



## A randomised controlled trial of a group intervention to reduce engulfment and self-stigmatisation in first episode schizophrenia

Elizabeth McCay<sup>1,2</sup>, Heather Beanlands<sup>1</sup>, Robert Zipursky<sup>3</sup>, Paul Roy<sup>4,5</sup>,  
Molyn Leszcz<sup>2,6</sup>, Janet Landeen<sup>7</sup>, Kathy Ryan<sup>8</sup>, Gretchen Conrad<sup>4</sup>, Donna Romano<sup>6</sup>,  
Daphne Francis<sup>1</sup>, Jennifer Hunt<sup>4</sup>, Lucia Costantini<sup>1</sup> and Eugene Chan<sup>1</sup>

1. School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario, Canada

2. Department of Psychiatry, University of Toronto, Ontario, Canada

3. Department of Psychiatry and Behavioural Neurosciences, McMaster University, Hamilton, Ontario, Canada

4. Champlain District First Episode Psychosis Program, The Ottawa Hospital, Ontario, Canada

5. Department of Psychiatry, University of Ottawa, Ontario, Canada

6. Department of Psychiatry, Mount Sinai Hospital, Toronto, Ontario, Canada

7. School of Nursing, Health Sciences Centre, McMaster University, Hamilton, Ontario, Canada

8. Centralized Assessment, Triage and Support, Centre for Addiction and Mental Health, Toronto, Ontario, Canada

### Abstract

Young people coping with first episode schizophrenia may be predisposed to illness engulfment whereby the illness entirely defines self-concept. They require psychosocial intervention to preserve an identity distinct from illness, promote hopefulness, and minimise the impact of stigma, enabling them to embrace a healthy sense of self and an optimistic future. The purpose of this study was to evaluate a group intervention designed to promote healthy self-concepts by reducing self-stigmatisation and engulfment among young adults recovering from first episode schizophrenia. Participants at two first episode psychosis clinics, one in Toronto and one in Ottawa, were assigned to one of two groups: intervention plus treatment as usual, or a control with only treatment as usual. A repeated measures analysis revealed that immediately post-intervention, the treatment group significantly improved on engulfment, hope, and quality of life measures compared with the control. No improvement was observed in self-concept, self-esteem, self-efficacy, and stigma. Intervening early in the course of the illness to address engulfment and self-stigmatisation may enable young people to acquire positive attitudes toward themselves and the future. Future longitudinal data are needed to determine whether this intervention will prevent the development of chronicity and demoralisation over time.

### Keywords

*engulfment, self-stigmatisation, first episode schizophrenia, young people, group intervention*

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### Background

Young people encountering schizophrenia for the first time must cope with the impact of a highly-stigmatising illness on their overall sense of self and well-being (McCay & Ryan, 2002). Young people may feel that the illness defines the totality of their being, restricting all aspects

of their lives. This phenomenon is known as engulfment, whereby illness and its associated stigma entirely define self-concept. Individuals who are engulfed by their illness readily apply the associated negative labels and stereotypes to themselves, subsequently feeling that they are 'just schizophrenic' (Estroff, 1989; McCay & Ryan, 2002). Hence, young people engulfed by

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**Contact:** Elizabeth McCay, RN, PhD, Associate Professor, School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario, Canada [bmccay@ryerson.ca](mailto:bmccay@ryerson.ca)

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schizophrenia must cope with issues of self-stigmatisation, low self-esteem, hopelessness, depression, lack of self-efficacy, and decreased social adjustment over time (McCay & Seeman, 1998).

In addition to illness-related difficulties, young people must also deal with the developmental challenges of young adulthood: consolidation of a unique and independent self-concept, pursuit of educational and career goals, and creation of a social network (Zarrett & Eccles, 2006). The onset of schizophrenia in early adulthood frequently disrupts the attainment of these developmental milestones (Malla, Norman, Scholten et al., 2005). McDonald, Haynes and Baglioni (2000) found that individuals living with early psychosis had fewer sources of support than their peers who were not living with a mental illness. Macdonald, Sauer, Howie and Albiston (2005) found that young people recovering from first episode psychosis spent less time with the friends they had made before they became ill. The authors suggested that an underlying fear of rejection and being perceived as different from others may contribute to decreased contact with friends, observations which are consistent with the phenomenon of engulfment. Further, young people with early schizophrenia frequently experience prolonged periods of social isolation following the initial diagnosis (McDonald et al., 2005; Ridgway, 2001), precluding ongoing social contact with their peer group. Ridgway (2001) described the period of despair that frequently follows initial diagnosis; it is characterised by loss of hope for the future and self-stigmatisation, which involves accepting the negative expectations and stereotypes that are associated with a diagnosis of schizophrenia (Link, 2001).

