Perceived stigma and societal discrimination in individuals with mental illness: Understanding the importance of a sense of community

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Abstract
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the importance of a sense of community

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Background

Research shows that a person living with mental illness is more likely to struggle with unemployment, have less monthly income, have lower self-esteem or a diminished view of themself, and have fewer social supports. Research also suggests that, based on modified labeling theory, because stigma and discrimination is so prevalent in a person's life who has a mental illness, they are more likely to withdrawal and socially isolate from others, diminishing their sense of community, overall well-being, and quality of life.

Consequently, a qualitative study was conducted examining the effects of perceived stigma and societal discrimination on those with a mental illness and how social supports and a sense of community belonging moderate those effects. In addition to a thorough review of the literature, this capstone paper will report a qualitative study’s methods, findings/outcomes, and limitations; but will also include future considerations for additional research about the stigma surrounding mental health.

Literature Review

Understanding Mental Health and Mental Illness

According to The National Institute of Mental Health (NIMH), mental illness is more common in the United States than most believe. Approximately one in four adults (roughly 57.7 million Americans) experience some form of a mental health disorder in any given year. Furthermore, one in 17 Americans (nearly 6%) lives with a serious mental health disorder, which significantly impacts an individual’s quality of life (NIMH, 2012).

To fully comprehend the impact of American’s affected by mental illness, it is important to understand key terms associated with it. Over the years, researchers have struggled to define terms regarding mental health and mental illness. Macklin (1972) refers to four problem areas as
to why defining these terms may be difficult, “defining ‘mental health’ in terms of the notion of
mental illness; defining ‘mental health’ and ‘mental illness’ in terms of normality and
abnormality; obstacles to a clear conception of health or illness arising within or between
specific theories of psychopathology; and, problems with the conception of psychological
disorders and malfunctioning as ‘disease’ or ‘illness’” (p. 344).

Consequently, there are several historical explanations of mental illness. Research
suggests there are five dominant models which provide a clear overview of these explanations of
mental illness: the medical model; the social/economic/political model; the disability rights
model; the nutritional/orthomolecular model; and the spiritual model. According to Carling
(1995), the medical model suggests that mental illness is due to a malfunction in the brain; while
the social/economic/political model implies that mental illness is a result of environmental issues
surrounding the conditions a person faced growing up, or where/how they currently live. The
disability rights model “proposes [a] functional view of individuals, a rehabilitation approach to
treatment with independent living as its goal, and a need for rights protection and social change”
(Carling, 1995, p. 72). A problem that could be attributable to a biological imbalance, and could
be altered through dietary changes, refers to the nutritional/orthomolecular model. Finally, the
spiritual model, suggests that different states of mind could be a result of spiritual, psychic or
other paranormal causes. Carling (1995) also notes that all models may be affected, perceived or
interpreted differently, in relation to culture. Furthermore, regardless of which model one applies
to mental illness, Carling (1995) suggests that most researchers in the field view mental illness as
“reflecting some highly individual combination of biological, social, and psychological factors,
often including a heightened susceptibility to stress” (p. 73).
Because many misconceptions around the prevalent terms can arise, for the purpose of this paper the terms “mental health,” “mental illness,” and “mental disorders,” will use the definitions provided by the U.S. surgeon general’s mental health report (1999); which are outlined as:

- Mental health is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and an ability to adapt to change and to cope with adversity. …Mental illness is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning. (Goldman & Grob, 2006, p. 738)

In order for a mental illness to be classified as “serious,” research suggests at least one area of social functioning must be impaired; as previously stated, this is something nearly six percent of Americans are affected by at any given time (Goldman & Grob, 2006, p. 738; NIMH, n.d.). Approximately half of these individuals (2.6 % of American adults) experience a persistent and severe mental illness (Goldman & Grob, 2006, p. 738). The term “severe,” in regards to any aspect of mental health, will be used in context according to the Diagnostic and Statistical Manual of Mental Disorder’s (DSM-IV-TR) (2000), which states that a mental illness would be considered “severe” impairment if the individual has “many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning” (p. 2).

