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Determinants of Engagement in Mental Health Consumer-Run Organizations

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Abstract

Objective—Mental health consumer-run organizations (CROs) are a low-cost, evidence-based strategy for promoting recovery. To increase CRO utilization, characteristics that promote engagement need to be identified and encouraged. The study examined individual and organizational characteristics that predict three types of engagement in CROs—attendance, leadership involvement, and socially supportive involvement.

Methods—Surveys were administered to 250 CRO members attending 20 CROs. Leaders of each CRO reported organizational characteristics through a separate questionnaire. Multilevel regression models examined relationships between predictors and indicators of CRO engagement.

Results—Perceived sense of community was the only characteristic that predicted attendance as well as leadership involvement and socially supportive involvement. Perceived organizational empowerment, shared leadership, peer counseling, and several demographic characteristics also predicted some measures of engagement.

Conclusions—CROs that can effectively promote sense of community, organizational empowerment, shared leadership, and peer counseling may be better able to engage participants. The discussion considers several strategies to enhance these characteristics, such as collectively establishing values and practicing shared decision making.

Consumer-run organizations (CROs) are a low-cost strategy for promoting the well-being of mental health consumers, with evidence of efficacy coming from both randomized trials and quasi-experimental evaluations (1-3). Engagement and retention in mental health programs are strong predictors of treatment success, with CRO engagement being no exception (4-6). The goal of this study was to examine individual and organizational characteristics that predict engagement in CROs. Results should provide insight into which mental health care consumers may be most likely to join CROs and which organizational characteristics support engagement. The focus on organizational characteristics is particularly important, given that this area of research is largely underdeveloped (7,8).

disclosures

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AN OVERVIEW OF CONSUMER-RUN ORGANIZATIONS (CROs)

Unifying CRO principles include providing empowering roles, establishing an environment of respectful acceptance, and encouraging self-initiated participation and decision making (9). CROs often strive to foster mutual support by operating drop-in centers, organizing recreational activities, and hosting support groups (10,11). This study examined all CROs funded by the Kansas Department of Social and Rehabilitation Services, which are incorporated nonprofits with a consumer-led board of directors and a drop-in center. Additional goals and activities vary across organizations (12).

To understand engagement in CROs, this study drew from the role framework, which posits that individual and environmental characteristics interact to determine role and relationship development within a CRO (13,14). Leadership and friendship roles are of particular interest, in that both the role framework and empirical studies suggest that these roles contribute to recovery (4,15). To explore engagement in leadership and friendship roles, we examined predictors of leadership and socially supportive involvement. Socially supportive involvement is the development of mutually supportive friendships that include intimacy and sharing, which play a central role in buffering stress and enhancing emotional well-being (13,16). Leadership involvement includes contributions to organizational operations and decision making, which promotes empowerment as leaders learn to take initiative and contribute to the broader community (17,18). Our third measure of engagement was total attendance, which is commonly used across settings to represent quantity of involvement (19). Consistent with the role framework, this study examined individual and organizational characteristics related to CRO role engagement; these are outlined below.

Individual Characteristics Related to CRO Engagement

Demographic characteristics—Previous research suggests that women, individuals in racial-ethnic minority groups, and older and more educated individuals attend mutual support groups at higher rates than others (20-24). However, whites in predominantly white regions and blacks in predominantly black regions were both more likely than nondominant groups in respective regions to attend mutual support groups (25).

Sense of community—Sense of community represents the strength of bonding among community members, which facilitates emotionally supportive exchanges and has been linked to engagement in several settings (26-29).

Organizational empowerment—CROs are uniquely empowering because they are driven by mental health care consumers rather than by professionals (13,30). By providing opportunities for meaningful contribution and helping participants feel valued, CROs can encourage both continued engagement and recovery (31).

Organizational Characteristics Related to CRO Engagement

Group size—The impact of group size on engagement may be complex. Small groups may lack the critical mass needed for stability, whereas large groups can become impersonal

(32). Leadership in larger CROs may also be more exclusive if leadership positions are limited (33).

