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The Impact of Self-Stigma and Mutual Help Programs on the Quality of Life of People with Serious Mental Illnesses

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Abstract

Mutual help programs (MHPs) are informal services developed and operated by people with serious mental illnesses for peers with these illnesses. We expect MHPs to have positive effects on quality of life and inverse associations with self-stigma. We hypothesize group identification and social support to be key ingredients that lead to MHPs benefits and hence to also be significant correlates. Eighty-five people with serious mental illness reported current and past MHP experience and completed self-report measures of quality of life, self-stigma, group identification, and social support. Self-stigma was shown to be a significant and large correlate of quality of life. Satisfaction with current and past MHP participation was also associated with quality of life. Group identification and satisfaction with one's support network were significantly and largely associated with MHP satisfaction. MHPs are a specific example of the broader category of consumer operated services which also include drop-in centers and education-for-advocacy programs. Findings about group identification will inform ongoing development of MHPs and consumer operated services, as well as evaluation of these programs.

The stigma of mental illness harms people in many ways. One is self-stigma's effects on quality of life (Corrigan et al., 2010; El-Badri & Mellso, 2007; Staring, Van der Gaag, Van den Berge, Duivenvoorden, & Mulder, 2009). Consistent with a well-studied model of self-stigma, people who agree with the stigma of mental illness and apply it to themselves suffer lowered self-esteem and self efficacy (Corrigan, Watson, & Barr, 2006; Watson, Corrigan, Larson, & Sells, 2007) which corresponds with less satisfaction in important life domains including work, housing, relationships, and spirituality. Research has defined quality of life as satisfaction across life domains like these (Lehman, 1999; Price et al., 2008). Mutual help programs (MHPs) are thought to enhance quality of life. They are examples of consumer operated services which are developed and conducted by people with serious mental illness for their peers (Clay, Schell, Corrigan, & Ralph, 2005). Results of a multi-state SAMHSA-funded study suggested MHPs might be focused on educational, advocacy, and/or interpersonal concern (Campbell, 2005). Key to MHPs is the helper principle; program participants not only benefit from sharing with and learning from others but also from offering assistance to peers. The experience of shared help is found to bolster a person's esteem, hope, and confidence in one's self (Corrigan et al., 2005; Hsiung et al., 2010; Maton, 1989).

Improved self image corresponds with enhanced personal empowerment, perceptions that the person is able to determine his or her goals and the means to achieve those goals (Lundberg, Hansson, Wentz, & Björkman, 2009; Rusch et al., 2006; Watson et al., 2007). Elsewhere, we argued that personal empowerment is at the opposite end of a continuum defined by self-stigma. Namely, people high on a sense of personal empowerment report low self-stigma (Watson et al., 2007). Hence, we would expect MHP participation to be inversely associated with self-stigma and positively related to quality of life.

What is it about MHPs that might impact this association? Two sets of variables are relevant. First, mutual help seems to be associated with group identification. We use a definition of group identification from social psychology; the degree to which individuals describe themselves as or feel attached to an ingroup (Correll & Park, 2005; Tyler, 2001). The relationship with group identification might suggest it is wise for people to distance themselves from “stigmatized” groups that are publicly labeled with mental illness. Prior research, however, has found just the opposite. People with serious mental illness who identify with peer groups report less self-stigma (Corrigan, 2006; Corrigan et al., 2005; Hatzidimitriadou, 2002). A second important element of MHP impact is social support. Peer-based groups offer the potential for extending one’s network of people who might be availed for ongoing social exchange and intimacy. Research on social support is vast and complex; one body of research suggests it is not the size of the network (number of friends and family members) that leads to positive gains but satisfaction with it (Sarason, Sarason, & Pierce, 1990). Research on people with serious mental illness has shown satisfaction with one’s social support is related to self-esteem (Rogers, Anthony, & Lyass, 2004), recovery (Corrigan & Phelan, 2004; Hendryx, Green, & Perrin, 2009), subjective well-being (McCorkle, Rogers, Dunn, Lyas, & Wan, 2008; Mowbray, Bybee, Hollingsworth, & Oyserman, 2005) and mental health service use (Lam & Rosenheck, 1999). Research also suggests MHPs enhance social support (Mok, 2004; Mueller et al., 2006; Schutt & Rogers, 2009). A second goal of this study is to replicate these findings; examine the relationship of MHP participation with group identification and social support.

