to an accurate depiction of symptoms. Kay (1990), the author of the PANSS, reminds us that the fact that people agree on their judgment does not imply that the judgment is correct or meaningful. This literature on symptom evaluation and the results of the secondary analysis may be an indication for the need for measurement approaches that more completely capture the subjective experience of the person with schizophrenia.

These data support the potential utility of using the Symptom Management Model (Dodd et al., 2001) as a framework for understanding the relationships explored between

symptoms and physical health. Dodd et al. (2001) indicate that evaluation of symptoms involves a complex set of factors that characterize the symptom experience, including intensity, location, temporal nature, frequency, and affective impact. This evaluation is made more difficult when symptoms fluctuate and when insight into the illness is impaired as may be the case for some individuals with schizophrenia. An experienced patient, one with a long history of a specific symptom or symptoms, often learns to catalogue sensations associated with the symptom (Dodd et al., 2001). The older adult with schizophrenia may fit into this category quite well. The older adult with schizophrenia may function daily with a disabling symptom or set of symptoms but may not be functioning at their optimal level. This sub-optimal functioning can have negative consequences on physical health status, such as diminished understanding of diabetes care.

Several limitations need to be considered when reviewing the results of the current study. The sample may be a group biased towards a higher functioning portion of the population with schizophrenia that are enrolling in research programs. Perhaps, participants with more severe psychopathology or less well-controlled symptoms would have different outcomes when participating in a health education intervention. It may be that samples with greater symptomatology may show even less of a treatment effect or a treatment effect on the positive symptom subscale. Studies with samples that have more severe symptomatology, older samples, and less health care engaged samples are needed.

Another limitation of the study was that symptom severity and amount were captured at baseline and at completion of the intervention. This design does not allow for evaluation of symptoms while engaged in the intervention. Exploring the relationship of

symptoms during the entire intervention may expand on the moderating impact of symptoms on the intervention.

Conclusions

Despite the limitations, these data raise important issues about symptoms in relation to health to consider from both research and clinical perspectives. Patients with serious mental illness may need appreciation and recognition of their psychiatric symptoms from the physical health care provider. The way in which the individual responds and manages the condition is influenced by his or her symptoms, experiences, and thought processes. Yet, when the health care provider is not trained to deal with a specific set of symptoms, such as a non-psychiatric provider providing primary care to an individual experiencing symptoms of schizophrenia, the evaluation and management of symptoms as well as the potential to impact engagement in a treatment plan is made even more problematic. An appreciation of the symptom experience can come from providers realizing that the continuum of symptoms may influence self care and the ability to engage in care.

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Appendices: Tables

Table 1 PANSS Subscale Items

Positive Symptoms	delusions, conceptual disorganization, hallucinatory behavior, excitement, grandiosity, suspiciousness/ persecution, hostility
Negative symptoms	blunted affect, emotional withdrawal, poor rapport, passive/apathetic social withdrawal, difficulty in abstract thinking, lack of spontaneity and flow of conversation, stereotyped thinking
General	somatic concern, anxiety, guilt feelings, tension, mannerism and posturing, depression, motor retardation, uncooperativeness, unusual thought content, disorientation, poor attention, lack of judgment and insight, disturbance and volition, poor impulse control, preoccupation, and active social avoidance

Table 2 Sociodemographics and Clinical Characteristics by Group

	UCI, N=29 M±S.D.	DART, N=29 M±S.D.	Df	Test
Age	54 ± 8.36	52± 10.11	56	t =0.73**
Gender	29	29	1	Cramer's V=0
Female	11	11		
Male	18	18		
Education	12.17± 1.71	12.03 ± 2.67	56	t =0.23**
Age of Onset of Psychiatric Illness	29.31 ± 11.78	25.69± 12.26	56	t =1.15**
PANSS Total Symptoms*	76.31 ± 21.76	69.10 ± 21.49	56	t = 1.27**
PANSS Positive Symptoms*	17.48 ± 6.08	15.34 ± 5.81	56	t =1.37**
PANSS Negative Symptoms*	19.07± 5.73	18.10± 7.55	56	t =0.55**
PANSS General Symptoms*	39.76± 12.05	35.66± 10.98	56	t =1.36**

*Post-Intervention Score

** Not a significant difference

Table 3 DKT, Interaction

I.V.	Group by Symptom Interaction	df	Test	P value
PANSS Total Symptoms	Yes	1,53	F-change=4.95 R-square=0.61	.03
PANSS Positive Symptoms	No	1,53	F-change=1.10 R-square=0.53	.30
PANSS Negative Symptoms	Yes	1,53	F-change=4.74 R-square=.60	.03
PANSS General Symptoms	Yes	1,53	F-change=4.37 R-square=.60	.04

Table 4 Dissatisfaction and Readiness to Change*, Main Effects

I.V.	Df	Test	P value
PANSS Total Symptoms	2, 53	F-change=9.21 R-square=0.33	.00
PANSS Positive Symptoms	2, 53	F-change=6.11 R-square=0.27	.00
PANSS Negative Symptoms	2, 53	F-change=10.52 R-square=0.36	.00
PANSS General Symptoms	2, 53	F-change=7.79 R-square=0.30	.00

*A subscale from the Diabetes Empowerment Scale

Table 5 Setting and Achieving Goals*, Main Effects

I.V.	Df	Test	P value
PANSS Total Symptoms	2, 53	F-change=5.75 R-square=0.21	p=.00
PANSS Positive Symptoms	2, 53	F-change=4.31 R-square=0.18	p=.02
PANSS Negative Symptoms	2, 53	F-change=4.85 R-square=0.19	p=.01
PANSS General Symptoms	2, 53	F-change=5.0 R-square= .20	p=.01

** A subscale from the Diabetes Empowerment Scale*

Table 6 Managing Psychosocial Aspects*, Main Effects

I.V.	Df	Test	
PANSS Total Symptoms	2, 53	F-change=7.38 R-square=0.32	p=.00
PANSS Positive Symptoms	2, 53	F-change=6.51 R-square=0.31	p=.00
PANSS Negative Symptoms	2, 53	F-change=6.41 R-square=0.30	p=.00
PANSS General Symptoms	2, 53	F-change=6.86 R-square=0.31	p=.00

**A subscale from the Diabetes Empowerment Scale*

Paper 3

Older Adults with Schizophrenia: Finding a Place to Belong

Heather Leutwyler

Abstract

Introduction: Data suggest that the portion of older adults living with schizophrenia is growing and that the physical health status of this population is poor. The perspective of older adults with schizophrenia about their physical health has not been considered but may be an essential concept to explore in order to understand the poor physical health in this population. **Methods:** A grounded theory study was conducted among 28 older adults with schizophrenia living in a variety of settings using semi-structured interviews and participant observation. **Results:** Analyses revealed that finding a sense of belonging supported feeling healthy. Supporting a sense of belonging were a sense of connection with others, a physical place, social relationships, and a sense of meaning and purpose. The process of finding a place to belong appeared to be important to understanding the unique physical health status, health behaviors, as well as issues surrounding access to care for the older adult with schizophrenia. **Conclusions:** Nurses need to be aware of the facilitators and barriers to finding a place to belong in order to target care to improve the physical health of this vulnerable population.

Finding a Place to Belong

The number of people who struggle with schizophrenia that are over the age of 55 is growing yet their physical health status is poor. The age adjusted mortality rates for people with schizophrenia are two times that of the general population (Folsom et al., 2002) and people with schizophrenia have a lifespan that is on average 9-12 years shorter than that of persons not struggling with a severe, persistent mental illness (Copeland, Zeber, Rosenheck, & Miller, 2006). It is common for people with schizophrenia to struggle with cardiovascular disease, chronic obstructive pulmonary disorders, gastrointestinal diseases, liver disease, diabetes, and skin infections (Chafetz, White, Collins-Bride, Nickens & Cooper, 2006). In addition, older persons with schizophrenia are more likely to be diagnosed with multiple medical problems as compared to younger cohorts with schizophrenia (Kilbourne et al., 2005).

The purpose of this paper is to present findings from a grounded theory study that explored the individual perspective of physical health among older adults with schizophrenia. A key process involved in the individuals' perception of health that emerged during the study was finding a place to belong. A brief review of the literature will be presented followed by a description of the study design and results. The manuscript concludes with implications of the findings for future research and nursing practice.

Review of the Literature on Contributing Factors Underpinning Poor Health

Research exploring health related issues in people with schizophrenia across the life span has documented that multiple factors may influence their health status, including

higher rates of smoking, substance use and alcohol use in addition to socio-demographic variables (Chafetz, White, Collins-Bride, & Nickens, 2005; Chafetz et al., 2006; Chwastiak et al., 2006; Copeland et al., 2006; Dixon, Postrado, Delahanty, Fischer, & Lehman, 1999; Dickerson et al., 2005; Kilbourne et al., 2005). Research also has shown an association between psychiatric symptoms and difficulty in self care management, a decrease in activity involvement, increased numbers of medications and side effects, and disengagement from care as well as treatment disparities (Bartels, 2004; Chafetz et al., 2005, Chwastiak et al., 2006, Dixon et al., 1999, El-Mallakh, 2006, Folsom et al., 2002; McDevitt et al., 2006).

Contributing factors specific to the older adult with schizophrenia have been identified as issues relating to chronic disease management as evidenced by uncontrolled blood pressure despite medication adherence (Dolder, Furtek, Lacro, & Jeste, 2005). Other factors that may play a role in poor physical health include problems with weight management, the physiological impact of aging, and medication side effects (Bartels, 2004; McDevitt, Snyder, Miller, & Wilburn, 2006; McKibbin et al., 2006).

Factors in health care services that may impact the health of older adults with schizophrenia also have been identified. Health care disparities are evidenced by receipt of less than optimal screening, prevention, and treatment services (Folsom et al., 2002; Simon, Lauber, Ludewig, Braun-Scharm, & Umbricht, 2005). Provider difficulties in caring for the patient with schizophrenia, the patients' reported desire for advocacy and continuity of care that may not be met, as well as issues relating to delivery and reception of health information may all negatively impact health (Lester, Tritter, and Sorohan, 2005; MacHaffie, 2002).

Although multiple factors have been explored, studies have not explored the individual perspective of older adults with schizophrenia regarding their physical health. This perspective may provide the background for developing programs to improve physical health, support the patient's engagement in care, and diminish the health care disparities among this growing population.

Methods

Design

Grounded theory was utilized as the methodological basis for this study. Human subjects' approval was obtained from the sponsoring university's human subjects committee. In addition, the recruitment sites approved the study before the study was started. Confidentiality and anonymity were maintained according to the guidelines set forth by the sponsoring university's human subjects committee. Participants self selected a pseudonym to be used throughout the interview.

Inclusion and Exclusion Criteria

Inclusion criteria required that the participants be at least 55 years of age or older, be diagnosed with schizophrenia or schizoaffective disorder, and pass a capacity to consent test based on comprehension of the consent form. Potential participants were excluded from the study if they were younger than 55 years of age, did not have a diagnosis of schizophrenia or schizoaffective disorder, and/or if they did not understand study procedures and purposes determined by failing a capacity to consent form.

Procedures

In the early phase of the study, it became apparent that living situations influenced participants' conceptions of their health therefore the study was broadened to include three sites. This theoretical sampling was designed to ensure maximum variation and build the conceptual density of the emerging theoretical framework. The three recruitment sites included: a transitional residential and day treatment center for older adults with severe mental illness, a locked residential facility for adults struggling with serious mental illnesses, and an intensive case management program. Twenty-eight participants consented and completed an initial interview. Participants received 10 dollars for taking part in the study. The demographic characteristics of the 28 participants are summarized in table 1. As indicated, a majority of the participants were male and the age range was between 55-76 years old.

