

Stigma Resistance at the Personal, Peer, and Public Levels: A New Conceptual Model

Ruth L. Firmin¹, M.S.

Lauren Luther¹, M.S.

Paul H. Lysaker^{2, 3}, Ph.D.

Kyle S. Minor¹, Ph.D.

John H. McGrew¹, Ph.D.

Madison N. Cornwell¹

Michelle P. Salyers¹, Ph.D.

¹Indiana University–Purdue University Indianapolis, Indianapolis, IN

²Richard L. Roudebush VA Medical Center, Indianapolis, IN

³Indiana University School of Medicine, Indianapolis, IN

Corresponding Author:

Ruth L. Firmin, Indiana University–Purdue University Indianapolis, 402 N. Blackford St., LD 124, Indianapolis, Indiana, USA

Email: rfirmin@iupui.edu

Phone: (317) 274-6767

Fax: (317) 274-6943

Funding source:

This work was supported by the American Psychological Foundations' Violet and Cyril Frank's Scholarship.

Conflict of interest:

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

This is the author's manuscript of the article published in final edited form as:

Firmin, R. L., Luther, L., Lysaker, P. H., Minor, K. S., McGrew, J. H., Cornwell, M. N., & Salyers, M. P. (2017). Stigma resistance at the personal, peer, and public levels: A new conceptual model. *Stigma and Health*, 2(3), 182–194. <https://doi.org/10.1037/sah0000054>

Abstract

Objective: Stigma resistance is consistently linked with key recovery outcomes, yet theoretical work is limited. This study explored stigma resistance from the perspective of individuals with serious mental illness (SMI). **Methods:** Twenty-four individuals with SMI who were either peer-service-providers (those with lived experience providing services; $N = 14$) or consumers of mental health services ($N = 10$) engaged in semi-structured interviews regarding experiences with stigma, self-stigma, and stigma resistance, including key elements of this process and examples of situations in which they resisted stigma. **Results:** Stigma resistance is an ongoing, active process that involves using one's experiences, knowledge, and sets of skills at the 1) personal, 2) peer, and 3) public levels. Stigma resistance at the personal level involves a) not believing stigma or catching and challenging stigmatizing thoughts, b) empowering oneself by learning about mental health and recovery, c) maintaining one's recovery and proving stigma wrong, and d) developing a meaningful identity apart from mental illness. Stigma resistance at the peer level involves using one's experiences to help others fight stigma and at the public level, resistance involved a) education, b) challenging stigma, c) disclosing one's lived experience, and d) advocacy work. **Discussion:** Findings present a more nuanced conceptualization of resisting stigma, grounded in the experiences of people with SMI. Stigma resistance is an ongoing, active process of using one's experiences, skills, and knowledge to develop a positive identity. Interventions should consider focusing on personal stigma resistance early on and increasing the incorporation of peers into services.

Keywords: stigma resistance, self-stigma, identity, mental illness, recovery

Mental illness stigma consists of negative attitudes (i.e., prejudices), beliefs (i.e., stereotypes), and behaviors (i.e., discrimination; Link & Phelan, 2001; Rüsçh, Angermeyer, & Corrigan, 2005) towards people with mental illness. Stigma is prevalent, both among the general public and those with mental health training (Kingdon, Sharma, & Hart, 2004; Lyons & Ziviani, 1995; Parcesepe & Cabassa, 2013), is often perpetuated through the media (Chopra & Doody, 2007), and has persisted over the past several decades at a consistent rate (Rüsçh et al., 2005; Vahabzadeh, Wittenauer, & Carr, 2011). One consequence of public stigma is the self-stigma that can result among those with mental illness, where negative beliefs and attitudes about symptoms or recovery are internalized (Corrigan & O'Shaughnessy, 2007). In turn, self-stigma can lead to reduced self-efficacy, self-esteem, hope, empowerment, treatment adherence and poorer recovery, as well as greater symptom severity (Corrigan, 2004; Livingston & Boyd, 2010; Lysaker, Roe, Ringer, Gilmore, & Yanos, 2012).

However, public stigma does not always produce self-stigma in those with mental illness. Applying stigma to oneself can depend on the degree to which one is aware of and agrees with stigma, the salience of the stigmatizing condition, and the perceived legitimacy of the stigmatizing content (Corrigan & Watson, 2002; Watson, Corrigan, Larson, & Sells, 2007). Given the relationships between self-stigma and recovery outcomes, calls have been made for a greater understanding of the conditions where individuals resist internalizing the negative attitudes and beliefs associated with stigma (Thoits, 2011) and that foster individuals' capacity for resistance (Ritsher, Otilingam, & Grajales, 2003; Ritsher & Phelan, 2004).

Previously, stigma resistance has been conceptualized as being unaffected by stigmatizing attitudes (Ritsher & Phelan, 2004), actively challenging or deflecting encounters with stigma (Thoits, 2011), or holding a positive illness identity (King et al., 2007; Author cite,

in press). Some studies have also linked coping with stigma as a form of stigma resistance (Thoits & Link, 2015). Stigma resistance was originally assessed using reverse-scored sub-scales of broader self-stigma measures, the “Stigma Resistance” subscale of the Internalized Stigma of Mental Illness Scale (ISMI; Ritsher, et al., 2003) and the “Positive Aspects” subscale of the Self-Stigma Scale (SS; King et al., 2007). There has been a recent shift, however, regarding the theoretical model of stigma resistance—suggesting it is more than simply the absence of self-stigma. Indeed, preliminary empirical work also points to stigma resistance being a distinct construct, both in its measurement properties (Sibitz et al., 2011) and in the ways it relates to recovery outcomes (Author cite; Campellone, Caponigro, & Kring, 2013; Livingston & Boyd, 2010).

Currently, little work has examined the processes and mechanisms involved in stigma resistance—work needed in order to inform how stigma resistance may be facilitated. To our knowledge, only one publication by Thoits (2011) theoretically examines mental illness stigma resistance, defining it as: “opposition to the imposition of mental illness stereotypes by others and distinguish between deflecting (“that’s not me”) and challenging resistance strategies”. (pp. 13). Thoits (2011)’s theoretical work drew important attention to the process of stigma resistance, integrated existing literature, discussed conditions in which individuals might be most likely to resist stigma, and called for future work to continue understanding this process.