As we said, MHPs are complex constructs. In addition to type of MHP, quality of experience is also important to consider. “Experience” might be current or previous; impact of both are examined herein. Similar to our hypotheses about social support, we do not expect whether the person has had MHP experience to be the operative variable, but the person’s satisfaction with the program. Hence, we expect to show people satisfied with their MHP participation will have diminished self-stigma and improved in quality of life. We also expect that MHP satisfaction will correspond with group identification and social support.

Methods

Eighty-five persons with schizophrenia or other psychiatric disorders were recruited at mental health service centers in the Chicago area; this is a sufficiently powered sample given effect sizes found from previous research (cf Corrigan, 2005). Reported here are findings from a subset of the data; see Rüsch et al. (2009a) for a more complete description of the project. Research participants had at least an eighth grade reading level as assessed by the Wide Range Achievement Test (Wilkinson & Robertson, 2006). Axis I diagnoses were made using the Mini-International Neuropsychiatric Interview (Sheehan et al., 1998) based on DSM-IV criteria. All research participants were fully informed about the study and provided written consent. The protocol received approval from the institutional review board of the Illinois Institute of Technology and the community-based rehabilitation programs from which individuals were recruited.

Subjects completed self-report measures of psychological state which were administered in face-to-face interviews by fully-trained graduate students in clinical psychology. Self-stigma was assessed using the Internalized Stigma of Mental Illness Scale (ISMIS) which contains 29 Likert items rated on a 4-point agreement scale (4 = strongly agrees) (Ritsher, Otilingam, & Grajales, 2003; Ritsher & Phelan, 2004). The ISMIS contains 5 subscales: alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance. We used an overall score (the sum of all items with stigma resistance items being reversed) for the analyses in this study. Previous research has shown it to have good test-retest reliability and concurrent validity (as assessed against parallel measures of stigma) (Ritsher

et al., 2003; Ritsher, & Phelan, 2004). Data from our study showed its internal consistency was .88; higher scale scores meant greater self-stigma. The obverse of self-stigma is personal empowerment which we assessed using the Empowerment Scale (ES; Rogers, Chamberlin, Ellison, & Crean, 1997). The ES consists of 28 items that measure self-esteem, powerlessness, community activism, righteous anger, and optimism about the future. Items are scored on a 4-point Likert scale, with 4 indicating strong disagreement. It too has good test-retest reliability, internal consistency, and construct validity (Corrigan, Faber, Rashid, & Leary, 1999; Rogers et al., 1997, 2010). In order to obtain an overall scale index, several items were reverse scored, and then all items were averaged. Lower scores represent greater empowerment.

We proposed quality of life as a consequence of self-stigma. Research on quality of life has shown it to be a complex idea with some research defining it both as standard of and satisfaction with living domains (Price et al., 2008; Skantze, Malm, Dencker, May, & Corrigan, 1992). We used the latter, largely psychological definition based on satisfaction herein because standard of living is often influenced by SES and other societal factors (Lehman, 1999). We assessed the construct using 17-items of the Quality of Life Interview (Lehman, 1988) which has been used in more than 50 peer-reviewed studies and shown to have good internal consistency, test-retest reliability, and concurrent validity with parallel constructs. Higher scores indicate better quality of life (Cronbach's $\alpha=.91$ for our data).

Research participants were asked to report on mutual help, specifically to report current and past experience with these kinds of programs as well as amount of weeks, months, and years of prior experience. Mutual help was defined for participants as "a group for people with mental illness that is run by people with mental illness." Two sets of MHP scores were used for the analyses reported here. First, categorical variables represented yes or no regarding whether the person currently or in the past ("I have previously participated in mutual help groups for people with mental illness.") has participated in MHPs. Answering affirmatively on current or past experience, research participants then reported their satisfaction with said participation on a nine point scale with 9 being very satisfied.

We hypothesized that group identification and social support were components of mutual help. Group identification was measured using five items adapted from Jetten and colleagues (2001) to which research participants responded with a seven point agreement scale (7 = strongly agree): "I feel strong ties with the group of people with mental illness." Higher scores reflect more group identification. Up to now, the scale had largely been used in social psychological studies and shown to support many of the conceptual models it was meant to test (cf Correll & Park, 2005; Tyler, 2001). The group identification scale had not previously been examined in samples of people with serious mental illness. However, our data showed good internal consistency; Cronbach's α for the data was .85 for a total score.

