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Wearing the Label of Mental Illness: Community-Based Participatory Action Research of Mental Illness Stigma

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Abstract

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Keywords

Stigma, Mental Illness, Participatory Action Research, Mental Health Self Help Groups

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Wearing the Label of Mental Illness: Community-Based Participatory Action Research of Mental Illness Stigma

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Stigma remains an impediment to seeking and receiving the requisite care for mental illness. To enhance a local National Alliance for Mental Illness (NAMI) affiliate's understanding of community members' perceptions of mental illness and its associated stigma, a community-based participatory action research study was conducted. The study addressed the following research question: how do community members understand and experience the stigma associated with mental illness? Twenty-two participant-researchers wore mental illness labeled T-shirts around the local community, recorded their observations and reflections of this experience and recruited twenty-two community members for semi-structured interviews about mental illness stigma. Domain analysis of the interviews revealed community members' understandings of (1) sources of stigma, (2) impacts of stigma, (3) conceptualizations of stigma and (4) pathways to change stigma. Findings were presented to members of the local NAMI affiliate as well as other community members. Practical implications, specific to the community of interest, are discussed. Keywords: Stigma, Mental Illness, Participatory Action Research, Mental Health Self Help Groups

While mental illnesses are estimated to impact the lives of almost half of the adults in the United States over their lifetimes (Kessler, Berglund, Demler, Merkanigas, & Walter, 2005), misperceptions about the causes, symptoms and outcomes of mental illnesses contribute to the stigmatization of those affected by these diseases (Corrigan et al., 2002; Lauber, Anthony, Ajdacic-Gross, & Rossler, 2004; Overton & Medina, 2008; Sartouris, 2002). Despite extensive efforts to increase awareness and knowledge of mental illnesses, some studies suggest that stigmatizing attitudes and behaviors are still prevalent (Phelan, Link, Stueve, & Pescosolido, 2000; Rusch, Angermeyer, & Corrigan, 2005) and interfere with individuals seeking and fully participating in mental health care (Corrigan, 2004).

Mental health self-help groups seek to address the pressing need for community-based support systems for individuals with mental illnesses (Brown, Shepherd, Wituk, & Meissen, 2008; Leggatt, 2005). From grassroots beginnings with "couples meeting in someone's living room" (Katz, 1961, p. 32), these groups have formed alliances, consortiums, associations and coalitions. One of the most prominent organizations is National Alliance for Mental Illness (NAMI), which has grown since 1979 from 250 to 1200 local affiliates in all 50 states. As a powerful national organization, the primary objectives of NAMI are support, advocacy, research, and education (NAMI, 2013).

With the President's New Freedom Commission on Mental Health (2003) call for full community participation in mental health care, NAMI and other mental health self-help organizations have responded with programs such as StigmaBusters (NAMI, 2013) specifically designed to ameliorate mental illness stigma. However, a top-down approach implemented by nationally centralized mental health self-help organizations may not meet the needs of local affiliates. Understanding a community's unique and multifaceted perceptions of mental illness

is a key step in the development of targeted and effective programs to mitigate stigma (Levy, 1984).

Mental Illness Stigma

Mental illness stigma is a complex social construct that propagates damaging stereotypes, prejudice, and discrimination (Arboleda-Flórez, 2003; Walker, 2006). Modern mental illness stigma is part of the persisting belief system initially seeded by ancient primitive civilizations, which attributed mental illnesses to supernatural forces. Religious organizations that couched mental illness in moral terms and governments and societies that sought management of social order through incarceration or isolation then amplified and further solidified these primitive beliefs as socially accepted norms (Stuart, Arboleda-Florez, & Sartorius, 2012). Today, mental illness stigma remains culturally embedded through entertainment and news media that often reinforce these ancient stereotypes (Walker, 2006). Though present day biomedical and behavioral sciences provide explanations for brain-based mental phenomena, offer classification systems as frameworks for treatment, and deliver therapies that can sometimes transform lives, science has not fulfilled societal demand for the elusive “cure” that eliminates inconvenient differences between individuals without addressing the price of community engagement. As one consequence of this, attempts to reduce stigma through education based solely on scientific, biological evidence can actually reinforce negative attitudes (Kvaale, Haslam, & Gottdiener, 2013).