An important gap that remains in the literature, however, is understanding the process of stigma resistance from the perspective of people with serious mental illness (SMI). In this study we analyzed semi-structured interviews to explore the process of stigma resistance with the aim of building a theoretical model grounded in the experiences of people engaged in this process.

By using this approach, this study also sheds light on whether Thoits' theoretical propositions regarding stigma are consistent with the lived experience of persons with SMI.

Methods

Setting and Participants

In order to hear the perspectives of people engaged in stigma resistance, we targeted those in peer-support jobs and those referred by their providers. Twenty-four adults with self-reported serious mental illness participated: 10 were consumers of mental health services and 14 were peer-providers or individuals with lived experience of serious mental illness who provided mental health services. Demographic information is presented in Table 1. Briefly, most were white (75%) and male (54%). The primary diagnoses included bipolar disorder (46%), schizophrenia/schizoaffective disorder (33%), major depression (13%), and borderline personality disorder (8%).

Procedure

We recruited two types of participants who had achieved progress in their recovery and who were actively involved in resisting stigma. First, peer-providers, those with lived experience who also provide mental health services, were recruited through flyers distributed in two community mental health centers in a medium-sized Midwestern city and posted on an online forum for peer-providers. Second, consumers of mental health services were recruited through referral by mental health providers of those doing well in their recovery and actively resisting stigma. All participants self-identified as having a serious and persistent mental illness (having previously received mental health services for at least two years and previously experiencing periods of self-reported low functioning due to their mental illness (modified from Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). Interviews were conducted between December

2014 and April 2015. All participants engaged in informed consent conversations with a trained Master's-level research assistant (RF) and were paid with a \$10 gift-card; study procedures were approved by the institutional IRB board.

Measures

The interviews began by building rapport with the interviewee and asking participants open-ended questions in seven domains. First, participants were asked to broadly share about their (1) experiences with mental health and then (2) stigma. The interviewer next asked participants about experiences with (3) self-stigma, or the process of internalizing public stigma. Participants were next asked about (4) not internalizing stigma and what this looked like. When appropriate, this was followed up by asking participants to share a specific experience where they did not internalize stigma. Next, participants were asked (5) what came to mind when they heard the term "stigma resistance." After offering thoughts or a definition of this term, participants were then (6) presented with a potential theoretical definition of stigma resistance grounded in previous work (Thoits, 2011; Ritsher et al., 2003; Author cite, in press; Figure 1) and asked for broad feedback as well as which elements of the model seemed the most and least central to their experiences of resisting stigma. Finally, participants were asked to (7) share any additional thoughts they felt were important or wished to share regarding stigma or stigma resistance.

In our desire to have the interview be open-ended, we did not automatically provide definitions to these terms. We preferred for participant understandings of these terms to guide their responses. However, if participants inquired about the meaning of one of these terms or expressed uncertainty, we used brief definitions that were grounded in existing literature. For public stigma, we used negative attitudes (i.e., prejudices), beliefs (i.e., stereotypes), and

behaviors (i.e., discrimination; Link & Phelan, 2001; Rüsch, Angermeyer, & Corrigan, 2005) towards people with mental illness. For self-stigma, we used a definition of internalizing these experiences, by being aware of stigma attitudes, agreeing with them, and applying them to oneself (Corrigan & O'Shaughnessy, 2007). When participants were presented with Figure 1, the definition of each term presented reflected Thoits' conceptual model. Notably, the "deflecting" stigma term was explained as a set of strategies that assist in not believing and internalizing stigma; overall, participants felt "deflecting" was too passive of a term, but they confirmed many of the specific strategies involved.

Analysis

Interviews were audio-recorded, transcribed, and de-identified. Interviews were analyzed using a modified-grounded-theory approach (Charmaz, 2006; Kisely & Kendall, 2011; Firmin et al., 2015) that involved first applying a process of open coding (Leiva, Rios, & Martinez, 2006), where patterns and themes were identified as they emerged and then refined through an iterative process into focused codes. We employed this method with the aim of creating generalizable themes regarding perceptions of stigma resistance that could produce a theory (Meyrick, 2006). A potential theoretical model of resisting stigma (created by the authors from a summary of existing work by Thoits, 2011; King et al., 2007; Risther et al., 2003; Author cite) was presented to participants at the end of the interview, but this framework was not used for coding; instead, we began with a line-by-line coding process of identifying recurring themes and codes. We utilized this inductive process, rather than looking to confirm our hypothesized theoretical model, because we wanted the findings to reflect a definition of stigma resistance that emerged from participant perspectives. To help check for researcher biases in coding, themes identified were verified through a consensus process among a researcher familiar (RF) and unfamiliar

(MC) with the theoretical model and existing literature. Researchers coded transcripts independently and then met weekly throughout the development of the codebook and coding of individual transcripts. Consensus meetings included comparing coding and discussing any discrepancies or additional themes that emerged. Sometimes discrepancies led to different understanding of or merging of codes, which were then incorporated into the coding system. Using the themes generated, participant discussions of stigma resistance were integrated into a conceptual model. Information was organized using Atlas-TI qualitative coding software.

We employed several steps designed to enhance the rigor and internal and external validity of our findings. First, the primary coder held regular meetings with another researcher on the team (MP) with expertise in qualitative research methodology (Flick, 2006) who supervised steps taken in analyses and enhanced the validity of analyses by conducting data audits and providing feedback regarding how themes, results, and transcripts were linked. Our confidence in these findings was also enhanced through checking for principles of saturation, the point when coding additional transcripts does not contribute novel themes (Guest, Bunch, & Johnson, 2006), which tends to occur between 10 and 20 observations (Kisely & Kendal, 2011). This increased our confidence that findings might be generalizable to a population matching the qualities of our present sample (Meyrick, 2006). As codes emerged, we refined themes and patterns by removing codes no longer supported by the majority of our participants' narratives, adding additional codes that were pertinent but did not emerge early on, combining codes that highly overlapped, and refining codes where the original definition and understanding of constructs referenced by participants shifted. This was done to produce findings that were reflective of the majority of participants in our sample.