Services provided—The services provided at CROs can affect engagement in several ways. Recreational activities can provide a medium for ongoing participation and the development of close friendships (34). Similarly, hosting self-help support groups can encourage relationship development. Peer counseling programs may also increase engagement, especially for members uncomfortable sharing in larger groups (14).

Shared leadership—As a central tenet of self-help, shared leadership can help prevent member burnout, promote organizational goal achievement, and enhance group survival (35-37). Although the connection between organizational shared leadership and individual leadership involvement is clear, several other influences on leadership involvement exist. This study examined shared leadership in the context of several relevant predictors.

THE STUDY AND THE HYPOTHESES

In this study, we analyzed survey data to better understand how individual and organizational characteristics relate to total attendance, leadership involvement, and socially supportive involvement in CROs. Because of conflicting results in the literature, we did not formulate specific directional hypotheses related to demographic variables (24,38). We expected greater sense of community and higher organizational empowerment to be positively associated with engagement. Organizations providing more services than others were expected to be associated with increased engagement. Finally, we expected larger membership size to predict less leadership involvement, whereas we hypothesized that shared leadership would predict more leadership involvement (33).

METHODS

Study Setting

To test the above hypotheses, we analyzed data from 250 CRO members attending 20 CROs spread throughout the state of Kansas. The sample represented all CROs funded by the Kansas Department of Social and Rehabilitation Services, which requires members to have a severe and persistent mental illness. Geographically, 15% (N=3) of CROs are in large cities with more than 100,000 people, 60% (N=12) are in medium-size towns of 10,000–100,000 people, and 25% (N=5) are in small towns of less than 10,000 people. Annual operating budgets range from \$5,600 to \$132,000. All CROs operate a drop-in center and pursue various other activities, including hosting support groups, conducting volunteer community services, offering educational activities, and educating the public about mental illness.

Data Collection Procedure

On receiving approval from the Wichita State University Institutional Review Board, we collected anonymous individual-level data through the CRO member survey, which was administered during site visits to each CRO in December 2003 and January 2004. Only two of the 254 people who attended the CROs on the day of the site visit chose not to participate. In addition, two surveys were excluded because of obvious respondent error.

Organizational-level data came from the CRO activity survey and quarterly reports completed by organizational leaders.

Study Sample

The respondents ranged in age from 19 to 69 (mean=44), and 54% were female. With regard to race and ethnicity, 79% were non-Hispanic white, 8% were non-Hispanic black, 9% were mixed, 3% were Hispanic, 2% were Native American, and <1% were Asian. Nearly half (46%) of the participants were single, 17% were married, 6% were unmarried but living with their partner, 26% were divorced or separated, and 5% were widowed. In terms of educational attainment, 14% did not graduate high school, 37% had a high school diploma or GED, 40% had technical training beyond high school or some college, 4% graduated from college, and 4% had a graduate degree,

Measures

We used three categories of measures: CRO engagement, individual-level predictors, and organization-level predictors.

CRO engagement—The three measures of CRO engagement were total attendance, leadership involvement, and socially supportive involvement. Total attendance estimated the total number of times a respondent visited a particular CRO by multiplying how long they had been coming to the CRO (in years) by their frequency of attendance (estimated visits per year based on categories such as, “every day,” “about once a week,” and “a few times per year”). Leadership involvement was measured by asking members about the different types of involvement they had in organizational functioning and decision making (21 items, $\alpha=.91$). The measure was based on the organizationally mediated empowerment scale and modified to better fit the CRO context (39). Socially supportive involvement measured CRO member perceptions of the degree to which their CRO provided a supportive environment that fosters mutually supportive friendships with intimacy and sharing. The questions for this 11-item scale ($\alpha=.93$) are drawn from scales measuring “group support and mutual learning” and “intimacy and sharing,” which in turn are based on the Group Environment Scale (40,41).

