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The effect of stigma on the daily occupations of adults with mental illness

Kelley Lee

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The Effect of Stigma on the Daily Occupations
of Adults with Mental Illness

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in partial fulfillment of the requirements

for the degree of

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in

Occupational Therapy

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Abstract

This research explored the relationship between the stigma of mental illness and performance in daily occupations, using an ethnography approach. Additionally, the research examined stigma as an occupational injustice. Four adults with a diagnosed mental illness participated in this study. The results indicated that the daily occupations of adults with mental illness are affected by the experience of stigma. Most significantly, the experience of internal stigma had a large impact on participation in social activities. It was evident through the literature review and through this research that stigma can be defined as an occupational injustice. These results demonstrate the need for occupational therapists to begin to routinely examine stigma as a barrier to participation in their practices.

Chapter 1: Introduction

The purpose of this ethnographic study was to explore the experience of stigma and its effect on participation in daily activities from the perspective of adults with mental illness living in Southeast Michigan. The study used an occupational justice framework to examine the occupational experiences of these individuals as well as give voice to the people who experience the impact of stigma in their daily lives.

Problem Statement and Background

Most mental health advocates would argue that the plans for community integration of people with mental illness that began with the deinstitutionalization movement in the late 1950s were never fully realized (Carling, 1996; Accordino, Porter, & Morse, 2001). It was thought that when adults with mental illness were discharged from long-term psychiatric hospitals into the community with outpatient mental health services, they would experience community integration. However, deinstitutionalization began in the middle of an era when persons with disabilities did not have civil rights and society was still tolerant of segregation and discriminating policies. As such, adults with mental illness were discharged into the community with few opportunities to engage in activities of their choice and were not viewed as contributing community members (Carling 1996; Accordino et al., 2001).

Over the past fifty years, advances in mental health care have occurred, although full community integration remains elusive. The 1960s ushered in emerging social concern regarding the civil rights for adults with mental illness, with a continuing focus on deinstitutionalization and providing quality outpatient mental health services through Community Mental Health (CMH) agencies (Accordino et al., 2001). The 1980s brought

improvements in the diagnosis and treatment of mental illness in part due to advancements in psychotropic medications. The 1990s featured the passing of the Americans with Disabilities Act (ADA) that prohibited discrimination against people with disabilities, including those with mental illness. Accorindo et al. (2001) stated that in the 1990s there were positive changes for adults with mental illness, with larger networks of CMH agencies and treatment innovations. However, these same authors also stated that the complexity of community inclusion for adults with mental illness was underestimated. Today, many people with disabilities find that the basics of everyday living remain out of reach, including affordable housing, employment, access to health care, and pursuit of meaningful activity (Corrigan, 2005). Advocates would agree that this is especially true for adults with mental illness (Shapiro, 1993; Falk, 2001; President's New Freedom Commission on Mental Health, 2002).

In 1999, the Surgeon General's report indicated that stigma is the foremost obstacle to inclusion for adults with mental illness. In 2001, the United States President, George W. Bush, announced his New Freedom Initiative to promote greater access to opportunities for people with disabilities. The Commission, charged with researching and providing strategies of change for adults with mental illness, also identified stigma as the largest barrier to accessing equal opportunities in society.

It seems a natural fit that occupational therapists would partner with individuals with mental illness to continue working toward full community inclusion and to address stigma as a barrier to doing so. In addition to occupational therapy's focus on participation in everyday activities, occupational therapy values a "commitment to inclusion and nondiscrimination" (AOTA, 2008, p. 630). Further exploration of everyday

activities and the impact of the environment on those activities is supported by the developing occupational science discipline. Occupational science is devoted to expanding occupational therapy's understanding of occupation by studying the form, function, and meaning of human occupation (Zemke & Clark, 1996). Within the occupational science discipline, the concept of occupational justice has emerged.

Occupational Justice

Townsend, an occupational therapist and occupational scientist, applied the concept of social justice to occupational therapy practice and developed the occupational justice framework. This framework examines the barriers that affect an individual's engagement in activities in his/her community.

The occupational justice framework can be seen as a shift from focusing on the person and their disability to a politically oriented view of barriers that prohibit individuals with disabilities from accessing the community around them. The concept of occupational justice seeks to expand clinicians thinking about an individual's environment to include examination of social structures and policies that can be barriers to participation. Within an occupational justice framework, therapists can consider multiple external factors like "national priorities and social values [that] create an occupationally just society that provides the opportunity for all people to develop their potential..." (Jakobsen, 2004, p. 124). Also within this framework, injustices are identified. They are defined as "conditions rising from social structure and policy that create stressful occupational experiences" (Townsend & Wilcock, 2004, p. 251).

Personal Perspective

As an occupational therapist working in a community-based practice serving adults with mental illness for the past eight years, I have had multiple conversations with adults with mental illness. These conversations have, on occasion, revealed to me their experiences with stigma and an overall lack of opportunity to engage in meaningful and independently chosen activities. Such conversations left me wondering if stigma is a barrier to the pursuit of daily occupations. This barrier is not often addressed in occupational therapy practices. I feel passionately that stigma is a barrier and an injustice that should be addressed by all clinicians working with adults with mental illness. This has led to an exploration of the stigma my clients identify as a barrier and an examination of the concept of occupational justice. Their stories of stigma have driven me to research this topic more thoroughly in order to understand its impact on participation.

Additionally, I seek to understand how I, as an occupational therapist, can work with clients to eliminate this injustice. Because I view stigma as an injustice against my clients, it was a natural progression for me to also examine the topic of occupational injustice and how occupational therapists might begin to look at stigma through this framework. It is my belief that the adults with mental illness who share their stories with me are the experts on their lives. Therefore, I believe it is necessary to conduct research of their experiences using naturalistic inquiry methods. With this in mind, I embarked on the journey of story telling through research to complete this ethnographic study.

Justification and Significance

Researchers concerned with stigma urge ongoing research and discussion of the topic. Corrigan (2005) states that ongoing research is needed to facilitate greater

understanding of stigma as well as ways to eliminate stigma. Rasinski et al. (2005) pointed out that multiple qualitative studies have addressed stigma; however, only one of those studies (Muhlbauer, 2002) was designed to explicitly research the topic of stigma. In addition, Resinski et al. stated, “We would like to see more studies that are explicitly designed to study stigma...” and “give us a sophisticated understanding of the human experience of stigmatization” (p. 61).

This “sophisticated understanding” of individual’s experiences must also be sought out in occupational therapy practice and research. If occupational therapists (OTs) are to continue focusing on the environment’s impact on occupational performance as well as occupational injustices faced by individuals, thorough understanding of the interactions and the challenges faced in an individual’s surrounding environment is essential. An understanding of the barriers stigma creates to community inclusion is needed in order for OT’s to effectively develop plans that assist their clients with community participation.

In this ethnographic study I set out to explore the experience of stigma and its impact on daily living for adults with mental illness. The study attempts to answer the call to design research that addresses the experience of stigma and to do so using a qualitative approach. By partnering with adults who have mental illness, I hoped to provide an avenue for their voices to be heard and to add to the literature concerned with occupation and occupational justice.

Research Question

To reiterate, the purpose of this ethnographic study is to gain an in-depth understanding of the experience of stigma within the framework of occupational justice

for adults with mental illness in southeastern Michigan. The overall question being asked in this study is: What is the everyday experience of stigma and how does it affect daily occupations for adults with mental illness? This primary question leads to the following sub-questions: What is stigma from the participant's perspective? How is it experienced by the individuals in the study? What are everyday examples of stigma as defined by the participants? How have those experiences of stigma impacted daily pursuit of meaningful occupations and experiences of occupational injustice?

Chapter 2: Literature Review

An initial literature review is the first step in the qualitative research process and is conducted to familiarize the researcher with information relevant to the study topic. This literature review focused on stigma and the concept of occupational justice. While reviewing the concept, I asked the question: Is stigma an occupational injustice as it is defined in the occupational justice literature?

A comprehensive review of the literature revealed a plethora of research about stigma associated with mental illness. The majority of this research focuses on defining stigma, stigma's roots in society, the effects of stigma in the lives of adults with mental illness, and how to change stigmatizing attitudes. These identified themes in the literature are summarized below.

Defining Stigma

Stigma is largely defined in the literature as a social injustice that deprives individuals of opportunities. To further define the term *stigma*, the literature suggests that there is public stigma and self-stigma. Public, or external, stigma is the “actual experiences of rejection or discrimination from the general public” (Angell, Cooke, Korvac, 2005 p. 73). It is the process by which the public labels human differences and gives those differences meaning by using stereotypes and denying individuals of life opportunities through the exertion of power (Angell et al., 2005 p. 73).

Self or internal stigma is the “consequence of people with mental illness applying stigma to themselves” (Corrigan & Kleinlein, 2005 p. 12). In the study, *Adverse Effects of Perceived Stigma on Social Adaptation of Persons Diagnosed with Bipolar Affective Disorder*, it was stated that because persons with mental illness internalize the devaluing

attitudes of society, they begin to anticipate rejection and withdrawal from social interaction or develop a level of secrecy about their illness (Perlick, Rosenheck, Clarkin, Sirey, Salatri, Struening, & Link, 2001).