Data Collection and Analysis

Recruitment and data collection began in August 2007 and concluded in February 2009. Data collection consisted of interviews and participant observation. The interviews were conducted with a semi-structured interview guide that was malleable to the responses and emerging themes encountered. Interviews lasted approximately 30 to 90 minutes. Ongoing participant observation was completed during the interview and visits to the recruitment sites. This also allowed an opportunity to confirm initial analysis and interpretation with participants.

Data collection and analysis were conducted using a grounded theory approach of constant comparison analysis as initially described by Glaser and Strauss (1967). The base approach to grounded theory in this study was further informed by Charmaz (2006)

and Clarke (2005). The data collection and analysis was done simultaneously. The researcher transcribed interviews verbatim and then checked transcriptions with audio recordings. Interviews and field notes were coded by the researcher. Initial open coding was done through analyzing transcripts word-by-word and segment-by-segment. The researcher also engaged in axial and selective coding in order to determine salient themes and properties in the data and to eventually develop a conceptual framework of codes and categories. Theoretical memos reflected the developing conceptualizations about the codes and categories as well as about relationships between categories. Conceptualizations about these categories were further discussed with a small group of qualitative researchers. Theoretical and methodological notes were maintained regarding decisions made during this process.

Establishing Rigor

The methodological rigor of this study was based on criteria proposed by Guba and Lincoln to establish trustworthiness and authenticity (Guba & Lincoln, 1989). First, the process for recruitment and consent procedures was documented. Interviews were audio taped and transcribed verbatim. The transcripts of the interviews were checked for accuracy against the audio version of the interview. Data analysis was ongoing during the process of interviewing consistent with the iterative nature of grounded theory research. Member checking with participants was done in an informal manner during the interviews and at follow up discussions as needed to clarify observations and interpretations of the data. The ongoing process of interviewing allowed for the researcher to follow up with participants to clarify or expand upon information discussed

in previous interviews. An audit trail was maintained throughout the study to document contextual, methodological, analytic, and reflexivity issues (Holloway & Wheeler, 2002).

Findings

While discussing conceptions of health, finding a sense of belonging emerged as a key aspect supporting feeling healthy for these participants. Achieving a sense of belonging was facilitated by a sense of connection with others, a physical place, social relationships and a sense of meaning and purpose. Achieving a sense of belonging appeared to be important to understanding the unique physical health status, health behaviors, and issues surrounding access to care for the older adult with schizophrenia. Zach introduced vividly the importance of belonging.

Zach: "I feel like I don't belong here. I feel like, um, what am I doing here? I'm just here doing nothing. I'm just taking here — at mental health taking medication, and just being alive. But what's the purpose for me to be here?"

The next section will illustrate examples of participants not finding a place to belong.

The subcategories: Not connecting and searching for home will illustrate this failed process.

Not Finding a Place to Belong

Not Connecting

Connections appeared to be fleeting for most of the participants. Even the connections that on the surface appeared to be stable were dynamic. Doc well described the desire expressed by many in the interviews to connect with others and the fleeting nature of the connections in his life.

Doc: “have no friends ringing my phone, no friends knocking on my door. Isolated! Living that way! No one to call to reach out for....NO ONE!!! That’s what triggered the loneliness. Realizing the situation. I’m 65. You know. Just street people. So, I never had anything. Never...a truck driver, homeless for so many years. It’s always been that way...”

As participants aged and continued to be alone, they were less hopeful about the pursuit of connections. The symptoms of schizophrenia could also make connections difficult. For some, a lack of connections resulted in increased isolation, increased paranoia, increased delusions, and being physically sick. Mickey discussed his belief that the loss of a connection with his mother led to the development of diabetes.

Mickey: “yeah....even though I must have a lot of resiliency and a good immune system. I think. Except for the diabetes..... I don’t think I would have diabetes if my mother hadn’t died. It just was enough to spark it off.”

Mickey’s beliefs about the cause of an illness relating to the loss of an intimate relationship may not be substantiated by the traditional American medical model. His belief did illustrate the extreme importance of intimate connections.

Participants also talked about searching for a place to belong with providers and within the health care system. One Feather described how he thought providers perceived of him and how this perception may have contributed to not belonging and to not remaining engaged with treatment for a physical health problem.

One Feather: “It’s because I’m not a successful person. I’m not anything that you make a reputation by. I am just an ordinary person, possibly expendable in their eyes. Being expendable, you are ignored. They don’t pay attention to you unless you really make a scene.”

One Feather indicated that because he felt expendable, he decided not to collaborate with his provider on physical health problems. Another example of not belonging within the health care system was found during an interview with John.

John: “The thing is I had gone up about 10 or 12 times to [hospital] Emergency Room, and every time I told them that I had blood in my urine, and they never — never did a thing about it.”

Unfortunately, the hematuria was not detected until John was hospitalized in an acute psychiatric unit where a psychiatric nurse directly observed the blood. After the psychiatric nurses’ advocacy for further evaluation, it was determined that John had bladder cancer. The cancer had progressed to the point that removal of the bladder was necessary. At the time of the interview, John was not only adjusting to cancer treatment but also to the body alterations that came along with a urostomy.

Additional examples of not belonging with providers and therefore not collaborating in discussion and actions for treatment of physical health issues were discussed by Zach.

Zach: “I don’t know. He’s cool and everything. He’s just — to me, it seems like he’s always staring me down.”

Frances also described repeated failed attempts at finding a place of belonging that appeared to be impacted by judgmental providers.

Frances: “One was a female doctor. She was in the acute care at [hospital]. And I was really anxious. I was — it was horrible. It was horrible, horrible, horrible, and she didn’t believe me, so I went to [hospital] Emergency, and they believed me.”

How connections were sought often related to living arrangements. Some people only had to walk into the kitchen or community area to connect. However, some had to take a bus or a long walk to a community center to connect. Finding a home that a person felt they belonged in and that also provided connections was problematic for many. The next section will illustrate not finding home and the impact on physical health.

Searching for Home

Finding a home that provided the structure for achieving optimal physical health status and that promoted healthy behaviors could be a challenge. A few of the challenges discussed in interviews included high housing costs, the prevalence of substance use, crime and infestations (rats, lice, scabies) in single residency occupancy hotels, and isolating living situations. These challenges impacted aspects of both physical and mental health status. Doc is one participant who discussed how the struggles he faced in trying to find a home impacted his physical health negatively.

Doc: “any time I’m on the streets....I don’t really take care of myself food wise..... Candy bar you know and stuff like that....Twinkies ...you know you name it cokes....but.....um....I think the reason why I managed to stay so healthy throughout my childhood is that I grew up in institutions”

Doc found secure and healthy places to live in mental health facilities but his tenure in these facilities was short partly due to the focus of these facilities in getting clients back out into independent living situations. Doc turned to drug use to cope with the isolation that came along with independent living.

Doc: “You know. An apartment. A hotel. That’s not (home). Because you don’t get those sounds because you are at a certain age where there are no more second chances. You have to get adjust that you are always going to be alone and live with it otherwise you know you’ll kill yourself. I’m not suicidal and I’ve found

ways to live with it. You know. You just realize that and accept it. And discipline yourself and stay with it. And of course weed helps me a lot”

In the next quote, Malcolm described how he struggled to break this cycle of going from hospital to transitional housing to independent living and back again to the hospital.

M: “You know it took me three years of programs and I’ve never done no more than three months. It was just an institutional cycle of no change.”

This cycle was broken for Malcolm, and for many others, when they were taught the necessary skills needed to live independently. These skills were needed to maintain a sense of belonging and to begin to care for their physical health. However, finding advocates to teach these skills was a challenge. The next section will illustrate the process of Finding a Place to belong highlighting the subcategories of finding connections and finding home.

Finding a Place to Belong

Finding connections

John: “I think it helps. It gives you some — some hope.”

Connections made were sometimes intimate or personal as with a roommate or romantic partner. Other connections were more superficial such as by just being around others in a waiting room. Connections were even made with the researcher.

Mia: “you remind me of another doctor at [hospital], you remind me of her..... She used to come and visit me every morning. This is, I don’t even know if it is on my record or not, and sit with me in the living room, for about an hour or 2 hours talking about all kinds of things...”

Connections provided Mia with a sense of belonging but also needed health care. Maggie described how good health was a necessity for her to find and maintain connections. She had a passion for music and singing that she shared with others at local coffee houses during open mic nights.

Maggie: “I like my voice because in the past I’ve had uh...a bad sore throat and that lasted for months. And um. I couldn’t sing and play the guitar. And um so I like having a healthy voice now.”

Additionally, participants spoke about the impact of connections with family members on their self perceived health. Most often, connections with family members at their current age was rare. Many reminisced upon their growing up years with fondness and with sadness. Regardless of how they recalled these childhood experiences, they appeared to have taken away information that impacted their perspective on physical health.

Suzie: “Well, I know the smoking is damaging, and I know that my father died of lung cancer, and he didn’t smoke cigarettes. He only smoked cigars once in a while, but he still died of lung cancer. So, you know, I’ve always feared that, because my mother didn’t smoke, and my father really didn’t smoke. So it was always, you know, frowned upon. All my sisters and I smoked. There’s three sisters and myself — four girls — and we all smoked, and way too much, and it was always brought up that it was not good for you.”

This early exposure to the dangers of tobacco impacted how Suzie perceived her own health risks and how she took care of her health in the present day. For instance, during the interview, Suzie spoke about the success of her most current smoking cessation attempt. Frances illustrated how family members could serve as role models for physical health as well.

Frances: “Well, my grandmother — my poor grandmother — she was a country woman, and she’d work in her vegetable garden, and she had skin cancer on her ear. So when I was a tot, I grew up knowing that the sun could kill - could hurt.”

Participants also spoke about intimate, romantic connections as having an impact on their perception of their health. Maggie focused on the valued connection with her boyfriend and illustrated how this connection colored the way she viewed her health issues.

Maggie: “Well I dislike having herpes because there is a chance I can pass it on to (my fiancé) and I don’t want to do that.... Yeah, the herpes. I don’t know (laughs) Probably I should say my heart!

Interviewer: That what I thought you might have said was your heart but it sounds like um....why do you think that is that it is herpes and not your heart?

Maggie: Because I can pass it on.”

Despite having several other chronic health conditions that Maggie recognized could be life threatening, she saw herpes as an illness that warranted more of her attention and concern. The impact that herpes could have on her relationship was part of what made it Maggie’s overriding health issue.

For the participants, it seemed that if the connections were deleterious to their physical health but the person still desired the connection, then the connection was maintained despite negative health outcomes. Doc talked about using crack as a means to connect despite noticing the impact on his breathing and his physical agility.

Doc: “I became a crack addict for about 6 months only though. Because of the shelter situation. And uh, then those are the guys I was fighting in the shelter. We’d all hang out in the civic center, passing the pipe, and I had the atm card and I had no drug debts. And I’d empty out my bank account, buy crack, because you know why? It was the winter time and there was no pillow to sit on. You sit out there on the cement and you kill time and you wait until 4 o’clock until they let you back into the shelter cuz they kick you out at 8 o’clock in the morning”.

Smoking crack not only brought connections to other peers but also created a physical place to belong in an uncomfortable environment.

Other participants, like Pete, talked about the positive impact of connections on his engagement in care for a serious physical health problem. He described what it was like sitting in the waiting room with others while waiting for a radiation treatment for lung cancer.

Pete: “And so it was nice. And everybody was nice to me there. And that, it was different people in the waiting room and we’d talk and laugh. You know it was a big deal.”

Connections for Pete were supportive during a potentially emotional and frightening experience in that they brought a sense of belonging. Perhaps even the simplicity of strangers being nice helped to make this big deal a little easier as well as encouraged his continued engagement in the treatment plan. When connected, the participants often perceived their physical health as better.

Helping peers allowed one participant to find a place of belonging through assisting others in taking care of their own physical health care needs. This also brought a sense of purpose that reinforced her health promoting activities.

Mia: “and uh I helped here too at the [facility]. I bathed well. I took people out to the dentist. To doctors and brought them back.”

The impact of being connected on physical health for Mia was feeling healthy, feeling safe, and physically agile.

