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Signature:

Christina Paula Cabral Borba

Date

Examining Personal and Structural Determinants of Health among Women with a Serious
Mental Illness: A Mixed Methods Approach

By

Christina Paula Cabral Borba
Doctor of Philosophy

Behavioral Sciences and Health Education

Claire E. Sterk, Ph.D.
Advisor

Benjamin G. Druss, M.D., MPH
Committee Member

Frances A. McCarty, Ph.D.
Committee Member

Accepted:

Lisa A. Tedesco, Ph.D.
Dean of the James T. Laney School of Graduate Studies

Date

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Abstract

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By: Christina Paula Cabral Borba

Women diagnosed with a serious mental illness (SMI) experience co-morbid medical problems due to multiple factors. Additionally, they frequently experience inadequate planning and delivery of medical services. This is a mixed-methods research study examining the health related quality of life (HRQOL) and pathways to healthcare for women with a SMI. The first component of this research is a secondary data analysis of 197 adult women with a SMI who were recruited for a randomized controlled trial (RCT) and assessed at baseline. Determinants of physical HRQOL include income, housing, diagnosis of major depression, and chronic health conditions. Determinants of mental HRQOL include income and diagnosis of major depression. Findings suggest that improving HRQOL in this population will require addressing nonmedical domains in the lives of women with a SMI, such as income, housing, and symptoms of depression.

The second component of this research is a qualitative study with a sub-sample of 30 women diagnosed with a SMI, recruited from participants in the RCT. A complicated cycle of social disadvantage is evident among these women's lives. Salient themes of their stories include experiencing loss, isolation, and a sense of a lack of control. Additionally, this study highlights how a variety of nonmedical factors influence women's introduction to and engagement with the healthcare system. Findings indicate that support from mental health providers is an influential factor for women's access and utilization of healthcare services. Social support from nonmedical entities such as religious communities, family, and friends is also a major determinant of women's engagement with the healthcare system.

This research provides a deeper understanding of the nonmedical factors that impact the health of women with a SMI. Specifically, income, housing, and social support emerged as important factors. Ultimately, public health policy needs to acknowledge the larger social context of the lives of women with a SMI to facilitate their engagement in the healthcare system. Gaining additional knowledge about the structural and social components of the lives of women with a SMI may result in effective health promotion strategies that enhance healthcare utilization via changes in women's behavior and/or in the larger healthcare system.

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CHAPTER 1:

Introductory Literature Review

The quality and quantity of health care obtained by women increasingly has become a topic of interest (Clancy & Massion, 1992). Congress has increased its emphasis on women's access to appropriate medical care, including preventive care. The U.S. Preventive Services Task Force (USPSTF), a government-appointed expert panel, developed recommendations for primary care clinicians based on a systematic review of the published literature. The USPSTF was first convened by the U.S. Public Health Service in 1984, and since 1998 has been sponsored by the Agency for Healthcare Research and Quality (AHRQ). The USPSTF is the leading independent panel of private-sector experts in prevention and primary care. The USPSTF conducts rigorous, impartial assessments of the scientific evidence for the effectiveness of a broad range of clinical preventive services, including screening, counseling, and preventive medications. Its recommendations are considered the gold standard for clinical preventive services. The mission of the USPSTF is to evaluate the benefits of individual services based on age, gender, and risk factors for disease. They make recommendations about which preventive services should be incorporated routinely into primary medical care and for which populations and identify a research agenda for clinical preventive care.

The first edition of the *Guide to Clinical Preventive Services* was prepared under the supervision of the U.S. Preventive Services Task Force, with staff support from the U.S. Department of Health and Human Services. The Guide rigorously reviews evidence for over 100 interventions to prevent 60 different illnesses and conditions. The second and most recent edition of the Guide has been completely revised. The Task Force has

reevaluated each preventive service and rewritten each chapter. The *Guide to Clinical Preventive Services* (2nd Edition) summarizes the clinical effectiveness of preventive services which included screening tests, counseling interventions, immunizations, and chemo-prophylactic regimens. The *Guide* also provided age, sex, and risk factor specific recommendations about services that should be considered for periodic health examinations (DiGuseppi, Atkins, Woolf, & (editors). 1996). The 2nd edition carefully reviews the evidence for and against hundreds of preventive services, recommending a test, immunization, or counseling intervention only when there is evidence that it is effective. At a time when the leading causes of death are largely related to health-related behaviors-including tobacco use, poor diet, lack of physical activity, and alcohol use, it is particularly pertinent to highlight the importance of the health consequences of behavior. It remains important that physicians and other providers educate their patients about these matters (DiGuseppi et al., 1996).

Screening recommendations specific to women include body mass index (BMI); mammograms; pap smears; cholesterol; blood pressure; colorectal cancer; diabetes; depression; bone density; Chlamydia; and HIV infection (DiGuseppi et al., 1996). Enactment of these recommendations depends on several factors. For example, factors that have been identified to influence cancer-screening rates in women include socio-demographic characteristics (Hayward, Shapiro, Freeman, & Corey, 1988), knowledge, attitudes, and beliefs about screening and the disease (Burack & Liang, 1987); the efficacy of treatment (Burack & Liang, 1987); patients' compliance with recommendations (Margolis, Lurie, McGovern, & Slater, 1993); and structural factors, such as health insurance coverage (Woolhandler & Himmelstein, 1988).

WOMEN AND SERIOUS MENTAL ILLNESS

Serious mental illness (SMI) is any psychiatric disorder present during the past year that seriously interferes with one or more aspects of a person's daily life. These include the ability to carry out primary aspects of daily life such as self-care, household management, school or work, and the ability to form interpersonal relationships (Task Force on the Homeless and Severe Mental Illness, 1992). The most recent definition includes all psychiatric diagnoses that incur substantial disability and no required duration. Some estimates show this as encompassing 5-7% of the U.S. population ages 18 and older (Center for Mental Health Services and National Institute of Mental Health, eds. R.W. Manderscheid and M.A. Sonnenschein, 1992).

These disorders may include but are not limited to schizophrenia, schizoaffective disorder, bipolar disorder, major depression, obsessive-compulsive disorder, and post-traumatic stress disorder, with or without co-morbid substance use. Schizophrenia is a chronic, severe, and disabling brain disorder that affects about 1.1 percent of the U.S. population age 18 and older in a given year. People with schizophrenia sometimes hear voices others don't hear, believe that others are broadcasting their thoughts to the world or become convinced that others are plotting to harm them. These experiences can make them fearful and withdrawn and cause difficulties when they try to have relationships with others (National Institute of Mental Health, 2007d).

Schizophrenia does not affect men and women in the same way. Pre-morbid adjustment is known to be superior in women, the symptoms of schizophrenia begin later in life, and outcome for the first 10-15 years after onset is more favorable in women (Goldstein & Tsuang, 1990). Women show a second onset peak at a time that coincides

with menopause (Häfner et al., 1989). The symptomatic expression of the illness also differs between men and women. Men show more apathy, flat affect, cognitive disturbance, paucity of speech, and social isolation, whereas women are more often depressed (Goldstein & Tsuang, 1990).

Schizoaffective disorder is defined as the presence of psychotic symptoms in the absence of mood changes for at least two weeks in a patient who has a mood disorder. The diagnosis is used when an individual does not fit diagnostic standards for either schizophrenia or mood disorders such as depression and bipolar disorder. Some people may have symptoms of both a depressive disorder and schizophrenia at the same time or they may have symptoms of schizophrenia without mood symptoms (National Alliance on Mental Illness, 1996). The proportion of schizoaffective disorder identified in persons undergoing treatment for psychiatric disorders has ranged from 2% to almost 30%, depending on the study cited. More females than males suffer from schizoaffective disorder. However, similar to gender ratios in clinical depression and bipolar disorder, it seems that there is a much higher ratio of women to men in the depressive subtype whereas the bipolar subtype has a more even gender distribution. Thus, the higher ratio of women overall is primarily caused by the concentration of women within the depressive subtype of schizoaffective disorder (National Alliance on Mental Illness, 1996).

The term unipolar depression is used to distinguish it from depression which occurs within the context of bipolar disorder, a disorder in which a person experiences alternating periods of depression and mania. Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes shifts in a person's mood, energy, and ability to function (National Institute of Mental Health, 2007a). While bipolar disorder

affects both men and women, how the disorder is experienced and treated in both genders varies greatly (Leibenluft, 1997). Women, for example, tend to experience more of the rapid cycling type of bipolar disorder. It is approximately three times more common in women than in men. Rapid cycling describes incidences where a bipolar patient experiences four or more episodes of mania, hypomania, or depression within a time period of a year (Leibenluft, 1997).

Major depressive disorder is a mood disorder characterized by a depressed mood, a lack of interest in activities normally enjoyed, changes in weight and sleep, fatigue, feelings of worthlessness and guilt, difficulty concentrating and thoughts of suicide. If a person experiences the majority of these symptoms for longer than a two-week period they may be diagnosed with major depressive disorder (U.S. Department of Health & Human Services, 2007). Epidemiologic data indicate that major depression is approximately twice as common in women as in men (Weissman & Olfson, 1995). Major epidemiologic studies, such as the National Co-morbidity Survey and the Epidemiologic Catchment Area study, have consistently found significantly higher lifetime and 1-year prevalence rates of major depression in women (Kessler et al., 2003; Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993). The lifetime prevalence of depression in community samples varied from 10% to 25% in women, with an average prevalence of approximately 20%. By comparison, the lifetime prevalence in men was 5% to 12%, with an average prevalence of approximately 10%. The female-to-male ratio for the lifetime relative risk of a major depressive episode ranged from 1.7 to 2.4 (Kessler et al., 1993; Kessler et al., 1994).

Obsessive-Compulsive Disorder (OCD) is an anxiety disorder and is characterized by recurrent, unwanted thoughts called obsessions and/or repetitive behaviors called compulsions. Repetitive behaviors such as hand washing, counting, checking, or cleaning are often performed with the hope of preventing obsessive thoughts or making them go away. Performing these rituals however, provides only temporary relief, and not performing them markedly increases anxiety (National Institute of Mental Health, 2007b). The National Institute for Mental Health reports that about 3% of people in the United States have OCD. Typical age of onset for boys is 6 to 15, while for women it is often later, between 20 and 30. Risk factors like genetic predisposition and environmental stress contribute to OCD. Also, OCD is more common among people of higher education, IQ, and socioeconomic status. Men and women, however, are affected equally. Though its course is chronic and usually lasts a lifetime, it is treatable with medication, behavioral therapy, and, in extremely rare cases, brain surgery (National Institute of Mental Health, 2007b).

Post-Traumatic Stress Disorder (PTSD) is an anxiety disorder that can develop after exposure to a terrifying event or ordeal in which physical harm occurred or was threatened. Traumatic events that may trigger PTSD include violent personal assaults, natural or human-caused disasters, accidents, or military combat (National Institute of Mental Health, 2007c). A number of epidemiologic survey studies have shown that PTSD is twice as common in women as in men; in addition, there are gender differences in the type of trauma exposure, presentation of illness, and co-morbidities. For example, different types of traumas carry different risks for the development of PTSD. Rape, in both men and women, carries one of the highest risks for producing PTSD.

Approximately 0.7% of men in the United States reported being raped as compared with 9.2% of women (Spitzberg, 1999). Other forms of sexual abuse and interpersonal violence are also more commonly associated with PTSD when compared to accidents or natural disasters. A history of depression or anxiety disorder at the time of trauma is also a risk factor for the development of PTSD. A number of epidemiologic surveys have demonstrated that women with PTSD are twice as likely to have depression and anxiety disorders compared with men with PTSD (Breslau, Davis, Andreski, Peterson, & Schultz, 1997). As such, much of the increased prevalence of PTSD in women may be mediated by trauma type and co-morbidity rather than specific biologic differences.

In 2003, there were an estimated 19.6 million men and women aged 18 years or older with a SMI (U.S. Department of Health and Human Services & Substance Abuse & Mental Health Services Administration, 2005). The highest rate of SMI occurred among women in the 18-25 age groups, with 17.3 percent women reporting a SMI. The greatest disparity between men and women occurred in the 26-49 age group, with women being nearly twice as likely as men to have experienced a SMI (13.8 compared to 7.0 percent) (U.S. Department of Health and Human Services & Substance Abuse & Mental Health Services Administration, 2005). Mental illnesses affect women and men differently and some disorders are more common in women, and some express themselves with different symptoms (National Institute of Mental Health, 2008). Researchers are also currently studying the special problems of treatment for SMI during pregnancy and the postpartum period.

Women with a SMI experience co-morbid medical problems due to a history of trauma (L. Miller, 1997), barriers to treatment of physical illness (Druss & Rosenheck,

1998), high rates of smoking prevalence and substance misuse (Dickerson, Pater, & Origoni, 2002), obesity and diabetes mellitus related to certain psychiatric medications (Brady, 1989; Dixon et al., 2004), and consequences of the illness itself, such as neglect in self care (Lieberman, Stroup, Perkins, & editors., 2006). Although similar causes of co-morbid medical problems have been documented for both women and men with a SMI, the unique gender specific experiences of co-morbid medical problems and barriers to care are not fully understood.

WOMEN WITH A SERIOUS MENTAL ILLNESS AND HEALTHCARE UTILIZATION

The health status of women with a SMI has gained attention most recently (J. H. Coverdale, Bayer, McCullough, & Chervenak, 1995; L. Miller & Finnerty, 1996). It has been shown that women with a SMI are sexually active and need services that address family planning, HIV risk reduction, pregnancy, and childrearing (J. Coverdale, Aruffo, & Grunebaum, 1992). Although the reproductive needs of women with a SMI might be identified and addressed in some settings, it is not clear that other types of women's healthcare are being received by women with a SMI.

Women with a SMI are more likely to experience higher rates of medical disorders than women in the general population (Kessler et al., 1994). Women with a SMI have diverse diagnoses, treatment histories, functional levels and prognoses and share the experiences of inadequate planning and delivery of medical health services (V. Brown, 1998). They are also more likely to have physical complaints disregarded and their requests for services denied (V. Brown, 1998). There is some evidence that suggests that there are gender differences in the prevalence and detection of physical

illness among patients with schizophrenia. For example, in a study of psychiatric outpatients, the most common medical problem for women was gynecological disease (Roca, Breakey, & Fischer, 1987). Another study examined service use in women with schizophrenia and found that compared to a control group with no history of mental illness, significantly fewer women with schizophrenia had had a pelvic examination and Pap test in the past three years, had a mammogram in the past two years, and had ever received hormone replacement therapy (Lindamer et al., 2003). It has been found that women with schizophrenia are more likely to have indicators of estrogen dysfunction, for example, later age of menarche, fewer pregnancies and births, and earlier age of menopause (Riecher-Rössler, Häfner, Dütsch-Strobel, & Stumbaum, 1998). These findings show the importance of adequate gynecological care for this particular patient population.

Prior studies have found that women with a SMI may be at increased risk for developing breast and cervical cancer (Desai, Bruce, & Kasl, 1999; Druss, Rosenheck, Desai, & Perlin, 2002; Ettigi, Lal, & Friesen, 1973; Halbreich, Shen, & Panaro, 1996; Owen, Jessie, & De Vries Robbe, 2002). The reasons for this association may be due to under-utilization of preventive health care services, decreased access to treatment, the effects of mental illness and its treatment on the development of cancer, and/or risk factors that are common to both having a mental illness and cancer (E. Miller, Lasser, & Becker, 2007). It has also been found that both the category and severity of a mental illness is associated with initial and subsequent medical health care use. For example, a study found that women with anxiety, mood, psychotic, and substance disorders were at the greatest risk for not receiving a mammogram (Carney & Jones, 2006).

Previous studies have also found an association between a history of physical and sexual abuse and a lack of routine healthcare. Women who had been victimized were less likely to receive preventive healthcare services (Steiner et al., 1998). More than half of women with a SMI report a history of physical and sexual abuse (L. Miller, 1997; L. Miller & Finnerty, 1996; Rosenberg, Drake, & Mueser, 1996). These women also have twice as many gynecological problems and generally seek care in primary settings for insomnia, gastrointestinal problems, and chronic pain (L. Miller, 1997; L. Miller & Finnerty, 1996). Additionally, it has been found that women who have been abused may have difficulty accepting gynecological examinations that may trigger memories of abuse (E. J. Brown & Jemmott, 2000; Perese & Perese, 2003). For example, a study reported that pelvic examinations of psychiatric inpatients were avoided unnecessarily and that the gynecological needs of mentally ill women warranted further investigation (Handel, 1985). However, it is unclear whether women with a SMI are receiving the basic screening examinations. A study was conducted in an urban community mental health center to determine if women with a SMI were receiving preventive healthcare compared to those provided to low-income women in a local medical clinic (Steiner et al., 1998). The findings of this study found that access to medical care for women with a SMI was not limited and that many were receiving appropriate preventive medical care. However, the most pertinent findings were the associations between a history of physical and sexual abuse and a lack of routine preventive healthcare. In this study sample, the prevalence of all types of abuse including physical, childhood sexual abuse and rape as an adult was very high. The results have important implications for program development and treatment planning as staff in mental health clinics should identify women who may have

been physically or sexually abused and develop procedures to engage them in the healthcare system and ensure that appropriate preventive healthcare services are being utilized (Steiner et al., 1998).