Understanding the Connection between Stigma and Mental Illness
The term “stigma” derives from the Greek, “referring to a mark made by a pointed instrument or brand… a stigma was a sign, usually cut or burned into the body, indicating the status of a discredited individual…” (Scheyett, 2005, p. 81); however, for the purpose of this paper, the term “stigma” will refer to “undesirable characteristics linked to mental illness and the adverse cognitive and behavioral consequences” (Markowitz, 1998, p. 335).

While stigma can affect many vulnerable populations in the U.S., those with mental illnesses are especially susceptible. In fact, Scheyett (2005) states, “Mental illnesses are among the most stigmatizing of all conditions” (p. 86). Link and Phelan (2001) provide three major concepts that lead to such stigmatized outcomes: status loss (described as the “downward placement in the status hierarchy” [p. 379]); structural discrimination (composed of stereotyped beliefs); and damaging coping techniques (“people’s efforts to cope with stigma may have untoward consequences that are seemingly unrelated to the stereotype” [p. 379]).

Consequently, Link and Phelan (2001) suggest stigma (and the perceived perception of its existence) emerges when five interrelated components come together. The first component refers to distinguishing and labeling individuals. Essentially, society deems important attributes and characteristics of an individual and groups differences together with a label. In the second component, these labeled differences are linked to negative stereotypes. In the third component, the individuals who have been labeled are placed into categories that distinguish them as different (there is a level of separation between “us” and “them”). The fourth component reflects both status loss and discrimination amongst labeled individuals, leading to unequal outcomes. Finally, the fifth component pertains to the manifestation of stigma. Link and Phelan (2001) reflect on the process of interrelated components, stating, “…stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness,
the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination” (p. 367).

Another study which surveyed U.S. citizens showed that more than 70 percent of respondents would not want someone who had the mental illness of depression marry into their family; while another study found that 19 percent of American respondents wouldn’t be comfortable around someone who was living with a mental illness (Scheyett, 2005, p. 86).

Unfortunately, many people diagnosed with a serious mental illness report the rejection they face by friends and family; in addition to the loss of social supports, many have difficulty establishing new relationships as a result of stigma (Scheyett, 2005; Reidy, 1993).

**Shaping Society’s Perception of Mental Illness**

Because one of the major components of stigma begins with society’s reaction of distinguishing, grouping, and labeling, it is equally important to understand how people’s perceptions of the mentally ill are shaped. Scheyett (2005) explains current studies of the stigma etiology in serious mental illness have found three main components that support people’s attitudes about other’s with a serious mental illness: authoritarianism (those who believe that individuals with a serious mental illness are “worthless or irresponsible and unable to make life decisions”, [p. 85]); benevolence (those who view people with mental illnesses are “helpless and childlike”, [p. 85]); and fear and exclusion (those who believe that people with mental illnesses are “dangerous and in need of segregation from society”, [p. 85]).

Evidence suggests that fear is a major component of the stigma of mental illness because people associate those who have a serious mental illness with danger and violence (Scheyett, 2005). People not only fear violence, but they “fear the unknown, fear of a lack of reason and of predictability, and fear that mental illness may happen to oneself or someone close,” (Scheyett,
According to Scheyett (2005), studies have been conducted on the prevalence of stigmatizing attitudes within the U.S. An earlier study conducted in 1961, showed that the majority of the U.S. citizens polled agreed with statements that mentally ill people were “more dangerous, unpredictable, worthless, dirty, cold, and insincere” (p. 86) and, although, very little recent research was found that supported this, it is assumed these negative attitudes have persisted.

The media has a huge influence on how people perceive an individual’s behaviors who is living with a mental illness (stigmatization); and how people treat those with living with a mental illness (discrimination). According to Scheyett (2005) “Studies have identified highly publicized and unwarranted linkages between mental illness and crime in the print and television news” (p. 87). One U.S. study revealed that in American television dramas, 73 percent of mentally ill characters on the show were portrayed as violent; and that both the U.S. film and television industry often use the strategy of the “mentally ill killer” to increase suspense and explain the “bizarre” (Scheyett, 2005, p. 87). The media’s depiction of mental illness is considered “powerful perpetuators of stigma” (Scheyett, 2005, p. 87).

