A grounded theory investigation of public stigma, internalized stigma, and mental health recovery in the Wellness Management and Recovery program

David G. Medved
University of Toledo

Follow this and additional works at: http://utdr.utoledo.edu/theses-dissertations

Recommended Citation
http://utdr.utoledo.edu/theses-dissertations/1781

This Thesis is brought to you for free and open access by The University of Toledo Digital Repository. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of The University of Toledo Digital Repository. For more information, please see the repository's About page.
A Thesis

entitled

A Grounded Theory Investigation of Public Stigma, Internalized Stigma, and Mental Health Recovery in the Wellness Management and Recovery Program

by

David G. Medved

Submitted to the Graduate Faculty as partial fulfillment of the requirements for the Master of Arts Degree in Psychology

________________________________________
Wesley A. Bullock, PhD, Committee Chair

________________________________________
Gregory J. Meyer, PhD, Committee Member

________________________________________
Mojisola F. Tiamiyu, PhD, Committee Member

________________________________________
Janet M. Hoy, PhD, Committee Member

____________________
Patricia R. Komuniecki, PhD, Dean
College of Graduate Studies

The University of Toledo

December 2014
Mental illnesses are prevalent and impairing conditions in the United States, with a 26% 12-month prevalence, and a 46% lifetime prevalence (Kessler, Chiu, Demler, & Walters, 2005; Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005). In the United States, 5.8% of the population is considered as having a serious mental illness (SMI). The term SMI is used in federal regulations that refer to disorders that interfere with at least one area of social functioning. Mental illnesses are often stigmatized by the public and generally this stigma is regarded as an issue of concern, but the research indicates an inconsistent relationship between the presence of stigma and mental health (Mak, Poon, Pun & Chung, 2007). Given that stigma is both a social issue and a psychological issue, pitting in-groups against out-groups, it is often addressed in psychosocial treatment groups. The current study sought to generate a grounded theory model of stigma experiences and therapeutic changes experienced by those participating in a recovery-focused, psychoeducational group treatment program for persons with SMI, the Wellness Management and Recovery (WMR) program.
Qualitative data were collected from 12 participants of the WMR program. Two higher order themes emerged. The first theme regarded participant experiences with mental illness and stigma, while the second theme regarded their responses to these phenomena. These two themes, experiences and response to mental illness and stigma, provide a unique viewpoint on the relationships between mental illness, public stigma, and internalized stigma from the perspective of WMR participants. Subordinate themes including benefits, limitations, coping, and disclosure of mental illness are described by participants, as well as the role of WMR in promoting mental health recovery and lessening internalized stigma. Participants also reflected on their experience and put forth hypotheses for the development, persistence, and consequences of both public and internalized stigma. Finally, participants provided suggestions for reducing stigma in the general public.

Results of this study help to elucidate the complicated associations between symptoms of mental illness, coping, and how public and internalized stigma complicate the recovery process. Further support is provided for theories of stigma as a harmful social process with dire consequences for the internal and external environments of the stigmatized individual (Corrigan, 2004).
Acknowledgments

I would like to extend a sincere “thank you” to all the participants and employees at the agencies I worked with during data collection. The study would not have happened without your courage and dedication.

I would also like to thank the venerable Drs. Bullock, Hoy, Meyer, and Tiamiyu for their valuable guidance and feedback on this project. Your contributions to this project have each shaped it in some way, and for that I am grateful.

It would be impossible to make it through this process without having adequate social support resources. I would like to thank Jake Burmeister, Alex Stauder, Jill Brown, and Angela Szypa for their unwavering support and willingness to listen to me during the rough spots during this process.

Rick and Deb Medved. This project can be seen as a mile marker on your 20+ year journey of parenting. I’d say you did a fine job! The completion of this thesis, and this degree attests to your hard work throughout the years. Thank you!

Finally, I want to acknowledge the clients who I had the privilege of serving during my employment at Transitional Living Services in Wisconsin. You have had a profound effect on my development as a person and a professional, and I am glad to have known you. Your stories and experiences with mental illness and recovery have stuck with me, and serve as a constant reminder: there but for the grace of God go I.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>iii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>v</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>vi</td>
</tr>
<tr>
<td>I. Literature Review</td>
<td></td>
</tr>
<tr>
<td>A. History of the Consumer/Survivor Movement</td>
<td>1</td>
</tr>
<tr>
<td>B. History of Mental Health Recovery</td>
<td>3</td>
</tr>
<tr>
<td>C. Defining Mental Health Recovery</td>
<td>6</td>
</tr>
<tr>
<td>D. Stigma and Mental Health Recovery</td>
<td>8</td>
</tr>
<tr>
<td>E. Mental Illness Stigma: Public Stigma</td>
<td>10</td>
</tr>
<tr>
<td>F. Approaches to Public Stigma Reduction</td>
<td>11</td>
</tr>
<tr>
<td>G. Mental Illness Stigma: Internalized Stigma</td>
<td>13</td>
</tr>
<tr>
<td>H. Approaches to Internalized Stigma Reduction</td>
<td>14</td>
</tr>
<tr>
<td>I. Wellness Management and Recovery</td>
<td>16</td>
</tr>
<tr>
<td>J. Statement of the Problem</td>
<td>19</td>
</tr>
<tr>
<td>K. Purpose of the Study</td>
<td>21</td>
</tr>
<tr>
<td>L. Research Questions</td>
<td>21</td>
</tr>
<tr>
<td>M. Hypotheses</td>
<td>22</td>
</tr>
<tr>
<td>II. Method</td>
<td></td>
</tr>
<tr>
<td>A. Epistemological Background: Positivism and Interpretivism</td>
<td>23</td>
</tr>
<tr>
<td>B. Grounded Theory</td>
<td>23</td>
</tr>
<tr>
<td>C. Participants</td>
<td>24</td>
</tr>
<tr>
<td>D. Measures</td>
<td>27</td>
</tr>
</tbody>
</table>
E. Procedure

III. Results

IV. Discussion

References

Appendices

A. Semi-Structured Interview Protocol

B. Informed Consent Form

C. Sample Interview Protocol
Chapter One

Literature Review

History of the Consumer/Survivor Movement

There are a number of different ways to conceptualize what happens to a person after they experience a state of illness. For example, a cure is the end of a disease state, that the condition no longer inhabits the person. Remission refers to the lack of active disease activity, although the disease is expected to manifest again at a future time. Recovery refers to a return to health or functioning, which is most often independent of whether or not the disease has been cured. For example, an individual who has been cured of a disease may not have returned to a state of health, and someone may have recovered from a disease that is in remission, yet they are not cured (Shmerling, 2008). Recovery has commonly been used in terms of an outcome when discussing physical illness or disability (Wright, 1983). Given the episodic course of most mental illnesses, many individuals diagnosed experience periods of remission. Therefore, it is effective to consider an individual’s recovery from mental illness as a process in which they experience periods of remission, and learn to effectively cope with symptoms during active phases of their disorder, attempting to achieve an overall state of wellness in their lives.

Although some authors (Frese & Davis, 1997) trace the consumer/survivor movement back to the Alleged Lunatics’ Friend Society in England around 1845, the movement did not formally start in the United States until the 1970s. In England in the late 1700s the public began to become concerned over the lax criteria for admittance to psychiatric hospitals (originally called madhouses). For example, Defoe (1728) was
among the first to suggest regular inspection of psychiatric hospitals, citing that husbands were able to commit their wives for even very tenuous reasons. In 1838, Richard Paternoster, who was held in a psychiatric hospital over a financial disagreement with his father, advertised for other ex-patients to join him on a campaign to address issues in the psychiatric hospital system. Paternoster and others went on to publish accounts of their experiences in psychiatric hospitals, citing that they were not treated as individuals, and there was no communication between doctor and patient. By 1845, the Alleged Lunatics’ Friend Society was formed, aiming to campaign for change to lunacy laws, hoping to reduce the incidence of unjust incarcerations, as well as improve the condition of psychiatric hospitals (Hervey, 1986).

In America, the origin of the consumer/survivor movement was preceded by written accounts of persons in recovery, such as Elizabeth Packard and Elizabeth Stone, who wrote about their commitments to psychiatric hospitals at the hands of their husbands. In 1908, Clifford Beers wrote a book, A Mind that Found Itself, which ultimately led to the formation of the National Committee on Mental Hygiene. The first organized consumer/survivor groups were the Insane Liberation Front in Portland, Oregon formed in 1970, the Mental Patients’ Liberation Project in New York City, the Mental Patients’ Liberation Front in Boston, Massachusetts formed in 1971, and the Network Against Psychiatric Assault in San Francisco, California, founded in 1972. Perhaps the earliest unifying voice of the movement was the Madness Network News, a journal which published personal experiences, creative writing, art, political commentary, and facts from the ex-patient point of view. The input of the movement into early conferences of the Community Support Program, a division of the National Institute of
Mental Health, was essential in the funding of patient-run programs as a component of community support. Eventually the movement would expand to the operation of self-help programs, beginning with the Mental Patients’ Association (MPA) in Vancouver, Canada. The MPA offered a drop-in center and housing options, and was followed in the late 1970s by similar organizations in the United States (Chamberlin, 1990).

Concurrently, the family advocacy movement grew in the late 1970s. There are three major organizations which represent the family advocacy movement: the National Alliance on Mental Illness (NAMI), the Federation of Families for Children’s Mental Health (FFCMH), and the National Mental Health Association (NMHA). These organizations primarily serve family members of persons with chronic mental illness. They focus on advocacy, family support, research, and public awareness (US Department of Health and Human Services, 1999).

**History of Mental Health Recovery**

Historically, the prognosis of mental illnesses has been poor. For example, Emil Kraepelin’s original conceptualization of schizophrenia was that of a premature dementia, or “dementia praecox.” This definition suggests a progressively degenerative condition, essentially a sentence of misery and despair for the remainder of a person’s life. This pessimistic outlook was even a part of the diagnostic criteria for schizophrenia in the first and second editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM; Ralph & Corrigan, 2005). Even as recently as 1987, Harding, Zubin, and Strauss wrote that “every caseload of schizophrenic patients contains a group of patients for whom treatment does not seem to alter the downward trajectory of their illness. These patients appear to be dependent, apathetic, emotionally isolated
individuals.” This view of schizophrenia as a long-term disease with a chronic and poor prognosis is often referred to as the chronicity paradigm.

The chronicity paradigm was the prevailing ideology for conceptualizing serious mental illness (SMI) until the advent of the deinstitutionalization movement of the 1960s and 1970s. As psychiatric institutions closed down, the face of mental health service delivery was changed. In the mid-1970s the National Institute of Mental Health (NIMH) formed the idea of a community support system, which would be the new model for service provision to people with long-term mental illness. The concept of a community support system transitioned the burden of service delivery from inpatient care to community based care: aiming to provide eight different types of services to people with mental illness. These client services include: treatment, crisis intervention, case management, rehabilitation, enrichment, rights protection, basic support, and self-help (Anthony, 1993). By the 1980s the rehabilitation model (Anthony, Cohen, & Farkas, 2002) emphasized four components of mental illness: impairment, dysfunction, disability, and disadvantage. This model recognizes the symptoms (impairment), skill deficiencies (dysfunction), consequences (disability), and lack of opportunity (disadvantage) associated with having a mental health disorder.

In the field of mental health, the concept of recovery was introduced to the literature in the writings of mental health consumers, or persons who are in recovery from mental illness. Deegan (1988) makes a distinction between rehabilitation and recovery. She defines rehabilitation as services that help people with disabilities adapt to their world, and recovery as “the lived or real life experience of people as they accept and overcome the challenge of the disability.” In addition to adapting to or overcoming the
symptoms of a mental health disorder, a person may also have to cope with societal and internalized stigma about their mental health disorder, as well as enduring a lack of social opportunities, or iatrogenic effects of previous treatment.

Recovery is a fitting conceptual model for the mental health field since it is a universal human experience. All people experience adverse events at one time or another, and must learn to recover from the lasting effects of the event. This creates a unique opportunity for a personal connection between a professional and a receiver of services.

Some of the most compelling evidence for mental health recovery comes from longitudinal research studies of individuals diagnosed with schizophrenia. The first study of this type was conducted by Manfred Bleuler, the son of Eugene Bleuler, who had originally coined the term schizophrenia. The study (Bleuler, 1978) followed 208 first admission and readmission patients with psychotic symptoms for an average of 23 years. Bleuler interviewed each of the patients and classified them based on criteria he had determined as stable functioning for at least five years prior to the assessment. Overall, 53% of patients and 66% of the first admission group were judged to have recovered or significantly improved. Bleuler judged 20% of the patients overall and 23% of the first admission group as being fully recovered.

The Vermont Longitudinal Research Project (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987) followed 269 patients diagnosed with schizophrenia for an average of 32 years. The patients also participated in a rehabilitation program, and were released from hospitalization with community supports in place. At follow-up, one half to two thirds of all participants were judged as having improved or recovered. No further symptoms of
schizophrenia were displayed by 68% of participants at follow-up, and 45% displayed no psychiatric symptoms at all.

The World Health Organization (WHO) International Study of Schizophrenia (Harrison et al., 2001) followed 14 culturally diverse treated incidence cohorts, and 4 prevalence cohorts, totaling 1,633 patients diagnosed with schizophrenia or other psychotic illness. Of the entire incidence cohort 56% were rated as recovered, while 60% of the prevalence cohort was rated as recovered at fifteen year follow-up.

**Defining Mental Health Recovery**

Recovery can be defined as both a process and an outcome. In scientific studies, recovery is often defined as the elimination or reduction of symptoms and a return to premorbid functioning (Bellack, 2006). However, this definition does not mesh well with chronic illnesses, as it assumes the existence of a cure or end point to the disease state. In conditions such as schizophrenia, diabetes, or asthma the disease process may still be active, yet the individual has returned to a level of premorbid functioning.

Anthony (1993) published one of the earliest and most influential definitions of recovery. He describes recovery as a “deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (p. 527). The Substance Abuse and Mental Health Services Administration (SAMHSA; 2011) recently offered stakeholders an opportunity to contribute to the organization’s definition of mental health recovery. The final definition that emerged was “a process of change through which individuals improve
their health and wellness, live a self-directed life, and strive to reach their full potential.” SAMHSA also described four major dimensions of recovery, including: health, home, purpose, and community.

Jacobson and Greenley (2001) describe both internal and external components to recovery. Among the internal components, hope refers to the most basic level of recovery - the simple belief of a person that recovery is possible. The second internal component is healing, which refers to a process that includes self-redefinition as a person apart from their illness, as well as gaining control over symptoms whether it is using medication or other self-care strategies. The third component is empowerment, which refers to overcoming a sense of helplessness and dependency internalized after long-term harmful interactions with the mental health system. Empowerment consists of finding a sense of autonomy, courage to take risks, and taking responsibility for coordinating one’s own care. The final internal component of recovery is connection. Connection emphasizes the social nature of the recovery process and reconnecting with others, as well as finding a role that they can fit into. The external components of recovery refer to human rights and societal factors that affect a person’s recovery. The first external component is human rights, which refers to reduction of mental illness stigma, discrimination, and providing equal opportunities for persons with mental illness. The second component involves establishing a positive culture of healing, where service providers must promote an environment that showcases tolerance, empathy, compassion, respect, safety, trust, and cultural competence. The final external component necessitates the provision of recovery-oriented services, which promotes the attitude that recovery is possible and attainable.
Some of the most poignant writing on recovery includes the accounts of the lived experience of persons with mental illness. Deegan (1988) describes recovery as “a process, a way of life, an attitude, and a way of approaching the day’s challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, re-group and start again.” In Ridgway’s (2001) qualitative analysis of recovery narratives, a core narrative and common themes were identified from the four narratives included in the analysis. The core narrative describes a shift from feeling stuck in chronic disability to a feeling of having a much more complex and dynamic life story: an ongoing journey of recovery. Some common themes include “Breaking Through Denial and Achieving Understanding and Acceptance,” “Moving from Withdrawal to Engagement and Active Participation in Life,” and “No Longer Viewing Oneself Primarily as a Person with a Psychiatric Disorder and Reclaiming a Positive Sense of Self.” A common barrier to mental health recovery is stigma, and the relationships between these constructs will be explored below.

**Stigma and Mental Health Recovery**

Demographic factors do not typically affect the manifestation of internalized stigma. Variables such as gender, age, education, employment, marital status, income, and ethnicity do not consistently correlate with self-reported internalized stigma (Livingston & Boyd, 2010). Psychosocial variables are commonly found to be significantly associated with internalized stigma. Livingston and Boyd (2010) performed an independent meta-analysis on psychosocial variables and internalized stigma. For example: hopelessness ($r = -.58, p < .001$), poor self-esteem ($r = -.55, p < .001$), low self-efficacy ($r = -.54, p < .001$), decreased quality of life ($r = -.47, p < .001$), and low social
support \((r = -0.28, p < 0.05)\) were all significantly associated with high levels of internalized stigma.

The relationship between internalized stigma and psychiatric variables is a bit more inconsistent. Symptom severity was significantly associated with internalized stigma \((r = 0.41, p < 0.001)\) in 50 studies (none of the studies found a significant negative relationship). Seven studies demonstrated a significant relationship between treatment adherence and internalized stigma \((r = -0.38, p < 0.001)\). Other psychiatric variables such as: diagnosis, illness duration, hospitalizations, insight, treatment setting, functioning, or medication side effects were not found to be reliably correlated with internalized stigma in a majority of the studies reviewed (Livingston & Boyd, 2010).