The role of mental illness, physical illness and substance use in the lives of women is complex. Prevalence data for men and women indicate that 41-65% of individuals with a lifetime substance-abuse disorder also have a lifetime history of at least one mental disorder (Kessler et al., 1996). Data from the Center of Substance Abuse and Treatment (Center for Substance Abuse Treatment, 2005) report that, when compared with the general population, 30% of women with a SMI have coexisting substance-abuse problems. In a large, cross-sectional prevalence study of 26,332 Medicaid recipients, half of the sample (n = 11,185) had been treated for a SMI. The findings showed that co-morbid substance use increased the risk for multiple medical disorders (Dickey, Normand, Weiss, Drake, & Azeni, 2002).

The increased risk of physical health problems associated with substance use disorders among women not only includes sexually transmitted diseases, such as HIV and AIDS, but also sexual and physical violence. All of these are demonstrated to a greater degree among women with a SMI (Fullilove & Fullilove, 1994). Treatment components for women with a SMI and substance use disorders need to include screening for accompanying medical problems (Burman, 1994; Hagan, Finnegan, & Nelson-Zlupko, 1994; Harris, 1994).

BARRIERS TO HEALTHCARE UTILIZATION AMONG WOMEN WITH A SERIOUS MENTAL ILLNESS

Different types and levels of barriers might prevent women with a SMI to obtain adequate healthcare services. These can include individual and systemic level barriers. Individual level barriers include behaviors directly resulting from symptoms of mental illness such as poor nutrition, obesity, smoking and alcohol and drug misuse which can increase the risk for medical illness (Glassman, 1993; Lasser et al., 2000; Silverstone, Smith, & Goodall, 1988). Additionally, symptoms of mental illness can reduce a person's willingness to seek medical care (Felker, Yazel, & Short, 1996). For example, the incidence of breast cancer among women with long-term psychiatric problems is 9.5 times greater than the general population (Halbreich et al., 1996). It has also been found that the presence of psychiatric conditions, substance abuse, or dual-diagnosis predicted lower rates of mammography screenings compared with women without such conditions (Druss et al., 2002). These findings are supported by another study suggesting that a high burden of depressive symptoms was an independent predictor for not receiving subsequent mammography screenings (Pirraglia, Sanyal, Singer, & Ferris, 2004).

Systemic level barriers may lead to under treatment of patients with a SMI. Healthcare providers may not be willing to devote the additional time needed to gather appropriate histories for women with a SMI which may lead to under treatment among this population (Graber et al., 2000). Healthcare providers who are not familiar with patients with a SMI may be uncomfortable in dealing with these patients (Bunce, Jones, Badger, & Jones, 1982). A study in which focus groups were conducted among primary care physicians found that physicians have very high rates of mental illness in their practices; approximately 20% of their patient population has a SMI (E. Miller et al., 2007). However, physicians reported that a lack of time and distraction by acute

problems make preventive healthcare a lower priority (E. Miller et al., 2007). In another study, physicians identified several barriers for women with a SMI for not receiving preventive healthcare. They noted that these women may be less organized and less able to remember appointments scheduled many months in advance. They also identified fragmentation of the healthcare system including disintegration of healthcare records between multiple providers as barriers for women with a SMI in receiving healthcare services (Owen et al., 2002).

Research has found a relationship between having an SMI and lower socioeconomic status (SES) (Coryell et al., 1993; Dohrenwend et al., 1992; Weissman & Olfson, 1995). Low SES can hinder access to healthcare through multiple factors such as lack of transportation or the inability to afford out-of-pocket medical expenses. Also patients with a SMI are under or uninsured which additionally hinders access to healthcare (Sturm & Wells, 2000). There is also no system in place to help women attend their health care appointments or an efficient system to identify women who have not received specific services. Women with a SMI who do not have a support system in place may be more likely to miss their appointments without a clinician noticing (E. Miller et al., 2007).

THEORETICAL MODELS FOR HEALTHCARE UTILIZATION

Some of the theoretical models used to help explain healthcare screening utilization include the Health Belief Model (Rosenstock, 1966) and the Theory of Reasoned Action (Fishbein & Ajzen, 1975). The common themes addressed by these two models relate to perceived risk, perceived severity, perceived self-efficacy and expected benefits and costs of adopting a particular health behavior. These models are

based on cognition and do not consider the emotional and structural components of health-seeking behavior. Also, these models tend to view individual risk perception as existing independent of the social and cultural context. Individual knowledge, attitudes and beliefs are seen as the basis for determining healthcare utilization behavior (Bloom, 1994). In addition, the biomedical model paradigm has been used to identify women's knowledge, attitudes, and beliefs regarding preventive healthcare. This approach is based on a deficit model where women's knowledge is compared with biomedical based information relating to risk factors and screening practices (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995). For example, a study examining breast cancer screening practices among minority women found that biomedical knowledge did not translate into actual breast cancer screening practices. In this study, there was a discrepancy between women's knowledge of screening protocols and their actual practices (Danigelis et al., 1995). Health professionals can be seen as members of a profession with their own subcultures. Health professionals' belief systems are a product of the professional socialization process including a body of knowledge grounded in the biomedical model (Pachter, 1994). The biomedical knowledge is held in empirical, observable and measurable data. The emphasis is on physical, measurable facts rather than on psychological and socio-cultural issues (Helman, 1994). The biomedical model conceptualizes the medical decision-making process as individualistic, autonomous, and rational (Pescosolido, 1992).

These models represent a more etic perspective of healthcare utilization. The etic perspective relies upon the extrinsic concepts and categories that have meaning for scientific observers (Pike, 1954). Etic constructs are accounts, descriptions, and analyses

expressed in terms of the conceptual schemes and categories that are regarded as meaningful and appropriate by the community of scientific observers. Etic constructs must be precise, logical, comprehensive, replicable, falsifiable, and observer independent (Pike, 1954).

EXPLANATORY MODELS FOR HEALTHCARE UTILIZATION

In contrast to extrinsic models, explanatory models operate from an insiders' view of the world and consists of what people in a given setting or culture believe about the nature, cause, prevention, and response to an event. Explanatory models are a product of social, cultural and historical factors among different subcultures. They are held by both non-health professionals/lay individuals and health professionals and provide an explanation for the process by which illness is patterned, interpreted, and treated. The explanatory model of lay individuals relates to the way a person conceptualizes illness (Pachter, 1994) and helps to give meaning and coherence to a physical condition (Gregg & Curry, 1994). These explanatory models are characterized by vagueness, multiple levels of meaning, frequent changes, and blurred boundaries between ideas and experiences. Explanatory models can include the etiology, nature of symptoms, diagnosis, methods of treatment, types of preventive methods, and roles and expectations of the individual (Helman, 1994; Kleinman, 1980). These conceptions of illness are laden with emotional meaning, can stem from socio-cultural context which can include cultural beliefs, socio-economic factors, social networks and social supports, personal and idiosyncratic beliefs, popular conceptions of illness, and biomedical explanations of illness. These models are not static but are subject to revision over time (Chavez et al., 1995). Explanatory models represent an emic perspective. Emic constructs are accounts,

descriptions, and analyses expressed in terms of the conceptual schemes and categories that are regarded as meaningful and appropriate by the members of the culture under study. The validation of emic knowledge thus becomes a matter of consensus, namely the consensus of native informants, who must agree that the construct matches the shared perceptions that are characteristic of their culture (Pike, 1954).

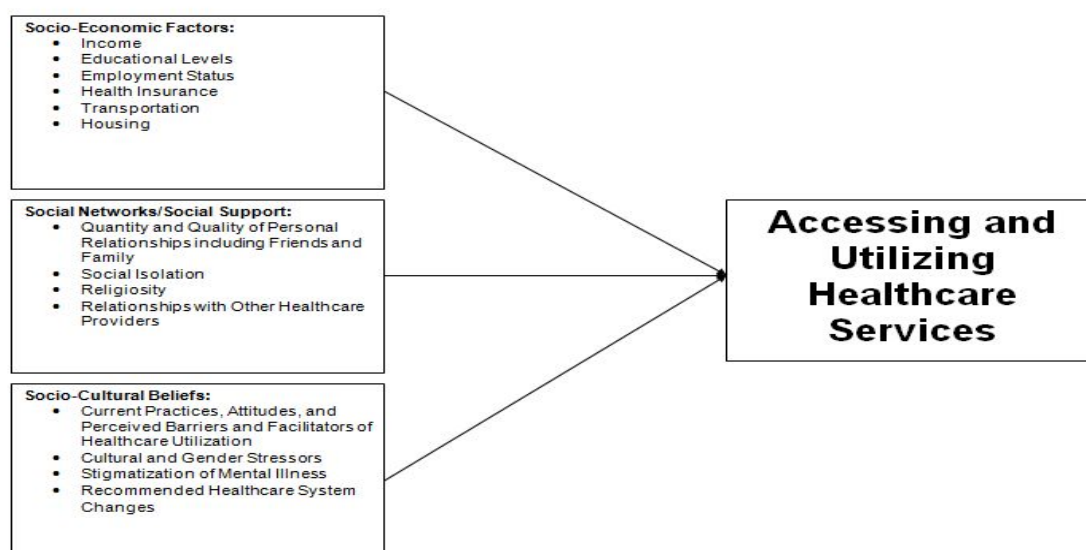
A relativistic framework seeks to elicit the explanatory model of the individual (Rajaram & Rashidi, 1998). It assesses the potential impact the explanatory model may have on healthcare utilization. This framework allows health professionals to maintain a nonjudgmental stance while eliciting the explanatory models of an individual without necessarily adopting or rejecting them. The relativistic framework strives to acknowledge and respect the cultural and individual explanations of their patients (Rajaram & Rashidi, 1998). Also health professionals need to be aware of their own explanatory models and their respective bias (Pachter, 1994). The relativistic framework allows health professionals to provide alternative explanations within a broader framework. It encourages them to find ways to successfully negotiate between an individuals' explanatory model and their own model in order to ensure positive healthcare outcomes. This relativistic framework allows for open lines of communication which can lead to mutual understanding, respect, and trust between healthcare professionals and patients that may facilitate more patient satisfaction (Rajaram & Rashidi, 1998). Only by adopting a relativistic framework can future interventions succeed in improving healthcare for women with a SMI. However, before a relativistic framework for healthcare utilization can be achieved between women with a SMI and

healthcare professionals, the explanatory model of women with an SMI needs to be elucidated.

EXPLANATORY MODEL FOR THE PROPOSED STUDY

The current study proposes to study the explanatory model of women with a SMI and healthcare utilization (Figure 1.1). Particularly, this study proposes to assess the socio-cultural beliefs, socio-economic factors, and the social network/social support of women with a SMI and its impact on healthcare utilization (Figure 1.1). Explanatory models for women with a SMI may not accord with health professionals' explanations and this might have an impact on these women's health and illness behavior. This possible misunderstanding of women's explanatory models by health professional may result in a breakdown in the communication process between the subculture of biomedicine and that of women with a SMI resulting in barriers to utilization of healthcare services.

Figure 1.1: Explanatory Model of Healthcare Utilization among Women with a Serious Mental Illness



PREVIOUS RESEARCH ON EXPLANATORY MODELS FOR WOMEN

Socio-Cultural Beliefs

Socio-cultural beliefs can result from women's desirable and/or undesirable life experiences, past experience with the medical system, stigmatization, and past illness experiences (Rajaram & Rashidi, 1998). For example, it has been shown that explanatory models relating to breast cancer risk factors differed between physicians and Latinas (Chavez et al., 1995). In this study, physicians' explanatory models were grounded in biomedical literature but in contrast, Latinas' explanatory models were related to their social context which included physical trauma to the breast and behaviors such as smoking, drinking, drug abuse and a lack of physical hygiene (Chavez et al., 1995). Another study on the explanatory models of low-income African American women demonstrated that these women believe that the mental distress associated with the knowledge of cancer and/or treatment was as bad as, or worse than, the physical illness itself (Gregg & Curry, 1994). They felt that screening merely catches the disease after the fact and is not an effective preventive tool. Another study showed a relationship between cultural beliefs associated with physical abuse and breast cancer screening (Wardlow & Curry, 1996). The findings of this qualitative study indicated that low-income black women attributed breast cancer to the effects of violence in their lives. These women felt that when bruises resulting from domestic violence are not reported or given medical attention, they can later turn into cancer. However, women were reluctant to acknowledge the presence of physical abuse and felt that screening for breast cancer may reveal the existence of the abusive situation (Wardlow & Curry, 1996).

Socio-Economic Factors

Women's explanatory models are influenced by the social and economic organizations of society or opportunity structures. An individual's decision to seek healthcare may depend on whether she can take time off from work or has adequate health insurance (Dutton, 1978; Rundall & Wheeler, 1979). For example, it has been found that among lower socio-economic status minority women the primary reason for not obtaining healthcare is a result of social and financial constraints (Dutton, 1978; Rundall & Wheeler, 1979). Women's experiences with system barriers include complexity of the medical system and a lack of personal contact with the medical system. These are added deterrents for lower income women who may be uncomfortable negotiating their way through the medical system (Strauss, 1970).

Social Networks and Social Support

The decision of whether to see a physician may be influenced by lay norms and may not necessarily follow a rational health seeking process that logically leads to healthcare professionals (Zola, 1973). Social networks are organized by the culture and structure of communities through which knowledge is interpreted and evaluated (Pescosolido, 1992). Individuals in a social network influence help seeking behavior and also can be seen as a therapeutic network through which advice and information about the effectiveness of treatments are assessed. It is through these social interactions and networks that individuals recognize or fail to recognize a problem, find appropriate social resources and find ways to evaluate the outcomes of action (Pescosolido, 1992). Women's positive and negative experiences with healthcare professional are transmitted through the social network and healthcare seeking behavior is greatly influenced by social interaction with friends, family, and acquaintances (Friedson, 1970).

SIGNIFICANCE OF THE PROPOSED PROGRAM OF RESEARCH

Previous work has documented both high rates of medical disorders and challenges in obtaining quality healthcare services among women with a SMI (Kessler et al., 1994) . This mixed methods study will examine women's health related quality of life (HRQOL) and its impact on utilization of healthcare services along with a more holistic perspective on the lives of women with a SMI. Additionally, it will provide a deeper understanding of healthcare utilization by elucidating the relationship of nonmedical factors and its impact on obtaining and receiving healthcare services among women with a SMI. The findings from this study will provide essential formative and interpretive data for future intervention efforts in aiding women with a SMI in receiving and obtaining healthcare services. Gaining this knowledge may result in effective health promotion strategies used to enhance healthcare utilization among women with a SMI via changes in women's behavior and/or in the healthcare system.

While the current evidence is useful for conceptualizing the barriers and facilitators to healthcare utilization among women with a SMI, the limitations of prior studies suggest that there are a number of areas for future research to make substantive contributions. The proposed research seeks to fill several gaps in the existing research by: (1) assessing the determinants of HRQOL. By understanding HRQOL in women with a SMI, we can identify subgroups with poor physical or mental HRQOL which can help guide policies or interventions to improve their health; (2) describing and interpreting women's lived experiences as this will provide new understandings about the nature and needs of women living with a SMI; (3) investigating the pathways to healthcare services

among women with a SMI. More specifically, how do women with a SMI get into the healthcare system and what enables them to utilize medical healthcare services.

The proposed program of research took place in two separate studies. In the first study (Chapter 2), a secondary data analysis of 197 adult women with a SMI was conducted. The sample for this cross-sectional study were recruited for a randomized control trial and assessed at baseline. This research study makes a contribution to the existing knowledge base by examining social and other nonmedical factors that could have an important impact HRQOL among women with a SMI.

In the second study (Chapters 3 and 4) in-depth face to face qualitative interviews were conducted on a sample of 30 women with a SMI. This qualitative study of low income women with a SMI, who lived in an urban city, explored how they describe and interpret their life experiences. The strength of engaging women with a SMI in discussing their lived experiences through qualitative interviews enables them to reveal thoughts and feelings within the context of everyday living in a way that surveys and other quantitative methods cannot. The goal of this qualitative study was to uncover common experiences among women with a SMI and to highlight how social and environmental factors help women with a SMI engage in the medical healthcare system.