**Modified Labeling Theory**

Understanding the underlying theory of stigma is important for several reasons. Specifically, it greatly affects those living with mental illness, but equally important the need to understand the underlying theories that result in stigma and discrimination. Labeling theory was first applied to mental illness by sociology professor Thomas Scheff, in 1966, who posited that
antisocial behavior (deviance) was due to mental illness. Later, Markowitz (1998) adjusts Scheff’s theory to incorporate the component of stigma and how that impacts behavior, which is more closely correlated to the perception of how a person with mental illness views themselves through the eyes of society. This theory would be called the modified labeling theory. Consequently, “careers in residual deviance [is replaced by] a subtle approach to how stigma affects the course of illness” (Markowitz, 1998, p. 336). Markowitz (1998) further discusses the modified labeling theory, stating “In this version, stereotypical attitudes about the mentally ill, (e.g. as incompetent and dangerous) become personally relevant to an individual diagnosed with a mental illness” (p. 336). Markowitz (1998) then goes on to explain that the labeling these mentally ill people experience, results in them being “devalued and discriminated against [and] these beliefs act as self-fulfilling prophecies, leading to lowered esteem and demoralization” (p. 336).

According to the modified labeling theory, those who are labeled then try to avoid rejection, will often develop coping strategies such as “secrecy, disclosure, or social withdrawal, which may constrict social networks, leading to unemployment and lowered income” (Markowitz, 1998, p. 336). Additionally, research on stress “predicts that a low sense of self and reduced social and material resources increases stress, placing persons at greater risk for continued symptoms [concluding that] …labeling and stigma indirectly leads to sustained illness” (Markowitz, 1998, p. 336). Furthermore, evidence suggests that once a person with mental illness anticipates rejection a pattern of withdrawn behavior occurs resulting in additional isolation, anxious behavior, and shame; which only perpetuates the feelings of rejections (Carling, 1995; Farina, Glihan & Boudreau, 1971; Gilbert, 2001; Link & Phelan, 2001; Link et al., 1992; Reidy, 1993; Scheyett, 2005).
Link’s Study on Self-Esteem, Stigma, Secrecy, and Withdrawal

In Link’s (2001) study, measuring self-esteem and stigma in regards to the modified labeling theory, he found that not only was self-esteem significantly lower among mentally ill participants, but 74 percent (n=88) of mentally ill participants felt that employers will discriminate against them; 81 percent felt partners would discriminate against them; 66 percent felt the same about close friends discriminating against them; 69 percent felt former psychiatric patients will be seen as less trustworthy; 59 percent felt they would be seen as less than intelligent; and finally, 69 percent of mentally ill participants felt their opinions would be taken less seriously than those without a mental illness.

Applying the theorized predictions from the modified labeling theory, Link’s (2001) study also identified the behaviors of secrecy and withdrawal in participants who had been labeled with a mental illness. In fact, 63 percent of participants, all of whom were diagnosed with a mental illness, asserted they would “avoid a person if they believed that person thought less of them because they had received psychiatric treatment” (p. 1623). In addition, Link’s (2001) study found that 67 percent of participants felt it was easier to be friendly with people who had previously been a psychiatric patient; and 71 percent of participants felt people with a serious mental illness found it less stressful to socialize with peers who also had a serious mental illness.

Additional Negative Consequences of Perceived Stigma/Societal Discrimination

As previously noted, those living with mental illness are often victims of perceived stigma and societal discrimination, which can result in reduced availability of resources necessary to live. Carling (1995) outlines how mentally ill people are subject to housing and employment barriers as a result of stigma and discrimination. Some landlords “refuse to rent to
individuals with psychiatric disabilities, and employers refuse to hire them, cutting off access to normal housing and jobs” (Carling, 1995, p. 29). Scheyett (2000) claims that the “stigma of mental illness and resultant discrimination” (p. 87) has led to unemployment rates as high as 85 percent. In one study, people with a serious mental illness had reported being overlooked for a job, between 12-40 percent of the time, in which they felt they were qualified to get (Scheyett, 2000, p. 88).