In a meta-analysis of 49 empirical studies of stigma and mental health (Mak, Poon, Pun & Cheung, 2007) it was found that the population correlation (corrected for sampling error, unreliability, and other artifacts) between perceived stigma and a composite measure of both positive and negative indicators of mental health was \(-0.28\). Results for the population correlation between stigma and positive indicators of mental health \((r = -0.34)\) and negative indicators of mental health \((r= -0.28)\) were very similar, but suggest that stigma may interfere more with the maintenance of mental health as opposed to exacerbating mental health problems.

These meta-analyses suggest that when considering the results of a plethora of studies on stigma and variables related to mental health recovery there is not a reliable and significant relationship between stigma and recovery outcomes. Most importantly, the variables most affected by stigma include: hopelessness, self-esteem, self-efficacy, quality of life, and social support. Interestingly, stigma does not seem to favor a
particular gender, age range, or socioeconomic status. Similarly, stigma does not seem to vary reliably when considering psychiatric variables such as diagnosis, number of hospitalizations, or insight.

**Mental Illness Stigma: Public Stigma**

In ancient Greece, people such as slaves, criminals, and traitors were often marked with a quite literal stigma, or a sign on the body, which identified that person as unusual or undesirable. Although society no longer marks individuals physically if they are different, there is a societal stigma surrounding many different types of disability. For example, individuals with mental retardation, individuals with obesity, individuals identifying as gay/lesbian, individuals with psoriasis, individuals with epilepsy, individuals with HIV/AIDS, individuals with cancer, as well as members of a variety of racial, ethnic, and religious groups all experience stigma (Kurzban & Leary, 2001).

Perhaps one of the earliest formal definitions of stigma was written by sociologist Erving Goffman (1963) when he described a person who possesses an “attribute that makes him different from others,” which causes the person to be seen as “less desirable” as a person, thus “reduced from a whole and usual person to a tainted, discounted one.” Link and Phelan (2001) describe stigma as more of a process, in which different characteristics about a person are identified, stereotypes are constructed, the labeled person then separated into a distinct group, and finally the person is disapproved, rejected, excluded, and oftentimes discriminated against because of their different qualities. Kurzban and Leary (2001) offer an evolutionary approach to conceptualizing stigma. They assert that social exclusion is driven by evolved adaptations designed to
avoid interactions with people who may provide challenges to an individual’s adaptive fitness.

**Approaches to Public Stigma Reduction**

Three major ways of public stigma reduction have been identified in the literature: protest, education, and contact (Corrigan & Penn, 1999). Protest campaigns which seek to suppress negative attitudes on mental illness are often ineffective due to rebound effects. Protest efforts may actually cause a short-term increase in prejudice and stigma as people may be more likely to recall negative information about individuals with mental illness after being instructed to suppress their negative attitudes. Many protest efforts lack an educational component which actually seeks to change attitudes about people with mental illness. Educational efforts to reduce stigma which seek to contradict prejudicial attitudes are often more effective than protest efforts (Corrigan & Penn, 1999). However, educational material should be combined with discussion in order to provide the most robust stigma-reduction effects. Recent attempts from groups such as the National Alliance on Mental Illness (NAMI) sought to decrease stigma and promote treatment seeking by informing the public about the neurobiological basis for mental illness (Shostak, Conrad, & Horwitz, 2008). However, in an analysis of data from the General Social Survey collected in 1996 and 2006, this medicalization of mental illness supports an increase in the public’s attitudes towards treatment, but is associated with no significant decreases in the amount of social distance or rejection expressed towards persons with mental illness (Pescosolido, Martin, Long, Medina, Phelan, & Link, 2010). Perhaps one of the most effective stigma-reduction strategies is contact with persons that have a mental illness. For ideal stigma-reduction, participants should be of equal status,
engage in a cooperative task, and the person with a mental illness should not differ too greatly from the stereotype being challenged. A meta-analysis (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012) including 72 studies and 38,364 participants found similar results. Education and contact both had a positive effect on reducing public stigma in both adults and adolescents. Greater benefits were seen when contact strategies were used in adult samples, and education appeared to be more effective in studies with adolescents.

Recently, an imaginal exposure-therapy based approach has been studied for reducing negative reactions toward stigmatized groups, including persons with schizophrenia (Birtel & Crisp, 2012). The authors found that imagining a negative encounter with a stigmatized individual just prior to imagining a positive encounter resulted in significantly less anxiety about interacting with the stigmatized person than in a condition where participants were instructed to imagine two consecutive positive interactions. Although anxiety is just one component of stigma, and this method still seeks to establish efficacy outside of imaginary situation, the technique holds promise.

Changing attitudes however, does not always guarantee a change in behavior. A meta-analysis by Kraus (1995) found that the mean association between attitudes and future behavior is \( r = .39 \). However, this association is increased if the attitudes are formed as a result of direct experience and are personally relevant.

Social distance is often used as a proxy measure of stigma towards those with mental illness. Previous research has found that persons with higher knowledge about schizophrenia express lower levels of desired social distance from persons with mental illness. Having a family member with a mental illness also decreases the amount of
desired social distance a person might express (Smith, Reddy, Foster, Asbury, & Brooks, 2011).

**Mental Illness Stigma: Internalized Stigma**

People with chronic illnesses who have experienced stigma from healthcare workers can internalize the stigma, such that they start to believe these negative public perceptions to be true of themselves. Given this, they then continue to expect stigma from healthcare workers, and as a result seek healthcare services less, often leading to a decreased quality of life (Earnshaw & Quinn, 2012).

One of the greatest barriers to mental health recovery is stigma surrounding mental illness. Stigma has been identified as a relevant factor for why people with mental health problems fail to engage in treatment, whether it means seeking initial treatment, or following through with treatment recommendations (Corrigan, 2004). Even among college students, those with mental illness are reluctant to disclose due to fear of discrimination in their studies and professional employment (Martin, 2010).

The present study focused on two aspects of stigma: public stigma and internalized stigma. Corrigan (2004) distinguishes between public stigma and internalized stigma (self-stigma). Public stigma is what members of the public exhibit when they endorse prejudicial attitudes towards a stigmatized group. These attitudes can often translate in behavioral discrimination of the stigmatized group. Internalized stigma refers to a stigmatized individual who starts to consider that the negative attitudes perpetuated by the public are true of themselves.

Cook, Purdie-Vaughns, Meyer, and Busch (2014) propose a multilevel approach to conceptualizing stigma and stigma reduction interventions. The authors use an
ecological systems model to describe stigma processes at the intrapersonal level (personal coping with stigma), interpersonal level (dyadic or small groups interventions), and the structural level (sociopolitical interventions, such as laws and policies) and describe the dynamic interactions between these levels. This approach is well-suited to handle the challenges of characterizing a phenomenon that spans across domains of the person, the culture, and the historical context.

**Approaches to Internalized Stigma Reduction**

There are a number of interventions identified in the literature that help to reduce internalized, or self-stigma. Corrigan and Calabrese (2005) identify cognitive therapy to be an effective way for people to cope with the effects of self-stigma. Cognitive therapy involves training a person to identify, challenge, and modify negative beliefs about their self (Beck & Beck, 2011). Hall and Tarrier (2003) found that a cognitive-based intervention designed to improve self-esteem among inpatients with a psychotic disorder resulted in increased self-esteem, decreased psychotic symptoms, and improved social functioning. Some authors (Link, Mirotznik, & Cullen, 1991) argue that stigma is a problem that must be solved on the societal level, and some of their research indicates that avoiding situations where rejection might occur is actually a harmful coping strategy.

Stigma as a societal problem is promoted in part by media depictions of mental health and illness. Thornton and Wahl (1998) found that participants who read a newspaper article about a violent crime committed by a person with a mental illness reported harsher attitudes towards those with mental illness than a control group. Additionally, Wahl and Lefkowits (1989) found that participants who viewed a film about a killer with a mental illness reported significantly less favorable attitudes towards
mental illness than participants in a control group. In a review of international studies of media portrayals of mental illness by Francis, Pirkis, Dunt, and Blood (2001) it was found that mental illness is portrayed negatively in the media; these presentations promote stereotypes and negative attitudes; there is a firm link between mental illness and violence in the media; and stories about mental illness and violence were featured more often than those presenting mental illness in a favorable light.

Utilizing support groups is also another potential strategy for reducing internalized stigma. However, only recently has the first pilot study been published of a group intervention specifically designed to address internalized stigma. This intervention, “Ending Self-Stigma” (Lucksted, Drapalski, Calmes, Forbes, DeForge, & Boyd, 2011) is a structured nine session group, with a specific intention of reducing internalized stigma in persons with serious mental illness. Results indicated significant decreases in self-reported internalized stigma, substantial increases in mental health recovery, and significant increases in social support.

In a qualitative investigation of how the WMR program promoted mental health recovery, O’Rourke (2009) found that a common theme reported by participants was that by participating in the WMR program individuals felt that they were better equipped to deal with problems related to stigma. This study aimed to explore this finding in more detail.

The current zeitgeist involves the explanation of mental illness as a biological phenomenon using the “chemical imbalance” theory. It has been hypothesized that viewing mental illness as an “illness like any other” would decrease stigma and increase treatment-seeking. However, a recent experiment demonstrated that participants with past
or current depressive episodes who received a bogus “neurotransmitter test” and feedback that their depression was due to a chemical imbalance did not reduce self-blame, and elicited worse prognostic pessimism (Kemp, Lickel, & Deacon, 2014).

This study investigated the role of a specific group therapy, WMR and its role in reducing internalized stigma. The history and structure of the WMR program will be reviewed below.

**Wellness Management and Recovery**

At a meeting of the Robert Wood Johnson Foundation Consensus conference in 1997 it was suggested that the various psychological treatments and interventions for helping persons with serious mental illness be consolidated into a single program that could be studied and implemented. As a result of this suggestion, the Illness Management and Recovery program (IMR) was developed as part of the National Implementing Evidence-Based Practices (EBPs) Project. IMR was developed after reviewing controlled studies of teaching self-management strategies to people with serious mental illness (Mueser et al., 2002). IMR includes empirically-supported interventions that already have research support: psychoeducation, cognitive-behavioral approaches to medication adherence, developing a relapse prevention plan, engaging in social skills training, and learning coping skills for coping with residual symptoms. IMR includes nine different curriculum topic areas, which are completed in approximately nine months. IMR has been implemented in individual and group formats (Mueser, Meyer, Penn, Clancy, Clancy, & Salyers, 2006), in an individual format with a peer specialist as the provider (Salyers, Hicks, McGuire, Baumgardner, Ring, & Kim, 2009), with modifications to the
name (Rychener, Salyers, Labriola, & Little, 2009), as well as modifications to the curriculum and delivery (Salerno, Margolies, Cleek, Pollock, Gopalan, & Jackson, 2011).

An adaptation of the original Illness Management and Recovery program which has been implemented throughout the state of Ohio is called the Wellness Management and Recovery Program (WMR). WMR was developed by the WMR Coordinating Center of Excellence (CCOE), funded by the Ohio Department of Mental Health (ODMH) to encourage the adoption of evidence-based mental health treatments across the state of Ohio. The WMR program in Ohio is an adaptation of IMR (Mueser et al., 2006) and the Ohio Medication and Algorithm Project (Bullock, O’Rourke, & Smith, 2005). The name and curriculum have been modified to emphasize a strength-based approach, and to promote holistic wellness. Additionally, the WMR curriculum is implemented in a group format, over the course of 10 weeks. Groups are co-facilitated by a mental health professional and a person in recovery from mental illness (peer)\(^1\). Both professionals and peers are trained together in the implementation of WMR. This emphasizes the unique nature of the WMR program, which seeks to convey that each individual person is at the center of their own recovery, and it is imperative for them to work side by side with their treatment team to best address their goals for wellness and recovery.

The ten group sessions provide education and skills training around different aspects of mental health recovery and wellness. Session one is entitled “Mental Health

\(^1\) There is current disagreement in the literature and professional/peer communities on how to refer to persons receiving mental health services (Lloyd et al., 2001; McGuire et al., 2003; Simmons et al., 2010). Some commonly used terms include: patient, client, consumer, peer, service user, and survivor. For the purposes of consistency in this document, “peer” will be used due to its popularity among the participants of the WMR program.
Recovery” and provides an introduction to the concepts of mental health recovery and goal-setting. Session two is entitled “Wellness” and discusses holistic wellness and creating an individual wellness plan. Session three is titled “An Understanding of Mental Health” and discusses the relationship between mental health and overall wellness, the process and significance of diagnosis, and feelings about stigma. Session four is entitled “The Role of Medication in Recovery and Wellness” and provides education about medication, feelings about medication, and working collaboratively with a prescriber to address medication issues. Session five is “Learning to Manage Symptoms and Side Effects” and discusses how to differentiate between psychiatric symptoms and side effects of medication, as well as the impact of stress, alcohol, tobacco, and other drugs on wellness and recovery. Session six is entitled “Effective Communication” and highlights the importance of communication in promoting positive relationships, as well as cultural differences in communication. Session seven is “Communicating with Your Providers” and emphasizes personal responsibilities in treatment, developing good relationships with providers, and utilizing effective communication skills. Session eight is titled “Coordinating Your Care” and emphasizes active participation in treatment, education about the roles and responsibilities of providers, and development of strategies to promote self-directed care, including a relapse reduction plan. Session nine is entitled “Developing Relationships and Building Social Supports” and provides information on developing healthy relationships, building a social support network, and the importance of intimacy and boundaries in relationships. Session ten is “Planning for Wellness” and emphasizes early detection of problematic symptoms, integrating the social support system in wellness planning, and completing the relapse reduction plan.
In keeping with ODMH’s goal to promote evidence-based practices in public mental healthcare, the WMR program is currently being evaluated in the form of an open clinical trial. Data is collected at three time points from participants in the WMR program: prior to their participation, after the final session, and six months after completion of the WMR Program. The outcome evaluation includes two core measures: the Mental Health Recovery Measure (MHRM; Young & Bullock, 2003), and the WMR Client Self-Rating. The MHRM is a 30 item self-report measure that inquires about behaviors used in the respondent’s recovery process. It was developed using a grounded theory model of recovery derived from individual and focus-group interviews with individuals in recovery from mental illness. The WMR Client Self-Rating is a 20 item self-report measure used to assess progress in a respondent’s recovery in specific areas targeted in the WMR curriculum. This scale has been adapted from the IMR Client Self-Rating Scales (Salyers, Godfrey, Mueser, & Labriola, 2007) to reflect the strength-based focus of WMR.

Statement of the Problem

The preceding review of the literature on mental health recovery, stigma is commonly identified as one of the key barriers to mental health recovery. While research has been conducted on particular strategies designed to reduce mental illness stigma in the public domain, stigma remains a problematic barrier for those experiencing mental illness and for those trying to move forward in their mental health recovery. In addition to strategies for reducing public stigma, some strategies have been outlined above for reducing internalized stigma. Of these approaches to reducing internalized stigma, group therapies provide a way for stigmatized members of an out-group to join together and
form an in-group on the basis of their shared experiences. However, there has only been one published pilot investigation of the effect of a group therapy program designed for the reduction of internalized stigma. This program was able to significantly decrease internalized stigma in participants, as well as increase perceived social support and mental health recovery (Lucksted et al., 2011). Thus, there is much research that must be done in order to delineate the specific processes at work in reducing internalized stigma within the context of a group treatment program.

There has also been contention in the literature over the negative and potentially empowering effects of internalized stigma (Crocker & Major, 1989; Corrigan, 2005). It seems that for some individuals, stigma may be harmful and a barrier to overcome. For others, stigma can be empowering, especially when allying with members of the same out-group. In still others, stigma may have no discernible effects. Thus far, stigma theories have been primarily generated by the academic community. It would seem prudent to clarify these disparate ideas about stigma by creating a theoretical model incorporating the stigma experiences of persons with mental illness.

In previous research, participants of the WMR program were found to improve in their mental health recovery (O’Rourke, 2009), trauma symptoms (Lee, 2011) and social support (Hupp, 2008). In addition, a qualitative investigation of the WMR program found that overcoming prejudice and stigma was a common theme found in participants interviewed about their experience in the program (O’Rourke, 2009). While the content of WMR is not specifically designed to reduce stigma, a qualitative inquiry could be very useful in illuminating the specific group processes that promote the reduction of
internalized stigma, as well as determining common stigma experiences among persons in recovery. The current study sought to fill this current gap in the literature.

**Purpose of the Present Study**

There is research to suggest that group therapies in general can help in overcoming stigma. In addition, an ancillary finding of early research on the WMR program was that it helped participants to overcome stigma and prejudice. However, there has been no research to date which looks directly at the effect of a recovery-oriented group therapy on the reduction of internalized stigma. As such, the current study was designed to make two contributions to the existing stigma literature. The most general goal of the study was to augment existing literature on the experience of stigma among persons with mental illness: both to validate previous findings and to add novel information to the literature on the stigma associated with having a mental illness. The theory generated from this study, from the perspective of persons with mental illness, may help to clarify the different ways in which people experience stigma. A more specific goal of this investigation was to generate the first qualitative data on how a recovery-based group treatment process may aid in reducing stigma. The use of qualitative approaches in this particular investigation was essential so that the stigma-reduction process could be accurately captured in the words of persons who have lived experience with mental illness, stigma, and mental health recovery.