Stigma Roots

Stigma towards individuals with mental illness can be traced back to early Greek and Hebrew sources when mental illness was thought to be demonic or punishment from God (Falk, 2001). This explanation of mental illness lasted well into the 18th century. Other early beliefs attributed mental illness to the influence of the person's family (Falk, 2001). To date, research provides evidence that the families of individuals with mental illness still share an attached stigma with their loved ones (Angell et al., 2005). In today's society, Falk hypothesizes that people with mental illness continue to be stigmatized because they are viewed as a group that deviates from the norm or expected behavior (2001).

A number of authors have examined the role that the media plays in the development and persistence of stigmatizing views of mental illness. Corrigan and Lundin (2001) discussed the images in film and in print that represent individuals with mental illness as people who should be feared or, conversely, protected due to their inability to care for themselves. These portrayals are watched by others, who internalize these images and, as a result, stereotypes that contribute to discrimination are promoted (Shapiro, 1993; Angell et al., 2005). In addition, the general public is underexposed to content about the treatment of mental illness, especially treatment efficacies (Sullivan, Hamilton, & Allen, 2005).

As mentioned above, research indicates that a cause of stigma is the public's reaction to expected behaviors associated with a mental illness. This is considered stereotyping of individuals. According to Accordino et al., historically persons with mental illness generate the most negative attitudes in society because they are perceived as violent and dangerous (2001). However, research does not support the perception that individuals with mental illness are violent and dangerous. Research indicates that men and young adults are more likely than an individual with mental illness to be violent (Corrigan, Watson, Byrne, Davis, 2005). Although research disproves the negative stereotype, the public's perception of danger has increased over the past 40 years. This has led to the general public desiring greater social distance from adults with mental illness (Corrigan & Kleinlein, 2005).

While stereotypes are the result of preconceived notions, Link's labeling theory suggests a person's behavior signals the public to label him or her as mentally ill (2005). Labeling also occurs when someone is diagnosed or an individual may label him or herself as mentally ill, and once this label is applied, the individual is exposed to adverse reactions from others. The label itself "sets into motion cultural stereotypes and negative images that result in the devaluation of those labeled" (Falk, 2001, p. 50). Studies have been conducted to control for atypical behaviors to determine if the public would stigmatize a person solely as the result of the label *mentally ill* (Link, 1987; Piner & Kale, in Falk, 2001; Farina & Ring, in Falk, 2001). The studies suggest that even in the absence of aberrant behaviors, stigmatizing attitudes were present.

Still another cause of stigma identified in the literature is the "paternalistic assumption" (Shapiro, 1993 p. 25). Shapiro uses this term when the public, perhaps

family members and even treatment professionals, assume that individuals are not competent to make their own decisions simply because they have a mental illness diagnosis. When considering this “paternalistic assumption,” research suggests that discrimination in the name of being helpful or charitable is perhaps the most hurtful form of stigma (Shapiro, 1993; Corrigan & Lundin, 2001).

Stigma is a Barrier

No matter the cause of stigma, literature indicates that adults with mental illness have fewer opportunities to engage in activities of their choice than the general public (Corrigan, 2005; Angell, Cooke & Kovac, 2005; Surgeon General, 1999; New Freedom Initiative, 2001). Additionally, adults with mental illness are more limited in their access to health care as a result of stigma. Corrigan and Kleinlein (2005) stated that individuals with mental illness receive fewer medical services and are less likely to have insurance benefits equal to individuals without a mental illness.

Studies suggest that it is the stigma of having a mental illness that discourages a person from seeking care in order to avoid diagnosis and treatment (VanLeit, 1996; Davidson, 2001). Perlick stated that studies have shown stigma affects a person’s willingness to take medications prescribed to treat mental illness and that stigma negatively impacts the recovery of mental illness (2001).

Stigma has also played a role in the criminalization of adults with mental illness. “With the stigma attached to mental illness intensifying over the past four decades the number of people with mental illness entangled in the criminal justice system also rose significantly” (Corrigan & Kleinlein, 2005, p. 20).

Stigma Change

Methods for changing stigmatizing beliefs and attitudes are also discussed in the literature. These include public education about mental illness and targeting public images of negative stereotypes through protest (Corrigan, 2001). In addition, changing the language used in everyday culture that suggests a person is “sick, pitiful, childlike, [and] dependent” (Shapiro, 1993 p. 32) is a method of reducing stigma (Corrigan & Lundin, 2001). The promotion of contact between individuals with mental illness and the public is also recommended to reduce stigma (Accordino et al., 2001).

According to Corrigan and Lundin (2001), research has shown contact to be one of the most effective ways to foster stigma reduction. Contact allows the general public to hear the stories of persons with mental illness and to come to a realization that mental illness is a challenge that can be met. Creating opportunities for the general public and adults with mental illness to interact and engage in a sharing of community resources reduces the fears of the public and is empowering for adults with mental illness (Marden, 2001; Huxley, 2001; Watson & Corrigan, 2005).

Empowering individuals with mental illness is a theme common to the stigma literature as well as literature in occupational therapy. Empowerment can be defined as a sense of mastery over an individual’s illness and control over his or her life (Corrigan & Lundin, 2001). When individuals with mental illness feel empowered, they have “good self-esteem, believe they are effective in life, and are optimistic about their future” (Corrigan & Lundin, 2001, p. 180). Perhaps more important, persons who are empowered are not impacted as greatly by stigma because they are not likely to internalize others’ misperceptions of them.

Occupational Justice

Empowerment was central to discussions that developed the concept of occupational justice. Townsend and Wilcock stated the occupational justice framework grew out of research on the occupational foundations of human existence (Wilcock), and on the principles of empowerment and justice that implicitly inform practices that are client centered (Townsend). We lacked a language and concept to raise concerns about the unfairness of some people flourishing...while other people are leading unhealthy, empty, or dangerous lives (2004, p. 244).

While Corrigan and Lundin argue that the continuing emphasis on distinctions and differences in people undermines the sharing of resources, the occupational justice framework proposes “enablement of *different access* [emphasis added] to opportunities and resources in order to acknowledge individual differences...” (Townsend and Wilcock, p. 262). In this way, occupational justice goes beyond the concept of social justice, which calls for equal access to opportunities. Townsend and Wilcock believe that by acknowledging human differences and demanding recognition and acceptance of those differences, people and social policy can move beyond equal access to opportunities that allow people to choose and pursue what is meaningful to them.

A review of the occupational justice framework literature did not include discussion of stigma as any or all of the four identified injustices within the framework. However, upon reviewing the stigma literature, it is evident that the stigma attached to mental illness can result in occupational alienation, marginalization, deprivation and imbalance. Each of these injustice concepts is discussed briefly below.

Occupational alienation is defined as “the absence of meaning or purpose in the occupations of daily life” (Bryant et al., 2004, p. 283). Occupational deprivation focuses on an individual’s isolation and an absence of opportunity to engage in occupations. This experience is also characterized by the influence of external barriers to participation (Townsend & Wilcock, 2004; Whiteford, 2000). Occupational marginalization speaks to the force of societal norms and expectations placed on people. Individuals experience marginalization when they are denied access to opportunities because they do not fall within an expected norm (Townsend & Wilcock, 2004). Occupational imbalance is a concept that refers to use of time. Occupational therapists believe that a determinant of overall health and quality of life is a balance among the occupations in which a person participates. An imbalance is seen when people are either over-occupied or have little to do (Townsend & Wilcock, 2004; Jakobsen, 2004).

As detailed in the above review, stigma can lead to segregation and isolation for adults with mental illness. Furthermore, stigma has been shown to limit a person’s access to a balance of meaningful occupations that enhance the quality of life. These effects of stigma experienced by adults with mental illness can be viewed as occupational injustices.

Corrigan et al. advocate that stigma be framed as a social justice issue to remind the public that all people are equal and share the right to dignity and respect (2005). Davidson et al. state that it is only in the case of mental illness that society appears to demand that the symptoms of an illness be erased before an individual can gain access to the community around them (2001). The concept of occupational justice states that differences must be recognized and respected, and justice occurs “when individuals are

able and empowered to participate in occupations of their own choice...and contributing to the community” (Townsend and Wilcock, 2004, p. 245).

In reviewing the literature I found a voluminous amount of information about stigma attached to mental illness, multiple discussions of the concept of occupational justice, and some research about different occupational injustices. Studies about occupational injustices in the literature targeted exploration of the experiences of refugees, individuals living in underdeveloped countries, and the experiences of mental health consumers (Algo & Cardona, 2005; Algo & Burgman, 2005; Kramer-Roy, 2005; Whiteford, 2005; Whiteford, Craik & McKay, 2004). As stated previously, literature that specifically addressed stigma as an occupational injustice was not located during the literature review. Occupational therapy literature directly addressing stigma as a barrier to participation in meaningful activities was not located during the extensive review.

A Case for Stigma Research in OT

Corrigan stated that one of the fundamental ways we are able to facilitate change is through research. Other writers recommend that stigma continue to be explored, specifically exploring the consumer’s experience (Angell et al., 2005; Executive Summary, 2003; Corrigan & Kleinlein, 2005). Townsend stated that issues of power and justice need to be explored if OT’s are to be effective advocates for facilitating changes with their clients and in their communities. It is my goal with this study to explore experiences of stigma related to mental illness, to use this knowledge to become a more effective advocate for the individuals I serve, and to contribute to the science and profession of which I am a part. It is my hope that a thorough understanding of the

experiences of stigma can be shared through research and inspire movement towards greater community participation faced by adults with mental illness.