Because of this, many individuals living with mental illness are forced to live in very low-income communities where “substandard housing and high crime rates are typical, or [they] are employed in entry-level or ‘dead-end’ jobs” (Carling, 1995, p. 29). With the diminished self-confidence and self-efficacy due to perceptions on stigma and societal discrimination, combined with income instability and substandard housing, it is hard for people to ever move beyond this environment.

In addition, people living with mental illness in the U.S. have found other discriminating factors against them within society, including: limiting physical structures (separate bathrooms/eating areas); being ignored by professionals in treatment planning and interventions; coercive or mandatory unwanted treatments; dehumanizing admission and treatment practices within mental health institutions; being placed into residential housing based on diagnosis’; lack of privacy; and “over interpretation of behavior” (Scheyett, 2000, p. 87).

Understanding the Benefits of a Sense of Community

For individuals living with mental illness, the pressures of perceived stigma and societal discrimination creates a nearly unavoidable fate of social isolation or a lack of community. However, the modified labeling theory implies that reducing an individual’s internalized stigma, may help to reduce their negative impacts of stigma. Being around other individuals diagnosed
with a mental illness can help decrease the effects of perceived stigma. In fact, research shows that social contact with an individual, who has had successful mental health treatment of some kind, has been an effective intervention in decreasing perceived stigma related to mental illness (Huxley, 1993; Read & Law, 1999; Scheyett, 2005).

**Distinctions of Community**

There are two major uses of the term “community.” It is either referred to as being a geographical location (i.e., town, city, community-neighborhood); or, as a psychological aspect, and relational, without any specific reference to geographical location. This paper will focus on the psychological/relational aspects of a sense of community.

The psychological sense of community can be described as the “phenomena that one belongs to and is an integral part of a larger collectivity” (Townley & Kloos, 2011, p. 437). Additionally, McMillan and Chavis (1986) suggest that a sense of community is “a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together” (p. 4).

McMillan and Chavis (1986) propose four elements for both definition and theory based on a sense of community. The four elements are: membership, influence, reinforcement and shared emotional connection. Membership means there are boundaries in place; people have invested something to become a member and have a sense of a right of belonging. Having influence means one has gained some kind of positive relationship with the others because they are acknowledging their needs, values and opinions; thus creating a sense of respect and loyalty. Reinforcement refers to how the group meets the individuals’ needs, strengthening his/her desire to remain a member. Finally, the shared emotional connection is based off of the history of the
relationship formed while a member. The longer and more loyal the history (i.e., respect and loyalty increases with needs being met), the stronger the shared emotional connection.

**Impact a Sense of Community has on Mental Illness**

Research shows that a sense of community can be associated with a variety of social and individual functioning outcomes; for example: an individual’s length of residence; community involvement; safety; loneliness; political participation; mental health/malaise symptoms; and overall life satisfaction (Ellaway et al., 1996; Hughey et al., 1999; Perkins et al., 1990; Pretty et al., 1996; Prezza et al., 2001; Sarason, 1974; Townley & Kloos, 2011; Ziersch et al., 2005). This paper will reflect how a sense of community, or lack thereof, impacts individuals living with a mental illness.

For individuals with mental illness, researchers suggest that the lack of a sense of community can be associated with loneliness, emotional and psychological distress, and alienation/social isolation (Sarason, 1974; Townley & Kloos, 2011). In one study, which examines U.S. community college students (n=379), research shows that a sense of belonging in relation to a variety of factors (social supports, conflicts, involvement in community activities, attendance in religious services; and mental illness in regards to anxiety, depression, and suicidality) is negatively correlated to both stress and depression. (Hagerty et al., 1992; Hagerty & Patusky, 1995; Hagerty & Williams, 1999; Kitchen, Williams, & Chowhan, 2012). More specifically, Kitchen (2012) states a “sense of belonging is closely related to indicators of both social and psychological functioning” (p. 279); subsequently, “negative social support and conflict were related to lower sense of belonging” (p. 279).