Self-stigmatisation has a negative impact on self-concept in the earliest phases of schizophrenia (Knight, Wykes & Hayward, 2003; Ridgway, 2001). In addition, decreased self-stigmatisation and increased social support are associated with improved outcomes among those with a recent onset of the illness (Erickson, Beiser & Iacono, 1998; Mueller, Nordt, Lauber et al., 2006). Providing people with schizophrenia with opportunities to improve social contact in a community-based peer support program reduces social isolation, improves overall functioning, and decreases hospital readmission (Chinmon,

Weingarten, Stayner & Davidson, 2001). These findings suggest that early psychosocial therapy directed at minimising self-stigmatisation and social isolation among young people with first-episode schizophrenia may reduce social deficits (Barrowclough, Haddock, Lobban & Jones, 2003; Macdonald et al., 2005) and improve overall quality of life.

One review of psychosocial treatment for early psychosis (Penn, Waldheter, Perkins et al., 2005) concluded that adjunctive psychosocial treatment supports symptomatic and functional recovery. Jackson, McGorry, Henry et al. (2001) reported mixed results for their individualised cognitive psychoeducation (COPE) intervention, indicating a need for further research in this area. Group intervention in particular may play a role in preventing symptom and functional deterioration (Albiston et al., 1998), given the importance of peer groups to young adults, generally. Peer groups have also been described as a source of critical support in the initial phases of recovery (Ridgway, 2001). Descriptive literature about group treatment for first-episode schizophrenia is evolving (Albiston, Francey & Harrigan, 1998; Lecomte, Leclerc, Wykes & Lecomte, 2003; Malla, Norman, Manchanda et al., 2002; Malla, Norman, McLean et al., 2003; Miller & Mason, 2001), but few studies have systematically evaluated the impact of group interventions in first-episode schizophrenia. Nonetheless, some studies of long-term schizophrenia have indicated that cognitive behavioral group therapy (CBGT) yields positive results. Using a randomised controlled trial of 113 individuals with schizophrenia, Barrowclough et al. (2006) found that those who received CBGT were more likely than controls to improve on hopelessness and self-esteem measures at the 12-month mark. Halperin, Nathan, Drummond et al. (2000) and Kingsep, Nathan and Castle (2003) both reported statistically significant improvements in social anxiety among individuals with long-term schizophrenia who received CBGT. Based on these promising findings, Penn et al. (2005) suggested the need for additional randomised controlled trials to evaluate the effectiveness of psychosocial interventions, including group treatments, for early psychosis. We developed an innovative group intervention to promote healthy self-concepts by reducing self-stigmatisation and

engulfment among young adults recovering from first-episode schizophrenia. Our pilot findings suggested that this group intervention encourages young adults to embrace a healthier sense of self and to resist internalising the stigmatising aspects of the illness (McCay, Beanlands, Leszcz et al., 2006). Currently we are conducting a randomised controlled trial (RCT) to test the efficacy of this novel intervention using a much broader range of outcome measures (see Measures). This paper reports the findings of Phase 1 of the longitudinal RCT, in which outcomes were measured immediately upon completion of the intervention.

## Method

### *Hypothesis*

The literature and results from the pilot group (McCay et al., 2006) led to the hypothesis that participants receiving the group intervention in addition to treatment as usual would demonstrate a significant improvement in self-concept, self-esteem, self-efficacy, engulfment, self-stigmatisation, quality of life and hope as compared with participants receiving only usual treatment. Although the intervention was not hypothesised to influence symptoms, we monitored symptom levels in order to control for any possible influence on outcomes. For Phase 1, comparisons between the experimental and control groups were made on all outcome measures at two time intervals: pre-intervention (baseline), and at three months immediately post-intervention.