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CHAPTER 2:

Health Related Quality of Life among Adult Women with a Serious Mental Illness

ABSTRACT

Although medical morbidity is well documented among women with a serious mental illness (SMI), less is known about the determinants of their health related quality of life (HRQOL). The objectives of this study were (1) to assess the determinants of HRQOL as measured by the Medical Outcomes Health Survey Short Form (SF-36) and (2) to explore whether HRQOL is a determinant of primary healthcare utilization among women with a SMI. The sample for this cross-sectional, secondary data analysis included 197 adult women with a SMI. Data analysis involved two separate multiple linear regression and multiple logistic regression models used to investigate the predictors of HRQOL and utilization of primary healthcare services respectively. Predictors of higher levels of physical HRQOL included higher income and living in a halfway house as compared to being marginally housed/homeless. Women who had more chronic health conditions and a diagnosis of depression compared to other psychiatric diagnoses had the lowest physical HRQOL. Low income was a significant predictor of lower mental HRQOL. Women with a diagnosis of major depression had lower mental HRQOL than those with other conditions. Both physical and mental HRQOL were significant predictors of utilizing primary healthcare services, with higher levels of HRQOL decreasing the odds of primary healthcare service utilization. Nonetheless, only about three quarters of women even in the lowest quartile of HRQOL had one or more primary care visit. Additional research is needed to learn more about the role nonmedical factors have on the impact of HRQOL among women with a SMI such as income, housing, and the symptoms of depression.

INTRODUCTION

In the United States, an estimated 26.2 percent of individuals ages 18 and older suffer from a diagnosable mental illness in a given year (Kessler, Chiu, Demler, Merikangas, & Walters, 2005). About 6 percent of those suffer from a serious mental illness (SMI) (Kessler et al., 2005). Elevated rates of co-morbid medical conditions such as obesity (Holmberg & Kane, 1999; Wallace & Tennant, 1998), cardiovascular disease (Appleby et al., 2000; Dickey, Normand, Weiss, Drake, & Azeni, 2002), diabetes (Appleby et al., 2000; L. Dixon et al., 2000), and HIV (Stoskopf, Kim, & Glover, 2001) have been found in persons with a SMI. Additional studies show that persons with a SMI who have such co-morbid conditions tend to experience more severe forms of these co-morbid disorders (Jeste, Gladsjo, Lindamer, & Lacro, 1996). For example, major depression has been shown to increase the risk of cardiovascular disease (Carney, Freedland, Miller, & Jaffe, 2002; Eaton, 2002) and having schizophrenia may predispose people to metabolic syndrome which has been attributed to psychotropic medication (Cohn, Prud'homme, Streiner, Kameh, & Remington, 2004; Ryan & Thakore, 2002). Epidemiological indicators show that people diagnosed with a SMI die at least 25 years earlier (*Morbidity and Mortality in People with Serious Mental Illness.*, October 2006), largely due to these preventable medical conditions (Brown, Inskip, & Barraclough, 2000; Hannerz & Borga, 2000; Hansen, Jacobsen, & Arnesen, 2001).

Women, specifically those between 26 and 49 years old, are nearly twice as likely as men to have experienced a SMI (U.S. Department of Health and Human Services & Substance Abuse & Mental Health Services Administration, 2005). Research findings also show that women with a SMI experience higher rates of medical disorders than

women in the general population (Kessler et al., 1994). These co-morbid medical problems are due to factors such as high rates of smoking and substance misuse (Dickerson, Pater, & Origoni, 2002), obesity and diabetes mellitus related to certain psychiatric medications (Brady, 1989; L. B. Dixon et al., 2004), and consequences of the illness itself, such as neglect in self care (Lieberman, Stroup, Perkins, & editors., 2006).

Health related quality of life (HRQOL) is becoming an important outcome measure in healthcare, reflecting (1) the transition of disease burden from infectious diseases to chronic conditions and (2) a renewed respect for a patient's subjective evaluation of their own health status (Murray, Lopez, & eds), 1996). The focus in medical healthcare outcomes research has shifted more to the individual (Geigle & Jones, 1990), specifically an individual's ability to maintain physical functioning and mental well being (Cluff, 1981; Schroeder, 1987). In the general population, it has been found that chronic health conditions are associated with adverse effects on a person's HRQOL (Stewart et al., 1989). Also, it has been demonstrated that depression and depressive symptoms are also associated with a diminished HRQOL (Wells et al., 1989). Additionally, nonmedical factors such as employment and marital status have been found to be significant predictors of HRQOL (O'Dea, Hunter, & Anjos, 1999).

Several researchers have looked at HRQOL among individuals with a SMI. A study comparing bipolar patients with those with chronic back pain found that bipolar patients were less compromised in areas of physical and social functioning than chronic back pain patients, but had similar impairment in mental health (Arnold, Witzeman, Swank, McElroy, & Keck, 2000). Another study identified self-reported health problems and functional impairment associated with screening positive for posttraumatic stress

disorder (PTSD) in women. PTSD was associated with self-reported mental and physical health problems and poor HRQOL in these patients (Dobie et al., 2004). Other studies have found that depression was associated with physical and emotional dysfunction as bad or worse than that found in other chronic medical conditions, including diabetes, arthritis, and back, lung, or gastrointestinal disorders (Wells et al., 1989).

Although medical morbidity is well documented among women with a SMI, less attention has focused on the determinants of HRQOL in this population. Understanding HRQOL in women with a SMI can identify subgroups with poor physical or mental HRQOL and can help guide policies or targeted interventions to improve their health. Additionally, several studies have shown that HRQOL is an important determinant of health service utilization (Mulunpalo, Vuori, Oja, Pasanen, & Urponen, 1997; Nelson et al., 1998). More specifically, a study found that physical functioning and mental health were important predictors of both hospital and outpatient services utilization for patients with chronic diseases (Nelson et al., 1998). Given the findings regarding HRQOL, it is important to further examine HRQOL among women with a SMI including how HRQOL relates to healthcare service utilization in this population. Therefore, the objectives of this study were to assess the determinants of HRQOL as measured by the SF-36 (Ware, Kosinski, & Keller, 1994) and to explore whether HRQOL is a determinant of primary care healthcare utilization among women with a SMI.

METHODS

Sample

The sample for this cross-sectional study included 197 adult women with a SMI who were recruited for a randomized controlled trial (RCT) and assessed at baseline. The

RCT was developed and tested a population-based medical case management model for improving primary medical care for patients with a SMI (Druss et al., In Press).

Participants for the RCT were randomly selected from a roster of 3,400 active patients from a community mental health center in a southeastern urban city, resulting in a sample of 407 subjects. Consenting individuals received a baseline interview and chart review to assess psychiatric diagnosis, baseline quality of primary care, mental and substance use symptoms, baseline medical morbidity, physical health status, service use and cost data and then were randomized to receive care in either medical case management or usual care. Additionally, biannual assessments were conducted during the two year study period. The community mental health center's target population is individuals age 18 and older who are economically disadvantaged and who experience a SMI with or without co-morbid substance use disorders. The present study involved a secondary analysis of data obtained from the women (n=197) who completed the baseline assessment. The RCT was approved by both the Emory University Institutional Review Board and the Grady Health System Research Oversight Committee.

Measures

HRQOL status was assessed by the Medical Outcomes Health Survey Short Form (SF-36), a self-report measure of physical and mental HRQOL. The SF-36 is composed of 8 multi-item scales (Ware, Kosinski, & Gandek, 1993; 2000) assessing physical function (10 items, alpha = .938), role limitations due to physical health problems (4 items, alpha = .843), bodily pain (2 items, alpha = .896), general health (5 items, alpha = .648), vitality (4 items, alpha = .784), social functioning (2 items, alpha = .703), role

limitations due to emotional problems (3 items, $\alpha = .870$) and emotional well being (5 items, $\alpha = .717$).

The subscales of physical functioning, role limitations due to physical problems, and bodily pain have been shown to be the most valid SF-36 scales for measuring physical health (McHorney, Ware, & Raczek, 1993). The subscales of general mental health, role limitations due to emotional problems, and social functioning have been shown to be the most valid of the SF-36 scales as mental health measures (McHorney et al., 1993). These eight scales can be aggregated into two summary measures, the Physical Component Summary score and the Mental Component Summary score (Ware et al., 1994). Summary scores were calculated by weights derived from an oblique factor analysis (Farivar, Cunningham, & Hays, 2007). Possible scores range from 0 to 100, with higher scores indicating better functioning. The SF-36 has been employed successfully in studies of people with a SMI (Arnold et al., 2000; Strassnig, Brar, & Ganguli, 2003; Wittchen, Carter, Pfister, Montgomery, & Kessler, 2000).

Demographic information included age, self identified racial background (African American versus other), marital status, educational attainment, and average monthly income. Current psychiatric diagnosis was captured via the participant's psychiatric chart during the baseline assessment. Psychiatric diagnoses included schizophrenia, bipolar disorder, major depression, and other psychiatric disorders. Employment status and health insurance status were dichotomized as unemployed or employed and uninsured and insured. Housing status included the following response options: owning a house or apartment; renting a house or apartment; government subsidized housing; halfway house; and living in a homeless shelter or living on the streets. Additionally, participants were

asked if they had ever been incarcerated and this information was captured as a dichotomous variable (no/yes).

The Alcohol and Drug Composite Problem Indices from the Addiction Severity Index (McClellan, Luborsky, Woody, & OBrien, 2000) was also administered at baseline. The alcohol and drug use subscales (McClellan et al., 2000) was calculated and then dichotomized into low and high alcohol and drug use based on the non-normal distribution of the data.

Chronic health conditions were assessed by self report by asking the participant if a doctor had ever told them they had the following problems: “High blood pressure; asthma; a hearing condition or an ear, nose and throat condition; an eye or vision problem, except for needing glasses; cancer; heart trouble; a stroke; bladder/urinary problems; arthritis or rheumatism; HIV positive test or AIDS; problems with kidneys; diabetes; a stomach or digestive disorder; lung trouble; liver problems; and tooth decay.” Participants answered no or yes. These items were summed for a total number of chronic health conditions for each participant.

Utilization of primary care services was assessed by the following question “In the last 60 days, how many visits did you make to an internal medicine or primary care doctor or provider for a medical reason, not a psychiatric reason?” The response options were dichotomized as no visits to a primary care doctor and any visit to a primary care doctor.

Statistical Analyses

All analyses were conducted using SPSS version 17.0. Descriptive statistics including frequencies/percents and means/standard deviations were computed for all

study variables. All continuous variables were assessed for normality. Bivariate relationships were investigated using Pearson correlation coefficients and one-way analysis of variance. Two separate multiple linear regression models were used to investigate the predictors of physical HRQOL and mental HRQOL. In addition, two multiple logistic regression models were used to investigate the effect of HRQOL on utilization of primary care services. All associations with $p < .1$ at the bivariate level were considered statistically significant and entered into the regression models. All association with $p < .05$ were considered statistically significant in the multiple regression models.

RESULTS

Sample characteristics included 197 women with a SMI. The majority of the sample had a diagnosis of Major Depression (49.7%). Participants had a mean age of 46.93 (SD = 8.07). The sample was primarily African American (81.7%). Approximately three quarters of the sample had a high school diploma or less (74.7%) and more than half the sample lacked health insurance (52.8%). For those who were insured, the entire subsample was on a government assistance program for health insurance. The demographic characteristics of the sample are reported in Table 2.1. Table 2.2 shows socio-demographic characteristics, HRQOL, and utilization of primary care services by psychiatric diagnosis. In terms of HRQOL, the average scores for both physical HRQOL (34.17, SD=11.06) and mental HRQOL (35.17, SD=10.13) in this sample were below the population norm/average score (mean=50, SD=10) (Kosinski, Bayliss, Bjorner, & Ware, 2000; Ware et al., 1993; 2000). Additionally, only about three quarters of the sample in the lowest quartile of HRQOL were receiving any primary care services.

Demographic variables including marital status, highest education level, history of incarceration, and drug misuse were not significant at the bivariate level in relation to HRQOL. Both monthly income and health insurance status were significant at the bivariate level with HRQOL at $p < .05$. However, monthly income and health insurance status were highly correlated ($r = .730$, $p < .001$) and therefore only income was included in the multivariate regression models.

Results of the multivariate linear regression model showed that socio-demographic variables and chronic health conditions predicted 22% of the variance in physical HRQOL when entered into the model at the first step. Psychiatric diagnosis (dummy coded) increased the R^2 significantly by 5% at the second step. Finally, housing status (dummy coded) also increased the R^2 significantly by 5% at the third step. The final multivariate linear regression model for physical HRQOL (model 1a, Table 2.3) had an adjusted R^2 of .289 ($F = 6.955$, $df = 12, 164$, $p < .001$). A total of four predictors contributed significantly to the outcome variable. Women who had a higher income reported greater physical HRQOL. Women who reported more chronic health condition and had a diagnosis of depression had a lower physical HRQOL. Additionally, women who lived in a halfway house had higher physical HRQOL than women who were marginally housed/homeless.

Results of the multivariate linear regression model showed that socio-demographic variables including alcohol misuse predicted 12% of the variance in mental HRQOL when entered into the model at the first step. Psychiatric diagnosis (dummy coded) increased the R^2 significantly by 9% at the second step. Finally, housing status (dummy coded) did not increase the R^2 significantly at the third step and therefore was

removed from the final model. The final multivariate linear regression model for mental HRQOL (model 1b, Table 2.3) had an adjusted R^2 of .203 ($F=8.106$, $df=7, 188$, $p<.001$). Significant predictors were income and a diagnosis of major depression. As in physical HRQOL, women who had higher incomes also reported higher levels of mental HRQOL. In regards to psychiatric diagnosis, women with the diagnosis of major depression had lower mental HRQOL than those with other conditions.

In the multivariate logistic regression model for utilization of primary care services, physical HRQOL was a significant predictor (Model 2a, Table 2.4). Women who reported higher physical HRQOL had a decrease in the odds of utilizing primary care services. Additionally, race was also a significant predictor, where women who were not African American had a decrease in the odds of utilizing primary healthcare services. Both employment and chronic health conditions were approaching significance. Being employed, an enabling factor for care was associated with an increase in the odds of utilizing primary healthcare services. Having multiple chronic health conditions was also associated with an increase in the odds of utilizing primary healthcare services.

In the multivariate logistic regression model for utilization of primary care services, mental HRQOL was also a significant predictor (Model 2b, Table 2.4). Women who reported higher levels of mental HRQOL had a decrease in the odds of utilizing primary healthcare services. Additionally, race was a significant predictor in utilizing primary care services where women who were not African American had a decrease in the odds of utilizing primary healthcare services. Age was approaching significance ($p=.051$) where women who were older had an increase in the odds of utilizing services.

DISCUSSION

Findings reveal much lower HRQOL compared to population-norm averages, confirming the poor health and functioning in this population. Additionally, the findings show the importance of social and other nonmedical factors on the HRQOL among women with a SMI. For example, income was a significant predictor of HRQOL. Others have identified a link between a person's socioeconomic status (SES) and self-reported health functioning in the general population (Hunt, McEwen, & McKenna, 1985). In studies examining the association between SES and HRQOL among various patient populations, similar findings were reported. For example, a study looking at HRQOL and asthma found that low educational level, unemployment, yearly income under \$20,000, dependence on public assistance, and lack of health insurance were negatively related to HRQOL (Apter, Reisine, Affleck, Barrows, & ZuWallack, 1999). In another study to determine the effects of income inequalities on self-rated health status while controlling for individual characteristics, found the effects of income inequality on self-rated health were as strong as other individual risk factors (Kennedy, Kawachi, Glass, & Prothrow-Stith, 1998).

The difference between women who lived in a halfway house and those who are marginally housed/homeless were interesting findings. Women who lived in a halfway house reported higher physical HRQOL compared to women who were marginally housed/homeless. The importance of stable, affordable and adequate housing to meet the needs of women with a SMI is important. Research has found that people with a SMI identify income and housing as the most important factors in achieving and maintaining their health (Trainor, Pomeroy, Pape, & (Eds), 1999). Housing is a stabilizing force which allows individuals to develop and maintain a daily routine (Trainor et al., 1999).

However, due to low incomes, stigma of having a mental illness, and difficulties in daily functioning, individuals with a SMI have a difficult time obtaining appropriate housing. Consequently, many live in substandard accommodations such as homeless shelters or even on the streets. The challenge of providing stable housing options for persons with a SMI is reflected in the estimated 45% of homeless persons in the US who have experienced mental health problems in the past year and the 31% who have experienced mental health and substance abuse problems (Burt, Aron, Lee, & Valente, 2001).

Recently, HRQOL and utilization of healthcare services have been examined in regards to housing status. The strongest evidence of the effect of housing on HRQOL among people with a SMI comes from those who were once homeless. In one study, the mean HRQOL scores increased significantly after one year in a group home (Middelboe, 1997). Homelessness is prevalent among women with a SMI (Davies-Netzley, Hurlburt, & Hough, 1996; Goodman, Dutton, & Harris, 1995) and many factors contribute to this. There were no significant differences between women who owned or rented versus women who were marginally housed/homeless. This suggests a possible protective effect of living in a halfway house. Future research is needed to fully understand the impact of housing on women's HRQOL.