Individual-level predictors—Demographic predictor variables, including gender, relationship status, age, race-ethnicity, and educational attainment, were each measured with a single question. Perceived sense of community (13 items, $\alpha=.85$) is a measure that captures feelings of belonging, loyalty, and connectedness (42,43). Response options range from 1, “not at all,” to 3, “a lot,” with scale scores computed as the mean of the ratings from all items. An example item is “I feel like I belong to the community here.” Perceived organizational empowerment (seven items, $\alpha=.85$) measures empowerment-promoting characteristics of the organization. Response options range from 1, strongly disagree, to 5, strongly agree, with the mean serving as the scale score. This measure is unpublished, and items include “This organization provides opportunities for meaningful participation and contribution” and “This place helps people feel valued and respected.”

Organization-level predictors—The CRO Activity Survey measured all predictors except membership size, which came from quarterly reports. Availability of peer counseling was captured with a yes-no question about whether the CRO offers peer counselors for members to contact by phone or in person. Number of self-help group meetings was the sum of all self-help group meetings hosted by the CRO in the past month. Number of recreational activities was the sum of all organized recreational activities in the past month. Number of members involved in quarterly reports and number of members involved in planning activities served as indicators of shared leadership that were estimated by the CRO director. Membership size was the unduplicated number of individuals who attended the CRO during the quarter of data collection.

Plan of Analysis

To examine relationships between each predictor and indicator of engagement, we first ran univariate multilevel regressions that accounted for the clustering of individuals within CROs. We subsequently ran multivariate models, using the univariate results to prevent overfitting by excluding predictors that were not significantly related to one or more engagement indicators. To ease interpretation, we standardized leadership involvement, socially supportive involvement, perceived sense of community, perceived organizational empowerment, educational attainment, age, and membership size. We used SAS 9.3 Proc Mixed for analyses predicting leadership involvement and socially supportive involvement. Total attendance was a count variable with overdispersion, which we modeled with multilevel binomial regression using Proc Glimmix.

RESULTS

Table 1 describes engagement and predictor variables before standardization.

Univariate Regression Models

Table 2 presents the results of univariate regression models predicting each indicator of engagement. The incidence rate ratio estimates for total attendance indicate how much total attendance would increase (if greater than 1) or decrease (if less than 1) with an increase of one standard deviation (SD) in the predictor variable. The beta (B) estimates indicate by how many SDs socially supportive and leadership involvement would increase or decrease, given a 1-SD increase in the predictor variable. Perceived sense of community is the only predictor that was significant across the three indicators of engagement. A 1-SD increase in perceived sense of community predicted 1.63 times more total attendance ($t=5.99$, $df=224$, $p<.001$), a .40-SD increase in leadership involvement ($t=6.96$, $df=229$, $p<.001$), and a .42-SD increase in socially supportive involvement ($t=7.12$, $df=205$, $p<.001$). Perceived organizational empowerment was a significant predictor of leadership involvement and socially supportive involvement, predicting increases of .20 and .58 SD, respectively ($t=3.28$, $df=220$, $p<.01$, and $t=11.37$, $df=210$, $p<.001$, respectively).

The demographic characteristics of race-ethnicity, relationship status, and gender had significant relationships with leadership involvement only. Leadership involvement was .37 SD higher among non-Hispanic whites compared with persons of other race-ethnicity

($t=2.44$, $df=229$, $p<.05$). Being single, never married, and not living with a partner predicted a .34-SD decrease in leadership involvement ($t=-2.76$, $df=229$, $p<.01$). Male leadership involvement scores were .25 SD lower than those of females ($t=-2.03$, $df=225$, $p<.05$). Respondent age had a significant relation with only total attendance, where a 1-SD increase in age (11.2 years) predicted 1.21 times more total attendance ($t=2.25$, $df=214$, $p<.05$). Educational attainment predicted an increase in leadership involvement of .19 SD but a decrease in socially supportive involvement of .13 SD ($t=3.18$, $df=226$, $p<.01$, and $t=-2.06$, $df=222$, $p<.05$, respectively).