**Research Questions**

This investigation concerned the phenomenon of mental illness stigma generally, and the group processes involved in stigma-reduction specifically. This study was designed to answer the following questions: 1) What, if any, types of stigma have
participants in the WMR program experienced? 2) How did participants of the WMR program react to, and cope with, any experienced stigma? 3) Do participants in the WMR program feel that the experience has helped them to overcome stigma? 4) What, if anything, about the WMR program was instrumental in leading to any changes in internalized stigma that the participants have experienced?

**Hypotheses**

The inherent nature of qualitative inquiry is to allow findings to arise from the data (Glesne, 2011), thus no formal hypotheses were generated. However, it was expected that participants in this study would reflect on their experiences with stigma and describe their experiences in the WMR program as it related to their stigma experiences. Of particular interest was how the participants viewed stigma in relation to their recovery process. For some, stigma may have been detrimental in the early part of the recovery, while others might have come to new insights about themselves and stigma after completing the WMR program.
Chapter Two

Method

Epistemological Background: Positivism and Interpretivism

Qualitative research is fundamentally different from quantitative research in that it was founded in the interpretivist paradigm. Interpretivist researchers see reality as a social construction that is complex and constantly changing. Quantitative research arises from positivism which regards the world and its phenomena as being made up of observable and measurable facts (Glesne, 2011). The goal of quantitative research is generally to objectively describe and measure phenomena in a representative sample of participants, with the goal of generalizing the results to a larger population. Qualitative inquiry however, values the subjectivity of the human experience and the relationship of the researcher to the participants. The goal is to gather in-depth information about a particular group of participants in order to describe and explain the phenomena of interest in that particular group of participants (Glesne, 2011). Theoretical sampling entails deliberately selecting specific types of participants to inform and illuminate emerging themes in the data analysis. Unlike quantitative research, the qualitative research process is often an iterative process, with new questions and explanations developing as the study progresses.

Grounded Theory

Grounded Theory research is a method of qualitative research that gained traction in the late 1960s in response to the criticism of qualitative research as being non-systematic and non-rigorous. Grounded Theory is a methodology that emphasizes the discovery of theory through the analysis, or grounding, in the data. In grounded theory,
the researcher generates a theory of a process, action, or interaction through themes that emerge from the data generated by the participants. The grounded theory methodology employs the constant comparative method of data analysis, in which data collection and data analysis are concurrent processes. During the early stages of data collection, data are grouped into categories, or units of information such as events, happenings, or instances. The constant comparative method of data analysis is an iterative process in which the researcher collects data and then groups it into categories, continuing data collection until the categories become saturated with data (Creswell, 2012).

Shortly after publication of their seminal book on grounded theory, Glaser and Strauss (1967) began to disagree about how their methodologies should be carried out. Glaser and Strauss would go on to publish books on grounded theory separately, with Strauss publishing his book *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* with Juliet Corbin in 1990. The book is now in its third edition (Corbin & Strauss, 2008) and was used as the guiding framework for this study, along with techniques from Kathy Charmaz’ (2006) constructivist approach to grounded theory. Together these approaches take into account the need for a systematic approach to the method, as well as the impact that the researcher’s knowledge and biases have on the emerging theory.

*Participants*

Participants in the current study were twelve individuals recruited from four different consumer-operated support (COS) sites across the state of Ohio. Participants were selected through a process which was informed by theoretical sampling (Corbin & Strauss, 2008), such that four theoretically distinct sub-groups were sampled: positive
responders, negative responders, neutral responders, and non-completers. These theoretical groups were defined based on each participant’s change score on the Mental Health Recovery Measure (MHRM). A reliable change (reliable change index; Jacobson & Truax, 1991) for the MHRM is represented by a change of +/- 15 points on the MHRM Total score. Individuals with MHRM Total change scores of 15 or greater in a positive direction are considered to have reliably improved on the MHRM and in the present case presumptively responded positively to the WMR intervention; those with MHRM Total change scores of 15 or greater in a negative direction are considered to have reliably deteriorated on the MHRM following their participation in the WMR program. Those who achieved a change score of less than 15 points in either direction are considered to have neither reliably improved nor deteriorated on the MHRM. Individuals who completed the pre-intervention MHRM only but had no post-intervention MHRM data were considered to be non-completers of the WMR program.

The ages of participants in the sample (N = 12) ranged from 22 to 67 years old, with a mean age of 48.25 years (SD = 13.59). The sample was 58% female (n = 7), and was comprised of 75% European-American participants (n = 9), 17% African-American participants (n = 2), and 8% Latino participants (n = 1). The educational level for the participants ranged from high school graduates to completion of some college. Two participants reported part-time employment, one reported being retired, and four reported that they were unemployed. Regarding marital status, two were never married, four were separated or divorced, and one was currently married. In terms of living arrangements, six lived in their own home or apartment, and one lived in a supervised environment. Demographic data was missing for five participants. 33% of participants (n = 4) received
services at the Thomas M. Wernert Center in Toledo, OH; 33% participants ($n = 4$) received services at The Main Place in Mount Vernon, OH; 17% of participants ($n = 2$) received services at Bridges in Painesville, OH; and 17% of participants ($n = 2$) received services at The Main Place in Newark, OH. Please refer to Table 1 for a summary of the demographic information of the participants.
Table 1

**Descriptive Statistics of Participant Demographic Variables (N =12)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48.25</td>
<td>13.59</td>
<td>22</td>
<td>67</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>42</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>58</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>European-American</td>
<td>9</td>
<td>75</td>
</tr>
<tr>
<td>African-American</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>Latino</td>
<td>1</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>High school diploma/GED</td>
<td>5</td>
<td>42</td>
</tr>
<tr>
<td>Some college</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>42</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never married</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>4</td>
<td>33</td>
</tr>
<tr>
<td>Married</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>42</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Living Arrangements</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Own house or apartment</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Supervised group living</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>42</td>
</tr>
</tbody>
</table>

**Measures**

**Semi-Structured Interview Protocol.** A semi-structured interview protocol (Appendix A) developed by the researcher was utilized to collect qualitative data from participants in the study. The questions for the interview protocol were adapted after a review of current self-report measures of perceived stigma (Bagley & King, 2005; Hayward, Wong, Bright, & Lam, 2002), experienced stigma (Bjorkman, Svensson, &
Lundberg, 2007; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009; Wahl, 1989), and internalized stigma (Corrigan, Watson, & Barr, 2006; Kanter, Rusch, & Brondino, 2008; King et al., 2007; Ritsher, Otilingam, & Grajales, 2003). The interview protocol was pilot tested and refined in consultation with peer representatives from the WMR CCOE. All interviews were audio recorded, after written informed consent of the participant was obtained. Participants were contacted prior to their interview to confirm verbally that they intended to provide consent to participate.

**Mental Health Recovery Measure.** The Mental Health Recovery Measure (MHRM; Young & Bullock, 2003) is a 30 item behaviorally-anchored self-report measure of mental health recovery. The MHRM was developed using a grounded theory model of mental health recovery from the perspective of persons living with SMI (Young & Ensing, 1999). The measure contains eight conceptual subscales: 1) Overcoming Stuckness, 2) Self-Empowerment, 3) Learning and Self-Redefinition, 4) Basic Functioning, 5) Overall Well-Being, 6) Spirituality, 7) New Potentials, and 8) Advocacy/Quality of Life. Responses to the MHRM are given on a 5-point scale, ranging from *Strongly Disagree* to *Strongly Agree*. Normative data for the MHRM has established (M = 80, SD = 20), with strong internal consistency (α = .91). Normative data was collected (N = 279) from persons with psychiatric disorders utilizing community mental health services. Convergent validity has been established with the Making Decisions Empowerment Scale (Rogers, Chamberlin, Ellison, & Crean, 1997) r = .70 as reported by Bullock (2005). Further psychometric evaluation of the MHRM has been completed by Salyers, Godfrey, Mueser, and Labriola (2007).
Procedure

A protocol application detailing the procedures of the study was submitted and approved by the Social, Behavioral & Educational Institutional Review Board (IRB) within the Department for Human Research Protections at The University of Toledo before data collection began. Following the IRB approval, participants were identified from archival MHRM data. Coordinators of the WMR program at each of the four agencies were then contacted and provided with a description of the study as well as a list of potential participants that were identified by the investigator. The WMR coordinator at each site then approached potential participants to gauge their interest in the study, or provided their contact information to the investigator. Interviews were then coordinated to take place at the participant’s convenience at the location of the site where they had participated in the WMR program. Interviews were conducted in a private room at each site.

Data collection. Interviews were conducted on May 6, 2013 at the Wernert Center; on May 7, 2013 at The Main Place – Newark; on May 8, 2013 at the Wernert Center; on May 9, 2013 at The Main Place – Mount Vernon; on October 21, 2013 at Bridges; with the final interview being conducted on October 28, 2013 at the Wernert Center. Before the interview was conducted, the informed consent form (Appendix B) was presented to and reviewed with each participant. The informed consent included information about the purpose of the study, what the participants’ involvement would entail, risks and benefits of participation, and contact information of the researcher. Participants were made explicitly aware that the interviews would be audio recorded for the purposes of later transcription and analysis. Participants initialed a special section on
the consent form to indicate their awareness and consent for the interview to be recorded. Participants were provided with light refreshments during their participation in the interview.

All interviews were conducted by the principal investigator, a second-year doctoral student in clinical psychology with five years of experience working with persons with mental illness. The interview protocol included 37 questions across five domains. Seven core questions (which were identified in consultation with members of the WMR CCOE during the pilot testing of the interview protocol) were asked of each participant. Interviews were generally guided by the responses of the participant, with follow-up questions being asked by the researcher to further elucidate their experiences. Participants who were less verbose and forthcoming were generally asked more questions from the protocol than participants who were more loquacious and forthcoming. Each interview lasted between 17 and 81 minutes, depending on the amount of information shared by the participant. The interviews were digitally recorded to allow for later transcription and in-depth analysis of participants’ verbatim responses.

Data preparation. Following completion of the interviews, they were transcribed by the researcher using the online application “Transcribe” (transcribe.wreally.com). This application allows the user to easily slow down the playback speed and pause audio streams while transcribing. Audio recordings were transcribed fully and included non-word utterances such as laughing which was deemed relevant to the content of the interview. Transcription did not include non-word utterances such as “um” or false starts, as the level of analysis did not concern these verbalizations. Recordings were transcribed
in the order in which they were received and generally coincided with breaks in between data collection.

During this analysis of the transcripts, the qualitative data analysis software “ATLAS.ti” was used. The ATLAS.ti program allows the user to organize transcripts from a research project, create numbered lines for each of the transcripts, create memos and codes, as well as the ability to organize these codes into higher level categories and families. The software also provides some analytic capabilities, such as providing frequencies for each of the codes as well as individual words. In this project, the ATLAS.ti software was also used to facilitate the auditing process of the data, so that the researchers could simultaneously review the same meaning units.

*Data analysis.* Following data preparation, the first step in the data analysis was to engage in what Corbin and Strauss (2008) call “memoing.” Memoing is the first stage of data analysis, in which the researcher first reviews the raw data (in this case, transcripts). During this first phase of analysis, the investigator makes notes or “memos” about his or her initial thoughts regarding the data, including observations that might have occurred during the data collection process itself. These memos are the “running logs of analytic thinking,” and usually evolve into the first concepts (codes) which emerge from the data.

After memoing, the open coding phase begins. The units of analysis, or meaning units, are often subjective and can vary from single words to multiple sentences or entire paragraphs. Open coding is the process of breaking data apart and delineating concepts (codes) to stand for blocks of raw data (Corbin & Strauss, 2008). Previous descriptions of the grounded theory method have also described a process of axial coding, which is the
act of relating codes to each other and to categories (themes) emerging from the analysis. However, the distinction between these coding processes is artificial and these processes occur simultaneously (Corbin & Strauss, 2008).

During the first phase of coding, codes were synthesized into themes, which varied by level of specificity. Level one themes provide synthesis of meaning at the broadest level, level two themes become more specific, and level three themes provide the most specific information about a particular phenomenon. Following the initial phase of coding, the researcher met with his thesis committee chair to review representative interview transcripts for an in-depth discussion of the resultant codes and themes. These discussions provided a framework for proceeding with the second phase of coding, in which the transcripts were reviewed with the familiarity of completing phase one as well as having discussed the emerging results.

Following this second phase of coding, the researcher began the process of code synthesis, in which all of the existing codes were reviewed for similarity. Codes which were similar in meaning were collapsed into a new code. Codes which occurred with a low frequency were also collapsed into other more frequent codes, if possible. Codes which were low frequency and did not share meaning with other codes were retained. Following this phase of code synthesis, level three codes were examined again so that they could be synthesized further into common themes.

Throughout these steps in the analysis, the researcher met frequently with the committee chair of this project to engage in a process of auditing, which is an iterative process of ensuring that the data and resultant interpretations of it are reliable and valid.
Data entry and storage. Data from each participant were assigned a participant number for identification purposes. Following data collection the informed consent forms were stored separately from the interview transcripts so that identifying information could not be traced back to a participant’s raw data. Physical copies of the informed consent were stored in a locked office, and interview recordings and transcripts are stored on a password protected computer.
Chapter Three

Results

*Saturation.* According to Corbin and Strauss (2008), the researcher knows when sufficient sampling has occurred when “the major themes show depth and variation in terms of their development.” This development is also known as saturation, or when no new themes are being discovered in the data. Saturation is generally a subjective judgment by a researcher. In addition to using subjective judgment of saturation, the researcher evaluated saturation using a novel method which relies on quantitative data. This method was inspired by the work of Guest et al. (2006), who systematically examined the amount of new codes emerging from a dataset after each new interview protocol was added to the analysis. Their findings indicated that quantitatively, saturation is often reached within the analysis of twelve interview protocols, although basic elements for constructing grounded theory are often present in as few as six interviews.

Guided by the framework set forth by Guest, Bunce, and Johnson (2006), who conducted an empirical investigation of how many interviews was typical for reaching saturation, the researcher systematically examined the number of new codes that emerged from each consecutive interview protocol analyzed. This process was conducted twice, once during phase one of coding, and again during the second phase of coding. These trajectories were then compared to ensure that saturation was indeed achieved. It was apparent from this process that the number of new codes emerging from the data precipitously decreased after the third interview was added to the analysis. Please refer to Figure 1 for a graphic depiction.
Figure 1: New codes emerging across interviews

**Trustworthiness.** Issues of validity are often handled differently in qualitative studies than they are in quantitative studies as concerns of “truth” or “accuracy” is less relevant when operating from a framework that assumes reality is socially constructed. Multiple methods are available to ensure that qualitative findings are trustworthy (Glesne, 2011), and this study used a process of bracketing and auditing to establish the trustworthiness of the findings. At the outset of the study, the researcher engaged in a bracketing exercise, in which he synthesized his a priori knowledge and assumptions about the area of study using an ecological systems model. This aided in identifying biases and preconceptions which might enter into the analysis. Additionally, the researcher met with the committee chair of this project multiple times throughout the data collection and analysis process to engage in data auditing. This provided an opportunity to synthesize
two different perspectives on the data and emerging themes and build consensus about
the resulting theory.

**Thematic Analyses**

Emerging themes coalesced into two higher order concepts. These concepts
reflect the participants’ experiences with mental illness and stigma, and their responses to
these phenomena. Within these two broad level concepts were subordinate categories,
which are described in more detail below.

*The benefits of mental illness.* Participants reflected on unique aspects of living
with a mental illness which were subjectively construed as positive. Most commonly,
these themes involved a sense of self-improvement, or a greater connection to others and
better understanding of humanity. In reference to better understanding humanity, one
participant remarked:

> A lot of us out there that have made the world a better place because of
> that, because we understand where the other person in coming from and
> we understand what it’s like to be stepped on and how to resolve it. It’s
> what we do. {P03; L105}

Participants also remarked on how living with mental illness has provided them with
additional opportunities for individual growth outside of their mental health recovery. A
participant stated, “working on my mental illness has helped me work on other parts of
my life that need to be worked on like self, for example, self-esteem.” {P06; L135}

Some participants also identified financial benefits associated with having an
impairing mental illness, such as Medicaid insurance or social security disability
payments. For example, a participant remarked, “when I was working fast food, I was making about the same amount of money that I do now, and I don’t work.” {P12; L129}

**Limitations associated with mental illness.** In addition to some of the benefits participants identified, they also described a number of limitations. The most frequently cited themes related to limitations include poor social support, guardedness, low social tolerance, and dangerousness.

