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

Patrick W. Corrigan [a,*], Jonathon E. Larson [a], Patrick J. Michaels [a], Blythe A. Buchholz [a], Rachel Del Rossi [b], Malia Javier Fontecchio [b], David Castro [b], Michael Gause [b], Richard Krzyżanowski [b], Nicolas Rüsch [c]

[a] Illinois Institute of Technology, Chicago, IL, USA
[b] Center for Dignity, Recovery, and Empowerment Mental Health Association of San Francisco, San Francisco, CA, USA
[c] Department of Psychiatry II, University of Ulm and BKH Günzburg, Germany

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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.

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 (Schrank 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 pre-judice 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 (Rüsch 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

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 Rüsch 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 (Rüsch 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 (Rüsch et al., 2014). Four items represent the primary appraisal of stigma as harmful

(e.g., "Prejudice against people with mental illness will have a severe impact on my life.") and four items represent the secondary appraisal of perceived resources to cope with stigma-related harm (e.g., "I have the resources I need to handle problems posed by prejudice against people with mental illness.") (Rüsch et al., 2009a, 2009b). Internal consistencies for data from this study were acceptable (stigma harm: $\alpha = 0.90$; coping resources: $\alpha = 0.81$).

2.3.3. Center for Epidemiological Studies Depression SCALE (CESD)

Depression was assessed using the ten item Center for Epidemiological Studies Depression Scale (CESD) (Radloff, 1977; Eaton et al., 2004). Internal consistency for the CESD was acceptable ($\alpha = 0.68$). Consistent with concerns about labels and stigma, we collected no information about diagnoses or related disease course.

2.4. Data analyses

Hypotheses were tested with 2×3 (group by time point) ANOVAs separately for three sets of dependent variables: self-stigma, stigma stress, and depression. We were unable to use an intent-to-treat framework because of the significant loss in participants from randomization to pre-test. Instead, we used an as treated approach, including all participants who completed pre- and post-measures. Post-hoc tests examined group differences between time points in situations where significant interactions emerged.

3. Results

Only 51 of 107 attended COP groups after consenting and completed pre and post-tests; 75 of 98 people in the control group completed pre- and post-tests. Thirteen groups were recruited (n varied from 9 to 22); therefore size of COP groups varied from 4 to 11. All participants in any COP group were also research participants of the study. Unfortunately, no information was obtained on dropouts, so we were unable to test for differences between those who chose to enroll in the study after randomization and those who did not. A post-hoc power analysis with effect size drawn from an earlier meta-analysis (ES=0.45(Corrigan et al., 2012b)) and sample size of 126 yields an observed power of 0.81.

Demographics by group are summarized in Table 1. Overall, the sample was 63.5% female with a mean age of 45.6 years (SD=12.6) overall. In terms of race and ethnicity, 50.0% of the entire sample self-identified as European American, 27.0% as African American, 21.4% as Hispanic/Latino, 7.9% as Asian, 6.3% as Native American, and 1.6% as Pacific Islander. For marital status, 51.6% of the total were single and never married, 7.9% married or with partners, 5.6% widowed, 32.5% separated or divorced, and 2.4% not reporting. For highest attained education, 30.2% had some high school or a high school diploma, 36.5% had some college, 9.5% earned an associate's degree, 11.1% earned a bachelor's degree, 8.7% completed some graduate school or earned a graduate degree, and 4.0% did not respond. Participants showed a varied range of current primary employment with 6.3% reporting full time work, 18.3% part-time work, 2.4% were retired, 4.8% were students, 30.2% were unemployed, 19.8% volunteered, and 18.3% reported other. The sample was 44.4% urban, 27.8% suburban, 19.8% rural, and 7.9% not responding. No demographic differences were found between COP and control groups except for Asian ethnicity; individuals in the control group self-identified as Asian more than the COP group. There were not sufficient Asians in the study to determine whether COP effects differed by ethnicity. Regarding differences between pretest scores on outcome measures across the two conditions there was one significant difference on only one set of scores. Harm due to stress was significantly higher for those randomized to COP.

Table 1
Summaries of demographics by Coming Out Proud (COP) and control groups.