Consequently, research has shown increased social networks (increased sense of community/belonging) can help develop self-confidence, self-efficacy/determination, and
decrease the negative impacts perceived stigma, labeling, and discrimination; which in return, promotes an overall positive mental health status. Therefore, individuals who are living with mental illness may find much relief in peer social supports, or belonging to a mental health community. Carling (1995) suggests through the strong identification of the mental health community an individual can fill a “significant core of [their] social network” (p. 45). One effective way to minimize social isolation and integrate into the mental health community is through peer support groups. In fact, self-help (or peer) support groups for individuals living with a mental illness provide several common characteristics, including: members of equal power; peer-to-peer support (non-clinical); confidentiality (and autonomous from mental health system); special populations (LGBT, disabled, bilingual, etc.); and self-definition (individual defines own needs) (Carling, 1995). Furthermore, peer support groups can provide: outreach programs, resources, crisis support, education; and they help individuals feel connected to like-minded others, which, again, helps diminish social isolation. Carling (1995) suggests another benefit to peer support and self-help groups is that they can be used as an aid into community integration (where members can continue to expand social networks).

Finally, Carling (1995) implies that, with an individual living with a serious mental illness, relapse (a slip in stability or functioning) is inevitable; however, psychiatric relapses are much less disruptive if the individual has strong social supports (or a sense of community). Because individuals with mental illness are more susceptible to socially isolate and withdraw (according to the modified labeling theory and an individuals perceived stigma), this cessation in relapse suggests the positive impact strong social supports, or a sense of belonging/community, can have on mental illness.

**Research Question**
Upon researching the prevalence of mental illness in the U.S., how stigma and discrimination manifests (including the role society plays), and the impact that a lack of community can negatively have on an individual with mental illness, the following research question was constructed: “What is the impact of social/community supports on individuals living with mental illness?”

**Methodology**

In order to really get to the heart of people’s stories, and hear their thoughts and feelings on their history’s with mental illness, their experiences with stigma and discrimination, and how having a sense of community belonging impacts their mental health, a qualitative study was conducted, using a grounded theory approach, on members of a well-known community support and advocacy center in Oregon. This project was approved by Pacific University’s Institutional Review Board (IRB). The study began in March 2013; and concluded approximately one month later, in April 2013.

**The Sample**

The sample was comprised of six members at an affiliate of the National Alliance on Mental Illness (NAMI). Three males and three females were interviewed; all ranging in the age of 20-65 years. The researcher selected sample participants based off of prior social interactions, judging, not only their ability to articulate their thoughts and experiences verbally, but on their overall emotional stability. The sample was then approved by the agency’s Executive Director.

**Interviews**

The individual interviews all took place at the agency location in Oregon. The researcher and participant were the only people present for the interview, which were conducted in a private counseling room. The interviews ranged in time from 20-45 minutes, with a maximum time of
60 minutes allotted. For transcription ease and content analysis purposes, the interviews were all audio recorded.

Prior to the interviewing session, participants signed an informed consent document giving approval to take part in the study, and ensuring they reviewed the documentation regarding confidentiality and agreeing to be audio recorded (Appendix A). Additionally, participants were given a voluntary demographic survey, which was not used in the content analysis (Appendix B).

The interview questions focused on three specific domains: the participant’s mental health history; their experiences with mental health stigma and discrimination; and their thoughts and feelings on community, and having a sense of community belonging (Appendix C). While the majority of questions were constructed, noted, and referred to off of a guide, a grounded theory approach was used, and some questions were added during the interview based on participant responses. For example, if a participant disclosed dual stigmatizations/discriminations due to their sexual orientation, a question about that experience would be asked to another participant of similar sexual orientation for further clarity on the issue.

Additionally, upon completion of content analysis, appropriate measures to protect confidentiality were taken. All audio recordings were locked away with the study documents, (including informed consent for the IRB and any demographic surveys taken), inside the researcher’s study advisor’s office.