Results

Participants discussed resisting stigma at three distinct levels—personal, peer, and public stigma resistance. Personal stigma resistance often provided the foundation for engaging in stigma resistance at the peer and public levels. These three domains served as the overarching framework for our conceptual model of stigma resistance (see Figure 2).

Personal Stigma Resistance

First, participants discussed needing to fight public stigma within their own thoughts and behaviors so that they would not endorse self-stigma. Participants discussed specific mechanisms involved in resisting stigma at the personal level, including: a) not believing stigma/catching and challenging stigmatizing thoughts, b) empowering one's self through learning about mental illness and one's own recovery, c) maintaining one's own recovery and proving stigma wrong, and d) developing a meaningful identity and purpose apart from one's mental illness.

Not believing/Catching and challenging stigma. Being aware of stigma and intentionally evaluating stigma was discussed as an important first step in resisting stigma, as one participant explained when discussing an encounter with stereotype threat: “[It’s] assessing the stigma...not necessarily thinking ‘Oh, they’re right, I have a mental illness, I can’t do this or I’m not capable or not as worthy’...It’s not internalizing it--not just accepting what they say. It’s facing it. It’s evaluating it” (P1). After deliberately considering stigma, some participants described a process of challenging these beliefs and attitudes. Stigma evoked strong internal reactions in participants, particularly when it involved others expressing value judgments or beliefs about limitations that accompany having a mental illness. In the face of stigma, participants reported that not believing these judgments *and* having positive beliefs about oneself was key: “The biggest part in resisting stigma is keeping your own positive mindset about you.

It's about what you have accomplished, it's about knowing who you are. Because there is always going to be some type of stigma out there that gets created...[but] it's not what society thinks I am. I am who I am...some people think that's arrogant, but no; it's assertive...I use those challenges to strengthen me" (P17).

Notably, this process of maintaining a positive view of oneself in the face of stigma involved a capacity to identify and differentiate the thoughts of another person as distinct from one's own (i.e., metacognition). Participants repeatedly shared the importance of "not focusing on what other people think, but focusing on what you think about yourself" (P3). Individuals strongly voiced their refusal to let the opinions of someone else make them feel less about themselves and many expressed the importance of knowing that a negative judgment from someone else doesn't "determine my value as a person. I'm just not going to do that anymore" (P12). Participants also believed the way they viewed themselves had the potential to impact how others saw them. Several participants, such as P3, specifically expressed beliefs that changing stigma started with their own beliefs about herself as a person with a mental illness: "I need to have enough self-worth to say that, you know, I don't care what people say. It's me and I know who I am. You know, for me to be well then I have to know myself, because I am good and I am okay. Honestly, to get anybody else to believe it, I have to believe it myself first."

Empowerment through learning about one's own mental illness and recovery. A second important aspect of stigma resistance at the personal level was educating oneself about mental illness. Participants shared that education was empowering, as it provided them with more tools to make informed decisions about their recovery: "By knowing what my diagnosis was, I could get information, whether that was from the internet, going to the library, contacting NAMI [National Alliance of Mental Illness], wherever, but knowing that empowered me." (P2)

Moreover, greater empowerment also took the form of becoming more aware of why stigma is wrong and, thereby feeling more prepared to respond to it and more alert against self-stigma.

P15, for example, described arriving at a greater sense of agency after growing in his understanding of his illness and choosing how to respond:

Because you internalize it without knowing that you're internalizing it. And you feel that about yourself, you feel like you're a bad person, you feel like you're incapable, you feel all these things and you don't even know why you feel them. You haven't come to that awareness so I think in order to be able to resist it, you have to have an awareness that it's happening to you. You have to identify that label that is applied to you, you have to almost claim that label and say, "Yes, that is part of my story but it doesn't define me completely and this is how I want to interact with having that label."

Maintaining one's recovery and proving stigma wrong. Many participants talked about the link between their mental health and their ability to resist stigma. Some individuals noted that stigma was harder to resist during times when they were not feeling their best:

"Because if I don't feel good about myself, then what's the point? I mean, that's the whole point in recovery is to feel good about yourself and that in itself challenges the idea of stigma. Not just to others but to myself that they're not right." (P14) On the positive side, many participants reported that maintaining recovery was one of the most important steps toward resisting stigma. For example, P13 explained: "Self-stigma leads you to be a victim of stigma. Because it, you're tearing yourself down and you're allowing these things to come in...it's stopping it at that point. It's having a WRAP [recovery] plan...start doing the things that make me feel better about me. And that helps me with my self-stigma and it helps me fight stigma."

Like recovery, stigma resistance was described by participants as a continuous activity, with times where it was easier and times where it was more difficult. Most participants discussed recovery and stigma resistance as having the potential to influence the other, like P11: “If you’re helping your mental illness, you’re also going to help your stigma. Because if you’re helping your mental illness, you’re helping who? You’re helping yourself. So if you’re helping yourself...you’re going to have a better outlook about yourself and of who you are.”

Making strides towards recovery was discussed as a process that had the power to boost confidence and provide content for challenging stigma. The daily work involved in recovery, as P8 shared, was part of what helped him resist stigma: “Living my life every day, being a productive person every day, helps me realize that, you know, the negative stereotypes aren’t true. That I can be productive and the people I work with can be productive, too.” For many, maintaining recovery was a process that was both empowering and confidence building. Participants understood the nature of up’s and down’s in the process and they identified that being able to make progress toward the things in their life they want to accomplish was evidence—both to themselves and to others—that stigma was wrong:

[Things that give me a positive view of myself] are exercise, getting sleep, leisure time. Just self-management type stuff. Prayer. Looking at how I was versus how I am now. I was working at a job that paid less than \$10 an hour versus the job that I work now that pays a lot more...and being able to walk into that place that say that, you know, I no longer work there. To do well is the best revenge.

Developing a meaningful identity apart from mental illness.