Being labeled with a mental illness such as schizophrenia, generalized anxiety, major depression, or one of the hundreds of other disorders found in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* is a major deterrent to seeking help and complying with treatment plans (Alexander, 2003; Corrigan, 2004). Once an individual is labeled as mentally ill, he or she is viewed as having a host of socially unacceptable characteristics, which include being dangerous, undependable, weak-willed, lazy, and abnormal. A psychiatric label elicits a host of negative stereotypes that are exemplified by slang terms such as “Schizo!”, “Lunatic!”, “Crazy!”, and “Psycho!” Name calling along with disparaging and disrespectful remarks especially about a person's competence are among the primary examples of stigma reported by persons with symptoms of mental illnesses (Wahl, 1999). Whether a diagnosis or a pejorative schoolyard taunt, labels contribute to stigmatization of persons with mental illnesses (Alexander, 2003; Corrigan, Kerr, & Knudsen, 2005; Wahl, 1999). Wearing the social as well as diagnostic label of mental illness undermines self-esteem and self-efficacy when society's stigmatizing attitudes are internalized (Corrigan & Watson, 2002).

Researchers have differentiated categories of stigma into public, structural, courtesy, and self-stigma (Corrigan, 2004; Corrigan, Markowitz & Watson, 2004; Corrigan & Miller, 2004; Corrigan & Watson, 2002). Globally held negative stereotypic beliefs about individuals with mental illnesses contributes to public stigma and is manifested when a community withholds help, avoids contact, or segregates those affected (Corrigan & Watson, 2002). When negative stereotypes influence laws and public policies, structural stigma can lead to discrimination or restriction of the rights of those diagnosed with mental illness (Corrigan, Markowitz, & Watson, 2004). While any association with a person diagnosed with a mental illness may lead to courtesy stigma (Corrigan & Miller, 2004; Koro-Ljungberg & Bussing, 2009), parents are often blamed “for causing their child's mental illness” and siblings and spouses are accused of “not assuring that relatives with mental illness adhere to treatment plans” (Corrigan & Miller, 2004, p. 537). Since secrecy and denial are common coping mechanisms adopted to avoid stigma, those affected by mental illness and their families are not likely to get the treatment and support they need for recovery (Weiner, Wessely, & Lewis,

1999). When these forms of stigma are internalized, self-stigma may be the reason some individuals and their families fail to seek treatment and avoid employment and social opportunities (Boo, Loong, & Ng, 2011; Corrigan, 2004). Moreover, a study by Chronister, Chou, and Liao (2013) suggested that self-stigma which results in secrecy and withdrawal may contribute to negative outcomes for those who live with severe and persistent mental illnesses.

Pathways to Stigma Reduction

Given the adverse effects of stigma, research highlights the need for stigma reduction. Mental illness stigma is a social construct with culture-dependent manifestations, and therefore mental illness anti-stigma strategies are most effective when tailored and targeted in the manner of social marketing (Corrigan, 2011). Typical strategies to pursue stigma reduction include protest (which suppresses stigmatizing attitudes about mental illness), advocacy (which influences public-policy and resource allocation, education (which dispels the myths of mental illness with facts), and direct contact with consumers themselves (Corrigan, 2004; Rusch, Angermeyer, & Corrigan, 2005). The first three strategies have made some headway either alone or applied together in various combinations; however, research indicates that direct contact by consumers has made the most impact among all marketing approaches (Corrigan, 2004; Corrigan et al., 2012). The high efficacy of consumer contact mitigating stigma is likely due to its experiential nature, in which a real person replaces the myth behind the stigma. Numerous studies report that contact with a person with a mental illness, especially a relative or friend or in recovery, can change negative perceptions about mental illness (Corrigan, 2004, 2012; Corrigan, Kerr, & Knudsen, 2005; Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012; Rusch, Angermeyer, & Corrigan, 2005; Wood & Wahl, 2006). Anti-stigma programs that combine education with contact, such as the NAMI's video and live presentations of individuals in recovery, are reported as moderating stigma (Corrigan, 2004; Wood & Wahl, 2006).