Mia: “I couldn’t run because of my age but I went up and down the stairs like nobody’s business.”

Some participants found meaningful connections in creative ways. Despite struggling to find this meaningful connection in a human relationship, Suzie described how she found this type of meaningful connection with her cat.

Suzie: “Oh, it just — everything. My heart — it keeps my heart open. It keeps me alive. I feel just soft and open with him. I feel like I go to another level of understanding and communication, and we connect on a level that’s just straight from the heart. And it doesn’t have anything to do with the ego....you can go straight through their eyes to their fiber of their being, and their existence, and not have to pay for it, or earn it, or talk your way in there, or anything, you know? And they just will accept you no matter what, and they’ll keep on and never give up on you. They’re so loyal. They’re so everything that is good about life.”

Some participants did find this meaningful connection with a health care provider. One Feather described how he felt a sense of belonging when he was remembered and cared for by a nurse.

One Feather: “Well there was a nurse remembered me. She said, “I remember you. Did you ever find your dog again?” I said, “No, I never did.” She said, “It is about time don’t you think you had another dog?” I said, “How did you know about my dog?” She said, “The first time you were here, that’s all you talked about was your dog.” So she had somebody wash my clothes and they took me and ran a big tub and soaked me and washed me down for about a half hour.....”

Feeling cared for was a rarity as was finding home. The next section will describe successes in finding a place to belong in a home.

Finding Home

Participants discussed the positive health impact of living in an ideal home. Structure played a critical role. If structure was found in a home, it seemed perceptions of physical health, physical health status, and health behaviors improved. Finding a home

that provided a structured environment was facilitated by a number of factors including mental health crises, committing crimes, or the work of advocates. Advocates helped participants to find a place to belong by merely engaging in conversation about the housing search or by actually locating the participant a place to stay. Some advocates would also teach the necessary skills to prepare for and remain in an independent living situation that a person felt they could finally call home. For example, Suzie found a home through being placed in a residential treatment program. This quote also highlights the impact on her health that the structure of a residential program brought to her life.

Suzie: “Because most of my life has been lived with an addiction of some sort to where I wake up in the morning, I don’t want to even see daylight. It’s like oh, no, because it’s always been sick in the morning, have to go get a fix, you know, something — to face some kind of trauma. And it wasn’t — it just was much easier. Life was so much simpler.”

Being in this structured environment allowed Suzie the time and space to pursue treatment for physical health concerns that she had not been attending to until living in this healthy home.

Some participants found that going to jail was a last resort in finding home as well as to get the care they needed to find mental health stability. For example, Earl identified that jail was the home where he felt the healthiest:

Earl: “When I was in [prison] — when I was at [prison]. I was happy with everybody around me, once I had been there and got settled in. I think that was the most — I was at my best then.”

Earl was stabilized on psychiatric medication and daily therapy sessions with his psychiatrist while living in jail. When he was released, he went back out into the

community prepared to care for both his physical and mental health needs. John illustrated the important role of advocates in finding a home.

John: “when I was homeless, I didn’t have a place — well, I didn’t have any place to live, or any place to eat, or any — anything going on at all. And I just existed off of stuff that I found on the streets, and then you panhandled. And finally I got off being homeless and got into [homeless advocacy program].”

Yet, often when people did find a home that allowed them to live independently; they were then faced with a whole new set of issues. Participants talked about the difficulties dealt with in adjusting to living on their own in an apartment after breaking the cycle of going from hospital to home and back again. Difficulties included cooking, cleaning, managing medications and multiple doctor appointments. This might explain why Joe, who had spent most of his life living in a locked facility, talked about feeling safest and healthiest while living in a locked facility.

Joe: “I’m glad that I do have people here in this hospital who care about me like my [social worker], he cares about me. My case manager does. I get along with the patients perfectly well. I like being in the hospital.....”

Although a few participants were prepared by programs or advocates to live independently, participants like Joe felt that they could never be ready for an independent living situation because of their struggle with mental illness. Finding a place to belong with others and a place to belong in a home was a challenge for the participants that impacted their physical health status, health behaviors and access to care.

Discussion

Limitations

Several limitations need to be evaluated when reviewing the results of this study. First, it was not possible to confirm the details of every encounter between the participants and the health care system. It is possible that the health care providers caring for the participants have a different perspective on the same situations. Gathering the perspectives of health care professionals may provide more information to better understand the physical health of this population. Also, this was a restricted sample of older adults with schizophrenia. For example, it could be that a sample with more women could bring up more gender specific issues. Participants were also all engaged with the care system to some extent. Different perspectives on how an older person with schizophrenia belongs could be found by speaking with participants who are not receiving any health care services.

Despite these limitations, this is the first study to date to evaluate the individual perspective of older adults with schizophrenia regarding their physical health. Participants spoke about the importance of a sense of belonging and the impact on their perception of health. The process of finding a place to belong with others and in searching for a home had the potential to influence both physical health behaviors, physical health status, and access to care. Common facilitators to belonging discussed were mental health stability, mental health crisis, advocates, structure, substance use, and smoking. Barriers to belonging that were commonly found were the diagnosis and experiences associated with schizophrenia, living situations, shaky support systems, judgmental health care providers, and stigma

A few researchers have evaluated the individual perspective of adults with schizophrenia regarding psychiatric illness. Using qualitative interviews, Davidson

(2003) explored the experiences of recovery from psychiatric illness among people with schizophrenia and found that they often felt a sense of not belonging. He drew a parallel between the sense of alienation and isolation described by people with schizophrenia and the experience of a person not struggling with schizophrenia who becomes lost in a foreign country where no one speaks their language and the fear that comes along with possibly never finding anyone who does speak their language.

Researchers have elaborated on this sense of belonging. Aspects of social isolation have been shown to increase and positive connections to decrease during the lifetime of a person with schizophrenia (DeNiro, 1995). A sense of belonging can lead to increased engagement in care (Davidson, 2003; Leiphart & Barnes, 2005). When belonging is measured as a component of social support, it appears to moderate the relationship between psychiatric symptoms and number of hospitalizations (Huang, Sousa, Tsai, & Hwang, 2008). A sense of belonging may be an important component to quality of life (Laliberte-Rudman, Yu, Scott, & Pajouhandeh, 2000) and has been indicated as a coping skill in dealing with the uncertainty of psychiatric illness (Lester, 1999). The literature suggests that a sense of belonging impacts the course of psychiatric illness. The results of the present study suggest the sense of belonging may also impact physical health.

Some of the facilitators to finding a place to belong identified in this study add to the current knowledge base about this sense of belonging among people with a serious mental illness. For example, Tarko (2002) developed a substantive theory on “spirituality as connection” for people struggling with serious mental illness. Tarko (2002) found that attending drop in centers specifically for people with serious mental illness established a

sense of connection. The participants in this study also found connections through programs that focused on the needs of a person struggling with a serious mental illness.

A key barrier to finding a place to belong was the symptoms of mental illness such as psychotic symptoms or severe anxiety. At times, the symptoms of schizophrenia could be a barrier to discussions with health care providers or could keep a person from leaving their home for the day. This finding supports the literature that engaging in self-care for physical health is impossible when schizophrenia symptoms become overwhelming (El-Mallakh, 2006). Tarko (2002) also found that a barrier to connecting was the effect of psychiatric illness on relationships with other people.

Nursing Implications

Recognition of the importance of finding a place to belong for the older adult with schizophrenia can help nurses maximize the facilitators to belonging and minimize barriers in a manner that optimizes physical and mental health status among older adults with schizophrenia.

For example, awareness of being judgmental and how this can negatively influence relationships with patients may be a critical step. Secondly, educating the older adult with schizophrenia about their physical health by first asking about their health needs and concerns may facilitate healthy ways to belong. If a connection is established and nurtured between a nurse and patient, it may open the door to discussion about the various social, mental, and physical aspects of the patients' life that are impacting their physical health behaviors and physical health status. Chinman et al. (1999) and Leiphart and Barnes (2005), suggest that entering into a relationship with a provider can be

especially powerful for someone with schizophrenia as they are often isolated and lack positive relationships in the past. This may be especially important for the older person with schizophrenia. Davidson (2003) also indicates that recovery from psychiatric illness has been fostered by a nurse believing in a client. Providing a safe and healthy connection with the nurse can pave the way for the older adult with schizophrenia to find belonging with healthy people in healthy places.

Research Implications

Nursing is an ideal profession to research the physical health needs of older adults with schizophrenia. Patients with serious mental illnesses often receive care in the primary care sector (Daummitt, Pratt, Crum Powe, & Ford, 200), in the ER or through multiple different providers. A nurse may be the provider intercepting a patient at the boundary of the mental and physical health care environments. Thus, nursing science provides the insight, experience, and perspective for better understanding this problem. Future nursing research should explore the relationship between the older adult with schizophrenia and the health care system and providers in order to better understand how this relationship impacts physical health behaviors, health access, and physical health status.

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Table 1 Demographic Characteristics

Characteristic	
Age in years	61 mean, 6 s.d., range=55-76
Sex	
Male	22
Female	6
Ethnicity	
European American	17
African-American	5
Asian/Pacific Islander	3
Native American	2
Hispanic	1

Paper 4

Understanding Older Adults with Schizophrenia: Building And Eroding Trust

Heather Leutwyler

Abstract

Introduction: Adults who struggle with schizophrenia are living longer. At the same time, data suggest that older adults living with schizophrenia face health care disparities that contribute to poor physical health. The purpose of this paper is to present findings from a qualitative study that explored the understanding of physical health among older adults with schizophrenia. In gathering the individual perspective, one of the study goals was to understand factors that might influence experienced health care disparities.

Methods: A grounded theory study was conducted among 28 older adults with schizophrenia living in a variety of settings using semi-structured interviews and participant observation. **Results:** The concept of trust evolved from the data as a dynamic process that was built with factors of respect, caring, advocacy, and consistency and eroded through factors of disrespect, not being heard, lack of time and provider inaction, and stigmatization. This process of building and eroding trust was influenced by the symptoms of schizophrenia. **Conclusions:** The fluctuating and chronic nature of schizophrenia, the societal response to the disease, and the fragmented health care system all impact trust. When trust is given and received between providers, the health care system, and the older adult with schizophrenia, physical health outcomes may improve and health care disparities may decline. These findings provide insights for the design of future research interventions and clinical practice to promote optimal physical health outcomes for this growing population.

Understanding Older Adults With Schizophrenia: Building And Eroding Trust

Health care disparities can impair the ability to achieve optimal physical health. One especially vulnerable group that may experience health care disparities is comprised of older adults with schizophrenia. Common medical problems experienced by people with schizophrenia are cardiovascular disease, chronic obstructive pulmonary disorders, gastrointestinal diseases, liver disease, diabetes, and skin infections (Chafetz, White, Collins-Bride, Nickens & Cooper, 2006). The prevalence of some diseases are higher in the population with mental illness than the general population (Himmelhoch, McCarthy et al., 2009; Dixon, Postrado, Delahanty, Fischer, & Lehman, 1999). Older persons with schizophrenia are more likely to be diagnosed with multiple medical problems when compared to the younger cohorts with schizophrenia (Kilbourne et al., 2005). Despite indications of this less than optimal physical health, less than 10% of published research in schizophrenia is done on older adults (Mittal et al., 2006). In addition, physical health problems in the context of schizophrenia contribute to increased cost to the health care system. In an examination of the cost of care for adults with mental and physical illness, Bartels, Clark, Peacock, Dums, and Pratt (2003) found that the annual per person cost for the person with schizophrenia over the age of 65 was 40,000 dollars per year. This estimation was three times the amount of care for a patient with only physical illness.

The purpose of this paper is to present the findings of a grounded theory study that explored the understanding of physical health among older adults with schizophrenia. One of the study goals was to better understand factors that might influence the noted health care disparity. Building and Eroding trust was a key process that emerged from the data and may provide insights into strategies to minimize these disparities. The

emergence of this process is discussed below. A brief review of the literature on factors within the health care system that contribute to the poor physical health often experienced by older adults with schizophrenia will be presented followed by a description of the study design and results. The paper concludes with a discussion of the implications of the findings for nursing practice and future research.