A final aspect of stigma resistance at the personal level involved having a sense of identity that was more than being a person with a mental illness. One participant shared that a

“breakthrough” in his life was when a caseworker refused to let him apply stigma to himself, and instead challenged the participant to view his identity separate from being a person with a mental illness. For many, this process of discovery could be challenging because of the intensity of public stigma they had encountered both in and out of the mental health system. P13 summarized this struggle shared by many participants: “Everything in your body and your mind is going to be saying do the opposite, but you have to fight against that. And you can fight against that by learning as much as you can about yourself—your true self—and about your illness. Because your illness is a part of you, but it’s not who you are.” Nearly every participant identified that their mental illness was a part of their life, but just one part of who they are. Stigma resistance was closely tied to having a positive sense of identity—rather than believing stigma or seeing mental illness as their identity. P1 explained:

And it’s just knowing – knowing what you’re good at and what you’re not good at and realizing that your mental illness doesn’t enter into that. And granted that you have to take other steps to maintain your wellness, your recovery. Because you have a mental illness, there are certain things you have to do, but it’s not your whole person. It’s just part of you, and understanding that and realizing that and internalizing that. That you are not – you are not your illness... just knowing that I’m capable and I’ve done a lot of things in my life before and after my mental illness.

Peer Stigma Resistance

Resisting stigma at the personal level enabled participants to engage in a second step—resisting stigma at the peer-level. This involved using one’s lived experiences with both mental illness and fighting stigma to help others resist stigma and make progress toward greater recovery. For several participants who were involved formally as peer-providers, motivation to

help others came from the positive influence of another person with lived experience previously had on their own recovery. For other peer-providers, their desire to help came from the lack of peers when they were early in their experience with mental illness and their desire for others to know recovery is possible: “Yeah, I know when I was at my worst, I was looking for somebody who made it. Somebody that actually came over and did it. I couldn’t find anybody. Nobody that had gone through it and got better, and that to me was devastating.” (13) Similarly, P4 shared: “I’m less likely to internalize stigma [now] because there are people that are at different level[s] than I am, and I may have been at that level at a previous time. So I wish there would have been other people there at that time to have stepped up for me and to educate others when I couldn’t.” (P4)

Several participants expressed that helping others with mental illness, both informally and through peer-service involvement, was motivated by seeing first-hand the powerful negative influence stigma could have. Their desire to help others was a response that they hoped could have an equally large impact on the lives of others with mental illness and on the fight against stigma. P6 articulated sentiments shared by many participants who discussed the relationship between stigma they experienced and their desire to be involved in helping peers:

I don’t want you walking away thinking we have arrived...I still deal with self-stigma daily...what keeps coming to my mind is stigma steals hope...whether it’s self-inflicted or if it’s internal or external...I think collectively [we have] accumulated some tools [so] that it doesn’t have to steal our hope today, that’s part of the battle...it’s about educating my culture about mental illness, educating my community...like I said, I’m a certified recovery specialist, I love what I do. Because I think the only way to help and address stigma for real is to give them the power from within.

Participants who were formally involved as peer-providers all discussed the powerful ways this role involved combatting stigma among those they worked with. Resisting stigma at the peer level involved helping others with mental illness challenge stigma beliefs or attitudes about whether or not they could achieve recovery and meet their goals, as well as discussing stigma and self-stigma.

Participants who were not formal peer-providers empathized and expressed a desire to support others. For example, when offering advice he shared with someone newly diagnosed with a mental illness, P13 stated: “Eventually somebody on the news is going to say something that is stigmatizing. But if you know people in your life who are doing well, who are moving beyond it, at least I’m moving with it, it’s not having me stop right here...you can have that positive to go with the negative.” Many participants stressed the importance of a support system in resisting stigma: “Experiencing stigma can be very triggering emotionally and you need to have those supports in place in order to be able to resist it” (P15). Participants also expressed their desire to help provide a safe space for others to process stigma, understanding how difficult resistance can be, as highlighted by P8:

[I want to] let them know that it’s ok...that people just don’t understand us...who we are, what we’re capable of...allowing them to talk about it because a lot of people don’t allow you to talk about that stuff. They tell you you’re being silly or “Oh, that’s now what they meant,”...and cut you off because they’re unconformable talking about it.

Participants also communicated that the process of helping peers is mutually beneficial to their own recovery and stigma resistance. Some who were not formal peer-providers discussed a deep connection they felt with others with shared lived experience. P2, for example, discussed valuing friends with lived experience and the ways they were able to be there for each other:

“The more I learn about myself and everything [the more] I find friends that [have] bipolar and OCD. They have, you know, their quirks and what not and, you know, it’s just easier to relate to [them]. It’s easier to talk.” Participants involved in providing formal peer services also talked about this involvement as beneficial to their own recovery through regular exposure to recovery-oriented curriculum, teaching skills, and actively helping others resist stigma. Accountability was another result of using one’s lived experience to help others resist stigma. P8 summarized:

I keep trying to improve my life and I try to find new things to help me improve my life all the time. And I try to transmit those to other people. And my role in this job is educator and role model. The – the scariest thing I think when I first realized that, you know, we do model behavior for other clients. In my group, a lady was saying one day she was in a situation she didn’t know what to do and she thought to herself, what would [Peer-provider] do in this situation? I thought, boy that’s a scary thought...A big compliment. I never thought of people thinking that way, but you know, they do. They do take what you say seriously. Because you’ve been there.

Public Stigma Resistance

Finally, building on their experiences helping their peers, participants identified that resisting stigma publicly was an important means of taking stigma resistance a step further. Both peers and consumers described engaging in this process through educating others, asking questions that challenge stigma, disclosing one’s personal experience, and pursuing opportunities for advocacy work.

Educating others. First, participants chose to view encounters with public stigma as an opportunity to share with others the changed thinking about mental health they experienced: “I just have to say, you know, I was in their shoes. They’re ignorant. And I don’t mean ignorant in

a bad way. I mean they just don't know. If they were in my shoes, they'd have a different perspective. And I usually take the opportunity to educate the person." (P15) While educating others is an integral aspect of peer work, peers and non-peers discussed embracing opportunities to educate others beyond the context of services, such as educating family members, friends, and even acquaintances in public settings through sharing information with others, discussing stories that counter public stigma, and modeling person-first language.