Community-based participatory action research provides a vehicle for including a community's experiential knowledge into research which, in turn, may impact local policy decisions (Dadich, 2009). Engaging stakeholders in the community to participate in the design, implementation and analysis of a research project brings together "action and reflection, theory and practice, in participation with others, in pursuit of practical solutions to pressing problems." (Reason & Bradbury, 2005, p.1) The various forms of participatory action research are distinguished from other types of research due to their participatory goals, collaborative roles, and shared commitment to change. More specifically, participants and researchers may also be participants, experiences are often transformative for all involved and research design is cyclic, continuously moving between action and reflection (Heron & Reason, 2006; Reason & Bradbury, 2005; Schneider, 2012). Since participatory action research is "not research on or about people but with people," the roles of participants and researchers are not mutually exclusive (Heron & Reason, 2006, p. 145). Rather, embracing and utilizing many ways of knowing, participants and researchers actively partner in collaborative inquiry. While the action component may vary considerably from one project to another, the promise of participatory action research is for individual transformation and social change (Altpeter, Schopler, Galinsky, & Pennell, 1999).

Community-based participatory research is an outgrowth of "disillusionment with the traditional, 'outside expert' approaches to understanding and addressing some of our most complex health and social problems" (Minkler & Wallerstein, 2010, p. 18). This type of research is consistent with the characteristics and missions of mental health self-help groups since these groups typically have grassroots foundations, highly participative memberships and respect for the experiential wisdom of community members (Chesler, 1991).

Our Community Based Project

While some community-based participatory action research has been conducted with consumer/survivor run groups (Nelson, Janzen, Ochocka, & Trainor, 2010; Nelson, Ochocka, Griffin, & Lord, 1998; Ochocka, Janzen, & Nelson, 2002; Schneider, 2012), there is a lack of research which explores the concerns of local mental health self-help groups. Therefore, the purpose of this research project was to offer a local NAMI affiliate insight into community members' understanding of mental illness and its associated stigma by exploring the following research question: how do community members understand and experience the stigma associated with mental illness? Similar to most NAMI affiliates in the United States, this community organization began as a small grassroots initiative spearheaded by parents and friends. However, with little membership growth over the past decade, the board of the local NAMI affiliate heeded the call to "stop preaching to the choir" and initiated this research effort (Lundin, 2002, p. 281).

The president of the local NAMI affiliate (first author) approached the students and professor of a doctoral level introductory qualitative research course in a large southeastern public university in the United States. Modeled after the public service announcement by BringChange2Mind (2013), some of the graduate students in this course volunteered to wear T-shirts bearing a label of schizophrenia, depression or bipolar disorder for about a week during self-selected community activities. While wearing these T-shirts during their regular activities at school, work and home, the participant-researchers encountered members of the community. Community members who approached the participant-researchers were invited to participate in individual interviews about their perceptions of mental illnesses. A culminating presentation and discussion was attended by the local NAMI membership along with other community members.

Methods

Theoretical Perspective

Adopting an interpretivist theoretical perspective facilitated the use of a hermeneutical lens to explore the impact of personal experiences on interpretations (Heidegger, 1962). Hermeneutics is consistent with a constructionist epistemology that maintains "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, 1998, p. 42). Since our prior experiences influenced our pre-understandings of mental illness stigma as well as the data analysis, the participant-researchers' observations and reflections of their experiences in the project were incorporated into each stage of the project. All the authors have ongoing, close contact with loved ones diagnosed with mental illnesses and two of the authors are Board members of the local NAMI affiliate. In addition, two authors provide mental health services such as assessment, diagnosis and counseling. The first three authors were among the participant-researchers who elected to wear T-shirts during the project.

Sample and Participants

Researchers conducted this study in a southeastern university town in the United States. The university students and employees represent about 45% of the total residents of this community. Before the project began, the university's Institutional Review Board approved the

design and informed consent was obtained from each interviewee. The “predetermined criterion of importance” (Patton, 1990 p. 176) in identifying community members to interview was whether they engaged the participant-researcher who wore the T-shirt with mental illness labels. Community members who approached the participant-researchers were invited to participate in individual interviews about their perceptions of mental illnesses. The twenty-two community members who participated in interviews (five men and seventeen women) were between the ages of eighteen and forty-six years old (Close to half of the community population is between 20 and 45 years old). Since the participant-researchers wore the T-shirts primarily during their activities at the university, all the interviewees except two were affiliated with the university. Eight interviewees were undergraduates and the balance was graduate students or professionals. The interviewees identified their ethnicities as follows: White (16), Hispanic (2), Chinese (1), African American (1), Cuban (1), and Puerto Rican (1). When asked if they knew anyone with a mental illness diagnosis, only three interviewees stated that they had no contact with persons affected by mental illnesses. Collectively, the interviewees stated they knew 8 persons with depression, 6 with bipolar disorder, and 3 with schizophrenia. Finally, two interviewees disclosed that they had a diagnosis of obsessive-compulsive disorder and generalized anxiety disorder.