### *Sample*

Participants were recruited between the summer of 2003 and the winter of 2006 from the First Episode Psychosis Clinic at the Centre for Addiction and Mental Health in Toronto and the Ottawa First Episode Psychosis Program at The Ottawa Hospital in Canada. Ethics approval was obtained from the respective ethics boards prior to conducting the study. Recruitment criteria included: (1) a diagnosis according to DSM-IV criteria of Schizophrenia, Schizophreniform Disorder or Schizoaffective Disorder; (2) absence of previous psychiatric hospitalisations and no antipsychotic medications received for more than eight weeks prior to the study; (3) within two years of initial treatment (in hospital or out-patient setting) for a first episode of

schizophrenia; (4) between the ages of 18 and 35; (5) ability to read, comprehend, and speak English; and (6) capacity to give informed consent to participate. Exclusion criteria included drug-related psychosis, significant medical illness and/or organic brain syndrome. Participants were randomly assigned to one of two groups: intervention plus treatment as usual, or a control with only treatment as usual. Both the treatment and control groups received high quality, systematic, and standardised follow-up care, which was provided by the clinical team following the initial diagnosis of first episode schizophrenia.

This study is a randomised controlled clinical trial of a 12-week group intervention with a treatment and control group. Of the 136 persons we approached, 67 (49.3%) gave their consent to participate. The refusal rate is in keeping with clinical intervention studies (Goodwin, Leszcz, Quirt et al., 2000). It was necessary to adopt a 2:1 randomisation ratio favoring the intervention group to attain sufficient participants to conduct the group intervention. Participants were allocated to groups by randomly pulling group assignment (group vs. control) from an envelope. At baseline, 41 participants were randomly assigned to the treatment group and 26 participants to the control group. Two participants (one from each group) did not complete the data collection at 3 months (T2) and thus they were not included in this analysis; however, they remained in the study. Eighteen participants (26.9%, eleven in treatment group, seven in control group) dropped out of the study. The final sample described here includes 47 participants (treatment = 29, control = 18).

### *Intervention*

The group intervention was a 12-week manual based intervention with 1.5 hours of treatment per week. The manual was developed by our group and was used previously in our pilot study (see McCay et al., 2006 for more detail). The overall treatment promoted five distinct goals: (1) developing a personally acceptable interpretation of the illness experience; (2) minimising self-stigmatising attitudes; (3) reducing engulfment; (4) developing a sense of future, hopes, and dreams; and (5) developing and pursuit of meaningful life goals for each individual. Each group goal provided the content

for 2 sessions. The remaining 2 sessions were used to introduce the group and wrap-up the group, respectively, resulting in a total of 12 sessions. The group sessions consistently focused on reinforcing the individual characteristics of each group member. An emphasis was also placed on the group process (sharing, altruism and group learning), thus enabling group members to learn that they were not alone in their struggles. The sessions addressed the group content, yet also allowed plenty of opportunity for open discussion.

Two group leaders facilitated each session. These leaders were experienced clinicians who had a specific interest in this population and who had previous experience with the intervention techniques. Group leaders had training specifically for this study through exposure to relevant literature and standardised group manual, as well as supervisory sessions with Dr. Melyn Leszcz, a group expert and study investigator. The study investigators reviewed transcripts for at least four group sessions and held debriefing sessions with group leaders to provide consistent feedback to the leaders regarding the implementation of the group manual.

### **Measures**

Measures and scales were administered to participants in both the treatment and control groups at baseline (T1) and at three months (T2). For the treatment group, T2 measures were administered immediately following the group intervention and for the control group they were administered approximately 12 weeks after the baseline assessment. Between these two assessment times, the treatment group received the group intervention and treatment as usual, while the control group received treatment as usual. Measures with established psychometric properties were used to assess the outcome variables of engulfment, self-concept, self-esteem, self-efficacy, perceived stigma, quality of life and hope, as well as two other variables: symptom severity and global functioning.

*Modified Engulfment Scale (MES)*. This tool measures the degree to which illness defines an individual's self-concept. It is a 30-item scale rated on a five-point Likert scale. Possible MES scores range from 30 to 150 where higher scores indicate greater engulfment. McCay and Seeman

(1998) obtained a reliability coefficient of .91 in a group of 100 heterogeneous outpatients with a diagnosis of schizophrenia. The alpha for this study was also .91.

*Tennessee Self-Concept Scale (TSCS)*. The TSCS (Fitts & Warren, 1996) assesses six external and three internal domains of self-concept. It is a 100-item scale consisting of statements to portray an individual's self-picture, providing measures of self-esteem, personality integration and defensiveness. The alpha coefficient reported by Fitts and Warren was .95.

*Rosenberg Self-Esteem Scale (RSES)*. The RSES (Rosenberg, 1979) is a 10-item self-report inventory to measure global self-worth (Byrne, Woodside, Landeen et al., 1996; Lecomte, Corbière & Laisné, 2006). The scores range from 10 to 40 and lower values suggest low self-esteem. The alpha for this study was .93.