Questioning and challenging stigma. Remaining silent in the face of public stigma, for many participants, was equivalent to perpetuating these false beliefs and negative attitudes. In fact, when presented with the original theoretical model of stigma resistance (Figure 1) at the end of the interview, nearly all participants had negative reactions to the idea of "deflecting" stigma if it meant a passive approach, such as changing the subject. While participants said that it was not always feasible to overtly challenge stigma, they expressed that to deflect felt like they were *not* resisting stigma. In fact, participants described feeling a sense of responsibility to do something about the stigma, usually through addressing it directly. Participants wanted these conversations to be thoughtful, rather than defensive. One participant discussed the need to address stigma but in an effective manor:

I absolutely think [resisting stigma] is confronting it, for me, because I'm that, that's me, I'm going to challenge it to the end...For me, if we're talking about it, we're talking about it. That's an open door. That's an opportunity for me to empower you with knowledge about a true mental illness or whatever that looks like with that person. Yeah, I like talking about it...if the door has been opened for a dialogue, I'm all with that. I don't want to shut anybody down, and I don't want nobody to shut me down because how are you going to learn? (P10)

Disclosing one's lived experience. Self-disclosures were described as powerful means of resisting stigma. Many participants, like P14, discussed their frustration with the media showing only negative portrayals of people with mental illness and how this led them to speak out:

Tell some good stories. Educational stories are good... [A] lady did a series on mental illness. The truth about mental illness. She did an article on, on me and my wife and story of my mental illness. And that's exactly what I think we need more of. Is—it's educational. If you're gonna tell the bad, then tell the good with it, too. There are a lot of people out there with mental illness that're doin' just fine. To normalize as much as possible because people—stigma is all about people being treated differently. And if we learn to normalize, especially within the media, then just and that's saying "they're not any different," we're not any different, then hopefully it will reduce the amount of being treated differently.

Speaking out publically about one's diagnosis was a powerful moment for many participants, and they felt part of what made this meaningful was the potential to challenge negative stereotypes about people with mental illness:

During that time, no one but my professor there at the college knew that I had a mental health diagnosis. So I did my paper on mental health and its recovery. It'd been six months that I'd been in the school, people had gotten to know me as who I was, which is you know the important aspect. So what I did my paper on was basically to educate the people in that classroom, which also that paper was also put in the community college's newsletter afterwards...And students both in the classroom and out of the classroom said "This is you know, this can't be true. You're not." And I said, "Yes I am. What makes

me any different?” And from that point on, it’s been my passion to educate society to get them away from that negative stigma. I mean I work in the community. (24)

For some, the power in sharing their experience helped them to overcome their hesitations to disclose. While the nature of formal peer work necessitates disclosing one’s lived experiences, the power of disclosure for those without a formal peer-provider role often involved risk: “You don’t know if you’re going to be breaking a connection. You don’t know what people’s response is going to be. But I think the tension that I feel between not sharing versus sharing—I’m more likely to go toward sharing just because the power, how powerful it is for people to actually hear your story.” (P18)

Advocating for others. Finally, both groups of participants talked about their decision to pursue opportunities for advocacy work. Opportunities included positions as peer-providers, but participants also talked about sharing their story in the community or through groups such as NAMI, speaking out about political reform, or hosting events that educate others about mental health. This work was discussed as a means to give back to the community and create change regarding attitudes toward mental illness. P21, for example, discussed her advocacy work using the metaphor of a garden:

You first have to kill that bad soil. We are out there teaching people, you know, about mental illness to get rid of the stigma. The first thing you’ve got to do is dig up the trash in the barren soil. And you have to pull out the bad rocks and all that to make the soil in the process of growing...that’s why I go out there and do these presentations at the colleges, the prisons, at the homeless shelter, groups, churches, wherever I’m asked to go, I go.

Discussion

This study investigated stigma resistance from the perspective of people with serious mental illness. Stigma resistance is a process of using skills, knowledge, and experiences and occurs at the personal, peer, and public levels. The levels appear relatively sequential, resisting personal stigma often appeared to be a pre-requisite that facilitated resisting stigma at the peer and public levels. Moreover, participants also discussed stigma resistance as an ongoing process, rather than something at which they “arrive” – akin to current conceptualizations of recovery (Davidson et al., 2005; Davidson & Roe, 2007). Although past research suggests that stigma resistance is a key element of recovery (Author cite), the theoretical framework to understand this process was crafted from an expert perspective but lacking the perspective of the targets of this theory. The current findings, therefore, fill an important gap and provide guidance regarding future work that seeks to understand and facilitate stigma resistance.

Participant discussions of stigma resistance revealed several factors that appear key to this process. One factor was having a sense of identity that was distinct from being a person with a mental illness. This is consistent with previous discussions by Davidson and Strauss (1992) on the important role of one’s sense of self in recovery. Another important factor that may be a prerequisite for resisting stigma is having the metacognitive capacity to differentiate stigmatizing attitudes and beliefs of others from one’s own thoughts and identity (Nabors et al., 2014; Author cite). It may also be that a certain degree of empowerment is necessary for individuals to feel capable or interested in resisting stigma beyond the personal level. Others have discussed one’s sense of empowerment as central to resisting stigma (Campellone et al., 2014), and it may be that education about mental illness and recovery or particular supports (e.g., social support,

employment security) are factors that would promote greater capacity for stigma resistance at the peer or public level.

Existing theoretical work by Thoits (2011) proposed that stigma resistance involves deflecting and challenging stigma. Thoits' discussion of blocking the internalization of stigma at a personal level and challenging at a public level were consistent in many ways with perspectives our participants discussed. For example, both Thoits and our participants discussed identifying when one doesn't fit a stereotype and that mental illness is not one's entire identity. However, in contrast to Thoits' model, which presents deflection as a primarily cognitive strategy, participants in our study discussed stigma resistance at the personal level to involve additional strategies and components (e.g., education, maintaining one's recovery, taking steps to develop a more meaningful sense of identity and purpose). We also note that, when presented with Figure 1, participants either were unsure what "deflection" meant regarding stigma resistance or they did not care for this term, assuming initially that it meant taking a more passive response to stigma (e.g, changing the subject). We believe the current findings grounded in participant responses build on the work by Thoits, confirming many aspects of this theoretical work, and extend our understanding of the cognitive processes involved (i.e., catching and checking one's cognitive processes), as well as illuminating novel factors involved (i.e., metacognition). Moreover, while Thoits discusses resisting stigma occurring at the personal level (e.g., deflecting) and public level (e.g., challenging), the present findings suggest that an additional component of stigma resistance occurs at the peer level, for both peer-providers and non-peer providers.