Research Design

This research project was designed to meet the three primary goals of participatory action research outlined by Schneider (2012) which are “to produce practical knowledge, to take action to make that knowledge available, and to be transformative both socially and for the individuals who take part” (p. 153). The project was divided into three phases where knowledge production, action, reflection and transformation permeated each phase.

Phase 1: Wearing mental illness labeled T-shirts. All the participant-researchers were responsible for recording personal reflections and observations as well as conducting at least one interview. During the initial stages of the project’s development, one participant-researcher wondered,

Do I even know what stigma means? So I did what any other college student would do: I looked it up online (laughter). ...the definition I found used the word ‘disgrace’ to describe a stigmatizing experience. I immediately thought about people I knew that had a mental illness and the feeling of disgrace that may be put upon them by others or that they might feel themselves. I thought of my mom’s youngest sister. This is hard to admit but...I have always discounted her as a part of my family. It occurred to me, I had been stigmatizing her because of what she had and how she was. I had neglected her existence. I had avoided her at family gatherings. I never thought she could do anything on her own or that she could have a family or that she was worth my time.

Many participant-researchers shared that they knew persons with symptoms of mental illness who were affected by stigma. One participant-researcher admitted that “having a parent with mental illness has been a mark of shame. I self-stigmatize probably more than others would if they knew, so worried that others will know my dirty little family secrets.”

During one week, some participant-researchers intermittently wore the T-shirts both on and off campus and recorded their observations of the community’s reaction as well as their own feelings about wearing a mental illness label. One community member told a participant-researcher who was wearing a T-shirt with the words “bipolar disorder” that she was “too pretty

to have bipolar disorder.” In her journal, the participant-researcher objected by writing “that was to me a very stigmatizing phrase. People with mental illness are not pretty? This guy obviously has a preconceived idea about what people with mental illness look like.”

Phase 2: Interviewing community members. Semi-structured and open-ended interviews took place in a variety of settings such as private study rooms at the university’s library, classrooms that were not in use and graduate student offices. Time was spent to establish rapport so the interviewees were comfortable speaking with the participant-researcher. The individual interviews were audio-recorded and transcribed. All transcriptions were begun within three days of the interviews. Identifiers were removed from the transcriptions and interviewees were assigned a pseudonym.

Typically, the initial questions probed to capture the interviewee’s thoughts and feelings about seeing the mental illness labels on the T-shirts. The participant-researcher then moved along with ‘grand tour’ questions (i.e., “What do you know about mental illness?”). The discussion was guided into more in-depth inquiry, or ‘mini tour’ questions, in order to understand the more complex nuances of the interviewees’ experiences and understandings of mental illness and related stigma (Spradley, 1980). (See the appendix for a complete interview guide.) Because the interviews were semi-structured, the participant-researcher asked follow-up questions that related directly to the interviewee’s remarks, or they used other questions from the interview guide. While most interviews lasted an average of about 45 minutes, four interviews exceeded 75 minutes and a few ended before 30 minutes lapsed.

Phase 3: Community forum. The results were compiled into PowerPoint and Prezi presentations for the members of the local NAMI affiliate and the community at large. Held at the university, the forum was attended by approximately 40 community members in addition to the 22 participant-researchers. After the participant-researchers presented the literature review, their observations and reflections about wearing the T-shirts and findings from the domain analysis of the interviews, community members shared their experiences and understandings of mental illness stigma.

Data Analysis of Interviews

Domain analysis was selected to systematically analyze units of cultural knowledge by transforming the interview data into semantic relationships, covers terms and included terms (Spradley, 1980). Each of the 22 participant-researchers began by open coding their transcribed interviews and identifying prominent themes (which later evolved into included terms). The transcriptions and initial analyses were then shared with the data analysis team, which comprised seven self-selected participant-researchers who conducted a domain analysis. The transcriptions and preliminary analyses were divided among the data analysis team members who carefully reread the interviews to verify initial themes and search for more overarching ideas. These overarching ideas led to the development of cover terms. During brainstorming sessions, a domain analysis worksheet was utilized to highlight semantic relationships among the many included terms and the fewer cover terms.