Two items were included in the interview to assess social support based on Blake and McKay (1986). This instrument defined social support in terms of "people you have near you who you can readily count on for help in times of difficulty." First, research participants reported the number of people they have in this role. Next they reported their degree of satisfaction with their overall social support network. They responded to the second item using a 9-point Likert satisfaction scale (9=extremely satisfied).

Data Analyses

Analyses were conducted using SPSS for Windows with a significance level of $p < .05$ for all analyses. Pearson product-moment correlations were completed to examine relationships between all hypothesized predictor variables and the outcome variable, quality of life. These

correlations were also completed to examine relationships among indices of MHP participation, self-stigma, group identification, and social support.

Results

Participants were, on average, 44.8 years old ($SD=9.7$), had a mean age of 13.5 years of education ($SD=2.3$), and were 68% male. More than half (58%) were African American, about a third (34%) Caucasian, 5% Hispanic or Latino (5%), and 4% mixed or other ethnicities. Twenty-three (27%) participants met criteria for schizophrenia, 22 (26%) schizoaffective disorder, 30 (35%) bipolar I or II disorder, and 10 (12%) recurrent unipolar major depressive disorder. Findings from the interviews showed 48.2% ($n=41$) of subjects currently participated in mutual help programs, 51.8% ($n=44$) had done so in the past. Twenty-five of 85 research participants (29.4%) had both current and past experience. Current and past MHP participation were not found to be highly related to each other ($r=.13$, $n.s.$). Current and past satisfaction ratings were highly associated; $r=.40$, $p<.05$. Therefore, we used a single index of satisfaction for the remainder of the analyses which was the mean of the two ratings.

None of the demographic variables were found to differ across yes-no groups of current and of past program participation. Empowerment was inversely and highly associated with self-stigma supporting one hypothesis ($r=-.68$, $p<.001$); the size of this correlation, however, suggests significant collinearity that may confound additional analyses. Also note that personal empowerment was not significantly associated with satisfaction with current ($r=.01$) or past ($r=.13$, $n.s.$) participation in mutual help programs. For these reasons, only self-stigma remained in subsequent statistical tests.

Table 1 summarizes Pearson product moment correlations. The first column of indices shows quality of life and the other measures of psychological state all to be highly associated with p -values less than .01 for all indices. Note the size of some of these correlations; for example, the inverse relationship between self-stigma and quality of life accounted for 44.9% of the shared variance. Support satisfaction was highly associated with quality of life as was size of the support network; the latter finding was contrary to our assumptions. Support network size and satisfaction was also significantly associated with each other ($r=.49$, $p<.001$). Despite this collinearity, results of a multiple regression showed size and satisfaction were significantly and independently associated with quality of life (beta was .41 and .30 respectively, $p<.005$). R^2 for this analysis was .61.

The first row of indices in the Table summarizes correlations between quality of life and the indices of MHP participation. Quality of life was not found to be significantly associated with yes or no responses to questions about past or current MHP participation. However, satisfaction with MHP participation was highly correlated with quality of life with R^2 equal to 21.2%. Table 1 also summarizes the association between MHP satisfaction and its hypothesized components: group identification and social support. Note that size of correlation indices needed to be higher in this column than for the other analyses because the N of these analyses was lower. The r for group identification and MHP satisfaction was highly significant ($R^2=.48$). Size of social support network was not found to be associated with the mean MHP satisfaction score, though social support network satisfaction was and accounted for 38.4% of the shared variance which makes sense; these are different sides of the same construct.

Table 1 also provided the correlations among the categorical yes/no indices of current or past participation and the other measures. Note that correlations between yes/no indices and mean program satisfaction were missing because satisfaction ratings were nested with

affirmative answers to the current or past participation; i.e., people who said they had not currently or previously participated in mutual help programs cannot then rate their satisfaction with the programs. Only one of the remaining ten correlations was significant, suggesting yes-no response to experience was not a sensitive index for testing our hypotheses.

Discussion

Findings from this paper suggest satisfaction with participation in mutual help programs and decreased self-stigma impact quality of life. Findings from the study replicated previous assertions about self-stigma having a significant and large, inverse effect on quality of life. In fact, results suggested self-stigma to be the single greatest predictor of quality of life among the various measures included in the study to assess psychological constructs. About half of research participants were currently or had previously participated in MHPs. Almost thirty percent had done both. Although participation in MHP *per se* was not found to be associated with quality of life, satisfaction with these programs was. We found the mean of satisfaction ratings for current and past MHP participation to yield the most stable index which was then included in remaining analyses. Mean satisfaction with MHP participation was significantly associated with quality of life accounting for more than 20% of the shared variance.

