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Women's Experiences Living with Depression

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WOMEN'S EXPERIENCES LIVING WITH DEPRESSION

By

Susan M. Jarchow

A Dissertation Submitted in
Partial Fulfillment of the
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ABSTRACT

WOMEN'S EXPERIENCES LIVING WITH DEPRESSION

By

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The University of Wisconsin-Milwaukee, 2014

Under the Supervision of Aaron Buseh, Ph.D.

In the United States, depression affects many Americans at different levels. Depression among women is a major public health problem. According to the National Alliance on Mental Illness), about 1 in 5 women develop depression at some point in their lives, and are nearly twice as likely as men to have depression. Much of the research about depression in women are quantitative studies aimed mostly at collecting epidemiological or survey data that focus on rates of mental illness, while not taking into account the qualitative subjective and contextual illness perspectives of women living with depression.

The purpose of this study was to explore the perspectives of women living with depression in the context of their daily lives including (a) their experiences of symptoms and sequelae; (b) their cumulative exposure to social adversity; and (c) their efforts at recovery in the context of their larger sociocultural and sociopolitical environments.

Qualitative in-depth interviews were conducted with women (N = 17) who self-identified as having experienced depression at some time in their lives, to learn about their experiences living with and recovering from depression. Participants were recruited from a private psychological counseling practice and peer-led mental health recovery-

focused organizations, and were interviewed twice, 5 to 14 days apart, to add credibility to the study's findings. The transcripts of their illness narratives were analyzed using thematic analysis.

Findings emerging from the analysis were clustered and into six broad themes: (a) Suffering Adversity in Childhood and Adolescence; (b) Shutting Down and Giving Up; (c) Isolation, Not Fitting In, and Social Stigma; (d) Managing Symptoms and Experiences with Healthcare; (e) Coming to Terms: Facing It and Working Through It; and (f) Becoming a Resource Person: Connecting, Learning, and Giving Back.

Results from this study have implications for healthcare providers working with women living with depression. Eliciting illness narratives from women living with depression is an important starting point for mental healthcare professionals as they try to gain an understanding of what these women deal with every day in order to better meet their mental healthcare needs.

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My heartfelt thanks is extended to my father, who did not live to see this day, but always had an unwavering belief in me and my abilities to complete this journey.

CHAPTER I

INTRODUCTION AND BACKGROUND

This dissertation has resulted from many years of work in the area of depression, including the complex challenges experienced by women living with depression. Chapter 1 is arranged in the following order: Introduction, Background, Statement of the Problem, Purpose and Specific Aims of the Study, Assumptions, Definitions of Terms, and Significance of the Study.

Introduction

The World Health Organization (WHO) (2009) identifies depression in women as a major public health problem and a top priority for research. Studies are needed to inform mental healthcare interventions, programs, and social policies for women, especially related to their disproportionate exposure to social or contextual risk factors for depression in the context of their lives. Although depression is one of the most researched depression, the vast majority of findings from research about depression are based on quantitative studies that fail to take women's experiences of depression in the context of their daily lives into account (Wahl, 2012).

The WHO further clarifies the importance of research about women's life contexts, stating that it is not simply the presence of social or contextual risk factors, but the perceptions of meaning and symbolism attached to these life events and experiences that strongly influence women's mental health. This includes their understanding of depression, its causes, and its influence on their life worlds or daily lives, as well as the impact of living in social contexts that heighten their vulnerability to depression.

The purpose of this qualitative study was to explore the perspectives of women living with depression in the context of their daily lives including (a) their experiences of symptoms and sequelae; (b) their cumulative exposure to social adversity; and (c) their efforts at recovery in the context of their larger sociocultural and sociopolitical environments.

The sample for the study included women (n = 17) who self-identified as having experienced depression at some point in their lives. Sample members participated in two in-depth interviews with the researcher to discuss their experiences living with depression in the context of their lives. Interview transcripts or illness narratives were analyzed utilizing thematic analysis to identify important themes related to the purpose and aims of this study. Findings enhance the understanding of the mental healthcare needs of women with depression, and provide meaningful guidance for the development and implementation of effective treatment interventions and support.

Background

The mental health of women is extremely important not only to women as individuals, but also to the health of children, families, and society (WHO 2009). Depression is twice as prevalent, and is more persistent and recurrent in adult women as it is in men. In 2006, the lifetime prevalence of depression in all adults in the U.S. was 15.7%, including 20.2% of women and 11.1% of men (Strine et al., 2008). Depression is identified as the leading cause of disability in both men and women; however, the burden of depression in women is 50% higher (WHO, 2008). Major depression alone is associated with an annual economic burden of \$44 billion in the U.S. (National Institute of Mental Health [NIMH], 2009a). Current strategies to meet the mental healthcare needs

of women with depression are insufficient, as depression is expected to be the second leading cause of disability worldwide by 2020 (Kessler & Bromet, 2013), and the largest contributor to disease burden by 2030 (WHO, 2008).

It is estimated that prevalence rates represent only part of the total number of women experiencing depression. An even greater proportion of women experience depressive symptoms and associated functional impairments that do not meet thresholds specified in the criteria for diagnosis, yet these account for 51% of disability days, a greater number than the more severe acute major depressive episodes (WHO, 2009). This underestimation of the prevalence of depression in women is thought to exist in spite of gender stereotypes, including the social assumption that women tend to be prone to emotional problems and men tend to be more prone to alcohol problems, making it more likely for women to be diagnosed with mood disorders and prescribed mood altering psychotropic medications (SAMHSA, 2009). According to Simoni-Wastila (2000), women are 48% more likely than men to use any psychotropic medication after controlling for demographics, health status, economic status, and diagnosis.

The recurrent nature of depression is identified as the most important contributor to its high morbidity (Greden, 2001). Evidence shows that depressive episodes increase in frequency and severity over time, with the probability of recurrence increasing by 16% with each depressive episode (Solomon et al., 2000). More recent literature shows that the lifetime prevalence of depression is 2 to 3 times that of the 12-month prevalence; suggesting that one-third to one-half of the individuals representing lifetime cases have recurrent episodes (Bromet et al., 2011). As the lifetime prevalence of depression increases, so do the associated functional impairments (Bromet et al.)

In spite of evidence-based treatments, only about a third of patients treated for depression respond to the first antidepressant medication prescribed, whereas the majority require several medication trials before effective medications are identified, and need to continue taking these medications for 6 to 12 months to prevent relapse and remain in remission (Harvard Mental Health Letter [HMHL], 2009). Data on recovery rates indicate that as many as 20% of patients with major depression do not recover in two years, while 12% do not recover after 5 years (HMHL). Individuals who do not fully recover from depression are more likely to relapse, suffer persistent depression, and have more difficulty achieving recovery with each successive episode (Fava, Ruini, & Belaise, 2007; Solomon, et al., 2007). As a result, a number of women with depression continue to experience symptoms and associated impairments in functioning over a number of months or years, which can have lasting impacts on their role functioning abilities, interpersonal relationships, quality of life, and productivity (WHO, 2009).

Efforts to better understand the complexity of depression in women include social theories of health as espoused by the WHO (2009), and the shift in mental health interventions and treatment to a recovery-oriented model. Social theories of health provide a socially contextualized model for viewing the mental health of women based on the interactions between the illness-specific characteristics of depression, individual factors of women, and social or contextual factors in their lives. Social factors that increase women's vulnerability to depression include low income and education levels, poverty, marital disruption, unstable employment and job loss, and exposure to violence and acute and chronic stressors (Kessler & Bromet, 2013). The importance of social risk

factors is further supported by evidence that relapse rates for individuals living in adverse social environments are higher, irrespective of treatment (Groh, 2007; Brown et al., 2010).

Current conceptualizations of recovery in mental illness define recovery not only as the alleviation of symptoms, but also as the improvement in psychological well-being and quality of life (Burcusa & Iacono, 2007; Fava et al., 2007), living a meaningful life beyond the restrictions of the illness (Anthony, 2000), and becoming more fully human (Deegan, 1996). Recovery is considered to be a highly individualized process occurring in each person's life context, and is best informed from the subjective experience of the individual struggling with depression (Borg & Davidson, 2008; Davidson & Roe, 2007). Recovery includes considerations of the individual's culture, interpersonal relationships, existential crises, and the meaning of a person's experience with mental illness and its impact on his or her life (Johnstone, 2000).

In spite of the increased recognition of the multitude of factors influencing depression in women and the importance of understanding their subjective experiences of recovery, the vast majority of research about depression is based on objective measures or surveys. Therefore, study findings do not include consideration of the multitude of factors influencing depression and current conceptualizations of recovery from mental illnesses. Information regarding women's experiences of living with and recovering from depression would improve healthcare interventions to meet the needs of this population.

Statement of the Problem

As stated above, the WHO (2009) identifies depression in women as a major public health problem and a top priority for research in order to inform mental healthcare

interventions, programs, and social policies, especially related to women's disproportionate exposure to social or contextual risk factors for depression. The vast majority of findings from research about depression are based on quantitative studies that fail to take into account women's experiences of depression in the context of their daily lives (WHO).

Further, the treatment of depression, including depression, has been dominated by the medical model, which focuses on symptom alleviation. Even with treatment, the prolonged experience of symptoms associated with poor treatment response can contribute to increased depression and hinder recovery through decreased energy levels, feelings of poor self-esteem, competency, and control over life events; impaired cognition and decision-making abilities (American Psychiatric Association [APA], 2013); and increased sensitivity and response to stressors (Hammen, Kim, Eberhart, & Brennan, 2009; Shih & Eberhart, 2008; Hammen, 1991). In addition, information is needed about how women experience the dynamic remitting and recurring course of depression, which is characterized by alternating periods of symptoms and changing healthcare needs over time.

Although information about women's experience of continued symptoms over the course of their illness would improve healthcare strategies to meet their mental health needs, alleviation of symptoms is only one aspect of the recovery process. Despite increased awareness of women's disproportionate exposure to social or contextual risk factors for depression, the majority of supporting research findings are based on survey data that do not capture depressed women's experiences of social adversity (Wahl, 2012), or the meaning and symbolism they attach to these life events (WHO, 2009).

In addition, the role of social or contextual risk factors is more clearly understood in relation to the onset rather than the ongoing experience of depression (Groh, 2007; Brown et al., 2010); nor does the literature address the impact of women's cumulative exposure to social adversity over time. Evidence also shows a wide variation among individuals' responses to social adversity (Brown et al.); however, the reasons why some people exposed to social risk factors develop depression and others do not are not known.

Purpose and Specific Aims of the Study

Purpose

The purpose of this study was to explore the perspectives of women living with depression in the context of their daily lives.

Specific Aims of the Study

The specific aims of the study were to explore the perspectives of women living with depression in the context of their daily lives, including (a) their experiences of symptoms and sequelae; (b) their cumulative exposure to social adversity; and (c) their efforts at recovery in the context of their larger sociocultural and sociopolitical environments.

Assumptions

1. The participants in this study are willing to talk about their experiences.
2. Illness narratives can be analyzed to understand how people experience their life worlds and how people make sense of their illness experiences.
3. Narratives reflect not only the problems in living associated with illness, but also the answers to these difficulties (Barker, 2003).

Definitions of Terms

Depression is determined by participants' self-reports of having experienced depression at some point in their lives. This does not require an official diagnosis or treatment.

Recovery is a subjective process occurring in each person's life context. It is more than just the alleviation of symptoms; rather, it includes their living of a meaningful life in spite of mental illness, and includes developing insight, redefining their sense of self, and making meaning of their experience.

Illness Narratives are stories constructed and told by individuals that represent their illness experiences. Characteristics of the person, the illness, and the person's life context influence the illness experience and the narrative of what it is like to live with the illness in their daily lives. Illness narratives can be analyzed to determine the meaning or importance of living with the illness in the context of the person's life, including her life world.

Significance of the Study

Traditional use of the biomedical model does not adequately address the complexity of depression, nor has it addressed the disproportionate burden of health problems women face related to their social, educational, economic, and political disadvantages, and the psychological consequences of depression (WHO, 2009). Despite the increased recognition of the importance of the reciprocal interactions of factors associated with depression as an illness, women as individuals, and the social or contextual factors in their lives, the majority of the research findings are based on survey data that do not account for women's experiences of depression in their daily lives (Wahl,

2012). Information is also needed regarding the meaning or importance women ascribe to the experiences in their lives, their understandings of depression, and the impact of living with depression in social contexts that heighten their vulnerability to depression (WHO, 2009).

Justification of illness narratives to reflect subjective illness experiences.

Similar to individuals suffering from other depression, the majority of women with depression live their lives outside of hospital or treatment settings. Recovery from depression is increasingly recognized as a highly subjective process occurring within each individual's unique life context, based in a narrative framework (Borg & Davidson, 2008). Therefore, no two people experience recovery in the same way. Understanding women's recovery from depression requires knowledge from an "insider" as opposed to an "outsider" perspective (Adame & Knudson, 2007), which is to say a woman's subjective experience living with depression.

Although there is still much to be learned about women's subjective experience of depression, much of what is known about how individuals recover from depression in general is based on the study of individuals' illness narratives. Although illness narratives are told at a specific time, they also have the capacity to reflect individuals' illness experiences over time. Therefore, illness narratives of women with depression will provide insight into their ongoing and ever-changing illness experiences with depression, including its remittent and recurrent course and trajectory, characterized by prolonged symptom experience and impairments in functioning. Information gained will improve the understanding of how illness symptoms and problems influence women's day-to-day experiences, relationships, and pursuits (Borg & Davidson, 2008) as they attempt to

integrate various aspects of their lives, including interpersonal relationships, social structures, roles, parental duties, home and work life, and leisure activities (Gullestad, 1989).

Information about women's experience of depression over time also adds to knowledge about the impact and meaning of depression in their daily lives, and their experiences of factors influencing their vulnerability to depression. Improved insight into women's experiences living with depression over time improves the understanding of how ongoing exposure to social or contextual risk factors, including the availability of personal and social resources to promote positive coping, self-care, and self-management strategies, influences women's experience of depression (Katon & Ludman, 2003).

Contributions to nursing and mental healthcare. This study contributes to nursing theory and practice, and the design and implementation of individualized interventions along the illness course and trajectory. Ruffing-Rahall (1986) stresses the importance of understanding the perspective of the person living with health and illness through gaining an insight into their experiences as a critical part of nursing's focus on any human condition. Further, information in textbooks about different illnesses does not address the complexity and diversity of human responses to health and illness (Kleinman, 1988; Ruffing-Rahal). As a result, there are differences between nurses and patients on the meaning of health and illness. Client-centered knowledge, such as personal accounts of the illness experience, can bridge the gap among philosophies of science, nursing theories and medical and nursing research (Silva & Rothbart, 1984). Through greater empathetic understanding of women's experiences with depression, nurses are better

prepared to provide a higher quality of care for this population (Fleming, Mahoney, Carlson, & Engebretson, 2009).

This study is also consistent with focus areas identified by the American Psychiatric Nurses Association [ANPA] for research, clinical practice, educational programs, and resources (2008). These priorities include depression, disparity, and high-risk and vulnerable populations. Scientific inquiry regarding illness narratives of women with depression contributes to the knowledge base for setting standards of practice, designing effective interventions, and specifying roles of advanced practice nurses in the care of women struggling with depression.

Additional support for the importance of this study is the NIMH's call for prioritizing advancements in the personalization of mental health interventions based on individual variation in symptoms, illness trajectories, and treatment responses (2009). Further, while traditional intervention research studies have addressed alleviating symptoms, they have failed to address the totality of peoples' lives, including their ability to function in their communities and workplaces. Although treatment interventions commonly utilized can prevent or alleviate the symptoms of depression, there is also the possibility that interventions not personalized for the individual may not help or may even impair daily functioning levels (NIMH; Ridge & Ziebland, 2006). Further, research studies need to gather a wider array of data to increase health care providers' abilities to improve the personalization of treatment approaches. This includes the incorporation of patient, family, community, and provider perspectives in the development of mental health care interventions (NIMH).

Summary

This chapter provided an overview of the importance of this study, which explored the perspectives of women living with depression. This research makes a unique and important contribution to the field of nursing by adding to the scientific knowledge base about how women live with and recover from depression in the context of their lives. This knowledge informs healthcare interventions and strategies to better meet the needs of women along the course and trajectory of their illnesses as they respond to their ongoing exposure to social adversity.

CHAPTER II

REVIEW OF RELATED LITERATURE

Chapter II provides the context for this study and describes the current literature related to women with depression. Headings in this chapter include: Social Theories of Health and Influencing Factors, Challenges in Treating Women Living with Depression, Recovery Paradigm and Recovery-Oriented Care, and Women's Recovery from Depression.

Social Theories of Health and Influencing Factors

Efforts to understand and reduce the disproportionate prevalence and burden of depression in women has resulted in a shift from traditional understandings of women's mental health based on the biomedical model, which focuses mainly on the influence of biological and primarily hormonal factors, to a more socially contextualized model that accounts for the social risk factors for mental illness disproportionately present in women's lives. According to the WHO (2009), health is a multidimensional concept that emphasizes the importance of social and personal resources and physical capacities.

Accordingly, mental health is viewed as a complex web of interrelating factors on multiple levels in individuals' lives. Social theories as espoused by the WHO also include consideration of structural determinants of mental health including age, family structure, education, occupation, income, and social support. Utilizing social theories of mental health in women provides a broad socio-contextualized framework for understanding the multidimensional relationships among individual, social or contextual, and protective factors important to women's mental health. In addition, mental health is characterized by

individuals realizing their own abilities, coping with normal stresses of life, working productively, and contributing to their communities (WHO, 2009).

Individual factors. Individual factors affecting women's vulnerability to depression include neurobiological and hormonal processes, and physical and mental health status. Mental health is thought to result from the interaction of neurobiological factors such as neurotransmitters, specifically serotonin and norepinephrine, and external or environmental conditions or events including life experiences (U.S. Surgeon General, 2004). These neurobiological factors are further influenced by reproductive hormones including estrogen and progesterone, especially during events in the reproductive years such as menarche, childbearing, and menopause (Kessler & Bromet, 2013; WHO, 2009). Some studies have indicated the possibility that female hormones may also influence the processing of emotionally arousing information; however, further research about this is needed (Cahil, Uncapher, Kilpatrick, Alkine, & Turner, 2004). Understanding the influence of reproductive hormones on women's processing of emotionally arousing information is especially important when considering responses to stress and exposure to other risk factors for mental illness, including violence, abuse, and other traumatic events.

Chronic physical illnesses, including cardiovascular disease, cancer, and diabetes mellitus, are associated with high rates of mental health disorders, including depression, ranging from 20% to 67% depending on the illness (Alter, 2006). Co-occurring physical and mental illnesses can increase illness demands, and decrease coping and functioning abilities and social support, all of which contribute to depression and poorer outcomes (Kessler & Bromet, 2013).

Race and ethnicity also influence the prevalence and experience of mental illnesses. Ethnicity influences people's attitudes toward and responses to mental illnesses. Different ethnic groups attach cultural significance to mental illnesses, which influences not only the recognition of symptoms but also the explanations regarding the causes, importance or meaning, experience of stigma, and preferred treatment modalities (U.S. Department of Health and Human Services, [USDHHS], 2001). Culture can be an important source of resilience in women; however, it can also increase barriers to healthcare related to the recognition and acceptance of mental health issues (USDHHS, 2009). Further, in spite of the support offered women through cultural connections, there are also cultural pressures to remain silent about personal issues, not to discuss problems outside the family, or be too strong.