One of the most prevalent themes was related to poor social support. This theme reflected a variety of issues such as lack of friends, the social disconnect between those living with mental illness versus those living without mental illness, and parental rejection. For example, one participant stated, “I know my parents didn’t want me whatsoever, so I had big problems with parents pushing me away all the time, not wanting to hear anything I had to say.” {P11; L019} Closely related to the theme of poor social support is the theme of guardedness, or difficulty expressing or opening oneself in social situations. For example, one participant remarked:

That and like, like what I do, like don’t know you like that, like I’m not going to tell you, even my positive points, you know, I won’t tell you. I’ll just wait until I see you around more and stuff and maybe, you know, and that’s hard and stuff too though. It’s who I’ve known for years and they don’t know me like that, and I have, a person look at me over the weekend, you don’t really like, you don’t really open up, you’re so closed from people that you, you don’t even, you don’t know what you’re doin’. {P01; L139}
Another theme closely related to poor social support and social guardedness was that of low social tolerance. Participants who reflected on this theme commented on their decreased desire and tolerance of social situations. For example, one participant remarked, “I can deal with people for only so long, and then I’m ready to go back to my little corner and just do my own thing.” {P01; L131}

Finally, another theme which commonly arose when speaking about limitations associated with mental illness was that of unpredictability of behavior that often accompanies uncontrolled or untreated symptoms. This theme reflected the feeling among some of the participants that when they were most symptomatic they might act out in ways which were dangerous to themselves or others. One particularly striking example came from a younger participant who was applying to college at the time of the interview: “I was homeless for a while and I was doing stuff. I was lighting like- I lit my work hat on fire and she got mad at me and kicked me out of the house.” {P12; L109}

Themes such as symptom impairment or side effects of treatment were mentioned only a few times as considerable limitations. Other themes related to limitations associated with mental illness that emerged from the analysis infrequently included: imposed limitations, and denial of mental illness.

Means of coping with mental illness. Other themes emerged from the analysis related to a variety of positive and negative methods of coping with mental illness. The most common responses were reflections on traditional treatment strategies, such as psychiatric medication, individual psychotherapy, psychoeducational or support groups, or case management services. Additionally, poor social support and its consequences were often cited as limitations of having a mental illness, but the availability of social
support was also cited very frequently as an effective coping method. In addition, acceptance of self and illness, as well as an understanding of one’s mental illness were often mentioned as means of coping. Acceptance could be viewed as both a process and a goal, with acceptance of mental illness functioning as a means to facilitate self-acceptance.

The theme of traditional treatment for mental illness, such as medications, individual and group psychotherapy was often cited, but many times they were cited as things which were obvious or “given” for progressing in their journey of recovery. For example, one participant stated:

It’s not so much a battle anymore after I turned 30. I realized I have to be on meds, I have to better myself, I have to go to therapy, I could go to groups, find ways to cope with my mental illness and figure out how to deal with life. It’s a long journey. {P02; L029}

Despite many participants citing poor social support or a lack of desire for socialization as a significant limitation of their mental illness, many participants also described social support as a widely used method of coping. One participant described the necessity of social support very succinctly, “it’s not something I could get out of myself, I don’t know if anybody can.” {P09; L031} Other participants described the importance of friends, family, and peers in caring for themselves and coping with their mental illness.

Another frequently emerging theme related to coping with mental illness was that of acceptance. Acceptance, as used by participants, refers broadly to both acceptance of
self and acceptance of the mental illness they have been diagnosed with. One participant reflected on how coming to an acceptance of her illness was a process itself:

> It took me ten years to accept myself. To say, hey, you didn’t ask for this mental illness when you were born, it’s not your fault, it doesn’t make you any less. But a lot of mentally ill people think less of themselves because we’re not normal, whatever that is, I don’t wanna know. {P02; L109}

Understanding, or being educated about one’s mental illness, was another widely-reported means of coping. This theme reflects the importance of being able to identify the problems that one is living with, and to know the best way to ameliorate those problems. An example of this process in action follows:

> Me, I was tickled to death. I was like, now some of this makes sense why I’ve been like this all my life, you know, and that’s when I started to work on it. Well, over the years since I’ve studied different mental illnesses and read up on them, I began to wonder if I wasn’t bipolar instead of just depressed because I knew I had mood swings and now I am on Depakote which is for bipolar. {P06; L059}

**Sharing/Disclosing Mental Illness.** Participants also reflected on factors that influence whether or not they will disclose that they have a mental illness to others. Themes reflected the contrasting ideas of attempting to keep their mental illness a secret or limiting disclosure to family and close friends, as well as disclosing their mental illness with no shame. These seemingly opposed views provide evidence of the variation in how individuals approach the matter of disclosing their mental illness.
Against the more common backdrop of secrecy or limiting knowledge about their mental illness to close friends, many participants nonetheless reported that they felt no shame in disclosing their mental illness. One participant addressed his attitudes towards disclosure and early detection being beneficial to recovery:

> It’s not good to be secretive about those kinda things cause you know it’ll come up, whatever, it’ll come up you know and I think maybe the best thing to do is to handle it when it’s small. Before when you can still handle it and everything you know. If it gets too blown out of proportion it may be too late to do anything you know, that’s why you catch it when it’s small. {P04; L141}

Likewise, other participants reflected on their feelings of openness and frankness when sharing their experience of mental illness with others. One participant remarked, “I’m very open about it. I’m very open about it and everything else like that because I’m like you know you can accept me for who I am or you can’t.” {P03; L057}

Conversely, others described that it was important for them to maintain a level of secrecy around their mental illness. Many of these reactions centered on not wanting to be perceived as different, or “not normal,” as one participant stated:

> People that don’t know that I’m like that, I try to keep it quiet and so the less people that know that I’m different, the better, the better off I am. The less people know, the better off I am because they think I’m normal, a normal child, and that’s how I like it kept. {P10; L189}

Finally, participants also reflected on how sharing their experiences with mental illness with their family and close friends had impacted their relationships. Some
observed that their families generally avoided speaking about mental illness, or even refused to acknowledge it. However, others spoke about how their experiences with mental illness brought them closer to their family. For example:

Actually, with that, it’s actually brought me closer to them because they can relate what I’m going through because some of them have the same mental illnesses as me so it makes it easier for me to talk to those people than it is than say, the mayor or something, just using it as an example. So yeah, I feel more comfortable talking to someone that’s real close to me and it has brought me and my wife together a lot closer. And a lot of my friends. {P07; L207}

*The relationship of WMR to mental illness and stigma.* Participants were asked specifically if and how participating in the WMR program had an effect on their mental health recovery and their experiences and responses to both public and internalized stigma. Common themes that emerged in this area were related to the educational component of WMR, the nature of empowerment inherent in the underlying philosophy of WMR implementation, the nature of WMR to push them forward by expanding their comfort zone, and the fostering of self-love or self-acceptance.

The most frequently cited theme related to the WMR program itself was that the education component was most helpful. Several participants described that while going through WMR they were able to attach their subjective experience of mental illness to learning the common ‘language’ of mental health recovery. One participant remarked, “Every time I learn something different or I see something in a different light that I didn’t see before.” {P06; L087} Another participant specifically noted the focus on both mental
and physical health, “I understand about the medication how you’re supposed to work your medication, and eat the right kinda food, make sure it’s healthy stuff.” {P08; L107} Another participant spoke about his deeper, more nuanced understanding regarding the persistence of his mental illness:

I learned more about like, I can’t think of the actual term, I learned like you know, no matter what you’re gonna…the problems are gonna be there no matter what. Whether you take medication for it or not or get treatment, those problems are always still going to be there regardless. {P07; L107}

In terms of its relationship to internalized stigma, themes that emerged from the analysis included the empowering nature of participating in the WMR program, as well as the push from the group to expand one’s comfort zone. One participant reflected, “that’s what I got from the program, this is where I didn’t want to hide anymore, I’ve been, I mean I’ve been hiding from a lot of things, but it helped me turn around and come to grips with my world.” {P03; L089} Additionally, many participants reflected on how WMR encouraged them to bring more novelty into their lives. For example, “it’s just a good growing experience for me, you know? We’ve had some wonderful support from the people in Columbus and I’ve met Dr. Bullock more than once and have talked to him at length.” {P06; L083} Most importantly, another common theme was that of WMR building self-love or self-acceptance. Numerous participants remarked about how WMR fostered this type of change in them. A participant stated, “It’s made me feel more comfortable about myself than other groups have.” {P07; L143} Other examples of this personal transformation are included below:
Personally, what changed me, a little bit is how I view myself. And how I increased how much I love myself now. So it made a positive impact on me, it made me see things in a different light. {P01; L055}

I’m okay with who I am and the, it’s the world that’s got a problem, it’s not me that’s got the problem. It’s the world that’s got the problem and it helped me go recognize what I could deal with and what I couldn’t deal with, you know? {P03; L089}
Table 1

Outline of themes: Experiences of Mental Illness

I. Benefits of mental illness
   A. Understanding humanity
   B. Self-improvement
   C. Financial benefits
II. Limitations associated with mental illness
   A. Poor social support
   B. Guardedness
   C. Low social tolerance
   D. Unpredictability of untreated symptoms
III. Means of coping with mental illness
   A. Traditional treatment
   B. Social support
   C. Acceptance of self and mental illness
   D. Understanding mental illness
IV. Sharing and disclosing mental illness
   A. No shame
   B. Secrecy
   C. Friends and family
V. Relationship of WMR to mental illness and stigma
   A. Education
   B. Empowerment
   C. Comfort zone expansion
   D. Self-acceptance

Descriptions of stigma. Participants were asked to describe stigma in their own words. The most frequent themes which emerged from this section of the analysis was that stigma was dehumanizing. For example, one participant reflected on his experience living in a group home:

   Right, not yelled at, not treated like a dog not treated like a doormat, but like a human being you know? I understand that people can be troublesome, I understand that people need to stay in line but people also need to know that their rights are being heard, being acknowledged, and you know, being listened to, being respected. {P01; L111}
In addition to a feeling of dehumanization, another common theme reported by participants was the feeling of being judged as different and therefore inferior. For example, one participant described stigma as, “being punished for who you are and that’s what it is.” {P03; L011} Another participant described a similar fear of negative evaluation by others, “I feel like they’re judging me. I feel like they’re, they are waiting for me to mess up or they’re, they won’t give me a change, they won’t give me the time of day.” {P01; L147} Related to these feelings of judgment or evaluation, many participants described stigma as simply equivalent to stereotyping and subsequent prejudice. Themes of stereotyping and overcoming prejudice will be explicated in more detail below.

*Development of stigma.* The next emerging theme included hypotheses generated by the participants about why and how stigma has developed around mental illness. The most prevalent explanation given by participants was that stigma arises out of a denial or unwillingness to acknowledge and accept mental illness. One participant described her efforts to educate her mother about her mental illness, with little success:

She still thinks, there’s really nothing, I’m just using problems or whatever to have the bipolar disorder. She doesn’t understand it’s a chemical imbalance that’s way off or something. I tried giving her pamphlets and stuff to read up on my disability so she knows, but she, you know, she’ll read it, she’ll comprehend it, but she still don’t believe it. And there’s quite a few people like that. That’s another stigma, people don’t believe it. It’s like, ah, quit whining, just go on with your life. {P02; L105}
Related to the idea of simply denying the existence of mental illness, participants commonly reflected that avoidance of dealing with mental health concerns as they arise contributed to the development of stigma. A participant stated, “There’s thousands of people running around out there that really need mental help, don’t either don’t want to know it, know it and don’t want to admit it, or just won’t even think about it you know?” {P06; L035} Others reflected on the avoidance of mental health problems due to the perceived cost of admitting to them and the implications they would have for one’s definition of self. For example:

We know about it and we know, we don’t wanna accept it because it’s something that’s different that means that we as human beings, you know especially as parents we don’t want to accept because it’s like, okay, what did I do wrong? {P03; L069}

The final common theme which participants used to explain the development of stigma was the portrayal of persons with mental illness in the popular media. This theme described the popular media dramatizations of persons with mental illness and the barbaric psychiatric treatment depicted in movies, as well as the over-representation of crimes perpetrated by individuals with mental illness in the media. One participant stated, “It’s just more of movies where you see asylums and you see all these crazy people supposedly and stuff like that. Like One Flew Over the Cuckoo’s Nest. That mental hospital.” {P02; L053} Another participant reflected on how popular music has sometimes equated being mentally ill with being homicidal, “Tupac was saying, he was saying like, I think I’m partly schizophrenic and then like he’d be talking about shooting people and stuff.” {P12; L031}
Reasons for the persistence of stigma. Another common theme within the stigma domain were reasons for the continued existence of stigma despite efforts to eradicate it. Common explanations that were cited by participants included lack of information, unwillingness to change attitudes, and fear. Participants reflected that mental illness stigma continues to exist because, “people aren’t educated about it,” {P09; L023} and “information isn’t being put out there,” {P12; L049} with regard to advances in mental health research, as well as improvements to both psychosocial and psychiatric treatments. Another common reason given for lack of stigma reduction was simply an unwillingness to change attitudes. As one participant stated, “I’m not saying they’re stupid, just ignorant of what we’re about. Ignorance, or unwillingness to even delve into it farther and find out what we’re about.” {P06; L039} The same participant stated, “some of it is just plain they don’t care, you know?” {P06; L035} Other participants remarked about the influence of fear on the persistence of stigma, “We fear sometimes what we don’t understand, we don’t know. Fear of the unknown.” {P01; L027}

Early messages about mental illness in the development of stigma. When exploring the themes that emerged out of the participants’ earliest experiences and messages about mental illness, there was a generally equal distribution of responses between learning nothing about mental illness, and learning that mental illness was normal. By contrast, the frequency of codes in which early messages about “mental illness as negative” were double the frequency of the codes of no early learning experiences or neutral early learning experiences. One participant illustrated his knowledge of mental illness prior to being diagnosed, “I don’t think anyone ever told me anything about mental illness until I was mentally ill.” {P05; L063} Similarly, another
participant indicated that she was naïve about mental illness, “Until I faced the fact that I really had mental illness, I didn’t really start learning about it, you know?” {P09; L051} Some participants did reflect that some of the earliest things they learned about mental illness were that these things (e.g. symptoms) were normal. One participant said, “I kinda accepted it I guess, like insurance or death or taxes, you know, I kinda accepted everything and didn’t really question it.” {P04; L043} One participant even reported having positive associations with the word “psychotic”. He stated, “I just remember hearing like psychotic in music like psychotic, I just thought it was cool and everything.” {P12; L053} Finally, some participants acknowledged that their earliest messages about mental illness were negative. One participant reflected that she learned, “you cannot raise yourself, you will not be able to take care of yourself.” {P03; L170} Another common early message received about mental illness was that personal responsibility had little to do with recovery from mental illness. He stated:

That it can’t be helped. That we, that only way we can change is if we take meds, we take psych meds, you know? That we are powerless to it, of our own will, that we have to have some doctor prescribing some kind of medication to us. {P01; L031}

*Common stereotypes about mental illness.* Common themes that emerged regarding prevalent stereotypes about mental illness included the conflation of mental illness with low intelligence or stupidity, the perception of people with mental illness as invalids, associations between mental illness and criminal behavior, and stereotypes related to visible symptoms of mental illness. Many participants remarked on the
stereotype of persons with mental illness as “stupid” or “retarded”. One participant stated:

A common stereotype is they’re stupid. Automatically we gotta be stupid, automatically we don’t know what we’re talking about. Automatically we gotta be slow, it’s just a bunch of very negative, cruel things how people treat people with mental illness. {P01; L103}

Similarly, other participants described common stereotypes related to persons with mental illness being perceived as invalids. One participant remarked that someone with a mental illness is, “not somebody who sits around and they see us as not being able to provide for ourselves not being able to take care of ourselves. They come in and feed us and bathe us like we’re little invalids.” {P03; L015} Another participant expressed his anger over feeling like others were patronizing towards people with mental illness:

They look at them like they don’t know what they’re doing and they “ooh,” like a baby, they’re treated like a goddamn baby, “oh that’s okay dear,” and it’s like motherfucker, I ain’t, I’m not like, well first of all I’m not a kid, so you can’t talk to me like, with more dignity or respect. {P01; L223}

Other participants described the interaction between mental illness and crime as the genesis for other stereotypes. A participant remarked that “all the crimes and the majority of the time big crimes are done because of mental illness.” {P02; L196} The last most prevalent theme regarding stereotypes was stereotypes related to symptoms of mental illness, such as “not thinking right,” “can’t act right,” as well as stereotypes which
might arise from side effects of medication, “some of them (stereotypes) are like, medicine making you move slower.” {P12; L105}

*Public or stigma directly experienced.* When asked about the types of stigma that they have directly experienced, participants commonly described incidences of stigma from professionals, as well as a feeling of being patronized. In addition, many participants cited name calling as a frequently experienced form of stigma, as well as negative attitudes from their community towards mental health community centers. The most widely reported form of experienced stigma was that from mental health professionals. One participant recalled, “I wasn’t supposed to have kids at all. That’s what the doctor told me.” {P02; L120} Another participant reflected on the criminalization of mental illness as a result of the involuntary hospitalization process:

> Next thing you know there’s like six police officers up there. Like yeah, you’re not under arrest but yeah we’re going to take you. And then they took me to Rescue Crisis and then after Rescue Crisis they took me to Flower Hospital psych ward and I was like, ‘what the?’ Y’all didn’t tell me I was coming here, I thought I wasn’t under arrest. {P12; L109}

Another common form of stigma experienced by participants was being patronized by others. As explained by one of the participants, “I have a mind of a 12 year old. That’s what my father keeps telling me.” {P10; L189} Another participant added, “They’ll talk to me like all young, they don’t really treat me any different, but they’ll talk to me in a different way, they’ll speak to me in a more soft tone or something like that.” {P12; L137}
Surprisingly, participants also described name-calling as a commonly experienced form of stigma. One participant remarked, “People used to say ‘oh look at that ugly girl,’ and some other things they said but I don’t want to say it right now cause it’s not proper.” {P08; L191} Another participant added, “In this outpatient program a guy called me an environmental menace, that’s what he called me.” {P05; L197} Other participants spoke about public perceptions of their community mental health centers. For example, one participant remarked, “there’s a pretty shitty opinion of this place in the public.” {P09; L187}

*Internalized or self-stigma.* The most common theme related to internalized stigma was the feeling of not being good enough. A participant described it as feeling, “I’m not worthy, I really can’t do anything, I’m a piece of shit, you know, so on and so forth. Um, so I took that internally for a while.” {P09; L203} Others described feeling as if they deserved the sorts of public stigma that they experienced:

Some people feel like, ‘yeah okay maybe this is what I deserve. I mean I deserve to be shunned, I don’t deserve to be happy. I deserve to be sad. I don’t deserve to have a life.’ Because of the way society treats them.