Review of the Literature

Health care disparities are illustrated by receipt of less than optimal screening, prevention, and treatment services (Folsom et al., 2002; Simon, Lauber, Ludewig, Braunscharm, & Umbricht, 2005). Provider difficulties in caring for the person with schizophrenia, the patients' desire for advocacy and continuity of care that may not be met, and issues relating to delivery and receipt of health information may all negatively impact physical health (Lester, Tritter, and Sorohan, 2005; MacHaffie, 2002).

For example, Lindamer et al. (2003) provide evidence of screening and prevention differences. A sample of 65 older women with schizophrenia (between the ages of 50-79) was recruited from an ongoing study of late life psychosis (Lindamer et al., 2003). Gynecologic service use was compared to a control group of 51 older women with no known mental health diagnosis. The women with schizophrenia were less likely to receive mammograms, pelvic examinations, pap smears, or to have used hormone replacement therapy for indicators of osteoporosis when compared to women without a mental health diagnosis. Similar disparities are seen with significantly lower utilization of osteoporosis drugs and hormone replacement therapy in a sample of 46 women with schizophrenia when compared to age matched controls (Bishop, Alexander, Lund, &

Klepser, 2004). In this latter study, the 65 and older women in the control group were 2.2 times more likely to receive osteoporosis drugs (Bishop et al., 2004). Folsom et al. (2002) and Daumit, Crum, Guallar, & Ford (2002) add to these findings by documenting fewer preventive care visits among people with serious mental illness.

Acute and chronic care differences are also apparent. An analysis of a national cohort showed patients with schizophrenia differed in the care received post myocardial infarction in that they were less likely to undergo cardiac catheterization and had a greater one year mortality rate than patients without a mental illness (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001). Furthermore, Himelhoch, Leith et al. (2009) found that adults with schizophrenia and type 2 diabetes who smoke were less likely to receive services and treatments known to improve cardiovascular outcomes, such as cardioprotective pharmacotherapy, when compared to non-mentally ill smokers with type 2 diabetes. Moreover, when compared with age matched peers in the general community, the older adult with schizophrenia may receive less adequate medication treatment for certain chronic conditions (Vahia et al., 2008). These data all support the presence of health care disparities in older persons with schizophrenia and suggest the need for further study to understand contributing factors.

Methods

Design

Grounded theory was used as the methodological basis for this study (Glaser & Strauss, 1967). Symbolic interactionism, which provides the theoretical framework of grounded theory methodology, supports the view that individuals' understandings occur

within the context of relationships (Blumer, 1969). The creation of conceptually dense analyses, the one-on-one interview approach to data collection, as well as not imposing a predetermined framework on the person's experience make this method ideal for exploring the understanding of physical health for the older adult with schizophrenia. Exploring how the older adult with schizophrenia understands their physical health through data gathering methods that are situated in the participants' everyday life can help to show the socio-cultural influences on this understanding as well as the unique perspective of each participant. The method also draws on a constructivist approach showing that the researcher is constructing grounded theory through past and present involvements and interactions with people, perspectives, and practices (Charmaz, 2006). The theories produced by grounded theory from this constructivist approach offer an interpretation of the studied world and attempt to create a construction of reality.

Human subjects' approval was obtained from the sponsoring university's human subjects committee. In addition, the three recruitment sites approved the study before the study procedures were implemented. Confidentiality and anonymity were maintained according to the guidelines set forth by the sponsoring university's human subjects committee. Participants self selected a pseudonym to be used throughout the study. After signing consent to participate and passing a capacity to consent test, each participant completed a semi-structured interview with the researcher in a private setting that lasted an average of 60 minutes.

Participants and Settings

Inclusion criteria required that the participants be at least 55 years of age or older,

be diagnosed with schizophrenia or schizoaffective disorder, and pass a capacity to consent test based on comprehension of the consent form. Potential participants were excluded from the study if they were younger than 55 years of age, did not have a diagnosis of schizophrenia or schizoaffective disorder, and/or if they did not understand study procedures and purposes determined by failing a capacity to consent form.

In the early phase of the study, it became apparent that living situations influenced participants' conceptions of their health therefore the study was broadened to include three sites. This theoretical sampling was based on the participants' living situation to ensure maximum variation and to build the conceptual density of the emerging theoretical framework. The three recruitment sites included: a transitional residential and day treatment center for older adults with severe mental illness, a locked residential facility for adults struggling with serious mental illnesses, and an intensive case management program. Twenty-eight participants consented and completed an initial interview. Participants received 10 dollars for taking part in the study. The demographic characteristics of the 28 participants are summarized in table 1. As indicated in the table, a majority of the participants were male and ranged in age from 55-76 years old.

Data Collection and Analysis

Recruitment and data collection began in August 2007 and concluded in February 2009. Data collection consisted of interviews and participant observation. The interviews were conducted with a semi-structured interview guide that was malleable to the responses and emerging themes encountered. Ongoing participant observation was

completed during the interview and on return visits to the recruitment sites. This also allowed an opportunity to confirm initial analysis and interpretation with participants.

Data collection and analysis were conducted using a grounded theory approach of constant comparison analysis as initially described by Glaser and Strauss (1967) and further informed by Charmaz (2006) and Clarke (2005). The data collection and analysis was done simultaneously. The researcher transcribed interviews verbatim and then double-checked to the tape for accuracy. Field notes and interview transcriptions were entered into NVIVO, version 8.0, software to aid with data organization and retrieval. Initial open coding was done through analyzing transcripts word-by-word and segment-by-segment followed by axial and selective coding in order to determine salient themes and properties and to eventually develop a conceptual framework of the codes and categories. Theoretical memos reflected the developing conceptualizations about the codes and categories as well as about relationships between categories. Conceptualizations about these categories were further discussed with a small group of qualitative researchers. Theoretical and methodological notes were maintained about decisions made during this process.

Establishing Rigor

The methodological rigor of this study was based on criteria proposed by Guba and Lincoln to establish trustworthiness and authenticity (Guba & Lincoln, 1989). First, the process for recruitment and consent procedures was documented. Data analysis was ongoing during the process of interviewing consistent with the iterative nature of grounded theory research. Member checking with participants was done in an informal

manner during the interviews and at follow up discussions as needed to clarify observations and interpretations of the data. The ongoing process of interviewing allowed for the researcher to follow up with participants to clarify or expand upon information discussed in previous interviews. An audit trail was maintained throughout the study to document contextual, methodological, analytic, and reflexivity issues (Holloway & Wheeler, 2002).

Findings

Twenty eight participants took part in the study. Demographic characteristics are summarized in table 1. A majority were male and ranged in age from 55 to 76.

The concept of trust emerged while discussing health care experiences and interactions with health care providers and the health care system. The process of how trust was built and eroded between the older adult with schizophrenia and their health care providers, the health care system, and themselves became prominent throughout the interviews and participant observations. Trust was a fluid, dynamic process that evolved through interactions with the environment. Factors that built trust consisted of respect, caring, advocacy, and consistency. Trust was eroded through factors of disrespect, not being heard, lack of time and provider inaction, and stigmatization. This process of building and eroding trust was influenced by the symptoms of schizophrenia. The trust building and eroding factors were not distinct and independent entities. Factors that built and eroded trust could interact leading to greater or lesser amounts of trust along the continuum of trust. Regardless of how trust was built or eroded, a commonality was that

trust was necessary for the older adult with schizophrenia to relate to, interact with, open up to, and collaborate with health care providers about their health concerns.

The next section will illustrate trust building and eroding factors between participants and providers and the health care system. Providers are defined broadly to include doctors, nurses, psychiatrists, case managers, and social workers.

Building Trust

Respect. Trust was established for some participants based on respect. Respect could be earned with a reputation that was built through time or a professional status. In the following quote, Suzie shows the value of a reputation earned through actions when she described where and why she would seek treatment for skin abscesses that were a result of heroin use.

Suzie: "They would get taken care of their habit and their body at the same time. So [hospital] has always been good about that. They never make you kick heroin when you get there. They do put you on methadone right away and morphine. They're not cruel that way. They don't say well, you're going to deal with a lot of pain and kicking a habit at the same time. They don't do that. They never have."

Suzie further described why she trusted this hospital.

Suzie: "I trust [hospital's] experience. They've seen almost everything. They have a lot of hands-on experience with different conditions. I don't think that you could present anything to them that they don't have some kind of prior experience with. And they seem to just be efficient, and somewhat caring."

Finding a hospital that Suzie could trust helped her to pursue treatment for physical health problems. Trusting someone because of their professional status, like a case manager, was another trust building factor that emerged. Joe stated why he trusted his psychiatrist showing the significance of just being a health care provider.

Joe: "He's the only psychiatrist I have. So the only psychiatrist I have, I accept."

This respect and acceptance of the provider played a role in following treatment recommendations. Freud illustrated how taking a medication consistently was a result of trusting both someone and places with professional status.

Freud: "I'm not sure it's helping me, but I don't have any qualms about taking it. It was prescribed. I took it, um, um, in — at the suggestion of the [health center]...But anyway, [psychiatrist], her cohort as a psychiatrist there, she prescribed me the Abilify for the first time...And I kept it up in jail, and without fail, and I keep it now - loyally...And I guess it's helping me. I don't want to give it up, just as a safety precaution."

Trust gained through a respectful reputation could also impact the pursuit of treatment for physical health concerns.

Howard: "Yeah, I have a bunion on the bottom of my foot I think I have to have operated on,,,,,Yeah, because sometimes it pains me...."

Interviewer: "...What are you going to do about that?"

H: "I'm going to go to, um, not my, oh, primary doctor — not the family doctor, but I'm going to go to the doctor who saved my leg, because he's a surgeon."

Other participants talked about how this trust in their providers could play a role in minimizing their concerns about serious physical health issues.

Maggie: "They were very concerned about my heart murmur for a while. I went to a heart specialist and he told me I wouldn't have to worry about a valve replacement until I was 90. So that made me feel pretty good."

Big Larry, a participant who was suspicious of the health care system, gave an example of why he trusts his psychiatrist.

Big Larry: "It means when you talk to them, everything will be confidential."

However, sometimes the professional status of a provider could play a role in a patient trusting and therefore taking a medication with little awareness for the reason or purpose of the medication.

Interviewer: "What about with the stomach thing. You said you take Nexium?....."

What does that do for you?"

Frances: "Well, you know what? You'll have to tell me what it does, because I don't know."

Caring and advocacy. Another factor that established trust echoed throughout the interviews was receiving adequate care and advocacy. Trust for some participants was built with bare minimum care. Yo added more clarity to the value of minimal caring when he explained what it meant to be treated decently and with "no hostility".

Yo: "Well, [hospital], I was in the ICU. And when they transferred me over to [psychiatric unit], I was just in a room, you know, a room with a — well, they let me keep my own room. I mean, you know, a regular room with no patients except me, so I had my own private room."

Other participants needed care that was more soothing for trust to build. For example, MJ talked about why he trusted the case manager.

MJ: "No. He soothes you. Uh-huh. You know how he can do that, and the way he talks real quiet, and he makes sense, you know what I'm saying?.....He makes sense. When people come in, he goes to everybody....and he's just smiling and all this stuff, you know?"

Regardless of whether trust was established with a subtle or an abundant amount of caring, the resulting trust facilitated engagement in the treatment process. For example, John described his experience with bladder cancer focusing on his initial difficulty in obtaining a diagnosis. Providers in the emergency room consistently ignored his complaints of hematuria. John talked about finally getting attention for his concerns in the following excerpt.

John: "I think she was a little bit better nurse, because she really cared, you know. She said, you know, that's not right, and there's got to be a reason for it, and we're going to take care of it and find out why."

