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Diminishing the self-stigma of mental illness by coming out proud

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ABSTRACT

This randomized controlled trial examined the impact of the Coming Out Proud (COP) program on self-stigma, stigma stress, and depression. Research participants who experienced mental health challenges were randomly assigned to a three session COP program ($n=51$) or a waitlist control ($n=75$). Outcome measures that assessed the progressively harmful stages of self-stigma, stigma stress appraisals, and depression were administered at pre-test, post-test, and one-month follow-up. People completing COP showed significant improvement at post-test and follow-up in the more harmful aspects of self-stigma compared to the control group. COP participants also showed improvements in stigma stress appraisals. Women participating in COP showed significant post-test and follow-up reductions in depression after COP compared to the control group. Men did not show this effect. Future research should determine whether these benefits also enhance attitudes related to recovery, empowerment, and self-determination.

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1. Introduction

People who internalize the prejudice of mental illness suffer self-stigma and, as a result, diminished self-esteem (Boyd et al., 2014). Self-stigma and diminished self-esteem may exacerbate depression in people with mental illness (Schränk et al., 2014). Anti-stigma programs that include education (countering the myths of mental illness with facts) and cognitive restructuring (challenging internalized stigma using cognitive behavior therapy approaches) have been developed to decrease internalized prejudice and self-stigma, though outcome research on their impact is unclear (Mittal et al., 2012; Yanos et al., 2014). Alternatively, research suggests people with disorders that are not relatively manifest to the public, such as mental illness and HIV-AIDS, who disclose their experiences report reduced self-stigma (Smith et al., 2008; Bos et al., 2009). Studies show people who are out with their mental illness experience less self-stigma and great quality of life (Corrigan et al., 2010). In this light, advocates believe that strategic disclosure might be taught to people to manage self-stigma (Corrigan et al., 2013). Coming Out Proud is a three session

program facilitated by people with mental illness to teach adaptive aspects of disclosure: pros and cons of disclosure (so people decide for themselves whether to come out), safer ways to come out (if they opt to come out, there are strategies to do so with less risk), and format of one's personal story (get feedback about messages used in one's story). Coming Out Proud (COP) was developed in a multi-year, iterative process led by a steering committee of people with mental illness in Australia, Canada, and the U.S. The program comprises manual, workbook, fidelity instrument, and training plan (Corrigan and Lundin, 2014).

COP was tested with 100 people with mental illness living in Zurich Switzerland, 50 randomized to COP and 50 to a treatment-as-usual condition (Rüsçh et al., 2014). Those assigned to the COP group, compared to control, showed significant reductions in stigma-related stress after three weeks. Pre-post differences for COP compared to control also emerged as decrements in disclosure-related distress and secrecy as well as increased benefits of disclosure. However, no significant interaction was found for self-stigma. Self-stigma in this study was assessed using the Internalized Stigma of Mental Illness Inventory (ISMI), a well-used, omnibus index of self-stigma (Ritsher et al., 2003). The ISMI model has been contrasted to a model that represents self-stigma as four levels of progressively harmful effects on the person (Corrigan et al., 2011; Corrigan and Rao, 2012). Is the person aware of the stereotypes about mental illness? Does the person agree with the

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stereotypes? Does the person *apply* these stereotypes to him or herself? Does application lead to *harm*; e.g., the person experiences diminished self-esteem. Typically, distributions of the four progressively harmful levels start high with relatively more people being aware of stereotypes, and then diminishing thereafter. Awareness reflects Link's (1987) research on perceived, public stigma and its pernicious influence at broad societal levels. Self-stigma then emerges in steps from agreeing with public stigma and applying it to one's self. Neither of these levels necessarily means a person suffers diminished self-esteem (Corrigan and Watson, 2002). The most pernicious effects of self-stigma occur when a person reports harm due to self-applied stereotypes. Perhaps COP effects are pronounced on the more harmful stages of self-stigma which might only be detected with a measure sensitive to all the stages

This paper reports results from a second randomized controlled trial of COP using a measure of the progressively harmful stages of self-stigma. We expect participation in COP to have greatest effects on the self-application and harm levels of self-stigma and fewer effects on awareness, which reflects perceived stigma that reflects population level influences. Similar to Rüschi et al., we expect people who participate in COP to show greater reductions in stigma stress than a comparison group. Reductions in stigma stress correspond with less perceived harm due to stigma and with greater perceived resources to cope with stigma (Rüschi et al., 2014); hence, a measure that captures both harm and coping resources is included in this evaluation too. Finally, this study examined clinical implications of reduced self-stigma and corresponding feelings of less self-worth and self-esteem; namely, is depression reduced in people who complete COP? Because the experience of depression and its treatment varies by gender (Parker et al., 2011), the interaction of gender and COP effects were examined. We expect women with greater rates of depression and more frequent treatment contacts will benefit more from participating in COP.