{P03; L081}

Many other participants described internalized stigma as problems with low self-esteem, as one participant noted, “I’ve had big self-esteem issues over the years.” {P06; L119}

Another common theme related to internalized stigma was the idea of stigma existing even within communities designed to support those with mental illness. One participant remarked that even within her mental health agency, “people here kinda like push me off to the side, that’s what it feels like to me.” {P11; L023} Additionally,
another participant noted that not everyone was welcome at her mental health center, “we have a rule that anybody who is a sexual predator cannot be here.” {P06; L035}

Consequences of stigma. Participants described two major consequences or ways in which they responded to stigma that they experience. The first of these responses was a sense of isolation. Multiple participants commented that others might avoid contact with them. As one participant put it, “They’re running away, they don’t want to be your friends no more or they don’t want to be around you no more, they don’t want nothing to do with you no more.” {P03; L015} Another participant simply described feeling “nonresponsive” {P05; L051} as a result of the stigma he had experienced. A female participant vividly described the consequence of stigma in her own life, “A lot of time too I feel pushed like into the corner, like I’m not there, I don’t exist, I’m a ghost to a lot of people. So it makes me feel kind of yucky, you know, sickening, a little bit because I feel like I’m not wanted.” {P11; L019}

Others described the consequences of stigma as narrowing their experience. For example, “it makes me not want to try, it makes me in some cases not want to try different things.” {P01; L327} Another participant described his experiences with stigma and social rejection:

I don’t know for sure, maybe you know, meeting girls, being with women, needing to go in a store, you know. You want to put your best foot forward and everything but being you find out you have mental illness or something now, they’ll reject you. Rejection and everything you know. {P04; L149}
Hypotheses for reducing stigma. Two major themes emerged from participant responses on how to best reduce stigma in the general public. These included education, and the promotion of dimensional thinking. One participant reflected on the prevalence of television advertisements for antidepressants, and suggested greater efforts to include other mental illnesses:

You see the commercials for depression and you know, I mean, there’s more out there than depression. There’s borderline personality disorder, there’s schizophrenia, there’s multiple personalities, I mean, there’s so many out there that all you see is depression, well where’s the ones for these other ones? Maybe short commercials, maybe pamphlets or something, because, mainly because the commercials would work because of course people love TV. So if they’re watching TV and here comes a schizophrenia commercial it’s like, ‘huh? Oh I see.’ And you can call this 1-800 number to find out more information. {P02; L242}

Another commonly suggested strategy for reducing stigma was the promotion of dimensional thinking, or emphasizing the ubiquity of mental illness. This participant eloquently stated:

If we try and ignore that fear in us, then I think that can help decrease and just open people’s eyes to what’s really happening inside some of these people’s heads. Some people with really bad mental illness. I believe everybody got mental illness: you, your professors, everybody got some kind of mental illness, just on a different level. Yours may be lower, thank goodness for that, you go dude. Mine may be a little higher than yours,
some of ours just work on a different level and stuff, but if we could all remember at the end of the night that we’re human and that we do have power to try and decrease this. {P01; L047}
Table 2

Outline of themes: Experiences of stigma

I. Descriptions of stigma
   A. Dehumanizing
   B. Judgment as inferior
   C. Stereotyping and prejudice

II. Development of stigma
   A. Denial of mental illness
   B. Avoidance of problems with mental health
   C. Popular media construal

III. Reasons for the persistence of stigma
   A. Lack of information
   B. Unwillingness to change attitudes
   C. Fear

IV. Early messages about mental illness in the development of stigma
   A. Negative messages
   B. Mental illness as normal
   C. No messages received

V. Common stereotypes about mental illness
   A. Low intelligence or stupidity
   B. Invalids
   C. Criminals
   D. Symptoms and side effects

VI. Public or stigma directly experienced
   A. From professionals
   B. Patronized
   C. Name calling
   D. Community mental health stigma

VII. Internalized or self-stigma
   A. Not good enough
   B. Stigma within stigma

VIII. Consequences of stigma
   A. Isolation
   B. Narrowing of experience

IX. Hypotheses for reducing stigma
   A. Education
   B. Promotion of dimensional thinking
Chapter Four

Discussion

Stigma has been identified in the research literature as a significant barrier to seeking mental health services, an obstacle on the path of mental health recovery, and a barrier towards pursuing housing, healthcare, education and employment (Corrigan, 2004; Desai, Rosenheck, Druss, & Perline, 2002; Farina & Felner, 1973; Martin, 2010). A variety of explanatory models and methods for reducing stigma have also been proposed in the literature (Corrigan, 2005; Corrigan & Penn, 1999), but with little attention paid to the subjective experiences of public and internalized stigma from the perspective of individuals who have experienced these phenomena firsthand. This study sought to explore the experiences of participants of the WMR program with both public and internalized stigma and the potential effects of participating in a group psychotherapeutic intervention in changing the way they think about stigma, both experienced and internalized. The study was exploratory in nature and in the spirit of qualitative research, no specific hypotheses were set forth. However, the following research questions were put forward: (1) What, if any, types of stigma have participants in the WMR program experienced? (2) How did participants of the WMR program react to, and cope with, any experienced stigma? (3) Do participants in the WMR program feel that the experience has helped them to overcome stigma? (4) What, if anything, about the WMR program was instrumental in leading to any changes in stigma that the participants have experienced? In addition to these primary research questions, additional implications of the study are discussed, such as differences across the four groups selected for the study, and reasons cited by participants for their attrition from the program. Finally, the
implications of this study for the continual refinement of the WMR program and approaches to public and internalized stigma reduction are examined.

Research Question 1: What, if any, types of stigma have participants in the WMR program experienced? Participants were given time to reflect on and share their experiences with both public stigma and internalized stigma. In terms of public stigma, or experienced stigma, participants reported things such as betrayal among friends, overt discrimination, impatience from others, denial of any experienced stigma, ostracism and social avoidance, difficulties with family relationships, negative attitudes towards utilizing services at a community mental health center, being called pejorative names, feeling patronized by others, and experiencing stigma from mental health professionals. In the domain of internalized stigma, participants described feelings of isolation, loss of a promising future, memorized and repetitive messages about themselves, feeling as if they needed to explain their behavior, feelings of decreased self-efficacy, stigma towards peers even within groups of peers with mental illness, and feeling “not good enough.”

The most commonly cited forms of public, or experienced, stigma included stigma from mental health professionals, feelings of patronization, and name calling. The most frequent feelings associated with internalized stigma were not feeling good enough, as well as feelings of stigma towards peers with mental illnesses.

Although the participants sampled are only a small subsection of those living with mental illness, the prevalence of stigma experienced from mental health professionals was surprising, although it has received a small amount of attention in the literature (Deegan, 1990; Sadow, Ryder, & Webster, 2002; Sartorius, 2002; Schulze, 2007). There
are a few potential explanations for this. For individuals who live with more serious mental illnesses such as bipolar disorder and psychotic disorders, a great deal of time is spent engaged in activities related to treatment. Some of these individuals might live in a hospital setting, or a group home, where the entire course of their day includes interaction with mental health professionals. Even among those individuals who live independently in the community, their activities may be centered around their mental health treatment, and often individuals such as case managers or therapists serve as a large source of social support. As such, the sheer amount of time that persons with mental illness spend around those who are mental health providers simply makes it more likely that they will experience stigma from these individuals as opposed to others. Indeed, there is evidence to suggest that individuals with mental illness utilize healthcare services at a rate higher than the general population (Dickerson, McNary, Brown, Kreyenbuhl, Goldberg, & Dixon, 2003; Sokal, Messias, Dickerson, Kreyenbuhl, Brown, Goldberg, & Dixon, 2004). Additionally, it is only within the last few decades in which advances in treatments for mental illness have evolved to be more humane (although most treatments were considered humane in their historical context). With these more effective treatments, the attitudes and approach towards individuals with mental illness from treatment providers has changed as well. In the approximately 20 years since Anthony’s (1993) paper on recovery, mental health professionals have been afforded the opportunity to change the way that they deliver the services they provide, with continued improvement always possible.

Additionally, participants also reported quite frequently stigma in the form of name calling and patronization. While this is not often reported in the scientific literature,
it may be an appropriate area for further investigation. Interestingly, these findings fit
together nicely with some of the most commonly reported stereotypes about mental
illness reported by participants in this study. Among the frequently coded stereotypes
about people with mental illness, participants indicated that “stupid” and “invalids” were
among the most common. Following this, it would make logical sense that participants in
this study had also experienced being patronized and called pejorative names.

Research Question 2: How did participants of the WMR program react to, and cope with,
any experienced stigma? Participants in the study reflected on a number of adverse
consequences of stigma, including: anger, difficulty seeking mental health treatment,
feelings of being bullied, difficulty with trusting others, fear of being discovered as a
person with mental illness, pain and hurt, narrowing of experience, ostracism, and
substance use. One participant referred in a vague way to stigma being helpful in their
recovery process stating, “I don’t know how to explain it, it just does.” In terms of
coping, most participants commented on taking advantage of traditional forms of
treatment, such as psychiatric medication, psychotherapy, and case management. In
addition they described how social support, as well as self-acceptance and understanding
of their mental illness were useful in coping with stigma.

As has been described in the literature (Corrigan, 2004), the results of this study
provided additional support that stigma has adverse effects on social opportunities, as the
most cited effect of stigma in this study was that of ostracism, social exclusion, and the
narrowing of experiences. Of particular importance is the relationship between social
support and positive coping with mental illness and the way that individuals with mental
illness are often ostracized as a result of stigma. This finding has important implications for the relationships between stigma and mental health recovery. For example, internalized stigma may have an inverse relationship with mental health recovery since it makes seeking treatment more difficult. Stigma may also be indirectly related to mental health recovery as one of the consequences of stigma is ostracism, which ultimately gets in the way of developing intimate social relationships which are so often identified as crucial to mental health recovery (Corrigan & Phelan, 2004).

An additional finding from this study provides support for the idea that one response to stigma is anger. In this sample, anger was often described as a reaction to being patronized by others. Perhaps the most jarring example was one participant’s response to someone who told her that she should be “locked up.” Her response was, “I told the one guy, um, who told me that, I says, ‘You know what?...Get fucked. Fuck off.’ And I walked away from him.” In addition to this anger as a direct response to stigma, there was also some evidence to suggest that stigma could lead to anger, which ultimately led to recovery. One woman reflected that initially stigma negatively impacted her recovery, “but then I think I got to the point where I wasn’t going to let it.” {P06; L155} For some, this anger can be useful (Chamberlin, 1978; Corrigan & Watson, 2002; Deegan, 1990), and at the opposite end of the spectrum the anger can be turned inwards as internalized stigma (Watson & River, 2005).

Research Question 3: Do participants in the WMR program feel that the experience has helped them to overcome stigma? The WMR program has the potential to influence both public and internalized stigma. For example, participants may find themselves
empowered by the group discussions and philosophy and be motivated to take action in their immediate environments to change others’ attitudes about mental illness. Additionally, the educational components of WMR may provide participants with an increased lexical knowledge, enabling them to notice and identify stigmatizing attitudes that they have internalized and overcome them. During the interview, participants were asked if participating in the WMR program had changed their understanding of stigma, or the way that they cope with stigma (both public and internalized). Responses to this portion of the interview generated very few codes, and do not suggest a strong and direct relationship between WMR participation and changes in either public or internalized stigma. One participant stated that WMR simply had no effect on her relationship to stigma. Others suggested that WMR helped them to connect the term “stigma” with things that they had previously experienced, as one participant stated, “I just thought it was just people being mean and rude.” {P02; L148} Some participants noted that WMR helped with managing public stigma as the WMR program was empowering, both in the sense that they felt more capable, and in the sense that they were better able to help others.

This finding is not unexpected, as WMR is a manualized treatment, and stigma is only briefly covered in one of the modules. Facilitators are also encouraged to foster group discussion, personal involvement, and experiential learning. It is likely that since the discussion of stigma is only a small portion of the content, participants were not as exposed to this material as they were to the more psychoeducational aspects of the treatment, which most participants in the study identified as most valuable. As the WMR curriculum includes plenty of educational material, (some participants have even referred
to it as a “class”) the quantity and structure of the educational components are likely to be
easily remembered by participants, and may ultimately overshadow the more experiential
elements of the group that do not occur as frequently. Although this study only examined
qualitative data, and not quantitative data on stigma reduction it suggests that future
efforts to reduce internalized stigma would need to have interventions incorporated that
more directly address stigma reduction. Multiple approaches to reducing internalized
stigma have been suggested and evaluated already. Corrigan (2005) cites evidence that
cognitive therapy is helpful across myriad outcome variables for individuals with
psychotic disorder. Corrigan suggests that internalized stigma can be averted by changing
cognitive schemata related to stigmatizing attitudes. Fostering empowerment has also
been hypothesized to be useful in reducing internalized stigma. Examples of this include
 Assertive Community Treatment (ACT; Stein & Test, 1980), which emphasizes
community-based support for individuals with mental illness. Additionally, individuals
can seek peer support at clubhouse-model support centers, much like the ones from which
these data were collected (Beard, Propst, & Malamud, 1982). Newer and promising
approaches to reducing internalized stigma include: Acceptance and Commitment
Therapy (ACT; Luoma, Kohlenberg, Hayes, Bunting, & Rye, 2008), Ending Self-Stigma
(ESS; Lucksted et al., 2011), and Coming out Proud (COP; Corrigan, Kosyluk, & Rusch,
2013; Rusch, et al., 2014).

Research Question 4: What, if anything, about the WMR program was instrumental in
leading to any changes in stigma that the participants have experienced? Although
participants did not report drastic changes in their relationship to either public or
internalized stigma after participating in the WMR program, some participants acknowledged that the educational aspects of the WMR program were helpful in overcoming internalized stigma, while the empowering philosophy of WMR inspired them to become advocates for themselves and others in overcoming public stigma. Participants described simply learning the term “stigma” helped them to attach meaning to experiences and feelings with which they were already accustomed. It would seem that WMR facilitates the transmission of a new vocabulary that participants can then use to better understand and validate their emotions. This is a common strategy of cognitive-behavioral approaches which seek to help individuals to notice and identify their emotions (Linehan, 1993). Additionally, participants responded to the empowering spirit of WMR, often describing their admiration for group facilitators or others in the group. Fostering this empowering spirit seems to be an important component of overcoming internalized stigma.

Additional Findings

An additional opportunity afforded by the approach to sampling in this study was the ability to subjectively compare the richness of interview protocols across the four differing groups sampled: reliable improvement, no change, reliable deterioration, or non-completion. Overall, there were no striking differences in interview richness or quality across the four groups. Within each group, there seemed to be one participant who stood apart from the rest in terms of the richness of the data obtained from their interview. Overall, this finding suggests that despite their utility as a psychometric self-report outcome measure, change scores on the MHRM can still only capture a very small picture of an individual’s personal recovery process.
Participant attrition is a crucial issue in any research study, as it is when engaging in treatment for mental illness. Three individuals who did not complete the entire WMR curriculum were interviewed and asked about any reasons why they did not complete the program. The responses were unique and could not be classified into broader themes. As such, each of the relevant responses will be presented, followed by a brief discussion.

One participant responded:

Oh, I got sick and I wound up in the hospital, so I had to drop it. Only to lesson three and once to lesson six because I’m in the hospital a lot because I have a bad heart so, um, yeah. But I’m gonna take it again in January and I’m going to go through the whole thing. {P10; L121}

This participant indicated that she was experiencing physical health problems which prevented her from completing the group. When asked if there were any undesirable parts of her experience in WMR, she did not cite any. In fact, she pointed out that she planned to re-take the WMR curriculum when her health improved. Another participant indicated the following when asked why she did not complete the WMR program:

Well, I didn’t feel like I could finish only because I have a very negative attitude. I’m not a happy jolly person. And they said specifically you have to have a happy personality. Well I can’t. I have bad memories and they just don’t wanna leave my brain, the bad memories. {P11; L129}

Following this, the interviewer attempted to clarify the nature of her departure from the WMR program. The participant indicated that she made the decision to leave on her own free will, and was not specifically asked by the group facilitators to leave. She attributed this decision to her discomfort with feeling comfortable being “herself” in the group.
These circumstances could be interpreted in many different ways. The most favorable explanation would be that this participant experienced an idiosyncratic aversion to the group members in this particular group. Presumably, she would be able to enroll in another WMR group where she might mesh better with group members. Another explanation might hypothesize that this is a personal problem area for this participant, and she is currently working towards better social and interpersonal functioning. A final explanation has important implications for how WMR facilitators are trained. Although negative thinking is a common human problem, the cognitive model of psychotherapy has permeated the culture to the extent that sometimes the power of positive thinking is overstated. It is possible that in this instance, the “positivity” associated with the WMR curriculum may have been invalidating for this participant, who ultimately decided to stop attending the group.