Social or contextual factors. Social or contextual risk factors, also referred to as social adversity in this study, for depression that have a disproportionate effect on women include the stressors of home and work responsibilities; care for children and aging parents; abuse; poverty; relationship strains; gender-based violence; socioeconomic disadvantage, low income and income inequality; and low or subordinate social status and rank (SAMHSA, 2009). Further, severe life events that cause a sense of loss, inferiority, gender inequality, humiliation, or entrapment can predict depression. Stressful life events and exposure to chronic stressors are also associated with increased onset, severity, and recurrence of depression (Hammen et al., 2009; Seifert et al., 2004; Jackson & Huang, 2000; Kaslow et al., 2002; Major, Richards, Cooper, Cozzarelli, & Zubeck, 1998).

Protective factors. Increased recognition of the importance of the disproportionate exposure to social adversity in women's lives has also resulted in the identification of factors that protect women against or lessen the impact of social or contextual risk factors for depression. Such protective factors include having autonomy and some control in response to severe events, access to material resources to improve the opportunity to make choices, and psychological support from family, friends, and healthcare providers (SAMHSA, 2009). Additional protective and resilience factors include increased coping skills for stress and emotional issues, assertiveness skills, self-esteem, and feelings of well-being (WHO, 2009). These protective factors are not necessarily qualities individuals are born with, but rather are influenced by life experiences and contextual factors (Davidson, Stewart, Ritchie, & Chaudieu, 2010). Therefore, meeting women's mental health care needs involves both reducing risk factors and enhancing protective factors for mental illness.

Social theories and social adversity. Of the social risk factors for depression in women, low socioeconomic status, especially poverty, has been identified as a major risk factor for depression among women in various life circumstances and across the life span (Kendler & Bromet, 2013; Belle & Doucet, 2003). High levels of depression have been identified in low-income mothers with young children (Seelig, Seifert, Finalyson, Williams, & Delva, 2007) and homeless women (Bassuk et al., 1996).

According to social theories of health and illness, it is not simply the presence of social risk factors but how these factors influence women's lives, both directly and as a result of their reciprocal interactions with each other. For example, some social risk factors can increase the likelihood of being exposed to additional social risks, as is the

case with poverty and depression in women, as poverty often places poor women in unsafe and vulnerable positions.

Life circumstances or contextual variables associated with poverty include having decreased access to educational and employment opportunities and adequate, stable housing; having an increased likelihood of living in disadvantaged neighborhoods; experiencing social disorder (delinquency, drug use, public intoxication); being refused services (credit card applications, taxi service, and food service); and being exposed to chronic stressors associated with economic insecurity and neighborhood disorder (Cutrona et al., 2005). Poor women report higher rates of physical and/or sexual abuse and posttraumatic stress compared to women in higher socioeconomic groups (Kessler & Brumet, 2013; Bassuk et al., 1996), and they experience more uncontrollable life events in the context of ongoing chronic deprivation (Ennis, Hobfoll, & Schroder, 2000).

Living in disadvantaged neighborhoods may also provide few economic opportunities and role models for economic success, which undermines optimism and belief in personal mastery. Negative life events occurring in this context often have an intensified effect because the individual's life world offers little hope for assistance and little experience with personal efficacy (Cutrona et al., 2005). In addition, the functional impairment and disability associated with depression can contribute to decreased household earnings, unemployment, and job loss (Bromet et al., 2011); decreased educational success (Breslau, Sampson, & Kessler, 2008); and increased poverty and homelessness (Collins, Geller, Miller, Toro, & Susser, 2001), as well as social isolation and loneliness (Linz & Sturm, 2013; Chernomas, Clarke, & Marchinko, 2008; Chernomas, Clarke, & Chisholm, 2000).

Poverty may also have a negative impact on the quality of socially supportive relationships with family and nonfamily members. Although support from siblings and, to a lesser extent, mothers, is important in predicting positive mental health outcomes, the lack of adequate—or even worse, conflicted—family and nonfamily social support is associated with poor mental health (Schulz et al., 2006; Bassuk, Mickelson, & Perloff, 2002). The association between poverty and low income and conflict with family members may be due in part to the reciprocal relationship between depression and increased interpersonal stress (Chun, Crinkite, & Moos, 2004),

Families of low socioeconomic status often have few or no social resources to share because many face the same stressors and scarcity of resources. In addition, neighborhoods high in social disorder make it difficult to establish supportive relationships with neighbors, prevent a sense of predictability, and pose threats to personal safety (Cutrona et al., 2005). Further, when poor or conflicted social support is combined with low income, poverty, and living in disadvantaged and dangerous neighborhoods, the combined effects may have even more detrimental mental health consequences for women, especially for members of minority groups, including African American and Hispanic women, who are disproportionately poor.

Reciprocal relationships of stress, depression, and protective factors. In addition to the reciprocal interactions between social risk factors, efforts to understand the cumulative impact of ongoing exposure to social or contextual risk on the lives of depressed women have focused on the reciprocal interactions between stress and depression, referred to as having a multiplicative rather than an additive effect (Kendler, Kuhn, & Prescott, 2004). Depression is thought to contribute to stress due to genetic

factors associated with depression (Wichers et al., 2009) and to the experience of ongoing residual symptoms of depression even after treatment (Shih & Eberhart, 2008). The “stress generation” hypothesis (Hammen, 1991) identifies the contribution of depression to stress generation through a combination of increased sensitivity and responsiveness to stressors in general, increased stress related to interpersonal relationships and behaviors (Shih & Eberhart; Eberhart & Hammen, 2009; Hammen et al, 2009), and an increased likelihood of being exposed to additional social stressors (Chun et al., 2004).

The increased interpersonal stress associated with depression can adversely impact social support, further contributing to depression, interfering with recovery, and increasing the risk of relapse (Eberhart & Hammen, 2009). Therefore, focusing on interpersonal functioning in women with depression is an important aspect of relapse prevention (Shih & Eberhart, 2008). The importance of personal relationships and social support in women’s lives is supported in the qualitative literature related to depression in women (Karp, 1994; Schreiber, 1996; Owen, Repper, Perkin, & Robinson, 1998; Repper, Perkin, & Owen, 1998; Ritsher, Coursey, & Farrell, 1997; Ridge & Ziebland, 2006; McKay, 2010). Chronic social stressors that provoke depression also make self-management and self-care difficult (Katon & Ludman, 2003), and decrease the availability of personal and social resources to cope with acute stressors.

Chronic stressors interact reciprocally not only with depression but with the factors that protect women’s mental health status. Leskela et al. (2006) and Grote, Bledsoe, Larkin, Lemay, & Brown (2007) further clarified the interrelationship between stress and depression by including the buffering effects of protective factors on social risk factors. Leskela et al. found that in women experiencing severe life events, perceived

social support had a positive effect on depression in all women studied; however, differences in the degree of positive effects were identified between women in the partial versus full remission groups. Although the reasons for these differences were not accounted for, as results were based on survey data, this is an important area requiring further study due to the variance in the interrelationship between stress, depression, and perceived social support along the course and trajectory of depression.

In a study of stress, depression, optimism and perceived control, Grote et al. (2007) found that among women experiencing a high number of exposures to acute and chronic stressors, optimism and perceived control were associated with less severe depression. Positive outcomes were found to be enhanced by encouraging women's use of problem-focused coping such as planning and seeking instrumental social support (as opposed to avoidance coping [denial, withdrawal, and giving up]) and promoting feelings of optimism, perceived control, and hope. When individuals feel they can better control life stressors, increased energy is available for using positive coping strategies such as reframing perspectives on situations, seeking emotional support, acceptance, and the use of humor, religion, spirituality, and prayer.

Although the findings of Leskela et al. (2006) and Grote et al. (2007) add to our understanding of the role of protective factors in buffering against the effect of social risk factors for depression in women's lives, findings from both studies are based on survey data. Although the importance of perceived social support, optimism, and perceived control over life events are recognized as having a buffering effect against the negative impact of social risk factors for depression, there is still much to be learned about how these factors influence the recovery process. This is important, especially in light of the

differences in the positive effects of perceived social support found in women who were in partial versus full recovery (Leskela et al., 2006). Knowledge is also needed related to the influence of social adversity on women's experiences living with depression and their capacities for protective factors in order to inform mental healthcare interventions that will best enhance women's capacities for these protective factors and address the cumulative exposure to social adversity in the lives of women living with depression.

Summary. Factors contributing to depression in women exist on both individual and social or contextual levels as described in social theories of health espoused by the WHO (2009). Based on women's disproportionate exposure to the social risk factors for depression, the WHO identifies the importance of research regarding women's experience of depression in the context of their daily lives, including the need for information regarding the reciprocal interactions of depression, women as individuals, and the social or contextual risk factors of and protective factors for depression in women.

Although progress in understanding depression in women includes recognizing the importance of social adversity in women's lives, the role of social risk factors in the onset of depression is much more clearly understood than their role in the ongoing experience of depression (WHO, 2009). In addition, differences have been identified between individuals' responses to social adversity or social risk factors; however, the reasons why some individuals who experience certain risk factors develop mental illnesses and others in similar situations do not is largely not understood at this time (Groh, 2007; Brown et al., 2010). The impact of women's ongoing exposure social adversity or the cumulative effect of social risk factors over time has not been addressed

in the literature. Further, little is known about how women go about recovering from depression in the context of their lives, especially in relation to the reciprocal interactions among depression, social adversity, protective factors, and coping skills they utilize.

Challenges in Treating Women Living with Depression

Several challenges may act as barriers to effectively meeting the healthcare needs of women with depression. Such factors include the nature of depression, mental healthcare delivery systems, and variability of treatment outcomes related to social adversity.

Nature of depression. Depression in this study is defined as the women's perception that they had lived with depression. The diagnosis of depressive disorders is based on criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) that represent clusters of symptoms that, when considered together, impair functioning ability in a variety of life roles (APA, 2013). Symptoms of depression may include sustained feelings of depression, sadness, hopelessness, worthlessness, and powerlessness; anhedonia (loss of interest or pleasure); changes in appetite and sleep; fatigue; suicidal ideation; unrealistic negative evaluations of self-worth and ruminations of guilt about minor past failings; misinterpretation of trivial day-to-day events; and cognitive deficits including impaired thinking, concentration, decision-making, and remembering over a specified period of time (APA, 2013). Although several subtypes of depression exist, they all have similar long-term effects on health and quality of life (HMHL, 2009).

Treating depression in women is especially challenging due to slow improvement of symptoms, prolonged recovery periods, and an increased likelihood of partial versus

full recovery (HMHL, 2009). Data regarding the duration of recovery periods from depression indicate that approximately 20% of patients who experience major depression have not recovered in 2 years, while 12% have not recovered after 5 years (HMHL, 2009). Further, a number of women continue to experience either residual or sub-threshold symptoms after treatment or relapse within 2 months.

Findings from clinical trials examining the effectiveness of medications and various psychotherapies in the treatment of depression offer further support for the need for longer treatment regimens for depression, as only 25% to 35% of patients receiving antidepressant therapy responded to the first medication prescribed, whereas the majority of patients required several medication trials before effective antidepressants were identified (HMHL, 2009). Many of the patients treated for depression needed to continue taking medications for 6 to 12 months to prevent relapse and remain in remission.

Additional challenges in treating women with depression include its persistent course and trajectory and high risk of relapse (HMHL, 2009). Although the time intervals between recovery and recurrence of depression are highly variable for different individuals, the risk of recurrence decreases as the duration of recovery increases (Solomon et al., 2007), emphasizing the need for treatments and rehabilitation services that support ongoing recovery, relapse prevention, and reintegration of individuals into their communities and the workforce. In addition to treatment with antidepressant medications, various psychotherapies focused on improving responses to distressing events, perspectives on situations, self-perceptions, positive coping strategies, and assertiveness and social interaction skills have been proven to be helpful in treating

depression; however, these also require up to a number of months to show improvement (HMHL, 2009).

Mental healthcare delivery. The provision of mental healthcare in the United States occurs in different sectors of the healthcare system, including the specialty mental health sector, the medical/primary care sector, the human services sector, and the voluntary support network sector. The specialty mental health sector includes the provision of mental health care by specially trained mental health care workers in a treatment setting designed specifically for providing mental health services. The general medical/primary care sector includes a variety of health care professionals and settings designed for the full range of healthcare services including but not specialized for mental health services. The human services sector includes social welfare, criminal justice, education, religious, and charitable services. The voluntary support network includes self-help groups and organizations that extend beyond formal treatment settings.

Prevention, early identification, and treatment using combinations of medications, various forms of psychotherapy and skills training, and psychological and social supports have been shown to improve the lives and functional abilities of women experiencing depression (U.S. Surgeon General, 2004). Of the women experiencing depression who seek treatment, the vast majority receive mental healthcare in the primary care setting, where most of the research to improve depression in women is focused (Seelig & Katon, 2008). Priorities for treating depression in the primary care setting identified in the literature include improving the accuracy of diagnosis, preventing relapse, (Seelig & Katon), and utilizing a more holistic approach that addresses mental and physical health

needs and includes treatment to a functional level of social role recovery in addition to symptom relief (Goldstein, 2002).

Improvement efforts have been focused on addressing challenges to effective identification and treatment of women in primary care settings, including competing demands and lack of time to provide education and activation of women as partners in care; infrequent follow-up visits; lack of objective proactive monitoring of recovery; non-adherence to medications or lack of follow-through with referral to mental health care; and lack of access to mental health specialist consultation due to the separation of primary care and the mental health system (Seelig & Katon, 2008).

Findings related to the use of collocated care models, in which mental healthcare is provided in the primary care setting and improvements in monitoring and follow-up visits with patients treated for depression have shown improvements in treatment outcomes (Wells et al., 2000). In addition, the use of strategies to improve patient self-management, engagement in treatment, medication adherence, and follow-through with referrals for psychotherapy have also been more effective when compared to treatment as usual. Collaborative and collocated services have also been shown to positively affect access to mental health services (Blout, 2003), especially for poor populations (Lieberman, Adalist-Estrin, & Sloan, 2006).

Social adversity and variability in outcomes. Further challenges to treating women with depression are emphasized by findings that remission rates among patients treated for depression who live in aversive social contexts are consistently much lower irrespective of treatment (Groh, 2007; Brown et al., 2010).

Increased recognition of the importance of addressing women's mental healthcare needs within the context of their lives emphasizes the need for care providers to ask more detailed questions about women's housing situations and the neighborhood context in which they live, including the quality of various dimensions of instrumental, emotional, and social support (Groh, 2007). In addition, women need information regarding social service agencies, the services provided, and the application process for legal assistance, housing, clothing, food, baby and child supplies, churches, and medical equipment, supplies, and medications.

Summary. Evidence shows that even with treatment, women's prolonged symptom experience and associated impairments in functioning over a number of months or years can have a lasting impact on abilities, interpersonal relationships, quality of life, and productivity (WHO, 2009). Current strategies for meeting the healthcare needs of women with depression are far from adequate. Further, in spite of the evidence-based treatments available and efforts to improve the delivery of mental health services, the disproportionate prevalence and burden of depression in women continues to increase.

Recovery Paradigm, Illness Narratives, and Women's Recovery from Depression

The literature also identifies great variation in the course and outcomes of depression, both across individuals and within individuals over time (HMHL, 2009), adding yet another dimension to the complexity of meeting the needs of women with depression. Efforts to explain differences between individuals' experiences of mental illnesses, including the effectiveness of interventions and variability in treatment outcomes, have resulted in the conceptualization of mental illnesses such as depression as multi-dimensional disorders comprised of several domains of functioning to varying

degrees over time, and a shift to a recovery-focused model of mental health care. Similar to the multidimensionality of depression, recovery from mental illness is a multidimensional concept, and means more than just the reduction or alleviation of symptoms (Borg & Davidson, 2008; Davidson & Roe, 2007). Efforts to address the multidimensionality of mental illnesses have resulted in the shift to a recovery paradigm both nationally and globally.

Recovery paradigm. Over the past 30 years, the focus of mental healthcare has shifted to a recovery-focused paradigm. The main impetus of this shift was the analysis of illness narratives written by mentally ill individuals during the 1980s that described both their negative experiences with the mental healthcare system and their positive experiences of recovery, describing it as a journey characterized by affirming aspects including hope and empowerment (Adame & Knudson, 2007). These narratives stood in contrast to the prevailing mental health system narrative based on the biomedical model, characterized by a focus on pathology, chronicity, and decline. Recovery is no longer defined merely as the absence of symptoms but as an experience of living a meaningful life beyond the restrictions of the illness (Anthony, 2000) and becoming more fully human (Deegan, 1996). Recovery includes consideration of the individual's culture, interpersonal relationships, existential crises, and the meaning of peoples' experience with mental illness and its impact on their lives (Johnstone, 2000). In this example, illness narratives were utilized to give voice to individuals with mental illnesses and have brought about social change.

Further, the concept of recovery in mental illness is understood in a narrative framework in which patients determine key aspects of their recovery and healthcare

professionals facilitate this process (Borg & Davidson, 2008). Recovery-oriented care emphasizes the individual's strengths and involves a collaborative relationship between the patient and healthcare provider based on respect, honesty, and shared goals for growth and change (Adams & Drake, 2006; Deegan & Drake, 2006; Roe, Goldblatt, Baloush-Klienman, & Swarbrick, 2009; Adame & Knudson, 2007). Further, mental healthcare needs are based on the uniqueness of each individual occurring within each person's life context; therefore, recovery is subjective in nature and best informed by knowledge about the person's experience living with and recovering from mental illness. Illness narratives provide a rich source of information regarding individuals' illness experiences.

Illness narratives. A narrative is a story that describes past actions or events and how the narrator understands these actions and their meaning (Riesman, 1993). An illness narrative is initiated by an illness and the individual's search for meaning in it (Kirkpatrick, 2008). Narratives are more or less accurate representations of "what really happened" and the individual's understandings of that reality (i.e., data for subsequent analysis) (Baldwin, 2005). It is the accounting of the person's experience of their reality. Characteristics of the person, the illness, and the person's life context influence the illness experience and the narrative or story told about what it is like to live with the illness in their daily lives. Just as individuals' lives are subject to constant change, so do their narratives. Although illness narratives represent the individual's representation of their experience at that time, they also reflect the individual's perspective over the course of their illness. Illness narratives from interviews over time can also provide useful information regarding the dynamic experience of living with a chronic illness.

An illness refers not only to a disease as defined from the healthcare provider's perspective as a biophysical problem, but also as the process of how the sick person and significant others perceive, live with, and respond to symptoms and disability (Kleinman, 1988). The term illness "connects the experiences of suffering and symptoms often, but not always associated with a diagnosis of any disease" (Kleinman, 1988, p. 3), and extends beyond healthcare to include the individual's lived experience (Overcash, 2004). Study of illness narratives is well suited for examining depression in women due to the number of women experiencing symptoms and impaired functioning associated with depression that either do not meet diagnostic criteria as depressive disorders or the number of women who do not have access healthcare providers. Each individual experiences illness within her unique contextual environment, which includes multifaceted interactions between illness-specific, individual, and social or contextual factors.

Components of the illness experience reflected in illness narratives include characteristics of depression, individual factors, and social or contextual factors. Illness-specific factors include the physiological, structural, or functional characteristics of the illness, including its diagnosis, cause, trajectory, treatment, and expected outcomes. The course and trajectory of illnesses influence stability and predictability, which impact the individual's physical, psychological, social, and spiritual health status; energy levels; functioning abilities; life activities and goals; and the strategies required to deal with and integrate the illness into the person's life context. Although illness narratives reflect individuals' representations of their illness experience at the time they are telling their

story, illness narratives also reflect their ongoing experience of living with illness over the course of time.