Demographics	COP group, $n=51$ M(SD) or %	Control group, $n=75$	Differences?
Age	46.1 (1.78)	45.23 (12.76)	$F(1,119)=0.14$, n.s.
Gender	Female=70.6%	58.7%	$\chi^2(3)=0.24$, n.s.
	Male=25.5%	34.7%	
	Transgender=0	4.1%	
	Not answered=3.9%	2.7%	
Ethnicity	European American=52.9%	48.0%	$\chi^2(1)=0.29$, n.s.
	African American=25.5%	28.0%	$\chi^2(1)=0.09$, n.s.
	Hispanic/Latino=24.0%	20.0%	$\chi^2(1)=0.28$, n.s.
	Asian=2.0%	12.0%	$\chi^2(1)=4.19$, $p<0.05$
	Native American=3.9%	8.0%	$\chi^2(1)=0.85$, n.s.
	Pacific Islander=0	2.7%	$\chi^2(1)=1.38$, n.s.
Marital status	Single=57.1%	50.0%	$\chi^2(5)=3.64$, n.s.
	Married=8.2%	5.4%	
	Partnered=0	2.7%	
	Widowed=6.1%	5.4%	
	Separated=4.1%	10.8%	
	Divorced=24.5%	25.7%	
Education	Some high school=10.2%	15.3%	$\chi^2(3)=12.2$, n.s.
	High school diploma=22.4%	15.3%	
	Some college=24.5%	47.2%	
	Associate's degree=18.4%	4.2%	
	Bachelor's degree=12.2%	11.1%	
	Some grad school=2.0%	1.4%	
	Grad degree=10.2%	5.6%	
Employment	Full time=8.5%	5.6%	$\chi^2(3)=2.26$, n.s.
	Part time=14.9%	22.2%	
	Retired=2.1%	2.8%	
	Student=6.4%	4.2%	
	Unemployed=34.0%	30.6%	
	Volunteer=23.4%	19.4%	
	Other=10.6%	15.3%	
Urban/rural	Urban=52.1%	45.6%	$\chi^2(2)=0.52$, n.s.
	Suburban=27.1%	32.4%	
	Rural=20.8%	22.1%	

Note. Multiple chi squares are reported for ethnicity because participants could endorse multiple categories; i.e., individual ethnic group endorsements are not independent of each other.

Impact of COP on the four levels of self-stigma is summarized in Fig. 1. As found in previous research, endorsement in stages diminished as those stages became more harmful. People reported greater awareness of stigma; agreeing with stereotypes was less commonly endorsed. Far fewer people applied stigma to themselves or expressed harm in self-esteem as a result. Change in self-stigma across groups was not found to interact with gender.

We expected COP to have greater effects on the personally detrimental aspects to self-stigma: applying stereotypes to one's self or admitting harm through diminished self-esteem. To examine differences, 2×3 (group by time point) ANOVAs were completed for each of the four self-stigma levels. Change in harm was greater for COP and control, although this difference is supported by a non-significant trend ($F(2,98)=2.66$, $p<0.10$). Post-hoc tests showed no significant changes in the control group but significant reductions in harm from pre to post-test ($F(1,44)=6.49$, $p<0.01$) and pre to follow-up ($F(1,44)=3.95$, $p<0.05$) for those who participated in COP. A significant interaction was found for change in applying stereotypes to self across groups ($F(2,98)=3.74$, $p<0.05$). People in COP showed a significant reduction in applying stereotypes to self from pre to post-test ($F(1,44)=6.67$, $p<0.05$), an effect still evident at one month follow-up ($F(1,42)=6.98$, $p<0.05$). We also completed 2×3 ANOVAs to examine specific effects of COP versus control on agreeing with stereotypes and
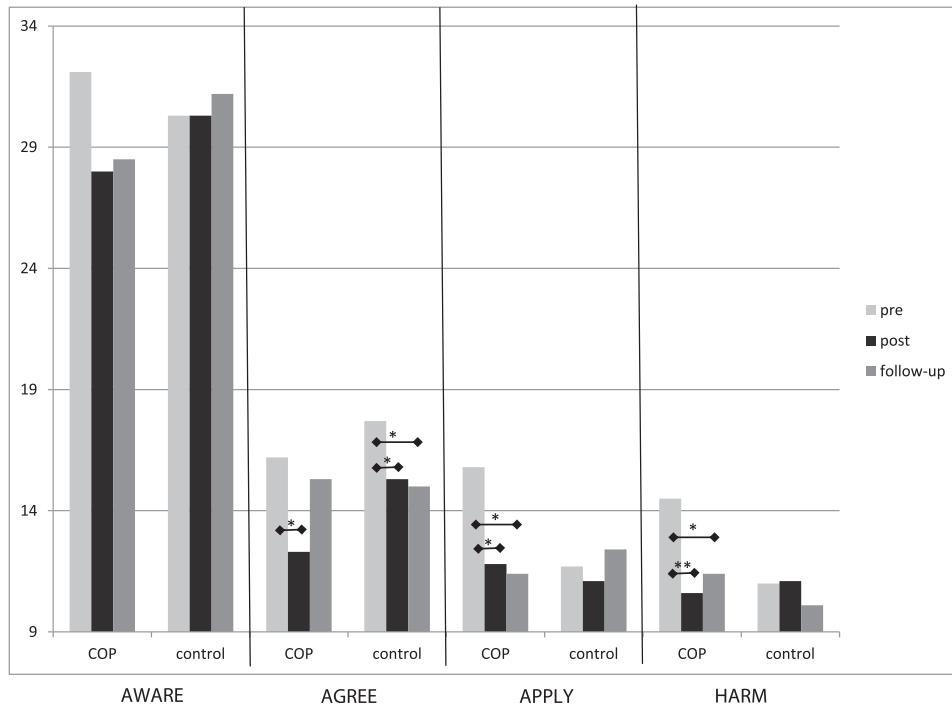
Fig. 1. Means of pre, post, and follow-up scores across Coming Out Proud (COP) and control groups for the four levels of the regressive model of self-stigma: agree, aware, apply, and harm. $\pm p < .10$; $* = .05$; $** = .01$; $*** = .001$.

