

Adapting Disclosure Programs to Reduce the Public Stigma of Mental Illness

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Abstract

A 2016 report from the National Academy of Sciences describes strategies that reduce the stigma of mental illness. Prominent among these are contact between people with and without mental illness and strategic disclosure for lessening both public and self-stigma. The report also recognizes the complexity of stigma in the realm of psychiatric phenomena. As a socially constructed phenomenon, mental illness stigma intersects with race-ethnicity, gender, age, and sexual orientation to affect ways in which it is perceived and experienced. Stigma also differs by condition, such as mental illness versus substance use disorder. Hence, anti-stigma strategies need to actively incorporate diversity concerns into future adaptation. This Open Forum reviews adaptations of the Honest, Open, Proud (HOP) program to reflect adaptation challenges for age and condition. HOP is an evidence-based program that involves strategic disclosure to manage both self- and public stigma. This essay ends with consideration of the additional intersectionality challenges of adaptation.

Adapting Disclosure Programs to Reduce the Public Stigma of Mental Illness

In a 2016 consensus report, the National Academy of Science (NAS) concluded that strategic disclosure is one approach that is effective for decreasing the harmful effects of stigma. As a result, strategic disclosure programs emerged for addressing the public health effects of mental health stigma; Honest, Open, Proud (HOP) is one evidence based approach to strategic disclosure. Rapid fire efforts to develop and evaluate strategic disclosure programs have highlighted the complexity of the task. Stigma is a social construct, defined differently by, among other things, culture, gender, age, and sexual orientation. As a result, strategic disclosure programs like HOP need to be adapted to the local community that seeks to integrate it into its anti-stigma efforts. In this paper, we highlight some of the lessons that emerged in this kind of adaptation.

Stigma and Stigma Change

The NAS report distinguished the stigma of mental illness into public stigma (the discrimination that results when the general public endorses negative stereotypes about people labeled with mental illness) and self-stigma (the loss of self-esteem and self-efficacy when people with mental illness internalize stigma). Public stigma seems to be diminished best by contact-based approaches: interactions between people in recovery from serious mental illness and the general population (Corrigan, Morris, Michaels et al., 2012). Self-stigma is weakened when people with mental illness associate with peers in recovery (Yanos, Lucksted et al., 2015). Both contact and peer association are advanced through selective disclosure (Bos, Kanner et al., 2009). Contact requires people with mental illness

to be out with their stories of recovery. Peer association is easier when people decide to strategically disclose their mental health history.

Honest, Open, Proud (HOP¹) is a three-lesson, peer led group that supports strategic disclosure decisions. Lesson one helps participants consider the pros and cons of disclosing their mental health experiences. Lesson two teaches ways for the person to “test” others, to judge before any disclosure whether the other person is likely to respond positively. Lesson three helps people craft the story of their experiences. Two randomized controlled trials (RCT) showed HOP led to significant reductions in stigma stress and depression (Corrigan, Larson et al., 2015; Rüsch, Abbruzzese et al., 2014). A more recent RCT examined HOP effects on adolescents finding robust benefits on stigma stress, depression, help-seeking intentions, and quality of life (Mulfinger et al., in press). The investigators of the last two RCTs went through an extensive process to adapt HOP for a German speaking audience and for adolescents, illustrating the need for careful adaptation of strategic disclosure programs like HOP for different communities.

Adapting the Program

Adaptation needs to be rooted in community-based participatory research (CBPR) (Minkler & Wallerstein, 2013). CBPR is a set of principles and practices that guide researchers in partnering with a community in developing or adapting a service to meet the needs of that community. Researchers bring expertise in methods and analyses. Community members are the subject matter experts and are especially important going into and coming out of a study. Going in, they guide the CBPR team in lived experience about the problems the team seeks to address and relevant solutions. Coming out, CBPR

¹ HOP was formerly known as ‘Coming Out Proud to Erase the Stigma of Mental Illness’.

team members with lived experience are likely to implement the intervention in real world settings to address their problems. Ownership of the process is essential to subsequent real-world implementation.

Note that the CBPR process is based on research. Hence, the team informs their conceptualizations of stigma and strategic disclosure as a response through qualitative and quantitative investigation. CBPR is a labor-intensive process with team members needing to commit a year or more for adaption of a program to their interests. Examples of HOP adaptations provided in this paper represent fully completed CBPR efforts.