Chapter 3: Research Design and Methodology

Ethnography through the Description, Analysis and Interpretation Process

To achieve the objectives described above, a naturalistic inquiry method was used. Specifically, an ethnographic approach was employed in this study. The process I used followed the description, analysis, and interpretation (D-A-I) procedure as outlined by Harry Wolcott (1994) in *Transforming Qualitative Data*.

In this process, Wolcott suggests that the beginning to ethnography research is description and this is done by addressing the question, “What’s going on here?” by compiling data through observation of study participants in their natural context and through self-reports of lived experiences of study participants (1994). Wolcott suggests that when the observer has a particular professional interest, observation naturally gains direction and purpose (1994). Therefore, the foci of concern were what participants were doing and in what context action occurred. This research sought to give participants a voice in the process and to allow them opportunity to share their narratives. Therefore, semi-structured interviews were used to gather the participants’ reports of their experiences within the community.

The second step in the D-A-I process is analysis. This is described by Wolcott as “the identification of essential features and the systematic description of interrelationships among them – in short, how things work” (1994, p.12). Analysis in this study attempted to present the reader with perceived critical components of the data gathered from observations and interviews. At this stage in the process there is no attempt to draw conclusions, but rather to identify common patterns in the data (Wolcott, 1999).

The last piece of the D-A-I process is interpretation. This step looks at the data after the common patterns of data have been established and asks, “What does this all mean?” To state it simply, the final step is to make sense of the data and to find its meaning and application. For this study, the meaning and application were directly related to the participant’s engagement in occupations. This is again a result of how my professional interests and perceptions shape the process.

Data Collection and Analysis

Prior to beginning data collection, all participants read and signed the consent form for this study (See Appendix B). I explained to each research participant that the interviews would be tape recorded and later transcribed. I also explained to participants that their information would be handled in a confidential manner. In addition, each individual was given a pseudonym, and any identifying information was changed or removed.

Consent forms were stored in a locked cabinet separate from transcribed data and field notes to maintain participant confidentiality. The tapes on which interviews were recorded were also stored in a separate locked cabinet, and participants were notified that the tapes will be destroyed after five years.

During data collection, in each interview, I made notes in a field notes journal of observed behaviors that appeared significant. After leaving each interview, I immediately tape-recorded more field notes that consisted of observations as described above as well as my own personal feelings and reactions to the interview. Recorded field notes were transcribed along with the interview data and were reviewed and incorporated into the data analysis. I transcribed all of the interviews and field notes in order to be submerged

in the data. Transcribed data were reviewed multiple times, to the point I felt I was saturated with the information.

Interviews with participants varied in length with the longest interview lasting approximately three hours and the shortest interview lasting approximately 45 minutes. I used a semi-structured interview process (see Appendix A for sample interview questions). One participant was interviewed twice, as questions arose during data transcription that required further exploration.

Analysis was approached by highlighting significant study findings and identifying patterns and regularities in the data (Wolcott, 1994). The common threads running through the observations and interviews were identified and then coded into working categories. These initial categories were transferred from the transcribed data to index cards that were labeled with a working category title. Those categories were reviewed and more themes emerged, creating smaller and more refined data. This process was repeated again until it was felt final categories reflecting the data had emerged. These final categories were again transferred from labeled cards to a working manuscript.

Summarizing the data and exploring how they related to existing stigma literature completed interpretation of the research data. Last, I examined how the data might inform occupational therapy and discussed the study's limitations as well as questions for future research.

I attempted to assure trustworthiness by asking participants to review the completed research document. They were asked to verify that I had not manipulated the data from the interviews in any way and to confirm that I was accurately reflecting what they had shared with me about their experiences. However, this was not possible with one

participant, as he passed away prior to this step in the research process. The thesis committee chair was given a copy of all interview transcripts and was able to read and verify that no information was manipulated during the review process.

Additionally, to insure rigor I kept an audit trail that included all coded transcripts, working categories on labeled index cards, and personal reflections. “Sandelowski (1986) referred to this process as leaving a ‘decision trail,’ so that the reader would be able to track and verify the research process” (Rofle, 2006). The index cards containing the working categories and data were regularly checked against the transcripts of data to insure that correct wording and translation was maintained during the “narrowing down process.” I also met with the thesis chair routinely throughout the research process to discuss study findings and to problem solve any research method questions that arose.

Participants

In order to participate in the study, individuals had to meet the following criteria: be an adult ages 18 to 65, have a diagnosis of a mental illness for a minimum of three years, reside in Southwest Michigan, live in the community independently or receive minimal assistance with daily living activities, and be able to reflect on and articulate their experience of living with a mental illness.

Individuals were recruited for the research by recommendation of their client services manager (CSM). These individuals are a valuable referral source, as they know each of their clients, including their goals, values, interests, and engagement in the community in which they live. CSMs working in a community-based mental health services agency in Southwest Michigan were given a letter describing the research project

(Appendix C). Approximately 48 letters were distributed. The letter asked CSMs to identify individuals who could talk about their experience of having a mental illness and would benefit from having an opportunity to do so. A total of six recommendations from CSMs were received. The first four individuals identified by CSMs were contacted. I explained the purpose and the design of the study to these four individuals and all agreed to participate. At the end of each interview I asked each participant if he or she knew any other individuals meeting the study's inclusion criteria outlined above who might benefit from engaging in the research process. None of the participants made a recommendation.

Two of the study participants were female and two were male. They ranged in age from 43 to 68 years old. Three individuals in the study were diagnosed with Bipolar Disorder and one individual was diagnosed with Schizophrenia. All participants were Caucasian. Each participant lived in an apartment setting. One participant shared his space with roommates. This same participant received supported living services in the community. Support services were provided by an agency that contracts with the mental health agency to provide assistance with daily living activities such as household management, supervision of medications, and grocery shopping. Both female participants were followed by the Assertive Community Treatment (ACT) team through the mental health agency. ACT is an intensive community program, and its primary focus is supervising individuals' medication regimen to keep them stable and independent in the community. The remaining participant received only minimal mental health support in the community. He received only case management services, which include annual planning of goals and assistance with needs in the community as they arise.

Participant Description

I believe it is an important and necessary step in establishing context to provide the reader with a description of the participants interviewed. In ethnography we are asking the reader to become a part of the process by connecting with the stories and experiences of the subjects. I believe that having a brief description of the participants facilitates that connection for the reader. Participants were each assigned a pseudonym and they are used throughout this paper.

Jan

Jan was identified by her ACT CSM as a good candidate for this study. Jan and I had first met two years prior to this study when she was referred for occupational therapy (OT) services.

In my previous contacts and again during this research, it was evident that Jan possessed intelligence and a sarcastic sense of humor that was frequently also self-deprecating humor. During the interview Jan wore sweat pants, sweatshirt, and a bandana to hold back her short blond hair. She shifted on the couch and smoked continuously while talking. She was respectful prior to lighting up the first cigarette and made sure that the smoke would not bother me during the interview. I observed Jan had tremors in her hands that had worsened since our last meeting, likely a result of her medications. Jan shared that she used to live with a friend for whom she had to assume a caretaker role for years ago. Since this friend passed away, Jan reports a lack of meaning in her daily life. She continues to grieve the loss and over the years I have known her has frequently said her life is not the same without this friendship that allowed her to be a care-giver and feel cared for in return. She lives alone in a clean and peaceful neighborhood at this time.

Emma

Emma was a very pleasant woman who was eager to be a part of the study and enjoyed talking. We met on two separate occasions for interviews, because at times she had difficulty answering questions secondary to tangential speech. Additionally, she frequently repeated stories about her family and relationships and it was evident it was very important for her to feel that those stories were being heard and shared. During both meetings, Emma was very nicely dressed and was wearing make-up along with a neatly styled wig. She explained she wears a wig because her hair fell out as a medication side effect. Emma is the mother of two sons; one is, by her report, “severely and profoundly disabled,” and the other is in the military. Emma lives alone in a low-income high rise in the community. Her apartment is very neat, although cramped with furniture. She reported that her son has told her he does not like the neighborhood she currently lives in and feels it is a “rough” neighborhood because of all the abandoned buildings across the street from her.

Jay

After my time spent with Jay, I was impressed by his thoughtful responses and the insight he holds regarding his illness. At age 43, Jay is the youngest of the study participants; however, it seems life’s experiences have made him wise beyond his years. Jay met with me in the middle of packing up his apartment to move to another, more affordable apartment. This move was not a personal choice Jay had made. Rather, he had been living in an apartment that was partially funded by the County as part of a “relocation program.” Jay had been living in the YMCA hotel, which was found uninhabitable by an inspector called out to look at the building’s heating system.

Therefore, the residents living in the YMCA were forced out and relocated in an apartment building with the agreement that their rent would be subsidized for one year. Within that year, relocated residents were expected to find and secure affordable living options for themselves. Jay is a large man, tall and broad. He referred to himself as “fat and not very good-looking” during the interview; however, I did not find him to be either. He displayed nervous habits, such as tapping his fingers on the table while talking to me and made very little eye contact during the interview. He was the only study participant who was employed at the time of the interviews.