Our findings also emphasize the impact depression has on HRQOL. This is consistent with previous studies that have found that patients with mood disorders report lower levels of HRQOL than those with schizophrenia (Atkinson, Zibin, & Chuang, 1997; Coulehan, Schulberg, Block, Madonia, & Rodriguez, 1997). Those with a mood disorder, while reporting lower HRQOL, reported higher educational achievement, better financial situations, less health impairment, and more social involvement than those with

schizophrenia. Depression may also exacerbate the disabilities associated with physical illness affecting functioning in a number of areas, including social functioning, productivity, self-care, and physical functioning (Hays, Wells, Sherbourne, Rogers, & Spritzer, 1995; Wells et al., 1989). Also, women who reported more chronic health conditions reported significantly lower physical HRQOL. In a study comparing the SF-36 to a wide range of chronic diseases found that patients who were older, female, had a low level of education, were not living with a partner, and had at least one co-morbid medical condition reported the poorest level of HRQOL (Sprangers et al., 2000).

Additionally, HRQOL impacted utilization of primary care services. The data showed that self-perceived HRQOL as a proxy measure of need is an important contributor to the utilization of primary care services. Women with low levels of both physical and mental HRQOL utilized more primary healthcare services. Studies have identified HRQOL as an important predictor of health service utilization. For example, a study found similar results where subjects with SF-36 physical and mental summary scores below 40 were more likely to use outpatient and in-patient services than those who had scores over 50 (Matsumura, 2000). Inasmuch as HRQOL can be seen as a proxy for need, this suggests that the women with the highest need are receiving at least some primary care services. Nonetheless, only about three quarters of women in the lowest quartile of HRQOL had used any primary care services. This underlines the need to improve access to primary care in this vulnerable population.

This study has several limitations. Cross-sectional data was used for this secondary data analysis and therefore the relationship between predictors of HRQOL and the relationship between HRQOL and utilization of primary care services cannot be

interpreted as causal. Further research is needed to determine the degree to which these nonmedical factors are truly associated with HRQOL and how HRQOL is associated with the utilization of primary care services among women with a SMI. Also, participants who agreed to participate in the clinical trial may differ from other women with a SMI. However, the inclusion criteria for this study were made broad to be representative of persons with a SMI in outpatient mental health treatment in urban areas. Furthermore, data on social support was not captured in this study. However, studies have found a significant relationship between social support and HRQOL in people with a SMI (Caron, Tempier, Mercier, & Leouffre, 1998). Studies have also found that negative social interactions were related to worse HRQOL, especially if these interactions were perceived as stigmatizing (Yanos, Rosenfield, & Horwitz, 2001). Therefore, understanding the social support and social interactions of women with a SMI can have an impact on their HRQOL.

Overall, the findings show the impact of nonmedical factors such as income, housing, and symptoms of depression on HRQOL among women with a SMI. A poor self-reported HRQOL has been shown to be an independent risk factor for increased mortality (Idler & Benyamini, 1997). Therefore, additional research is needed on the impact of HRQOL among women with a SMI. Moreover, our findings show low HRQOL even among women utilizing primary healthcare services, suggesting that improving HRQOL in this population will require addressing other domains in these women's lives. Interventions that aim at improving the HRQOL of women with SMI may reduce their demand for unnecessary healthcare services while improving their overall health.

Table 2.1: Socio-demographic Characteristics of Women with a Serious Mental Illness (n=197)

	Mean	SD	Range	n	Percent
Age	46.93	8.07	24-74		
Race					
African American				161	81.7%
Other				36	18.2%
Marital Status					
Married or Living as Married				15	7.7%
Widowed				19	9.7%
Separated				24	12.2%
Divorced				60	30.6%
Single, Never Married				78	39.8%
Education Attainment					
Less than a High School Diploma				61	31%
High School Diploma				86	43.7%
Some College Credits				40	20.3%
College Degree				4	2%
Graduate Degree				6	3%
Finances*					
Monthly Income during the Past Month	405.45	346.13		197	
Monthly Income from Employment	490.24	316.22		17	8.6%
Monthly Income Disability	661.03	174.86		68	34.5%
Monthly Income Food Stamps	169.77	122.33		43	21.8%
Monthly Income Supplemental Security Income	578.71	189.76		21	10.7%
Monthly Income General Assistance	136.97	70.03		30	15.2%
Monthly Income Other Sources	316.82	384.90		17	8.6%
Psychiatric Diagnosis					
Schizophrenia				53	26.9%
Major Depression				98	49.7%
Bipolar Disorder				28	14.2%
Other Psychiatric Diagnoses				18	9.1%
Employment Status					
Unemployed				176	89.3%
Employed				21	10.7%
Health Insurance Status					
Uninsured				104	52.8%
Insured				93	47.2%
Type of Health Insurance					
Medicare			20	10.2%	
Medicaid			43	21.8%	
Both Medicare and Medicaid			29	14.7%	
Medicare, Medicaid and Private Insurance			1	.5%	

Housing					
Own a House or an Apartment				8	4.1%
Rent a House or an Apartment				112	56.9%
Government Subsidized Housing				10	5.1%
Half-way House/Residential Program				15	7.6%
Marginally Housed/Homeless				52	26.4%
Self Reported Medical History*					
High Blood Pressure				99	50.3%
Asthma				60	30.5%
Cancer				11	5.6%
Heart Problems				34	17.3%
Stroke				11	5.5%
Arthritis or Rheumatism				86	43.7%
HIV/AIDS				8	4.1%
Diabetes				39	19.8%
Digestive Disorder				45	22.8%

*Percentages do not add up to 100% because participants could report more than one category

Table 2.2: Socio-Demographic Characteristics, Health Related Quality of Life (HRQOL) and Utilization of Primary Care Services for Women with a Serious Mental Illness by Psychiatric Diagnosis

	Schizophrenia (n=53)	Bipolar Disorder (n=28)	Major Depression (n=98)	Other^a (n=18)	Total (n=197)
Age^b (mean \pm SD)	47.33 \pm 10.14	44.39 \pm 6.43	47.86 \pm 7.33	44.67 \pm 6.72	46.93 \pm 8.07
Race^c n(%)					
<i>African American</i>	47(88.7%)	18(64.3%)	85(86.7%)	11(61.1%)	161(81.7%)
<i>Other</i>	6(11.3%)	10(35.7%)	13(13.3%)	7(38.9%)	36(18.3%)
Monthly Income^d (mean \pm SD)	554.64 \pm 289.77	405.07 \pm 382.51	349.63 \pm 354.52	270.67 \pm 261.40	405.45 \pm 346.13
Alcohol Misuse n(%)					
<i>No</i>	43 (81.1%)	20 (71.4%)	73(74.5%)	11(61.1%)	147 (74.6%)
<i>Yes</i>	10 (18.9%)	8(28.6%)	25(25.5%)	7(38.9%)	50(25.4%)
Housing Status n(%)					
<i>Own</i>	3(5.7%)	0(0%)	4(4.1%)	1(5.6%)	8(4.1%)
<i>Rent</i>	42(79.2%)	12(42.9%)	54(55.1%)	4(22.2%)	112(56.9%)
<i>Government Subsidized</i>	3(5.7%)	3(10.7%)	2(2.0%)	2(11.1%)	10(5.1%)
<i>Marginally</i>	4(7.5%)	10(35.7%)	31(31.6%)	7(38.9%)	52(26.4%)
<i>Housed/Homeless</i>	1(1.9%)	3(10.7%)	7(7.1%)	4(22.2%)	15(7.6%)
<i>Halfway House</i>					
Employment Status n(%)					
<i>Unemployed</i>	48(90.6%)	21(75.0%)	89(90.8%)	18(100%)	176(89.3%)
<i>Employed</i>	5(9.4%)	7(25.0%)	9(9.2%)	0(0%)	21(10.7%)
SF-36 Physical Component Summary^e (mean \pm SD)					
	39.48 \pm 10.23	36.43 \pm 11.67	30.95 \pm 9.91	32.54 \pm 12.42	34.17 \pm 11.06

SF-36 Mental Component Summary^f (mean ± SD)	40.70 ± 9.89	38.17 ± 12.15	31.98 ± 8.11	31.56 ± 9.56	35.17 ± 10.13
Total Chronic Health Conditions^g (mean ± SD)	2.98 ± 2.27	2.72 ± 2.42	2.99 ± 1.95	3.00 ± 2.72	2.95 ± 2.17
Utilization of a PCP n(%)					
<i>No</i>	28 (52.8%)	11 (39.3%)	36 (36.7%)	5 (27.8%)	80 (40.6%)
<i>Yes</i>	25 (47.2%)	17 (60.7%)	62 (63.3%)	13 (72.2%)	117 (59.4%)

^a All other psychiatric diagnoses

^b Data were missing for age (schizophrenia n=52)

^c Statistical association between race and psychiatric diagnosis, Fisher's Exact Test= 12.97, df = 3, p=.003

^d Statistically significant difference in monthly income (F=5.380, df 3, 193, p=.001); differences between participants with the diagnosis of schizophrenia and major depression (Bonferroni Post Hoc Test, p = .003) and between schizophrenia and other psychiatric diagnoses (Bonferroni Post Hoc Test, p = .013)

^e Statistical significant mean difference on the Physical Component Summary Score (F=8.173, df 3, 193, p<.001) between participants with the diagnosis of schizophrenia and participants with the diagnosis of major depression (Bonferroni Post Hoc Test, p < .001)

^f Statistical significant mean difference on the Mental Component Summary Score (F=11.752, df 3, 193, p<.001) between participants with the diagnosis of schizophrenia and participants with the diagnosis of major depression (Bonferroni Post Hoc Test, p <.001), between participants with the diagnosis of schizophrenia other psychiatric diagnoses (Bonferroni Post Hoc Test, p = .003) and between participants with the diagnosis of major depression and bipolar disorder (Bonferroni Post Hoc Test, p = .014)

^g Data was missing for total chronic health conditions (Schizophrenia n=47, Bipolar Disorder n=25, Major Depression n=89, Other n=17, Total n=178)

Table 2.3: Multivariate Linear Regression Model for Physical and Mental HRQOL Scores Regressed on Socio-demographic Characteristics, Medical Co-Morbidity, and Psychiatric Diagnosis

Characteristic	Physical Health Related Quality of Life (Model 1a)						Mental Health Related Quality of Life (Model 1b)					
	B	SE	Beta	t	p	CI	B	SE	Beta	t	p	CI
Age	-.010	.094	-.007	-.108	.914	-.196, .176	.032	.081	.026	.397	.692	-.128, .193
Race <i>0=African American 1=Other</i>	.004	1.946	.000	.002	.998	-3.837, 3.846	1.849	1.744	.071	1.060	.291	-1.592, 5.289
Employment <i>0=Unemployed 1=Employed</i>	.354	2.346	.010	.151	.880	-4.278, 4.986						
Alcohol Misuse <i>0=No 1=Yes</i>							-2.387	1.510	-.103	-1.580	.116	-5.367, .592
Monthly Income	.012	.003	.379	4.645	<.001	.007, .017	.007	.002	.255	3.773	<.001	.004, .011
Total Chronic Health Conditions	-1.769	.368	-.348	-4.808	<.001	-2.496, -1.043						
Schizophrenia compared to Major Depression	6.327	1.773	.253	3.568	<.001	2.826, 9.828	6.840	1.606	.300	4.260	<.001	3.673, 10.007
Bipolar Disorder compared to Major Depression	2.584	2.305	.082	1.121	.264	-1.967, 7.135	5.550	2.001	.193	2.773	.006	1.602, 9.497

Other Psychiatric Diagnoses compared to Major Depression	.109	2.587	.003	.042	.966	-4.998, 5.216	-.120	2.385	.003	.050	.960	-4.585, 4.826
Owning a House compared to Being Marginally Housed/Homeless	-6.376	4.507	-.096	-1.415	.159	-15.274, 2.523						
Renting compared to Being Marginally Housed/Homeless	-1.712	2.041	-.077	-.839	.403	-5.741, 2.317						
Government Subsidized Housing compared to Being Marginally Housed/Homeless	-2.544	4.324	-.045	.588	.557	-11.081, 5.993						
Living in a Halfway House compared to Being Marginally Housed/Homeless	6.932	2.940	.176	2.358	.020	1.127, 12.738						
Constant	33.167	4.604					28.195	4.040				
Adjusted R ²	.289						.203					

Table 2.4: Multivariate Logistic Regression Model for Utilization of Primary Care Services Regressed on Physical and Mental HRQOL Controlling for Socio-demographic Characteristics, Medical Co-Morbidity, and Psychiatric Diagnosis

Characteristic	Utilization of Primary Care Services Regressed on Physical Health Related Quality of Life (Model 2a)						Utilization of Primary Care Services Regressed on Mental Health Related Quality of Life (Model 2b)					
	B	SE	OR	Wald	p	CI	B	SE	OR	Wald	p	CI
Physical Health Related Quality of Life	-.042	.019	.959	4.832	.028	.924, .995						
Mental Health Related Quality of Life							-.060	.019	.942	10.422	.001	.908, .977
Age	.018	.022	1.018	.641	.424	.975, 1.063	.039	.020	1.040	3.811	.051	1.000, 1.082
Race <i>0=African American</i> <i>1=Other</i>	-.911	.457	.402	3.977	.046	.164, .984	-.846	.420	.429	4.066	.044	.189, .977
Employment <i>0=Unemployed</i> <i>1=Employed</i>	1.138	.608	3.121	3.503	.061	.948, 10.275						
Alcohol Misuse <i>0=No</i> <i>1=Yes</i>							-.290	.365	.748	.634	.426	.366, 1.529
Monthly Income	.000	.001	1.000	.017	.897	.999, 1.001	.001	.001	1.001	.1.503	.220	1.000, 1.002
Total Chronic Health Conditions	.185	.097	1.203	3.629	.057	.995, 1.455						

Schizophrenia compared to Major Depression	-.492	.428	.611	1.325	.250	.264, 1.414	-.316	.392	.729	.649	.421	.338, 1.572
Bipolar Disorder compared to Major Depression	.508	.565	1.662	.808	.369	.549, 5.027	.578	.506	1.783	1.306	.253	.662, 4.803
Other Psychiatric Diagnoses compared to Major Depression	.974	.682	2.649	2.041	.153	.696, 10.083	.902	.637	2.465	2.004	.157	.707, 8.596
Owning a House compared to Being Marginally Housed/Homeless	.752	1.307	2.121	.331	.565	.164, 27.480						
Renting compared to Being Marginally Housed/Homeless	.159	.499	1.173	.102	.749	.441, 3.116						
Government Subsidized Housing compared to Being Marginally Housed/Homeless	-.755	1.032	.470	.536	.464	.062, 3.551						
Living in a Halfway House compared to Being Marginally Housed/Homeless	-.639	.709	.528	.811	.368	.131, 2.121						
Constant	.458	1.235					.592	1.075				

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CHAPTER 3:

The Role of Being Socially Disadvantaged in the Lives of Women with a Serious Mental Illness: A Qualitative Investigation

ABSTRACT

Few studies have taken a holistic perspective on the lives of women with a serious mental illness (SMI). This qualitative study of women with a SMI describes and interprets women's experiences and provides a new understanding about the nature and needs of women living with a SMI. For this qualitative study, a sample of 30 women with a diagnosis of a SMI was recruited from an ongoing NIMH study's enrollment roster. Data were collected through individual face-to-face interviews. The interviews were audio-recorded and transcribed verbatim. Data analysis occurred concurrently with data collection using a modified constant comparative method. The NVIVO software application was used to facilitate data management. The majority of the sample had a diagnosis of major depression, was African American, single, with a high school diploma and either unemployed or on disability. Women in this study spoke of their experiences living as a woman with a SMI. A complicated cycle of being socially disadvantaged was evident among these women's lives and the salient themes of their stories included experiencing loss, isolation, and a sense of a lack of control. Findings from this study revealed the complex and varied experiences women with a SMI experience. For instance, poverty combined with other risk factors such as substance abuse and violence. This can put a woman with a SMI under chronic stress. Mental health professionals can have a pivotal role in improving the quality of life for women with a SMI by taking a contextual approach to the treatment of their mental illness.

INTRODUCTION

Serious mental illness (SMI) is any psychiatric disorder present during the past year that seriously interferes with one or more aspects of a person's daily life (Task Force on the Homeless and Severe Mental Illness, 1992). The most recent definition includes all psychiatric diagnoses that incur substantial disability with no required duration. Some estimates show this as encompassing 5-7% of the U.S. population ages 18 and older (Center for Mental Health Services and National Institute of Mental Health, eds. R.W. Manderscheid and M.A. Sonnenschein, 1992). These disorders may include but are not limited to schizophrenia, schizoaffective disorder, bipolar disorder, major depression, obsessive-compulsive disorder, and post-traumatic stress disorder. The highest rate of SMI occurs among women in the 18-25 age group, with 17.3 percent reporting a SMI. The greatest disparity between men and women occurred in the 26-49 age group, with women being nearly twice as likely as men to have experienced a SMI (U.S. Department of Health and Human Services & Substance Abuse & Mental Health Services Administration, 2005).