2. Methods

2.1. Participants

This evaluation was completed as a multi-site study in California using the California network of COP. The network was established after two train-the-trainer sessions were conducted in Northern and Southern California to develop a set of trained COP certified trainers with lived experience. Training is described more fully below. Certified trainers returned to their California community and recruited participants for the study using standardized flyers that stated COP is for people with mental illness "who worry about keeping your mental health condition a secret and/or telling others." Flyers were posted with agencies in which certified trainers worked: community mental health centers, advocacy groups, and drop-in centers. Given that certified trainers and agencies were distributed across the state, we decided to manage recruitment through a central phone contact noted on the flyer. In terms of recruitment, 205 people consented to participate during a central telephone screen and were randomly assigned to COP ($n=107$) or control group ($n=98$). The screen was looking for affirmative answers to: Do you see yourself as a person with mental illness or mental health challenges? Do you feel some sense of shame because of the mental illness or mental health challenges? Those randomized to COP were then informed of site and time of first meeting. Calls and e-mail were sent to remind people about upcoming meetings. Participants were reimbursed for measure completion: pretest (\$10), post-test (\$10), and follow-up (\$30). People gave verbal consent to participate in the study on the

phone that was documented by phone interviewer. People randomized to COP then signed a hard copy of the consent form during the first sessions. Those in the control group signed an e-copy or hardcopy depending on mail/online completion. The project was approved by the IRB at the Illinois Institute of Technology.

2.2. Intervention

Training-the-trainers sessions were two, 8-h days, which combined education and experiential exercises as well as in class evaluations, using the COP manual and workbook (Buchholz and Corrigan 2014; Corrigan and Lundin, 2014). COP comprises three sessions. (1) Facilitate a cost-benefit analysis of disclosure realizing that disclosure varies in different life settings; e.g., the costs and benefits of coming out at work differ from this kind of decision in one's faith-based community. (2) Teach different ways of disclosing, being mindful that some strategies are safer than others. (3) Help the person craft his or her disclosure story combining elements of mental health challenges and recovery. Each session takes approximately two hours and can be done in separate meetings over three days, or one daylong group. Trainers were certified if they exceeded 75% on the COP fidelity measure during training.

2.2.1. Fidelity

COP includes a fidelity checklist corresponding with workbook items for lesson one ($n=75$), two ($n=65$), and three ($n=88$). Research assistants were present in 12 of the 13 community sessions completing the checklist during each session. Frequency of demonstrated items varied by lesson across sites: lesson one (80.5–100%), lesson two (76.0–100%), and lesson three (48.8–100%). Mean frequency across the three sessions for the 12 sites was 94.4% ($SD=6.9\%$). There is not yet an empirically established standard for acceptable COP; we decided not to use fidelity ratings to conduct "as treated" sub-analyses in this paper because of small sample size.

2.3. Outcome measures

After providing demographic information, research participants completed measures of self-stigma; stigma stress appraisals; and depression at pre-test, post-test, and one month follow-up.

2.3.1. Self-Stigma of Mental Illness Scale (SSMIS)

The progressively harmful stages of self-stigma were assessed using the short form of the Self-Stigma of Mental Illness Scale (SSMIS). The short form has five items per scale, which participants answer with a 9-point Likert Scale (9=strongly agree) representing: aware of stereotypes (e.g., "I think the public believes most persons with mental illness are dangerous."), agree with stereotypes ("I think most persons with mental illness are dangerous."), apply stereotypes to self ("Because I have a mental illness I am dangerous.") and suffer harm from self-applied stereotypes ("I currently respect myself less because I am dangerous."). Items were summed for each subscale yielding four indices with higher scores representing greater self-stigma. Both short and long forms of the SSMIS have good reliability and validity (Corrigan et al., 2006, 2012a). Internal consistency for the scales for this sample was also strong (aware: $\alpha=0.84$; agree: $\alpha=0.87$; apply: $\alpha=0.79$; harm: $\alpha=0.86$).

2.3.2. Stigma stress scale

Stigma stress was assessed using a scale adapted from Lazarus and Folkman's (1984) model of stress appraisal (Rüschi et al., 2014). Four items represent the primary appraisal of stigma as harmful

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