*Self-Efficacy Scale (SES)*. Sherer (1982) developed the SES based on Bandura's (1997) theory of self-efficacy. The scale consists of 30 items rated on a five-point Likert scale. The SES has established good reliability amongst an outpatient schizophrenia population (McCay & Seeman, 1998). Scores range from 1 to 150 with higher scores signifying higher self-efficacy. The alpha coefficient here was .90.

*Link Perceived Stigma Questionnaire (LPSQ)*. The LPSQ (Link, Mirotznik & Cullen, 1991) is one of the few well-developed stigma scales. It consists of 29 items rated on a six-point Likert scale with scores ranging from 29 to 174. The higher the score the more perceived stigmatisation associated with the illness. Four subscales comprise the LPSQ, specifically: devaluation-discrimination, secrecy, withdrawal, and education. For this study, the LPSQ has an alpha of .79.

*Quality of Life Scale (QLS)*. The QLS (Heinrichs, Hanlon & Carpenter, 1984) is a semi-structured interview assessing a comprehensive range of social functioning in outpatient schizophrenia populations. The scale assesses deficit symptoms in intrapsychic functions, relationships, instrumental roles and activities. Scores may range from 1 to 21 with higher scores suggesting no illness related impairment. The QLS had an alpha of .84, for this study.

*Miller Hope Scale (MHS).* The MHS (Miller & Powers, 1988) is a 40-item Likert self-reported scale measuring multi-dimensional attributes of hope. The MHS ranges between 40 to 200 and higher scores indicate high perceived hopefulness. The tool has acceptable psychometric properties when administered in psychiatric populations (Holdcraft & Williamson, 1991; Landeen, 2000). The MHS had an alpha of .96 in this study.

*Positive and Negative Symptom Scale (PANSS).* The PANSS is the most widely-used measure of symptom severity in schizophrenia (Kay, Opler & Lindenmayer, 1988; Peralta, Cuesta & De Leon, 1995). A trained interviewer administers the PANSS in a 40-minute interview as standardised training has demonstrated to increase inter-rater reliability (Muller & Wetzel, 1998). Interviewers for this study trained with expert interviewers to establish inter-rater reliability.

*Global Assessment of Functioning Scale (GAF).* The GAF (Endicott, Spitzer, Fleiss & Cohen, 1976) scale indicates a clinician's overall judgment of a person's psychological, social and occupational functioning. The scale measures overall severity of psychiatric disturbance. Psychometric properties of the instrument are adequate with evidence for moderate reliability ( $r = .61 - .91$ ) (Piersma & Boes, 1997).

*Demographic characteristics.* Participants reported their age, gender, marital status, educational level, date of last employment or school attendance, and current and previous living arrangements, as well as the hours of treatment received in their respective clinics including their length of hospitalisation and previous medical treatment, if any. Participants also reported their age of illness onset as a potential indicator of illness severity. All this information was collected by self-report from the participants using a semi-structured interview guide developed for the study.

### **Data analysis**

In order to describe the sample for all study variables, we calculated frequencies, means, and standard deviations. To compare characteristics of dropouts versus treatment group participants, independent sample t-tests were conducted for

continuous variables and chi-square tests for categorical data. In order to establish the equivalence of groups at baseline, study variables were compared between treatment and control, as well as between study sites (Toronto versus Ottawa), also using independent sample t-tests for continuous variables and chi-square tests for categorical data. When demographic characteristics or outcome variables differed significantly at baseline – specifically, treatment versus control, and/or study site – we entered the variable as a covariate into the repeated measures ANOVA.

To test for group (treatment versus control) by time (T1 versus T2) effect, a repeated measures ANOVA was conducted for all outcome variables. When a difference was detected between study sites, the study site was entered as a covariate into the repeated measures ANOVA. If the repeated measures ANOVA revealed statistically significant effects of group by time, post hoc t-tests were conducted to determine whether improvements in outcomes over time were related to the group intervention or treatment as usual. We conducted all analyses using Statistical Package for the Social Sciences for Windows, and set the alpha value at .05.

### **Results**

At baseline, there were no significant differences in sociodemographic measures between treatment and control groups or treatment and dropout groups (Table 1). However, the dropout group had significantly lower engulfment scores than those who completed the treatment intervention, as well as significantly higher quality of life, self-efficacy, and general functioning scores at baseline (Table 2). As well, the control group reported significantly lower levels of negative symptoms ( $p = .017$ ) than the treatment group. Since PANSS scores were significantly correlated with QLS at baseline, PANSS negative was used as a covariate in the repeated measures ANOVA for QLS. We also observed significant differences between study sites on measures of engulfment and quality of life, and thus study site was entered as a covariate in the ANOVA for engulfment and quality of life.