Showing she "really cared" not only built trust with John but also impacted his physical health. Through the nurses' caring and advocacy efforts, John eventually received the

needed care and was more motivated to pursue the difficult treatment that came along with the bladder cancer.

Malcolm also described a provider that gained his trust through advocacy efforts. His psychiatrist coordinated with his multiple providers about a myriad of physical and mental health issues.

Malcom: “Oh, that’s my new — that’s my new psychiatrist. And she said I’ll call to make sure it’s not anything that I’m doing. I’m going to fax, to your doctors, and I’m going to check when your blood tests come in to see what level, you know, your depakote and seroquel is — the depakote to see if it’s causing your blood sugar to stay high”

Providers acting as advocates built the trust needed for the participant to stay engaged in care, such as through getting follow up lab tests. Mr. Eugenides described the advocacy received from a case manager.

Mr. Eugenides: “She gives me my money every week. She makes sure that I am doing the things that I am supposed to do like find out when my appointments are and make my appointments like that.”

Consistency. Mr. Eugenides also showed the value of a provider being consistent and the role this consistency plays in building trust. Big Larry described trust that was built on receiving consistent care.

Big Larry: “I can talk to her because.. she talks to me every week. Once a week.”

Providers could also build trust through consistently giving time and sometimes building the room for a little extra time.

Yo: “Yeah. He listens to what I have to tell him, you know, for 45 minutes or something like that — 30 minutes. Maybe an hour, yeah, he’s given me an hour of time before.”

Zach also found consistent care from his case manager when he requested help with his finances.

Zach: “when I came here, I had like 400 or 500 bucks. And instead of spending it, I gave it to [case manager] to hold for me. So when I need money, I just ask him, and he’ll give me like maybe \$50.”

Trust builders. Case managers were commonly referred to as providers that were easily trusted because they often excelled at combining the qualities of advocacy, caring, and being consistent. Earl described a trusted case manager that exemplified these qualities.

Earl: “Yeah, we talk once a week about anything I want to talk about.....And we meet every Friday at 11:00, and she tells me — she says — she tells me what she thinks I should be doing, or I shouldn’t be doing. She asks me a lot of questions about, you know, how I feel. She’s kind of like a psychiatrist. She’s more or less interested in my mental, and she worries about my physical condition too, because she makes appointments for me to go to the doctor.”

Case managers were also skilled at managing a participant’s multiple mental and physical health issues. Zach illustrated one of the outcomes of this trusting relationship with a case manager.

Zach: “[case manager] knows. I tell him everything, because he’s my case manager.”

When trust was built, patients became physically healthier partly because of a collaborative relationship with their providers. For example, John illustrated the impact of the collaborative, trusting relationship with the nurse that advocated for him when he was seeking a diagnosis for bladder cancer. Her advocacy and caring efforts were part of the impetus to pursue treatment for the bladder cancer once it was detected.

John: “I finally decided to get it taken care of. Like I said, I put it off for months and months, and I finally decided to get it taken care of. And so I went there and I went to [hospital], and I told them I was ready to get it taken care of. And so I went into the hospital”

The trust built impacted John's post-surgical care and collaboration as well. He described the relationship he had with the visiting nurse who helped him to learn how to care for his ostomy.

John: "The nurse who...comes and does my changes is really a lifesaver... Well, because I got out and I thought oh, no, I'm not going to know how to change my bag, or change my wound, or anything. And then she showed up at the place where I live, and she was really good...Oh, she — she's quite helpful. Besides just changing the bag and taking care of the wound, she also worries about me — my health in general, that I'm getting healthy and doing healthy things, and being healthy, so yeah."

Trust Eroding

Disrespect. Despite the many examples of trust that was built between patients and their providers and the system, much was also said about trust erosion. One of the ways that providers could erode trust with participants was by their disrespectful actions, such as not being punctual.

Earl: "If she says I've got an appointment exactly at 1:00 and she ain't there, I'm gone. It's not that I'm angry. It's just that I'm punctual, and I think people should be punctual too, and not just make me wait, because it changes — my mood changes. I'm not so outgoing when I do see you."

As Earl illustrated, when trust eroded it could impact how the participant communicated and possibly even if the participant would attend an appointment. Providers could also make statements that eroded a trusting connection with a participant as Mr. Eugenides described.

Mr. Eugenides: "There was a woman during one of my hospitalizations who said I would never amount to anything...She saw a bunch of patients who were there on the ward. She was assigned to me. After seeing me a couple times she said: "You will never amount to anything"...I was pretty young. I don't know that—I haven't amounted to anything have I? She was right...I am just a mental patient."

Suzie also recalled providers making disrespectful statements indicating that this influenced her perception of the health care system.

Suzie: "I hold my mud and I take it where I can take it, and then dump it, whether it be in therapy, or at a meeting, or with a friend....but I don't say whatever I think to ruin someone's day. I use some discretion. I would only ask that from them, but they have a tendency to become a little bit of this power play with you."

Similar to Suzie, a few participants emphasized they merely wanted their providers to treat them the way that they would want to be treated.

Not being heard. One Feather also spoke about a lack of trust with providers. He described how trust eroded with doctors because they did not attempt to have a thorough understanding of his experience.

One Feather: "Well I make sure that I don't become under-nourished and that things don't inhibit me to where I am traumatized by my own reflections and my own findings and my thinking. I trust to myself much more than to the doctors now because I experienced all these things. What they say is only a different world than what I experienced. They never have given me a decent appraisal or assessment of what I had experienced."

As One Feather indicated, provider inaction and lack of follow-through would lead to trust erosion. One Feather illustrated how this inactivity could negatively impact physical health when he stopped engaging in discussions about diabetes with his provider. The feeling of not being heard was common and was also revealed when Suzie talked about providers not gathering her input on treatment plans

Suzie: "Well, just everybody makes the decisions for my life but me. You know, I have all these case managers, and the doctors, and the psychs, and the this and the that, the judge, the case manager here and over there — they're all saying what's going to happen with me and they're not even present. They tell me after the fact. I'm not included, you know? I'm not even a human. I'm just objectified again."

Not being heard also impacted treatment for pain and anxiety. Frances described many experiences of untreated pain. The following quote highlights one of these episodes.

Frances: “I had some dental work done when I was young, and I would go to a doctor and he’d say, no, there’s nothing wrong with you. But I was having like shooting pains. What happened was I had all this dental work done and I went out in the cold weather. And in the cold weather, walked to where my new work was and it was just hell. I just felt the most horrible pain. And finally I went to the doctor, and the doctor would look at me and just shake his head.”

Experiences of untreated pain were discussed by some of the participants. Some participants would cycle through various aspects of the system to get the care they needed. As Frances described, age and experience helped navigating the system to get the care needed. Yet, sometimes even age and experience were not enough to access the needed care.

Lack of time and Inaction. Providers could also erode trust by not giving adequate time and attention to a participant. For example, Suzie described a common interaction with nurses.

Suzie: “They’re angry, they’re short with you, they’re abrupt, they forget things, they’re too overwhelmed, overloaded, they’ve got short-out, you know. They’re just like they’re not there. They’re not present. “Okay, let me do this, let me —, and I’m doing this and I’m doing that,” and then they’re talking over here, and they’re doing this here, and then they act like they have — they’re an octopus with eight hands and they can do all these things at once. And you know — no, no, no, no — you know, give me my time instead of doing five things at one time. You’re human. I know you’re efficient, but you’re also human. And I am also, you know -- you keep wanting people to treat you as they would want to be treated, but that’s a difficult proposition.”

Spin was another participant that stopped trusting providers because of what he perceived as their inattentive care for a skin condition.

Spin: “and since she wasn’t um...doing anything against the disease I didn’t believe that to um...she was of any use. And may have even been harmful to

continue under her care.”

After leaving the care of the provider discussed above, Spin resorted to some unusual measures to attempt to treat persistent lower extremity ulcers, treatments that may have seriously delayed the healing process.

Stigmatization. Another commonly discussed trust eroding factor was being stigmatized. The participants wore many stigmatizing labels such as having a serious mental illness, being an older adult, being a current or former drug addict, being homeless, being a prostitute, and being a criminal. Sometimes the participants labeled themselves with a stigma, the providers acted upon or reinforced stigmatizing labels onto the patient, and the system of care perpetuated stigmas. For example, Doc described how he perceived the jacket of schizophrenia as tainting much of what he said.

Doc: “That’s the main point that I want to get across. So that I don’t get that jacket on me so that I’m believed when I you know talk or tell a story or something’s happened and you know that’s the hardest thing for me to you know when you get that diagnosis of paranoid schizophrenic.”

Frances described that she felt her history of substance use could erode a trusting connection with a provider.

Frances: “Uh, I want you to trust me and know that I’m not out for cheap thrills.”

This stigmatizing label led Frances in a long quest to access care.

Frances: “Well, she - maybe she thought I wanted — I wanted to get high. I didn’t want to get high. I wasn’t — I wasn’t in — I was acutely anxious. One time when I was anxious, I couldn’t sleep for three months. I’m not kidding you. Out of three months, I couldn’t sleep, and it was terrible. And my — well, my counselor wouldn’t believe me; nobody would believe me until I went to [psychiatric inpatient unit]”

When self labeling with a stigma, some participants did not value their instincts and often did not act on a health concern. Participants described incidents of not trusting their own

ability to care for their health or to make an impact on their health behaviors. Another participant, Mr. Eugenides, described how he wanted to quit smoking and had multiple cessation attempts in the past that all resulted in smoking again. When asked if he trusted that he could quit smoking on his own, he replied:

Mr. Eugenides: I have in the past for lengths of time. I just have to try harder. My life span isn't very long given that I smoke. I probably will die when I am about 66 or so.

This quote showed that although he had a desire to quit smoking, he had lowered his expectations about his life span. The lowered expectation appeared to relate to interactions with the health care system and the feeling that he is “just a mental patient.” Similarly, Big Larry stated a strong distrust of the health care system and for most of the providers within it.

*Big Larry: “I will never trust a doctor again.”
“Um, I'm talking about physical doctor, dentist, all that stuff”*

He also expressed a strong desire to quit smoking yet also much distrust in what the system had to offer for smoking cessation.

Big Larry: “I can't. I tried. The other day last week, I bought — what did I buy? I bought some nicotine lozenges, but it said on the box — it said if you get dizziness, you can get vomiting, you can get diarrhea, you can get — what else — nausea. There's all these things if you're over-addicted to nicotine; if you take a lozenge and smoke too. And I got scared and said I'm not going to do that. Anyway, I think I'm able to quit smoking pretty soon — I think very soon.”

Impact of Schizophrenia Symptoms the Trust Process

Where and how do the symptoms of schizophrenia come into the trusting connection with providers, the system, and the self? Doc, a participant that has struggled with the symptoms of schizophrenia since early childhood, defined trust in a follow up

discussion.

Doc: "Honor goes hand in hand. Trustworthy is how I use the word. Is he or she worthy of my trust? A person like me who should never have been born, curse the day, thrives on being trusted. I live just to keep my word, when all about me are breaking theirs... Integrity is the father, the mother, of all things, honorable and good. To be trustworthy among friends, family and business brings honor and respect, vitamins for the ego. Trust is the most abused word in the world."

Although beginning to trust happened for some participants despite dealing with severe schizophrenia symptoms, it was difficult to trust even the most trustworthy provider when feeling paranoid and suspicious. Earl described this in the following quote:

Earl: "Yeah, yeah, but if — I found out it was hard for me until I started opening up, you know, and I guess it takes you a long time before you've got the confidence up — once you've got the confidence in the doctor, you'll open up. You know, at least I did."

Earl described how he felt about opening up once he had the confidence in the provider.

Earl: "Beautiful, yeah. I've got a doctor to talk to, to get my medication, and see, since last — I got dependent on talking to doctors, because the last 18 years, I always — the last — it was the last 18 years, I always had to go to see a psychiatrist. Not that any — not that the courts ordered me to do. It's just what I've been doing, and it's been helping me, because sometimes I get so uptight, I have to find somebody that I feel comfortable — like you. I feel comfortable sitting here and talking to you about what I think is going on up here. And that's religious — that like going to make a confession to me to tell you what the voice is saying this, if it's saying that. Why, it's not a total relief but it's a relief."