Content Analysis

The researcher first transcribed all of the audio recordings from the interviews; and then, began to look for common themes and similarities. Consequently, specific theme words started to emerge. In order to track and code the emerging themes, the researcher performed a count of
how many times specific words and/or phrases manifested. Specific patterns of experiences and behaviors became evident; and contingent conclusions were formulated.

**Results**

**Findings**

A thorough content analysis resulted in three key themes: Interpersonal relationships; employment; and a sense of community belonging.

**Interpersonal Relationships**

The most commonly expressed limitation that individuals living with mental illness appeared to face was in regards to their interpersonal relationships. The dominating theme was a lack of family support that participants received. Every participant discussed some form of estranged relationships amongst family members; and most received little to no emotional support from them, resulting in classifying their families as not playing any part of their immediate feelings on their sense of community belonging.

When asked about receiving family support, a participant stated:

> ... To the whole family, I became ‘persona non grata’; they are more the problem than the solution. I wish it were otherwise. I’ve begged cousins, I’ve begged every member of my family to go through the family-to-family education course that NAMI has. But of course none of them will. ...I don’t hold it against them; I feel kind of sad for them because they’re stuck in denial. I have a first cousin that committed suicide for god’s sake. You don’t do that without mental illness! They’re in their bubble. I can’t pop it.

(participant)

Aside from a lack of family support, participants also lacked friendships outside of their main sources of community. Whether or not this is more closely related to fear of stigma and
discrimination, or if it is due to prior attempts of disclosure resulting in rejection (that feeds that sense of fear), is a rather complex issue and findings varied among participants.

When asked directly about disclosing their mental illness to others, one participant stated:

> It's like there was this constant anxiety and pressure; I know it's a distortion, but there's this feeling that you have this giant neon sign across your forehead that says: defective, or broken, or ill, or whatever it is that labels you for everybody to clearly to see. Like I said, I know this is a distortion, but it's that constant fear that was a heavy burden...

Another participant, who also struggled to maintain friendships outside of his or her dominant choice of community, shared: “I’ve lost all those friendships. I had a lot of friends before. And I attended church and I left the church because people didn’t understand.”

An additional emerging theme was the difficulty many participants faced in both pursuing and maintaining romantic relationships. While very few participants were married, the majority experienced many barriers when deciding “the right time” to tell potential partners about their mental illnesses.

One participant reflected:

> Let’s say, if I’m dating and I get to know a girl, or a woman; they kind of freak out once they find out I’m taking medication. And, I’m not trying to bash on women, it’s just like, people out there aren’t educated. They don’t know that I can function like a normal person, you know? I can live a normal life. I’m not just some… I don’t say this word because it’s stigmatizing… but some ‘crazy dude,’ just ‘cause I’m taking medication.

**Employment**

During analysis, several key themes emerged around employment issues as most participants are currently receiving disability benefits due to their mental health disorders,
implying the difficulties of maintaining employment, partly out of fear of perceived stigma and discrimination within the workplace.

When asked about experiences with employment, one participant shared:

   …It was really hard to try to explain to my bosses why I couldn’t come in on a certain day… why it was hard for me to get out of bed… It was just really hard to explain to these people because they’d seen me a certain way for so long, and then I kind of flipped the script on them and they didn’t understand it, and it was embarrassing… you know, to have to admit that something wasn’t right.

Additionally, it was implied that most had given up the struggle of being employed because the various symptoms of their mental illnesses created this dynamic instability issue on being a reliable, and ultimately, a valuable, employee. Supporting this notion that individuals struggle to maintain employment due to symptomatic episodes, another participant shared: “I think the depression, in the end, was why I didn’t hold the jobs for more than 6 months… I think 6 months is the longest I’ve held any full-time jobs.”

A Sense of Community Belonging

One of the most surprising elements that emerged from the study indicates that the majority of participants had only one place they considered to be their community support, and where they gain a sense of community belonging, that being this particular NAMI affiliate agency in Oregon.