Dan

I have had the privilege of knowing and working with Dan in different capacities for the past four years. I initially worked with him to provide OT services and following that he was a regular participant in a multi-family group I co-facilitate twice a month. Dan was a self-described scholar who loved to challenge your thoughts and ideas and enjoyed a good debate. He frequently shared his philosophies on life and mental illness, which I have always found fascinating. Dan was frail in appearance, very thin and hunched at the shoulders. He wore large, round, dark glasses on his gaunt face and he kept his gray hair shaved close to his head. Dan walked with a cane, and frequently gestured with it when talking. He had an oversized grin, a sharp tongue, and a quick wit. The last time I saw Dan, after one of our regular groups that he did not attend because he could not get out of bed, he proclaimed, “I’m half dead” because he was going through exhaustive kidney dialysis. I disagreed with him and tried to be encouraging about the status of his health. However, shortly after this exchange Dan was moved to Hospice Care and died within the week.

These are the individuals who honored me by sharing their stories. I am equally indebted to them all for their time, their honesty, and their courage.

Chapter 4: Results

There were five dominant themes that emerged during data analysis. During analysis it became apparent to me that there were statements made by participants that summarized the data themes best. Therefore, I titled three of the following subsections below using a quote from one of the study participants. The themes illustrated how the participants feel that living with a mental illness alone is a barrier to participating in day-to-day activity. The experience of having stigma attached to their illness is another layer of barrier, one that creates social isolation, feelings of inadequacy, and hopelessness.

A “road block built into your body”

Jay described living with a mental illness by saying,

...in general it's no fun to have anything remotely close to having a mental illness or being depressed. It just drains your whole body. It drains your energy level...it kills your mood, it kinda kills the spirit of wanting to go out and do things...a lot of times you really have to struggle and fight to get up and do the basic things...it's just having that road block built in to your body.

Jay's description of an internal “road block” that prevents him from engaging in day-to-day activities was a common theme that emerged in the interviews when discussing living with a mental illness. Other participants also described feeling “drained” by their illness and struggling to engage in daily occupations. Jan described living with a mental illness as losing the motivation to keep up with things or to care about not keeping up with them. She also said living with a mental illness means you lose hope. Jan shared that routine tasks such as “getting dressed, taking a bath, [and]

cooking...” are difficult. She explained this is a result of losing “your ability to organize and think...” as well as a general lack of interest in many activities, which are symptoms she relates to having a mental illness. She further stated that she tries to find some internal motivation to engage in daily activities but feels that “being sick so long” only reinforces a lost sense of hope for something different in her life. I was deeply saddened by Jan’s statement during our interview that at times the only thing she has hope for is death in order to be released from the pain and struggles of daily life. Not only did Jan talk about feeling hopeless, she again said that having a long-term mental illness has decreased her sense of self-efficacy. While my previous interactions with Jan left me confident in her abilities, she shared that she intended to “get my brother to be legal guardian and go...to a group home, you know, have him make the decisions.” She further described that having the motivation to do anything required having someone to “literally hold my hand.” Living with a chronic mental illness has left Jan feeling hopeless and powerless.

Along with descriptions of feeling that day-to-day living is more challenging when living with a mental illness, participants talked at length about feeling as if life was interrupted by hospitalizations and medications associated with treating mental illness. Participants had mixed views on the effectiveness of the treatments offered for mental illness at this time. All participants, however, shared that their experiences of being hospitalized for their psychiatric condition were negative. Dan shared that the biggest change in his life since receiving a psychiatric diagnosis has been numerous hospitalizations, which he views as the disruption to the direction his life was going. Dan stated, “...after I was in and out for so much I could really just think of myself as a

patient, a mental patient.” He further described how multiple hospitalizations early on made him feel that he was then too far removed from his graduate studies, so much so that he did not return to them.

Jay also experienced an interruption in his college education secondary to his mental illness. He shared he has approximately 90 college credits. He started out taking psychology classes and later switched from a psychology focus to pursuing a degree in business. Jay said he changed his major in college because he felt it was not appropriate to take such classes “‘cause of the issues I have.” Jay shared he would like to return to school and finish a bachelors degree but has not because his illness has changed “‘things” and he is not sure if he will return.

Emma felt her life was interrupted by hospitalizations, saying, “...I lost three months of my life...and I can’t afford to lose that kind of time.” She described her experience of being admitted to the hospital and feeling “tricked” when she was told by doctors that they planned to keep her for “60 days.” While in the hospital Emma said she told the doctors she had to return home to manage her finances and shared with them she was concerned she was going to lose her home if she remained in the hospital. In fact, she did lose her apartment while hospitalized and was homeless for a brief period of time once discharged. While homeless, Emma stayed with friends in the community. She talked about how she believes homelessness created additional stigmatizing attitudes, even from the friends who were housing her.

In addition to experiencing hospitalizations as an interruption to the flow of daily life, Emma viewed treatment with psychotropic medications as further impairing daily function. Emma experienced extreme side effects to an injectable medication, Prolixin.

She shared, “I was shaking so badly I couldn’t even brush my teeth...my body was vibrating and shaking so badly I couldn’t hold a cup in my hand.” Furthermore Emma said, “I was wetting my pants...I didn’t wear make-up, my hair was a mess and it was falling out.” Emma began crying during the interview while talking about trying to live with medication side effects and said, “I really thought, ‘I’m not gonna make it...I’m gonna die.’” After trials of medications, Emma is currently taking a mixture of prescribed antipsychotics she is content with. She said, “I didn’t have any qualms about taking the medication at all as long as it was the right medication.”

Jay also expressed an appreciation for being prescribed the “right” medications. He shared that mental illness is manageable as long as you “find the right combination of medicine.” Jan felt that treatment within the mental health system consists only of medications and that this is inadequate. She feels that if she is ever to be well, it is up to her to change her life, independent of services and medications.

When examining the themes that emerged from the data regarding living with a mental illness, the last common thread through the interviews was discussion about receiving disability income. Two participants, Emma and Jay, have felt limited and restricted in their pursuit for work as a result of being placed on Social Security disability income. Jay felt that having this income created yet one more difference between him and others. He also explained that having this income is a barrier to working full-time, as your disability income is lowered or stopped altogether if an individual earns above a specified amount of monthly income through employment. Emma was fearful about returning to volunteer work at Red Cross, something she used to do and found very meaningful. She shared, “...if they see me working, [Social Security will say] ‘Why

doesn't she have a job?' you know?" She fears that if she pursues volunteer opportunities her monthly income will be in jeopardy.

Dan felt differently about receiving Social Security income monthly. He has equated this monthly income with receiving funding to pursue independent, scholarly studies. Disability benefits aided Dan in fulfilling the life role he felt had been taken from him when he was told he could not return to graduate school. Dan said, "...supplements have been like one big fellowship for forty years. I've been able to use them for my scholarship."

"Stigma breaks your spirit"

Jan said that stigma "breaks your spirit." She further stated, "...if you've been stigmatized it affects the way you do your daily things." All participants identified in some way that stigma is the result of people who do not understand what it means to live with a mental illness. Another common belief about the experience of stigma from all participants is the concept of labeling. Jay and Dan both talked about stigma being the direct result of having the diagnosis of a mental illness and the fear that the diagnosis generates in society. Jay shared that once you are labeled, others "see [us] as second class or third class citizens."

Three participants identified experiences of external stigma, those harsh societal reactions stemming from the knowledge that one has a mental illness. Throughout the interview with Emma she described conflictual relationships with her family members as a result of her mental illness. She shared that her brother had gone so far as to call her "demonic" during a time she says she "was having a breakdown." Emma said her brother doesn't listen to her ideas and opinions because "...he thinks I'm the 'crazy one.'" She

stated that she believes both of her siblings feel this way because she has been psychiatrically hospitalized in the past and said, "...they never get off of that...they think they don't have to listen to me at all now because, 'Oh, she was in a mental hospital.'" She further stated, "...in my family they would just go around...and treat me like I'm an idiot because [my diagnosis] is Bipolar."

Emma feels a sense of hopelessness over no longer feeling connected to her family and said, "...you're never forgiven...no matter what you do, you cannot rise above it." During a more recent encounter with others living in her apartment building, the idea that a psychiatric hospitalization seems to disqualify one's place in society was reinforced for Emma. She described an encounter with another resident after they saw her giving another woman her empty returnable soda bottles. They told Emma, "Don't give her anything, they've been in a mental hospital, she and her husband." Emma went on to say, "...when he said it I thought, 'that's how my family feels about me' it made me feel really bad."

Emma has gotten the message that having been psychiatrically hospitalized is cause for a stigmatizing response; she also felt that during her hospitalization she experienced external stigma from treatment professionals. While in the hospital Emma was court ordered to remain inpatient involuntarily for up to two months for treatment. In response to the court order Emma said, "God! I feel like I'm being kidnapped!" She then laughed while telling me, "You know what they did? They wrote that in there as me being paranoid."

Dan also described feeling that his family avoided him while he was in the hospital and continued to do so for some time after. He shared the following about his

relationship with his sister: "...ever since I've had my mental illness issues she maintained a very distant relationship with me. Every year at my birthday she would call on the phone and we'd have a conversation, an hour or less, and that would be it for the year."

Another experience of stigma within family, by Dan's account, occurred when his nephew got married. The wedding was out of state and many family members planned to stay overnight in his brother's home. Dan said, "...but my brother wouldn't let me stay overnight because of my mental illness."