Community is meant broadly here; ethnicity to be sure but also age, gender, SES, and veteran status. These are any groups who may share a common perspective towards mental illness and ways this commonality influences stigma. Community and commonality can be an empirical question. Does a group recognize its commonality vis-à-vis stigma such that it organizes against stigma and for empowerment? Do community members vote with their feet and somehow assemble to address their perspective towards stigma? Nature of the health condition is also likely to define a community. For example, the stigma of mental illness is a markedly different experience than substance use disorder (SUD) (NAS, 2016).

Adapting for Age

The original HOP program was developed to address the stigma concerns of adults with serious mental illness. A CBPR team led by college students adapted HOP based on their research that called for three adaptations. (1) Mental health challenges that emerge in young adulthood often begin in college, especially for students who move away from home. The CBPR team identified disclosing to one's family-of-origin as a key challenge. (2) While HOP focused on disclosure in the work setting, students who informed HOP for

college students were concerned about disclosing to professors and fellow students. (3) HOP for college students noted the complexities of social media and disclosure, a topic absent from the original HOP-adult program. The HOP-college manual also illustrated a recurring value to disclosure decisions. It did not presume to prescribe whether and how an individual student should disclose on social media. Instead, it provides questions which the group uses to identify options. The discussion among peers helps individuals recognize the pros and cons of their individual decisions.

HOP for high school students reflects the HOP-college vision with one major change. HOP-college is led by peers with lived experience, other students in recovery. HOP generally evokes discussion of trauma related to mental health and stigma. In cases where trauma reflects abuse, HOP facilitators working with youth become mandated reporters, required to inform the appropriate government authority of abuse to a minor. Hence, HOP-high school needs to be co-led by an appropriately credentialed professional, typically a teacher or school social worker. This changes the power dynamic typical to other HOP programs where stigma disclosure discussions are led solely by people who themselves have had to make decisions about coming out.

Adapting for Health Condition

The stigma of mental illness is likely to vary by nature of the mental illness (Ebnetter & Latner, 2013). Hence, strategic programs like HOP may need to be adapted for different conditions. For example, HOP has already been adapted to meet the needs of people with Tourette Syndrome, and is currently being adapted for people recently diagnosed with dementia and Autism Spectrum Disorder. In each case, people with lived experience are recruited for the CBPR team that leads the HOP adaptation. Two lessons have emerged from these efforts. First,

who is the person with lived experience that joins the CBPR team? Self-identity, rather than a need to meet DSM criteria for a specific disorder, is clearly the more important requirement. Sometimes there can be a disconnect between diagnostic interview and self-report. Regardless of whether people meet DSM criteria for Tourette Syndrome, do they perceive themselves as troubled by this condition and by its corresponding stigma?

Second, can people with some types of lived experience fully participate in CBPR? A frequent assumption that, for example, the cognitive or social impairments associated with dementia or Autism Spectrum Disorder prevent a person from engaging meaningfully in CBPR reflects the stigma of a condition itself and hence illustrates the need for people with lived experience to be closely involved in program adaptations. Reasonable accommodations are excellent adjuncts to CBPR to help a person with disability join in research and development activities (Hassouneh, Alcala-Moss, & McNeff, 2011).

Intersectionality

People do not neatly sort into individual stigmatized conditions. Work we have done in the Cook County Jail illustrates this issue. “Sure, I’m concerned about the stigma of mental illness. But I also struggle with SUD, am in jail, and HIV-positive. Each of these have equally harmful stigmas.” Social psychologists and sociologists describe this dilemma as intersectionality (Cole, 2009). They believe the experience of multiple stigmas is more than what might be explained by a simple additive model (those with more stigmas are harmed more); and that stigma is moderated by salience, concealability, situation, and peer group. Intersectionality not only poses a conceptual but also a practical challenge for disclosure. Consider county jail inmates with mental illness engaged in HOP. While they might agree that considering costs and benefits of disclosing past mental health experiences is beneficial, they

might be more troubled by the harm of stigma directed at their SUD. On one hand, a value of inclusiveness might suggest engaging anyone, regardless of stigmatised condition, who wants to consider disclosure decisions. However, HOP is based on peers. Can a person with mental illness really meaningfully support the person considering disclosure of their SUD?

Summary

Work on stigma is rightly propelled by a sense of progressivism demanding rapid plans to erase its impact. Strategic disclosure has emerged as one way to realize these goals leading to organized approaches to guiding people in whether and how to come out. This paper means to support these goals but with caution. Stigma is fundamentally a social construct defined by the culture from which it emerges. Hence, approaches to erasing stigma must reflect the local interests of the culture in which they occur. This means, anti-stigma advocates need to adapt programs to meet local needs.