One of the study questions asked what keeps participants coming back to NAMI. The following are personal reflections on how individual participants have been affected by having a sense of community belonging at NAMI:
...The way that I felt before I came here, and the way that I felt after I came here was night and day. I felt like I was out in the wilderness, in the cold, by myself, just struggling. And now I feel like I’m surrounded by people that understand and are there to support me when I need it. But also, I can give back and support people that are needing help when they need it. And my children are seeing that; and my children want to give back, so they’ve gotten involved. And there’s just a real sense in me that all of the struggles I’ve had and all of the pain I’ve gone through can be worth something or mean something by being able to help someone else who is just starting to figure out what their struggle is. (participant)

Another, states:

To me NAMI is better than seeing a therapist… You don’t have to relive your story, over and over again. I know that if I can make it out of it and get here, I know I’ll be okay; and I won’t be judged; and there’s always somebody here to talk to. And you don’t have to have a special invitation, you know? You don’t have to have a specific reason why you want to come, you can just show up! (participant)

Lastly, a participant reflects on her experiences at the agency:

We have more in common than not. Even though I have a diagnosis that is way out on the fringe and very exotic for most people, the same issues that bug, torment, and befuddle me, befuddle the next five people in the support groups... and I find that I’m not such a freak. That’s very reassuring; that’s also very affirming for me... It’s a normal human desire to want to be understood; that’s what I most want. I want to be understood. I want to be respected; and I want to make that positive difference... If NAMI didn’t exist and I didn’t have those outlets, I would spend a lot more time in the hospital then I do, and a
lot more frequently. It’s not just the contributing to the community but it is that comradory with other people that have walked similar paths that get me…

Other key terms surfaced in regards to describing what community means to them, including: hope; trust; acceptance; safety; support; friendship; understanding; and the most significant term used was “family.” Regardless of the participants relationships with their biological families, most used the term “family” to describe their dominant choice of community support (in this case, being NAMI of Washington County, Oregon). One participant reflected, “We talk about NAMI family [here], and that’s very true. I consider quite a few people here, my family.” Additionally, in response to a question asking the participant to sum up their feelings on their only community support (NAMI), one person replied, “family” (participant).

Lastly, when asked about whether convenience of location mattered when participating in their choice community location, participants strongly indicated that while the convenience of location is nice, all would travel an appropriate distance to continue their membership at their specific NAMI affiliate, implying that strong social bonds had been created. One participant shared, “I would still come out here. I’ve gone to other affiliates… and I’m just more comfortable here. These people… it’s just different. It’s hard to explain, it’s just the feeling you get.”

Limitations

The most prominent limitation of this study was that the community sample that participants made up was limited to one specific NAMI program. Had the sample come from several different communities (but stayed true to the mental health diagnosis) results could have been different. For example, taking samples from other avenues, such as churches, colleges, and/or hospitals, could have provided more insight into possible other community supports.
Another limitation to this study was the mental health functioning level of the sample. All of the participants had to meet specific criteria in relation to their mental illness. Because of the sensitive nature of many individuals living with mental illness, to protect them from any trauma (PTSD, emotional triggers), participants had to be approved by agency staff to take part in this study. Specifically, the participant’s mental health functioning levels (and overall resiliency and adaptation) had to be factored in. NAMI members who had recently been hospitalized for any suicidal ideations or attempts, or members that showed any sort of emotional instability were not able to take part in this study.

Finally, one potential limitation has to do with researcher bias. The researcher had worked with all of these members for several months prior to the interview. On one hand, the researcher was able to build trust and rapport that most likely contributed to the rich qualitative stories that were given in the interview process; on the other hand, because that trusting bond was already there prior to interviews, the interviews may have been slightly skewed as the participants may have given answers to “please” the researcher.

Discussion

Individuals living with a mental illness have a variety of obstacles that impact their overall emotional well-being and quality of life. The modified labeling theory suggests that perceived stigma and societal discrimination results in an individual applying labels that diminish their view of themselves, lower their self-esteem and self-efficacy, and in return, cause them to withdraw and socially isolate. A sense of belonging to a community, often through peer-support, can help diminish social isolation, and protect from psychiatric relapses in mental health, in addition to increasing self-esteem and raising the chances for social integration into the community.
Consequently, the literature suggests a sense of community is so critical to individuals living with mental illness; therefore, a qualitative study was conducted, using the grounded theory approach, to better understand what encourages those living with mental illness to seek out, and stay connected, to social supports that provide a sense of community belonging.