For Earl, trust facilitated disclosure of mental health concerns. Other participants talked about the impact of trust on disclosing physical health concerns to a provider. Yo was one participant that described trusting his physical health care provider despite his struggle with severe paranoia.

Yo: "He's a physician. He says don't worry about it, you know? I'll give you a jar of Seno tablets, and you just take one a day, or twice a day. And so I do that and it helps, but, well, [doctor] says there's no need to worry, you know? And, you know, he feels my stomach and he says, no, you don't need any, you know, any kind of serious consideration, because it's not jeopardizing your life."

A trusting relationship allowed Yo to get reassurance that nothing was wrong physically and alleviated some of his paranoia.

Trust was an interactive process. Providers also had to trust the participants. Gaining trust from providers happened through time, experience, and actions as well. Big Larry built trust with providers with honesty.

Big Larry: “And I don’t lie.....and my doctor knows I do not lie.”

The examples of trust eroding and trust building factors showed that trust can impact physical health. In summary, participants described trust in the context of their relationships with the health care system, varying levels of trust in the providers, and their own abilities to care for their physical health needs. When trust eroded, a patient became disengaged in care, less satisfied, less savvy about self care, and less physically healthy.

Discussion

The findings must be considered in the context of the study limitations. The sample was recruited from one region within the United States. It is possible that a larger sample might present a different array of trust building and eroding factors based on different sociodemographic characteristics. Further, this is a one-sided story. Gathering the providers’ perspective may bring a better understanding of the process that builds and erodes trust.

Despite the limitations, this article described a key process to understanding the physical health of older adults with schizophrenia. Factors of trust building that emerged were respect, caring, advocacy, and consistency. Case managers and some nurses were

highlighted as providers that excelled at building trust. Trust eroding factors that emerged were disrespect, not being heard, lack of time and provider inaction, stigmatizing labels, and the reaction to these labels.

In a review of the literature on trust within the patient-provider interaction, Pearson and Raeke (2000) noted that empirical research has been limited and the theoretical perspectives conflicted. Trust has been viewed as a belief and an affective nature (Pearson & Raeke, 2000). Some define trust as a state and not a trait (Thom, Hall, and Pawlson, 2004). Trust has also been defined as “the acceptance of a vulnerable situation in which the truster believes that the trustee will act in the truster’s best interests” (Thom et al., 2004). Sheppard, Zambrana, and O’Malley (2004) suggest a commonality in trust definitions are optimism and vulnerability on the part of the patient. Thom et al. (2004) propose that trust is a global concept supported by data illustrating that trust measurement scales to date have a single factor structure and that all the domains of trust are interrelated.

Pearson and Raeke (2000) point out that few studies have attempted to ground the conceptualization of patient-physician trust in actual patient experiences and perspectives. The few studies that have gathered the patient’s perspective on trust revealed common factors of provider behavior that established trust including competence, caring, actions made on the interest of the patient, continuity of relationships, and communication (Thom et al., 2004; Sheppard et al., 2004; Thom & Bruce, 1997). Many of the factors were echoed by participants in this study.

Thom and Campbell (1997) conducted a focus group with patients and found trust in the physician increased the likelihood of adhering to a treatment regimen (Thom & Campbell, 1997). An observational study revealed that patients with higher levels of trust were more likely to request medication and to be prescribed medication (Thom, Kravitz, Bell, Krupat, & Azari, 2002). Similarly, participants with lower levels of trust correlated with lower adherence (Thom et al., 2002). In addition, patients with lower levels of trust were more likely to not receive services requested or needed (Thom et al., 2002). Sheppard et al. (2004) also found that patients with lower levels of trust were less likely to follow treatment recommendations. Participants in the present study add clarity to these findings when they spoke about how trusting relationships could lead them to be more engaged in care and more likely to follow treatment recommendations.

Furthermore, studies have highlighted the critical role of trust in the treatment of serious mental illness. Trust can be difficult for a person with schizophrenia (Leiphart & Barnes, 2005). The symptoms of schizophrenia can make the development of trust difficult (Leiphart & Barnes, 2005). However, when trust is established in a patient-provider relationship, it has been shown to have a beneficial impact on treatment engagement, such as taking medications, meeting with a psychiatrist regularly, and attending groups (Allende, Bailey, Maust, & Davidson, 1999). Research has also pointed to the role of trust in establishing a sense of belonging (Leiphart & Barnes, 2005). Researchers suggest that providers can take steps to establish a trusting relationship through taking the time to get to know patients as people (Chiman et al., 1999). Leiphart and Barnes (2005) showed trust began to develop during the first two to three months as providers listened consistently, provided practical supports that enabled clients to avoid

hospitalization, and establish a place in the community. Although no studies to date have elaborated on the link between trust and the impact on physical health in older adults with schizophrenia, the results of this study suggest it is possible that trust plays a similarly critical role in primary care.

Implications for Nursing

Nursing is ideally positioned to care for both the physical and mental health needs of this population. Nursing may focus on building trust through delivering care to older adults with schizophrenia in a respectful, consistent, attentive, and caring manner. The stigma of schizophrenia impacted trust and made trust even more important for the person to feel at ease in an encounter. The person needed to trust their provider but they also needed to be trusted by their providers. Nurses may have difficulty in trusting a patient when seeing the person through a stigmatizing lens. This brings up the need for nurses to be aware of how they act upon both subtle and more directly stigmatizing views. In addition, through collaborating with other health care professionals, such as case managers and psychiatrists, the nurse can build trust with the older adult with schizophrenia. Similar to the findings of studies looking at the role of trust in mental health treatment (Chinman et al, 1999; Leiphart & Barnes, 2005; Davidson, 2003), participants in this study also showed the positive outcomes of trusting the case manager: Engagement in life and engagement in activities, including health activities. Perhaps when nursing collaborates with a variety of health care disciplines, these positive outcomes may be amplified.

Conclusion

This study fills a gap in the literature through attempting to ground the conceptualization of trust in actual patient experiences. Moreover, most studies on trust have looked at patient-physician relationships only (Sheppard et al, 2004). These findings build upon previous research about the physical health care disparities of older adults with schizophrenia through gathering the individual perspective of the older adult with schizophrenia. The fluctuating and chronic nature of the disease, the societal response to the disease, and the fragmented health care system all impact the process of building and eroding trust. When trust was built between patients, providers and the health care system, patients were better informed, took more healthy actions, and were more likely to receive timely care. Next steps include gathering the providers' perspective on the challenges and successes in caring for the physical health of older adults with schizophrenia. Attention to older adults with schizophrenia must be a research priority in order to evolve scientifically supported interventions that will allow these individuals to live healthy and satisfied lives into their later years. Incorporating the findings of this study into the development of targeted interventions may be a step to improving the physical health of this population.

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Table 1 Demographic Characteristics

Characteristic	
Age in years	55-76 years 61 means, 6 s.d.
Sex	
Male	22
Female	6
Ethnicity	
European American	17
African-American	5
Asian/Pacific Islander	3
Native American	2
Hispanic	1

Synthesis

Synthesis

The purpose of this dissertation was to explore how older adults with schizophrenia understand their physical health. This purpose was achieved through triangulating data from quantitative and qualitative sources. First, the literature was reviewed to determine the current state of the science regarding contributing factors to poor physical health among older adults with schizophrenia. Then, a secondary data analysis was conducted to explore the relationship between the symptoms of schizophrenia experienced by older persons diagnosed with schizophrenia and type 2 diabetes mellitus and their response to a health promoting intervention. Finally, a grounded theory study was conducted exploring the understanding of physical health among older adults with schizophrenia. The purpose for this final section of the dissertation is to synthesize the dissertation results. First, the study results will be summarized, followed by a reflection on theoretical concepts that guided this dissertation, next key themes identified across the studies will be presented, then the limitations will be discussed, followed by implications for clinical practice, and concludes with directions for future research.

Summary of literature review

Reviewing the literature showed key factors that contributed to poor physical health among older adults with schizophrenia. Factors identified that play a role in the poor physical health of adults with schizophrenia across the lifespan were the impact of schizophrenia and schizophrenia symptoms, higher rates of smoking and alcohol use, and sociodemographic factors. Contributing factors specific to the older adult with

schizophrenia were identified as issues relating to chronic disease management, the physiological impact of aging as well as iatrogenic effects of treatment. Finally, factors in health care services were identified as health care disparities, provider difficulties in caring for the patient with schizophrenia, the patients' reported desire for advocacy and continuity of care that may not be met, as well as issues relating to delivery and receipt of health information.

Summary of the secondary data analysis

The findings from the secondary data analysis add to the knowledge base about the interaction of schizophrenia symptoms on physical health by suggesting that symptoms may impact disease management. The results revealed that the impact of treatment with the diabetes lifestyle intervention was moderated by higher levels of total schizophrenia symptoms. In addition the impact of treatment on diabetes knowledge was moderated by higher general and negative symptoms. However, treatment on diabetes knowledge was not moderated by the impact of greater positive symptoms. For the total sample, change in diabetes self-efficacy was moderated by total, positive, negative and general symptoms. Patients with lower diabetes knowledge and lower levels of self-efficacy to manage diabetes may be more susceptible to difficulty with self-care and at risk for additional co-morbidities as well as death related to unmanaged diabetes.

Summary of grounded theory study: belonging

The grounded theory aspect of the dissertation addressed a gap identified in the literature reviewed as it was the first study to date to evaluate the individual perspective of older adults with schizophrenia regarding their physical health. A salient study finding

was the importance of a sense of belonging. The process of finding a place to belong with others and in searching for a home had the potential to influence physical health behaviors, physical health status, access to care, and perceptions of health. Common facilitators to belonging discussed were mental health stability, mental health crisis, advocates, structure, substance use, and smoking. Barriers to belonging found were the diagnosis and experiences associated with schizophrenia, living situations, shaky support systems, judgmental health care providers, and stigma.

Summary of grounded theory study: trust

Another valuable insight gained from the grounded theory study was the process of building and eroding trust. Trust building factors that emerged were respect, caring, advocacy, and consistency. Case managers and some nurses were highlighted as providers that excelled at building trust. Trust eroding factors that emerged were disrespect, not being heard, lack of time and provider inaction, stigmatizing labels, and the reaction to these labels.

Theoretical Concepts

Exploring the question of how the older adult with schizophrenia understood their health was guided by theoretical concepts identified prior to conducting the dissertation and included concepts from Andersen's Behavioral Model of Health Services Use (Andersen, 1995), Social Cognitive Theory (SCT) (Bandura, 1989), and the Health Belief Model (HBM) (Rosenstock, 1966). These concepts were particularly helpful in the development of a semi-structured interview guide and in the analysis of these interviews. Utilizing a grounded theory method that was embedded with the theoretical

underpinnings of social interactionism helped explore the multi-level context of health understanding discussed in these models and supported by the critical reflection on these models. Social interactionism suggests the interactional context and processes, including environment, people and the encounters within it, can affect the kind of aging process a person experiences (Estes et al., 2001; Blumer,1969). Andersen's Behavioral Model of Health Services Use (Andersen, 1995), Social Cognitive Theory (Bandura,1989), and the HBM (Rosenstock, 1966) begin to account for these contextual and interactional aspects by looking at the demographic characteristics, social status and beliefs that potentially influence access to care, health conceptions, and behaviors for the person. A grounded theory approach allowed the researcher to bracket professional beliefs underlying the models to investigate the understanding of health from the point of view of the person with schizophrenia. The phenomena of health and schizophrenia was understood more completely on an individual level by asking the older adult with schizophrenia specifically about their concepts of health and schizophrenia within the context of their unique lives and to their individual health care needs.