The third participant who had not finished the entire WMR curriculum remarked that he felt as if he did not fit in with the group because he was significantly younger than most members in the group.

An essential component of evidence-based practice is measuring outcomes and responding to needs for change. Although gathering feedback for the purposes of improving WMR was not a primary goal of the study, some valuable information can be gleaned from the data. Most notably, and perhaps most surprisingly, the most frequently used code related to the components of WMR was its educational function. This means that participants reflected frequently on how useful they found the psychoeducational material presented as part of the WMR curriculum. It would seem that for many, participating in the WMR program is the first time that these participants were provided
with proper psychoeducation regarding their illness. Bolstering and strengthening the psychoeducational components of the program may be a useful modification to the current WMR curriculum.

The youngest participant in the study reflected on the age of members of his WMR group, and of the age of others in general at the site where he was being interviewed. Clearly, attracting younger individuals living with mental illness is not a problem endemic to the WMR program. It is, however, something that should be considered when WMR is being implemented at new sites. Having this information, individuals who are responsible for implementing WMR at a particular site should pay close attention to the age range of participants in the first WMR groups. Setting a precedent that the group is open to participants of all ages would be most effective in ensuring that future groups continue to have diverse constitution. There is scant, yet promising evidence that intervening with specialized treatment during the prodromal phase of psychosis (usually between ages 16 and 30) is helpful (Marshall & Rathbone, 2011).

Additional participants reflected on the amount of paperwork associated with participation in the WMR program. The individuals were referring to the self-report outcome measures that are collected to examine the effectiveness of the group. While the number of outcome measures changes over time, use of reliable and valid outcome measures is a central part of maintaining any evidence-based clinical practice, and will continue to be a key component of WMR implementation. Nonetheless, future modification to the WMR program should consider the burden of completing outcome measures on the participants.
Additionally, one of the findings of the study which is not reflected in the extant literature is the idea of individuals with mental illness may also experience stigma from others within their peer groups. Multiple participants reflected on this idea that even within their peer groups, individuals might avoid certain places or activities due to other individuals that they perceive as different because of their mental illness. This illustrates that even within cultural “out-groups” there can be further divisions still. Calling attention to this phenomenon as it occurs within the group environment could be a good starting point in reducing stigmatizing attitudes and behaviors even within stigmatized groups.

Limitations of the Current Study

Although the present study yielded rich data from a wide variety of participants in the WMR program, the sample remains a limitation. The sample size in this study was typical for this type of research, and there is good evidence to suggest that saturation was reached. However, the results of this study cannot be generalized to the population of persons living with mental illness at large. The concepts may be salient to furthering additional research on the processes of stigma. In particular, the data collected in this study were collected entirely from participants at consumer-operated sites, as opposed to community mental health centers. Potential participants were identified in archival WMR outcome data from both consumer-operated sites and community mental health centers alike. However, in reaching out to WMR site coordinators at various agencies, it proved difficult to recruit participants at community mental health centers. This may be reflective of the exceedingly high productivity expectations, and possibly subsequent burnout (Pines & Maslach, 1978; Prosser, Johnson, Kuipers, Szmukler, Bebbington, &
This further highlights the need for traditional forms of treatment such as those obtained in community mental health centers, but also for peer-delivered services, such as those offered at consumer-operated sites. Additionally, even if the sample had been collected equally from both community mental health centers and consumer-operated sites this would not include individuals with mental illnesses who receive services in the private sector, or those not formally involved in traditional methods of treatment.

From the viewpoint of an interpretivist, a crucial limitation of this study is the level of familiarity with the existing literature on the topic under study. As a result, the data that were collected in this study were also processed through the filter of the researcher’s experience in addition to that of the participants. An alternative approach would have been for the researcher to first collect and analyze the data before consulting the existing literature.

An additional limitation is the approach to determining trustworthiness of the data. Although a process of auditing was conducted with the researcher’s committee chair, both individuals are from a similar background and likely share many of the same biases given their occupation. Adding a member to the research team who is not involved in academia or healthcare might add a different perspective to the auditing process and ultimately increase the trustworthiness of the findings.

Directions for Future Research

As has been demonstrated before, the mental health recovery process is dynamic and nonlinear. Current efforts to evaluate the effectiveness of WMR rely on comparisons of group means of the MHRM at two or three discrete points in time. Data from this
study suggest that individual change scores on the MHRM do not necessarily capture individual global changes in mental health recovery. Future research on WMR effectiveness might focus more deeply on session-to-session changes in mental health recovery and associated outcomes. For example, Ben-Zeev, Kaiser, Brenner, Begale, Duffecy, and Mohr (2013) have detailed the development and usability of a smartphone self-monitoring system for individuals with schizophrenia. This type of mobile assessment and intervention may yield detailed data that would be useful in assessing the recovery process over multiple points in time.

A novel finding of this study is the frequency with which participants identified that they had experienced stigma from mental health providers. Providers are uniquely positioned and poised with the knowledge to effectively combat stigma, but their close contact with individuals diagnosed with mental illness also places them in a position to unintentionally (and sometimes intentionally) convey negative attitudes or make recommendations to their clients that could be perceived as stigmatizing. Future studies might examine quantitatively how common it is for individuals with mental illness to perceive stigma from their providers, and what might be done to decrease how often this happens.
References


of the Swedish versions of two stigma scales measuring
devaluation/discrimination and rejection experiences. *Nordic Journal of
Psychiatry, 61*(5), 332-338. doi: 10.1080/08039480701642961

Yale University Press.

Bullock, W., O'Rourke, M., & Smith, M. (2005). Implementing illness management &
recovery in mental health practices and agencies. *Family Therapy Magazine, 4*(3),
32-36.


Chamberlin, J. (1990). The ex-patients’ movement: Where we’ve been and where we’re

qualitative analysis: Pine Forge Press.*

and across levels: a multilevel approach to stigma and public health. *Soc Sci Med,
103*, 101-109. doi: 10.1016/j.socscimed.2013.09.023

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and
procedures for developing grounded theory: Sage.*


and social change: American Psychological Association.*


Defoe, D. (1728). *Augusta triumphans: or, The way to make London the most flourishing city in the universe.*


outcome of subjects who retrospectively met DSM-III criteria for schizophrenia.

*American journal of Psychiatry, 144*(6), 727-735.


therapy: Model, manual development, and pilot outcomes. *Addiction Research & Theory, 16*(2), 149-165. doi: 10.1080/160866350701850295


Sokal, J., Messias, E., Dickerson, F. B., Kreyenbuhl, J., Brown, C. H., Goldberg, R. W.,
serious mental illness who are receiving community psychiatric services. *The
Journal of nervous and mental disease, 192*(6), 421-427. doi:
10.1097/01.nmd.0000130135.78017.96

of experienced and anticipated discrimination against people with schizophrenia:
a cross-sectional survey. *The Lancet, 373*(9661), 408-415. doi: 10.1016/S0140-
6736(08)61817-6

toward mental illness. *Journal of community psychology, 24*(1), 17-25. doi:
10.1002/(SICI)1520-6629(199601)24:1<17::AID-JCOP2>3.0.CO;2-0

Services, Substance Abuse and Mental Health Services Administration, Center for
Mental Health Services, National Institutes of Health, National Institute of Mental
Health.

mental illness. *American Journal of Community Psychology, 17*(4), 521-528. doi:
10.1007/BF00931176

to Stigma.


Appendix A

Semi-Structured Interview Protocol

**Domain I: Personal Narratives**
1. Core: Are you familiar with the term “stigma”? How would you describe it?
   1a. Where does stigma come from?
   1b. Why does stigma continue to exist?
2. Core: What are some of the first things you remember being told about mental illness?
3. Core: How have you overcome stigma in your own life?
4. How do we prevent stigma from developing?
5. How can we decrease stigma in the general public?
6. How can you decrease stigma you feel about yourself?

**Domain II: The Role of WMR**
7. Optional: Was there anything which prompted you to leave the WMR program? If not, why did you leave?
8. Core: Please describe what happened during your participation in the WMR program. What change, if any, in the way you view yourself took place during your participation in WMR?
9. How did WMR differ from other groups you have attended in the past?
10. What did you take away that was different?
11. What, if any, were the undesirable parts of attending the WMR program?
12. Did the WMR program contribute to your recovery? How?
13. Do you feel that the WMR program has had any impact on your relationship to stigma?
   14a. What part of WMR was most helpful in doing this?

**Domain III: Internalized Stigma**
14. Core: What are some common stereotypes about people with mental illness?
   15a. Do you believe any of those to be true of yourself?
15. Has your mental illness changed the way in which you interact and connect with other people?
16. How do you feel about being around people without mental illness?
17. Does having a mental illness affect how often you interact with other people?
18. Do you feel that it is important to keep your mental illness a “secret”?
19. Do your family/friends know that you are receiving mental health services?
   20a. How do you think they view you now that they know you are receiving services?
20. How do you feel knowing that you have a mental illness?
21. What are some of the benefits of having a mental illness?
22. What has been your outlook on life since being diagnosed with mental illness?
23. How does having a mental illness change the way you relate to other people?

**Domain IV: Public Stigma**
24. Core: Do people treat you any differently because you have a mental illness?
25. What are some attitudes that you believe people hold about people with mental illness?
26. What do the media and the general public think about mental illness?
27. Do you feel stigmatized? In what ways?
28. Have your friends or family treated you differently since they know you have a mental illness?
29. What effect has telling people that you have a mental illness had on your relationships with them?
30. How would your life be different if you did not have a mental illness?
31. Has having a mental illness impacted the quality of your life?
32. How did you react to and cope with any stigma that you experienced?

**Domain V: Stigma and Recovery**

33. **Core: Did your experiences with stigma interfere with your recovery process?**
34. Did stigma interfere with your recovery at the very beginning?
35. Does stigma continue to influence your recovery journey?
36. Has stigma interfered with the way you seek/receive services?

37. Have you ever been arrested, charged with, or convicted for a crime?
   37a. Was law enforcement or the courts aware that you had a mental illness?
   37b. Did this knowledge influence your experience with the criminal justice system?
   37c. Has your mental illness and history of criminal justice involvement had an effect on your life?
   37d. What does the public think about people with mental illness that are involved in the criminal justice system?
ADULT RESEARCH SUBJECT - INFORMED CONSENT FORM

Developing a Theory about the Role of Stigma in the Recovery Process

Principal Investigator: Wesley Bullock, PhD, Faculty Advisor, 419-530-2719
David Medved, BS, Graduate Student, 419-530-2721

Purpose: You are invited to participate in the research project entitled, Developing a Theory about the Role of Stigma in the Recovery Process which is being conducted at the University of Toledo by David Medved, BS under the direction of Wesley Bullock, PhD. The purpose of this study is to learn about your experiences with stigma and how it relates to your recovery process.

Description of Procedures: This research study will take place in the community mental health center or consumer-operated site in which you are receiving therapeutic or supportive services. You will be asked to speak and answer questions about your experiences in the Wellness Management and Recovery (WMR) program, and your life experiences as they relate to stigma and recovery. This will include questions regarding how helpful or hindering the WMR program was, in addition to other questions relating to the stigma and your recovery process. Your entire participation will take about 1.5 hours. Your interview will be audio recorded, with your permission.

Permission to record: Will you permit the researcher to audio record during this research procedure?

YES ☐ NO ☐

Initial Here Initial Here

After you have completed your participation, the research team will debrief you about the data, theory and research area under study and answer any questions you may have about the research.

Potential Risks: There are minimal risks to participation in this study, including loss of confidentiality. In taking part in the interview process you will be answering questions and speaking about your WMR experience as well as aspects of your personal life relating to stigma and recovery. It is possible that you may experience short-term anxiety in discussing aspects of your participation in the WMR treatment group and process. However, the investigator you will be working with is trained to encourage and support you in obtaining a positive experience through your participation. Furthermore, your information will remain confidential and will not be shared with any of your WMR treatment facilitators. You may choose to stop participating in the study if at any time you feel uncomfortable.
**Potential Benefits:** The benefit of taking part in this research is that you will have an opportunity to reflect on and discuss the experiences you had while taking part in the WMR program. Others may benefit by learning about the results of this research.

**Confidentiality:** The researchers will make every effort to prevent anyone who is not on the research team from knowing that you provided this information, or what that information is. The consent forms with signatures will be kept separate from responses, which will not include names and which will be presented to others only when combined with other responses. Although we will make every effort to protect your confidentiality, there is a low risk that this might be breached.

**Voluntary Participation:** Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled and will not affect your relationship with The University of Toledo or your current treatment provider or consumer-support organization. In addition, you may discontinue participation at any time without any penalty or loss of benefits.

**Contact Information:** Before you decide to accept this invitation to take part in this study, you may ask any questions that you might have. If you have any questions at any time before, during or after your participation or experience any physical or psychological distress as a result of this research you should contact a member of the research team (David Medved, BS, 419-530-2727; Wesley Bullock, PhD, 419-530-2719).

If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, the Chairperson of the SBE Institutional Review Board may be contacted through the Office of Research on the main campus at (419) 530-2844.

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

**SIGNATURE SECTION – Please read carefully**

You are making a decision whether or not to participate in this research study. Your signature indicates that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research.

The date you sign this document to enroll in this study, that is, today's date must fall between the dates indicated at the bottom of the page.

<table>
<thead>
<tr>
<th>Name of Subject (please print)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Person Obtaining Consent</td>
<td>Signature</td>
<td>Date</td>
</tr>
</tbody>
</table>
Appendix C

Sample Interview Protocol

So I'll just start out with the first question, are you familiar with the term stigma?

Yes.

How would you describe it?

Mmm...sometimes with unfortunately with my illness I know things, sometimes it's hard for me to explain it because like my brain doesn't work like it used to and I'm always on medication but to me stigma is like kinda like stereotyping as well.

Mhmm.

Kind goes hand-in-hand because once people learn that you're, you have a mental disorder it's like "oh my god you have the black plague." [chuckles] Or something like that, you know? Or everybody like freaks out.

Ok. So it's like a stereotype, people..

Yes.

..are not quite sure what to do, it sounds like.

How do we act? How to talk to you, how to ask you anything. When I first learned about my ill- my mental illnesses I went and got a bunch of brochures, handouts, everything, to read about my disability. Now I read all this but I'm not going to like, baby myself or anything and use it as um a way to get away with everything because that's not how it works. Or it's not supposed to work that way. [chuckles] So I um, I deal with a lot of things with my mental illness but it's just education of mental illness needs to be upped quite a bit.

Ok. So you just get the sense that people, the general public doesn't know a whole lot about it. That's right. Even family members, some family members don't believe in mental illness, they don't want to, um, don't know how. They don't get information about it, I have repeatedly tried to give information to my mom. My dad, he reads it, he understands more than my mother. My mother always said 'just pull yourself up by the bootstraps and go on with life,' but that's not always, um, it's not, you can't, it's not always going to work that way.

Mhm.

So I try to give family members, even my kids, give 'em information when they were teenagers to understand what's wrong with their mother, well, not really wrong, but what I have to deal with and suffer, you know, it's not really suffering either, it's just, everything in my life changed when I turned 17. You know, it, it was scary. [chuckles]

Yeah.
I knew there was something wrong with me from the get-go, I just didn't know what and then I used to uh self-mutilate, and then I tried to commit suicide when I was 17, so as soon as I realized I will never do that horrible thing again, my parents, instead of, my parents kind of went both ways after I tried to commit suicide. They were very angry at me because I'm their daughter. And they were angry that I would actually want to take my life and cost them money and all this, you know, then they turned around and actually got me to a psychiatrist. And that's when I was diagnosed with my illnesses and put on medication and it's been a battle ever since with myself sometimes. It's not so much a battle anymore after I turned 30 it's, it's, I realized I have to be on meds, I have to better myself, I have to go to therapy, I could go to groups, find ways to cope with my mental illness and figure out how to deal with life. It's a long journey.

Yeah, yeah, that's what I hear from a lot of people.

VERY LONG journey! I'm going to be 42 this year and I'm still learning and still finding different ways to cope and stuff like that, so, yeah. Mhm. I think I will be probably in many ways finding new ways and everything until I die because whenever that is I'll be still goin'.

Yeah. Ok. Where, uh, where do you think that stigma comes from?

I don't know. To be honest.

Ok.

It started way back then when um, children were born mentally ill or sadistic or whatever or even deformed and I'd be scared to death to be in an insane asylum because I know they don't have asylums anymore but that's where you put somebody with a mental illness and they treated them like worse than animals or they lock you in a room or in a attic or a basement. Yeah, I don't, I think it started, oh jeez, whenever the asylums started, I don't know. Couldn't start with Adam and Eve, well it could, but you never know [chuckles].

Yeah. So yeah, it seems like, it seems like people never really got over that part where we were locking people in basements or locking them in a hospital and so a part of that is still really relevant in people's minds maybe.

Mhm. They don't realize that mentally ill people, regardless in my opinion any kind of mental illness you still need proper care and you still need to talk to people, you still need, you just can't be locked away somewhere and just fed or whatever and then a guinea pig with electric shock therapy or lobotomies or whatever, man those are horror stories ...eee...

Yeah, yeah, I think we've come a long way since those days.