Findings

Pre-Understanding of Mental Illness Stigma

Each author’s close relationships with individuals with a mental illness diagnosis informed his or her understanding of mental illness stigma. One author reflected that “prior to

the study, I understood mental illness stigma only in reference to my own experience with a family member who suffered from bipolar disorder. Perhaps because I viewed my family's experience as isolated, I had not given much thought to how others outside my family might also have experienced these phenomena in their own lives." While the pre-understandings of all of the researchers was largely based on interpersonal contact with a person with a mental illness diagnosis, two authors also held leadership roles in the local NAMI affiliate. One of these researchers explained that "internalizing the experiences of other community members heightens my sensitivity to mental illness stigma."

Community's Understanding of Mental Illness Stigma

The analysis of the interview data led to the identification of several domains which are broadly explained using the cover terms

- 1) sources of stigma;
- 2) impact of stigma;
- 3) conceptualizations of stigma; and
- 4) pathways to change stigma.

For each cover term, semantic relationships were developed to capture the relevant included terms.

Sources of stigma. The four prominent sources of mental illness stigma conveyed by the interviewees were inadequate information, media, religion and ethnicity. Inadequate information and the media serve to create and perpetuate negative stereotypes while religion and ethnicity are mediators of stigma, at times augmenting mental illness stigma.

Inadequate information leads to reliance on stereotypes. Most of the interviewees attributed the persistence and pervasiveness of stigmatizing attitudes and behaviors to the absence of formal training about mental illnesses. While some interviewees perceived the limited training they received in a high school or college psychology class as a general overview, one interviewee explained "there's not a good place to get information about it in daily life unless you seek it out. I mean no one ever sits down and talks to you about it in school." A lack of formal education led some interviewees to rely on the Internet for information about mental illnesses. One interviewee admitted that, "despite the fact that we sometimes walk around and tell people, 'oh, you're such a skitzo, or you're such a spaz', I don't actually know what it means. I do now; I looked it up on Wikipedia." Indeed, many interviewees did not perceive available information on mental illnesses as objective and accurate. One interviewee expressed consternation that "most of what we hear about mental illness is extremely derogatory so of course our assumptions about people with mental illness are going to be derogatory at least with the thoughts first pop into our heads."

Media contributes to negative stereotypes about mental illness. For the interviewees, the media was the key source of information about mental illnesses. However, most interviewees perceived media's depictions of persons with mental illness as stereotypic. One interviewee's comments exemplified the bias of a popular television show's portrayals of persons with mental illnesses.

TV shows like Criminal Minds are just very popular, one out of every 3 times it is going to be someone with a mental illness. That definitely does not portray

the truth but it is all about ratings. So I don't think people get the proper viewpoint.

Another interviewee emphasized the high frequency of characters with severe mental illnesses compared to the low prevalence in the population. For example, the portrayals of individuals with schizophrenia were consistently about "you know, homeless, you know, who don't have good jobs, and can't take care of themselves, that sort of thing..."

Religion contributes to avoidance of conventional treatment. Religious attitudes influenced the way some interviewees understood mental illnesses. For one interviewee, a common response to concerns about mental illness symptoms at her church was "take it to the pastor" or "take it to God." Another interviewee noted the prevailing message regarding mental illnesses at her church was "...it is not in my hands... it's in a higher power." Taking medicine was stigmatized since there is a "God will provide mentality ... [God] kinda supersedes any kind of medicine..." While for some interviewees symptoms were attributed to problems with spiritual relationships, others rejected this connection. An interviewee expressed his frustration and disappointment when his Baptist school teachers attributed his mental illness to his "relationship with God." He admitted that the lack of support for traditional medical treatments among his religious community contributed to his intermittent compliance with prescribed medications.

Ethnic identity mediates mental illness stigmatization. Ethnic differences in perceptions of mental illness were detected in the comments of many interviewees. Some interviewees believed that some ethnic groups stigmatize individuals with mental illness more than others. One Cuban-American interviewee explained her experience as "coming from Cuba, it's like...you would be totally isolated...there is something wrong with you, you are crazy. Schizophrenia, depression, anxiety, or whatever...it's just the culture." Another interviewee speculated that secrecy and denial of symptoms contributed to why "we (African-Americans) don't discuss mental illness."

Impacts of stigma. Perceptions of mental illness were strongly influenced by negative stereotypes which precipitated fear of unusual, unpredictable and potentially dangerous behavior. Those interviewees experiencing symptoms of mental illnesses as well as interviewees who had relatives and friends with diagnoses reported they resorted to secrecy because of their shame and embarrassment. Shame often led to avoidance of treatment.