Individual factors include individual and family characteristics that contribute to or protect the person against depression, and how these factors either enhance or diminish management of depression. Individual characteristics reflected in illness narratives include age, gender, ethnicity, cognitive and emotional status and processes, perspectives, self-awareness, knowledge, beliefs, attitudes, self-efficacy, sense of control and autonomy, self-determination, energy levels, motivation, developmental stages, capabilities, functioning levels, literacy, and the ability to locate and utilize resources. Illness narratives improve understanding of women's cognitive abilities, emotional status, and self-awareness as they relate to women's gaining of insight and redefining their sense of selves in the process of recovery. In addition, information regarding functioning levels will improve identification of needs related to impairment in role function and women's capacities to utilize protective factors, including their sense of control, autonomy, self-determination, and the ability to take responsibility for their own recovery.

Social, contextual, or interpersonal factors interact with individual or intrapersonal and illness factors, allowing healthcare providers to glimpse into individuals' "life world," which is subjective and unique for each person and can either enhance or diminish the integration of their illness into their lives. Interpersonal factors range from relationships with family, friends, and peer groups to interactions in wider social networks in the environments in which people live, including neighborhoods, schools, workplaces, communities, religious or community organizations, cultural groups and norms, gender role expectations, healthcare systems, and broader social and political

arenas. Within these social settings, individuals function in a variety of roles, including that of parent, professional, worker, student, athlete, and patient, all of which may be experienced differently as a result of the impact of the illness on the individual's life. Functioning within each of these roles provides information about experiences related to that role, including strengths, abilities, limitations, struggles, competencies, actions, desires, relationships, employment, interests, and achievements and failures (Morgan, 2000).

Analysis of illness narratives provides insight into the experience of living with a chronic condition such as depression and how this experience is meaningful to the person in terms of its symptoms, cultural significance, influence on his or her "life world," and explanations (Kleinman, 1988). The meaning of symptoms refers to how individuals understand, treat, and associate certain behaviors with illnesses based on their shared understandings of sickness, or accepted knowledge about the body, the self, and their relationship to each other, which are derived from local systems of knowledge, social situations, relationships, and culture (Kleinman).

As part of an individual's understandings of illness, culture may ascribe significance to certain symptoms and illnesses influencing their interpretation as culturally important in society, which may at times be stigmatizing, and may "mark the sick person, stamping him or her with significance often unwanted and neither easily warded off or coped with" (Kleinman, p. 18). Mental illnesses, including depression, can have a negative cultural significance, which can interfere with symptom recognition and health-seeking behavior. Stigma can distance the individual from those around her and her own sense of self (Fleming et al., 2009), which can result in feelings of isolation.

Family and cultural influences can affect how families respond, how mental health services are obtained, and how well individuals respond to different treatments (USDHHS, 2001). Further, women from different races and ethnicities may be at greater risk for mental illness due to the combination of racism, discrimination, violence, and poverty.

Meaning related to the person's life world includes the interaction among the individual's internal cognitive processes, emotions, attitudes, and beliefs and interpersonal interactions within their broader social systems. In addition to close interpersonal relationships, social interactions also occur in neighborhoods, schools, workplaces, communities, and healthcare systems as individuals function in a variety of roles, all of which may be experienced differently as a result of the impact of the illness on the individual's life. Functioning within each of these roles provides the opportunity for an unlimited supply of stories about various experiences related to that role.

The term "explanations" refers to the information about the illness and its treatment; patient and family concerns and expectations regarding the course and trajectory of the illness; the ability of healthcare providers to meet their needs; and measures to control or improve the effects of the illness (Kleinman, 1988). Leventhal, Meyer, and Nerenz (1980) describe a process by which individuals construct both emotional and cognitive representations of their illnesses based on the organization and interpretation of subjective experiences and information from external sources related to the illness's cause and impact on functioning and quality of life; the course, whether it is acute or chronic; and prognosis for being cured or controlled; as well as the individual's beliefs about the illness label (Hagger & Orbell, 2003). Through organizing and

interpreting this information, the individual makes sense of and manages the illness by choosing, implementing, and evaluating appropriate coping skills (Hagger & Orbell).

Importance is represented in individuals' stories to convey the meaning they want the audience to understand (Mishler, 1995) through consideration of statements, questions, tone and cadence of speech, posture, gestures, movements, and facial expressions (Kleinman, 1988), and through elongated vowels, emphasis, pitch, and repetition to indicate both what is important and the emotions of the narrator (Riessman, 2008). Storytelling can also be viewed as a kind of performance in which the teller tries to convince the person listening who was not there that something important happened (Goffman, 1959).

Recovery: Narrative findings. In spite of the global endorsement of recovery as the expectation for people with mental illness, there is little consensus on the precise meaning of the term recovery. In a review of clinical and rehabilitative practice literature over the past 30 years, Davidson and Roe (2007) identify two main meanings of recovery, referred to as "recovery from" and "recovery in" mental illness (p. 459). Recovery from mental illness is defined as a subsiding of symptoms and returning to a state of health following the onset of the illness related to signs and symptoms and deficits, whereas recovery in mental illness focuses on treating the condition and on how people can learn to live with mental illness through reclaiming control of their lives and destinies while incorporating ways to minimize the destructive effects the illness (Roe, Chopra, & Rudnick, 2004; Davidson & Roe, 2007). Further, recovery in mental illnesses moves beyond focusing on symptoms, deficits, and the reduction of symptoms following the onset of illness to how the person can learn to live with mental illness and reclaim her

right to a safe, dignified, and personally meaningful life as a valued member of the community. Emphasis is placed on self-determination and normative life pursuits such as education, employment, sexuality, friendship, spiritually, and voluntary membership in faith and other types of communities that are beyond the limits of a person's illness and the mental health system and consistent with her goals, values, and preferences (Davidson & Roe).

Borg and Davidson (2008) describe recovery the process of individuals living with their mental illness and its consequences within the context of their daily lives and overcome challenges to find their place, a sense of meaning and purpose, and a valued social role as members of their communities. The provision of practical, material, instrumental, and social support may be as valuable in facilitating mental health recovery as interventions such as medications (Borg & Davidson). Further, findings emphasize the importance of community arenas for recovery as opposed to mental health service settings, where individuals with mental illness are believed in and expected to be competent, where they gain positive physical, emotional, and spiritual self-care and coping strategies, and where they also gain the ability to perform everyday tasks such as paying bills and making and keeping friends. Psychosocial rehabilitation has also been shown to be helpful in building skills for socialization and employment, establishing and maintaining a comfortable sense of home on a limited income, pursuing enjoyable social and recreational activities, and developing the capacity to give back to others and sustain connection to a sense of meaning and purpose greater than oneself.

The study of illness narratives has also improved the understanding of recovery from mental illnesses as not simply an outcome, but a process that occurs in the

individual's social and material environment and within the context of social relationships (Davidson, Tondora, & Ridgeway, 2010). Although qualitative literature identifies that supportive social relationships have been shown to be associated with improved well-being, Green, Hays, Dickinson, Whittaker, and Gilheany (2002) found social contacts to be both protective and damaging, thus emphasizing the importance of realizing the impact of mental illness on an individual's social networks. This stresses the importance of utilizing illness narratives in assessing individuals' social network related to its availability, adequacy, and responses to and support of their mental illnesses, especially in light of the reciprocal interactions between stress, depression, and interpersonal relationships.

Overall, the subjective aspects of recovery in mental illness identified in the qualitative literature include hope (Ridgeway, 2001; Houghton, 2007; Adame & Knudson, 2007; Waynor, Gao, Dolce, Haytas, & Reilly, 2012), having choices regarding treatment strategies and shared decision making (Adams & Drake, 2006; Deegan & Drake, 2006; Roe et al., 2009; Cohen, 2005; Jacobson & Greenley, 2001; Sullivan, 1994), self-determination (Jones, Corrigan, Drexler, Parker, & Larson, 2013; Ochocka, Nelson, & Janzen, 2005), and meaningful activities and work (Mancini, Hardiman, & Lawson, 2005; Ridgeway; Sullivan, 1994). Recovery has also been described as including enhanced coping skills, the ability to formulate and achieve goals (Mueser et al., 2002), the use of a holistic recovery viewpoint (Kravetz & Roe, 2007; Mueser et al.), changes in personal values, acceptance of vulnerability, and the readjustment of goals and expectations in light of changes (Kravetz & Roe).

Essential aspects of recovery. Qualitative research on depression identifies that individuals can develop a distorted or false sense of themselves from an early age and that recovery from severe depression involves the disintegration and rebuilding of oneself. Narratives can help individuals recover from depression if they find or construct more useful stories to tell about themselves (Ridge & Ziebland, 2006). Further, it is well accepted in the recovery literature that mental illness creates a “crisis of meaning” (Roberts, 2000, p. 435) for individuals and that making sense of their experience of altered mental states to gain psychological equilibrium is critical to recovery (Klienman, 1988). Meaning making in mental illness has a significant impact on the recovery process, as it helps individuals understand their illness and place it in the context of their lives (Davidson et al., 2005; Mancini et al., 2005). Therefore, the process of recovering from mental illness includes individuals gaining insight, redefining their sense of selves, and making meaning or sense of their illness experience.

Gender-based differences in mental illness. Gender-based differences are not a focus in this study; however, findings are mentioned briefly to provide insights related to women’s experience. Although evidence did not identify a straightforward relationship between gender and engagement with health professionals, Maxwell (2005) identified implications for healthcare providers including the need to be sensitive to difficulties in expressing emotional distress regardless of gender, as gender stereotypes that women find it easy to express emotions and that men find it difficult are not always accurate. In addition, the determining factors in women’s decisions to seek mental healthcare included realizations that their mental health status was a problem that could not be attributed to other factors; concerns regarding the effects of their behavior on others,

including the effects on family functioning and relationships; and concerns about their ability to function in other social roles.

Research findings related to gender and depression identified differences between the experience of men and women. Gender-based differences were found related to the sources of and responses to depression, main life priorities, social interactions, and emotions. While the narratives of both men and women showed experiences of high demands, men tended to place a higher priority on work and women tended to place a higher priority on home responsibilities (Danielsson & Johansson, 2005). Further, men tended to discuss their emotional distress in terms of physical problems such as heart problems, whereas women spoke more directly about emotional distress, feelings of shame and guilt, and physical symptoms that involved the stomach. Coping strategies for alterations in mental health also differed by gender; for example men dealt with insecurity by aggrandizing their previous competence, while women tended to express their insecurity through the use of self-effacing statements (Danielsson & Johansson).

Scientific inquiry into the influence of gender on the process of meaning-making in living with and recovering from mental illnesses is limited (Schon, 2009); however, studies of physical illnesses have found gender to be a contributing factor to social adjustment (Degner, Kristianson, Bowman, & Sloan, 1997; Evagelista, 2000). For example, men and women were found to differ in their perceptions of health and meanings ascribed to their illnesses, showing women were more likely to find positive meaning in their illness, while men were more likely to experience feelings of loss and perceived weakness (Degner et al., 1997). Women who reported a more positive meaning in their illnesses also reported being more able to develop effective coping strategies and

learn from their experiences (Evangelista). Gender-based differences related to recovery from mental illnesses included women's focus on relationships and men's focus on mastery (Williams, 2005) and use of more unfavorable coping strategies (Kravetz & Roe, 2007).

Women's Experiences of Recovery from Depression

The qualitative literature related to how women recover from depression in the context of their lives is limited. In addition to studies from the U.S., a number of studies are from other countries such as Canada (Schreiber, 1996; Schreiber & Hartrick, 2002), Ireland (McKay, 2010); and the United Kingdom (Owen et al., 1998; Repper et al., 1998; Ridge & Ziebland, 2006).

Utilizing data from focus groups of women in United Kingdom, Owen et al. (1998) identified themes of loss, including loss of past relationships with partners and children; loss of independence, work, and opportunities for meaningful activity; having little input in decisions affecting their lives; and experiencing feelings of powerlessness in all aspects of their lives. In contrast, these women also stated that they continued to have hopes, including "ordinary aspirations such as getting married, having friends, a job, a house, and something to do with their time" (Owen et al., 1998, p. 287). Repper et al. (1998) utilized the same focus group data, and identified losses and hopes similar to Owen et al., as well as social disadvantages such as poverty, divorce, and sexual abuse that occurred prior to the onset of women's mental health problems. In addition, Repper et al. found that women's hopes and aspirations were limited by healthcare staff attitudes that were not supportive, concluding that negativity of healthcare providers may be detrimental to women's feeling of well-being and recovery from mental illness.

In a survey of 107 American women and 59 American men, Ritsher et al. (1997) examined aspects of living with severe mental illness, including women's perceptions of the causes of their illness, their self-perceptions and identities, and the themes arising from these perceptions. Causes of their mental illness and associated problems were attributed to bad things in the past or as a result of the way they were raised, with only one-third attributing their problems to a chemical imbalance in the brain. Interestingly, women reported that having a mental illness was not central to their identities or sense of selves, with one-third believing that they did not have a mental illness. Almost half of the sample, or 47%, reported losses as they were forced to give up or change life goals such as jobs, attending college or having children, and emphasized the importance of relationships and social supports in their experience with and recovery from mental illness, consistent with the findings of Owen et al. (1998) and Repper et al. (1998).

Research that has added the most to understanding women's experiences of depression has involved the study of illness narratives that view recovery in women as a "moving" perspective or journey over their illness career, including studies by Karp (1994), Schreiber (1996), Ridge and Ziebland (2006), and McKay (2010). Karp (1994) analyzed illness narratives from in-depth interviews of 20 individuals diagnosed with depression. The experience with depression was described as a moving perspective over time in which individuals try to make sense of their illness with benchmarks along the way. These key aspects included having inchoate feelings of distress, coming to feel that something was "really wrong," having a crisis, coming to grips with an illness identity, and, for some participants, defining depression as a condition one can get past.

Each stage corresponded to transformations in the individual's self-conceptions. Inchoate feelings of distress were described as times when things seemed different; however, participants did not have the vocabulary to name their problem. Eventually respondents concluded that something was really wrong with them, followed by a time of crisis in which almost everyone had the realization that they were "mental" patients. Next, during the coming to grips with an illness identity phase during which they sought treatment, they reconstructed and reinterpreted their past in terms of current experiences, looked for causes of their situations, constructed theories about the nature of depression, and established ways of coping. In defining a condition one could get past, some perceived depression as something they could get past forever; however, some individuals viewed depression as a lifelong condition that they would never fully defeat.

Schreiber (1996) analyzed data from in-depth interviews of 21 women who identified themselves as having recovered from depression, finding that women described the recovery process as *(Re) Defining My Self*, consisting of six phases moving along the course of their illness or career. The phase *My Self Before* was described mainly as living with conflicted relationships, caring for others, and making uninformed decisions due to a lack of understanding of themselves and their worlds, followed by *Seeing the Abyss*, which included recognizing depression in themselves. Next, women identified *Telling My Story* and *Seeking Understanding*, during which they began to understand the cause of their illness and learned about themselves, or *Clueing In*. This was followed by *Seeing with Clarity*, characterized by reflecting on where they had been and appreciating where they were now. *Clueing In* was identified as vital to recovery, involving coming to a cognitive and emotional realization of themselves in relation to the world and

understanding who they were, or their true selves. For women to recover, it was necessary to discover the things and people they were and were not responsible for in their lives, and focus on caring for themselves as opposed caring for others and trying to live up to others' expectations while suppressing their own feelings and needs. Jack (1991) identified similar findings in that women began recovering when they were able to articulate own needs and wishes. Overall, recovery was described as a growth experience in which individuals developed skills and knowledge they lacked before their illness and a search for their personal identity within the social context of their lives.

Although Schreiber (1996) has added to our understanding of women's recovery from depression over the course of time, limitations of this study are related to the education level of participants, as almost all had some college education, many had advanced degrees, and only one was unemployed. Women in the study may have had less exposure to social adversity related to these areas and therefore would not be representative of the general population. In addition, the majority of participants had not pursued formal education prior to the time of their first experience of depressive symptoms, so their experience of gaining a formal education during the recovery process may have affected their experience of gaining insight.

Schreiber & Hartrick (2002) explored how women understand and explain depression. Explanatory models described by women were ever-evolving and changing as a result of new information. Findings emphasize the importance of biomedical perspectives; however, they were not sufficient to reflect women's experience of depression in their daily lives. Women found a broader explanatory model of depression and enhanced their understanding of their experience and their ability to "*keep it*

together” as they lived with depression. The study is helpful in understanding the importance of how women explain their experience with depression; however, focus was placed on depression and its treatment as opposed to the richer descriptions of the multidimensionality of the recovery experience.

Ridge and Ziebland (2006) studied illness narratives from men and women with depression to determine gender differences related to how they went about understanding and organizing recovery, including their approaches to and meanings in overcoming depression. Aspects of the recovery process identified by women included the meanings of recovery such as *chemical imbalances*, *types of insight*, *authentic self and living*, *assuming responsibility for recovery*, and *struggling with recovery*. “Recovery” involved moving from not knowing to an awareness of selves in world (similar to “*clueing in*” in the research of Schreiber [1996]), which included developing insight into destructive thought patterns, distortions of self-concept, and difficulties with personal circumstances. Participants also described a sense of an “authentic self and living,” which involved taking full responsibility for and struggling with recovery, and accepting themselves instead of forcing change and focusing on things depression had stopped them from doing. Part of developing an authentic sense of self involved “re-storying” their experience around authenticity and rewriting their illness into their selves in more positive way.

“Assuming responsibility for recovery” was described as identifying personal needs, developing increased assertiveness, and becoming more proactive in gaining adequate care and knowledge. “Struggling with recovery” referred to the telling of specific types of stories about depression and the self that allowed the individual to go on

living what at times was a better life than before they experienced depression. Telling more positive or constructive stories or narratives as a part of the recovery process is also identified by Ridge and Ziebland (2006), and is one of the foundations for the recovery paradigm. Ridge and Ziebland also state that healthcare providers can assist individuals in developing insight and rebuilding their sense of selves by challenging negative thinking; however, it is critical that this be done at the right “moments” and that salient messages challenge the patient in a useful rather than negative way.

The findings of Ridge and Ziebland (2006) add to our understanding of how women develop insight, including the authentic sense of self and taking full responsibility for their recovery, as opposed Schreiber’s (1976) findings of women shifting from taking responsibility for caring for others to taking care of themselves. In addition, Ridge and Ziebland also describe the importance of women constructing more positive narratives to tell about themselves and challenging their own negative thinking, as well as the importance of providing the right interventions at the right times during the recovery process.

In a more recent study, McKay (2010) analyzed illness narratives of women living with enduring mental illness, including bipolar disorder and depression, over a 2-year period related to their illness experience and occupational functioning throughout their lives. Participants reported experiencing complex life roles and needs over time, while acting as agents in defining a better life for themselves and others. Findings identified six themes in the recovery process: *present life*, *surviving*, *life roles*, *relationships*, *help*, and *cultural context*. “Present life” referred to women’s perceptions of their lives at time of the study, perceiving that they had come through a series of life

events during which there were times when they were unable to establish control over lives and other times in which they could pursue opportunities for control and change. “Surviving” was described as acceptance, self-responsibility and self-management in their approaches to coping, similar to findings of Ridge and Ziebland (2006), including descriptions of self-acceptance, developing self-awareness and an authentic sense of self, and taking full responsibility for recovery.