Oh yeah. But like you said, some people still just go by that, that's where they get their stigma or whatever because they make a lot of movies...

Mhmm...
And then they do have true story shows, but not very many, it's just more of movies where you see asylums and you see all these crazy people supposedly and stuff like that. Like One Flew Over the Cuckoo's Nest. That mental hospital.

Yeah.

You know, I mean, it's not like that at [chuckles] anymore. It's just like medication and therapy now [chuckles].

Yeah, yeah, that's um, that's actually one of the other questions that I've been asking, and it's oh, right here. What are the media and general public think about mental illness and like what you were saying was that in the movies...

They scare people!

...they scare people, yeah.

Or then they kinda make it funny too, like the One Flew Over the Cuckoo's Nest, they tried to make it funnier, it's not really scare- you're not supposed to be scared, and you're not supposed to laugh, there's an in between...

yeah.

...and it's called reality.

So the movies don't really get the idea that there's not, there's a lot of space in between the two extremes.

Yeah, they don't, they don't get that. [chuckles]

Ok. Uh, why, why do you think that stigma continues to exist, I mean, given that treatments have improved and to some extent we know a little bit more, why is it still a problem?

Not enough information. I said earlier before you started recording, you see the commercials for depression and you know, I mean, there's more out there than depression. There's borderline personality disorder, there's schizophrenia, there's multiple personalities, I mean, there's so many out there that all you see is depression, well where's the ones for these other ones? Maybe short commercials, maybe pamphlets or something, something, because, mainly because the commercials would work because of course people love TV. So if they're watching TV and here comes a schizophrenia commercial it's like "huh? ...oh, I see." And you can call this 1-800 number to find out more information...

Yeah, just gettin' that exposure out there.

Exposure for mental illness really needs to be out there. You got it for sex, you got it for kids, you got it for everything under the sun except more information about mental illnesses. There's quite a few of them. You can't just advertise for one and expect everybody to understand the other ones.
Yeah.

Because when people hear schizophrenia and multiple personalities, they freak out, just like asylums, they get scared, they're like “oh my god”, there's your stigma, there's your stereotype, there's your everything.

Mhm. Ok. What are some of the first things that you remember being told about mental illness?

Give me a moment…

Sure.

I've got a little ways to go back. [chuckles]

Ok.

Um. When I really started knowing and figuring out was when I was 17, I used to, I knew there was something wrong with me, in my, in my mind, before 17, probably like maybe 12-13 cause that's usually when mental illnesses start kicking in and I used to self-mutilate and then when I was 17 I committed, I tried to commit suicide. And after I, you know, my mom and dad were mad at me and then got me diag- got me to a psychiatrist, and diagnosed with bipolar disorder, that's when I really started paying attention.I got information about my disorder, you know handouts, questions from the psychiatrist, you know anything. And that's pretty much when I started really figuring out about the mental.

I know you said that your, your mom really didn't believe in it, your parents didn't really know a whole lot, did you, prior to being 17, did you know a whole lot about mental illness, like other family members or other people in your city?

Well, my family members kinda [chuckles] I guess my behavior um, they just kinda like didn’t have me around as much.

Mm…mk.

At schools, oh my lord, in elementary, I guess I, now I'm starting to remember quite a bit. In elementary I had behavioral problems. In elementary school. They did testing when I was in the sixth grade, they discovered I had the smarts of a twelfth grader but my um behavior was like a 5 or 6 year old because I was the mental. So…junior high I had a lot of trouble. I was in a special class for behavioral problems. Um, I started out with one kind of class and then the second class was just being in a portable and this was before uh, 17, I mean, they had me in a portable in junior high where everything was structured and somebody was on my butt 24 hours, well, at school hours, and that's how it was at home, I had to have structure, somebody had to be on my tail tellin' me what to do, what not to do cause I couldn't my thought process, I couldn't figure out well if I do this, this is going to happen. Sometimes I still have that problem. But long story short, I've been in behavioral problem [clears throat] classes since I was in junior high. And then um, yes, my mom and, well, my mom mostly, my dad understands
me more. He's more down-to-earth in dealing with reality than my mother. She's uh, my mother came from a very, excuse me, bad situation and she's just pulled her bootstraps up and went on and became a very strong, great person. I mean, she's a great mom, she's a great everything, but she's so strong on the pull your bootstraps up, bootstraps up and go on that she kinda like ignores [sigh] mental illnesses even though she had to somewhat deal with it when I was 17 and got diagnosed, um, she still thinks, there's really nothing, I'm just using problems or whatever to have the bipolar disorder, she doesn't understand it's a chemical imbalance that's way off or somethin'. She, I tried givin' her pamphlets and stuff to read up on my disability so she knows, but she, you know, she'll read it, she'll comprehend it, but she still don't believe it that. And there's quite a few people like that. That's another stigma, people don't believe it. It's like, ah, quit whining, just go on with your life. Well, you know that makes me think that people don't deal with some of the stuff they had to go through or did or whatever and they just put it in the back of their mind and that's how they come up with their stigma about mental illnesses because they don't deal with their own. A lot of people are like that, they don't want to believe it, they don't care, they're like whatever...and in my opinion, this is neither here nor there, kind of a stigma in my opinion is men don't really seek it out, don't really want to seek it out. My ex-husband um, supposedly a husband diagnosed with bipolar and stuff like that but he refuses to do anything about it.

Men are stubborn, huh?

VERY! Outrageously stubborn! But then you know it doesn't help because when you have two mentally ill people, one is taking medication and is um going to therapy, I don't know if this helps with your research but let me tell you somethin', when you're with somebody that doesn't believe in it and supposedly you love them so much and you have children with them, er, or even just parents or whatever and they say "you don't need your medication, I'll help you, it's ok, blah blah blah" I have been on and off my medication until the age of 27, so that's ten years of on and off, on and off, because I would believe my, my ex husband. Well, when we were husband and wife, I would believe him and say ok, I don't need it. But then I wind up self-medicating. Which is not good. Long story short, it doesn't help when somebody tells you they can help you and you don't need medication. That's another thing mentally ill people have to battle. That's another stigma kinda in a way too because here's your, here's my husband, that I have two beautiful children with, trying to tell me that I don't need medication and I'm just fine the way I am, but then uh, when things get tough and my mood swing is going the opposite direction, he's like "oh my god you're crazy [nagging sounds]" I'm like, I told you I need my medication. It took me ten years to accept myself to say hey, you didn't ask for this mental illness when you were born, it's not your fault, it doesn't make you any less, but a lot of mentally ill people think less of themselves because we're not "normal", whatever that is, I don't wanna know [chuckles]. But we're you know, we get down on ourselves, we don't want, we, sometimes we have our own stigma to our own self. We kinda put ourself [unintelligible] like "there's something wrong with me, I shouldn't be taking meds, I shouldn't do this, I shouldn't do that" and it's really hard but finally after ten years I dropped the attitude and I accepted myself, accepted I have to take medication and accepted that I need therapy and coping skills and everything else to help me with just living differently.

Made a lot of progress it sounds like.

Oh yeah. It still goes on [chuckles]. Might happen til the day I die... I might change another
thing the day of my death, I never know. [chuckles]

Um, alright, uh. [drums fingers on table] How, how have you overcome stigma in your own life?

That's a good question. Well, ok, like I said, sometimes I even stigmatize myself but now, um, I deal with um, first the public. Well, first of all, I take the medication and learn coping skills and stuff like that. Anger is one of them. When you get mad at somebody because they don't wanna understand you or they don't know how or whatever, I just calmly say to myself “these people are ignorant to the mental illness.” If they are worth somebody, if that is somebody that is worth, I shouldn't say, worth, but, like if it's just some stranger on the street and then makes a remark or whatever, I just ignore it and go one, whatever. But if somebody important in your life is making fun of you or whatever, then you, you kinda get hurt and upset but instead of gettin' mad and freaking out and throwing a fit or whatever, I would sit down with that person and talk with them and even children, I will sit down with them to a certain extent to explain to them what the mental illness is. I'm not a doctor, I'm not a therapist, I'm not a counselor, I'm not a research student [chuckles], but I am pretty um, intelligent in the area of mental illness, or at least I try to be because this will, this is a neverending epidemic. It started back when and it's 2013 and we still have kids born to um mentally ill parents. My daughter, my oldest, is schizophrenic-affective, she has already given me two grandchildren. I have a grandson and I have a granddaughter, but I, I know my daughter is not able to take care of her, her children and that's a whole different story but my grandson is being adopted because he was taken away from my daughter. My granddaughter is with her, with my daughter and (whispers: could you end this, I gotta go...)

Sure.

Anyway, with my daughter, she'll be twenty-two this year and she has one child with her and one being adopted. And um, I love my daughter, but she has the mind of a, what is it, a ten year old? Because unfortunately, um, I wasn't supposed to have kids at all. That's what the doctor told me. Two years later after I was told that I uh, I had gotten pregnant with my daughter but I was drinking. Alcohol was one of my best self-help at the time. It is not now [chuckles]. I don't need that, right. I unfortunately, the first month and a half I had drank, she had got fetal alcohol syndromes, uh syndrome, it's like a, um, a mild case of it.

Ok.

And, that didn't help to her, the rest of what I gave her genetically. And because she has the fetal alcohol syndrome, the schizophrenia, etcetera, etcetera, she really does act like she's ten, I mean, she, she cannot really do the thought process and she is battling the same thing I battled. She, I don't think, in my opinion, my daughter has not fully accepted it and because she is not taking her meds, she just told me the other day she took herself off her meds, well I can't sit there and tell her 'you got to you got to', she's gonna have to find out herself. You can only do so much and show and teach and whatever so much. So, um, I personally don't think she should have um her child, her youngest, let's see, she's going to be four months old. I don't think she should have her because she's not well herself. I shouldn't have had my children until I ...it's a woulda coulda shoulda, but I'm just lettin' people know that I should not have had children until I could accept myself, get better, get on meds, go to therapy, but see you can
only be on meds so long until it starts hurting the baby. But if you can find ways for the nine months, um, I mean because I think mentally ill people should still be able to have children. Um, I, and this is the stigma that you are talking about. In my opinion, I think every person in this world, including children, somehow, have some kind of mental illness. Or, um, not just illness, but the way they think, the way they process. There is no perfect person in this world. There is no real normal person in this world, in my opinion. But I am also a Christian, so I believe we're all here for a reason. We may not be here in the best way or with the best, um, genes or whatever. Mental illness is also a problem just like it needs to be taken care of and monitored just like diabetes or, you know, illnesses that, I mean, everyone’s got an illness somewhere, over- being overweight, because they’d rather have food or you know, to deal with problems or whatever, its just there is no perfect person in this world. The only perfect person I know is up above and he’s the one that put us, you know, yeah, we mom and dads put kids down here, but there's a reason why because I was not supposed to have kids and I have three. My youngest daughter is not mentally ill. At what point you can determine. She has got her heads, head, she's eighteen, she has her head on, head on her shoulders, she's doing good, you know. My son, I believe has mental illnesses and he refuses to go get help. So I think two out of my three have a mental illness. And you can only do so much. You can help them when they're children, because they all, all of 'em started out with ADHD, oh my lord, heh, especially, the oldest, oh my god it was like three kids in one, but anyway, long story short, you know, they, I helped them over the years, taught them, teached them, showed them brochures, read to them, helped them understand as much as I can about my mental illness, about what illness they might have, or might get. This runs in the family, blah blah blah blah. Does not mean you're going to have every single one, but I think my two oldest have mental illnesses. Well, my oldest definitely does, she’s been treated for it since pft, she was five. My son, he's of course my son, a boy, a male, a man, will not get help. He’s just like his dad. [mocking voice] I don't have mental illness, I don't need no medication [end mocking] oy, whatever. So I mean, I can only do so much. I can help make people get rid of that stigma. I can help people get informed and educated and or recommend or speak out like I am now to help but there's only one person that I can help and that is me to continue every day to figure out how to deal with somebody saying “Oh, you’re just a crazy mmmm” and, you know, I, I try not to let it get to me, but everybody, of mental illness people are different, of course. Somebody else might get mad and go off. Me, I don't do that anymore, I just, it's not worth my time. They want to be ignorant and they want to be, and ignorant is not a bad word it just means not educated. I’m sure sure you know that [chuckles]. But when you're not educated I don't think you should really open your mouth and that's how I feel about it.

Yeah.

Or if you do open your mouth, make sure it's a good question if you really want to learn what a mental illness is or, it's just like having a hobby, you know? “What do you do about this and this when you go fishing? What do you do about this and this when you go camping?” You know, it's just that way.

So again, just coming back to people not knowing and not being educated about it.

Exactly. And people of course with stigma would say “Oh, her, well her daughter’s crazy just like her, meh meh meh.” That's not fair to the kid, they may have mental illness, but don’t refer to me, it’s different than mine. I could go, I mean, I’m, I’m sure you're probably tired of
listening to me but there's so much I could go on about mental illness and what I've learned and observed and read and all that. I probably should write a book though. [chuckles]

There you go! Well, I have, um, a couple more questions hopefully we could get to. The next one is about WMR a little bit and I was wondering if you could describe what happened during your participation in WMR and what change, if any, in the way you view yourself took place during your participation in WMR.

Okay. Give me a moment.

Sure.

Okay. W, I get the...

WMR.

W what?

WMR. Okay [chuckles].

I get the things mixed up. I think of WCAREP in Cincinnati I don't know. But anyway, um, um, definitely the one thing I did learn was about the stigma and how to cope with stigma, like how people are uneducated about mental illnesses, um, let's see. How I dealt with it, I, this kinda goes hand in hand, with the two questions you had. I never really looked at the stigma until I went to this recovery program. I just thought it was just people bein' mean and rude. You know, I, sometimes I think morals and values and manners went out the door about ten years, maybe twenty years ago, I don't know. But yeah, I just thought, but when Rhonda was explaining to me about stigma, I was like "Ohhh, okay." I learned how to deal with the stigma a lot better and I, I told you earlier about the how I deal with it and I, that was the main thing that really, I really, you, I don't know how to explain it, I really concentrated on the stigma thing than anything else. Uh, I mean, it might sound bad, but I'm able to take that again, so maybe next time, you know, I've got stigma out of the way, so let's work on this. But stigma I really kinda concentrated on because I never knew all those years it was the stigma that was the one of my issues on recovery. If I knew stigma was the stigma was there, it'd be like "oh, okay."

Yeah.

But that is one definite thing that helped me is to learn how to deal with it or maybe show things differently to educate, but me as a person, I can only do so much.

Mhm.

You know, it's not like I can go out and save the whole world, no. [chuckles] I need these pamphlets in this language, no. But you know I mean seriously, I'm not trying to make a joke of it or anything, but that's that's my opinion. [clears throat] And being around, another thing that helped in that group is being around other people like me and listening to their feedback or their advice or their anger or problem. It really helps to be in a group like that because you
can learn a lot. Lot more than just individual.

Mhm. Ok.

I think that's it. I would recommend that group for any mentally ill person.

Okay, good to hear that. Um, what, what are some common stereotypes do you think about people with mental illness?

Stereotypes?

Mhm.

Well, let's see, "that person crazy", um, stereotypes...oh. This is it. Just because one mentally ill person, or just one person is mentally ill, everybody that is mentally ill is crazy, you shouldn't hang around 'em, you should be scared of 'em, you shouldn't, and um, you shouldn't give 'em the time of day, you shouldn't be friends, you shouldn't's. It's like we are, like I said, it's like we have, what is it, where you have leprosy or somethin'. "Oh my god stay away from 'em!"

Okay. So people get one bad example in their head and they think that everybody..."

Exactly. They get one bad example and they think everybody else is the same. And everybody is not. Everybody's different. Whether you have a mental illness or not, everybody's different period. End of story, you know? But yeah, the stereotyping would be you get one bad apple, the rest, the whole tree is bad. Might as well cut it down and get rid of it. That wouldn't be good. That'd be a lot of people. [chuckles]

Yeah. So, in your, in your personal recovery, did, did you ever have a time where you were sort of struggling with that, like with those stereotypes, like you were thinking that they were true of yourself?

Yes. Yes, I played the uh, pity party for myself quite a bit in the past, but then, like I said, when I turned thirty I just, it's like light bulbs goin' off up above my head, ding! ding! ding! It's like, no! This is not how I need to be or should be, I need to be who I wanna be, not what people think I'm going to be or going to act or how I should be, or shouldn't. So it was, it was a struggle for a while.

Mk. Um, do people treat you any differently because you have a mental illness?

Well, uh, a lot of people don't know. It's not like I have it, you know, Nathaniel Hawthorne, with the scarlet letter, and they wore, she, Hester Prynne, wore a "A" for adultery...

Mhm.

It's not like I have "Hey! I'm a psycho!" Stereotype, stigma, stereo-, whatever. You know, but the people that do know that I have a mental illness I do find myself still to this day for some reason explaining. To uh, my future husband who I've been with for thirteen years, I still
explain to him to this day for some reason why I did something, or why I didn't do something, or how I did something or some, it's hard to explain so much in words, but it, I don't know how to explain it, it's just, my mom and dad, we, ok, here's an example. I just told you about my future husband and then my mom and dad. My mom and dad'll call. They try to make funny light about it and say "Well, the weather is bein' bipolar here." You know, of course, mood change, weather change, in and out [chuckles], you know, I mean, its different with everybody. Sometimes I do explain myself, sometimes I don't. Sometimes it's like "whatever."