being aware of them. A significant interaction was found for agree ($F(2,95) = 5.75$, $p < 0.01$). Post-hoc analyses on agreement reveal an improvement in COP participants as well as a in the control group. One-way repeated measure ANOVAs were significant between pre- and post-test for both COP ($F(1,43) = 6.04$, $p < 0.05$) and control groups ($F(1,66) = 3.69$, $p = 0.05$). However, while follow-up agreement scores returned to baseline for the COP group ($F(1,41) = 0.39$, n.s.), they remained significantly different from baseline for the control group ($F(1,58) = 3.70$, $p = 0.05$). The group by time interaction for awareness scores was non-significant ($F(2,95) = 1.78$, n.s.)

Changes in stigma harm and coping resources were not found to interact with gender. Fig. 2 summarizes pre, post, and follow-up scores across groups for stigma stress appraisals. Results of a 2×3 ANOVA (group by time point) for stigma-related harm yielded a significant interaction ($F(2,98) = 4.23$, $p < 0.05$). No changes were evident in the control group. A non-significant trend suggested decreased stigma-related harm from pre- to post-test in the COP group ($F(1,44) = 3.02$, $p < 0.10$). Moreover, stigma harm decreased significantly from pre to follow-up ($F(1,43) = 8.45$, $p < 0.01$) yielding a small effect size (0.16). Results of a 2×3 ANOVA for resources to cope with stigma were non-significant ($F(2,98) = 1.42$, n.s.).
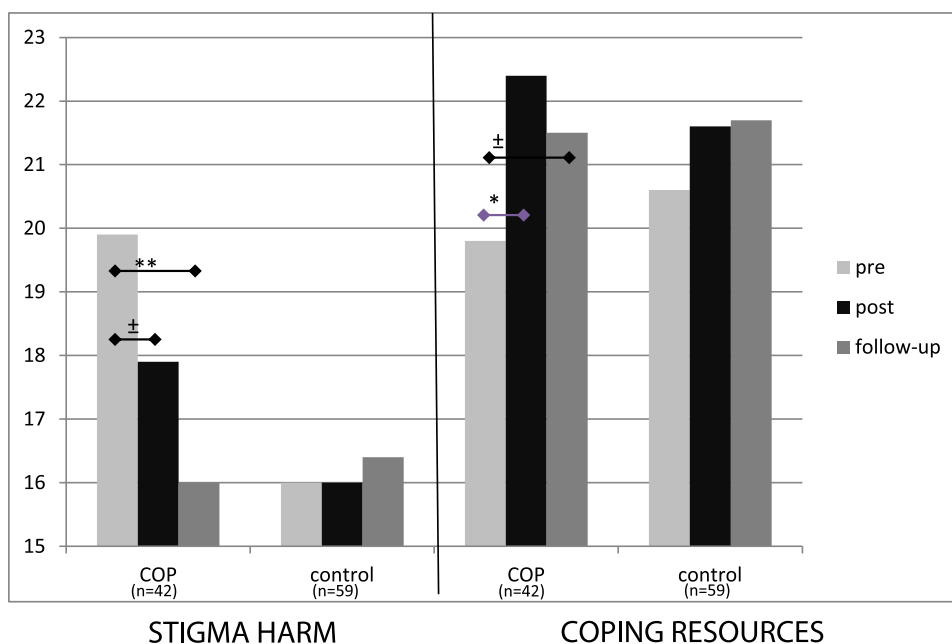