Dan talked about his experience of not completing college as an example of external stigma that altered the course of his life drastically. He said, "...I was a graduate student, I was gonna be a professor, a psychology professor, I could've been very successful...and then when I got hospitalized they just said, 'Oh you can't have any of that and do any of that'..." When I inquired why he was told he could not finish his degree at that time he said, "Because they said I'm a schizophrenic and schizophrenics can't do that." Dan declared, "That's stigma right there!"

Jan said that stigma is "in the workplace, it's in families and friends..." In fact, she shared examples of external stigma from all those social groups. Jan told her story about working in a local hospital in the Gerontology Department years ago and said once while talking to a supervisor she confided that she had a Bipolar diagnosis. She then said her supervisor "...asked me to transfer out...within three months." While Jan agreed that she was having some difficulty with learning some part of her job in the Gerontology Department she said she doubted this was the reason she was asked to transfer and believes her transfer was a result of stigma. Jan described being ignored by friends in

public and having friends who no longer keep in touch with her after seeing her actively psychotic.

Jan explained another type of external stigma from friends and family members, a type of paternalistic treatment when other individuals “impose what would be good for me from their standpoint...” Jan shared the following impression of some of her friendships, “...they kinda tell me what to do and ‘you should really’ and ‘it’s gonna be difficult for ya’ and all this garbage when they’re not professional people.” During the interview Jan expressed on multiple occasions that she has a supportive family and their support is valuable to her. However, on one occasion she said, “...family helps, but again...they give you the ‘Oh, you’re doing so well’ or they make judgments. People are judgmental to the mentally ill...” In addition, Jan described how this paternalistic type of treatment also lends itself to others having no expectations of her to do well or live an active and full life. Jan stated that “nothing” is expected of her from her family and friends except to “...get better, well just stay out of the hospital I guess, take your medications and um do the best you can.”

Self-efficacy in Question

Jay stated,

...at times a mental illness can definitely make you feel worthless, less than...like the stigma, that’s kind of inbred in a normal mental illness...after a while you realize that you are different and that you’re not wired right and you’re not like everybody else and...you gotta do all these things to maintain the sanity when someone else doesn’t.”

Jay also said, “I’ve always known I was different...” Jay’s statements about not feeling “normal” prompted the question what he would consider “normal?” He responded, “...not having to be on medicine...” He further shared that moving towards normal would also consist of holding a full-time job and not having Social Security benefits. He shared that he felt he would be more “normal” if his memory was better and he finished school. Jay reflected

...people aren’t going to like me because I don’t have a whole lot to say, I don’t do a whole lot, I don’t have a whole lot going for me, I’m not good looking, I’m overweight right now and fat.

Jay believes that because he has not met certain criteria that make up “normal” he does not have value or a place as a member in society. Jan also shared this belief. When talking about her personal view of her illness she attributed her views to her father whom she described as “never very loving.” She said her father had told her to leave home a couple of times until she returned with a job. Jan insightfully said, “...I think that had a lot to do with the way...I view my mental illness and...the way I feel about how others look at me too...” Like Jay, Jan feels that society has a certain expectation of individuals in order for them to fit in.

Jan believes she would be more accepted if she volunteered, or in her words was “functioning at a higher level than I [am] now.” Jan feels it is important to contribute something and feels that because she is not employed or volunteering her time she is “just existing.” She further said she does not pursue those activities she feels are expected of her because “I don’t have the confidence to do it alone. I’ve been so sick for forty years, that it’s really been a blast [to my self-esteem].” Jan said her “self-efficacy” is always in

question internally. She believes her lack of confidence comes from both symptoms of her mental illness and the stigma attached to the mental illness.

While talking about an experience of external stigma in the community, Emma immediately internalized the experience and took action to change herself. During a walk outside, an activity she loves, Emma encountered others on the street who would not make eye-contact with her or say hello to her. After thinking about why others would avoid her in this manner she thought, “It must be the way I’m dressed or something...” She said she went out and bought maternity tops to wear while out in public and said since this change in clothing she feels people have been nicer to her. Emma said, “...so that’s basically my biggest hurdle, is to figure out how to dress and how to act and stuff...”

Dan did not share the other participants’ feelings that he needed to change himself in order to better fit in. Instead, Dan shared, “...I’m pretty normal right now so [stigma] doesn’t affect me too much right now.” He explained he measures himself against his roommates and others with a mental illness and feels that he is doing well by this measure.

Social Categorization

Dan said that because his roommates “act more strange” they experience stigma to a greater degree. He believes this is because his roommates have schizophrenia, which includes symptomatic behaviors others see as odd. He said,

I have to tell you, you know, people...say of all this program they think I might be the highest functioning. I do see people as um dysfunctional, like my roommates, all they do is sit, sleep, smoke, eat.

They don't watch television, they don't read, they kinda talk to themselves...also the medications make people very sedated, you know kinda retarded. So, uh, I think people um see that and don't like it, don't want anything to do with it.

Dan further explained, "...basically [stigma] comes from differentiation people make between self and others" and "...it's hard to know how to relate to people when they're so different from you."

Dan was not the only participant to measure himself in this way. Emma also talked about knowing she was doing better now, because she did not look or act like other adults with mental illness she sees in the local CMH. Emma pretended to hold her nose while telling me that at times other clients of the CMH come in the building and sit next to her and she thinks to herself, "Yuck. Because they're so dirty, you know...and I feel so sorry for them. Because I was like that when I first got out of the hospital." She also expressed feeling that others who did not take their medications as prescribed are "crazy for not taking the stuff."

Throughout the interviews with the participants a prevalent theme was that the impact of stigma (externally or internally) was greatest on the occupational performance area of social participation. While external stigma had a slight impact on this area, internal stigma seemed to create more of a barrier to pursuing social interactions. Many of the participants felt that they needed to change themselves or distance themselves from others with a mental illness in order to be accepted as members of society. To protect themselves from the rejections of not fitting in, the participants maintained distance from society. All the while, social interaction is what the majority of participants craved most.

“People are important!”

During an interview, Jan made the emphatic statement, “People are important!” while talking about feeling socially isolated. Social isolation arose as a common thread among the participants. Jan and Jay expressed social isolation as a negative experience, whereas Emma talked about feeling secure when isolated. While Dan did not express feeling social isolation at this time, he recalled feeling this way in the past and its impact on his life.

Of all the participants, only Jay was employed at the time of the study. He described his typical day as “waiting around” to go to work at night. While he enjoyed working, he continued to say that his greatest desire is to have a social network of people. Jay shared that he enjoys shopping and going to the movies but does not frequently engage in these activities. When I asked him what prevented him from doing so he shared,

...it’s kinda boring after awhile to do it by yourself and to know that you’re alone in a crowd. That’s kind of a shitty feeling, you know, being out there with all these people...and know that you’re alone by yourself, all by yourself...

Jay further shared that he would like to “find a place, a social gathering place” where he felt comfortable meeting new people. He explained that he has a “hard time” meeting new people and adjusting to new surroundings “for whatever reason.” However, during our meeting he spoke eloquently about his experiences and shared personal life details with me easily. While Jay expressed a desire to find a place he was comfortable in to

meet new people he also said that when he was diagnosed with a mental illness almost 20 years ago he resigned to keeping to himself.

Emma has made the choice to be more isolative and chuckled as she said, “I don’t go around anybody...I know um it makes people uncomfortable, you know, to have someone around them that’s crying all the time.” While Emma talked about avoiding social situations, she also talked about feeling that her apartment is a sanctuary and it is peaceful for her to remain home alone. She explained that at times when friends or family members call her it interrupts her peace. When asked how she spends her time while trying to protect herself in the home she described her typical day by reporting what shows she watches on television every day.

Jan and Dan both talked about suicidal ideations as a result of feeling socially isolated. Jan said, “...trying to be so isolated and make it, makes you want to give up and seek other avenues like suicide...” Approximately three years ago Dan was living independently in an apartment with the support of the ACT team. During that time Dan was psychiatrically hospitalized for suicidal ideations. While he was receiving treatment in the hospital, his treatment team, in coordination with the State Hospital, decided that it would be best if Dan no longer lived independently in the community. Dan’s apartment lease was terminated and he waited in the hospital until he could be discharged into one of the “group home” facilities identified by the mental health agency. Dan reported experiencing frustration over having his apartment packed up by someone other than himself, as many of the books he had collected and cherished were either thrown away or lost. However, he agreed with the decision not to return home to his apartment. It had been explained to him by the clinical treatment team that they felt his suicidal ideations

were the result of social isolation. Dan agreed with this assessment. Since moving in to an apartment with two other roommates, Dan expressed satisfaction with his day-to-day routine. He kept busy by writing articles for the newsletter at the local psychosocial rehabilitation clubhouse that he attended twice weekly. He also described having full days, which consisted of attending “therapy appointments” and visiting with his ex-wife once a week. Additionally, Dan enjoyed having time alone to read and use the Internet.

A theme that emerged when talking about being socially isolated was the idea that the participants felt they needed to keep a certain distance from society in order to “stay safe.” All of the participants claimed they did not easily share with others that they have a mental illness diagnosis. They all felt this was a means of shielding themselves from external judgments. It was Jay who described this as a means of staying safe. He said,

I keep myself pretty safe, that’s one thing that I do...it keeps me safe if I don’t make contact with a whole lot of people. Then I don’t have to worry about a whole lot of people asking questions about me...I think that’s...one of the reasons why I don’t really have any friends, um, it just keeps me safe.