McKay (2010) also identified the importance of meaningful engagement in occupations across the lifespan, and although occupations involving paid work were associated with increased positive self-perceptions, social relationships, and skill development, many sought meaningful occupations through reading, crafts, singing, and gardening, and involvement in church, youth programs, and other types of volunteer work. All women experienced occupational disruption as result of mental illness, including a significant time of absence, and although many returned to work, they found the transition was not easy. All reported contact with others with mental health problems through regular phone calls and emergency telephone trees, sharing the responsibility for sustaining contact with others in their network.

Further, the importance of gaining an understanding and making sense of their experience was described by women as involving the naming and framing their diagnosis, and moving from not knowing or understanding to being able to make sense of what was happening or could happen to them. During the time period they characterized as “not knowing,” they found it was more difficult, if not impossible, for them to seek out information, thus making them more passive recipients of care rather than equal partners.

Findings also emphasized the importance of healthcare providers listening to and accepting a person's perspective as the expert on her life, offering hope, and assisting her with coping strategies and friendships.

Although McKay's (2010) findings do not describe benchmarks of recovery, women described an overall perspective of surviving and the importance of life roles, relationships, help, and cultural context in this process. In addition, McKay identified the importance of meaningful occupations, not necessarily paid employment, as well as the occupational disruption experienced by all participants, which had not been addressed previously. The importance of participants staying in contact with others experiencing mental health problems and sharing responsibility for sustaining contact with others in their network also adds to our understanding of social factors facilitating women's recovery from depression.

The qualitative literature related to women with depression, has also added to knowledge regarding the social interactions of women related to their life roles. Information about women's experience of their life roles is important related to impairments in parental, gender-specific, and occupational roles associated with depression. For example, although being a parent can provide motivation for recovery, motherhood, especially having children less than 18 years old in the home, can contribute to increased perceived illness demands, thereby decreasing social support and increasing depression (Hough, Brumitt, & Templin., 1999).

Findings related to social gender-specific roles identify the critical necessity of women realizing what and who they are responsible for and shifting from gender roles of being responsible for caring for others to caring for themselves (Schreiber, 1996; Ridge

& Ziebland, 2006). Jack (1991) goes a step further by stating that it is only through caring for themselves that recovery is possible for women. Further support of the importance of roles in women's lives is identified by McKay (2010), who found that women identified complex life roles and the importance of meaningful occupations throughout their lives; McKay also described the experience of occupational disruption as a result of depression for all women participants.

The findings of Schreiber (1996), Ridge and Ziebland (2007), and McKay (2010) add to the understanding of the process of women's recovery from depression, including depression; these findings include the importance of gaining insight, redefining the sense of selves, and determining meaning in their experience; the importance of complex roles; taking responsibility for their recovery; accepting themselves; and having positive relationships and social supports, including contact with others who are experiencing depression. The consistency in themes of loss and hope in women's recovery experience is important, especially as it relates to roles and relationships, meaningful occupations, feelings of control over their lives, and involvement in decisions affecting them. Implications for healthcare providers include being positive, listening to individuals' perspectives, helping them with coping strategies, challenging distorted thoughts, and helping them construct and tell more positive stories about themselves as part of the recovery process.

Summary

Qualitative research has added to our knowledge of important aspects of recovery from mental illness, describing it as an ongoing process that emphasizes self-

determination and normative pursuits (Davidson & Roe, 2007), community settings for recovery, and the importance of building skills for self-care, positive coping, socialization, employment, and a sense of meaning and purpose greater than oneself (Borg & Davidson, 2008). Essential aspects of recovery include individuals' making meaning or sense of their experiences and redefining their sense of selves.

Illness narratives contribute to nursing care as they represent the totality of a person's experience of living with an illness. Consistent with findings in overall recovery research in mental illness, studies utilizing the illness career view of women's recovery have identified the importance of women gaining insight, redefining their sense of selves, and making meaning or sense of their experience living with and recovering from depression (Schreiber 1996; Ridge & Ziebland, 2006; McKay, 2010). Additional findings include themes of loss and hope and the importance of personal relationships (Owen et al., 1998; Repper et al., 1998; Ritsher et al., 1997; Schreiber, 1996; & McKay, 2010).

Although the literature discussed here has added to our understanding of women's experiences with depression, the number of studies is very limited and the process by which women go about recovering in the context of their own lives is still largely unknown. Of the studies presented, only Ritsher et al. (1997) studied American women with depression, and this was survey research. Although this is a key study in understanding women with depression, it was conducted 15 years ago and does not address women's process of recovery in their daily lives.

The findings from the majority of studies involving women's illness narratives are from countries other than the U.S., and although these studies add to our understanding of women's recovery from depression, they do not address the importance of social or

contextual risk factors or social adversity in women's lives, nor do they account for the reciprocal relationships among depression, exposure to social or contextual risk and protective factors, and the influence of ongoing or cumulative exposure to social adversity. Although the countries represented in the studies of illness narratives of women in this review are considered comparable to the U.S. in terms of being high-income countries (WHO, 2009), differences in contextual factors and living situations, however subtle they may be, can have an impact on the daily lives of women with depression.

CHAPTER III

METHODS AND PROCEDURES

Introduction

This study uses a qualitative design to explore the illness experiences of women living with depression. The sample for the study included women (n = 17) who self-identified as having experienced depression during their lifetimes. Data were gathered utilizing narrative inquiry through in-depth interviews. A two-interview structure, in which participants completed two in-depth face to face interviews with the researcher 5 to 14 days apart, was utilized to strengthen increase rigor of this study. The beginning of the second interview included the participants' and the researcher's reflections on the first interview and provided an opportunity for the researcher to clarify her interpretations. Transcripts of subjects' illness narratives were analyzed using a thematic approach to identify important themes related to subjects' experiences living with depression in the context of their daily lives. This chapter includes the following sections: Research Design, Procedures, Sample, Sample Recruitment, and Data Collection: In-depth Interviews, Data Analysis, Ensuring Scientific Rigor, and Ethical Considerations.

Research Design

This study utilized a qualitative, exploratory, cross-sectional design congruent with a naturalistic paradigm. Naturalism was appropriate for this study because it values human complexity and individuals' abilities to shape and create their experience. Further, individuals' voices and interpretations related to their human experience of a given phenomenon allows that phenomenon to be better understood (Riessman, 2008).

Therefore, researchers can gain access to this information through the qualitative analysis of narrative subjective data.

Assumptions of naturalistic methods.

1. The nature of reality is multiple and subjective and is mentally constructed by individuals.
2. The researcher interacts with the participants; therefore, the findings are created by the interactive process.
3. The role of values and subjectivity is inevitable and desirable.
4. Evidence is obtained by an inductive process.

Limitations of naturalistic methods.

1. The subjective nature of findings may be idiosyncratic, meaning that two people studying the same phenomenon in similar settings may or may not arrive at similar conclusions.
2. The small sample size may create difficulty in generalizing findings.
3. Human beings are the instrument for data collection, with unique and different levels of intelligence, sensitivity, and ability to reflect on and articulate their experience.
4. As individuals, humans communicate through narratives. Individuals experiencing mental illnesses may experience cognitive and emotional disturbances that may compromise their ability to construct a recognizable narrative, which in turn influences social interactions, communication, and others' responses to that person.

Strengths of qualitative methodologies. Qualitative research is a process of inquiry to gain an understanding of a social or human problem (Cresswell, 2007), and is useful in studying abstract concepts, interpersonal relationships, and lived experiences. Knowledge gained through qualitative inquiry is based on the assumption that knowledge is relative, and is a creation of the interaction between the researcher and the researched (Lincoln & Guba, 1985). Through this interactive process, qualitative researchers provide ways of understanding experience from the perspective of those who have lived it (Schwandt, 2000).

Researchers using qualitative methodologies seek to explore, understand, and represent and interpret peoples' subjective experiences in terms of the meanings associated with them. Based on detailed accounts from informants and other sources of information, qualitative researchers attempt to develop a complex, holistic, and multifaceted conceptual picture of the phenomenon or area under study (Creswell, 2007).

In qualitative studies, data are often collected through interviews, focus group discussions, observations, documents or archival data, and audio-visual materials. Thereafter, the data are examined for meaningful categories or themes. Based on these categories or themes, the qualitative researcher may develop a theory, model, or description of the main issues that emerge from the data. The use of qualitative methods, including in-depth interviews and thematic analysis of interview transcripts, is appropriate for the purpose of this study because they overcome the challenges associated with gaining an understanding of human experiences of health and illness, and contribute to knowledge consistent with holistic nursing (Wojnar & Swanson, 2007).

Philosophical basis: Narrative inquiry. The methods used in this study were narrative inquiry and thematic analysis. Chase (2005) defined narrative inquiry as “an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches, and both traditional and innovative methods—all revolving around an interest in biographical particulars as narrated by the one who lives them” (p. 651). In other words, narrative inquiry is the study of the story about an experience (Connelly & Clandinin, 2006). Using narrative as an inquiry, the researcher invited the participants to tell stories about their lives and their experiences with a focus on stories of deep importance and significance, as opposed to eliciting facts and information (Chase, 2005). The primary focus of narrative inquiry is to “give voice to the subject: to collect, interpret, and present materials about human experiences that preserve this voice of the subject” (Bell, 1991, p. 245). In addition, the telling of narratives is also viewed as a meaning-making attempt to organize a coherent whole out of many experiences and to communicate that meaning (Chase, 2005; Josselson, 1995; Smyth & Pennebaker, 1999).

Data were collected using narrative inquiry, through the researcher’s conduction of 2 in-depth interviews of each participant. The actual interview questions asked included consideration of time, context, and place (Connelly & Clandinin, 2006). Events have a past, present, and future, and are in a constant state of transition in the social context of individuals’ lives. This social context or life world includes interactions between intrapersonal factors such as an individual’s feelings, hopes, and desires; and the interpersonal or social conditions such as the environment, other people, and to some extent the relationship between the participant and researcher. Place refers to the location or physical space where the described events occurred, and to a lesser extent, where the

inquiry interview occurs. For example, treatment for women with depression may occur in different healthcare settings, while recovery occurs at home and other community settings. In addition, personal interviews may occur in various locations. Interviews for this study were conducted at a time and place chosen by participants. Narrative inquiry and in-depth interviews are discussed further in the following section, titled Procedures.

Procedures

Sample. The process of sample recruitment began after the researcher received approval from the University of Wisconsin-Milwaukee Internal Review Board, (see Appendix A: Ethical Approval Notice from the UWM Institutional Review Board). The sample for the study included women (n =17) who self-identified as having experienced depression during their lifetimes, regardless of whether they sought healthcare, received an official diagnosis, or received treatment. The purpose of using this inclusion criterion was to allow women who either did not or were unable to seek healthcare for their symptoms or who experienced sub-threshold symptoms that did not meet the full criteria for diagnosis, but had a major impact on their lives (HMHL, 2009).

Due to the importance of individual and social variables, participants' other socio-demographic characteristics were gathered through a Socio-Demographic Information Sheet (see Appendix B). This information was utilized to describe sample composition in Chapter IV: Findings. Through ongoing analysis of interview data while simultaneously recruiting participants and conducting interviews, it was determined that there was sufficient coverage of the experience after 17 women were interviewed. According to Riesman (2008), under the narrative inquiry and analysis model, data collection and

analysis happen concurrently as the insights gained may cause new questions to emerge and the researcher to seek further evidence to confirm these insights.

Sample recruitment. Participants were recruited from the private practice of a psychologist (2 participants), and from a peer-run mental health recovery focused organization (15 participants) in a Midwestern city. The researcher met with the contact person in each setting to provide verbal and written information about the study, and answer any questions. The researcher recruited subjects by posting study recruitment information in common meeting places within the organizations, and on the peer-run organization's websites and newsletters.

The peer-run organization provided a structure emphasizing mutual self-help and support for individuals with mental illnesses to promote self-advocacy, self-determination and feelings of increased control over their lives, personal responsibility, and access to supports. The organization also offered additional resources: recovery skills classes, support groups, artistic programs, peer companions, and opportunities for supported education. Participants recruited from this organization identified it as having a very important role in their mental health recovery.

Women interested in participating in the study contacted the researcher by phone or e-mail, which were provided on recruiting flyers. During this contact, the researcher explained the study, obtained participants' verbal consent, and scheduled an interview for a specific date and time at a location chosen by the participant.

Data collection: In-depth interviews. Qualitative in-depth interviews were the primary strategy for data collection. Of the 17 women participating, 16 completed both Interview 1 and Interview 2 within 5 to 14 days. Each interview lasted 60 to 120 minutes.

Interviews were audiotaped and transcribed verbatim. Field notes were taken regarding the interviews, including participants' non-verbal responses and the researcher's reflections on the interview for later analysis along with transcripts.

The investigator obtained and documented the informed consent of each subject prior to participation in the research by providing both verbal and written information regarding the study. A copy of the signed consent form was given to each research subject. The process of informed consent was ongoing throughout the duration of the research, prior to both interviews. Participants were reminded that they could choose to withdraw from the study or stop the interview at any time without any consequences.

After informed consent was obtained and documented, the researcher completed the Socio-Demographic Information Sheet with participants. Participants' socio-demographic information was collected to provide a context or starting place on which to build throughout each interview, and to describe the sample in Chapter IV: Findings.

Interviews were semi-structured and used the interview guides in Appendix C: Interview Guide 1 and Appendix D: Interview Guide 2. The Interview guides remained the same throughout the study; however, Interview 1 tended to focus more on the most difficult symptoms, psychosocial stressors, and symptom management with medications, and Interview 2 tended to focus more on recovery efforts beyond symptom improvement, including the insights participants gained, and their advice for healthcare providers and women with depression. At the conclusion of the first interview, the researcher discussed subjects' participation in the second interview, including a follow-up phone call to verify oral consent to participate, answer any questions, and confirm a specific time, date, and location for the second interview.

Prior to the second interview of each participant, the researcher reviewed and reflected on the audiotapes of and notes about the first interview. The second interview began with participants' reflections on, and the researcher's interpretations of, their first interviews. This process enhanced the accuracy of the researcher's thematic analysis of interview transcripts, and the credibility of the study's findings, and was documented and included with other data collected. Reflecting also gave participants the opportunity to participate more directly in interpreting their narratives.

As one way of decreasing the researcher's influence, participants were asked and encouraged to tell their story in their own way (Clandinin & Connelly, 1994). Questions were applied flexibly to each participant to facilitate the use of active listening, probes for clarification, and changes in interview direction as appropriate (Fontana & Frey, 2005; Morrow & Smith, 2000; Warren, 2002). According to Warren, this approach provides rigor and allows for sound practice in conducting the interviews, while still promoting researcher flexibility to remain alert for relevant emerging meanings within the stories. Interview questions were paced so that participants had the time they needed to think about the questions, respond, and discuss topics of their own choosing. To facilitate these considerations, four hours were allotted for each interview, to include time for the researcher to prepare for and conduct the interviews, and then upon completion, reflect on the interview in a quiet place.

Denzin & Lincoln, (2005) describe the emergent quality of qualitative research in which the researcher (bricoleur) creatively takes different materials and puts them together in novel ways, through the use of self-reflection. As the qualitative inquirer, the researcher adjusted and adapted to each participant and context, and followed her story in

order to improve the understanding of her lived experience, while seeking clarification in the immediacy of the interview (Maykut & Morehouse, 1994; Rew, et al., 1993).

The researcher used additional strategies to facilitate participant interviews. Rapport was facilitated by using a warm, accepting attitude, establishing trust with participants, conducting interviews in a private or intimate setting, and being sensitive to participants' language and emotional and other responses. The researcher minimized the likelihood of participants experiencing any negative responses to or consequences resulting from their participation in interviews by distinguishing these research interviews from counseling interactions, and acting in the role of a researcher rather than a nurse providing mental healthcare. At times the investigator respectfully redirected the conversation back to the topic when participants sought advice that might be asked of a healthcare practitioner providing services. In addition, to help participants regain emotional stability as the interview was ending, the researcher ensured that the conversation became more lighthearted by using a more social tone of voice. At the completion of interviews, the researcher provided all participants with written information about mental healthcare resources.

Interviews were audio-taped and transcribed verbatim by a transcriptionist. The researcher then verified the transcripts' accuracy by closely and repeatedly listening to the audio recordings and comparing them with the written transcripts. After the transcripts' accuracy was verified, they were entered in N Vivo 10, a qualitative database that allowed the researcher to code interviews individually and then to compare within and across interviews for important themes, including areas of convergence and divergence between interviews.

All data collected were confidential. Interview audiotapes, transcriptions and re-transcriptions, field notes, memos, and journal entries documenting all information related to the research process, including all steps, reflections, decisions made regarding data collection and analysis, were documented utilizing N Vivo 10 software in a specific password-protected project file for this study and locked in a secure location accessible only to the researcher or those specifically involved in a part of the research project, such as the Major Professor.

Data Analysis

Thematic analysis: Overview. Interview transcripts of participants' illness narratives were analyzed using thematic analysis, related to the literature reviewed and the purpose and aims of this study, to explore the perspectives of women living with depression in the context of their daily lives including (a) their experiences of symptoms and sequelae; (b) their cumulative exposure to social adversity; and (c) their efforts at recovery in the context of their larger sociocultural and sociopolitical environments.

Thematic analysis followed an essentialist/realist research epistemology, which holds that data can be analyzed to theorize experiences, meanings, and the reality of participants in a straightforward way due to the simple one-way relationships assumed between meaning, experience, and language (Braun & Clarke, 2006).

Thematic analysis: coding of transcripts. The process of coding interview transcripts followed the approach described by Braun and Clarke (2006), consisting of six phases: *familiarizing yourself with your data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report.*

The first phase, *familiarizing yourself with your data*, involved the transcription and immersion in the data in an active way of searching for meanings and patterns. After interviews were transcribed verbatim from their audio tapes and verified as accurate, they were read through and a list of ideas for initial codes was completed. Phase two of coding interview transcripts, *generating initial codes*, involved the researcher finalizing a list of initial codes and then using them to code interview transcripts with N Vivo 10 software. In phase three, *searching for themes*, the researcher sorted codes into potential themes so that all relevant coded data were included within the identified themes. From this information, candidate themes and sub-themes were developed, and all extracts of data coded in relation to them were compiled to gain a sense of the importance of themes identified.

In phase four, *reviewing themes*, candidate themes were refined using criteria to ensure that themes were internally homogeneous or coherent with each other, yet different or clear and identifiable from each other. This phase involved reading all coded extracts of data for each theme to see if the pattern was coherent. After ensuring that candidate themes adequately captured the coded data, coding was refined so that themes worked in relation to the entire data set, including how they fit together and the overall story they told about the data.

In phase five, *defining and naming themes*, all data extracts for each theme were organized into a coherent and internally consistent account with an accompanying narrative describing what was of interest about them and why. When a theme's content could be described in a couple of sentences, it was named to give the reader an immediate sense of what it was about. In the sixth phase, *producing the report*, a concise, coherent,

logical, non-repetitive, and interesting account of the story both within and across themes was written. Evidence of the themes identified included enough data excerpts from interview transcripts to demonstrate the themes, and included especially vivid examples or extracts capturing the essence of the point being demonstrated.

Ensuring scientific rigor. Although some of the measures to assure scientific rigor were discussed earlier in this chapter, this section is intended to present the organized approach that was utilized in this study. The following information explaining how rigor was assured in this study is based on descriptions by Hall and Stevens (1991), who identify standards of rigor in qualitative research including trustworthiness, credibility, adequacy, consensus, complexity, reliability or dependability, honesty, and flexibility. Everything discussed in this section on scientific rigor was documented in an audit trail and field notes in a timely manner as they occurred.