Organizational characteristics had several significant relationships with CRO engagement indicators, although fewer than for individual characteristics. The availability of peer counseling predicted a .64-SD increase in socially supportive involvement ($t=6.62$, $df=224$, $p<.001$). Every additional self-help group meeting in the past 30 days predicted 1.14 times more total attendance ($t=2.17$, $df=226$, $p<.05$). The number of recreational activities and the number of members planning activities did not have a significant relation with any indicator of CRO engagement. Every addition to the number of members involved in quarterly reports predicted 1.21 times more total attendance ($t=2.26$, $df=132$, $p<.05$). Finally, a 1-SD increase in membership size (51 members) predicted a .21-SD decrease in leadership involvement ($t=-2.22$, $df=230$, $p<.05$).

Multivariate Regression Models

Table 3 presents the results of the multivariate models predicting each indicator of engagement. For total attendance, the only significant predictors were perceived sense of community and number of members involved in quarterly reports. A 1-SD increase in perceived sense of community predicted 1.64 times more total attendance ($t=5.46$, $df=209$, $p<.001$), and each additional member involved in quarterly reports predicted 1.22 times more total attendance ($t=2.05$, $df=79$, $p<.05$).

There were five significant predictors in the multivariate regression for leadership involvement. An increase of 1-SD in perceived sense of community and educational attainment predicted .38-SD and .22-SD increases in leadership involvement, respectively ($t=6.06$, $df=224$, $p<.001$, and $t=3.90$, $df=225$, $p<.001$, respectively). Each additional CRO member involved in creating quarterly reports predicted a .09-SD increase in leadership involvement ($t=2.01$, $df=133$, $p<.05$). Being single, never married, and not living with a partner predicted a .26-SD decrease in leadership involvement ($t=-2.18$, $df=224$, $p<.05$). A 1-SD increase in membership size (51 members) predicted a .29-SD decrease in leadership involvement ($t=-3.02$, $df=215$, $p<.01$).

In a multivariate regression, perceived sense of community, perceived organizational empowerment, and the availability of peer counseling all predicted increased socially supportive involvement. A 1-SD increase in perceived sense of community and perceived organizational empowerment predicted .21-SD and .48-SD increases in socially supportive involvement, respectively ($t=4.22$, $df=219$, $p<.001$, and $t=8.20$, $df=212$, $p<.001$, respectively). The availability of peer counseling predicted a .32-SD increase in socially supportive involvement ($t=3.19$, $df=216$, $p<.01$), whereas educational attainment predicted a .09-SD decrease ($t=-2.04$, $df=209$, $p<.05$).

DISCUSSION

This study responded to calls in the literature for more research examining the relative contribution of both individual- and group-level characteristics that may increase engagement in CROs (7,8). Results indicate characteristics to target for interventions aimed at increasing CRO engagement.

Individual-Level Characteristics

Perceived sense of community emerged as an important predictor of all engagement indicators, suggesting that CROs need to think strategically about how to promote sense of community. Some promising strategies include training leaders to model supportive behaviors; outlining conflict resolution procedures in a code of conduct; collectively establishing goals, values, and symbols; and organizing activities that promote bonding (44,45).

Perceived organizational empowerment predicted leadership involvement and socially supportive involvement as hypothesized, but not total attendance. To enhance empowerment, CROs can encourage a culture of shared decision making and problem solving and provide numerous opportunities for participation in volunteer opportunities and formal leadership positions (4).

Similar to previous studies, demographic characteristics emerged as important predictors of engagement (20,46). Interestingly, educational attainment predicted increased leadership involvement but predicted decreased socially supportive involvement. Qualitative research suggests that highly educated individuals sometimes struggle to connect with less educated CRO members but nevertheless excel in their leadership involvement (14). The lower levels of leadership involvement among single males has also been reflected in qualitative findings, and some CROs have a subgroup of single males who enjoy recreational activities but are less interested in organizational operations (14). Efforts to engage these members in organizational leadership may be difficult but particularly beneficial to the reluctant leaders, in that new roles could lead to substantial personal growth (15).