Fig. 2. Means of pre, post, and follow-up scores across Coming Out Proud (COP) and control groups for perceived stigma-related harm and perceived resources to cope with stigma. $\pm p < .10$; $* = .05$; $** = .01$; $*** = .001$.
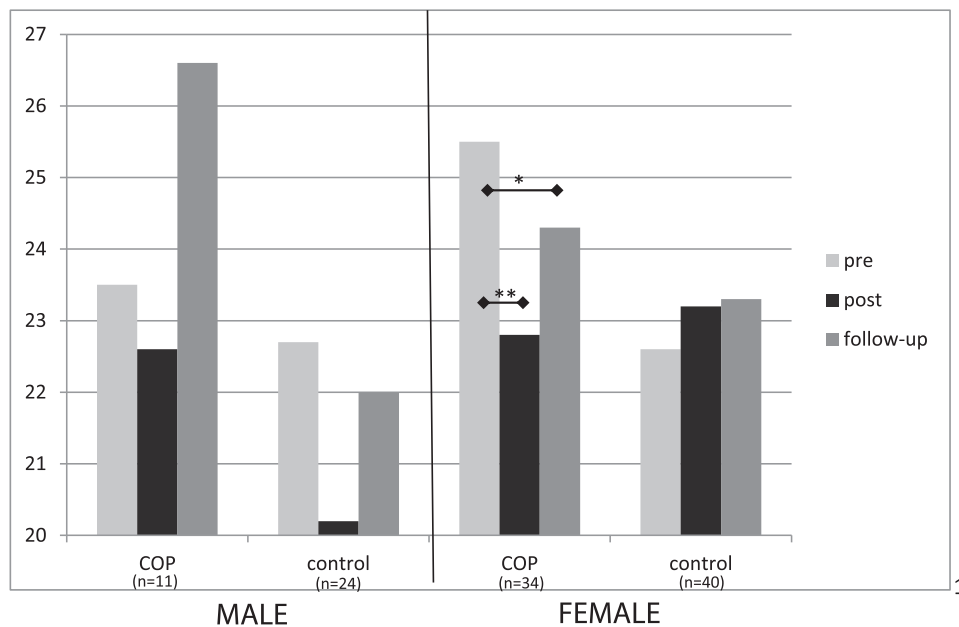
Fig. 3. Means of pre, post, and follow-up scores across Coming Out Proud (COP) and control groups for depression; these are split by gender. $^{\pm}p < .10$; $^{*}=.05$; $^{**}=.01$; $^{***}=.001$.

However, a one-way repeated measures ANOVA showed significant increase in coping resources from pre to post-test for those in the COP group ($F(1,44)=5.30$, $p < 0.05$; E.S.$=0.11$); a non-significant trend suggested follow-up coping resources were larger than pretest ($F(1,43)=2.74$, $p=0.10$).

As expected, COP's effects on depression as measured by the CESD interacted with gender and are summarized in Fig. 3. They are complex with the left half of the figure representing pre, post, and follow-up changes in stigma between groups for males, and the right for females. An overall $2 \times 2 \times 3$ ANOVA (group by gender by time point) yielded a significant interaction ($F(2,93)=5.47$, $p < 0.01$). Specific nature of these interactions was examined by gender. Results of a 2×2 ANOVA failed to find a significant interaction for men ($F(1,33)=1.75$, n.s.). However, a significant group by time interaction was found for women ($F(1,72)=7.66$, $p < 0.01$). Depression decreased significantly from pre to post in the group of women who completed COP ($F(1,33)=8.15$, $p < 0.01$). This yielded a small effect size of 0.20. Also, follow-up depression for women in COP was significantly less than baseline ($F(1,32)=4.60$, $p < 0.05$).

4. Discussion

Participating in Coming Out Proud had several benefits. People who completed COP showed significant improvement in the more harmful stages of self-stigma. A significant reduction in self-stigma harm was found between pre and post-test, and still evident at follow-up. Similar improvement was found for applying stereotypes to one's self: significant reduction from pre to post-test as well as pre to follow-up. Findings regarding stigma agreement were a bit more difficult to interpret with both COP and control groups showing significant reductions from pre to post; pre to follow-up was also significantly reduced for control group. This may represent a social desirability effect; agreement with stereotypes often decreases after repeated questions so a person does not appear to be prejudiced (Corrigan and Shapiro, 2010). No changes were evident in being aware of stigma, which also makes sense; cognizance of public stigma does not typically change over time.