Having a SMI affects women and men differently. Some disorders are more common in women and some express themselves with different symptoms (National Institute of Mental Health, 2008). For example, major depression is the leading cause of disease related disability among women (Murray & Lopez, 1996). The prevalence of major depression among women is between one and half to three times that of men (Blazer, Kessler, McGonagle, & Swartz, 1994). The public health burden of depression in women is not only from the high population prevalence but also from the characteristics of its clinical course including early onset, reoccurrence, chronicity, and co-morbidity (Blehar & Keita, 2003). Whereas in schizophrenia, the prevalence is the same for both

men and women, approximately 1% percent of the U.S. population age 18 and older in a given year (National Institute of Mental Health, 2007). However, schizophrenia does not affect men and women in the same way. Pre-morbid adjustment is known to be superior in women, the symptoms of schizophrenia begin later in life, and the outcome for the first 10-15 years after onset is more favorable in women (Goldstein & Tsuang, 1990). Women do show a second onset peak at a time that coincides with menopause (Häfner et al., 1989). The symptomatic expression of illness also differs between men and women. Men show more apathy, flat affect, cognitive disturbance, paucity of speech, and social isolation, whereas women are more often depressed (Goldstein & Tsuang, 1990).

The majority of research has focused on the biological aspect of a SMI (Kulkarni, 1997; Tamminga, 1997) whereas living with a SMI has received limited attention. Some research has found the lives of women with a SMI to be different from the lives of men (Miller, 1997; Ritsher, Coursey, & Farrell, 1997; Test, Burke, & Wallisch, 1990), however further research is warranted. Social problems such as substance abuse (Brady & Sinha, 2005; Drake & Wallach, 2000; K. M. Harris & Edlund, 2005), violence (Cloitre, Tardiff, Marzuk, Leon, & Portera, 1996; L. A. Goodman, Dutton, & Harris, 1995; Wenzel, Koegel, & Gelberg, 2000), poverty (Bassuk et al., 1996; Siefert, Finlayson, Williams, & Delva, 2007), and homelessness (Davies-Netzley, Hurlburt, & Hough, 1996; L. A. Goodman et al., 1995) are prevalent among women with a SMI. Several studies support the link between a history of abuse and subsequent substance use and/ or mental health problems among women (Briere, Woo, McRae, Foltz, & Sitzman, 1997; Bulik, Prescott, & Kendler, 2001; Coker et al., 2002; Kendler et al., 2000; Liebschutz et al., 2002; Widom, 1999a, 1999b). Recent research has demonstrated that

traumatic life events are disproportionately found in the lives of persons with a SMI and who abuse substances (M. Harris & Fallot, 2001; Sells, Rowe, Fisk, & Davidson, 2003). Women are particularly likely to have experienced various forms of sexual and physical abuse either before or simultaneous with mental illness and substance abuse (Gearon & Bellack, 1999; L. A. Goodman et al., 1995; Wenzel et al., 2000).

For women with a SMI, the risks of trauma and victimization are double that of women in the general population and invariably higher compared with their male counterparts (Wenzel et al., 2000). In studies that asked about lifetime abuse among these women, between 51 and 97 percent of women report some form of physical or sexual abuse. In addition, a significant proportion of respondents were multiply traumatized (Bell, Taylor-Crawford, Jenkins, & Chalmers, 1988; Cloitre et al., 1996; Davies-Netzley et al., 1996; L. A. Goodman et al., 1995). Also, it has been suggested that with these high rates of victimization, the majority of women with a SMI have experienced some type of violent victimization at some point in their lives and these women are further victimized throughout their lifespan (L. A. Goodman, Rosenberg, Mueser, & Drake, 1997). While causal links are not well understood, there is convergent evidence that victimization of women with a SMI is related to symptom levels (L.A. Goodman, Dutton, & Harris, 1997; Ross, Anderson, & Clark, 1994), and such co-morbid conditions as substance abuse (Gearon & Bellack, 1999; Sells et al., 2003) and homelessness (L. A. Goodman et al., 1995; Wenzel et al., 2000).

There are many factors contributing to homelessness among women. The increase in female-headed households, the continued participation of women in lower wage occupations, and the decline in low-income housing have all complicated the situation for

poor women (Merves, 1992). However, studies of homeless women have consistently shown that they report higher levels of childhood physical and sexual abuse than women in the general population, and often higher than other poor women who have housing (Bassuk & Rosenberg, 1988). In one of the first studies of this issue, homeless women were compared to poorly housed women. As opposed to 5% of the housed women, 41% of the homeless women in their study reported having been abused during childhood (Bassuk & Rosenberg, 1988).

Given the known correlations between childhood physical and sexual abuse and mental health problems in adulthood (Briere, 1992; Mullen, Martin, Anderson, Romuns, & Herbison, 1993), researchers have hypothesized that homeless women with a SMI will report even higher levels of physical and sexual abuse during childhood than other homeless women. A study was conducted examining rates of childhood physical and sexual abuse among homeless women with a SMI. Most of the women in their study had primary diagnoses of schizophrenia (59%), bipolar disorder (16%), or major depression (11%). In their sample, 74% of the women reported severe levels of physical abuse during childhood and 58% of the women reported sexual abuse during childhood. These levels of childhood abuse are substantially higher than those reported in other studies of homeless women (L. A. Goodman et al., 1995).

Research has found that the social context of the lives of women with a SMI can create a poor quality of life (Kulkarni, 1997). Women are at risk for losing custody of their children, having a lack of social support, and a limited ability to seek employment. All of which increases the likelihood of living in poverty (Miller & Finnerty, 1996). Living with a SMI can create chronic stress, numerous losses including self-esteem and

confidence and a risk of leading an increasingly isolated life (Seeman, 1998). In order to provide more equitable, accessible, and effective services for women with a SMI, we need to recognize the ways in which having a SMI and other social and environmental factors such as substance abuse, violence, poverty and homelessness are interrelated, taking into account the full range of women's lived experiences. Researchers have begun to illuminate the lived experiences of women with a SMI; however, most of this research has focused on only one or two phenomena at a time (DiPalma, 1994; Hall, 2003; Pilkington, 2000; Smith, 2003). There is limited research in the development of knowledge about living with histories of abuse, substance use, homelessness, and a SMI. Additionally, few studies have taken a holistic perspective on the lives of women with a SMI. This qualitative study of women with a SMI describes and interprets these women's experiences and provides new understandings about the nature and needs of women living with a SMI. Specifically, this paper focuses on the women's perspectives and the issues they face and how their lives are affected.

METHODS

Study Procedures and Participants

For this qualitative study, a sample of 30 women with a diagnosis of a SMI was recruited from an ongoing National Institute of Mental Health (NIMH Grant #R01MH070437) study's enrollment roster. The parent study is a two year longitudinal randomized controlled trial aimed at developing and testing a population-based medical case management model for patients with a SMI (Druss et al., In Press). Inclusion criteria for the parent study included only participants with a SMI documented by chart review. Participants could have the diagnosis of schizophrenia, schizoaffective disorder, bipolar

disorder, major depression, obsessive-compulsive disorder, post-traumatic stress disorder, with or without co-morbid substance use. Study participants must have been English speaking, at least 18 years of age and able to understand the consent form to participate in the parent study. Exclusion criteria for the parent study included sufficient cognitive impairment severe enough to impair informed consent. Participants who appeared to have difficulty with understanding the interview or consent form were administered a Folstein Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975). A score of 23 or less excluded the individual from enrollment.

To be eligible for the current study, participants must have participated in the parent study and have been randomized to the usual care group. We did not include women who participated in the intervention aimed at improving their primary medical care in order to prevent bias as it might have altered their responses about their life experiences. Also, study participants must have been able to understand the consent form to participate in this qualitative study.

Data were collected from August 2008 to September 2009 through individual face-to-face interviews. Following screening, the study was described in detail and informed consent was obtained by the first author. The interview guide was structured to enhance the understanding of the lives of women with a SMI and derived from a comprehensive literature review. In particular, study participants were asked to describe their lived experiences with a SMI including addiction, poverty, and sexual and physical abuse.

Interviews lasted up to 90 minutes and were conducted either in a private office at an outpatient psychiatric clinic or at the study participant's home. Study participants

received a small financial incentive for the time they devoted to the study. The interviews were audio-recorded and were transcribed verbatim. Transcriptions were anonymous, coded with only a number. All study procedures were approved by the Emory Institutional Review Board and the Grady Health System Research Oversight Committee prior to beginning data collection.

Data Analysis

Data analysis occurred concurrently with data collection using a modified constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The NVIVO software application (QSR, 2008) was used to facilitate data management. Transcripts were reviewed line by line and coded for categories, constantly comparing emerging categories to each other to determine their nature and significance (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The first and the second author developed the study codebook through independent open coding of 3 interviews. The study team met after the first two interviews to discuss and agree upon an initial draft of the codebook. The text of the initial two interviews were re-coded to reflect the agreed upon codebook. The additional third interview was independently coded with the revised codebook. The codebook was expanded and revised based on the analysis of the third interview. Following this, the team met once again and based on agreement, codes were collapsed and definitions were revised. The text of the third interview was also recoded to reflect the agreed upon revised codebook. All of the remaining interviews were coded independently by the first author and then reviewed by the second author in order to ensure inter-rater reliability. As coding proceeded, categories were clustered together and became more refined and abstract. For example, codes such as feelings of resignation and

feelings of not being heard were combined as having a sense of lack of control over one's life. The combined code was then clustered to a higher category of perceived disadvantage to having a serious mental illness. This grouping allowed for subcategories and relationships among the categories and subcategories to become more evident. Data collection and analysis ceased when no new information or insight was forthcoming.

RESULTS

Demographic characteristics of the 30 study participants are shown in Table 3.1. The average age of the study participants was 45.87 (SD=8.42) with an average monthly income of \$371.83 (SD=\$340.92). The majority of the sample was African American, single, with a high school diploma and either unemployed or on disability. Women in this study spoke of their experiences living as a woman with a SMI. A complicated cycle of social disadvantage was evident among these women's lives and the salient themes of their stories included experiencing loss, isolation, and a sense of a lack of control

Experiencing Loss

Even before their SMI was diagnosed, loss became a dominant theme in women's lives. The loss of jobs, relationships, and children were reoccurring losses. As their illness progressed, their symptoms interfered with their ability to connect to others, furthering their sense of loss.

One woman, before she was diagnosed with bipolar disorder, was very excited about starting a new job as a waitress. However, beginning symptoms of her mental illness caused her to lose her job within a few months.

"I was there two months, and I started having anxiety attacks and dizzy spells and, you know, I was like – everybody who worked in City Hall

would come up to the restaurant for lunch and breakfast. And in the beginning, you know, it was a lot of fun. You know, I got to meet everybody. And then I don't know, I started having these dizzy spells, and I was standing there, and I was feeling like I was standing in my bathing suit. And it just got so that I couldn't take it anymore."

Participants talked about the loss of friendships and relationships with family members who didn't understand their symptoms of mental illness such as the difficulty in relating with and connecting to the world around them. Women felt that people had turned away from them usually because of untreated psychiatric symptoms. This included not only friends and family but the system they thought was there to support them. One woman who thought her hallucinations and paranoia was from insomnia was struggling with financial problems and caring for her children. In addition to struggling on a daily basis, she felt that the system turned their back on her which led her back to drugs.

"So I tried to get myself together and I failed continuously – I had a very uncompassionate case-manager at DFCS, she wasn't compassionate at all. And so I just kept messing up so I lost custody of my child, and when I found out that my child was adopted it threw me for a loop. I became very depressed and – I was just very depressed. That was like about in the year of like 2000-something, I'm not sure, and so then I went back to drugs, I was still out there on drugs, homeless, and I began to hallucinate, and paranoia because of lack of sleep."

The women in this study who had lost custody of their children conveyed a deep sense of grief. When asked to reflect back on what was going on in their lives when they

lost custody of their children, one woman spoke about how she didn't know she had a mental illness and that she turned to drugs to help her cope with her symptoms. As a consequence she lost her children because of her drug addiction.

“The only thing I knew was that I felt different in many ways. I did not find out I suffered with depression until after I had my last baby and then I started using drugs. What happened was my mom called DFS and had my children taken away from me. So I went to my mom's house the next day and I fought my mom.”

Experiencing Isolation

Pervasive in this group of women was an overwhelming sense of loneliness and isolation. The normal human desire for love and belonging created potential dangers of vulnerability and victimization for these women, both emotionally and physically. Guilt and regret surrounded their stories of promiscuity and prostitution. Women spoke about having to deal with an undiagnosed mental illness and the consequence of that was the reliance on alcohol and/or drugs to help them cope which furthered their isolation. One woman with undiagnosed bipolar disorder was able to get treatment for her alcoholism but quickly relapsed because of her undiagnosed mental illness and her lack of a support system.

“My momma was alcoholic. I've been drinking since I was seven. I did relapse one time when I was in this program all for \$52.50. My mental state at the time was I wanted to drink to be honest with you plus I got lonely, so I went - I went to this guy that I knew - that drank, and his apartment was about as nasty as nasty could get, beer bottles, liquor

bottles, his clothes, everything else and all we did was sleep together and no condom, which was a risk taker. The neighbor, he knew it and he said, 'Well as low as he is, before he even knows he's got it he'll probably be dead anyway.' So no condom. I left. And it seemed like every five minutes it was sex, sex, sex, sex. You know, and I just got tired of it and my body was just worn out."

Other women felt compelled to hide their mental illness as a means to protect themselves from the negative response among those around them. Most women felt that if they were completely honest with their symptoms that they would be admitted to the psychiatric hospital again. This was such a constant fear in their life that the majority of the time they would deal with their mental health symptoms in isolation. One woman was so self aware of her mental illness and knew when things were not going well for her, however, she feared being institutionalized.

"I have bipolar disorder. And I was subject to very hard emotional loneliness or very lonely emotional illness. I just came out of a very deep depression. About 5 days ago. And I mean, that was not cool at all. The hardest part is that I didn't tell anybody how low I was, because I didn't want to go to the hospital. You know, that's – that's the big dreaded thing in people with mental illness – we do not want to end up in (the inpatient psych unit). And we do – you know, we tend to – I tend to – and I say "we" because I know many people who will hide their symptoms, do anything we can so that you don't know how bad we're really doing. And when my back was right up against the wall, it really was amazed to see

just how – how far down I was. And they were like, ‘Why wouldn’t you tell me this two weeks ago?’ And I said, you know, I don’t want to go to the hospital. And I struggled with it by myself.”

Several women moved frequently. This meant they had to adjust to new neighborhoods and locate resources they needed within that neighborhood. Moving also impaired the development of close relationships with others. Many of these women developed friendships with other women with a SMI, and if they were not the ones moving, their friends were. One woman who had been homeless for many years finally felt that she had a home and had made friends within her subsidized housing. However, all the residents were told they had to move because they were going to tear down the apartment complex.

“I liked what they did for it. It’s a lot different plus I’ve made a lot of friends. I’m gonna miss a lot of people that’s in here that we play cards and stuff together and we had good fun and I’m gonna miss them. So I don’t want to go too far. I’m trying to stay in the neighborhood because I know them. One of my friends stays up in this apartment so if I get over there at least I know I’ve got one of my friends still close by. But if I move I know everybody’s gonna go their separate ways so it’s all screwed up.”

Another woman recalls what it was like when she first started having symptoms of her mental illness. She didn’t know what was wrong but because of her undiagnosed mental illness she socially isolated herself.

“I know I suffered from headaches. I felt different. I felt like nobody loved me. I didn’t have many friends.”

A woman who suffers from major depression spoke about the isolating effects of her serious mental illness on her life today.

“I stay in my room. I don't want to be bothered by anybody, I mean real emotional, and I just stay closed in, you know. That's what I do”

Social integration and participation, as well as employment and meaningful life activities are compromised by the presence of untreated mental illness and worsen by homelessness. The ability to take steps forward was limited for these women due to a combination of poor life skills, ongoing mental health issues and/or substance use problems, as well as disruptive life events such as lack of stable residence, lack of regular income, and victimization. Together these obstacles complicated the lives of these women, setting them apart from an array of services, and prevented full community integration and participation.

One woman spoke about the lack of support she felt when she had a baby as a teenager. She didn't have a stable relationship with her mom and after having the baby she was thrown out on the streets for having a child out of wedlock. She was nineteen at the time with no job skills, no money, and no place to go with her baby.

“Well, I had a baby, like I said I wasn't married, I didn't have a place, a roof over my head, I didn't have an education. I was living on the streets, sometime I would live in a shelter. I was living on the streets for at least a year or so.”

Other women described how their mental illness inhibited them from acquiring job skills, further isolating them from society. Some women spoke of the stigma of having a mental illness and how this prevented them from acquiring a job. Others spoke

of the actual symptoms of mental illness interfering with their job prospects. One woman talked about how her first job was only when she was in her early twenties and she felt that this was problematic for her future success.