Negative stereotypes contribute to fear. Whether or not the interviewees had any direct involvement with persons affected by symptoms of mental illnesses, many acknowledged that fear was a common emotional response to negative stereotypes. Numerous interviewees relied on stereotypes about persons with specific mental illness diagnoses as a way to understand perceived abnormal behavior. While acknowledging that "I don't really know that much about schizophrenia because I never met people that had it," one interviewee stated that she was fearful "since they are not in contact with our reality, maybe they would have this crazy idea that they hear something and someone was telling them [to do] a violent act."

Numerous interviewees expressed strong opinions about the nature of some symptoms of mental illnesses by claiming that "when you hear voices; they are either from dead, ghost or even demon voices." These perceptions often elicited fear since "[persons with mental illnesses] are just different, so therefore different is something for most people to be scared of.... and the unpredictability, again, kind of brings up fear for some people." However, other interviewees struggled to counteract the impact of negative stereotypes by making "a conscious

effort to remind myself of...the reality of what mental illness is and I'll admit that my initial gut reaction is to be scared." Another interviewee frankly admitted his preference to limit his involvement with a person with a mental illness diagnosis by explaining "I wouldn't choose to live with someone with a mental disorder over someone who is considered 'normal' and it's just because you do assume the worst in every situation."

Shame and secrecy contribute to alienation and avoidance of treatment. The interviewees' descriptions of how their lives or their families' and friends' lives were impacted by a mental illness diagnosis included themes of shame and secrecy. One interviewee stated he was keenly aware of the societal pressure to be hard working, strong and without flaws. Since "we treat mental illness like a defect" or "something you've done wrong," he was reluctant to seek help at the University counseling center because he felt he would be judged. An interviewee with a young adult child with a mental illness diagnosis echoed these feelings when she described her interactions with her daughter's medical doctors. She explained that "with each related surgeon and knee specialist we had to explain all of the medications she is taking. I couldn't go into her whole psychological background with them, of course. ...I definitely felt the judgment from some of them [the doctors]." With her daughter "living on the fringe of society," the interviewee admitted that she and her daughter felt ostracized since "most everyone, except for me, has written her off."

Efforts to keep a diagnosis secret were reported by an interviewee who admitted that since his enrollment at the university, the participant-researcher was one of the first people to whom he disclosed his mental illness diagnosis. Another interviewee explained that keeping her diagnosis secret exacerbated her symptoms since,

When I was struggling with depression a little bit I had trouble keeping up my personality that everyone knew me to be... I'd have to be fake happy... it was like this huge ordeal and I was exhausted and I was just like stressed out and anxious.

Other interviewees acknowledged that keeping a mental illness diagnosis secret was an intentional strategy to protect themselves and their loved ones from stigmatization. One interviewee recalled her young student with a mental illness diagnosis who "isolated herself ... because she didn't want to interact with [her classmates], and then have an awkward moment and have them make fun of her. So, I think part of it was her trying to be protective of herself." Self-preservation can lead to avoiding interactions with people who are intolerant of symptomatic behavior.

Conceptualizations of stigma. Interviewees' frameworks for understanding mental illness stigma were evident throughout the interviews. By organizing mental illnesses into a severity hierarchy and making comparisons with other types of stigma, individuals articulated their understanding of mental illness stigma.

Perceptions of a mental illness hierarchy differentiate levels of stigmatization. Because the mental illness labels on the shirts worn during the study were limited to depression, bipolar disorder, and schizophrenia, these were the most commonly discussed mental illnesses during the interviews. Interviewees expressed a belief that there are varying degrees of stigma associated with some mental illnesses. One interviewee articulated her differential perception of mental illnesses as "I would kind of label them in level of extremeness. Because depression for me, it wasn't that big of a deal, but schizophrenia, I'm like 'Oh! I don't know about that!'" Another interviewee noted that she would rather wear a shirt with depression than

schizophrenia since mental illnesses perceived as more severe are more stigmatized than mental illnesses perceived as less severe.

Comparisons with other stigmas situate the perceived severity of mental illness stigma. In describing stigma related to mental illness, many interviewees made comparisons to other sources of stigma such as race, sexual orientation, body weight, physical illness and intellectual aptitude. However, the stigma of a mental illness diagnosis was perceived as “worse than like that of racism” and “even... like gay and lesbian people have it easier.” An interviewee differentiated between the distress of a physical versus a mental illness by explaining that, “if they told me I had AIDS, it won’t be as scary as if they told me I have schizophrenia.” Not only did interviewees compare mental illness stigma to other forms of stigma, it was evident that interviewees perceived that a mental illness diagnosis would elicit the most severe form of stigma.