Compared to the control group, people completing COP showed

significant improvements in stigma stress appraisals from pre to post and pre to follow-up. One method to reduce stress includes learning strategies to *prepare* for situations triggering stressful reactions. During COP, people may learn new and multiple methods to approach the complexity of disclosure thereby reducing the impact of stigma as a stressor when faced with disclosure decisions. Findings suggested research participants experienced stereotypes and prejudice of others as having less negative impact on them. People in COP showed significant post-test and follow-up improvements in stigma resources compared to the control group. They may increase stigma resources by learning decision making tools for disclosure, practicing disclosure options in various contexts, and crafting individual stories. This may also reflect greater resilience to stigma, rather than being victimized by it. Developing group unity around lived experiences potentially increases personal resilience to the negative influence of stigma and self-stigma. Furthermore, COP may build personal strength and resilience through people developing and sharing their own interpretations of life experiences rather than allowing others to define life experiences for them.

As hypothesized, gender was found to interact with COP benefits on depression as hypothesized. Women who completed COP reported significantly less depression on the CESD at post-test and follow-up while no change was found for women in the control group. Depression scores, however, were more complex for men. Although no significant interaction was found for men in the two groups, a large reduction was found for men in the control condition. This may have represented the kind of spontaneous remission from depression commonly found in people with mental illness. These, of all findings in the study, need to be replicated in future research.

There are limitations to the study that need to be considered in future research. We used a central phone screen to coordinate the multi-site study across the state of California. Unfortunately, this led to significant problems in recruitment and assignment. More than half of participants assigned to COP never entered the study after assignment. This may have reflected tactical error in plans to help people move from assignment to group participation. Anecdotally, some did not participate in COP because of exacerbation of symptoms or travel difficulties. This problem was not limited to

prospective COP participants, however. About a quarter of those in the control group also failed to complete measures even though their data were collected on line or by regular mail. This may reflect a general problem with research on peer support and self-help. People unmotivated to seek peer services are unlikely to engage in evaluation efforts (Corrigan and Salzer, 2003). These recruitment problems may have implications for making sense of the findings. Perhaps, for example, people who chose to come to COP, compare to the control, were skewed for greater self-stigma and stigma stress. Significant differences could represent regression to the mean. Future research needs to use randomization methods that better link screening, pretest assessment, and assignment to group.

Problems with study recruitment may have led to biases across groups. Unfortunately, data that might distinguish participants from dropouts were not gathered. Only one significant difference existed between groups in demographics (Asian ethnicity) and outcome variable (stress-related stigma harm). The study also failed to collect information about diagnosis and course of illness. As a result, we are unclear about how participation affected different groups of people with psychiatric problems. Future research needs to include indices like these for both representation and post-hoc tests to determine whether COP impact varies with any psychiatric phenomena.

Subsequent studies should also examine impact of self-stigma and depression change on the more affirming constructs embodied in the recovery model. How does hope and personal empowerment change as a person completes COP? Are participants more likely to endorse notions of self-determination? Another egregious outcome of self-stigma has been labeled the why try effect (Corrigan et al., 2009; Corrigan et al., in press). People who internalize stigma suffer diminished self-esteem and self-efficacy undermining their pursuit of goals. Why try to pursue a job; I am not able? Why try to live independently; I am not worthy? Future research should determine whether change in self-stigma leads to more optimism about the pursuit of work, independent living, and other important life goals. Findings representing one-month follow-up were encouraging. But, subsequent research needs to examine even greater follow-up to understand enduring outcomes.

Where does the person who benefits from COP go next? Some concerned about replacing self-stigma with personal empowerment might want to engage in peer support. Research suggests those engaged in mutual support and other peer services are less likely to be plagued by stigma and more likely to endorse recovery over time (Lloyd-Evans et al., 2014). In fact, COP ends session three with a brief discussion of peer services in participant communities. Others might wish to channel their new confidence by tackling the public stigma of mental illness through participating in contact-based programs. Research suggests public prejudice decreases when the population interacts with people telling their recovery stories (Corrigan et al., 2012b). Joining peer services or contact services may be additional outcomes for COP future research.

Crafting the story in COP may have benefits too. In many ways, this parallels narrative enhancement strategies meant to diminish self-stigma (Yanos et al., 2010). These strategies are based on theory that suggests one's identity congeals as narratives, cogent stories about one's self. These stories, and hence one's sense of self, can be undermined by cognitive distortions that reflect stigma. Narrative enhancement interventions are typically conducted among groups of peers where participants construct personally useful narratives of self, illness and self in relation to illness. Future research needs to examine the relative impact of narrative enhancement in COP.

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