“That’s too late. You should start really early 17, 16. So I haven’t worked much. Seemed like working caused me to lose focus and I would relapse after most of my jobs. I would hold a job for two months and go back to using drugs. So I wasn’t really successful in the job world, you know.”

Having a Sense of Lack of Control

For many women, using substances was a way to deal with their current circumstances, either with physical/sexual abuse and/or symptoms of mental illness. At times substance abuse became an escape from their physical and sexual abuse where other times it contributed to women getting into unsafe situations. Women who were abused as young children felt that they had few options. Many women reported that this sense of lack of control started during their adolescence where mental health symptoms preceded the development of an addictive disorder which also predisposed them to physical and/or sexual abuse. Women also linked violence to their substance abuse. Substance abuse became a means of coping with their emotional pain. One woman had never used drugs until she met her partner. She was physically and sexually abused by him for several years and during that time became addicted to drugs. At that point in her life she had not been diagnosed with her mental illness but talked about feeling that something was wrong and that she felt that everything in her life was out of control.

“I got some butt whippings for eight years I was smoking crack cocaine because that’s what I thought he liked. Me and him did drugs. I wasn’t doing drugs when I first met him. I was barely drinking when I first met him. I started drinking heavy, started smoking crack. He used to force me to have sex with his brothers. He used to force me to have sex with him. There was days when I didn’t want to have sex, but he would take, you know, and he would beat me on my back. It was just awful, really and truly. I mean it was something that I wouldn’t wish upon my worst enemy, being in an abusive relationship and doing drugs. I wouldn’t wish any of those on my worst enemy.”

Another woman, at the time had an undiagnosed mental illness, describes a similar situation where she got involved with drugs to avoid being beaten by her husband.

“I used to do cocaine. I used to try to keep up with my husband so maybe he wouldn’t beat on me. So I used to drink just as much as he did, you know, but it never worked. He always got to me.”

Several women talked about the lack of income and unemployment in their lives and how this caused them a tremendous amount of chronic stress. They felt that they didn’t have control over the circumstances in their life. Other women depended on family members for help with their finances and although extremely grateful for their support also felt that it showed that they were not able to take care of themselves.

“Can’t pay my bills like I need to. I have cut-offs. I’m going without electricity right now. I’m staying at my mom’s house. My electricity is off. I can’t pay it and that’s stressful. I want my lights on. I get so much

a month”

Among the ways in which their mental illness interfered with their daily life functioning, the women recalled an inability to care for themselves and their household, the inability to work, and the inability to form interpersonal relationships. A middle aged woman who lives with her family and receives financial support feels that she does not have control over her mental illness and that it deeply impacts her ability to function on an everyday basis.

“It's worse enough or bad enough to I will get moments where I want to just -- I stay in the bed. I stay in the bed. It takes every ounce to get a shower - and it's really not being -- this is how I describe it. It's like an overwhelming of sadness that just comes all over your body. You don't feel no -- you don't have any hope or no -- there's no -- it's like a headache and a headache, it's there for a while and it stop and if it's a migraine, it'll come back. But with these, they have this feeling stuck with you until, for whatever reason, it lifts.”

Another woman spoke about how having a mental illness really affects almost every aspect of her life and she felt that her life decisions would have been different if she didn't suffer from a mental illness. She felt that her mental illness inhibited her from fully participating in society, such as staying in school, having a job, and being able to take care of her kids.

“Well, I think that my mental illness -- if I wasn't mentally ill I believe I would be more into taking care of better of myself. Well, because the mind plays tricks on me, and sometimes I get depressed and I don't wanna do

anything. If I didn't have those symptoms I believe that I would be more active or more motivated to do more."

Women described the environmental conditions of their living arrangements in terms of poverty, violence, and the availability of alcohol and drugs. Women who already had a history of addiction felt that by living in such an environment didn't allow them to take control of their addiction. One woman who battled bipolar disorder for many years turned to drinking to cope with her mental illness. She was able to get help for her addiction but was still living with symptoms of bipolar disorder. She spoke about the everyday struggles of having a mental illness and being a recovering alcoholic.

"Alcohol was everywhere, and it was easy for me to just go ahead and start drinking again because I was miserable. So I started drinking. And drinking led me back to crack cocaine. And, um, and I went on this 16-year relapse."

Poverty when combined with other risk factors such as substance abuse, social isolation, financial uncertainty, and violence, can put a woman with a SMI under chronic stress. The entire sample consisted of low income women who lived in an urban city. They all struggled with issues of poverty and being able to pay for basic human needs such as food and clothing. Poverty for these women came at a very young age as a result of different life hardships.

Women who witnessed and suffered abuse in their lives ended up engaging in delinquent and criminal behaviors as teenagers and adults and also were involved in future violent relationships. Disability in terms of a SMI increased their vulnerability to abuse. Women spoke about how this lack of control over their lives came from a very

young age when the abuse started in their lives. This woman's earliest memories are memories of abuse.

"I was molested. I was – I come from a very dysfunctional family with incest. My brothers used to rape me and my twin sister 24/7. When we told the police or something about it my daddy would say, 'Well, if it happened, they asked for it'."

The above woman decided she was going to leave her abusive household as her way of gaining back control over her life. She left as a teenager for an older man whom she thought would take care of her, however, the abuse cycle continued in her life all the way through adulthood.

"I was trying to get out of an incest situation so when I got old enough I came with the first man that paid attention to me.....And I wished I hadn't because I kept getting the hell beat out of me from him too."

Another woman along with all of her siblings was abused by her stepfather. She talked about the lasting consequences of that abuse and how that it put her on a path of not being able to gain control over her life. She also expressed feelings of resentment towards her mother for allowing the abuse to take place by their stepfather. As an adult, she looks back and realizes how different her life could have been had she not been a victim of child abuse.

"And I couldn't concentrate in school. I had trouble learning, comprehensive, and I learned since I been grown that that's why because I had so much going on at home and children, they can't - people just don't realize you scar your children."

DISCUSSION

This qualitative study of low income women explored how women with a SMI describe and interpret their life experiences. This paper focuses on women's perspectives and the issues they face living with a SMI. The strength of engaging women with a SMI in discussing their lived experiences through qualitative interviews enables them to reveal thoughts and feelings within the context of everyday living in a way that surveys and other quantitative methods cannot. The goal of this qualitative study was to uncover common experiences among women with a SMI.

The women in this study had fewer social and psychological resources for coping with their life stressors. It is the interplay of all these factors that contributes to the complexity of the lives of women with a SMI. Although biology and heredity play a role in mental illness, other environmental factors like life trauma are also linked to mental illness (Cloitre et al., 1996; L. A. Goodman et al., 1995; Wenzel et al., 2000). Therefore a multi-disciplinary approach is warranted. One study highlighted the need for the continued development of preventive and early intervention strategies that pay particular attention to the devastating impacts of unemployment, economic displacement, and housing dislocation, including homelessness for people with mental illness (Hudson, 2005). There is also a need for more mental health outreach in poor communities and for programs linking mental health services with help obtaining jobs, housing, education and substance abuse treatment.

In terms of research, the majority of studies do not focus on the experience of living with a history of violence, substance abuse, and having a SMI from the perspective of women. A qualitative methodology can have a critical role in generating contextually

based knowledge about this complex issue. In terms of clinical practice, having a SMI often takes precedence over other significant issues in women's lives and mental healthcare providers may unintentionally contribute to their diminished quality of life by not contextualizing their treatment. Mental health providers can engage women in discussing options and providing support. A climate that promotes discussion of sensitive subject matters and adopting a practice of working with a woman in partnership could have lasting positive effects on these women.

Research has previously supported a path of childhood abuse and later subsequent substance abuse and mental illness (Bulik et al., 2001; Kendler et al., 2000; MacMillan et al., 2001; Molnar, Buka, & Kessler, 2001). However, findings from this study revealed complex and varied experiences among women with a SMI. These women were situated in a time and place where the context of their lives both created and limited their life possibilities. Regardless of the critical incidents that initiated violence, addiction, and mental illness, women reported a sense of loss, isolation, and a lack of control in their lives. Previous literature has found that women with a SMI have poor quality of life (Kulkarni, 1997) and lead isolated lives (Seeman, 1998). However, research has found that more frequent and higher-quality social relationships in the lives of women with a SMI can combat the effects of chronic stress (Pollock & West, 1987). For women in particular, being part of an emotionally and economically rewarding social network could be helpful in alleviating feelings of loss, isolation, and a sense of lack of control.

The findings of this qualitative study must be considered with respect to several methodological limitations. The sample was a small, purposive sample of women and the data were the perceptions of low-income women with a SMI. Their suggestions and

opinions may not reflect those of women with SMIs in other contexts. Also, selection bias cannot be ruled out. It is possible that women with a SMI who are not currently seeking mental health treatment differ in meaningful ways from the participants who engaged in the interviews. However, the focus of this study facilitated the collection of rich, detailed information on women's experiences of living with a SMI.

Mental health professionals are in a critical role in improving the quality of life for women with a SMI who have histories of violence, substance abuse, and poverty. A more multidisciplinary and contextual approach can allow the needs of women with a SMI to be fully understood.

Table 3.1: Demographic Characteristics of the Study Sample (n=30)

Demographic Characteristics	Mean	SD	N	%
Age	45.87	8.42		
Monthly Income	\$371.83	\$340.92		
Psychiatric Diagnosis				
Schizophrenia			10	33.3%
Bipolar Disorder			6	20%
Major Depression			13	43.3%
Other Psychiatric Diagnoses			1	3.3%
Race				
African American			28	93.3%
Caucasian			1	3.3%
Other			1	3.3%
Marital Status				
Married or Living as Married			2	6.7%
Widowed			4	13.3%
Separated			3	10%
Divorced			7	23.3%
Single, Never Married			14	46.7%
Highest Education Level				
Less than a High School Diploma			10	33.3%
High School Diploma			16	53.3%
Some College Credits			4	13.3%
Employment Status				
Unemployed			16	53.3%
Disability			14	46.6%
Housing Status				
Own a house			3	10%
Rent a House or an Apartment			16	53.3%
Government Subsidized Housing			2	6.7%
Lives with Friends/Relatives			5	16.7%
Half-way House/Residential Program			1	3.3%
Homeless Shelter			3	10%

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CHAPTER 4:

A Qualitative Study Examining the Pathways to Medical Healthcare Services among Women with a Serious Mental Illness

ABSTRACT

Previous work has documented high rates of medical disorders and challenges in obtaining quality services among women with a serious mental illness (SMI). However, little is known about the actual experiences regarding how these women are able to engage in the healthcare system. This qualitative study investigates pathways to accessing and utilizing healthcare services among women with a SMI. A convenience sample of 30 women with a diagnosis of a SMI was recruited from a NIMH longitudinal, randomized control trial. Data were collected from August 2008 through September 2009, through individual face-to-face interviews. Interviews were audio-taped and transcribed verbatim. The findings from this study highlighted how a variety of nonmedical factors influenced women's introduction to and engagement with the medical healthcare system. Women felt the relationship they had with their mental health provider was a turning point in their life for building a sense of trust with other healthcare providers. Additionally, a women's social network, including a religious community, family, and friends had a major influence in building and strengthening their sense of purpose in life which in turn motivated them to access and utilize medical healthcare services. Nonmedical factors and personal circumstances appear to be important factors influencing pathways to medical healthcare services among women with a SMI. Efforts to better engage and retain women with a SMI into healthcare services will need to better acknowledge and incorporate the larger social context of the lives of these women.

INTRODUCTION

Individuals with a serious mental illness (SMI) have higher levels of medical comorbidity and mortality compared with the general population (Felker, Yazel, & Short, 1996; Koran et al., 1989). Epidemiological indicators show that people diagnosed with a SMI die at least 25 years earlier, largely due to preventable medical conditions such as diabetes, cardiovascular disease and respiratory and infectious diseases (*Morbidity and Mortality in People with Serious Mental Illness.*, October 2006). Despite this pattern of suboptimal physical health, research indicates persons with a SMI utilize less general, preventive, and specialty healthcare services (Carney, Allen, & Doebbeling, 2002; Cradock-O'Leary, Young, Yano, Wang, & Lee, 2002; Druss, Bradford, Rosenheck, Radford, & Krumholz, 2000). Studies have suggested that poor access to adequate and quality healthcare may partly determine excess mortality (Bradford et al., 2008; Daumit, Crum, Guallar, & Ford, 2002; Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001). However, the research is inconclusive as some studies have found that people with a SMI are equally likely to have a primary healthcare provider compared with individuals from the general population (Druss & Rosenheck, 1998; Green & Pope, 2000).

Women with a SMI present themselves with different symptoms (Castle & Murray, 1991) and experience co-morbid medical problems due to a history of trauma (L. Miller, 1997), high rates of smoking and substance misuse (Dickerson, Pater, & Origoni, 2002), and obesity and diabetes related to certain psychiatric medications (Brady, 1989; Dixon et al., 2004). Women with a SMI are more likely to experience higher rates of physical medical disorders than women in the general population (Kessler et al., 1994). Moreover, their physical complaints frequently are disregarded and their requests for services may be denied (Brown, 1998). In a study comparing women with schizophrenia

and women in a control group with no history of mental illness, the findings show lower healthcare services use among the former. For example, fewer women with schizophrenia had had a pelvic examination and Pap test in the past three years, a mammogram in the past two years, and ever received hormone replacement therapy (Lindamer et al., 2003). These findings are consistent with previous research where preventive healthcare for women with a SMI is often overlooked (McConnell, Inderbitzin, & Pollard, 1992). One of the first studies to illustrate the neglect of healthcare of women with a SMI reported that among 415 women admitted to a general hospital and 35 to a state facility, pelvic examinations had been deferred in every case (Handel, 1985). However, more than 10 years later, a study found that one third of women with SMI were not receiving pelvic or breast examinations nor appropriate care for birth control and menopause (Ritsher, Coursey, & Farrell, 1997).

Some studies have found that women with a SMI do obtain and receive healthcare services at equal levels to women in the general population. A study in an urban community mental health center comparing preventive healthcare utilization among women with a SMI to low-income women in a local medical clinic found little or no differences (Steiner et al., 1998). However, out of the sample, two thirds of women who had been sexually abused were not receiving preventive care, physical examinations, Pap tests, and breast examinations (Steiner et al., 1998).

Despite the existing research documenting problems in service delivery in this population, there is limited research in examining why some women with a SMI receive healthcare services while others do not. Little is known about the actual experiences about how these women are introduced to and stay engaged with the healthcare system.

This qualitative study investigates the pathways to healthcare services among women with a SMI. The main research questions for this study were: (1) how do women with a SMI get introduced to the healthcare system and (2) what enables women with a SMI to utilize medical healthcare services.

METHODS

Sample

A convenience sample of 30 women with a diagnosis of a SMI was recruited from a National Institute of Mental Health (NIMH Grant #R01MH070437) parent, longitudinal, randomized control trial aimed at developing and testing a population-based medical case management model for individuals with a SMI (Druss et al., In Press). Eligibility criteria for the parent study included (1) having been diagnosed with a SMI in their medical chart, such as schizophrenia, schizoaffective disorder, bipolar disorder, major depression, obsessive-compulsive disorder, and post-traumatic stress disorder, with or without co-morbid substance use; (2) English speaking; and (3) be at least 18 years of age. Exclusion criteria for the parent study included sufficient cognitive impairment severe enough to impair informed consent. To be eligible for the current qualitative study, participants must have (1) participated in the parent study; (2) be able to understand the consent form to participate in the qualitative study; and (3) have been randomized to the usual care group. This was done because the intervention group participated in a program aimed at improving their primary medical care which would have biased their responses about their utilization of healthcare services.

Procedures

All study procedures were approved by the Emory Institutional Review Board and the Grady Health System Research Oversight Committee. Individual face to face interviews were conducted from August 2008 through September 2009. Study staff recruited women from the parent's study usual care group roster. Interested women were screened and when eligible, scheduled for an interview date. Prior to the start of the interview, eligibility was verified again, the study was described in detail, and informed consent was obtained.

The first author, who has extensive experience working with people with a SMI, conducted all the interviews. The interview guide was organized to capture several domains such as perceived general health, perceived psychiatric health, social networks and social support, socio-cultural beliefs, and socio-economic factors, and the relationship to healthcare access and utilization. Interviews lasted up to 90 minutes and were conducted either in a private office at an outpatient psychiatric clinic or at the study participant's home.