Jay talked about having minimal interactions with his co-workers and having little human contact outside of the work place. He shared this was deliberate and reassured him that he would not have to worry about how to avoid people and interactions. He further said, “I just keep my distance from people and just let the world kind of go by and do its thing and I just kind of participate as little as I can.”

Jay shared that to avoid being “put down” or “labeled” he chooses not to tell people that he has a mental illness. Jan reflected she too remains socially isolated to avoid

being “stigmatized.” She also said, “I almost prefer to deal with people who don’t know me. You know, a clerk in a store...” While Dan believed others perceive him as “pretty normal” he still said, “I don’t have that much contact with people” and further stated, “I don’t disclose my status that easily.”

Not disclosing a diagnosis of mental illness was a predominant theme while talking to Emma. She stated time and time again that she does not tell others her diagnosis. However, she felt that some mental illness diagnoses, such as depression and PTSD, are “legitimate” and she would tell others that she has these illnesses.

People ask me, ‘Well, what’s wrong with you?’ you know, because I’m shaking and stuff like that and I tell them...I have things wrong with me, other things...that are legitimate and make me look legitimate and I’ve got this [other] thing hidden in me... I told them I have essential tremor and that I have PTSD, so they see me shaking and they know that’s true.

Emma further explained to me that she felt it was all right to tell others she had PTSD because people know what that is and understand it. Emma also said, “I don’t tell people that I take Risperdal. I tell them that I take an anti-depressant.” She talked about how certain medications are acceptable now because of the heavy television advertisements of medications.

All of the research participants agreed that having a diagnosis of depression does not carry the stigma it once did. All participants shared the belief that bipolar disorder and schizophrenia diagnoses continue to have stigma attached to them, and having one of these illnesses was something that needed to remain hidden from society.

Chapter 5: Conclusion and Directions for Future Research

Discussion

This study was designed to portray the experience of stigma related to mental illness and how that experience impacts daily occupations. This study also sought to examine the experience of stigma within the occupational justice framework. Throughout the literature review related to the occupational justice framework, it was apparent that stigma qualifies as an occupational injustice. During this study, themes arose that confirmed this. Study participants experienced occupational alienation, deprivation, marginalization, and imbalance as a result of stigma. The participants experienced such injustices when they were isolated and rejected by family members or were not allowed to access educational, employment, and/or social opportunities of their choosing.

The study highlighted the experience of living with the symptoms of a mental illness and how this is in and of itself a large barrier to participation in daily living activities. Participants described feeling a decrease in energy and internal motivation so profound that it can rob the will to live. They voiced concern that the medications meant to treat their symptoms only added to an inability to engage in occupations. Medications further decreased energy and created physical side effects that made simple tasks like brushing one's teeth more difficult.

The predominant theme of this study was the connection between the experience of internal stigma and limited social interactions. All participants expressed frustration with having limited social networks. It was evident during this study that the experience of internal stigma prevented participants from pursuing social opportunities around them.

They described not feeling worthy of social relationships until they fit into what they perceive to be societal norms. Not pursuing social opportunities in their community was a means of “staying safe” or preventing rejection from others and society. While all participants did not actively seek opportunities for social interaction, they each craved social relationships.

That internal stigma should be a barrier to social interactions is not a new finding and is consistent with the literature. Angell, Cooke, and Kovac (2005) have identified that avoiding human contact is a means of preventing rejection. Corrigan and Calabrese (2001) have proposed that internal stigma is the internalization of public stigma, saying that “people are raised hearing negative things about mental illness and then later in life when they get one they anticipate rejection and devaluation of themselves.” Like Angell et al., Link and colleagues (2005) posit that the fear of this anticipated rejection leads to strained relationships with “potential stigmatizers.”

No consistent theme regarding stigma change emerged during the research and therefore it was not included in the results. However, I feel that it is important to note that all participants felt there had been change in stigma over the years because of media exposure to specific diagnoses. Participants felt that certain diagnoses, such as depression, are now acceptable to the general public because of the volume of discussion about this illness in the media. With that said, not all participants believed that stigma is something that can ever be changed or eliminated completely.

Conclusion

Relevance to OT

As occupational therapists, I feel it is imperative that we begin to routinely view stigma as an occupational injustice that impacts access to meaningful occupations. We must continue to expand our practices to look at the environment around individuals we serve, which includes the injustices they face daily. As occupational therapists we must become adept at intervening where there are injustices in order to facilitate the community integration deinstitutionalization promised so many years ago.

The literature suggests occupational therapists use empowerment as a means of intervention for addressing injustices. Bejerholm and Eklund (2007) stated, "...the sense of self seems to be an important aspect in relation to the level of engagement" in occupations and their environment. Empowerment can be gained through reflection on experiences of power and powerlessness and using those reflections to then examine ways to change behaviors (Townsend, 1996). Cognitive Behavioral Therapy (CBT) approaches are valuable tools for increasing an individual's self-awareness, which is then empowering. The literature supports the notion that people with greater self-awareness are not overwhelmed by their symptoms and labels and take a more active role in their treatment and recovery (Corrigan & Lundin, 2001). I also suggest that we incorporate empowering techniques with the families of persons living with mental illness. Family supports may also need to have a deeper understanding about mental illness and the impact it has on functional abilities.

While we must continue to sharpen our advocacy skills to effect change in a person's environment, we must continue to expand our clinical understanding of the

symptoms of mental illness. As OT's we must become more proficient in examining the impact mental illness has on daily occupations and researching more effective methods of treatment. Throughout this study, it was evident that the symptoms of mental illness impacted occupational performance in profound ways.

Study Limitations

The first potential limitation to the study was the loss of one of the participants. Because of the death, that participant was not able to read the completed study and verify the findings reported here.

A second potential limitation is the small sample sized used. It could be viewed by readers that the small size cannot predict the same outcomes and experiences for all adults with mental illness. I remind the reader that an ethnographic approach does not assume to predict conclusions that can be generalized to an entire population of people. An ethnographic approach only assumes to provide a picture painted in time of participants and their lived experiences. In addition, while only four participants were utilized for this research effort, Wolcott (1996) has recommended that beginning ethnographic researchers choose only one individual to engage in the research process with. He believes that even this singular contact and sharing of life experiences generates valuable themes from which we can learn.

Readers of this study may view my previous working relationships with two of the study participants as a limitation. It could be assumed by some that these participants provided me with stories based on "what I wanted to hear" because they knew me. However, I would argue that this did not occur. I am a therapist who always seeks to motivate clients to be involved in activity and their community. Therefore, if they were

telling me “what I wanted to hear” I believe they would not have shared with me their experiences of little activity and social isolation.

Directions for Future Research

The literature review indicated that there are currently very few research efforts directed at stigma in the occupational therapy literature. However, in other disciplines stigma is well researched and identified as a primary barrier for accessing meaningful activities. We, as occupational therapists, must begin to talk about and understand stigma as an occupational injustice. It is my hope that this study is a small stepping-stone to more discussion about the impact of stigma on occupational performance. Occupational therapists must also be having ongoing dialogues in our research and literature about methods for effectively empowering our clients. The profession will also benefit from sharing more client stories through qualitative research to illustrate how the people we serve are living. Additionally, research is needed in occupational therapy that focuses on the impact of the symptoms related to mental illness on daily living activities. The occupational therapy literature to date is sparse in this area. We would benefit from having a better clinical understanding of how a mental illness condition impacts function.

Specific questions for future research might include:

- How are occupational therapists addressing stigma in their practices?
 - What interventions and/or means of empowerment for clients is most effective in reducing the experience of internal stigma?
- How are occupational therapists providing support to families of an individual diagnosed with a mental illness?

- What interventions are most effective in facilitating continued family cohesion?

References

- Accordino, M. Porter, D., & Morse, T. (2001). Deinstitutionalization of persons with severe Mental illness: context and consequences. *Journal of Rehabilitation*. 67(2), 16-21.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process, 2nd edition. *American Journal of Occupational Therapy*, 62(6), 625-683.
- Angell, B., Cooke, A., & Kovac, K. (2005). First-person accounts of stigma. In P. Corrigan (Ed). *On the stigma of mental illness*. (pp 11-44). Washington, DC: American Psychological Association.
- Barros, D., Ghirardi, M.I.G., Lopes, R.E. (2005). Social occupational therapy: a socio-historical Perspective. In F. Kronenberg, S. Algado, & N. Pollard (Eds.). *Occupational therapy Without borders: learning from the spirit of survivors*. (pp 140-151). New York, NY: Elsevier.
- Bejerholm, U., & Eklund, M. (2007). Occupational engagement in persons with schizophrenia: Relationships to self-related variables, psychopathology, and quality of life. *The American Journal of Occupational Therapy*. 61(1), 21-32.

Bryant, W., Craik, C., & McKay, E. (2004). Living in a glasshouse: exploring occupational

Alienation. *Canadian Journal of Occupational Therapy*. 71(5), 282-290.

Carling, P. (1995). *Return to community*. New York, NY: The Guilford Press.

Corrigan, P. (2004). Target-specific stigma change: a strategy for impacting mental illness

stigma. *Psychiatric Rehabilitation Journal*. 28(2), 113-120.

Corrigan, P. (Ed.). (2005). *On the stigma of mental illness*. Washington, DC: American

Psychological Association.