The results of this study suggested a strong lack of social supports among this community population; implying severe detriment to the individuals overall well-being, if communities like NAMI, who provide such a strong peer-based support, were non-existent in their lives. For many participants of the study, the NAMI community was their only source of social support.

In light of all the research discussed, it is safe to conclude that increased social and community supports for individuals living with mental illness would be exceedingly beneficial to not only their mental health management and/or recovery, but would help to diminish the negative effects of perceived stigma and societal discrimination, and ultimately maximize said individuals overall quality of life. Further research and studies would be beneficial in supporting this notion.
References


Appendix A

Informed Consent

13. Statement of Consent

YES  NO

_____  _____ I am 18 years of age or over.

_____  _____ All my questions have been answered.

_____  _____ I have read and understand the description of my participation duties.

_____  _____ I have been offered a copy of this form to keep for my records.

_____  _____ I understand that audio recording of the interview is a necessary condition for participation.

_____  _____ I voluntarily agree to participate in this study and understand that I may withdraw at any time without consequence.

Signature Date

[Signature]

Participant Study Role

Printed Full Name

[Participant's Name]

[Study Role]

Signature Date

[Signature]

Interviewer Study Role*

Printed Full Name

[Name]

[Study Role*]

*This individual must be trained in obtaining informed consent and have authorization from the principal investigator and/or faculty advisor to do so.
Appendix B
Demographic Survey

Age: (Please write in your current age.) __________

Gender: (Please check the one option of gender that you most identify with.)
- Male
- Female

Relationship Status: (Please check the one option that best describes your relationship.)
- Single
- Married
- Separated
- Divorced
- Widowed
- In Committed Partnership

Household Income: (Please check the one option that best describes your yearly combined household income.)
- $0 - $10,000
- $10,000 - $19,999
- $20,000 - $29,999
- $30,000 - $39,999
- $40,000 - $49,999
- Over $50,000

Education Level: What is the highest grade or year of school you completed? (Please check the one option that best describes your highest level of education.)
- Never attended school or only attended kindergarten
- Grades 1 through 8 (Elementary)
- Grades 9 through 11 (Some high school)
- Grade 12 or GED (High school graduate)
- College 1 year to 3 years (Some college or technical school)
- College 4 years (College graduate)
- Graduate School (Advance Degree)

Race/Ethnicity: How do you describe yourself? (Please check the one option that best describes you.)
- American Indian or Alaska Native
- Hawaiian or Other Pacific Islander
- Asian or Asian American
- Black or African American
- Hispanic or Latino
- Non-Hispanic White
- Of mixed race/ethnicity
- Prefer not to answer

Religion:
What is your religious affiliation? ________________________________
Domain: Mental Health/Illness
• Tell me about the history of your mental health diagnosis. Possible prompts (i.e. When did it begin? OR When was the first time you were given a mental health diagnosis? - Did that diagnosis change over time? – level of severity, Have you ever self-harmed or been hospitalized? - Have you found any effective treatments? Tell me about those?)

Domain: Stigma/Discrimination
• Have you ever felt limited by your mental illness in your personal life? (Purposely a closed-ended question to direct into next question.)
• Have you ever felt stigmatized or discriminated against because of your mental health diagnosis? (Prompt: Can you tell me about that… can you give me specific examples? – Look for 3-4 examples – If they’re stuck, bring up employment/housing/education questions.)

Domain: Community
• Please define what the terms “Community” and/or “Sense of Community” means to you.
• Do you feel like you have it? Possible Prompt: Can you give me some examples of where/how you feel a sense of community?
• Describe what is it about [these places/supports] that keeps you coming back to them.
• How much does “convenience” determine your choice of community?
• Do community supports (like NAMI or any other major support they listed) aid you in living with your mental health symptoms/diagnosis? (Purposely a closed-ended question to direct into next question.)
• Do you feel that your family is part of your community? Why or why not?

Wrap-up
• Review what the questions.
• Is there anything else you’d like to add?