Interviews were audio-taped and transcribed verbatim and all transcriptions were anonymous, coded with only a number. Transcripts were coded using NVIVO, a qualitative data management software application (QSR, 2008). Data analysis occurred concurrently with data collection using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Transcripts were reviewed line by line and coded for categories, constantly comparing emerging categories to each other to determine their nature and significance (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

The first and the second author developed the initial study codebook through independent open coding of 3 interviews. They met after the first two interviews to

discuss and agree upon an initial draft of the codebook. The third interview was independently coded by the first and second author with the revised codebook. A total of 327 codes were identified. From this open coding process, patterns and themes emerged that were salient when compared across interviews. The themes that emerged were then grouped into categories, for example, systematic support for healthcare utilization. Under each category, the related themes were listed. The categories were reviewed further and themes that were irrelevant or inconsistent with access and utilization of healthcare services were eliminated. The final themes were differentiated into more refined and abstract categories. The remaining 27 interviews were coded independently by the first author and reviewed by the second author. Data collection and analysis ceased when theoretical saturation was reached (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

RESULTS

The majority of the sample had a diagnosis of major depression (43%) which was identified from a medical chart review. The average age of the study participants was 45.87 (SD=8.42) with an average self-reported monthly income of \$371.83 (SD=\$340.92). The majority of the sample was African American (93%), single (47%), unemployed (53%), renting a house or an apartment (53%), and had a high school diploma as their highest education level (53%).

Women reported that having a SMI posed a significant barrier to access medical healthcare services. They described how limited cognitive and social skills created difficulty for them. Their psychiatric symptoms were perceived as hindering the ability to negotiate the healthcare system and to advocate effectively for their care. In addition, a number of women spoke about when they were not feeling well mentally, they were less

motivated to seek medical healthcare services. This study highlights the complex web of nonmedical factors that influenced women's introduction to and engagement with the medical healthcare system.

Mental Health Treatment

Mental health treatment was the most consistent and important theme that women in the sample reported. Having access to quality mental health treatment strengthened and supported their ability to have and maintain healthy relationships, make better life choices, and handle the ups and downs of their life. More specifically, several women explained how they felt cared for and listened to by their mental health provider. This enabled them to deal with the struggles of their life. Additionally, women who had supportive mental health providers were able to access and utilize medical healthcare more frequently. Women felt the relationship they had with their mental health provider was the turning point in their life and this was based on building a sense of trust. This trust enabled them to trust other healthcare providers. A 43 year old woman, with the diagnosis of bipolar disorder, had been exposed to numerous mental health providers and only was able to begin dealing with her issues once she found a provider she trusted. The long process of building trust enabled her to also start trusting other providers such as her primary care doctor.

“And you know, it’s – what I like about her is that she doesn’t rush me, but she waits patiently for me to get to issues, and then she’ll say, ‘You know, I’ve been waiting on that. You know, I’ve been waiting on you to be ready to work on that.’ You know, and it’s a lot of trust that has to come before I can really get into stuff. But I really – I know that I can, but it’s

still taking me a long time to work on some really deep issues. But I think that, you know, that's the person that you really better know, the real me, and help me through, you know, through, to really deal with the issues that I have."

Another woman elaborated as follows on her mental health provider:

"He was just real comfortable to talk to. He smiled a lot. He just makes me feel really comfortable. He would pay attention to me. He would pay attention to what I said. When I come back, the following week, the following month, he would see me, you know, he would say, 'So how is this going in your life?' And I was like, "Damn! He was paying attention!" You know? And that made me feel good, to know that – that he was actually listening to what I was saying. And you know we would talk together about the medicine changes and stuff that, where I was taking. And before we – before he just said, 'Here, we're gonna do this,' he said, 'Well, how do you feel about this? And how do you feel about this?'"

Women who reported feeling understood by and who trusted their mental health provider tended to be more engaged with the healthcare system in general. For most women such a positive relationship became the main entry point into the overall healthcare system for several reasons. Women who trusted their mental health providers trusted them when they referred them to other medical health services. Additionally, because of being in mental health treatment, women had a sense of having something to live for and consequently wanting to get medical healthcare services to be able to take care of themselves. This led them to be cared for by a variety of healthcare providers and

less frequently in the emergency room. However, even after women were connected to the medical healthcare system, it was the mental health provider who continued to monitor both their mental and medical healthcare. A 40 year old woman, with the diagnosis of major depression, who lives with her family, talked about how her mental health provider would make sure she sought and received regular checkups and preventive laboratory tests. She described a time when her mental health provider went into the computer system to see if she was current with her preventive healthcare screening blood work.

“She goes into the system and she said, ‘You haven’t taken your labs in the last two years’ And she had told me because she’ll write a form. ‘ I want you to go over there right now.’ Mm-hmm. She does this.”

One woman credits her mental health provider with helping her understand how her mental health is connected to her physical health and that she needs to take care of both.

“If I stop taking my medication or if I stop working on talking about what’s going on with me, mentally, I start breaking down. And then my body is connected to my mind. This is how it has affected me all my life. If I get stressed out here, I start breaking out. I get – I get cysts all over the place. I just start breaking out. My skin starts reacting. You know. I get fatigued. I start having physical symptoms. And then, you know, if I’m not taking care of my mind, I’m not going to take my health medications, I’m not gonna care of taking my medicine, I’m gonna start getting - Inch by inch. Lock myself in my room, isolated.”

Not all women were as positive about their mental health providers. Some expressed dissatisfaction with the time and support they received from their mental health provider to become linked with the larger healthcare system.

“You know, and, you know, they – and they don’t understand why you’re not taking care of yourself. You know, and they’ll tell you that. They just give you brochures and send you on your way, or give you medication and send you on your way, have you come back, get blood medication. They think it’s a bother for them to talk to you. But you’re taking care of – you’re supposed to take care of me. I’m not supposed to be a bother to you. I was surprised about the lack of compassion. And maybe – and I thought about it. I said, “Maybe it’s because” – I know it’s hard to deal with people with mental illness. I know that. But that’s your field. If you can’t handle it, you don’t need to be in it. You just don’t.”

Social Support System

Support was provided by religious institutions and other community groups and organizations. Involvement in faith communities had a positive effect for these women. This type of support from a religious community provided these women with a different perspective which in turn helped them deal with stress and difficulties in their lives. When these women experienced chronic stress and trauma they often looked for a new sense of understanding and comprehension of their lives. Spiritual or religious beliefs had an important influence on how these women interpreted and coped with events that took place in their life. It also reduced the loss of control and helplessness and provided a framework that decreased these women’s suffering and strengthened their purpose in life.

Due to this new sense of purpose in life, women felt motivated and encouraged to access and utilize healthcare services. The majority of women spoke of the belief that their god put physicians on earth to take care of them.

“I believe in God and I believe in God’s healing, but I also believe that God gave me a mind to know when to go get some help from who He’s placed here to help me.”

When asked how religious beliefs affected one’s opinion about healthcare several women responded that it was their responsibility to take care of themselves because that was part of their religious teachings.

“I think it affects it a lot. I need to respect my body and my health. And cause I appreciate it, you know? Cause He thought enough of me to take care of me all these years, even after I tried to kill myself, taking dope and stuff, you know? So when I think about it, you know, I mean – I put myself in danger so much and yet He saw me through it, you know?”

Women depended on their religion and the support of their religious community to make sense of their own life and to help them deal with their everyday stresses. When things seemed to be out of control for these women, they turned to their spirituality to make sense of what was going on. One woman with bipolar disorder struggled for many years with issues of poverty and living on the streets. But instead of feeling hopeless about her situation she turned to her faith for guidance and strength.

“And I mean it’s amazing. People just don’t realize how going to church and – you don’t have to be perfect. You know I tell you something, Jesus is the only one who was perfect, so I just keep that. Church helps me 100

percent. 100 percent, I think that has a lot to do with my attitude and my – I don't feel good because I never knew it, because I lay down, I don't have a nasty attitude even though it took me 10 years to get my Social Security. I just started getting it this year, didn't have no money, my boyfriend didn't have no money either but I knew that I just had -. I didn't let it get me down, I just kept the faith. I just kept the faith.

Women found strength in being part of a religious community. Women spoke not only about the actual support they felt from their religious community but also about a sense of belonging. Women who stopped attending religious services felt a sense of loss in their lives and it was something they wanted to return to.

“Because to me it boosts your spiritual, want to take care of yourself. I guess it's a boost. It does help because I know when I first started going back to church, I felt a lot different when I was going to church because it felt I had inspirations and a lot of people backing me and love on the side. If felt like a rush and now that I haven't been going I do feel a little bit different.”

Family members were also key supports for women. They provided emotional and frequently financial support. One woman describes the economic support she received from her sisters. Currently she is almost blind from an abusive attack and although she is a recovering addict with a SMI, she tries to live as independently as possible, and she credits this to the financial support she receives from her sisters.

“I just love it. To know somebody loves me like that – I probably couldn’t do it all by myself – I can barely see. They take care of everything – my food, my bills, everything.”

However, some women were ambivalent about the support they received from their families. At times some women felt that family members were exerting too much control over their life. Women also reported that this family support usually came after they had begun mental health treatment and became psychiatrically stable. Several women reported turning to drinking and/or drugs to deal with their mental health symptoms and women felt that their family members didn’t understand what was happening to them. It wasn’t until they went through mental health treatment that family members became supportive.

“Well they felt more relieved to find out what was wrong with me and I had drank so it’s 10 of us, and all of my family -- I hate to use the word turned against me but they was tired of seeing me drink and worry them for money to get something to drink. But once I got sober and everything they – they come in and ever since then they showed me love and they did anything they can for me, and my life is beautiful now.”

Women reported having other female friends who also had a SMI who became social support systems for them. At several times women spoke of a referral system between the women. When friends received quality healthcare they would recommend their physician to the women in this study. One woman was receiving poor quality of care from her physician and her friend who also has a SMI found a doctor she really trusted and influenced the participant to seek her healthcare from this new provider.

“Matter of fact she’s the one that introduced me to the doctor. When she introduced me to him I started going and she was right, he was a good doctor. Like I said, she knows that the other one wasn’t going help me so she sent me to a nice doctor. He’s getting the job done.”

Continuity of Providers

Once women were engaged in the medical healthcare system there were several factors that allowed them to stay engaged. Women reported that having one consistent provider was beneficial for them to stay engaged in the healthcare system. They felt that having one provider would enable them to assess, diagnose, and treat their health ailments. Many women also regularly mentioned the importance of working with one provider who knows them and refers them to preventive tests and specialty services, if needed. Often the women explained how having one provider resulted in appropriate and timely care. One woman who has Medicaid as her health insurance spoke about going to different doctors until she found one she trusted and stayed with.

“Well you need somebody that knows your history. You need somebody that knows you that you feel comfortable with. I’m not comfortable with several different doctors. I like to try different doctors until I get one I’m comfortable with, but its better like that. You need a primary care physician.”

Women who did have access to one healthcare provider were usually on Medicaid. The women in the sample, who did not have a consistent healthcare provider, also did not have health insurance and they received free care from an inner city hospital. These women felt unmotivated to continue seeking care because they felt treated like a

number and not an individual person. A woman who lost her health insurance had to seek her care from the inner city hospital.

“You’re feeling that if you go in, you’re going to be part of a big number - - crowd or number. You are not going to get a person and that’s what kept me from going to [Hospital Name] as far as a doctor. I know I need one. I haven’t had a mammogram yet. I know this year I’ll be 42.”

Other women reported they thought they had a consistent physician until they called to schedule an appointment and found out that their physician no longer was available. Women were frustrated with physicians coming to train at their hospital and then leaving upon completing their training. One woman was hurt and upset when this happened to her. Now she doesn’t want to get close to another doctor if they are just going to leave.

“You might have a doctor down there like six months and then he’s gone and then the other doctor comes in and he don’t even know what’s going on with you. You’re like, “Where did my doctor go,” and they can’t explain nothing to you because they don’t know what’s going on. They’re asking you to tell them what’s going on and you’re like, “You’ve got my record. Where’s my record? It tells everything that’s going on with me,” and they don’t even have the record.”

The same frustrating feelings were iterated by another woman.

“And I hate that he had left because I mean, he gave me details so I’d know what was going on. He’d explain what was going on and he just really would explain everything but he didn’t stay there. He stayed there

long and I got used to going and seeing him but when I did go back to see him he was gone and that kind of just threw me off. I thought, "I finally got a good doctor and he's gone."

Socio-Economic Resources

Additionally, socio-economic factors influenced women staying engaged in the healthcare system. Income was a key determinant in accessing and utilizing healthcare services for these women. Women in this study that had adequate income felt that it drastically limited the economic burden they felt. One particular woman with the diagnosis of bipolar disorder was finally approved for disability benefits after many years of trying. During the interview she was asked how her disability benefits changed her life.

"It did because I can take care of myself. I don't have to – I don't like the dependency but I mean I can't work. I don't like to depend on nobody -- and now I'm able to do for myself, I don't have – and then I can help somebody along the way that's going through what I went through. So I'm – I'm just blessed."

Women who did not have adequate income from either the help of family members or disability benefits struggled to access healthcare services. Even the lowest co-payment was a struggle for these women. One woman with no health insurance was struggling with gynecological problems and really needed to see a doctor, however she was turned away because she didn't have the co-payment.

“I went to my gynecologist doctor and I didn’t have \$10 and they wouldn’t let me see him. I don’t have any income yet, I’m still waiting for my disability.”

Several women were not able to access healthcare because of a lack of health insurance and the inability to pay for their co-payments.

“These doctors are not going to see you without the co-pay. That was more than three years ago. My co-pay is \$3 and sometimes I didn't have that.”

Another woman needed to see her physician for a prescription refill and they were going to turn her away because she didn’t have the money to see her physician.

“Yeah. I need to see my primary care doctor and I need prescriptions, so they weren’t gonna let me see him and I told them all I wanted to do was get my prescriptions. I need my prescriptions.”

Women in this study spoke of how income was a key determinant to their health, both physically and mentally. They felt that income was directly related to their quality of life. Women who had disability benefits also had access to Medicaid. They felt this gave them more choices regarding their healthcare. Medicaid provided them a dependable means to pay for healthcare services which allowed them some autonomy.

One woman credits getting access to healthcare because of her Medicaid insurance coverage.

“Right now what I feel is making it easier for me to get my medical care is because I get Medicaid to pay for it, you know, my expenses because see

they pay for it and if I had to do it without that I probably wouldn't get the attention I need."

Feelings of Fear

Several women discussed the fear of learning that something was seriously medically wrong with them and this inhibited them from seeking any type of medical care. The majority of this fear came from knowing someone who was ill and this was sufficient in keeping a woman from seeking any type of medical healthcare. One woman had an extensive family history of cancer which went back several generations. She expressed that she might be next and she would rather not know if she had cancer.

"I know it's important, but I just – I guess –. I got this thing where I procrastinate, I'm always putting stuff off, and I remember sometimes my mother died of cancer at 73, her mother died of cancer at 73. So I've got this little thing in my head where I want to know but I'm scared to know, but I need to know, but I don't want to know."

However, other women used this sense of fear as a motivator to seek medical healthcare. When asked why some women seek healthcare on a regular basis, several women responded it was because of a personal experience of someone they loved being ill. One woman lost a very close to friend to breast cancer. The participant was a source of support for her friend and felt that her death was an eye-opener for her to continue getting healthcare.

"Cuz you know I had a girlfriend that I lost to cancer, had breast cancer. I kept telling her – she say she had a lump in her breast. I kept telling her

you better gone take that breast off. She didn't want to take that breast off and the cancer spread all over her body, and it killed her."

Feelings of Discrimination

Women felt that medical healthcare providers judged and disrespected them because of their mental illness. Women described feeling that physicians thought their complaints were not real and were part of their mental illness. These feelings of discrimination led to mistrust of medical professionals which ultimately led to the underutilization of medical services. Women also felt that they were given differential services because of their mental illness. This perceived discrimination led to a reduced access to healthcare services. The majority of women brought up feelings of discrimination when they were asked to describe a negative experience they had with a doctor. One woman felt that her doctor wouldn't really listen to her because she had a mental illness.

"Like some doctors, this is the way I felt when I was going to [Hospital's Name] to see the doctor, I felt like they were saying, 'Well hell she's got a health problem so she don't know what the hell she's talking about. It's all in her mind.' Some of those doctors used to say that, 'Maybe [participant's name] thinks it's all in her head,' and it kind of made me think, because I told them, it made me feel like they thought I was nuts and didn't know what I was talking about and it was all in my head."

Another woman was referred to a specialist because of the possibility of knee surgery. She was asked to fill out a form and one of the questions was if she had a mental

illness and she put down yes. She describes the encounter between her and the physician after he read her health form.

“So when I get back there, and the doctor comes, he says, ‘Oh, you have a mental illness. Who takes care of you’ And I said, “I take care of myself.” ‘How did you come here? Where do you live?’ I said, “I live in [Name of Neighborhood]” He says, ‘How did you get out of there?’ I said, “Excuse me?” I said, “I come and go as I please.” He says, um, shoot, ‘How do you get around?’ I said, “Take a bus.” He says ‘You’re not gonna have any problems coming down here if you have to have surgery?’ I said, “No!” And then he asked me what was wrong with me. Then he tried to act like I was crazy or stupid. I felt violated. I felt like, you know, like a crazy person. I was really, really uncomfortable with him. And I didn’t want to go back to him. You know? I had no intention of allowing him to become my surgeon.”

Another woman describes a similar situation when she was seen by a medical healthcare provider.