In qualitative research, it is commonly accepted that the researcher is the instrument of both data collection and interpretation (Maykut & Morehouse, 1994; Patton, 2002; Rew, Bechtel, & Sapp, 1993). This is also true for this study using narrative inquiry and thematic analysis. Although the researcher in quantitative studies remains objective, distant, and value-neutral, qualitative research is “inevitably entwined with the perceptual frames, histories, and values of the inquirer” and “is unabashedly subjective, unapologetically imbued with the individual perspectives and frames of the inquirer” (Greene, 1998, p. 390). Although objective truth is never completely captured, the goal for the qualitative researcher is to present an in-depth interpretation of the phenomenon under study by portraying the participants’ experience as accurately as possible and supporting the authenticity of their experiences (Cihlar, 2004). Therefore, the credibility

and rigor of the research depend to a great extent on the personal integrity, skill, competence, and life experience of the researcher (Patton, 2002).

The researcher ensured the trustworthiness of this research by considering her own personal and professional attributes to decrease the likelihood of these qualities affecting “data collection, analysis, or interpretation” (Patton, 2002, p. 566), and to indicate her position as an insider or outsider to the phenomenon of interest (Morrow & Smith, 2000). Prior to any interviews with participants, the researcher engaged in a process called “bracketing” (Janesick, 2000; Tesch, 1990), in which she identified her own presuppositions about the perspectives of women living with depression to differentiate between participants’ experiences, meanings, and understandings and her own.

Credibility was verified by using a two interview method, and especially at the beginning of the second interview, when participants and the researcher shared their reflections on the first interview to clarify and improve the accuracy of interpretations. In addition, the researcher ensured that the themes identified in the data included all the data gathered in the research process. Likewise, the researcher ensured that the conclusions from the thematic analysis of interview transcripts were based on all of the data gathered in the research process, and that this process of verification was included with other documentation related to the study.

Adequacy implies not only that the processes of the study are appropriate for the research question as discussed previously, but also that the results of data interpretations are accurately represented in the data collected. This study’s accuracy was assured because its process, qualitative inquiry and thematic analysis, were appropriate for its

purpose and aims exploring the perspectives of women living with depression in the context of their daily lives. In addition, the findings from data analysis were accurately represented in the data collected. As part of assuring adequacy, the researcher used reflexivity or integrative thinking at each step of the research process and the researcher's values, assumptions, characteristics, and motivations were examined to see how they were affecting all areas of the study.

Consensus was evaluated by looking at areas of agreement and disagreement such as which participants' experiences were represented or not represented in the data, and at what level of analysis these similarities or dissimilarities became relevant. Complexity was achieved by locating the analysis of interviews within the context of the participants' daily lives, assessing the influences historical background and larger social structures. Larger social structures included community organizations and groups, healthcare settings, places of employment, and treatment and insurance programs.

An honest account of information regarding the purpose and design of the study was given in writing, and reviewed with them prior to their participation. The researcher conveyed genuine interest in the participants' experiences, respect, and gratitude for their time and efforts. Questions were applied flexibly to participants to allow them to tell their stories in their own ways. In addition, the researcher collaborated with her Major Professor and dissertation committee members while designing, implementing, analyzing, and reporting the study at each step to further improve the scientific rigor of the research.

Dependability refers to the documentation of the "rationale, outcome, and evaluation of all actions related to data collection, sampling, analysis, and dissemination

of results...” (Hall & Stevens, 1991, p. 19). The researcher documented and maintained an accurate, timely, and organized audit trail for the study, including detailed descriptions of data collection and analysis, utilizing the N Vivo 10 software options of adding memos, comments, and subthemes that were linked to the transcripts individually and across cases.

Ethical considerations. Internal Review Board (IRB) approval was obtained for this study following approval from the dissertation committee. This study took longer than a year to complete so IRB approval was continued for a second year. Criteria for the approval of research protocols requires that risks to subjects are minimized and reasonable in relation to anticipated benefits, selection of subjects is equitable, legally effective informed consent is sought from prospective subjects, informed consent is documented, adequate provisions are planned to protect the privacy of subjects and maintain confidentiality of data, and measures are taken to safeguard subjects against coercion for their participation.

CHAPTER IV

FINDINGS

Introduction

This chapter presents the findings from the study. The purpose of this study was to explore the perspectives of women living with depression in the context of their daily lives, including (a) their experiences of symptoms and sequelae, (b) their cumulative exposure to social adversity, and (c) their efforts at recovery in the context of their larger sociocultural and sociopolitical environments. Questions asked during the in-depth interviews focused on their symptom experiences, encounters with the healthcare system for symptom management, interpersonal relationships and social stigma, and recovery efforts in their everyday lives.

Themes emerging from the analyzed transcripts of the interviews were clustered in the following broad domains/categories. Each domain is followed with a brief operational definition for the reader.

- *Suffering Adversity in Childhood and Adolescence*: Social risk factors during childhood and adolescence, such as parental abuse and neglect, and difficulties with school and peer relationships, that participants felt contributed substantially to their mental health problems.
- *Shutting Down and Giving Up*: Symptom experiences and associated functional impairments described by women as having the greatest impact on their roles and relationships; for example, repeated failures accomplishing life goals and feelings of hopelessness, worthlessness, powerlessness, and low self-esteem.

- *Isolation, Not Fitting In, and Social Stigma:* Challenging social aspects of women's experiences living with depression, including feeling isolated and alone, not normal, or different from others in society
- *Managing Symptoms and Experiences with Healthcare:* Women's mental healthcare experiences including medication and adherence, relationships and experiences with healthcare providers, and other helpful treatment strategies.
- *Coming to Terms: Facing It and Working through It:* Participants' experiences of truly engaging in their recovery from depression beyond efforts at symptom alleviation. Aspects of this theme include self-awareness and willingness to change, gaining insight, and developing self-acceptance.
- *Becoming a Resource Person: Connecting, Learning, and Giving Back:* Participants' experiences of gaining increased social support and feeling a sense of belonging, having role models for recovery, helping others learn about depression and recovery, having a purpose, and feeling a renewed sense of hope.

Description of the Study Participants

Participants included (n = 17) women who self-reported experiencing depression at some point in their lifetimes. Women ranged in age from 28 to 81 years (M = 53, SD = 13.3). Participants fell into the following ethnic groups: 82% were white; 6% were African American; and 12% were mixed. Their income source at time of the interviews included: 18% employed full time; 12% part time; 23% retirement funds; 47% SSI; and 6% no source of income. Participants who reported they had worked at some time in their lives: 65%. Women's annual income levels were: (12%) less than \$5000; (29%) 5-\$10,000; (18%) \$10-20,000; (12%) \$30-40,000; (23%) \$40-50,000; and 6% gave no

information regarding income. Sample members that described their income as adequate: 82%. In terms of insurance, 29% had private insurance; 59% had public insurance; and 12% had no insurance. Participants reported the following education levels: 18% had graduate degrees; 23% had bachelor's degrees; 6% had an associate's degree; 18% had some college; 23% were high school graduates/GED; 6% had some high school; and 6% had only elementary school.

Themes

Suffering Adversity in Childhood and Adolescence

Most women described their experiences with depression as beginning in childhood and adolescence. Their stories emphasized the impact not of symptoms, but of painful family of origin experiences and difficulties with school and peer relationships. Several women came from families characterized by physical, emotional, or sexual abuse and/or neglect. These participants felt their early life experiences contributed considerably to their mental health problems. They often remembered feeling unloved, unaccepted, and unsafe in their homes, which increased their vulnerability to depression in adulthood.

Some participants tried unsuccessfully to leave their unsafe home situations by seeking help from adults who may have been able to advocate for their safety. One participant described being repeatedly molested by her father beginning when she was 6 years old. After unsuccessfully trying to get her mother to protect her, she left the house in her late teenage years by marrying an abusive man. This doubly traumatic event is captured in the quote below:

I told my Mom that my Dad was molesting me, I was about 9 years old, and she stopped everything she was doing and then we went...and found my Dad in the bed with my sister...she stayed with him...we didn't leave, we had to stay...they wanted us to be quiet and not talk about anything that happened. So then I really became depressed, 'cause I didn't feel safe...So, I did what I thought I had to do, I got married to a guy at the place where I worked. Then he turned out to be abusive.

Some women escaped their home situations by going away to college. One participant described being physically and emotionally abused by her parents. She then recounted that going away to college was equally if not more stressful. She found that even though her parents were abusive, at least she knew what to expect in her home.

It was just as traumatizing to move out of that house as it was to be in the house 'cause...there was a certain sense of stability...when I went to college...I was so inept at knowing how to manage, I didn't know how to make friends, and I was sick...I couldn't tell people what was going on 'cause...I didn't even have the words... my schedule was changing all the time for my classes, I had two jobs trying to pay for school, um, and, um, everything changed constantly. There was just no stability.

Another participant described feeling unloved and unaccepted by her parents, who were distant, unavailable, and verbally abusive to her. As an adult, she felt an overwhelming need to be accepted and liked by everyone. She described her efforts to interact socially and make friends by "feeding" or giving food to all of her neighbors. She felt taken advantage of because very few of these people ended up becoming her friends. At the time of interviews, this participant no longer tried to get people to like her by offering them food, but it took a long time and the help of her healthcare providers to realize this and act differently. She said:

...growing up...my parents kinda put me down... I'm not sure what it feels like to love or to be loved...probably one of the worst things I go through living out here is abandonment...and the need of people liking me...other people's acceptance is really important to me...I would do almost anything...give away about everything

to get you to like me. And that's a problem...I've been taken advantage of many times for that.

Not all participants experienced abuse or neglect in their early lives; however, other psychosocial stressors experienced by participants are discussed under other themes in this chapter, mainly in the section *Isolation, Not Fitting In, and Social Stigma*.

Shutting Down and Giving Up

Shutting down. Participants' descriptions of their most difficult symptoms fit into the theme, *Shutting Down, and Giving Up*. *Shutting Down* includes women's symptom experiences and associated impairments in functioning. As part of shutting down, women reported physical symptoms including feelings of fatigue; disturbed sleep patterns such as insomnia, hypersomnia, and difficulty getting out of bed; wanting to be alone; and increased pain and vulnerability to physical illnesses. Women also reported anhedonia (loss of interest or pleasure in previously enjoyed aspects of life), difficulties with thinking, and feelings of severe anxiety.

One participant described her experience of shutting down:

I just become real withdrawn, I'm not interested in anything, I don't care about anything, I mean I do care...I don't do anything about anything. I can't focus...I have more pain in my body...and I get sick, like I catch colds and flus, everything that comes around.

The loss of interest and enjoyment in activities made coping with depression and efforts to increase positive emotions challenging. One participant said:

I try to help myself. I took up embroidery and I read but it's hard to concentrate, so I don't read a lot. And we have a big yard, and I have a lot of flowers, but I have no interest in going out there and working on 'em. Like, yesterday I tried. I walked out, pulled a couple of weeds, and went back in the house.

Participants also described their symptoms by referring specifically to how they interfered with their abilities to *function* in their daily lives. The ability to *function* was identified as an important outcome of mental health recovery. Several women talked about difficulties with roles and relationships, such as attending school, meeting employment responsibilities, parenting children, and interacting with friends.

Successful job performance was especially distressing for women and was tied closely with their self-esteem. One participant expressed her concerns with starting a job due to symptoms that interfered with successful employment:

I'm almost afraid to get started right now because I have, still have problems with my sleep, and depression, forgetfulness, um, not being organized. So, I feel like if I got one I probably wouldn't be able to keep it right now...and I don't know, I don't know what will help really.

Of the symptoms the women identified, cognitive impairments created difficulty for them to understand information necessary to do their jobs, memory problems such as forgetting steps in work procedures, and difficulty focusing and concentrating. One participant described difficulty understanding information necessary to perform her job, precipitating an exacerbation of symptoms requiring long-term treatment. Her fear of this happening again acted as a barrier to her participation in current and future employment and school opportunities.

But most of the time it was really confusing for me and hectic because all the codes and all that stuff that I didn't understand. Then when I understood it, I'd end up going into a crisis with my mental disability and freakin' ended up havin' to lose my job cuz I went into crisis housing for too long...they ended up firing me, which is one reason...it keeps me from gettin' a job. Now it keeps me from goin' to school now too because I'm afraid of my mental illness gettin' in the way...

Difficulties in thinking also adversely affected women's abilities to parent their children. One participant recalled how her difficulties thinking and resulting feelings of being overwhelmed interfered with her abilities to connect socially with her daughters.

I think the most frustrating for me was the muddled thinkin', you know, feelin' like I was in a fog...that really increased my anxiety. I don't have a lotta confidence anyway, so when I'm in that space, it's really difficult for me to interact with people...I had young girls at home, and it was really hard to be fully present for them.

Similar to feeling like being in a fog, another woman described her experience of feeling like she was not fully present in the moment, and less able to pursue her daily life activities and communicate with others.

I don't even know how I was getting by. I was not even hardly functioning and it was an awful way to exist, I wouldn't wish that on anybody, it's like you're a walking zombie. I wasn't even awake, it's like just numb not functioning very well and very hard to communicate...you're just, you check out, in a roundabout way...and my memory for a while, it wasn't very good... it's had a rippled effect throughout my whole life it affects relationships with a significant other or dating.

Women also talked about shutting down related to pervasive feelings of anxiety. One participant used the term "shut down" to describe a 3-year period she referred to as "lost years" when she was afraid to do anything.

'Cause when you shut down you're done, you know, I mean you just sit in a funk. My kids would leave and I'd shut down and sat there for 3 years for the most part unless they came back again...I was just sad all the time. I was scared, scared to leave my house. Scared to try life...those years are really jumbled for me. I don't remember hardly any of it from age 34 to age 37, it's like those 3 years were really bad...like lost years.

This participant went on to describe how shutting down also included not eating, and spending extended periods of time just sitting on the couch.

I was ready to leave. I wasn't going to actively kill myself...but when I decided to die, I just stopped eating. I think I was on the couch for a week before my

daughter started freaking out, I might have been there close to another week before my husband finally noticed.

Giving up. The theme *Giving Up* describes women's experiences of hopelessness, worthlessness, repeated failures, and powerlessness. At the time of interviews, only two of the seventeen women interviewed reported current feelings of hopelessness; however, the majority of the women reported that hopelessness was their most difficult symptom of depression. Women lost hope related to the slow improvement of their symptoms. One participant said:

Okay, you don't, you feel this totally lost, you feel like, you know, there's just a long tunnel and you can't see any light at it and that is one terrible feeling. You feel like that, you know, your depression is never gonna away and you're gonna be like that for the rest of your life. And I think that's one reason why people kill themselves when they're depressed, because you look at it, sometimes you really feel that way, you know...

As participants reflected on their prolonged experience of symptoms, they wondered if anything would ever help them feel better. One woman described:

...I just felt hopeless about everything, you know. Like I don't know how I'm gonna get outta this. Every—I mean, I just go through, and you do all the same things, and I don't feel any better.

As women lived with depression and associated impairments in functioning, their feelings of hopelessness were exacerbated by their repeated lack of success in accomplishing life goals. Participants often described feeling like they were worthless and useless, perceived themselves as failures, and felt powerless. One participant said:

I don't know if I'm ever gonna stop being depressed anymore. And I'm alone, lonely, I don't really want to date after everything I've been through. I'm pretty much just stuck here in the house again...I don't really want to do anything...go anywhere...not really interested in anything. I haven't got a job. I'm broke. I just feel like I can't do anything anymore... I just feel like burnin' and I just feel stupid and worthless all the time.

After experiencing many failed attempts to accomplish life goals and feel better, the women started to *give up trying* to improve their mental health and life circumstances.

One participant described:

...every time I tried anything it never worked out for me. I feel hopeless...what's the use of going on if every time I put any effort certain things, they don't work... I would try really, really hard, and I would fail at most everything I did. So for a long time I wouldn't try anything new because I was so afraid of failing...I don't want to keep failing.

Although all sample members described feelings of low self-esteem, one participant went so far as to talk about her just taking up space and being lost in time:

I feel like I wasted my life...I've been a detriment to my own self and a failure to my family, my kids, and society...I'm just here taking up space. No common goals, nothing achieved, just lost. Lost in time. I don't know where to go. Don't know what to do. I don't have no drive or ambition or motivation. I'm struggling to find my place in the world.

Several women talked about giving up as having pervasive thoughts of suicide and wanting to die during the course of their illnesses. At the time of interviews, only one participant spoke about passive thoughts of dying as she reflected on her past, including her extensive history of abuse beginning in early childhood. Now at the age of 68, she was struggling to find meaning in her life.

I know it sounds stupid and selfish, but I really wish I was dead; I wouldn't have to put up with nothing anymore. I mean, I know I have two children, and they would be devastated at first, but they'd get along without me...I don't see what's so great about living. I don't know why I'm even here...I really don't want to be here on Earth.

Isolation, Not Fitting In, and Social Stigma

Participants' experiences of social adversity in their adult lives are described here in the theme *Isolation, Not Fitting In, and Social Stigma*. Participants identified social isolation as the most difficult aspect of living with depression.

Self-imposed Isolation. Feeling isolated was related to symptom experience, feelings of not fitting in, and experiences of social stigma. It is interesting that even though feelings of isolation and being alone were especially distressing for the participants, one of the symptoms commonly experienced with depression was their own self-imposed isolation. Although she now realizes the importance of not isolating herself, one participant recalled:

...for a while there, I would get so depressed I would end up just staying in my room for days and days and days, you know, I didn't want to talk to nobody, I didn't want nobody around me.

Another participant described how her past history of abuse and feelings of anxiety further contributed to her sense of isolation. She described how her fear and perceived need to stay vigilant about watching the door of her apartment to ensure her safety kept her awake all night. She then needed to sleep during the day, when she would have otherwise been interacting with others.

I had a lot of traumatic experiences...I don't know which one makes me scared to go to sleep or have to watch the door all night, or turn my TV off so I can listen...It's just terrible. I would be up and lonely and lookin' out the window and it's dark... it's a normal thing for me to be up at night, on the lookout but...normal people go to sleep at night, so I hafta' deal with night people and they're usually not good...I just recently started gettin' on the internet a lot lately cuz that was my only way to socialize at 2:00 and 3:00 in the mornin'...It's, it's very depressing because in the daytime when I need to get up and take care of business, I can't sleep—I can't do anything but go to sleep.

Not fitting in. Feelings of isolation were also related to women's perceptions of *Not Fitting In* and experiences of *Social Stigma*. Women often referred to themselves as being "different" from individuals without depression. They said that they knew something was wrong, different, or not normal about them, but they did not always have

the words to describe how they were feeling. Some participants often reported not really knowing what was wrong until diagnosed by a physician. One woman said:

...I think the hardest symptom was the isolation, and feeling like I didn't fit in. I knew there was somethin' not right with me and, it wasn't actually until after my hospitalization...I was actually diagnosed by a doctor who could see that I didn't have very good coping mechanisms.

Participants often stayed away from others due to their fear of being judged or rejected, making it even more difficult to gain social support. One participant also identified how her fear of rejection increased the likelihood of becoming involved with “bad people”—people using drugs or committing crimes—or spending time in areas of the city where she was more apt to be a victim of violence or other crimes.

...I have problems making friends... 'cause I'm afraid of, being turned away or judgment because I'm a little different...I usually get friends that aren't very positive...I don't have good judgment on good and bad people sometimes...I stay to myself...

Women also identified not fitting in due to their perceived lack of social and self-care skills. Many participants felt that their early life experiences, such as parental abuse and neglect, or separation from their parents and families due to extended stays in long-term treatment and crisis housing facilities, had not adequately prepared them to live successfully in society. One participant said:

...they have different social skills in the hospital, and they don't fit with the real world. And I had to outgrow that.