Pathways to change stigma. The discussions about stigma with the interviewees were interspersed with comments about how to improve the quality of life for those affected by symptoms of mental illness. Two pathways to change stigma were identified as individual action and efforts to increase knowledge about mental illnesses.

Individual action mitigates stigma. An overwhelming number of interviewees expressed personal responsibility in changing beliefs about and behaviors towards individuals and their families affected by mental illnesses. One interviewee suggested that, “it’s about stretching ourselves and working to be open minded and conscious of how others might need our help and support. We all just need to slow down a little and let others just be, you know, different.” Similarly, being open to recognize similarities with others was proposed as a way to form connections and “that just makes people feel not alone.” A supportive approach was recommended since “you can’t really force someone to get help they don’t want so other than just trying to be as supportive as possible and not getting frustrated all the time there’s really nothing you can do.” Recognizing that blaming a person for their symptoms may be counterproductive, another interviewee recommended that “you just have to be really patient because it’s not his fault. That’s the most important thing, realizing he has no control over it, or very little control anyway.”

As a consequence of their interview experiences, some interviewees were interested in obtaining more information about mental illnesses. One interviewee reflected,

Now that you have asked me all these questions about schizophrenia and OCD, maybe I fear because of something I saw on movies and TV shows and they make it look so scary. Maybe it is not something I should be scared about at all, maybe I should be more educated about the subject and maybe have more awareness of it.

Increased knowledge facilitates decreased stigma. Along with contact with those affected by mental illnesses, many interviewees suggested that “education is the answer to get out of the situation [stigma against mental illness]...If we do encounter mental illness, we’re better equipped. You know, it opens doors.” Educational initiatives were viewed as essential and one interviewee wondered why so many Americans are depressed.

Is it, for example, the economy? Is it because there is so much war going on? Is this generation more depressed than previous generations who have also went

through tough times? Hopefully, research would be able to tell us something for employers to be able to help their employees.

Besides formal training in mental illnesses, many interviewees saw a benefit from learning directly from those who are in recovery. While health and science courses may increase general knowledge, one interviewee respected and admired a teacher who “was able to talk about his depression.”

Conclusions and New Understandings of Mental Illness Stigma

This study was both an intervention and an inquiry. Wearing the label of mental illness on their T-shirts thrust the participant-researchers into the world of mental illness stigma. The observations and reflections of the participant-researchers confirm that “the qualitative research process itself has the potential to transform the very phenomenon being studied” (Finlay, 2002, p. 531). Furthermore, while many of the findings are consistent with other research studies, two themes are notably poignant and serve as central elements of our new understanding of mental illness stigma. First, despite their affiliations with the university as undergraduates, graduate students or professionals, most interviewees noted they had limited training about mental illness. Consistent with the findings of numerous studies (Gabbard & Gabbard, 1992; Wahl & Lefkowitz, 1989), interviewees indicated that inaccurate information especially from the media contributes to negative stereotypes of mental illnesses which in turn exacerbates stigma. These perceptions about the influence of the media are supported by a study analyzing 11,000 Canadian news reports on mental illness from 2005 to 2011 which found that 40 percent of the articles also discussed crime and violence and less than 15 percent included the perspectives of those living with mental illnesses (English, 2012, June 1). Cognizant they were either uninformed or misinformed the interviewees resorted to web-derived information about mental illness. Even though Slater and Zimmerman (2003) question the veracity of such information, interestingly, reliance on the Internet for information is higher among individuals with mental illness diagnoses as compared with individuals with other illnesses (Berger, Wagner, & Baker, 2005). Since only few states mandate a mental illness curriculum in schools (Strauss, 2009), even individuals pursuing higher education have little to no framework to understand mental illness. Consequently, targeted educational programs for K-12 students, which include contact with individuals in recovery, may be beneficial in moderating stigma (Corrigan et al., 2012). Furthermore, as many interviewees believed that individual action would lead to decreased stigma, programs should promote active participation and interaction by community members.