**Table 1. Demographic characteristics of sample: Means, standard deviations and frequencies**

| Demographic variable               | Treatment (N=29) |          | Control (N=18) |          | Dropouts (N=18) |          |
|------------------------------------|------------------|----------|----------------|----------|-----------------|----------|
|                                    | Mean             | SD       | Mean           | SD       | Mean            | SD       |
| Age (years)                        | 25.07            | 4.86     | 26.17          | 7.03     | 25.17           | 3.96     |
| Age of onset (years)               | 22.54            | 5.17     | 22.00          | 7.85     | 22.83           | 4.68     |
| Length of education (years)        | 14.09            | 2.58     | 13.58          | 5.28     | 14.25           | 2.63     |
| Length of hospitalisations (weeks) | 5.16             | 7.37     | 4.19           | 7.94     | 2.89            | 4.88     |
| Employment (hours per week)        | 6.52             | 5.17     | 5.28           | 12.66    | 10.94           | 17.37    |
|                                    | <b>N</b>         | <b>%</b> | <b>N</b>       | <b>%</b> | <b>N</b>        | <b>%</b> |
| Gender                             |                  |          |                |          |                 |          |
| Male                               | 20               | 69.0     | 14             | 77.8     | 13              | 72.2     |
| Female                             | 9                | 31.0     | 4              | 22.2     | 5               | 27.8     |
| Marital status                     |                  |          |                |          |                 |          |
| Single                             | 29               | 100.0    | 17             | 94.4     | 17              | 94.4     |
| Married/de facto                   | 0                | 0.0      | 1              | 5.6      | 1               | 5.6      |
| Living arrangements                |                  |          |                |          |                 |          |
| With parents                       | 19               | 65.5     | 12             | 66.7     | 14              | 77.8     |

**Table 2. Baseline significant differences for Treatment Group versus Dropouts: Means, standard deviations and independent sample t-tests**

| Measurement | Treatment (N=29) |       | Dropouts (N=18) |       | t (45) | p   |
|-------------|------------------|-------|-----------------|-------|--------|-----|
|             | Mean             | SD    | Mean            | SD    |        |     |
| MES         | 85.99            | 19.38 | 73.48           | 17.63 | 2.225  | .03 |
| QLS         | 61.99            | 17.08 | 74.77           | 17.35 | -2.499 | .02 |
| SES         | 69.16            | 16.47 | 78.31           | 11.26 | -2.071 | .04 |
| GAF         | 48.38            | 11.36 | 55.78           | 12.92 | -2.059 | .05 |

Notes: MES = Modified Engulfment Scale; QLS = Quality of Life Scale; SES = Self-Efficacy Scale; GAF = Global Assessment of Functioning Scale.

The repeated measures ANOVA (Table 3) revealed a statistically significant group by time effect on measures of engulfment, quality of life, and hope. Post hoc t-test results (Table 4) revealed that the treatment group reported significant improvements in engulfment, quality of life, and hope measures. No significant changes were observed in these variables in the control group. These findings suggest that significant differences were related to participation in the group intervention and were not a result of time or usual treatment alone. The hypothesised improvement in self-stigmatisation and self-concept related to the group intervention was not supported.

**Table 3. Outcome variables: Repeated measures Analysis of Variance Group by Time effect**

| Measurement | df | F     | p    |
|-------------|----|-------|------|
| MES         | 1  | 6.50  | .014 |
| QLS         | 1  | 11.67 | .001 |
| MHS         | 1  | 6.15  | .017 |
| RSES        | 1  | .08   | .786 |
| SES         | 1  | .25   | .622 |
| LPSQ        | 1  | 1.92  | .173 |
| TSCS        | 1  | 0.03  | .866 |

Notes: MES = Modified Engulfment Scale; QLS = Quality of Life Scale; MHS = Miller Hope Scale; RSES = Rosenberg Self-Esteem Scale; SES = Self-Efficacy Scale; LPSQ = Linked Perceived Stigma Questionnaire; TSCS = Tennessee Self-Concept Scale.