Another participant described the opportunity she missed to learn how to make it in the world due to spending so much of her life in hospitals:

I've been in so many hospitals and different institutions I never had a chance to learn all that. I think a lot of people that are 48 years old like I am they, they make it in the world because they...learn how to through their years.

Women also described feelings of not fitting in due to their past life experiences, including failures. One participant described her fear of not living up to other people's expectations. Although she felt positive when involved in activities with others, once she got home, she became increasingly anxious and dwelled on negative comments from her past. Her self-critical thoughts had triggered relapses of her drug use in the past, and she feared it would happen again. Therefore, she tended to not participate in activities with others that would help to improve her mental health and self-esteem. Despite improving in this area, she still found social involvement with others a struggle.

It's like a success thing...if I'm here and they start to want me to be involved... they see a lot in me and I don't know why...they ask me to volunteer... and it feels good, but then I get home...those old voices come back... You can't do it...you'll never amount to anything...you're stupid... I get scared, like they're startin' to expect things from me...they're gonna get tired of me not makin' the mark. A lot of times I relapse is because I'm scared that I'll go backwards, so I'll distance myself...even though they're not treatin' me like that, I'll be feelin' like that. It keeps me from askin' for help...

Social stigma. Almost all the women interviewed discussed experiences of stigma, which contributed further to feelings of isolation and not fitting in. Women described experiencing difficulties with Credibility, Competency and Self-Determination, and Being Labeled.

Credibility. Participants had difficulty with credibility and were often not believed when trying to provide for their safety or when reporting abuse or unsafe situations. Participants often described feeling they did not have a voice when speaking on their own behalf. One participant reported feeling vulnerable and not having a voice due to her mental illness.

So, like you don't have a voice if you have mental health problems, no voice. If anything happens you're just crazy...people don't take you seriously...people can steal from ya and you're just crazy...take advantage of you, and then they can just say that you're crazy. Like somebody stole my identity, I still haven't worked that out.

Another participant, although currently living in a safe housing situation, described an incident that had occurred where she lived previously. The police had come to the apartment building to deal with a situation involving other residents. Although she was not involved in the reason for the police visiting, she still experienced stigma about her mental illness from the police officers.

So the police came, well I didn't even know they were coming...they went upstairs to talk to the guy, and I don't know what the guy told him, but the cop came back downstairs and asked me was I takin' my medication...I'm thinking why would you even ask me that, you know...I don't always do well with police officers when they talk to me like that. So I say, yes I am, are you taking yours... But there was no reason for that, I mean he didn't, you know, I'm not the one that called him for one thing...

Competency. A number of participants made specific references to stereotypes about individuals with depression, describing times when their intelligence and competency were questioned. They often began with the phrase, "Just because you have a mental illness doesn't mean you're...stupid...incompetent...etc." One participant described her experience of being stereotyped as "stupid":

... you know, there's nothing wrong with my intelligence...sometimes people think if you have a mental illness, that you're a stupid person, and most of the time it doesn't mean that...I had a GED when I was you know like 14, 15 years old... so I don't think I'm really stupid, I just don't have the skills I think, um, that a person normally would have at my age to live in the, the, the, um, outside environment.

Participants also described times when their legal competency to make their own decisions was questioned, which resulted in decreased feelings of self-determination,

autonomy, and control over their lives. At the time of the interviews, one participant was in the process of switching her psychotropic medications due to side effects, and was having an exacerbation of symptoms. She talked about her fears of being more vulnerable to losing her sense of autonomy and control over her life.

...recently I felt a little uneasy about my landlord because he's, talkin' like he wants to control my life...sayin' oh, I think I know what's best for you and I wanta help you make the right decisions...you need to be in more of a controlled situation like assisted living... that kinda scares me that somebody will take over my life, and start makin' my decisions...And because I live there, he might be able to do it. Plus I was in a mental hospital a year ago, if he's in cahoots with my grandmother he might try to declare that I'm incompetent. And I'm thinkin', no, I wanta make my own decisions. I'm 39 frickin' years old, I'm not a kid.

At the time of the first interview, this participant had started to question her competency. When asked about this, she stated, "Now I don't feel incompetent, no." By the time of the second interview, she was much more confident in her ability to care for herself and be responsible for her own life. She talked about her plan to ask someone to help prevent her autonomy and self-determination from being taken away.

I'm wantin' to talk to somebody and ask them, well can, is there any way that somebody could try to get power of attorney over me and, you know, wanta figure out what I can do to protect myself if that does happen, you know.

Questions about competency were also described related to the women's access to and choices about spending their money. One participant described concerns about receiving care from an agency she believed would take control of her money. This lack of trust could interfere with her future help-seeking behaviors and relationships with healthcare providers.

... they like take away your rights to do certain things after you let them know where you're at...they like take people's money from 'em and they take over your life... if you ask for help, we're gonna force the help, not just let you volunteer for us to help you, but if we feel that you're not capable of doin' certain things, we're gonna force it...so, I try not to, ya know, rock the boat too much.

Another participant described how having decreased access to and choices about her money contributed to feelings of being controlled just on the basis of her having a mental health diagnosis. Although her statement indicated her lack of understanding of the approval and distribution process for Social Security funds, the overall intent of her statement is interpreted here as meaning that it is wrong to control a person's money based on stereotypes about people with mental illness.

Just because you had a mental disorder does not mean that you cannot control your money...I think I'm being controlled...you are being controlled because they're only gonna give you so much money at a time...as far as I'm concerned, as long as all your bills are met, and your place is paid for, and you got plenty of food and all that, what does it matter how you spend the rest of it. I think that's kind of a, a stereotype...I think, Social Security is wrong for diagnosing people like that, I don't think they should be able to do that. But they do and I don't like that.

Being labeled. Participants also experienced social stigma from family members and other entities such as churches, which would otherwise be sources of strength and social support. One participant said:

My Dad does not understand mental illness. He thinks people that do mentally ill things, they have a choice about it you know but...people that have mental illness a lot of times do not choose the behaviors, sometimes they do, but most of the time not. I don't know of anybody that's gonna choose to hear voices.

Another participant described her experience of being stigmatized by members in her church group related to her diagnosis of bipolar disorder.

...the Elder's wife was goin' on about...her brother-in-law was bipolar...last time we even had a bipolar woman in here...and she hoped she never had to deal with someone like that again...the next week...they started in on about it again...and I'm ticked...I said, I think you all should know something, I'm bipolar. And they all stopped connecting with me as a person.

She then recounted her experience of being labeled and her feelings of shame and self-hatred.

...Because once again you do get labeled...somethin' is wrong with you, the world makes you feel like that something being wrong isn't different, so much as wrong... We shouldn't have to put up with people like you. I'm such a dirty wrong person...it's very self-loathing, yeah. I should stay hidden from the world, keep that front up. You feel very dirty. I, at least I do...

The women also described experiences with social stigma at their places of employment and schools, with many reporting lost opportunities as a result. One participant described how she was stigmatized by her employer after being hospitalized for a suicide attempt, and ended up losing her job.

But I could tell that there was writing on the wall as soon as that hospitalization where I took the aspirins, I knew I wasn't gonna be there long after that. I was one of their best guards...I'd heard that over and over...they acted like they were upholding me...but then they started really...my boss...he wrote me up one day...I'm very good, but sometimes you forget that step, and that step's important.

Managing Symptoms and Experiences with Healthcare

All participants had received mental healthcare services of some kind, including hospitalizations, medications, community mental healthcare providers, and counseling.

Access to care: Hospitalizations. Most of the participants perceived experiences receiving inpatient mental health treatment in hospitals as positive. One participant, who was not experiencing symptoms at the time of interviews, positively recalled the time she was receiving treatment in the hospital; however, she felt her length of stay was not long enough:

...it was the first time I had any hope that I could change my life. But the problem is it was a 3-week thing and then they throw you back out.

Another participant, who had experienced years of parental abuse, especially from her mother, felt a sense of safety in the hospital.

I felt like I had a bunch of moms up there so it felt safer...30 years ago, 25 years ago...I was always the youngest one on the unit. And there were nurses that were just really nice to me 'cause I had no visitors, you know, and, um, they would just do somethin' nice with me. Like I can, I remember all their names, I'm serious, I, you know, and I can't even remember who, like who I went to high school with, you know, (laughter), but I can remember every single nurse's name.

She went on to describe the gratitude she felt for the nurses who had taken care of her:

...the one sad thing is that, you know, I, I just wasn't able to go back and say, thank you, you know. Which, when I was, the, when I was goin' through the hardest time, you know and they saw me when things were so bad, but then they didn't see me when I started doin' better, you know. And I would've liked to thank a lot of them.

Medications use and adherence. All of the women interviewed had taken medications at some point during the course of their illnesses. At the time of interviews, two of the participants had been able to work with their prescribing healthcare providers to taper off their medications and still manage their symptoms. Both felt positive about their experience and said they would restart medications if needed. One participant reflected:

...the depression or feeling sad...I was used to as being normal...it was like I'd been in this dark, dark house, and every day...probably two weeks after I started takin' the medication...it was like every day when I woke up, somebody lifted up one shade...my ability I think to learn, um, was really heightened...It was just incredible to me.

The majority of the women described varying degrees of success with medications, as well as challenges they encountered finding medications with the greatest therapeutic benefits and fewest unwanted side effects. This process was time intensive and required rapport in the physician-patient relationship. A number of women discussed

difficulties finding healthcare providers who listened and responded to their concerns about medications. Participants often found it difficult to advocate for themselves during appointments, when their appointments were moved to a later date so someone else could see the physician sooner, or when trying to reschedule their next appointment at an earlier date due to medication concerns that had arisen.

Participants were able to recall medications they were prescribed over time, the symptoms they helped, and the side effects experienced. Many women needed a number of trials to find effective medications. One participant stated:

And I went on and off different mood stabilizers, and different medicines, but nothin' really worked that well. Um, I would take medicine for a month and then I would go off of it because of some kind of side effect. And then I'd take somethin' for another month and then I'd go off of it because some kind of side effect. And then it was just back and forth.

The women often reported side effects associated with medications. Medications to alleviate anxiety and improve sleep were often over-sedating and interfered with role functioning. One participant described taking medications that were effective in alleviating her feelings of severe anxiety; however, her resulting apathy or total lack of concern about anything made it difficult to meet routine expectations in her life.

Yeah, like showin' up to a place on time and, and being a little bit nervous about normal things which you should be, in order to be successful.

Participants also described receiving medications that had side effects but were only partially effective in eliminating their symptoms. One participant described how limited effectiveness and unwanted side effects decreased her motivation to adhere to her prescribed medication regimen.

The medication always throws me off...it does just the opposite of what I need it to do...it makes me feel like I'm drugged up all the time...lethargic. I can sleep but that's about the only thing I notice, but I'm still depressed...I just don't take 'em

sometimes. Like I'll take 'em like three or four days a week...and I hafta' make myself take 'em...so I'm workin' on that. I'm really workin' on that.

Another participant reported that she was unable to care for her infant son due to the over-sedating side effects of her medications. As a result, she ended up having to put her child up for adoption, which she perceived as a major loss. She described feeling that her healthcare providers did not want to deal with her real issues and sabotaged her parenting abilities.

I believe they sabotaged my parenting by, overdosing me with medications. The psychiatrists in the past, many of them just sedated me. They didn't wanna deal with me. They went on my past history, didn't get to the heart of the matter. Just wanted to keep me doped up, zombified. So—I couldn't function.

Relationships and experiences with healthcare providers. Similar to the experiences of the previous participant, a number of women stated that healthcare providers did not listen to them when they expressed concerns about the ineffectiveness of and unpleasant side effects associated with their prescribed medications. In addition to over-sedation, weight gain was also distressing for the women. Concerns with weight gain included physical health ramifications and decreased self-esteem.

One participant discussed her concerns about the limited effectiveness and side effects of her medications. She had also been unable to get prescriptions for medications to alleviate her symptoms of Attention Deficit Hyperactivity Disorder (ADHD) due to her past history of drug use. Although she had tried to talk with her doctor about her concerns, she did not feel heard and had lost her trust in him, both of which she said negatively affected her adherence to her medication regimen.

My doctor doesn't do anything but give me pills that don't work, and I mean, I've been seein' him for over two or three years...And I asked him to not give me

anything that involves weight gain because I weigh 340 pounds and it's like really bad on my knees cuz I have, um, bone-on-bone and osteoarthritis from all the injuries...And he gives me stuff that has weight gain and, and I just don't trust him and his opinions anymore, so a lot of times I won't take the medicine. I really wanna see somebody else, but I don't know what else to do...I've been tryin' to, ah, find some alternatives to what everybody else is usin'. Because it's not workin' for me...like the ADHD, it's hard for me to focus and concentrate and be successful, because my mind is not functionin' right. But because of my past drug use...

In addition to not feeling heard when talking with their prescribing doctors, the women also found it difficult to advocate for themselves during appointments. One participant talked about not being heard by her psychiatrist when telling him she was not doing well, and her difficulty advocating for herself due to her feelings of worthlessness and anticipation that her voice would not be heard.

...the last time he walked in the room and I was having really bad spells of hearing things and depression...I keep begging him for a different depression medication, and he said, how you doing, and I said lousy, and he goes, oh, that's good...like people comment in the street...how's it going, they really don't want you to say, you know, my dog died, I lost my job, they don't want to hear all that, they just want you to comment, hey, yup, I'm doin' good. So, he didn't hear me, and I just think he was repeating a nice, yeah, that's good...my boyfriend, sometimes he's gotta do it for me, 'cause I, I'm afraid my voice won't be heard, I feel kind of worthless sometimes.

Participants also described difficulty advocating for themselves when they needed to see their prescribing mental healthcare provider sooner because of medication concerns. In addition, they often experienced having their scheduled appointments changed to a later date because another patient needed to see the physician sooner. One participant described these challenges:

...I called him Thursday and I didn't get a response back. And I didn't want to bug them on Friday...I should've advocated stronger and said, why didn't you call me back. Sometimes they feel since I'm not severe enough that they'll push me back because I appear that I'm functioning fine...

Almost all participants had insurance coverage for medications at the time of interviews. The one participant without insurance or an income described trying to obtain medications without money or insurance.

I was havin' a problem getting' my medicine and I didn't have any money. Um, then they had all these loopholes, too, where it was hard for you to get your medicine. Like, you had to come in on, you had to come into this group every Thursday which made it difficult, like made it impossible, so you had to come to this group on Thursday in order to get your medicine, in order to see a doctor to get your medicine, but how are you gonna get a job if you have to make it to this group every, I mean who's gonna let you get off of work every, every Thursday at 1 o'clock to go to some stupid group. So I had, so I was stuck goin' in this group in order to get medicine.

The difficulties women described related to medication side effects and not being heard or responded to by prescribing healthcare providers raise important questions regarding healthcare provider neglect.

Other healthcare interventions strategies/approaches. When asked about receiving other mental healthcare treatment, participants identified experiences with therapists, case managers, and peer-support-specialists. Participants identified the importance of having consistent providers they could connect with, coordinated services, and services that improved social support and compliance.

One participant described her experience trying to find a therapist she could work with effectively.

...It's been years, I've been trying to reconnect, had a very good therapist, probably one of the best ones in town for a long while, he was well known and well respected, and then I had a, kind of a cool one, and he and I hit it off, um, but then his agency...and then I just went, bounced from one to another to another to another 'cause there was no connection, and I finally found a connection with this one I'm working with.

Participants found that using a variety of treatment strategies was more effective than using any single approach. One participant described the importance of different members of her healthcare team in meeting her mental health needs.

... My case manager helps me manage my day-to-day activities, like um, getting um, certain services provided for me... getting me certain destinations. The relationship with the therapist is helpful. We are working on self-esteem...

The women also described the importance of providers treating everyone with respect and compassion, listening without judgment, and understanding the patient's perspective on his or her own problems.

...treating everyone with respect and compassion, and listening...people share things or they start talkin', and it's like...You're not makin' any sense...but if I hang in there and I quit listening with judgment...I guarantee it will make sense. If not at the moment, within a period of time...So people tell things sometimes in convoluted ways.

In addition, the women stated the importance of healthcare providers allowing patients to find answers for themselves, rather than making decisions for them.

It's more letting them figure out the answer themselves, 'cause it's inside of them or me, or you. Nobody can give you the answer.

Another participant said:

...you need to trust that the person has the answers and that they know themselves...I think healthcare providers have an obligation to provide facts based on whatever knowledge they have, their expertise. But that ultimately, the individual does know themselves, their body, and their minds much better than we're given credit for.

Coming to Terms: Facing it and Working Through It

The theme *Coming to Terms: Facing it and Working Through It* is used to describe participants' stories of beginning to truly engage in their recovery from mental illness. Although women had sought treatment, including taking medications or going

for counseling, these measures had only limited effectiveness, and the women had problems adhering to treatment. The process of facing it and working through it involves the women gaining awareness and understanding of their need to address their mental health issues, including contributing factors. Participants identified the importance of being honest with themselves, taking responsibility for and not running away from issues, and being willing to make changes to improve their mental health status.

One participant discussed the importance of individuals facing their mental health issues sooner to improve outcomes and prevent further complications:

...lettin' go of the pride, which, which can be hard, you know, 'cause I mean nobody wants, I mean I didn't want to have mental health issues like my grandfather or my family but I do and I did, and...if you don't deal with it, it doesn't get any better. If you don't face it, it only gets worse...and it spirals down.

Participants also stressed being honest with themselves, not running away from issues, and not giving up on improving their mental health. One participant explained her perception of what being honest with herself meant.

...idea of rigorous honesty meaning I'm honestly freaking out of my mind right now...that's what helped me get better is being honest about how unwell I was...okay we're just gonna do this head on...what was the alternative? Run away? I'm tired of runnin.' If it's here it must be somethin' I need to work on...let's learn from this...it was a real struggle...I've developed a huge amount of resilience in not giving up.

Another participant said the most important aspect of recovering from mental illness is having the will to want to change:

...the most important thing is you have to have the will to want to change. I tell uh people, it's like going to college and taking a class. And you have to wanna change. People always think it's the other person, right?

The women told about learning about themselves and their depression, and developing problem-solving and positive coping strategies. They sometimes became

willing to face and work through their mental health issues when their recovery was perceived as having an impact on their roles and relationships, and was often associated with parenting. One participant described the importance of becoming a parent and wanting something different for herself and her son:

...my recovery started though really, um, you know, from being a parent. From wanting something different...I didn't do it great at first...but that connection ...just forming that trust bond was a big turning point...it was also a turning point for my eating disorder, when my infant son wanted to feed me a Cheerio...I was like, "Well let's see, is being rigid and this more important than my little two year old?"

Gaining insight. Participants also gained an awareness of stressors that exacerbated their illnesses and made recovery more difficult. One participant described how her lack of employment increased her feelings of depression and her involvement in activities and associations with people who affected her negatively. Gaining employment increased her self-esteem and productive use of time.

I stopped working...it made me feel better about myself. I slumped back into depression again...they say free time is the Devil's workshop. Idle mind. When I had open time, um, I got into not good things. Just hanging, ah, hanging in areas that wasn't good.

One participant provided insights about the impact of assuming too much responsibility for taking care of her grandchildren. She identified the importance of making herself a priority, taking back power over her life, and setting healthy limits with her children.

I've done better when I got strong again and decided to take power over my life back...then if I get messed with too much...I start doin' that slippery slope again...I can't handle a lot of stress...So I just don't allow it anymore...Feeling a sense of responsibility for everybody...I guess what the bottom line was finally that I had to start caring about me more than anybody else, I never got that before 'cause I always thought that's just new generation and selfishness, you do care for your family, their needs must come first, children have to come first. But if you have

no power, then you better put yourself first because they will eat you alive. I've learned that.