Organization-Level Characteristics

Consistent with the predictions of behavior-setting theory, membership size was negatively related to leadership involvement, and a limited number of leadership roles may restrict leadership involvement in larger CROs (47). To encourage leadership development, CROs need to maintain enough meaningful roles for all interested members (33). Findings suggest that shared leadership may promote leadership involvement, but effect sizes were relatively small.

The availability of peer counseling was a strong predictor of socially supportive involvement, as hypothesized, but was not predictive of leadership involvement or total attendance. Developing a peer counseling program may be an effective strategy for CROs to enhance relationship building between members because such programs offer people the opportunity to become actively engaged in their own recovery via reciprocity and self-disclosure (48,49).

Surprisingly, number of recreational activities did not predict engagement. Some organizations may attract members by organizing a smaller number of more interesting activities. Hosting self-help group meetings predicted total attendance but not leadership or socially supportive involvement. The quality of meetings may be more important than the quantity.

Limitations and Future Directions

The most notable limitation of this study was its cross-sectional design, which prevented causal inference. Future research could track new CRO members over time to better assess the engagement process. In addition, randomized trials aimed at enhancing specific aspects of organizational functioning may be able to identify pathways by which CROs can improve engagement. With only 20 CROs, the study may have been underpowered to identify relationships between some organizational characteristics and engagement. For future studies on this topic, investigators are advised to include over 50 CROs to be more optimally powered to detect organization-level effects (50). Another limitation was that the leader-reported organizational characteristics may have been biased by social desirability. Observational methods may reduce this bias. Finally, generalizability is limited because all CROs were in Kansas and may not be representative of CROs in other locations.

CONCLUSIONS

Consistent with the role framework, findings suggest that individual and organizational characteristics influence role engagement, with effects for predictors such as educational attainment depending on the type of role. From an organizational perspective, findings suggest that CROs that foster empowerment, a sense of community, shared leadership, and peer support may be best positioned to actively engage members as they work collaboratively toward recovery.

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Table 1

Descriptive statistics for variables in analysis of engagement in consumer-run organizations

Variable	N	%	M	SD	Minimum	Maximum
Engagement						
Total attendance	245		716.64	1,035.87	1	5,760
Leadership involvement ^a	250		9.91	5.85	0	21
Socially supportive involvement ^a	245		3.17	.62	1.36	4.00
Individual characteristic						
Perceived sense of community ^a	250		2.52	.33	1.56	3.00
Perceived organizational empowerment ^a	246		4.26	.59	2.55	5.00
Age ^a	234		44.21	11.21	20	70
Educational attainment ^{a,b}	247		2.47	.93	1	5
Less than high school	35	14				
High school diploma or GED	91	37				
Technical training beyond high school or some college	100	40				
Graduated from college	11	4				
Graduate degree	10	4				
Race-ethnicity	246					
White, Non-Hispanic	194	79				
Black, Non-Hispanic	19	8				
Hispanic	7	3				
Native American	4	2				
Asian	1	<1				
Mixed	21	9				
Relationship status	249					
Single	115	46				
Married	42	17				
Living with partner	16	6				
Separated or divorced	64	26				
Widowed	12	5				
Gender	245					
Male	113	46				
Female	132	54				
Organizational characteristic						
Membership size ^a	20		58.40	50.74	9	171
Availability of peer counseling	20					

Variable	N	%	M	SD	Minimum	Maximum
Available	5	25				
Unavailable	15	75				
N of self-help group meetings	20		2.15	2.68	0	8
N of recreational activities	20		8.10	4.10	4	22
N of members involved in quarterly reports	19		3.05	1.93	2	8
N of members planning activities	20		8.20	5.63	2	22