And sometimes, like I said, I'll make a joke about myself, but then when somebody starts makin' a joke that doesn't know me or tries to say something then I get mad. It's just...like a ball. If you do this, this happens. If you don't do this, that happens. With my mom, I call her up, "Hey, your bipolar daughter" which of course is me, eh. It's not a joke, but the people close to me know. They know how I can function. But other people that don't know, it's just like a normal thing. But the majority, I don't have a lot, unfortunately I don't have a lot of friends, I don't have a lot of family, so this, I feel safe here at the Main Place so I can deal with people that have and they can deal with me, that are sh- mentally ill. I feel safe at home. And I feel safe at church. And those basically are the only three places I feel safe. Um, I'm kinda antisocial because, in this stigma thing again or the stereotyping, I'm tired of the bigotry that, you know, the ignorance, the prejudice, the everything. I'm tired of that. If it's not that I'm mentally ill, it's that I'm white, or I'm a Christian, or whatever. I'm a female. I'm just so tired of it so like I said I just try to work on myself everyday, be here at Main Place, or my house, or church. I know I keep goin' on and on, I'm sorry.

No, that's fine. Just, just feels like you're constantly being judged no matter...

Yes.

...no matter what happens.

Mhm.

Mk. Um, let's see here. How did your experiences with stigma interfere with your recovery process? I know you've talked a little bit about this but...

Um, the stigma, my recovery, it affected the way I looked at people [sigh], it affected my anger management, it affected me in many ways, but like I said, goin' to this group and learning about it, learning how to deal with it, gettin' feedback and advice, it helped a lot. It definitely, definitely affected me and how I saw and spoke to people. You know, whatever happened to those little towns, "Hi, how are you? How's it goin'?" Or, like the movie, I mean, this, I'm probably living in a dream world which sometimes is ok to have a dream or write it down, but like Steel Magnolias. Everybody did everything for, I mean it was a community. I don't think we're ever going to have communities like that again. I mean we might now in little towns that if you blink you'll miss it, but [chuckles], like Newark? That's not going to happen.

And I will admit, I am a city girl. I am from Omaha, Nebraska. Omaha's a pretty big city. It's bigger than Columbus. And that's all I wanted was a community where everybody understood each other, respected each other, didn't stereotype, no stigma, no judging, no nothing, you know. Respect, morals, values, manners. I'm really living in a dream world because that...I don't think that exists anywhere any more. But like I said, I don't know of the little towns that you blink and you miss it. They might have that. But a lot of places don't, especially the
bigger, way bigger cities. You've got all the crimes and majority of the time big crimes are done because of mental illness. Just like the uh, the stigma of because you're a homeless person you're crazy. You're psycho, you're schizophrenic, you're this, you're that. Some people are homeless for a reason and I'm just sayin' who are we to, especially mentally ill people, just, to have this stigma, the stereotype, the judging, who are we? We're no better. Just like people that don't understand us or know better, they just need to understand and learn. Well they don't need to, I mean, it's not in the, but, it's kinda like the handicap. You've got handicap parking, you've got handicap this, handicap that kinda alter to people like that. I'm not saying really alter to us, but learn how to deal with us mentally ill people. Humanely.

[chuckles]

Yeah, get back to that sense of community.

Community. People caring about other people. You know I was there once before too where I didn't care. But that's because I was young. Yeah, I guess you're going to have to like grow up and mature before, and some people don't even do that. In a way, like my mother, she's going to be 74 years old and she's not really mature on the part of mental illness. Sometimes I wish we just had like magic wands. Poof! You understand me!

That would make it easier.

Yeah. Ok, I have this, this question doesn't apply to everyone, I've just been asking it to everyone that I talk with. Have you ever been arrested, charged with, or convicted of a crime?

If you call, four unpaid parking tickets, no, I've never been.

Ok. I've just trying to see what people's experience with the criminal justice system were. Um...

I see that a lot. Through friends and stuff, but I never dealt with it. I had to go to jail one time for a week for four unpaid tickets, woo. Um, but I kinda have an idea about the criminal justice system mental illness because my mom worked for three lawyers for forty years, um I've always been into the criminal justice thing since I was like 12 and I wanted to go to college to be a forensic scientist and before that I wanted to be a cop but when you have a mental illness you can't be a cop, you can't go in the military either. I'm like, really? And then um I guess a lot of uh, y-, you gotta know that in the criminal justice whether its a judge, an attorney, a cop, anybody that has, you know, the FBI, that has the upper-hand law-wise, you know at least one of them in five maybe, this is just my opinion, they have mental illness.

Well the, the statistics are that one in four person, one in four persons throughout their life will be diagnosable with mental illness, so you're pretty close there.

Wow. But I think a lot of them are mentally ill. Then like the, going into the service, the military, if you're not found out that you have a mental illness you will be found out eventually or you will get it while you're in the military. I have a stepfather that got PSTD, or post stress traumatic disorder or whatever and or something else, I don't know, while he was in the military he was in, what was he, what was that famous one? Vietnam. Sorry, pft. Got the Korean war, Vietnam, this and that. He was in Vietnam and he suffers from mental illness like.
And then sometimes in my opinion you really really, I mean this is like just neither here nor there. Some people that have mental illness use it to their advantage big time. Yes, I am on disability, but there's a reason why. There's two. One, ok, maybe three. One is I can't deal with the public any more. I have to re-learn that. Two is the medication that I take makes me tired. I have to take it during the day. I can't be at work sleepin'! [chuckles] And three, um, I don't think I could do it. I still have, you just asked me about how things or stigma or whatever has affected me. I think now that I think about it, getting, having a job would affect me because of stigma. I mean, I, not that they would know, but they might figure it out or hear or whatever because this is newer and people here have a lot of things about other people. This is a smaller town. [whispers] I don't like smaller towns. [end whisper] For that reason. It's the gossip and the "Did you know that..." It's like what? Why are you tellin' my business? But I don't think I could handle a job because I can't handle the public. I'm scared, I'm bein' honest, I'm scared of it, for now, until I continue to learn.

What is it that scares you?

Um, I'm not good enough. I might do something wrong. Somebody might not like the way I look or act or talk or the way I do my job. It's everything I guess. That's why I'm s- on disability and still working things out. I mean, I'm working on it. I'm not just gonna expect to be on disability the rest of my life. But like I said back with the disability, some people use it to their extent and they think it's a joke or they think it's funny, and they're like 'oh, if I played crazy I'll be able to do this or get this." That's another bad thing for us mentally ill people. That are truly mentally ill. Not the conniving person, you know. That doesn't help our situation either. And like I said, the law thing, I re-, I watch True Crimes all the time, like identification or discovery, or indiv- its investigation discovery, I watch snapped, I watch a lot of things. Snapped is a good example of mental illness in, in criminal justice. Some people really do snap, they've had enough and they'll kill somebody or, usually it's just killing. But there are a lot of mentally ill people out there that, I'm telling you, a lot of the people in prison in jail have mental illness somehow, some way.

Ok.

You just don't rape somebody, you know. You don't just kill somebody. Hurt somebody. There's a mental illness somether, somewhere there.

Alright. I have another question here. Do you feel that it's important to keep your mental illness a secret? To people that like aren't close to you and, you know, people that might not matter as much to you as like your family or friends, do you feel like it's something that you need to keep a secret?

Umm. That's a hard question. It's like a yes and no. Yes because of the stigma and the ignorance. No because I'm proud of who I am whether I have a meltel- mental illness or not. I mean, there's just so many different ways to look at it and to deal with it and learn and know, it's just, it's difficult.

How do you, how do you determine if, if you will tell somebody that you have a mental illness.

Ok, good example. I was just thinking that. [clears throat] My other half was born and raised
here in Newark. Like I said I was born and raised in Omaha, Nebraska. Well he was there for a while and we me, we'd been together forever and a year it feels like. Well he moved back here to be around his family that he hasn't seen for like 15 years. So we move in with his dad and his "stepmom" and sister. Right away I decided I needed to explain to them that I have a mental illness, I do take medication, I go to therapy, I'm on disability, um, and I can pay you somethin' for stayin' here, because of course he came here with no job. Long story short [sigh], this is what angered me. I told them that because I thought that they had the right to know because I was living in their house and they're supposed to be family. Excuse me. My other half, his dad pretty much accepts me and is really cool to me and doesn't treat me like dirt. His stepmom and sister treated me like I was a child, they treated me like I was the worst thing on Earth. It angered me because, like I said, I have to take my medication in the afternoon and I take a nap and I have to eat somethin' before I can take my meds. They got mad at me because I ate lunch and took a nap. I'm like, excuse me. You're not going to tell me what I can and cannot do. This may be your house but if I bring my own food in I will eat it and I yes I will take a nap because that is part of my disability, I don't, I'm not no good if I don't take a nap during the day. Another thing that angered me about that situation is those two, the sister and the stepmom, have some severe mental illness somewhere, they are like wow! And it's hard because I know I'm not crazy, I know I didn't do nothin' wrong and I take my meds and I do what I need to do, but these two are goin' off and being stupid and retarded and it's like they can't see that it's them and not me. They don't like me very much. Probably because they're scared of me. They're probably scared that, not scared in a bad way but in a good way, that I actually get help for my mental illness, that I do take medication. I'm like, whatever, you know, I ain't got time for this. I stay away from them as much as possible. That's why is because I wouldn't expect them [unintelligible] those two are the ones who don't believe in the mental illness as well. My ex husband, them two, my mom, there's quite a few people that don't believe in it, don't want to, uh, scared to, whatever and it's like you, um, whatever, you know, I'm just staying away from you because I know I'm not crazy, I mean, I'm crazy, "crazy", but I do take medication, I go to therapy, I got to groups, I learn how to deal with things. You two, you guys got, need some major help there. Pfft. And one thing, I'm, back real quick with my mom not believing in the mental illness, I know why she doesn't do that. She thinks she's perfect. I know that sounds funny but she does, she thinks she's perfect. She's got all her ducks in a row, everything is done like this, her house looks like a frickin' museum, it's like nobody lives there, it's always clean and everything. I'm not saying she needs to live like a slob, but good lord. I mean, she thinks she's perfect. And if she admits she has a mental illness, she's not perfect any more. I just figured that out talking to you.

Hmm mhm.

See? I learn something new everyday. And it helps me, because now I know why. I don't have to worry about it no more. I just, that's goin' back in the trash now because I know why. But the other people that they're just ignorant in my opinion. Oh wait, you know what? The ex husband doesn't believe in it because that would not make him a man. His pride. So we've got those two figured out, the other two...but those two matter because one's the father of my children and one is my mother but these other two in my opinion don't matter but I did it out of respect to them to explain to them wh- why I take meds, you know, explain to them that I do have a mental illness. So it does, it depends on your question, I know I keep goin' off on a tangent, but sometimes I feel like it might help somebody somewhere.
No, it's all good. A lot of the things that you've been saying have kind of been other questions that I've had, so it's been good.

So I've determined what needs to know about my disability, mental illness, whatever. If I see that it's somebody really really important, of course my mother and father, the man I've been with for 13 years, the man I had two children with, not so much the man I had my oldest daughter with unfortunately, um, but I don't know people that are going to be in my life that need to understand and know. Oh I told his grandmother and his aunt. His aunt I think needs some mental help too, I mean, I'm not a doctor, I don't want people to think I know everything and I'm higher than everybody and I'm a doctor or whatever because of course I'm not, but I can see mental illness in a lot of people right away. But I'm not judging and I'm not stereotyping. I'm feeling sorry for that person because they don't see it or they don't want to and they don't get help.

That's one of the things that interests me about stigma is that it gets in the way of people getting the help they could use sometimes.

Yeah, they all think they're a lesser person, they think they're retarded or something, I don't know. They don't, I think it's just because it's their pride, their self esteem, oh man, I still have self esteem problems I'm still working on, you know. I mean, there's a lot of topics, areas, whatever, to work on when you're mentally ill. Self-esteem is pretty low. Last, like I said, like you said, people in the stigma, they don't wanna be looked upon as lesser. Or maybe they see how somebody with mental illness is being treated, that could be it too. Some people can see how I'm being treated in my relationship and they'll be like "uh...ok, no. I don't want to be treated like that..." Well you don't necessarily have to be treated like that because if everybody wasn't ignorant to it everybody could be actually cool to each other. And like some of the mentally ill people here. I know when not to joke and when to joke. I know when not to talk to them and leave 'em alone and when I can. That's because I have studied, observed, listened, everything. That's just something we need out there with mental illness is more like, like I said the commercials for TV. "Abilify!" "Lunesta" for sleeping. But that's also kind of a problem for some people with mental illness, we can't sleep right. I mean there's so many areas. And people just don't understand, sometimes I don't understand, but I'm still, like I said, I'm still learning and I'm still wanting to learn. I don't want to be ignorant to a lot of things. I mean there's some things I have to be ignorant to like welding or something that I don't do of [chuckles] something you know, that kind of stuff.

Yeah.

When it comes to mental illness I don't want to be ignorant to it. I called the, there's numbers in the phonebook, there's numbers on pamphlets that call 1-800 number and they send you more information about that that um illness. I do that for myself, for my kid- my kid's disabilities so I know how to deal with her. It's hard to learn how to deal with your own kid when you're mentally ill and they're mentally ill. It's like, it's like, I don't know, how do we do this, heh. I mean it's very, it gets very frustrating sometimes with my daughter. Especially when she says "I don't need medication, I'm off of medication." I just wanna go down there and smack her upside her head. But see she's in Los Cruces, New Mexico. She's like "I got off my meds and I feel a little bit better and this and that" and I'm like Denae, go see your doctor, again. Get it figured out. It took me, mm, almost 10 years to get my medication situation. I'm
on this amount in this medication and it works. I don't want nobody messin' with my medication. Don't up it, don't down it, don't do nothin' with it please cause it works and I don't wanna, I'm, before, like I said before, we uh got the right thing to work, they tried me on a the medication Depacote, I was like what is this? I was on it for a week, maybe two weeks, I called my doctor, I said this ain't workin' I need my lithium back. You've got to get that back to me. Because this is not working and I'm ready to murder somebody and now I don't mean that. And to be honest, I will be honest, and this is just [sigh] an example, I would be afraid for me to be off my medications. That's why I never go without my medications. I scare myself. Whether I commit suicide or homicide, that's how bad it can get for me. I don't want to go that route ever again. Definitely don't want to commit suicide because I'll be in purgatory for the rest of my li-, well, you know. I don't want to commit suicide because I still wanna live for my grandchildren and I don't wanna do no homicide and that's neither here nor there and I'm not meaning this...

Right.

…but I'm just saying if it did happen, I don't want to be in prison for the rest of my life. What kind of life is that? I'm not saying I would do either one, but I know I am capable of doing it. There are many things I know I am capable and not capable of doing. And that's a lot, you gotta learn a lot about yourself too when you become mentally ill. You gotta, like with the, the W-

WMR.

Yeah, WMR. You have got to learn what you're capable of doing and not capable of doing.

It's lunch time. (?)

You've gotta learn that, um, how to deal with stigma, how to deal with everything. It's like you have to learn a whole different new life when you are diagnosed with a mental illness because you're going to be doing things differently, you're gonna be feeling different differently and you're gonna wanna do something differently. Yeah, depression, you're gonna wanna go back to your hobby or go somewhere or do something. I know in the past my depression kept me in bed, kept me in my home, I ain't goin' nowhere, I was like a hermit. Now obviously I'm not that way. I'm here talking to you. But it is like a whole "new life" you have to learn for yourself. And always, you've gotta always work on yourself before you can help or do or whatever somebody else. You're not doin' well, you're not taking your medications, you're not doin' what you're supposed to be doin', you're not gonna be well enough to deal with this idiot other here and your kid over there and you know, I, you really have to concentrate on yourself. I was codependent. I still somewhat am, but I was a very codependent where I helped everybody else, my heart was on my sh- my sleeve. I helped everybody else but I wasn't taking care of myself and that's not a good thing. So...I take it one day at a time as well, just like AA. One day at a time. Or the 1970s show or 80s, One Day at a Time. So, there's a lot to learn with mental illnesses whether you want to get a master's degree or be a psychiatrist or be a psychological-whatever, psychological person, or counselor or this and that, you've got to learn a lot, I mean, you really do. Or I recommend it.

Well I've certainly learned a lot today sitting here with you, so thank you.
No problem. I did notice um, just like I messed up on psychological, psychology, that's part of my illness, um, something in my brain or my medication or something has to do with my math and my brain. I know what I wanted to say but it doesn't come out the right way and as part of my mental illness it, I'm still learning how to deal with that. I get mad at myself. I get upset, sometimes I cry because I can't say stuff the way that I used to. Because I know what it means and I know how to say it back then but now sometimes I don't, I can't say it right. And that's another-, that's another issue I have to deal with.

Frustrating.

It is very frustrating because I'm not that dumb [chuckles].

Yeah.

Yeah, there's quite a few words I can't say right any more, it just, it makes me oh very upset and sometimes I have to exp, describe or do the definition of the word I'm trying to say and if somebody knows it they'll say the definition for me. I mean that makes me feel really, that's another reason why I don't have a job is pft, what happens if I can't say somethin' right, you know what I mean, that could be my job. And there's just a lot to, like I said I'm still learning every day. I will, until I pass away. Hey! I'm a poet and didn't know it. [chuckles]

[chuckles] Ok, I think I'll stop it there...