Critical perspectives of aging and health look at aging as not only biological but also social (Estes et al, 2001). Estes et al. (2001) indicate that the proportion of morbidity and mortality may be better accounted for with social, environmental, and behavioral factors rather than relying on biology alone. Estes et al. (2001) suggest that a critical approach can overcome the misgivings of traditional aging and health theories, such as fragmentation, by considering these multilevel relationships between social structure, social processes, and the population. Symbolic interactionism, which provides the theoretical framework of grounded theory methodology, supports the consideration of

these multilevel relationships (Blumer, 1969). Neither the Andersen's Behavioral Model of Health Services Use (Andersen, 1995), SCT (Bandura, 1989), or the HBM (Rosenstock, 1966) seem to completely address the multiple layers of the individual understanding of physical health.

Estes et al. (2001) suggest that the experience of aging is dependent in part upon how others react to the aging person thus making social context, interactions, and cultural meanings important aspects of this process to consider. Again, symbolic interactionism also supports the importance of evaluating social aspects (Blumer, 1969). Interactions that may influence the experience of aging and health may occur between the patient and health care provider. Neither the HBM (Rosenstock, 1966) nor Andersen's model (Andersen, 1995) explicitly addresses the influence or impact of provider and patient interactions on health beliefs or access to care. SCT (Bandura, 1989) suggests that the health care provider may be a role model for the patient to observe or the provider may also offer reinforcement for a behavior. Aspects of the dissertation highlighted the influence of patient-provider relationships on trust and a sense of belonging for the older adult with schizophrenia. Considering the influence of patient-provider interactions and the meaning of schizophrenia from the older adult's social world on the participant's health understanding allowed the emergence of trust and belonging, critical components to understanding their unique health conception.

Estes et al. (2001) describe that social context subsumes not only situational events and interactional opportunities but also structural constraints that may limit the range of interactions and degree of understanding for the aging person. Structural restraints can reinforce lines of action while barring other lines of action (Estes et al.,

2001). The grounded theory approach allowed the emergence of structural restraints that were perceived as most significant to the older adult with schizophrenia. A few of the structural restraints facing the older adult with schizophrenia were health care settings that were difficult to access and home environment that made self-management and self-care a low priority. The secondary data analysis indicated that symptoms may be a barrier to engaging in educational interventions. The grounded theory study also showed how schizophrenia symptoms could stand in the way of effective self care.

A central and unifying tenet to critical theories is the idea that problems faced by the elderly are socially constructed and result from social concepts of aging and the aged person (Estes et al., 2001). This social construction is a process that occurs at the micro level such as with personal interactions, the macro levels such as with the state and economy, and at the meso level such as with organizational and institutional structure and processes of the person's world (Estes et al., 2001). A critical perspective on aging expands the Andersen's Behavioral Model of Health Services Use (Andersen, 1995), Social Cognitive Theory (Bandura, 1989), and the HBM (Rosenstock, 1966) to a comprehensive framework that may guide the exploration of how these multiple levels impact the person's health understanding. It was concluded from critique of the models and SCT (Bandura, 1989) that the critical perspective gives us the tools to understand the broad social, economic, and political factors that can influence meanings in old age that may not be accounted for by relying only on the models and theory alone. The results of the grounded theory studies showed the value of this critical perspective through directly asking individuals with schizophrenia about their health rather than relying only upon the models to guide our knowledge and subsequent interventions.

Perhaps by considering the participant's experience of schizophrenia and physical health and adding in pieces of this understanding to the models may add to increased success of interventions. The models and SCT provide a solid starting point in creating a more individualized conceptual framework for the older adult with schizophrenia in attempt to improve their physical health. Grasping this health understanding may guide researchers and clinicians to tailor screening, prevention, and treatment interventions to the individual needs of the older adult population with schizophrenia.

A few key themes identified in the dissertation will be presented next. The themes are examples of how this individual perspective may inform conceptual frameworks to more completely meet the unique needs of the older adult with schizophrenia. Future conceptual frameworks underpinning interventions may need to account for the symptoms of schizophrenia, relationships with providers, trust, and a sense of belonging.

Themes

Impact of schizophrenia symptoms

These data add to the current knowledge base about the poor physical health of older adults with schizophrenia. As discussed in the secondary data analysis manuscript and the literature review, the relationship of symptoms to physical health outcomes has been largely ignored in the literature and is in need of further exploration. Dixon, Postrado, Delahanty, Fischer, and Lehman (1999) indicated in one of the initial studies on physical health status that there is a need to better understand this relationship between mental health status and medical comorbidity. Dixon et al. (1999) suggested the importance for future research to attempt to tease apart how medical illness and psychiatric status

interact. The findings from both the secondary data analysis and the grounded theory study are first steps in better understanding the relationship between schizophrenia symptoms and physical health. The secondary data analysis study showed that symptoms can impact disease management. In addition, the grounded theory study showed that schizophrenia symptoms can facilitate or block finding a place to belong. Being in this place of belonging and the process of finding this place could interact with physical health. Furthermore, building and eroding trust with the health care system and health care providers was influenced by schizophrenia and schizophrenia symptoms.

Relationships with health care professionals

Relationships with health care professionals played a critical role in the physical health of older adults with schizophrenia. For example, how the provider examined and understood the schizophrenia symptoms experienced by participants may have influenced the results of the secondary data analysis. Even though all raters in the study were highly trained and reliable in their ratings of participant psychiatric symptoms, the raters may not have completely captured the experience of psychiatric symptoms. When studies have explored patient self rating of schizophrenia symptoms, patient versus an observer reported rating of symptoms appear to hold different meanings; therefore the perceptions may not be equal (Biancosino et al., 2007; Preston & Harrison, 2003). Biancosino et al. (2007) indicate a few studies have suggested a lack of congruence between patients and clinicians when evaluating psychotic experiences and that the patient's perception of psychopathology provides an additional dimension that should be incorporated into decision making processes and in evaluating effectiveness of interventions.

The trust and belonging articles illustrated the influential role of providers on the physical health of the participants from playing a part in missed diagnoses to the other end of the spectrum when collaborating with members of the health care team. Providers could play the role of an advocate and guide patients through their interactions with the health care system as well as in their struggle to care for their complex physical and mental health needs. However, providers could also be a hindrance in achieving optimal physical health. Provider inaction, provider's stigmatizing views, and judgmental attitudes played a part in eroding trust and in the process of not finding a place to belong. The patient-provider relationship could impact a participant's willingness to seek care, engage in treatment, and stay involved with a course of treatment.

Similar to the findings of studies looking at the role of trust in mental health treatment (Chinman, Allende, Bailey, Maust, & Davidson, 1999; Leiphart & Barnes, 2005; Davidson, 2003), participants in this study showed the positive outcomes of trusting the case manager: engagement in life and engagement in activities, including health activities. Chinman et al. (1999) and Leiphart and Barnes (2005), suggest that entering into a relationship with a provider can be especially powerful for someone with schizophrenia as they are often isolated and lack positive relationships in the past. This may be especially important for the older person with schizophrenia. Davidson (2003) also indicates that recovery from psychiatric illness has been fostered by a nurse believing in a client. Providing a trusting connection with the nurse may pave the way for the older adult with schizophrenia to find places of belonging.

Sociodemographic challenges

The literature review indicated that living situations could play a role in the development of poor physical health. For example, schizophrenia is approximately 10 times more common in the homeless population in comparison to the general population (Folsom et al., 2002). Older adults living in shelters may face further burden through exposure to respiratory and skin infections due to close living quarters and inadequate hygiene (Chafetz, White, Collins-Bride, & Nickens, 2005). The grounded theory study further illustrated the relationship of living situations on poor health and how the person self managed complex and simple medical problems. Many participants recalled periods of homelessness or were currently homeless. The experience of living without adequate housing played a role in the delayed diagnosis and treatment of medical issues as serious as hepatitis C and cancer to even less life threatening issues but equally important such as vision.

Exposure to drugs and alcohol were also brought up frequently during interviews in the grounded theory study. For some participants, drugs and alcohol were never an issue in terms of abuse so being around the triggers was less problematic. Some participants could avoid drugs and alcohol by staying involved in social rehabilitation programs. However, for many participants avoiding drugs and alcohol was difficult due to a constant barrage of triggers to use such as people knocking on their door with drugs ready to share.

Limitations

One limitation identified early on in the dissertation was a severe lack of research on older adults with schizophrenia. However, this built an even stronger case for studying

the unique needs of older adults with schizophrenia. Due to the limited data, the literature included in the literature review related to both younger and older individuals with schizophrenia.

A limitation in conducting the secondary data analysis related to the sample. The sample was a group biased towards a higher functioning portion of the population with schizophrenia enrolling in research programs. Participants with more severe psychopathology or less well-controlled symptoms may have different outcomes when participating in a health education intervention. It may be that samples with greater symptomatology will show even less of a treatment effect or a treatment effect on the positive symptom subscale. Studies with older samples are also needed.

For the grounded theory studies, one of the critical limiting factors was missing the perspective of providers caring for this population. Reviewing chart notes provided some insight although limited. Gathering the provider perspective can help understand the factors that facilitate and block a sense of belonging. The provider perspective may shed further light on the dimensions that build and erode trust with participants.

Implications

Nursing Practice

These data raise important issues to consider in future research and clinical practice. In regards to clinical practice, patients with serious mental illness may need appreciation and recognition of their psychiatric symptoms from the physical health care provider. Providing comprehensive care that includes both caring for the mental as well as physical health care needs is imperative. Nursing is ideally positioned to care for both

the physical and mental health needs of this population. An appreciation of the symptom experience can come from nurses realizing that the continuum of symptoms may influence self care and the ability to engage in care. Multi-disciplinary collaboration may begin to improve the physical health of the older adult with schizophrenia through managing the myriad of physical, mental, and social needs. In addition, providing patient centered education that includes discussions about patient goals, addressing issues surrounding self care, and exploring the meanings that patients place on self-care were also emphasized in the literature review. (El-Mallakh,2006; Auslander & Jeste, 2002; MacHaffie, 2002; McKibbin et al., 2006; Mausbach et al., 2008)

Nurses may focus on improving relationships with older adults with schizophrenia. Trust may be built by delivering care to older adults with schizophrenia in a respectful, consistent, attentive, and caring manner. The grounded theory study showed that the stigma of schizophrenia impacted trust and made trust even more important for the person to feel at ease in an encounter. The person needed to trust their provider but they also needed to be trusted by their providers. Nurses may have difficulty in trusting a patient when seeing the person through a stigmatizing lens. This brings up the need for nurses to be aware of how they act upon both subtle and more directly stigmatizing views. In addition, through collaborating with other health care professionals, such as case managers and psychiatrists, the nurse can build trust with the older adult with schizophrenia.

Furthermore, recognition of the importance of finding a place to belong for the older adult with schizophrenia can help nurses maximize the facilitators to belonging and minimize barriers in a manner that optimizes physical and mental health status among

older adults with schizophrenia. For example, awareness of being judgmental and how this can negatively influence relationships with patients may be a critical first step to minimizing a barrier to finding a place of belonging with the nurse. If a place of belonging is established and nurtured between a nurse and patient, it may open the door to discussions about the various social, mental, and physical aspects of the patients' life that are impacting their physical health behaviors and physical health status.

Future research

Future nursing research should explore the relationship between the older adult with schizophrenia and the health care system and providers in order to better understand how this relationship impacts physical health behaviors, health access, and physical health status. Next steps to pursue in understanding the physical health of older adult with schizophrenia include exploring patient-provider relationships. The patient-provider relationship may be studied through direct observations during clinical encounters as well as gathering the providers' perspective in caring for this population. In addition, the literature on symptom evaluation and the results of the secondary analysis indicate a need for measurement approaches that more completely capture the subjective experience of the person with schizophrenia. Also, the concept of trust and how trust is built and eroded may be further studied through pilot testing trust measurement scales among older adults with schizophrenia. Incorporating the findings of this dissertation into the development of targeted interventions may be another step to improving the physical health of this population.