^aValues prior to standardization for regression analyses

^b1, less than high school; 2, high school diploma or GED; 3, technical training beyond high school or some college; 4, graduated from college; 5, graduate degree

Table 2

Univariate regression models between each predictor and each indicator of engagement in consumer-run organizations

Predictor	Total attendance		Leadership involvement		Socially supportive involvement	
	IRR ^a	95% CI	B	95% CI	B	95% CI
Individual characteristic						
Perceived sense of community	1.63***	1.39 to 1.91	.40***	.29 to .52	.42***	.31 to .54
Perceived organizational empowerment	1.08	.92 to 1.24	.20**	.08 to .32	.58***	.48 to .68
Race-ethnicity ^b	1.33	.88 to 2.00	.37*	.07 to .66	.20	-.10 to .50
Relationship status ^c	1.14	.83 to 1.58	-.34**	-.58 to -.10	.08	-.17 to .33
Age	1.21*	1.02 to 1.43	.06	-.06 to .18	-.08	-.20 to .05
Educational attainment	1.12	.95 to 1.31	.19**	.07 to .31	-.13*	-.25 to -.01
Gender ^d	1.10	.80 to 1.52	-.25*	-.49 to -.01	.07	-.18 to .32
Organizational characteristic						
Membership size	1.26	.85 to 1.88	-.21*	-.39 to -.02	.04	-.15 to .22
Availability of peer counseling	1.16	.51 to 2.66	-.02	-.46 to .42	.64***	.45 to .83
N of self-help group meetings	1.14*	1.01 to 1.28	-.01	-.09 to .06	-.05	-.11 to .01
N of recreational activities	1.00	.92 to 1.09	-.02	-.07 to .02	-.01	-.04 to .03
N of members involved in quarterly reports	1.21*	1.01 to 1.45	.04	-.06 to .14	-.01	-.10 to .08
N of members planning activities	1.03	.97 to 1.10	-.02	-.06 to .01	.01	-.02 to .04

^aIncidence rate ratio

^b1, non-Hispanic white; 0, other

^c1, single, never married, not living with partner; 0, other

^d1, male; 0, female

* p<.05

** p<.01

*** p<.001

Table 3

Multivariate regression models predicting each indicator of engagement in consumer-run organizations

Predictor	Total attendance		Leadership involvement		Socially supportive involvement	
	IRR ^a	95% CI	B	95% CI	B	95% CI
Intercept	157.35***	71.96 to 344.08	-.22	-.70 to .26	-.21	-.61 to .18
Perceived sense of community	1.64***	1.37 to 1.97	.38***	.25 to .50	.21***	.11 to .31
Perceived organizational empowerment	.92	.78 to 1.09	.06	-.16 to .18	.48***	.36 to .60
Race-ethnicity ^b	1.14	.76 to 1.70	.10	-.17 to .38	.01	-.24 to .26
Relationship status ^c	1.29	.89 to 1.79	-.26*	-.50 to -.03	.16	-.007 to .32
Age	1.12	.93 to 1.34	-.06	-.18 to .06	-.03	-.11 to .05
Educational attainment	1.12	.95 to 1.31	.22***	.11 to .33	-.09*	-.17 to -.003
Gender ^d	1.30	.93 to 1.82	-.14	-.36 to .08	-.02	-.21 to .16
Membership size	1.00	.99 to 1.00	-.29**	-.48 to -.10	.01	-.08 to .10
Availability of peer counseling	1.89	.83 to 4.28	.03	-.35 to .40	.32**	.12 to .51
N of self-help group meetings	1.15	.99 to 1.33	.02	-.05 to .08	-.03	-.06 to .003
N of members involved in quarterly reports	1.22*	1.01 to 1.47	.09*	.001 to .18	.04	-.01 to .09

^a Incidence rate ratio^b 1, non-Hispanic white; 0, other^c 1, single, never married, not living with partner; 0, other^d 1, male; 0, female

* p<.05

** p<.01

*** p<.001