Second, the significant influence of religion and ethnicity was noteworthy. Some interviewees indicated that their religious leaders discouraged them from seeking help from mental health professionals. These sentiments are corroborated by 30% of the almost 300 self-identified Christian participants of an online survey analyzed by Stanford (2007) who reported negative interactions with their churches in their discussions about mental illness. Cinnirella’s and Loewentahls’ (1999) qualitative study of 52 women identified as White Christian, Pakistani Muslim, Indian Hindu, Orthodox Jewish and Afro-Caribbean Christian revealed that over 80% believed that prayer was an effective treatment for depression. Similarly, the interviewees in this study also proposed that their ethnic identity influenced their views on mental illness and the likelihood of seeking mental health services. The findings of Givens, Houston, Van Vorhees, Ford, and Cooper (2007) verify that ethnic identity influences attitudes and behaviors towards mental illness. Utilizing a cross-sectional internet survey of almost 80,000 individuals with self-disclosed depressive symptoms, the authors found that African Americans, Asians/Pacific Islanders and Hispanics expressed treatment preferences of

counseling and prayer over anti-depressant medications. In some cultures, persons living and receiving treatment for a mental illness lose the support of their families. Rivera-Segarra, Rivera, López-Soto, Crespo-Ramos, and Marqués-Reyes (2014) discovered in their qualitative study of Puerto Ricans diagnosed with Borderline Personality Disorder that interviewees felt distanced and separated from their family members. Programs targeted toward community members of religious and ethnically diverse groups may be beneficial especially if respected leaders lead these interventions.

Unfortunately, regardless of the organizational efforts dedicated to ameliorating mental illness stigma through awareness and educational campaigns, stigmatizing attitudes are prevalent and may be increasing (Phelan et al., 2000). To create targeted and effective programs to mitigate stigma, it is vital to understand a specific community's multifaceted experiences with and perceptions of mental illness. Through this study, pertinent and relevant information was generated by and for the local NAMI affiliate. A noteworthy conclusion from this study is that stigma is moderated most effectively by a combination of education and contact with people with mental illness diagnoses. Education by itself does not reduce stigma. Contact helps others understand the reality of mental illness and begins the process of mitigating negative stereotypes. There needs to be a community conversation with the individuals and families directly affected. These findings prompted an evaluation and subsequent redirection of programs and services to include university-based awareness and educational programs. New emphasis will be placed on programs which incorporate contact with individuals in recovery.

Wearing the T-shirts labeled with mental illnesses was a catalyst for observation and reflection by the participant-researchers as well as the community members. The analysis revealed evidence that each phase of the project was transformative for those involved. Not only were the attendees of the culminating forum impressed by presentations that were "well-organized, thoughtful, and informative," the personal transformations of the participant-researchers were evident to one community member who observed that the "project idea clearly not only impacted your colleagues emotionally, but also raised their awareness about stigma." (J. Theurer, personal correspondence, April 23, 2012). One NAMI member wrote in an email thanking the participant-researchers that "it's moving to hear of the process the researchers experienced, affirming that there are people who care and experienced a shift themselves" (J. Theurer, personal correspondence, April 23, 2012). In light of the benefits as well as the limitations of this study, community based participatory action research has proven to be a powerful tool for the local NAMI affiliate to understand mental illness stigma.

Study Limitations

Despite the benefits of this community based participatory research, including knowledge production, action, reflection, and transformation, some limitations should be noted. First, the interviewees were limited to those community members who self-selected as they encountered the participant-researchers in their daily activities. While the university community comprises a large share of the local community, all but two interviewees were affiliated with the university. Second, the process of criterion sampling also resulted in only a couple of interviewees with a diagnosis of mental illness. Involvement of individuals with mental illness diagnoses may have been more impactful and empowering for all involved in this project. Future investigations should target a diverse sample of community members.

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Appendix

Interview guide

1. What did you think when you saw the words on my T-shirt?
2. What do you know about mental illnesses?

3. Tell me about your personal encounters with someone with a mental illness?
4. How does a mental illness enable or disable individuals from engaging in typical or important life events?
5. How do you feel about living and working with someone with mental illness?
6. How does knowing a person has a mental illness change your perceptions and feelings for that person?
7. Tell me about your experiences with stigma associated with mental illness?
8. How do you feel prejudice against those with mental illness compares to other kinds of prejudice?
9. How would you feel if you found out that someone you know had a mental illness?

Demographic questions:

1. How old are you?
2. How do you describe your gender and ethnicity?
3. What is your occupation?
4. Do you know somebody who has mental illness? (self, family member, friend, acquaintance) or would you rather not answer?

Is there anything else you would like to add?

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