The impact of social stressors is further illustrated by the women's emphasis on the importance of social support and being surrounded by positive people. One participant said:

I've managed to heal myself sometimes, when the social surroundings are good, and I think that when you're surrounded by people attacking you all the time, you get sicker easier, and much more. I have absolutely no way to fight it when the people around me don't help me, don't shore me up...but when they do, when I'm surrounded by healthy people, you'd be surprised what I can blow off, I actually get better from...since I started coming here...I've been getting strong here.

Participants also described gaining insight about their responses to situations they had previously found very upsetting. One participant described how she reframed her desperate need for everyone to like and accept her.

...I always thought it was against the law for somebody not to like me, you know, that's the way I would react to it, oh, my God that's terrible, so I try to tell myself, if this happens to you, it probably happens to everybody. Everybody's got those feelings...you're not gonna die if somebody doesn't like you...you're not gonna die if somebody gets angry with you.

This participant also had difficulty with assertiveness because did not think she was smart enough to take on any responsibility.

...I wasn't assertive. I didn't take on any, um—I didn't think I was smart enough to take on any kind of responsibility, um, cause I just have a—I shouldn't say just. I have a high school education and I believe recovery has educated me immensely in every facet of life. Now I can get up and speak before a group.

Another participant discussed realizing she didn't need to be perfect and the importance of liking herself:

Realizing that I didn't have to be perfect. That...liking myself was more important than liking other people.

The women also identified the importance of forgiving themselves and others as a part of recovering from depression and moving on with their lives:

...that was a life-changing moment for me...I mean I don't know how long I've got left here, I want to forgive the people and hopefully they can forgive me and, and move on with what I'm supposed to do with while I'm here. 'Cause if I have those blocks in me, I can't really totally fully give...

Self-acceptance. In addition to gaining insight, the women spoke often about the importance of accepting themselves in their recovery. This included accepting that they had a mental illness and needed to take medication. One participant described how acceptance improved her adherence to taking prescribed medications:

...I was constantly in denial...I felt I would get better naturally. Sometimes I didn't care at all if I got better or not. To me, I didn't have a problem. But I've learned to accept that it's goin' to be with me until the rest of my days on this Earth and I could either roll with the punches and do what it is I need to do to combat the illness or resist it and struggle with it. And I don't wanna struggle with it any more.

Participants said acceptance was part of developing positive coping skills for distressing emotions and thoughts that might continue throughout their lives. One participant reflected:

...I've come to accept that it doesn't mean that anxiety isn't ever gonna show up again...that's unrealistic to think about. Anxiety will still show up but I can handle it—it won't last forever...my skills are much better...I'm not afraid of the anxiety anymore either. I used to...it would last for months...Now it may last an evening or a day, not even that.

Participants also discussed accepting things they might not be able to change as easily, such as stigma in society. One participant explained:

...there's still that stigma...and the medication can't help with that. It can but I'm gonna have to go through that being uncomfortable and feeling a little depressed about it and learning to accept it, and sharing it with people because that's who I am.

Another participant talked about accepting her mental illness and seeing both the negative and positive aspects of her life. This participant was able to qualify for housing in part because of her mental illness and difficulties with addiction after being homeless for years. She perceived having a safe place to live as the most important aspect of her recovery from mental illness.

...I don't like having it, but, um, you know I've come to the other side I feel, so it's treatable and it's, it's gotten me here, you know, and I, it's gotten me where, I wouldn't have this place if I hadn't had a mental illness or an addiction problem...

Becoming a Resource Person: Connecting, Learning, and Giving Back

Social support and belonging. When women were asked about what was most helpful in their recovery, they identified being involved with mental health recovery-focused programs and organizations. The importance of social support and having a sense of belonging without being stigmatized was consistently important in the women's recovery process. One participant said,

...and you know you're accepted, and then generally that's what people need. I lost that somewhere along the way. I didn't know who I was, where I belonged anymore. This place gives that back. 'Cause when I come in here, none of these people go...get out, or you're bipolar, or you're stupid...They go, hey, how can we help you today if they see I'm havin' a hard time.

Another participant explained:

... Just bein' around other people with mental health problems and without bein' judged or feelin' like you're an outcast, 'cause that's kinda how I felt around a lot of people, you know, because there's so much stigma against people with mental health problems.

Role models for recovery. Participants also found it helpful to have role models for successful recovery. Spending time and talking with other individuals who were also recovering from depression helped increase the women's

motivation to more fully engage in their recovery, and instilled hope for improving their lives. One participant described

...people who have been doin' good with their mental illness for years...they just hang in there, you know...you get to listen to other people that have gone through this and...Maybe they have somethin' that'll help you. And maybe you have somethin' that'll help them.

Another participant said:

...so just havin' these role models, ya know, makes me wanna try. No matter how many times I fall, you know—just havin' positive people that I know are strugglin' too...I'm trying. Just taking it one step at a time, one day at a time. That's all I can do...

Improving themselves and learning. Participants often felt that attending classes and support groups was helpful in learning about coping, social, and recovery skills in a setting where they felt connected with others.

...I've been a hermit and a recluse for over 20-something years. Been isolatin' due to my depression. I fell into a funk and a tizzy for so long. I'm tryin' to improve myself. Trying to develop my social skills again...and connect with people...I feel better... people are embracin' me here. I like it. I feel comfortable here. I've came for the past three days straight.

In addition, going to classes and groups added structure to their daily routine:

They have all kinds of classes, yeah...I went to a nutrition class...I go to the art class...I go sometimes to the recovery groups and sometimes to the transformations groups...I think it helps...makes me get up and do things in the morning at a regular time every day, and that's real important for me to have a real steady wake and sleep cycle.

Instilling hope and building on past successes. Participants also emphasized the importance of not giving up, building on their past successes, and participating in new opportunities for success to promoting self-esteem and a sense of accomplishment.

Although participants identified feelings of wanting to give up as one of their most difficult challenges, they specifically referred to the importance of not giving up as part

of recovery. One participant talked about how her experiences doing things she never thought she could help increase her feelings of self-efficacy and set higher standards for what she could achieve:

...I read a lot and I like to watch the Discovery Channel. I like lookin' at foreign countries and I always dream about...goin' to different places and helpin' women and men that's been hurt. I just can't give up completely—even though I fall, I just can't stay there. It's like I'm never satisfied. I was clean for five years and, that was my first time ever had a job in my life. And I just was like, "Dang, I never thought I could it," and a lotta things that I never thought I could do, I did, and so now I have this, standard that I know I can go to...

Participants also told stories of their lives turning out differently than they had originally planned. One woman talked about how she had fallen short of her own and her family and friends hopes and expectations.

...I'm getting' older. I haven't accomplished anything. I sit back and watch how all of my friends are successful in life and everyone was banking on me...I was supposed to have been someone great. I had star potential...And my family felt that way, society, my friends, and even people here have felt that way about me, that I have a lot of potential; that I was supposed to be someone great.

She then described how she was beginning to see new possibilities for her future.

...it's not the end for me...they see I could overcome this and be someone of outstandingness, and that's what I want for myself. I don't know how to go about it, but I'll figure it out. And being here's a step...being around people, trying to improve on myself by goin' to groups or goin' to church, or lookin' up articles on the Internet about self-improvement. You know, I'm headed in the right direction. Just taking it one step at a time, one day at a time. That's all I can do.

Giving back and helping others. Several women who were involved in recovery-focused programs and organizations either had already participated, or were in the process of being able to participate, in community education initiatives related to mental illness. This involved individuals telling their stories about living with mental illness with a small group of their peers in schools and in community agencies and organizations. This created opportunities for success, feelings of increased competency,

and improved self-esteem because the women were able to contribute their expertise to help improve mental healthcare and societal attitudes and stigma related to individuals with depression.

One participant described how she realized how she could contribute by talking with people and how this increased her sense of self-confidence.

I just didn't feel when I went on disability that I can contribute to life anymore and she said, you know, you contribute by saying Hi, and, um, you know, asking people how they're doing or having a conversation with 'em or sharing with 'em and, um, so I started out small, like just that kinda thing and, and as my confidence grew, um, I've done a lot more.

Another participant, who at the time of interviews struggled with agoraphobia, described her ability to go out in public and tell her story:

But that's odd, because, well, you know, as a I said, I've done ___ group, when I'm in _____ I'm a completely different person. You know? It's like sometimes you hear about actors, you know, they're, you think, oh, wow, they'd be whatever, and then you find out that they're just horribly introverted, and it's like, when I'm on stage or, or you know up in front of a class, you know, I have no problems.

Another participant talked about sharing her journey of recovery and helping others with depression to not give up and be hopeful.

...I am trying to help them and let 'em know that, ah, you know sharing part of my journey, what I, where I've been and that, you know, help is available and that don't give up, you know, tryin' to give 'em some hope. I mean, 'cause sometimes ...it's like they're at rock bottom, I mean they're homeless, they have nothing...the only place to go is up. And it's a scary place to be, you know.

Summary of Major Findings

The symptoms of depression participants experienced were functional impairments, interference with roles and relationships, and feelings of hopelessness, worthlessness, powerlessness, and low self-esteem. Efforts at symptom management included psychotropic medications, inpatient hospitalizations, and outpatient counseling.

However, the women often experienced difficulties advocating for themselves and felt that their concerns were not heard or responded to by healthcare providers. The most helpful mental healthcare interventions received included case management, services from peer support specialists, and home visits from consistent community mental healthcare providers, as well as being able to share decision-making and find the answers to their own problems.

Participants identified the impact of increased social risk factors and fewer protective factors on their experiences of living with depression. Feelings of isolation, perceptions of not fitting into society, and experiences of social stigma were identified as being the most difficult. The women often perceived that their social support systems were inadequate or nonexistent, and that they lacked autonomy, self-determination, access to opportunities and resources, self-esteem, and control over their lives. They also described feeling ill-prepared to live successfully in society due to their lack of self-care and social skills.

Participants said their experiences of recovering from or learning to live with depression required them to recognize and acknowledge their mental health problems, learn about themselves, and do what was needed to help improve their mental health status. As the women gained increased insight about and acceptance of themselves, they became more adherent with medications and treatments, were better able to change their perspectives of themselves and their lives, and challenged distorted thought patterns.

Participants overwhelmingly identified their involvement with peer-run mental health recovery organizations as having the most positive impact on their recovery by

improving their perceived social support networks and opportunities to interact with positive role models for mental health recovery. In addition, the women were better able to identify their strengths, learn positive self-management and coping skills, increase their hopes of living better lives, and become resource people about mental health recovery for their peers and the community.

CHAPTER V

DISCUSSION

The purpose of this study was to explore the perspectives of women living with depression in the context of their daily lives. Information was also gathered on how they experienced depressive symptoms, social adversity, and how they approached recovery within the context of their daily lives. Using a qualitative, in-depth interview approach, data were collected from women who self-identified as having experienced depression at some point in their lifetimes, who lived in a Midwestern state, and received mental healthcare services from a psychologist (2 participants), or were involved with peer-run mental health recovery-focused organizations (15 participants). Discussion of the findings are organized and presented around the research aims.

Research Aim 1: Explore the perspectives of women living with depression, including their experiences of symptoms and sequelae.

The majority of the women in this study had been living with some type of mental illness, including but not limited to depression, for more than 20 years. They spoke of their experiences living with different types of symptoms, some of which were debilitating. Throughout the course of the women's illnesses, symptoms changed in type, severity, duration, and impact on their daily lives. The vast majority of women interviewed reported that their symptoms began in childhood and adolescence, or shortly after reaching age 18. They described knowing that something was wrong, different, or not normal about them, but they did not always have the words or language to describe how they were feeling. Several participants described not really knowing that they were

experiencing depression until they were diagnosed by a healthcare provider, or had learned more about themselves and their symptoms over the course of their illness.

These findings are consistent with existing qualitative literature including Karp's (1992) *inchoate feelings of distress*, or times when depressed women noticed something was different about themselves but did not have the vocabulary to name their experiences; Schreiber's (1996) *myself before*, or a time when depressed women lacked an understanding of themselves in their worlds; and McKay's (2010) *not knowing* or not understanding their experience.

Of the symptoms experienced, hopelessness was identified as the most difficult. Consistent with existing literature, participants described feeling hopeless about ever feeling better or improving their lives (Mancini et al., 2005). Participants also reported a history of repeated failures in accomplishing life goals, and feelings of worthlessness, powerlessness, and low self-esteem. As described in the theme, *Giving Up*, participants described how they had stopped taking risks involved with learning new skills, trying new situations, initiating and maintaining social relationships, and pursuing employment or education opportunities. At the time of interviews, all participants continued to struggle with their self-worth.

In addition to feelings of hopelessness, participants described experiencing self-imposed isolation, impaired thinking and memory, and difficulties communicating with others. The most distressing symptoms described by women were the associated impairments in functioning that interfered with roles and relationships, such as parenting and initiating and maintaining successful employment and interpersonal relationships. The importance women placed on the negative impact of symptoms on roles and

relationships is consistent with previous qualitative literature related to women's experiences of depression (Karp, 1994; Schreiber, 1996; Ritsher et al., 1997; Owen et al., 1998; Repper et al., 1998; Ridge & Ziebland, 2006; LaFrance & Stoppard, 2006; McKay, 2010).

Symptom management: Experiences with healthcare. One aspect of participants' recovery from depression included contact with healthcare resources for symptom management: use of psychotropic medications, inpatient hospitalizations, outpatient counseling, and community-based treatment such as home visits, case management, and peer-support specialists. Although all but one participant found medications at least somewhat helpful, the process of finding the most helpful medications was often time-consuming, and required several trials of medications before finding the right balance of effectiveness and minimal side effects.

This process was made even more difficult due to participants' perceptions that their healthcare providers did not listen or respond to their concerns about medications. Many also had difficulties advocating for themselves during appointments and when resolving appointment scheduling difficulties. Limited medication effectiveness and unpleasant side effects and the lack of shared decision-making in the doctor-patient relationship interfered with participants' adherence to medications and treatments. This raises a concern about healthcare provider neglect in prescribing psychotropic medications, as some of the participants continued to live with distressing symptoms and side effects despite attempts to ask their doctors to make needed changes.

Participants' perceptions of not being heard or acknowledged by their physicians are supported by Tillaart, Kurtz, and Cash (2009), who found that women with a mental

health diagnosis felt their stories were discounted or not taken seriously by healthcare providers. Mancini et al. (2005) offer further support of the negative impact of these findings, identifying the presence of side effects that interfered with emotional, cognitive, and physical function, and physicians' paternalism, or not allowing individuals to make decisions for themselves, as barriers to adherence and recovery.

The women identified receiving services from case managers, peer-support specialists, and consistent community mental healthcare providers as most beneficial, and associated these services with increased shared decision-making and goal setting, social support, access to resources including transportation, and adherence with prescribed medications and therapies. Although women felt positive about the inclusion of case management as part of their receiving community-based mental health services, the majority of women did not have a case manager. Decisions about the frequency and comprehensiveness of services, including the assignment of a case manager, were based on the agency's assessment each woman's needs.

Research Aim 2: Explore the perspectives of the women living with depression, including their cumulative exposure to social adversity.

Isolation, not fitting in, and social stigma. Participants identified the importance of the social aspects of their of their life contexts, and talked at length about how their experiences of increased social adversity throughout their lives contributed to the onset, continuation, exacerbation, duration, and recurrence of their symptoms (Groh, 2007; Brown et al., 2010). The social stressors they experienced included childrearing, marital difficulties and divorce, illness or death of and conflicts with family members, employment stress and job loss, and exposure to violence and unsafe living situations.

The majority of participants experienced social adversity beginning in childhood and adolescence, including parental abuse and neglect, and difficulties with school and peer relationships. They described feeling that they were unloved, unaccepted, and unsafe in their homes, and felt powerless to change their circumstances. Similar to the findings of Erdner, Magnusson, and Nystrom (2005), participants emphasized the importance of having a safe place to live and being accepted by others.

The most difficult social aspects of living with depression the women identified were feelings of isolation, perceptions of not fitting into society, and experiences of social stigma. The majority participants lived alone which added further to their feelings of isolation. Social interaction and participation in opportunities that would otherwise improve their social connections with people were made more difficult due to their lack of skills and fears that they would be judged and rejected by others. Current literature supports experiences of isolation and social stigma, and avoidance of others due to fears of rejection, low self-esteem, and perceived lack of social skills in individuals suffering with mental illness (Linz & Strum, 2013; Erdner, et al., 2005).

Unsuccessful employment experiences were identified as especially distressing, and contributed further to negative self-perceptions, experiences of repeated failures in accomplishing life goals, and feelings of hopelessness and powerlessness. Participants who had been employed prior to or at the time of interviews described how their illnesses had disrupted their occupational experiences. Current literature on women living with depression supports disruption of occupational experiences (McKay (2010), and themes of *loss* of personal relationships, jobs, and opportunities for meaningful activities identified by Karp (1994), Owen et al (1998), and Repper et al. (1998).

Participants recounted losing their jobs due to unsatisfactory performance issues, prolonged absences, and stigma from employers. Consistent with existing literature, work performance was also hindered by the participants' functional impairments, such as difficulties with thinking, memory, and concentration; inadequate coping with job stressors; and exacerbation of symptoms (Kessler & Bromet, 2013; Kessler et al., 2008; Erdner, et al., 2005).

The need for frequent or extended work absences made their mental health difficulties more obvious to employers, thus contributing further to stigmatization and subsequent job loss. Participants' experiences of social stigma against mental illness in the workplace are consistent with current literature describing how stigma can influence the hiring practices of employers, as well as the expectations of individuals' with mental illnesses of being stereotyped in the workplace (Cummings, Lucas, & Druss, 2013). Participants who were successfully employed at the time of interviews worked in supportive employment environments or for organizations that provided care for, advocated on behalf of, and/or employed individuals living with mental illnesses.

Current literature supports the importance of meaningful activities and work in recovering from mental illnesses (Provencher, Gregg, Mead, & Mueser, 2002; Mancini, et al., 2005); and the impact of work on increasing feelings of control over one's life, and decreasing social isolation (Vidler, 2005). Literature has also been increasingly focused on the need for supportive vocational education and employment opportunities for individuals living with mental illnesses (Dunn, Wewiorski, & Rogers, 2008; Corrigan, Powell, & Rüschi, 2012; Mueser & Cook, 2012).

Research Aim 3: Explore the perspectives of the women living with depression, including their efforts at recovery in the context of their larger socio-cultural and sociopolitical environments.

Facing it, gaining insight, and self-acceptance. For women in this study, recovering from depression required them to recognize and acknowledge their need to address their mental health issues and understand their contributing factors. This process, described in the theme, *facing it and working through it*, began with the critical step of acknowledging their mental health needs. Women identified the importance of being honest with themselves, not running away from or avoiding issues, taking responsibility for their recovery, and being willing to learn about themselves and the contributing factors to their mental health problems. Once they became aware of their mental health needs, key aspects of this process included *gaining insight* and *accepting themselves*.

The importance of the women *facing it* is supported by Higginson and Mansell (2008), who found that participants identified *facing up to* their problems as a major turning point in their recovery from mental illnesses. By facing up their mental health problems, participants were able to understand what was needed to overcome their difficulties or view their situation through a different lens. The process of facing it is also similar to literature identifying the importance of taking responsibility for recovery (McKay, 2010; Ridge & Ziebland, 2006), identifying their needs and becoming more proactive in gaining adequate care and knowledge (Schreiber, 1996).