**Table 4. Outcome measurements for treatment group at baseline (T1) and 3 months immediately post-intervention (T2): post hoc t-tests**

| Measurement | Baseline (T1) |       | 3 months post-intervention (T2) |       | Post hoc t-test |      |
|-------------|---------------|-------|---------------------------------|-------|-----------------|------|
|             | Mean          | SD    | Mean                            | SD    | t (28)          | p    |
| MES         | 85.99         | 19.38 | 77.64                           | 20.28 | 4.12            | .000 |
| QLS         | 61.90         | 17.08 | 72.76                           | 15.03 | -6.59           | .000 |
| MHS         | 137.05        | 28.83 | 143.52                          | 26.17 | -2.13           | .042 |

Notes: MES = Modified Engulfment Scale; QLS = Quality of Life Scale; MHS = Miller Hope Scale.

## Discussion

As hypothesised, our results indicate that young adults with first episode schizophrenia who completed the 12-week group intervention experienced significantly reduced levels of engulfment, and increased levels of hope and quality of life (immediately following the intervention) compared with those who did not. We did not, however, observe the expected improvement in measures of self-concept, self-esteem, self-efficacy, and stigma. This may have resulted from the relatively small sample size and the lack of power necessary to detect a group by time effect. In addition, it may take longer for individuals to exhibit noticeable improvement in self-concept, self-esteem, and self-efficacy. Given the immediate reduction in engulfment and illness-related self-definition, it is reasonable to expect that non-specific changes in these self-related variables may appear over time. According to Ridgway (2001), the rekindling of hope and the shifting of self definition away from illness ‘sparks’ the recovery process; the group intervention may have served as a catalyst by reducing illness-related self-definition and promoting hope.

This study revealed unique improvements immediately following the group intervention, which may be due to participation in this theoretically-driven group intervention. The group intervention was designed to address the propensity of young people to become engulfed by the illness’ label and its associated stigma, particularly self-stigmatisation. These preliminary results suggest that participants improved in the areas most closely linked to the theoretical underpinnings, while the control group did not.

According to engulfment theory, individuals are most vulnerable to the engulfing effect of an illness if the individual’s self-concept is less well-developed (as in the case of young people) and if the illness is highly stigmatising (Lally, 1989; McCay & Seeman, 1998). As predicted by the engulfment model, group participants exhibited reduced levels of engulfment (measured using the MES) and a significant increase in hope. They also reported significant improvement in quality of life on the QLS across three specific domains: intrapsychic functions, instrumental roles, and common activities. The QLS (Heinrichs, Hanlon & Carpenter, 1984) is used extensively to assess a range of schizophrenia populations, since it identifies the deficit syndrome that is characteristic of chronicity and significant disability.

The deficit syndrome is consistent with engulfment theory, which specifies that profound feelings of demoralisation and amotivation are associated with illness engulfment. As such, addressing the unique elements of engulfment (defining oneself as ‘just schizophrenic,’ believing that friends and family see only the illness, feeling incompetent, and perceiving a limited illness-centered future) early in the course of illness should minimise engulfment and the deficit syndrome, as well as increase hope. If so, it is reasonable to assume that quality of life should also improve.

The lack of observed change in the LPSQ (Link et al., 1991) may be related to the intent of the measure. The LPSQ is a measure of coping strategies; specifically secrecy, avoidance-withdrawal, and education. While the group intervention did address possible coping strategies to manage stigma, it was not the explicit focus.

### Limitations

This study had several limitations. Participation in the group intervention was voluntary, and the small number of participants and lack of an intention to treat analysis may preclude generalisability of the findings, particularly for individuals who do not feel comfortable participating in group sessions. The small sample size also limits the power of the statistical findings. In addition, dropouts exhibited significantly lower engulfment scores than participants, which may explain the high dropout rate (26.9%). Dropouts also scored significantly higher on quality of life, self-efficacy, and overall global functioning measures. These findings suggest that the dropouts may have a stronger self-concept and higher level of functioning, and so they might perceive less of a need for group intervention.

### Conclusion

Early intervention in a young person's illness may have the critical benefit of helping them acquire positive attitudes toward themselves and their future in the context of illness, which may be sustained over time. Our preliminary findings supported the value of this type of group intervention and validated our earlier pilot study (McCay et al., 2006). Longitudinal follow-up data are required to clarify how this type of group intervention modifies and shapes views of illness, self-concept, and future goals (Penn et al., 2005). We are continuing to monitor the individuals in both treatment and control groups for one year. Those results, and future phases of this project, will contribute to the developing body of knowledge related to psychosocial and clinical treatments for early schizophrenia.

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