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

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**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.

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**Coping Influences**

Ideally:
- Counter Messages
- Accurate Information
- Learned Coping Skills

- Realizing one has some power in stigma situations
- Reflection: Self/Other
- Self Compassion
- Decisions to Use Skills
- Take Actions, Seek +
- Respite, Safety

- Can develop, change over time

- Outside Hurt + Stigmatization Experiences Actual & Anticipated
- Immediate Reactions
- Emotional Cognitive Behavioral
- Direct Immediate Effects

- Long Term Response And Coping Patterns
- Long Term Effects for Individual and Social Network
- Many participants credit psych rehab, peers, and respectful supportive others as helping them be resilient in the face of stigma

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**Contextual Factors Affect Every Part:**
- Social Environments
- Personal Demographics
- Personality & Coping Styles
- Family & Social Sphere
- Beliefs & Info about MH / MI
- MI experiences, history, symptoms

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**Repeats each instance**

**Long term, patterns, effects influence instance responses**

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**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.**

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**I go in the tool bag now, [things that] have always kind of 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 used to.**

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**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.**

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**If 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.**