As part of *gaining insight* about themselves, participants described changing their perspectives about themselves and their life circumstances. Similar to what Schreiber (1996) describes as *cluing in*, women moved from not knowing what was wrong with

them to an increased awareness and understanding of themselves in the world. They were better able to identify and reframe destructive thought patterns that intensified feelings of hopelessness, worthlessness, and powerlessness, and begin to see new possibilities for their lives.

Although participants continued to identify low self-esteem as a problem, they were better able to recognize and challenge distortions in self-concept, such as needing to be perfect, and liking themselves. At the time of interviews, most participants were able to identify their strengths and make positive statements about themselves. Similar to existing literature, an essential aspect of gaining insight was determining who and what they were responsible for, and making caring for themselves as opposed to caring for others a priority (Ridge & Ziebland, 2006; Vidler, 2005; La France & Stoppard, 2006; Jack, 1991; Schreiber, 1976).

As women gained insight about themselves and their experiences living with depression, they became more self-accepting. This played a critical role in integrating their experiences of depression as a part of their lives, improving their adherence with medications and treatments, and learning to live productive lives in spite of their illnesses. The importance of self-acceptance in women's recovery from depression is supported in existing literature by McKay (2010), who describes a process of *surviving*, including acceptance, self-responsibility and self-management; and by Ridge and Ziebland (2006), who describe developing self-acceptance, self-awareness, and an authentic sense of self. Cunningham, Wolbert, Graziano, and Slocum (2005) add further support of the importance acceptance, finding that individuals who had accepted their

mental illnesses were further along in their recovery, and more likely to understand and make needed changes to improve their mental health.

Involvement with peer-run mental health recovery-focused organizations.

Findings regarding what was most helpful in facilitating participants' women's recovery from depression are congruent with current conceptualizations of recovery from mental illness as being more than just the reduction or alleviation of symptoms (Borg & Davidson, 2008; Davidson & Roe, 2007). Women overwhelmingly identified the importance of their involvement with peer-run organizations in facilitating their recovery from depression. Similar to existing literature related to the benefits of peer support in recovering from mental illness, participants described opportunities to interact with positive role models for recovery who shared positive coping strategies (Fukui et al., 2010) and advise on setting and achieving goals (Mancini, et al., 2005). Women also learned about accessing health resources such as obtaining psychotropic medications with limited insurance coverage.

Consistent with the findings of Linz and Sturm (2013), involvement with peer-run organizations decreased participant's feelings of isolation and loneliness, and provided an environment where they felt they belonged and were accepted by others. Participants perceived these social relationships as positive experiences that helped them recognize their personal strengths and accomplishments (Fukui et al., 2010), accept their vulnerabilities, and readjust their goals and expectations as part of their recovery from depression. As a result, women felt a renewed sense of hope about themselves and their futures and were more empowered to rebuild their lives in spite of having depression. Existing literature shows the effectiveness of peer-run programs in supporting mental

health recovery and increasing hope (Davidson, Bellamy, Guy, & Miller, 2012; Fukui et al, 2011), increasing self-esteem, self-efficacy, and perceived social support, and reducing psychiatric symptoms (Fukui 2010).

Participants also participated in classes and support groups offered by the organization that helped them learn needed skills such as interpersonal effectiveness, constructive use of free time, dealing with loneliness, and developing artistic talents. Current literature supports the importance of participating in educational and support groups as a part of recovering from mental illness (Linz & Sturm, 2013), and engaging in creative activities, such as art and music, in decreasing feelings of loneliness in individuals with mental illness (Nilsson et al., 2008).

As the women increased their involvement with peer-run mental health recovery-focused organizations, they offered their expertise as a way of being a resource person to guide others in their recovery. Participants described this as a mutual process of giving and receiving help and support. In a study of the social support networks of women with mental illness, Chernamos et al. (2008) found it was the “reciprocity” in these relationships and being considered by others as a person of value that were most helpful in facilitating the recovery of participants. The process of giving back to others also contributed women’s sense of meaning and purpose greater than themselves, which is identified in the literature as an important aspect of the mental health recovery process (Borg & Davidson, 2008). Some participants were also involved with a group of their peers in community education initiatives to increase public awareness of mental illness and decrease stigma by telling their stories to groups of students and healthcare providers. This also helped them to construct more positive narratives to tell about themselves as

part of their recovery process (Ridge & Ziebland, 2006), and contributed to feelings of increased competency and self-esteem.

Strengths and Limitations of the Study

Participants were recruited using a convenience sampling method and included a small sample size of 17 women who were willing and able to participate in face-to-face, in-depth interviews. The racial/ethnic make-up of the sample included mostly white women, and not representative of the general population. In addition, the majority of the participants were recruited from peer-run mental health recovery-focused organizations servicing one Midwestern state. Thus, narratives emerging from the participants in this study may have limited transferability to women suffering from depression who are of different ethnicities, living in different regions of the country, and not involved with peer-run mental health recovery centers.

The homogeneity of the sample may also be viewed as a strength, improving the credibility of study findings. In addition, the goal of qualitative research is not to produce results that are generalizable to a large population, but to collect the most comprehensive and rich description of the phenomenon of interest. One of the greatest strengths of this study was the use of a two-interview structure, in which participants completed two in-depth face to face interviews with the researcher 5 to 14 days apart. During the beginning of the second interview, the participants and the researcher shared their reflections on the first interview, providing an opportunity for the researcher to clarify her interpretations of participants' interviews. Areas identified as important to participants during the second interview were consistent with the first interview. However, given the difficulties in recruiting individuals who have a mental illness to participate in research studies, the

current study does provide accounts of illness experiences of a sample of women suffering from depression, information that is relevant for use in working with this sub-population and providing healthcare.

Implications

Understanding illness experiences of women living with depression is an important starting point to developing and implementing appropriate interventions and care for this sub-population. Participants in this study shared their stories with the researcher, which have been represented with an attempt to maintain their voices while presenting their narratives in a logical manner. This study has several implications that are discussed in the subsequent section: implications for future research, training and education, policy, and practice.

Implications for Future Research

This study's findings add to the existing literature related to women's experiences of living with depression. Additional insight about women's experiences with depression may be gained by including a more diverse sample related to race/ethnicity, age, and treatment and recovery experiences. Women's experiences living with depression could also be studied using a mixed methods approach in which qualitative interviews are combined with quantitative scales to assess symptoms, feelings of isolation, experiences of stigma, perceived social support, optimism, and self-esteem.

Exploring women's experiences living with and recovering from depression using a longitudinal research design would also add to our understandings of how to best help women recover from depression by increasing knowledge about providing the right interventions at the right times along the course and trajectory of their illnesses.

Conducting in-depth interviews of women over a 2 year period would provide insight about changing symptoms and functional impairments, adherence with medications and treatments, and the process of gaining insight and self-acceptance. Information would also be gained about women's responses to their ongoing exposure to social adversity, and how to best enhance their capacities for protective factors for depression.

As part of improving the quality and availability of mental healthcare services for women with depression, research providing evidence of the positive outcomes associated with receiving case management and community mental health services from consistent providers is needed. This is especially important due to limited funding and availability of these resources. Information gained would inform and improve these interventions, and provide support for increased financial support for these services.

The overwhelming identification of the positive impacts of participants' involvement with peer-support specialists and peer-led mental health recovery focused organizations warrants further study. Although literature on the benefits of peer support has proliferated over the past decade, research is only now beginning to address the specific correlates of peer support (Biegel, Pernice-Duca, Chang, & D'Angelo, 2013). Conducting in-depth interviews with peer-support providers, peer-support recipients, and individuals involved in peer-run recovery-focused organizations would provide insight to better understand and improve the provision of these interventions. These interventions. Findings would also improve the effectiveness and quality of non-peer, mental healthcare provider-patient relationships. Evidence of the positive outcomes associated with peer support could also inform policies to increase funding for and access to these services. .

Implications for Training and Education

This study's findings have implications for training and educating healthcare professionals, including nurses. Education and training need to include current conceptualizations of mental health recovery as not merely the absence of symptoms. Gaining an awareness of how mental healthcare has evolved from deinstitutionalization beginning in the 1960's (Drake, Green, Mueser, & Goldman, 2003) through current mental healthcare delivery approaches provides an important foundation for learning. During deinstitutionalization, state psychiatric hospitals released many of their patients to live and recover outside the hospital in hopes of their reintegrating into their communities.

Despite this shift from hospital-based to community-based treatment, traditional curriculum designs have focused on training nurses in inpatient psychiatric hospital settings. Unfortunately patients cared for in hospitals represent only a small proportion of individuals living with and recovering from mental illnesses, with a focus on short term crisis stabilization. Therefore, it is important that the clinical settings for mental health nursing education programs are situated outside of hospitals, in locations such as community mental health agencies, supportive housing developments, drop in centers, and peer-run mental health recovery-focused organizations.

Locating clinical training sites in the community increases opportunities for students to understand the impact of women's exposure to social adversity including financial stressors, unemployment, living in unsafe or inadequate housing situations, and violent or other traumatic events. In addition, students can gain learn how to access

healthcare and social support resources as part of a comprehensive plan of care addressing the impact of social stressors on women's mental health status.

Seminars involving students listening to illness narratives or stories told by women living with depression would enhance students' abilities to understand the perspectives of their patients. Through a process of reflective learning and group discussion in clinical conferences, students can identify women's mental healthcare and social support needs. Meeting with peer-support specialists and case managers providing mental healthcare would also provide insight about their roles as members of the healthcare team and the interventions identified as most and least helpful.

Implications for Policy

Implications for policy include the need for increased funding and availability of comprehensive individualized community-based mental healthcare services including services from case managers and consistent providers. Increased availability of and funding for peer-run recovery-focused organizations is also needed especially based on existing research about their benefits in facilitating mental health recovery. Health policies are beginning to address improved access to insurance for mental healthcare; however, continued efforts are needed to ensure the availability of comprehensive benefits including prescription medication coverage.

Findings supporting the importance of women's participation in meaningful occupations and the importance of employment as a part of mental health recovery emphasize the importance of increasing the funding, design, and implementation of supportive employment and vocational training programs. These services should also include assistance with completing formal education requirements such as degrees or

certifications, filling out job applications, and preparing for interviews. Policies that assist women to support themselves financially, rather than providing only income assistance, facilitates the recovery process by increasing their sense of autonomy and control over their lives, their self-esteem and self-worth, and access to resources.

To improve opportunities for supportive employment and vocational training, both state and local Temporary Assistance to Needy Families (TANF), Workforce Development and Vocational Rehabilitation programs would be logical partners with mental health recovery and social support programs. Official intergovernmental partnerships would make sense if state and federal agencies were more supportive of such innovations by providing grants. Even without funding, establishing and strengthening working relationships across agencies, and having interagency agreements of understanding that include exchanges of staff and trading referrals, can be utilized to increase opportunities for patients. It is important for the leadership within organizations to promote these initiatives to administratively support and sustain these partnerships.

Implications for Practice

Meeting the needs of women with depression involves not only alleviating symptoms, but also enhancing their capacities for living and managing their lives in spite of their mental illness. Mental healthcare providers need to consider the context of women's lives including housing situations, exposure to violence, the quality and availability of interpersonal relationships, and social support networks. In addition, interventions need to focus on assisting women in facing their mental health problems, gaining insight about and accepting themselves, and learning social and self-care skills.

Findings from this study emphasize the importance of the nurse-patient relationship and listening to women's stories about the impact of depression on their daily lives. Several participants identified the importance of letting patients find their own answers to their problems rather than imposing healthcare decisions on them. Therefore, providing mental healthcare for women living with depression needs to include a process of person-centered-planning characterized by shared decision-making and mutual goal-setting.

Participants' difficulty communicating their concerns to healthcare providers and advocating for themselves emphasizes the need to help women recognize and articulate their mental healthcare problems and needs, especially during appointments with prescribing doctors regarding medications. Providing women with information about their medications, other available treatment options, and how to access other healthcare and social support resources will help strengthen women's abilities to participate in treatment decisions with their mental healthcare providers and promote adherence with prescribed medications and treatments.

Facilitating women's reintegration into their communities as part of their recovery involves consideration of the social and interpersonal aspects of living with depression such as feelings of isolation, social stigma, and the quality and availability of their social networks. Establishing working relationships with community health and social agencies, and including these resources in the patient's treatment plan is also critical in providing comprehensive holistic mental healthcare. Informing women about the how to access health and social resources such as insurance, income assistance programs, educational

and vocational rehabilitation opportunities, transportation services, and safe and affordable housing will improve their recovery outcomes and quality of life.

Mental healthcare interventions identified as most helpful by participants including case management and peer-support services, and home visits from consistent community mental healthcare providers should be included as part treatment. This study's findings also emphasize the importance of nurses facilitating opportunities for women to interact socially with other women experiencing and recovering from depression by referring them to peer-run mental health recovery-focused organizations and drop-in centers. The social support network provided by participating in such an organization may be of more value than other healthcare interventions due to its impact on improving perceived social support and providing role models for successful recovery, opportunities for skills training, gaining a sense of competency and success, and opportunities to contribute to others by being a resource person.

Conclusion

Within mental healthcare, there continues to be a need to raise awareness of the experiences of women living with depression. The stories told by the women in this study illustrated their struggles living with and recovering from depression that extended beyond focusing on their symptoms and efforts at symptom management. They situated their stories within their life worlds, emphasizing the importance of social risk factors. Their descriptions of more difficult times included feelings of isolation and hopelessness, which were further compounded by functional impairments that interfered with role performance and relationships. Consistent with the literature, the participants' process of recovery involved not only a process of improving symptoms, but also gaining

understanding and acceptance of themselves; learning social, self-care, and positive coping skills; and interacting with others living with mental illnesses through involvement with peer-run mental health recovery organizations.

Implications for healthcare providers include the importance of listening without judgment to women's stories to help them articulate their concerns and the problems in living created by their mental illnesses. Treatment goals and interventions should involve a process of shared decision-making that respects women's expertise and assists them in developing insight and acceptance of themselves, gaining needed skills, and initiating and maintaining contact with their peers. Women's involvement in peer-run organizations can increase feelings of being accepted without stigma and provide role models for successful recovery, opportunities to give back and contribute to others, and find new hope, meaning and purpose for their lives.

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APPENDIX A

ETHICAL APPROVAL NOTICES FROM UWM
INSTITUTIONAL REVIEW BOARD



Department of University Safety & Assurances

Melissa Spadanuda
IRB Manager
Institutional Review Board
Engelmann 270
P. O. Box 413
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New Study - Notice of IRB Expedited Approval

<http://www.irb.uwm.edu>
spadanud@uwm.edu

Date: December 6, 2012

To: Aaron Buseh, PhD
Dept: College of Nursing

Cc: Susan Jarchow

IRB#: 13.198

Title: Women's Experiences Living With Depression

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under **Category 6 and 7** as governed by 45 CFR 46.110.

In addition, your protocol has been granted **Level 3** confidentiality for Payments to Research Subjects per UWM Accounting Services Procedure: 2.4.6.

This protocol has been approved on **December 6, 2012** for one year. IRB approval will expire on **December 5, 2013**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found on the IRB website.

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol must be reviewed by the IRB before implementation. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB and maintain proper documentation of its records and promptly report to the IRB any adverse events which require reporting.

It is the principal investigator's responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities the principal investigator may seek to employ (e.g., [FERPA](#), [Radiation Safety](#), [UWM Data Security](#), [UW System policy on Prizes, Awards and Gifts](#), state gambling laws, etc.) which are independent of IRB review/approval.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Melissa C. Spadanuda IRB
Manager



Melissa Spadanuda
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Department of University Safety & Assurances

Continuing Review - Notice of IRB Expedited Approval

<http://www.irb.uwm.edu>
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Date: December 5, 2013

To: Aaron Buseh, PhD

Dept: College of Nursing

Cc: Susan Jarchow

IRB#: 13.198

Title: Women's Experiences Living With Depression

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has received continuing approval as minimal risk Expedited under **category 6 and 7** as governed by 45 CFR 46.110.

This protocol has been approved on **December 5, 2013** for one year. IRB approval will expire on **December 4, 2014**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a Continuation for IRB Approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records, and promptly reporting to the IRB any adverse events which require reporting. The Principal Investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., [FERPA](#), [Radiation Safety](#), [UWM Data Security](#), [UW System policy on Prizes, Awards and Gifts](#), state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Melissa C. Spadanuda
IRB Manager

APPENDIX B

SOCIODEMOGRAPHIC INFORMATION SHEET

1. What is your age in years? _____
2. How would you describe your ethnic group? _____
3. What is your current relationship status?
 Married Single Divorced or Separated
 Widowed Partnered
4. What is your living arrangement?
 a. How many people live in your household: _____
 b. Who do you live with?
 Alone Partner Parent Friends
 Children Other Relatives Pets
5. What is your source of income?
 Employment Unemployment Financial Assistance
 Other: _____
6. What was the total household income from all sources last year (2011)?
 Less than \$5,000 \$5,000 to -\$9,999 \$10,000 to \$19,999
 \$20,000 to \$29,999 \$30,000 to 39,999 \$40,000 to -\$49,999
7. Is your income adequate for living? _____

8. Employment:

a. Do you have a paid job? _____

b. Type/Job Title: _____

c. Full Time Part Time Other

Work hours: _____

9. What is the highest level of education you have completed?

Elementary school or less Some college

Some high school College graduate

High school graduate/GED Graduate degree

10. Insurance:

Do you have health insurance? _____ Yes _____ No

If yes, type: Private Public Other

11. Have you ever been diagnosed with mental illness? _____

Age in years when first diagnosed? _____

Diagnosis given? _____

12. What symptoms of depression have you experienced?
- a. Feelings:
- depression sadness hopelessness guilt
- worthlessness powerlessness fatigue anxiety
- anhedonia (loss of interest or pleasure)
- Other: _____
- b. Difficulty with: thinking making decisions
- remembering
- c. Changes in appetite
- d. Changes in sleep
- d. Thoughts of hurting yourself
- e. Thoughts of killing yourself
13. Have you ever sought help for your symptoms? _____
- If so, what help or healthcare have you received? _____
- _____
14. Do you have a mental healthcare provider you see regularly? Yes No

APPENDIX C

INTERVIEW GUIDE 1

1. People experience depression in different ways. During this interview I would like hear about your experience with depression over time. With this goal in mind, please tell me about what it has been like for you to live with and recover from depression in the context of your daily life?

*This question invites the participant to begin their narrative at the point they feel is most appropriate or significant.

2. Probes will be used to facilitate the participants' narratives related to aspects of symptom experience and contextual and 'life world' factors verbalized by participants as specified in Appendix E: *Analytic Guide*.

- a. What was going on in your life at that time?
- b. What was most difficult for you?
- c. What was most helpful for you?
- d. What was most important for you to recover from depression? In what way or how?
- e. What do you know now that you wish you knew then?
- f. If you had a friend who was depressed what advice would you give them?
- g. Is there anything else you would like to tell me about your experience living with depression?

APPENDIX D
INTERVIEW GUIDE 2

1. Review of first interview interpretations and reflections by participant and investigator:
2. Have you thought any more about what we talked about the first time we met?
3. Utilize probes based on participants reflections,
4. I would like to review my interpretation of our first interview to make sure that my understanding of what you talked about is what you were trying to tell me about your experience living with depression.
5. Give synopsis of general understanding thus far in the analytic process.
6. Ask questions to clarify areas needing further explanation
7. Is there anything else you would like to tell me about your experience living with and recovering from depression?

CURRICULUM VITAE

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Publications

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