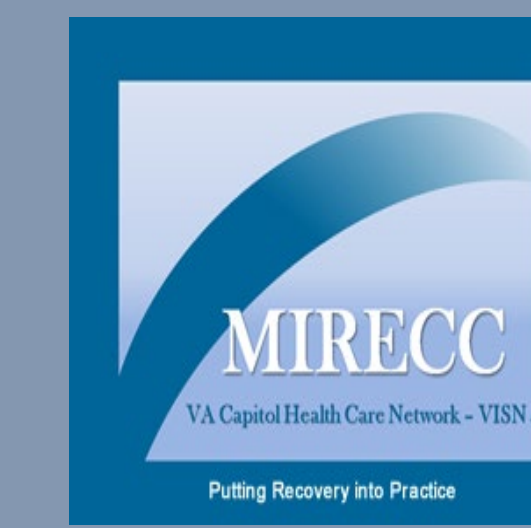




What Helps Coping with Self Stigma: Wisdom from Adults with SMI



Alicia Lucksted, PhD^{1,2} Amy L. Drapalski, PhD^{1,2}

¹ Veterans Administration VISN-5 MIRECC ²University of MD School of Medicine Dept. of Psychiatry

Background

The social stigmatization of mental illnesses and related labels is pervasive, causing profound harm to people's opportunities, morale, well-being, recovery, and quality of life.

Many parts of the picture are well known, including diverse ways stigmatization manifests, various effects, ways to reduce it, and factors to help people navigate experiences with it to best protect themselves from its corrosive effects.

We sought to better understand how these pieces fit together in the lives of such individuals: How do people respond to and get impacted by stigma over their lives and what wisdom do those experiences offer that might help others in similar circumstances?

This study was conducted within the VAMHCS system and all participants were Veterans. This study was supported by VA HSR&D grant 1I01HX000279-01A

Data Collection

During a large VA study testing Ending Self Stigma (ESS), a psycho educational intervention we designed to help adults with mental illness reduce internalized stigma, we interviewed 48 Veterans regarding their experiences coping with stigma over time.

Of the **252** participants in the trial, we randomly selected people 1:1 from the ESS condition and the control group until we interviewed 40 people. We also invited 10 additional participants who had attended less than 4 of the 9 ESS sessions as part of the interview focused on barriers and preferences against attending.

These qualitative interviews were part of the IRB-approved overall study consent process and forms. They took place at the 6 month follow-up time-point, were audio-recorded, lasted **30-90** minutes, and participants were paid **\$30**. We reviewed these and other elements of before each interview.

Data Analysis

Interviews were transcribed by a VA-approved professional, then proofread. First, we prepared a structured summary of each interview transcript, to become closely acquainted with each interview.

Second, we created an initial code list by open-coding 5 transcripts, then improved and refined it with additional interviews until stable.

Third, we coded all interviews in pairs, discussing differences to consensus by the team. This also led to minor code-list refinements.

Fourth, we reviewed all data passages under each code, writing preliminary code summaries re what interviewees collectively said.

Fifth, via extensive team discussion, we considered how ideas captured by each code related to others (interrelationships) and themes overarching multiple codes. = second gen themes memos

Sixth, we used the last 7 interviews transcribed to check step 5, closely examining how they contradicted, added to, or changed our themes. This and further team discussion, led to minor refinements and additional examples but no major changes.

It affects me terribly bad, because they have already judged me, and don't know me. ...and they have already painted the book, before reading the inside.

Even worse, [when] other people say something, you really catch onto... you own it. You know, "yeah, that's me." You're down, and down, and down. And that's not a good place to be; it's a terrible place to be.

The negative perception of one's self really prevents any kind of success, basically. [The stigma that] I'm not good enough, I'll never be able to achieve this... it prevents pretty much any action whatsoever

Gradually, I started realizing something is wrong and mainly I had a stigma against myself. And I finally came to acceptance with myself that I had a problem, but I was still ashamed towards others, with others

...there are up and downs, or ebbs and flows and things like that

That upset me. I said, "You stop telling people I'm crazy..." In other words, I still hold a grudge with him.

Due to some of the education, I recognize a lot of the things are that are going on with me. It makes me a little more aware [and] allowed me to develop positive coping techniques as opposed to a lot of the negative things I was doing.

I go in the tool bag now, [things] that have always kind of like been there. ...Because once you're aware, not saying that self-loathing won't come again, you know, but I've recognized, "wait a minute, come on out of this". You see what this is...so I don't stay stuck as long as I used to.

Sometimes it's so overwhelming because they embrace me as [myself]. They know I'm bipolar. I told them. But they embrace me as more than just a customer. ...as a living, breathing, wonderful person...and that is so enjoyable

It [stigma still] bothers me sometimes, but I'm getting better at it. I'm realizing that I still have to take care of myself, and I still have to consider myself as someone, even though I might have some problems.