“She acted like she didn’t use the same pen I used, she didn’t wanna touch the paper that I touched. She just acted very peculiar. And so I didn’t like the services after that”

DISCUSSION

Research has focused on the barriers individuals with a SMI face in accessing and utilizing healthcare services (Druss & Rosenheck, 1998). For example it has been found that people with a SMI who lack a support system (E. Miller, Lasser, & Becker, 2007)

and sufficient income and health insurance (Coryell et al., 1993; Dohrenwend et al., 1992; Weissman & Olfson, 1995) may not access healthcare services. Also, it has been found that providers often assume that patients with a SMI are presenting complaints that are psychologically rather than physically based (Graber et al., 2000) and physicians may be uncomfortable in dealing with patients with a SMI (Bunce, Jones, Badger, & Jones, 1982). Additionally, there have been several studies among women that have found fear to be a barrier to healthcare screening (Mainiero, Schepps, Clements, & Bird, 2001; Nekhlyudov, Li, & Fletcher, 2005; Silverman et al., 2001). A qualitative study on mammography screening in women with a SMI found that women had the same sense of fear as women in the general population (Kahn, Fox, Krause-Kelly, Berdine, & Cadzow, 2005). Women in this study also reported a sense of fear when a family member or friend had been diagnosed with cancer. The current study compliments previous work, providing insight about psychosocial and contextual factors' effect on how women with a SMI engage in the healthcare system, which is difficult to capture in quantitative studies.

Findings from this qualitative study highlight how social and environmental factors help women with a SMI engage in the medical healthcare system. These nonmedical determinants included a trusting relationship with a mental health provider, sense of meaning through religion, having a strong social network, and tangible financial resources. These factors also interact with each other in helping women with a SMI get into and stay engaged with the medical healthcare system.

Findings from this qualitative study revealed the centrality of the role of mental health providers in ensuring access to medical healthcare services for women with a SMI through the building of a trusting relationship. As such, the results suggest that mental

health providers have the potential to get women with a SMI established with other healthcare services. Furthermore, having a social support network was also acknowledged as a major determinant to get women engaged with the healthcare system. Their social support network gave women hope and a feeling of having something to live for. This meaning in their life was a major motivator to use healthcare services. Women consistently ranked religious institutions, family and friends among the top in their support systems.

In terms of women's spirituality, being part of a spiritual community allowed these women to continue to build their social networks. Spirituality is often used as a coping mechanism in people with a SMI (H. G. Koenig, Larson, & Larson, 2001). It has also been found that people in stressful situations seek support from religion (Bonanno, 2004). Studies have investigated the relationship between religious involvement and mental health. In most cases, they have found that higher levels of religious involvement are associated with greater feelings of well being and mental health (Moreira-Almeida, Neto, & Koenig, 2006). Positive religious coping has been associated with better physical and mental health outcomes (Pargament, Koenig, Tarakeshwar, & Hahn, 2004). Studies have also found that religion is associated with numerous healthcare related factors, such as the use of physician services and hospital visits (H.G. Koenig, McCullough, & Larson, 2001). A study found that church attendance was positively related to having blood pressure measurement in the past year among low-income African Americans (Felix Aaron, Levine, & Burstin, 2003). Another study found that attending religious services was related to an increase in the rate of female preventive service utilization (Benjamins, 2006).

Additionally, family was a key support for women, most often providing financial support. Friends of the women in this study who also had a SMI provided a referral system to their own medical healthcare providers. Research has found that women with a SMI tend to have smaller networks than people without a psychiatric disorder and these networks tend to include more family members (Pickens, 1999). As found in this study, when the frequency and length of hospital admissions increased, there were fewer friends and relatives in the social network (Holmes-Eber & Riger, 1990). Previous studies have reported that women with a SMI identified needing assistance dealing with emotional abuse within relationships, sexual abuse, information about reproductive health, and child custody issues (Cogan, 1998). But social support can also provide a sense of well-being, serve as a source of information, act as a form of coping (Thoits, 1986), enhance self-esteem, and provide access to material needs (Weber, 1998).

Women in this study faced issues of unemployment, social exclusion, and isolation which led to income levels below the poverty line. Due to these factors, these women often could not earn an adequate income and relied on income support programs that included access to health insurance. The women in this study without access to health insurance had lower levels of utilization of healthcare services. One study found that uninsured women did significantly worse than Medicaid-covered women on all access and utilization measures and were generally less satisfied with their care (Salganicoff & Wyn, 1999). People who were uninsured reported consistently lower levels of use than individuals with any type of coverage (Almeida, Dubay, & Ko, 2001; Berk & Schur, 1998; Marquis & Long, 1996). Alternatively, women with Medicaid

coverage had generally higher levels of utilization, as measured by both physician contact and the use of preventive services (Salganicoff & Wyn, 1999).

A trait of primary care is continuity of care, defined by seeing the same healthcare provider (Starfield, 1992). It is thought that provider continuity can have a positive impact on quality of care because of the accrued knowledge and personal relationship that develops between a patient and a provider (Blumenthal, Mort, & Edwards, 1995; Starfield, 1992). In this study, women who had continuity of healthcare providers were able to stay engaged with the healthcare system, as it provided them with a more satisfied experience, more likely to keep their follow-up appointments, and communicate better with their physician.

Women felt discriminated against by their healthcare providers because of the stigma of having a mental illness. Previous research has found that people with a SMI have a fear of negative attitudes associated with having a SMI and difficulties in communicating with their primary care doctor. It has been found that discrimination related to mental illness were important barriers that contributed to low levels of satisfaction in healthcare seeking behaviors among individuals with a SMI (Chou, 2000). These factors make it difficult for women with a SMI to communicate their health concerns to their healthcare providers and leads to diminished utilization of healthcare services.

The findings of this qualitative study must be considered with respect to several limitations. The sample was a small, convenience sample of women who were not representative of all women with a SMI. The sample was drawn from a single urban area and findings may be different for women from different socioeconomic groups or who

live in different environments. Also the data are based on the perceptions of low-income women with a SMI. As is true for all personal recollections, these women's suggestions and opinions may not reflect those of women with a SMI in other contexts. Therefore, interpretations of the results should be undertaken with caution. It is possible that women with a SMI who are not currently seeking mental health treatment differ in meaningful ways from the participants who engaged in the interviews. Future research needs to pursue the healthcare needs of women with a SMI with a larger sample and also include the views of mental health and medical healthcare providers since these are the professionals who most frequently treat the healthcare needs of this population.

However, our goal was to explore the experiences and attitudes of urban, low-income women with a SMI in accessing and utilizing healthcare services. As such, our findings shed important light in an area that has yet to be fully explored. Support from mental health providers such as listening, providing information, assisting in times of crisis, providing referral to other healthcare providers, and/or aid in acquiring disability services was an influential determinant for women in accessing and utilizing healthcare services. Long-term and consistent relationships with a mental health provider were valued as the most supportive for women. Additionally, a woman's social support network such as her religious community, family, and friends were also major determinants to get women engaged with the healthcare system. Non-medical factors and personal circumstances appear to be important factors influencing pathways to medical healthcare services among women with a SMI. Efforts to better engage and retain women with a SMI into medical healthcare services will need to better acknowledge and incorporate the larger social context of the lives of these women

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CHAPTER 5:

Summary and Conclusion

Women with a serious mental illness (SMI) experience co-morbid medical problems due to multiple factors such as a history of trauma (L. Miller, 1997), high rates of smoking (Dickerson, Pater, & Origoni, 2002), and type II diabetes related to certain psychotropic medications (Dixon et al., 2004). Additionally, women with a SMI are more likely to experience higher rates of medical disorders than women in the general population (Kessler et al., 1994). Women with a SMI have diverse diagnoses, treatment histories, functional levels, and share the experiences of inadequate planning and delivery of medical healthcare services (Brown, 1998). They are also more likely to have their physical complaints disregarded and their requests for services denied (Brown, 1998).

Different barriers might prevent women with a SMI to obtain adequate healthcare services. These can include individual and systemic level barriers. Individual level barriers include poor nutrition, obesity, smoking, and alcohol and drug misuse, which can all increase the risk for medical disorders (Glassman, 1993; Lasser et al., 2000; Silverstone, Smith, & Goodall, 1988). Systemic level barriers may also lead to under-treatment of patients with a SMI. For example, healthcare providers who are not familiar with patients with a SMI may be uncomfortable in dealing with them (Bunce, Jones, Badger, & Jones, 1982). Furthermore, low socioeconomic status (SES) can hinder access to healthcare through multiple factors such as lack of transportation or the inability to afford out-of-pocket medical expenses (Coryell et al., 1993; Dohrenwend et al., 1992; Weissman & Olfson, 1995).

This mixed methods research study examined the health of women with a SMI by investigating their health related quality of life (HRQOL) and their pathways to healthcare service utilization. This dissertation research provided a deeper understanding of the nonmedical factors and its impact on obtaining and receiving healthcare services among women with a SMI.

The first component of this research (Chapter 2) found that social and other nonmedical factors have an important role in HRQOL in women with a SMI. This study included a sample of women with a SMI who were recruited for a randomized control trial (RCT) and assessed at baseline. The RCT developed and tested a population-based medical case management model for improving primary medical care for patients with a SMI (Druss et al., In Press). The present study involved a secondary data analysis obtained from the women who completed the baseline assessment. HRQOL is becoming an important measure in healthcare where the focus has become more on the individual's point of view in medical healthcare outcomes (Geigle & Jones, 1990). One of the goals for individuals regarding their health is to maintain their physical functioning and mental well being (Cluff, 1981; Schroeder, 1987). Although medical morbidity is well documented among women with a SMI, less attention has focused on the determinants of HRQOL in this population. Understanding HRQOL in women with a SMI can identify subgroups with poor physical or mental HRQOL and can help guide policies or interventions to improve their health.

Income was identified as an important predictor for women with a SMI and their self-report of HRQOL. A strong relationship previously has been found between a person's SES and their self-report of HRQOL (Hunt, McEwen, & McKenna, 1985). Also,

the difference between women who lived in a halfway house and those who were marginally housed/homeless was found to be significant. Women who lived in a halfway house reported higher HRQOL compared to women who were marginally housed/homeless. Research has found that people with a SMI identify income and housing as the most important factors in achieving and maintaining their health (Trainor, Pomeroy, Pape, & (Eds), 1999).

Furthermore, the findings emphasize the impact of having a diagnosis of major depression on a person's self-reported HRQOL. Studies have found that patients with mood disorders report lower HRQOL than those with other psychiatric diagnoses such as schizophrenia (Atkinson, Zibin, & Chuang, 1997; Coulehan, Schulberg, Block, Madonia, & Rodriguez, 1997). Depression may also exacerbate the disabilities associated with physical illness affecting functioning in a number of areas (Hays, Wells, Sherbourne, Rogers, & Spritzer, 1995; Wells et al., 1989). Lastly, this study found that self-perceived HRQOL is an important determinant of the utilization of primary care services. Women with low levels of both physical and mental HRQOL utilized more primary healthcare services. Another study found similar results in which lower levels of HRQOL was associated with an increase in outpatient and inpatient services than those who had higher scores (Matsumura, 2000).

The second portion of this research (Chapters 3 and 4) investigated how women with a SMI describe and interpret their life experiences including their pathways to healthcare services. For this qualitative study, a sub-sample of 30 women with a diagnosis of a SMI was recruited from the ongoing National Institute of Mental Health study's enrollment roster. The strength of engaging women with a SMI in discussing their

lived experiences through qualitative interviews enables them to reveal thoughts and feelings within the context of everyday living. Understanding the pathways to healthcare services among women with a SMI through qualitative interviews can allow researchers to understand what influences women's introduction to and engagement with the healthcare system.

Women in this study spoke of their experiences living as a woman with a SMI. A complicated cycle of being socially disadvantaged was evident among these women's lives and the salient themes of their stories included experiencing loss, isolation, and a sense of a lack of control. Research has found that the social context of the lives of women with a SMI can create a poor quality of life (Kulkarni, 1997). Living with a SMI can create chronic stress, numerous losses including self-esteem, confidence, and a risk of leading an increasingly isolated life (Seeman, 1998). In order to provide more equitable, accessible, and effective services for women with a SMI, we need to recognize the ways in which having a SMI and other social and environmental factors are interrelated.

Also, the results found that women with a SMI have fewer social and psychological resources for coping. Although biology and heredity play a role in mental illness, other environmental factors like life trauma are also linked to mental illness (Cloitre, Tardiff, Marzuk, Leon, & Portera, 1996; Goodman, Dutton, & Harris, 1995; Wenzel, Koegel, & Gelberg, 2000). Therefore a multi-disciplinary approach is warranted as the majority of studies do not focus on the experience of living with a history of violence, substance abuse, and having a SMI from the perspective of women. Moreover, having a SMI often takes precedence over other significant issues in women's lives and

mental healthcare providers may contribute to their diminished quality of life by not contextualizing their treatment. Mental health providers can engage women in discussing options and providing support. A climate that promotes discussion of sensitive subject matters and adopting a practice of working with a woman in partnership could have lasting positive effects.

Additionally, the findings highlighted how a variety of nonmedical factors influenced women's introduction to and engagement with the medical healthcare system. Women felt the relationship they had with their mental health provider was a turning point in their life for building a sense of trust with other healthcare providers. A women's social network also had a major influence in building and strengthening their sense of purpose in life which in turn motivated them to access and utilize medical healthcare services.

Little is known about the actual experiences about how these women are able to engage in the healthcare system. Research has predominantly focused on the barriers individuals with a SMI face in accessing and utilizing healthcare services (Druss & Rosenheck, 1998). For example it has been found that people with a SMI who lack a support system (E. Miller, Lasser, & Becker, 2007) and sufficient income and health insurance (Coryell et al., 1993; Dohrenwend et al., 1992; Weissman & Olfson, 1995) may not access healthcare services. This study illuminated how social and environmental factors help women with a SMI engage in the medical healthcare system. These nonmedical determinants included a trusting relationship with a mental health provider, sense of meaning through religion, having a strong social network, and tangible financial resources. Other studies have also found that religion is associated with numerous

healthcare related factors, such as the use of physician services and hospital visits (Koenig, McCullough, & Larson, 2001). Having a social support network can provide a sense of well-being, serve as a source of information, and act as a form of coping (Thoits, 1986) for women with a SMI.

The findings of this research should be interpreted in light of a number of important limitations. Findings from chapter 2 used cross-sectional data for the analysis and therefore the relationship between predictors of HRQOL and the relationship between HRQOL and utilization of primary care services cannot be interpreted as causal. Further research is needed to determine the degree to which these factors are truly associated with HRQOL and how HRQOL is associated with the utilization of primary care services among women with a SMI. Additionally, because study participants were initially recruited for a RCT, those who agreed to participate in the clinical trial may differ from other women with a SMI.

The findings of the qualitative study (Chapters 3 and 4) must also be considered with respect to several methodological limitations. The sample was a small, purposive sample of women and the data were the perceptions of low-income women with a SMI. Their suggestions and opinions may not reflect those of women with a SMI in other contexts. Also, selection bias is a possibility as women with a SMI who are not currently seeking mental health treatment could differ in meaningful ways from the participants who engaged in the interviews. Therefore, interpretations of the results should be interpreted with caution. However, despite these limitations, our goal was to explore the experiences and attitudes of urban, low-income women with a SMI and their views on

accessing and utilizing healthcare services. As such, our findings shed important light in an area that has yet to be fully explored.

Despite these limitations, this research makes a substantial contribution in understanding the lives of women with a SMI. The findings from the secondary data analysis (Chapter 2) suggest that additional research is needed on the impact of HRQOL among women with a SMI. Research has found that a poor self-reported HRQOL has been shown to be an independent risk factor for increased mortality (Idler & Benyamini, 1997). This study found low HRQOL even among women utilizing primary healthcare services, suggesting that improving HRQOL in this population will require addressing other domains of these women's lives such as income, housing and symptoms of depression. Interventions that aim at improving the HRQOL of women with SMI may also reduce their demand for unnecessary healthcare services.

The findings from the qualitative study (Chapters 3 and 4) suggest that mental health professionals are in a critical role in improving the quality of life for women with a SMI who have histories of violence, substance abuse and poverty. A more multidisciplinary and contextual approach can allow the needs of women with a SMI to be more fully understood. Additionally, support from mental health providers such as listening, providing information, assisting in times of crisis, and providing referral to other healthcare providers can be influential for women in accessing and utilizing healthcare services. Supplementary, social support such as religious communities, family, and friends are also major determinants to get women engaged with the healthcare system. Therefore, pathways to medical healthcare services are much more impacted by nonmedical factors and personal circumstances for women with a SMI. Ultimately,

public health policy needs to acknowledge the larger social context of the lives of women with a SMI to enable them to enter and engage in the healthcare system. Gaining additional knowledge about the complex lives of women with a SMI may result in effective health promotion strategies used to enhance healthcare utilization via changes in women's behavior and/or in the larger healthcare system.

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