Corrigan, P. & Kleinlein, P. (2005). The impact of mental illness stigma. In P. Corrigan

(Ed.). *On the stigma of mental illness*. (pp 11-44). Washington, DC: American

Psychological Association.

Corrigan, P. & Lundin, R. (2001). *Don't call me nuts*. Champaign, Il: Albana Press.

Corrigan, P., Thompson, V., Lambert, D., Sangster, Y., Noel, J., & Campbell, J. (2003).

Perceptions of discrimination among persons with serious mental illness

[Electronic version], *Psychiatric Services*, 54, 1105-1110.

Corrigan, P., Watson, A., Byrne, P., & Davis, K. (2005). Mental illness stigma: problem

of public health or social justice? [Electronic version], *Social Work*, 50, 363-369.

Davidson, L., Stayner, D., Nickou, C., Styron, T., Rowe, M., & Chinman, M. (2001).

“Simply to be let in”: inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal*. 24(4), 375-389.

DePoy, E., Gitlin, L. (1998). *Introduction to research: understanding and applying*

Multiple strategies. USA: Mosby.

Duggan, R. (2005). Reflection as a means to foster client-centered practice. *Canadian Journal of*

Occupational Therapy. 72(2), 103-112.

Eklund, M. (2007). Perceived control: how is it related to daily occupation in patients with

mental illness living in the community? *American Journal of Occupational Therapy*. 61(5), 535-542.

Estroff, S. E. (1981). *Making it crazy: an ethnography of psychiatric clients in an american*

community. Berkeley and Los Angeles, Ca: University of California Press.

Falk, G. (2001). *Stigma how we treat outsiders*. Amherst, NY: Prometheus Books.

Fleming Cottrell, R. (2005). The olmstead decision: landmark opportunity or platform

For rhetoric? Our collective responsibility for full community participation.

American Journal of Occupational Therapy, 59(5), 561-568.

- Fransen, H. (2005). Challenges for occupational therapy in community-based rehabilitation: occupation in a community approach to handicap in development. In F. Kronenberg, S. S. Algado, & N. Pollard (Eds.). *Occupational therapy without borders: learning from the spirit of survivors*. (pp 166-182). New York, NY: Elsevier.
- Jakobsen, K. (2004). If work doesn't work: how to enable occupational justice. *Journal of Occupational Science*, 11(3), 125-134.
- Larson, E., & Zemke, R. (2003). Shaping the temporal patterns of our lives: the social coordination of occupation. *Journal of Occupational Science*, 10(2), 80-89.
- Law, M. (1991). The environment: a focus for occupational therapy. *American Journal of Occupational Therapy*, 28(4), 171-179.
- Lawlor, M., & Mattingly, C. (2001). Beyond the unobtrusive observer: reflections on researcher-
Informant Relationships in urban ethnography. *American Journal of Occupational Therapy*. 55(2), 147-154.
- Markowitz, F. (2005). Sociological models of mental illness stigma: progress and prospects. In P. Corrigan (Ed.). *On the stigma of mental illness*. (pp 129-144). Washington, DC: American Psychological Association.

Nagle, S., Valiant Cook, J., & Polatajko, H. (2002). I'm doing as much as I can:

occupational choices of persons with a severe and persistent mental illness.

Journal of Occupational Science, 9(2), 72-81.

O'Brien, P., Dyck, I., Caron, S., & Mortenson, P. (2002). Environmental analysis: insights from

Sociological and geographical perspectives. *Canadian Journal of Occupational Therapy*,

69(4), 229-239.

Peloquin, S. (2005). The art of occupational therapy engaging hearts in practice. In F.

Kronenberg, S. Algado, & N. Pollard (Eds.). *Occupational therapy without borders:*

learning from the spirit of Survivors. (pp 99-109). New York, NY: Elsevier.

Perlick, D., Rosenheck, R., Clarkin, J., Strey, J., Salah, J., Struening, E., & Link, B.

(2001). Adverse effects of perceived stigma on social adaptation of persons

diagnosed with bipolar affective disorder [Electronic version], *Psychiatry*

Services, 52(12), 1627-1632.

President's New Freedom Commission on Mental Health. (2003.), *Executive summary*.

Retrieved December 20, 2005, from <http://www.mentalhealthcommission.gov/>

Address.html

- Rasinski, K., Viechnicki, P., & O'Muirheartaigh, C. (2005). Methods for studying stigma and mental illness. In P. Corrigan (Ed.). *On the stigma of mental illness*. (pp 45-65). Washington, DC: American Psychological Association.
- Rebeiro, K. (2001). Enabling occupation: the importance of an affirming environment. *Canadian Journal of Occupational Therapy*, 68(2), 80-89.
- Shapiro, R. (1994). *No pity*. New York, NY: Three Rivers Press.
- Taylor, R. (2005). Can the social model explain all of disability experience? Perspectives of Persons with chronic fatigue syndrome. *American Journal of Occupational Therapy*, 59(5), 497-506.
- Townsend, E. (1993). Occupational therapy's social vision. *Canadian Journal of Occupational Therapy*, 60(4), 174-183.
- Townsend, E. (1996). Enabling empowerment: using simulations versus real occupations. *Canadian Journal of Occupational Therapy*, 63(2), 114-128.
- Townsend, E. (1997). Inclusiveness: a community dimension of spirituality. *Canadian Journal of Occupational Therapy*, 64(3), 146-155.

Townsend, E. (2003). Reflections on power and justice in enabling occupation. *Canadian Journal of Occupational Therapy*, 70(2), 74-87.

Townsend, E., & Whiteford, G. (2005). A participatory occupational justice framework: population based processes of practice. In F. Kronenberg, S. Algado, & N. Pollard (Eds.). *Occupationaltherapy without borders: learning from the spirit of survivors*. (pp 110-126). New York, NY: Elsevier.

Townsend, E., & Wilcock, A. (2004). Occupational justice and client-centered practice: a dialogue in progress. *Canadian Journal of Occupational Therapy*, 71(2), 75-86.

Townsend, E., & Wilcock, A. (2004). Occupational justice. In C. Christiansen & E. Townsend (Eds.). *Introduction to occupation*. (pp 243-273). Up Saddle River, NJ: Pearson Education, Inc.

VanLeit, B. (1996). Managed mental health care: reflections in a time of turmoil. *American Journal of Occupational Therapy*, 50(6), 428-435.

Vrkljan, B. (2005). Dispelling the disability stereotype: embracing a universalistic perspective of Disablement. *Canadian Journal of Occupational Therapy*. 72(1), 57-59.

Watson, A., Corrigan, P., & Angell, B. (2005). What motivates public support for legally Mandated mental health treatment? *Social Work Research*, 29(2), 87-93.

Warner, R. (2005). Local projects of the world psychiatric association programme to reduce

Stigma and discrimination. [Electronic version]. *Psychiatry Services*, 56(5), 570-575.

Whiteford, G. (2000). Occupational deprivation: global challenge in the new millennium.

British Journal of Occupational Therapy, 63(5), 200-204.

Whiteford, G. (2001). The occupational agenda of the future. *Journal of Occupational*

Science, 8(1), 13-16.

Whiteford, G. (2003). Enhancing occupational opportunities in communities: politics'

third way and the concept of the enabling state. *Journal of Occupational Science*,

10(1), 40-45.

Whiteford, G. (2005). Understanding the occupational deprivation of refugees: a case

Study from kosovo. *Canadian Journal of Occupational Therapy*, 72(2), 78-88.

Wilcott, A. (1998). Reflections on doing, being, and becoming. *Canadian Journal of*

Occupational Therapy, 65(5), 248-256.

Wolcott, H. (1994). *Transforming qualitative data: description, analysis, and interpretation*.

Thousand Oaks, Ca: Sage Publications, Inc.

Wolcott, H. (1999). *Ethnography: a way of seeing*. Walnut Creek, Ca: AltaMira Press.

APPENDICES

Appendix A: Sample Interview Questions

Appendix A: Sample Interview Questions

1. How do you think other people view mental illness?
 - A. How do you think people view individuals who have a mental illness?
 - a. How do you cope with others perceptions of individuals diagnosed with a mental illness?
 - B. Would you describe living with a mental illness?
 - a. What has the biggest change in your life since being diagnosed with a mental illness?
2. How would you describe stigma?
 - A. What does stigma mean to you?
3. Have you ever felt stigmatized?
 - A. Tell me about that experience.
4. Describe a situation when you felt you were stigmatized.
5. Where do you think stigma comes from?
6. Are there activities you would like participate in but don't have the opportunity to?
 - A. Explain those activities.
 - B. Why do you feel you don't have the opportunity to engage in those activities?
 - a. Have you experienced stigma as a barrier to accessing activities?
 - C. What do you feel would facilitate more access to engaging in those activities?
7. How do you believe stigma can be changed in society?
8. Is there anything else you want to share about your experiences with living with a mental illness or stigma that we did not discuss?

Appendix B: Participant Consent Form

Appendix B

Informed Consent Form

Project Title: The effect of stigma on daily occupations in the lives of adults with mental illness

Please read the following material to ensure that you are informed of the nature of this research study and how you will participate in it. Signing this form will indicate that you have been so informed and that you give your consent to participate in a free and informed manner. Federal regulations require written informed consent prior to participation in this research study.