We also proposed group identification and social support as important components of MHP participation. Correlations showed both variables were highly associated with MHP satisfaction with R^2 s over 38%, findings that correspond with our assertions about group identification and social support as important correlates of MHP satisfaction. Group identification was significantly associated with quality of life. In addition, both size and satisfaction with social support were found to significantly and independently account for quality of life, sharing more than 60% of the variance. This seems to suggest that recovery for many people with serious mental illness is enhanced by recognizing and engaging peers rather than trying to distance themselves from similarly stigmatized others in order to avoid the pernicious labels. The finding has implications for development of MHPs. Strategies that enhance identification should improve positive effects of mutual help. These may include ways to reframe perceptions of one's group that clash with personal values (Glasford, Dovidio, & Pratto, 2009) and social creativity approaches that enhance positive images of the group (Jetten, Schmitt, Branscombe, & McKimmie, 2005). These findings are from the basic social psychology literature and parallel another analysis of the data herein; namely, more valued groups foster greater group identification (Rusch et al., 2009b).

There are limitations to interpreting these findings. Descriptions of MHP participation in this study lacked depth of experience. Namely, we might expect positive benefits of MHPs to increase with amount of participation. As evident from other services research, amount of participation in a program is a complex construct. It might be operationalized as number of weekly meetings. But this assumes that MHPs can be defined as hourly meetings every seven days. MHP effects are probably not limited to formal, in-group, interactions. Members of MHPs often encourage spontaneous exchanges after or away from meetings. MHP participation effects are probably not limited to linear models. We expect some members show a simpler direct relationship -- those who go more do better -- while benefits for others result from an irregular pattern of attendance and engagement.

These findings were cross-sectional. Assertions about causality would be stronger in future research if done in a time-lagged fashion. We would hope to find, in this subsequent kind of study, that Time 1 measurement of self-stigma and MHP satisfaction is significantly associated with Time 2 quality of life. Also absent from these analyses were measures of

psychiatric symptoms. Depression, in particular, might confound our findings because it probably interacts with self-stigma and quality of life (Corrigan & Watson, 2005). In a related manner, this was a diagnostically heterogeneous sample of people with serious mental illness. However, N was not sufficiently large to examine diagnostic effects on the study's hypotheses. In fact, N may have been too small to test a variety of hypotheses so a follow-up study with bigger N is needed to replicate findings. The study also lacked a comparison group, thereby undermining the ability to tease out effects of the intervention *per se*. Future research should include such a comparison.

MHPs were offered as a form of consumer operated service (COS); future research needs to examine the range and impacts of COSs. A large SAMHSA-supported RCT on COSs divided these services into three models (Clay et al., 2005): drop-in centers, education-for-advocacy programs, and peer support programs which are similar to MHPs as defined here. The same study developed a COS fidelity scale based on extensive participatory action research with the consumer arm of its steering committee (Johnsen, Teague, & McDonel Herr, 2005). The fidelity scale listed several key components which individual COSs might incorporate including flexibility to current needs and desires of participants, a recovery and empowerment base that promotes self-determination, informality, openness to spiritual development, encouragement of humor and creativity, and advocacy inclinations. Although some of these components sound nebulous, the fidelity scale included operationalized and empirical indicators essential for careful measurement of these components. In sum, these various ideas provide guidance for the continued development of COSs in general, and MHPs in particular. They also yield hypotheses and methods to test the ongoing development of these kinds of programs.

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Table 1

Pearson product moment correlations between satisfaction with current and past participation in mutual help programs (MHPs) and measures of quality of life, group identification, self-stigma, and social support.

	quality of life of entire sample (n=85)	current MHP participation: yes/no (n=41)	past MHP participation: yes/no (n=44)	mean MHP participation satisfaction (n=25)
quality of life	1.0	.06	.15	.46 **
self-stigma	-.67 ***	.09	.11	-.25
group identification	.27 **	.43 ***	-.02	.69 ***
size of social support network	.55 ***	.12	.02	.18
satisfaction with social support network	.49 ***	.09	-.03	.62 ***
mean MHP satisfaction	.46 ***			1.0

Note: Significance of specific tests varies by number of subjects who completed the two measures in that test.

*
p<.05

**
p<.01

p<.005