This study also built on past work regarding self-stigma and recovery. Corrigan and Watson (2002) discuss self-stigma as the process of first being aware of public stigma and then

agreeing with it and applying it to oneself. Participants in our study similarly noted that being aware of stigma and then evaluating it were important requirements for personal stigma resistance. Further, both self-stigma and stigma resistance have consistently been linked with key recovery outcomes (Livingston & Boyd, 2010; Author cite); participant discussions of maintaining their own recovery to “prove stigma wrong” may illuminate part of the link between stigma resistance and lower symptoms and greater functioning. Further, maintaining a positive identity and being active in response to stigma may contribute to links seen between stigma resistance and reductions in negative symptoms (Campellone et al., 2014; Author cite). The present findings also build evidence that, more than being just the absence of self-stigma, stigma resistance is an active, multi-faceted, and ongoing process.

These results should be interpreted in light of their limitations. First, we actively recruited stigma resisters. We targeted peer providers and consumers referred to us as individuals actively engaged in stigma resistance. Given the paucity of existing work in this area, we believed this population would allow us to conduct preliminary work regarding perspectives from those actively engaged in resisting stigma. These individuals may have distinct experiences and results should be compared with the perspectives of individuals at varying stages of recovery and who endorse varying levels of self-stigma. For example, it is possible that peer-providers have protective factors that facilitate resisting stigma, such as potentially safer contexts for disclosure or challenging stigma in the workplace, given the nature of their job. The perspectives shared by our participants, may not generalize to participants who are not engaged in treatment, deny having a mental illness, or who are newer to experiences with mental illness. Our findings also do not include a discussion of potential negative consequences of stigma resistance. While these themes did not emerge, we also did not directly ask about negative consequences to resisting

stigma. Future research could investigate potential negative consequences, such as whether burnout or burden emerges from the disclosure process. Finally, in a spirit of reflexivity that is key to grounded theory methods (Charmaz, 2006), while we took several steps to reduce the potential for researcher biases, we acknowledge that unintended biases (for example, familiarity with prior literature) may have still impacted coding.

The current findings also have potential implications for interventions that target and facilitate stigma resistance. Several existing interventions that aim to lessen self-stigma target aspects of stigma resistance that were shared by our participants, such as the importance of education (Mittal et al., 2012; Pinfold et al., 2003), catching/challenging stigma at the cognitive level (Lucksted et al., 2011; Yanos et al., 2012), developing a richer sense of identity (Yanos, Roe, & Lysaker, 2011), and sharing one's story (Corrigan, Kosyluk, & Rüsch, 2013). The model put forth in this paper could suggest that facilitating stigma resistance may involve integrating aspects of existing self-stigma interventions to target specific processes involved in stigma resistance. For instance, it may be that particular interventions more effectively promote stigma resistance at the personal level (e.g., education, metacognition, CBT) and other interventions target stages of stigma resistance that come subsequently at the peer and public levels (e.g., disclosing one's illness). For example, it may be necessary for individuals to have the capacity to differentiate their own thoughts and sense of self from the thoughts of others before they are able to engage in directly confronting or challenging stigma, suggesting that it may be helpful to develop one's metacognitive capacity prior to engaging in interventions that target specific cognitions (Nabors et al., 2014). The current findings also support and provide indirect evidence for the benefits of greater involvement of peers in providing services, and is consistent with past work strongly supporting the effectiveness and benefits of peer-providers (Davidson, Bellamy,

Guy, & Miller, 2012) and of the helpfulness of peer-related helping behaviors in non-formal roles in fostering a greater sense of recovery and empowerment (Firmin et al., 2015).

References

- Campellone, T. R., Caponigro, J. M., & Kring, A. M. (2013). The power to resist: The relationship between power, stigma, and negative symptoms in schizophrenia. *Psychiatry Research, 215*(2), 280-5.
- Charmaz, K. (2006). Measuring pursuits, marking self: Meaning construction in chronic illness. *International Journal of Qualitative Studies On Health and Well-Being, 1*(1), 27-37.
- Chopra, A. K. & Doody, G. A. (2007). Crime rates and local newspaper coverage of schizophrenia. *Psychiatric Bulletin, 31*(6), 206-208.
- Corrigan, P. W. (2004). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614-625.
- Corrigan, P. W., Kosyluk, K. A., & Rüsch, N. (2013). Reducing self-stigma by coming out proud. *American Journal of Public Health, 103*(5), 794-800.
- Corrigan, P. W. & O'Shaughnessy, J. R. (2007). Changing mental illness stigma as it exists in the real world. *Australian Psychologist, 42*(2), 90-97.
- Corrigan, P. W. & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice, 9*(1), 35-53.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: Sage Publications, Inc.
- Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry, 11*(2), 123-128.
- Davidson, L., Borg, M., Marin, I., Topor, A., Mezzina, R., & Sells, D. (2005). Processes of recovery in serious mental illness: Findings from a multinational study. *American Journal of Psychiatric Rehabilitation, 8*(3), 177-201.