Conclusion

It is clear that older adults with schizophrenia face multiple challenges in achieving optimal levels of mental and physical health. The symptoms of schizophrenia, the experience of schizophrenia, the health care system, and the health care providers are all critical factors to consider when promoting better health outcomes for this population.

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Committee on Human Research
 Project Summary Sheet
CHR: H6362-31103-02

Study Title

Older Adults with Schizophrenia: How do they understand physical health?

Principal Investigator

Margaret I. Wallhagen Title: Associate Professor
 Department: Physiological Nursing
 Phone: 476-4965 Fax: E-Mail: meg.wallhagen@nursing.ucsf.edu
 Address: Box 0610

Contacts

<u>Name</u>	<u>Position</u>	<u>Box</u>	<u>Phone</u>	<u>E-Mail</u>
Wallhagen, Margaret I.	PI	0610	476-4965	meg.wallhagen@nursing.ucsf.edu
Kools, Susan	Former PI	6060	476-4040	susan.kools@nursing.ucsf.edu
Leutwyler, Heather	Co-PI	0606	415-341-5344	heather.leutwyler@ucsf.edu

Human Subjects Training

The PI and Co-PI must complete the UCSF online training course: Protecting Human Research Subjects

<u>Name</u>	<u>Last Completed</u>
Wallhagen, Margaret I.	10/24/02
Leutwyler, Heather	2/24/06

Review Details

<u>Approval Number</u>	<u>Status</u>	<u>Received</u>	<u>Reviewed</u>	<u>Approved</u>	<u>Expires</u>
H6362-31103-02	Approved	6/9/2008 12:	7/15/2008 12:	7/15/2008 12	7/24/2009 :
H7350-31103-01	Approved	6/18/2007 10	7/24/2007 12:	7/24/2007 12	7/24/2008 :

Attachments: Consent Form, Dated 6/9/08
 Consent Form, Dated 6/18/07

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Older adults with schizophrenia: How do they understand physical health?

This is a research study about the physical health of the older adult with schizophrenia. The principal investigator for this study is Margaret Wallhagen, PhD, GNP-BC, AGSF, FAAN, from the Department of Physiological Nursing. Heather Leutwyler, a family nurse practitioner and a nursing doctoral candidate in the Department of Physiological Nursing, is working with Dr. Wallhagen as the Co-principal investigator on this research. Ms. Leutwyler will explain this study to you. She is available to answer any questions about the study you might have.

Research studies only include people who choose to take part in the study. You are being asked to consider taking part in the study because you are an older adult with schizophrenia or schizoaffective disorder who may have experience with physical health problems or concerns. Please take your time in making the decision about participation in this study. You can talk about whether you want to join this study with friends or family if you wish. If you have any questions, you may also ask Heather.

Why is this study being done?

The researchers would like to better understand the physical health of older adults with schizophrenia because this may help us provide better care in the future.

How many people will take part in this study?

About 20 to 40 people will be interviewed for this study.

What will happen if I take part in this research study?

If you agree to take part in this study, the following will happen:

You will be interviewed by Heather in a private location on site at the facility you attend, in your home, or an agreed upon location, such as a local coffee shop. During the interview, Heather will ask you questions about your physical health.

Heather will make a sound tape recording of the conversation. After the interview, Heather will type into a computer a transcription of what is on the tape and will remove any names from the typed document. The tape recording will then be destroyed or given back to you if you wish to keep it.

Heather will interview you at least once. After reviewing her notes, she might contact you by phone or in person to ask you if she could talk with you a second time. It is up to you if you would like to have a second interview. Heather will not ask you to do more than 2 one-on-one interviews. Each interview will take about 60 minutes.

Heather will review your medical and legal records that are on site at the facility. Heather will note information such as medical or psychiatric diagnosis, medications used (if any), and other treatments. She will also review information about your previous, current, or projected living situations. You may refuse to allow Heather to access your medical records and still participate in the study.

How long will I be in the study?

Participation in the study will take up to 2 hours over a period of 1-2 days. You may be asked to participate in further interviews and observations in the future.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the researchers right away if you wish to stop being in the study.

Also, the researchers may stop you from taking part in this study at any time if she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

What risks can I expect from being in the study?

- You may feel uncomfortable about discussing details of your health.
- You may also be concerned that the confidentiality of your health may be at risk.
- The time needed to complete the interviews may be a problem for you.
- You may also become bored during the interview process.

You are free to decline to answer any questions you do not wish to answer and may stop the interview at any time.

Are there benefits to taking part in this study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand and learn more about your physical health.

What other choices do I have if I do not take part in the study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your care the way you usually do.

Will my medical information be kept private?

We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

If a health situation is uncovered by the researcher that poses an immediate threat to you, the researcher, as a mandated reporter, will be obligated to report this to the proper authorities. Potentially reportable situations include, but are not limited to, any form of elder abuse, self-neglect or risk for suicide. You may be at risk of intervention by state and local authorities if a reportable situation is detected.

In this study you will be asked about drug use and other possibly illegal activities. The researchers will keep information about you as confidential as possible, but complete confidentiality cannot be guaranteed. On rare occasions, research records have been subpoenaed by a court. Your name will not be used in any published reports about this study.

During the study, it is possible that information about how you take care of your health may come up. If Heather considers this information to be unsafe, then Heather will discuss these issues with you at the end of the interview.

Participation in research may involve a loss of privacy, but information about you will be handled as confidentially as possible.

What are the costs to taking part in this study?

You will not be charged for any of the study procedures.

Will I be paid for taking part in this study?

You will be given 10 dollars in cash immediately after the first interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits, and you can still get your care from our institution the way you usually do.

Who can answer my questions about the study?

The Principal investigator is Margaret Wallhagen, PhD, GNP-BC, AGSF, FAAN, and can be reached at 415-476-4965 to answer questions about the study. Heather Leutwyler, the Co-principal investigator, may also answer any questions you have about the study and can be reached at 415-341-5344.

If you have any questions, comments, or concerns about taking part in this study, first talk to the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights). The CHR is independent of the research team and is available to answer any questions about your rights and welfare as a study participant.

You can reach the CHR office at **415-476-1814**, 8 am to 5 pm, Monday through Friday. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

Consent

You have been given a copy of this consent form for your records.

You will be asked to sign a separate form to authorize access to your health information.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below

Subject Signature

Date of signature

Signature of Person obtaining consent

Date of signature

Capacity to Consent Questions

1. Are we offering you your usual medical care, or are we asking you to be in a research study?
2. Do you have to take part in this study or is it all right to say no?
3. What is the purpose of this study?
4. Will this study mainly help you or others?
5. Please tell me one risk of being involved in this study?
6. If you want to drop out of the study, when can you do this?
7. Considering the risks and benefits we have discussed, what have you decided about taking part in this study?

Interested in talking about your physical health?

Heather Leutwyler, is a family nurse practitioner and a nursing doctoral student at UCSF. Along with Dr. Margaret Wallhagen, she is doing a study to better understand the physical health of older adults with schizophrenia or schizoaffective disorder.

Heather is looking for volunteers for her study. To be eligible for the study, you must be 55 years or older, have a diagnosis of schizophrenia or schizoaffective disorder, and speak English.

If you are interested in being a volunteer, you will meet and talk with Heather at this facility or a nearby location at a time that is convenient for you. Participation in the study will take up to 2 hours over a period of 1-2 days. To thank you for your time when participating in the study, you will receive 10 dollars in cash.

The study is completely voluntary, you decide whether or not to participate, and you can stop participating at any time.

If you are interested in being in this study, please fill in the information below and Heather will contact you.

Please feel free to contact Heather directly at 415-341-5344 if you have any questions about the study or if you would like to schedule an interview. The Principal Investigator, Margaret Wallhagen PhD, GNP-BC, AGSF, FAAN can be contacted at 415-476-4965.

The researchers may also be contacted at UCSF School of Nursing, 2 Koret Way, #N-319X, UCSF Box 0602, San Francisco, CA 94143-0602.

Thank you!

I agree to have Ms. Leutwyler contact me.	
Signature_____	Date_____
Phone_____	Best time to call or visit? _____

Interview Guide

Hello Mr./Ms._____. Thank you and I appreciate you agreeing to spend some time talking with me. Before we begin, is there anything you would like to ask me?

I have asked you to spend some time talking with me today so that I may better understand how you experience and understand your physical health. I hope that you can feel comfortable talking with me. I am asking questions so that I may learn from you. There are no right answers to these questions. I am interested in your experiences and ideas.

1) To begin with, please tell me a little bit about yourself?

2) Please tell me what being healthy means to you?

Follow up questions/probes

- a. Can you tell me about a time when you felt good/healthy?
- b. What does someone look like when they are healthy?
- c. Please tell me about how important it is to you to be healthy?

3) Please tell me what being sick/in bad/poor health means to you?

Follow up questions/probes

- a. Can you tell me about a time when you felt sick/badly?
- b. What does someone look like when they are sick?
- c. Please tell me the concerns you might have about your health?

4) Please tell me about your health?

Follow up questions/probes

- a. Can you tell me about any medical problems you have?
- b. Can you tell me how you manage your health and/or medical conditions?
- c. What things do you do to take care of your health? Or to take care of your medical problems?

5) What do you like most about your health?

Follow up questions/probes

- a. When do you feel your best?
- b. Tell me about your thoughts and feelings when you are healthy?
- c. What helps you maintain this good health/feelings?

6) What do you like least about your health?

Follow up questions/probes

- a. When do you feel your worst/least well?
- b. Can you tell me about your thoughts and feelings when you don't feel well?
- c. What do you think contributes to not feeling well?

7) Where or from whom do you get information about your health? Whom do you talk to about your health?

8) Please tell me about your most recent visit to a health care provider and what type of provider this was (such as a nurse practitioner or physician)?

Follow up questions/probes

- a. Why did you go in for a visit?
- b. What went well during this visit?
- c. What did not go well during this visit?
- d. What else would you like to have happened during this visit?
- e. How did you feel about your health after this visit?

9) In what living situation have you felt the least health? Most healthy?

10) How do your relationships effect your health?

- a. Do you feel healthier or less healthy when connected with other people?

11) Do you drink alcohol (or smoke marijuana or used other substances)? Have you in the past?

Follow up questions/probes

- a. Other people have mentioned that heroin use is common in this neighborhood, have you tried it before?
- b. Does Marijuana (or other drug discussed) affect your health? How so?

12)Is there anything else you would like to tell me about your health?

13)Is there anything you would like to ask me?

14)May I contact you for a second interview?

Probes:

Could you tell me a little more about that.....

Before we talked about your doctor, you were telling me about a time you felt sick.....

What do you mean.....

Could you give me an example

What can you tell me about...

I distracted you with that question, you were talking about...

How did you feel about (the topic you are discussing)

Description of the Recruitment Sites

Transitional Residential Facility

This facility provides community-based residential treatment for individuals who are considered severely disabled due to mental illness. Many clients also have a co-occurring substance abuse disorder. This program consists of 2 six-bed houses for adults over 60 serving a total of 12 clients in residence and another 12 clients who attend day treatment only. The average length of stay is four to six months. The majority of residents and day treatment participants are male.

Locked Facility

The second recruitment site is licensed as a locked 24 hour mental health rehabilitation center. The center treats severely and persistently mentally disordered clients, including clients with a dual diagnosis of mental illness and chemical dependency. The facility has a registered nurse on duty 24 hours per day. The average length of stay is between six to eight months. Typically, the majority of residents are male. A little less than half of the residents are over the age of 55.

Intensive Case Management Program

The third recruitment site is a program that uses an Assertive Community Treatment (ACT) model for delivering comprehensive, wrap-around services for the highest users of the local behavioral health system. The agency provides clinically competent and comprehensive psychiatric services to individuals with severe and persistent mental illness, often co-existing with substance abuse. The majority of clients served are male and the majority of clients are under the age 60.

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

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I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Heather Deutscher
Author Signature

5-21-09
Date