Principal Investigator: Kelley Lee, OTR

Graduate Thesis Advisor: Valerie Howells, Ph.D., OTR

Purpose of the Study: You are being asked to participate in a study designed to explore the experience of stigma for adults with mental illness and how this phenomenon impacts participation in daily occupations.

Procedure: If you agree to participate in the study, you will be asked to engage in an interview with the principal investigator. A description of the interview is listed below:

- I. The interview will be scheduled at a time and place that is convenient to you.
- II. The interview will last a minimum of one hour and no more than two hours.
- III. The questions you will be asked will focus on your experience of living with a mental illness, stigma related to mental illness, and the effect of those experiences on your daily life.
- IV. You are free to decline to answer any questions during the interview and may stop the interview at any time with no penalty to you.
- V. You will have the opportunity to review and verify any information with the interviewer following the interview.

You may withdraw from the study at any time without consequences.

Risks: Minimal risks are anticipated as a result of participation in this study. It may be inconvenient to schedule time with the principal investigator for the interview process. The investigator will adjust her schedule to accommodate you and will meet you at a private location of your choosing. Some participants may experience stress or discomfort as a result of the interview process. You are free to answer questions or not. You may stop the interview at any time without consequence.

Benefits: A potential benefit includes the opportunity to give voice to the experience of stigma and explore it's meaning with the principal investigator.

Appendix C: Letter of Referral Request

Appendix C: Letter of Referral Request

January 15, 2007

Dear CSTS Client Service Managers,

I am writing to ask for your assistance with a research project I am conducting for my masters degree that has the potential to increase our understanding of the stigma our clients experience in their lives. The goal of the study is to investigate the experience of stigma for an adult with mental illness and to learn how stigma impacts daily participation in meaningful occupations.

I am asking that you offer your clients an opportunity to share their stories with me, so that I may begin to understand our client's experiences of stigma through interviews. Clients referred for research should be able to articulate their experience of having a mental illness. Upon referral, I will contact clients to discuss the research purpose and process with them and they can decide at that time if they wish to participate. Interviews will be conducted at the convenience of the research participant. Participation in the research will be voluntary and the participants will have the opportunity to withdraw from the project at any time without penalty to them. All information gathered during the interviews will be kept confidential and the participant's names will not be used in the thesis document.

I hope that you will decide to provide you clients with the opportunity to communication their experiences. A benefit of participation in the research is the opportunity to have their voice heard and share their stories.

I am happy to share more detailed information about the research project or to answer questions for you and your client. You can contact me, Kelley Lee, OTR at ~~734.330.9500~~ or at ~~kelley.lee@csts.org~~

Sincerely,

Kelley Lee

Principal Researcher

Please Send 3 copies of your proposal AND 3 copies of this completed form

**EASTERN MICHIGAN UNIVERSITY
Request for Approval of Research Involving Human Subjects**

Date Submitted: _____ Due Date of Proposal _____

Principal Investigator: Kelley Lee, OTR

Co-PI/Project Director: Valerie Howells, Ph.D., OTR

Title of Project: The Effect of Stigma on the Daily Occupations of Adults with Mental Illness

From what sources are funds expected for this project? N/A

Department: School of Health Sciences Telephone: 734-487-4094

I. Is this application: New X Renewal _____ Modification _____

If Renewal or Modification:

- a. Date of last approval by this Committee: _____
- b. Principal Investigator previous research: _____
- c. Describe any modifications in the in the previously approved research protocols:

d. Were any human subjects encountered in previous research? If yes, how were they handled?

II. Numbers, Types and Recruitment of Subjects

- a. Numbers and characteristics of subjects (e.g., age, ranges, sex, ethnic background, health status, handicapping conditions, etc.):

Four to six adults (ages 18 to 55) diagnosed with a mental illness will be interviewed in this study. Study participants will acknowledge they have a mental illness and live in southeastern Michigan

- b. Special Classes. Explain the rationale for the use of special classes of subjects such a pregnant women, children, prisoners, mentally impaired, institutionalized, or others who are likely to be particularly vulnerable:

Study participants are competent to consent to participation.

- c. How is the individual subject to be recruited for this research? Is it clear to the subjects that participation is voluntary and that they may withdraw at any time without negative consequences?

Participation in the study will be voluntary. The informed consent form that each participant will read, or have read to them, will inform them they are able to withdraw from the study at any time without any consequence. Participants will be selected through convenience sampling and snowball sampling methods.

III. Informed Consent

- a. To what extent and how are the subjects to be informed of the research procedures before their participation?

Informed consent forms will be reviewed by the investigator with each individual who participates in the study. Each participant will be apprised of the purpose of the study, each procedure to be used, length of time each procedure will likely take, and the risks and benefits to the individual. Written consent will be obtained and each participant will get a signed copy of the consent.

- b. Attach a copy of written "Informed Consent Form" or a written statement of the oral consent.

IV. Risks Involved in the Research

Does the research involve any of the following procedures?

Deception of the subject.....	yes	<input checked="" type="radio"/> no
Punishment of the subject.....	yes	<input checked="" type="radio"/> no
Use of Drugs in any form.....	yes	<input checked="" type="radio"/> no
Electric Shock.....	yes	<input checked="" type="radio"/> no
Deliberate production of anxiety or stress.....	yes	<input checked="" type="radio"/> no
Materials commonly regarded as socially unacceptable.....	yes	<input checked="" type="radio"/> no
Use of radioisotopes.....	yes	<input checked="" type="radio"/> no
Use of chemicals.....	yes	<input checked="" type="radio"/> no
Drawing of blood.....	yes	<input checked="" type="radio"/> no
Any other procedure that might be regarded as including in the subject any altered state or condition potentially harmful to his/ her personal welfare.....	yes	<input type="radio"/> no
Any other procedure that might be considered as an invasion of privacy.....	yes	<input type="radio"/> no
Disclosure of name of individual subjects participating in the research.....	yes	<input type="radio"/> no
Any other physically invasive procedure.....	yes	<input type="radio"/> no

a. If the answer to any of the above is "YES", please explain this aspect of the research in details:

b. Describe the procedure for protecting against or minimizing any potential risk:

Minimal risks are anticipated as a result of participation. Minor stress may occur during the interview process. Participants can refuse to respond to any question or stop the interview without consequence. The clinician is a trained clinician capable of modifying the interview to meet the needs of participants.

Inconvenience secondary to scheduling time to complete interviews may occur. The investigator will schedule interviews around participants schedules and will meet with participants on multiple occasions to complete interviews as needed.

V. Confidentiality

a. To what extent is the information confidential and to what extent are provisions made so that subjects are not identified:

All qualitative data will identify study participants by a pseudonym only. Names will appear only on a signed consent form and a single log sheet that assigns the study participant a pseudonym. These forms will be kept separate from all other documents in a locked file in the thesis advisors office.

b. What are the procedure for handling and storing all data so that the confidentiality of the subjects is protected (particular attention should be given to the use of photographs, video, and audio recordings):

All audiotapes, transcriptions, and field notes will identify the participants by pseudonym only and will be stored in a locked file in the investigators office. Audiotapes, transcriptions, and research data will be destroyed five years from the last interview conducted. Also, as stated above, participant names will only appear on a signed consent form and single log sheet that assigns the participant a pseudonym. These will be stored separately from other data in a locked file in the thesis advisors office.

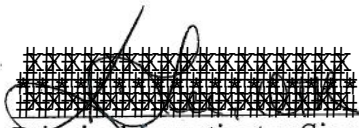
c. By what means will the results of the research be disseminated? Will the subjects be informed of the results? Will confidentiality of subjects or organizations be protected in the dissemination?

Findings will be published in the investigators thesis at Eastern Michigan University. Portions may also be published in professional journals, professional conferences and may be discussed with clinical treatment teams in southeastern Michigan as an executive summary of research findings. However, no identifying data will be used. Subjects will be referred to by pseudonyms only. The investigator will have a brief follow up contact with participants for purposes of validating the findings during the data analysis phase. This will serve to provide preliminary study findings. Interested participants will receive a final summary upon request.

VI. Describe any anticipated benefits to subjects from participation in this research:

Participants in this study will have the opportunity to give voice to the exploration of stigma. Participants will have the potential to influence policy and mental health practice in Washtenaw County.

VII. Attach a copy of the full research proposal including copies of all instruments or tests to be used. If instruments are not fully developed attach drafts and so indicate.


Principal Investigator Signature

10-1-06
Date



EASTERN MICHIGAN UNIVERSITY

October 17, 2006

Kelly Lee, OTR
c/o Valerie Howells, PhD
School of Health Sciences
Eastern Michigan University
Ypsilanti, MI 48197

Dear Ms. Lee,

The CHHS Human Subject Review Committee has reviewed your request entitled "The Effect of Stigma on the Daily Occupations of Adults with Mental Illness", submitted on 10/2/06. The Committee finds that it meets the Minimal Risk Standards and is approved for initiation with the following suggestions:

- On the Informed Consent Form, remove the sentence, "Participants will have the potential to influence policy and mental health practice in Washtenaw County"
- Remove the name, address and phone number of the student from the Informed Consent Form

The Committee may request further approval if secondary analysis of the data is conducted.

Sincerely,

A handwritten signature in black ink, appearing to read "Stephen A. Sonstein".

Stephen A. Sonstein, PhD
Chair, CHHS Human Subjects Review Committee