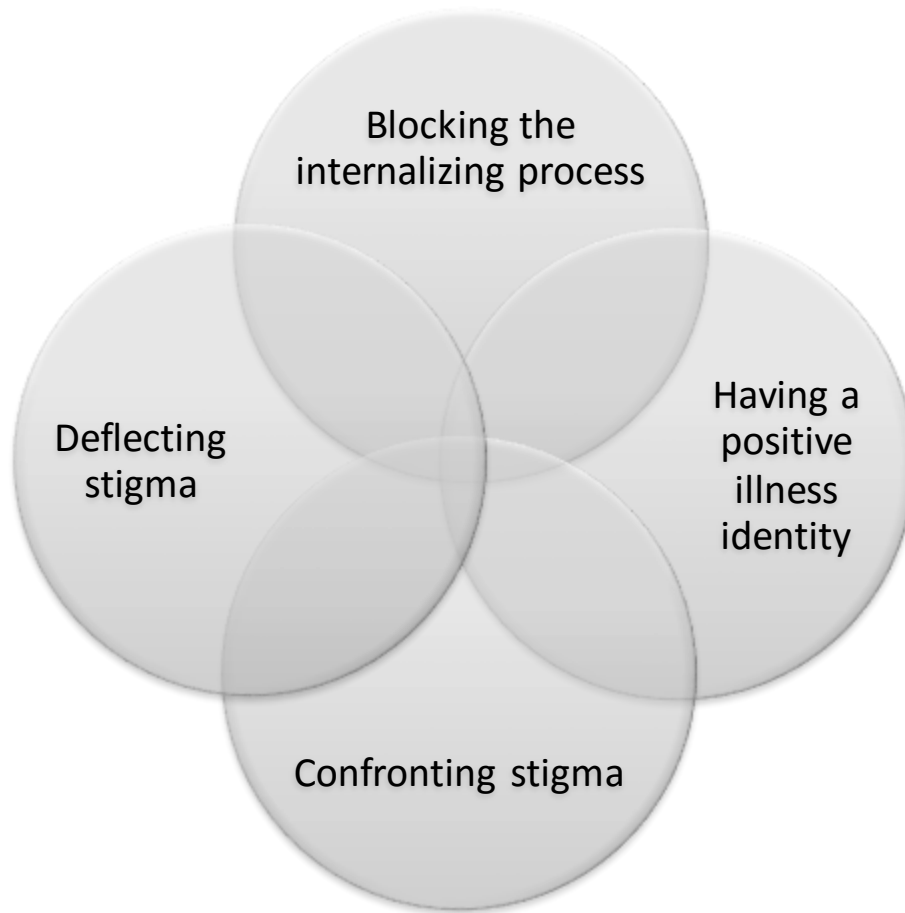
- Davidson, L., & Roe, D. (2007). Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *Journal of Mental Health, 16*(4), 459-470.
- Davidson, L. and Strauss, J. S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology, 65*, 131–145.
- Firmin, R. L., Luther, L., Lysaker, P. H., & Salyers, M. P. (2015). Self-initiated helping behaviors and recovery in severe mental illness. *Psychiatric Rehabilitation Journal, 38*(4), 336-341.
- Flick, U. (2008). *Designing Qualitative Research*: Sage. Thousand Oaks, CA.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.
- King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F., . . . Serfaty, M. (2007). The stigma scale: Development of a standardised measure of the stigma of mental illness. *The British Journal of Psychiatry, 190*(3), 248-254.
- Kingdon, D., Sharma, T., & Hart, D. (2004). What attitudes do psychiatrists hold towards people with mental illness? *The Psychiatrist, 28*(11), 401-406.
- Kisely, S. & Kendall, E. (2011). Critically appraising qualitative research: a guide for clinicians more familiar with quantitative techniques. *Australasian Psychiatry, 19*(4), 364-367.
- Leiva, F., Rios, F., & Martinez, T. (2006). Assessment of interjudge reliability in the open-ended questions coding process. *Quality & Quantity: International Journal of Methodology, 40*(4), 519-537.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 36*-385.

- Livingston, J. D. & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, 71(12), 2150–2161.
- Lucksted, A., Drapalski, A., Calmes, C., Forbes, C., DeForge, B., & Boyd, J. (2011). Ending self-stigma: Pilot evaluation of a new intervention to reduce internalized stigma among people with mental illnesses. *Psychiatric Rehabilitation Journal*, 35(1), 51.
- Lyons, M. & Ziviani, J. (1995). Stereotypes, stigma, and mental illness: Learning from fieldwork experiences. *The American Journal of Occupational Therapy*, 49(10), 1002-1008.
- Lysaker, P. H., Roe, D., Ringer, J., Gilmore, E. M., & Yanos, P. T. (2012). Change in self-stigma among persons with schizophrenia enrolled in rehabilitation: Associations with self-esteem and positive and emotional discomfort symptoms. *Psychological Services*, 9(3), 240-247.
- Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology*, 11(5), 799-808.
- Mittal, D., Sullivan, G., Chekuri, L., Allee, E., & Corrigan, P. W. (2012). Empirical studies of self-stigma reduction strategies: A critical review of the literature. *Psychiatric Services*, 63(10), 974-981.
- Nabors, L. M., Yanos, P. T., Roe, D., Hasson-Ohayon, I., Leonhardt, B. L., Buck, K. D., & Lysaker, P. H. (2014). Stereotype endorsement, metacognitive capacity, and self-esteem as predictors of stigma resistance in persons with schizophrenia. *Comprehensive Psychiatry*, 55(4), 792-798.

- Parcesepe, A. M., & Cabassa, L. J. (2013). Public stigma of mental illness in the United States: A systematic literature review. *Administration and Policy in Mental Health and Mental Health Services Research, 40*(5), 384-399.
- Pinfold, V., Toulmin, H., Thornicroft, G., Huxley, P., Farmer, P., & Graham, T. (2003). Reducing psychiatric stigma and discrimination: Evaluation of educational interventions in UK secondary schools. *The British Journal of Psychiatry, 182*(4), 342-346.
- Ritsher, J. B., Otilingam, P. G., Grajales, M., 2003. Internalized stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Research, 121*(1), 31-49.
- Ritsher, J. B., Phelan, J. C., 2004. Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research, 129*(3), 257-65.
- Ruggeri, M., Leese, M., Thornicroft, G., Bisoffi, G., & Tansella, M. (2000). Definition and prevalence of severe and persistent mental illness. *The British Journal of Psychiatry, 177*(2), 149-155.
- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry, 20*(8), 529-539.
- Sibitz, I., Amering, M., Unger, A., Seyringer, M. E., Bachmann, A., Schrank, D., . . . Woppmann, A. (2011). The impact of the social network, stigma and empowerment on the quality of life in patients with schizophrenia. *European Psychiatry, 26*(1), 28-33.
- Thoits, P. A. (2011). Resisting the stigma of mental illness. *Social Psychology Quarterly, 74*(1), 6-28. Pp. 13.
- Thoits, P. A. & Link, B. G. (2015). Stigma resistance and well being among people in treatment for psychosis. *Society and Mental Health: doi:10.1177/2156869315591367*.

- Vahabzadeh, A., Wittenauer, J., & Carr, E. (2011). Stigma, schizophrenia and the media: exploring changes in the reporting of schizophrenia in major U.S. newspapers. *Journal of Psychiatric Practice, 17*(6), 439-446.
- Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin, 33*(6), 1312-1318.
- Yanos, P. T., Roe, D., & Lysaker, P. H. (2011). Narrative Enhancement and Cognitive Therapy: A new group-based treatment for internalized stigma among persons with severe mental illness. *International Journal of Group Psychotherapy, 61*(4), 576-595.
- Yanos, P. T., Roe, D., West, M. L., Smith, S. M., & Lysaker, P. H. (2012). Group-based treatment for internalized stigma among persons with severe mental illness: Findings from a randomized controlled trial. *Psychological Services, 9*(3), 248.

Figure 1. Original Model of Stigma Resistance Based on Authors' Review of Existing Literature



Note: All participants were first asked to discuss thoughts about stigma resistance and share understandings of this process before being presented with this model. This figure was developed by the present authors for the purpose of this study and is based on a summary of previous literature by Thoits (2011), Risther et al., (2003), King et al., (2007), and [Author cite].

Figure 2. New Model of Stigma Resistance Grounded in Participant Interviews

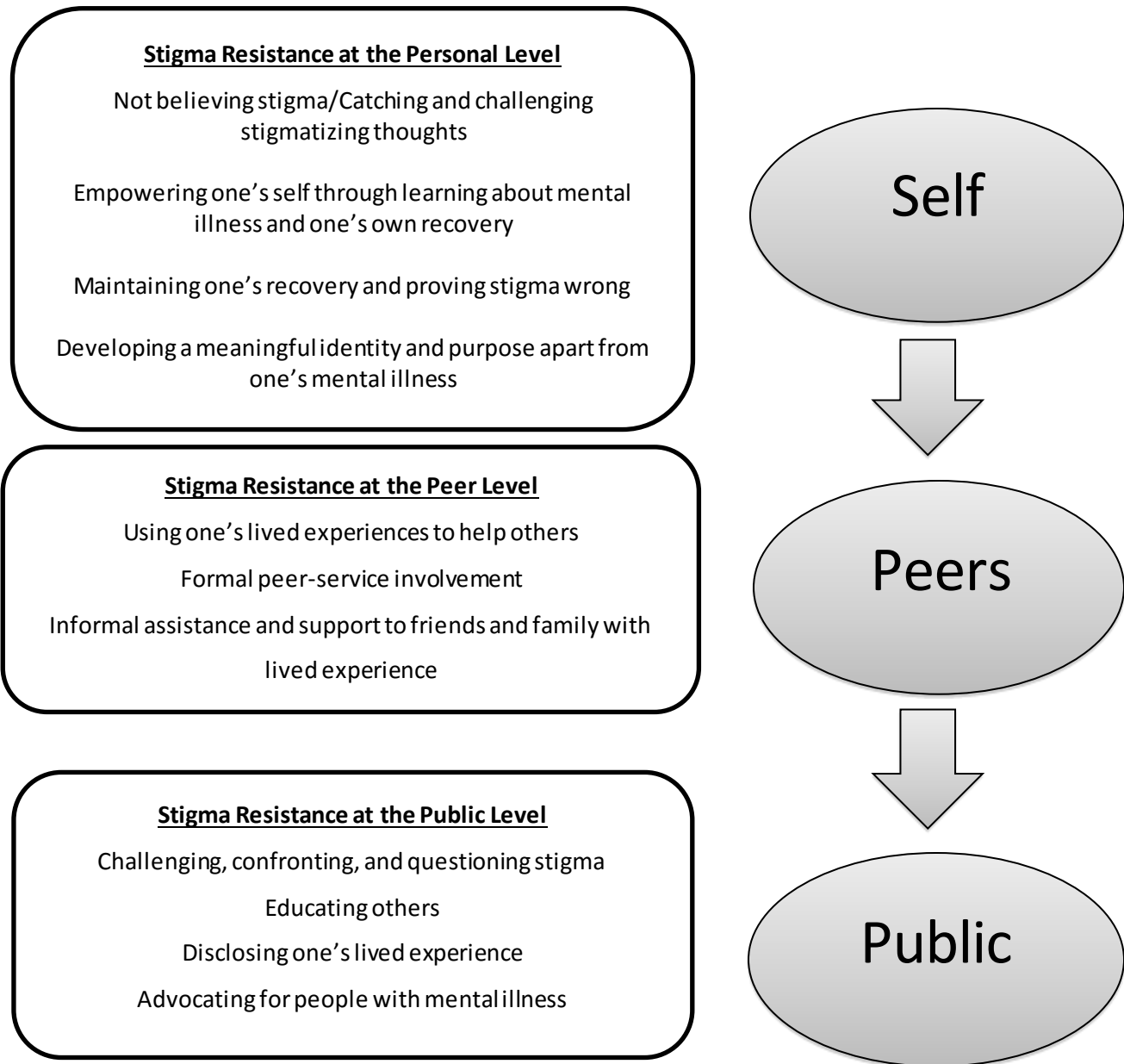


Table 1	
Participant Demographic Characteristics (N = 24)	
Peer-provider	
Yes	14 (58.3%)
No	10 (41.7%)
Gender (% Female)	11 (45.8%)
Black/African American	12 (25.0%)
White	18 (75.0%)
Age	45.3 (6.5; range: 34-63)
Primary diagnosis	
Bipolar	11 (45.9%)
Schizophrenia-Spectrum	8 (33.3%)
Major Depression	3 (12.5%)
Borderline Personality Disorder	2 (8.3%)
Interview date	12/1/14 - 4/24/15
Interview length (minues)	45.3 (11.6; range: 25 – 65)