

# Professional-supported, problem-solving, self-learning programme for family carers of people with recent-onset psychosis: abridged secondary publication

WT Chien \*, SY Chan, LK Yip, T Karatzias, D Bressington, ID Lubman

## KEY MESSAGES

1. The professional-supported, problem-solving, self-learning programme can be an effective intervention for families of people with recent-onset psychosis.
2. The self-learning programme significantly improved family carers' burden, problem-solving ability, and caregiving experiences, as well as patients' psychotic symptoms, recovery, and duration of re-hospitalisation at the 12-month follow-up, compared with family psychoeducation group or usual care.
3. Family caregivers perceived that the intervention could enhance their caregiving skills/abilities of psychosis care, be more positively hopeful for

independent family care and patient recovery, and reduce their perceived social stigma.

Hong Kong Med J 2023;29(Suppl 2):S42-7

HMRF project number: 15161091

<sup>1</sup> WT Chien, <sup>2</sup> SY Chan, <sup>3</sup> LK Yip, <sup>4</sup> T Karatzias, <sup>3</sup> D Bressington, <sup>5</sup> ID Lubman

<sup>1</sup> The Nethersole School of Nursing, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong SAR, China

<sup>2</sup> Caritas Integrated Family Services Centres, Hong Kong SAR, China

<sup>3</sup> School of Nursing, The Hong Kong Polytechnic University, Hong Kong SAR, China

<sup>4</sup> Faculty of Health and Social Sciences, Edinburgh Napier University, United Kingdom

<sup>5</sup> Eastern Health Clinical School, Monash University, Australia

\* Principal applicant and corresponding author: wtchien@cuhk.edu.hk

## Introduction

Psychosis is a major disabling and disruptive mental illness, affecting over 30% of psychiatric patients worldwide. People with psychosis often have high risks of relapses in the first few years of illness. More than half of them with early-stage psychosis are cared for in the community by their families who often face high levels of physical, psychological, and financial burdens, which can adversely affect their caregiving experiences and general well-being.<sup>1</sup> Although family psychoeducation groups are effective in supporting family caregiving, many families have difficulties in participation owing to time constraints, feelings of stigma to use mental healthcare services, and worrying about other people's negative responses to mental illness.<sup>2,3</sup> We translated (into Chinese) and validated a five-module problem-solving self-learning programme based on an Australian self-help family programme for early psychosis.<sup>2</sup> We aim to evaluate the effects of the self-learning programme for family carers of people with recent-onset psychosis on both carers' and patients' outcomes, compared with the effects of family psychoeducation group or usual psychiatric care.

## Methods

Patients with recent-onset ( $\leq 3$  years) early-stage psychosis and their family carers aged 18 to 64 years

who attended one of the six community centres for mental wellness in Hong Kong were invited to participate. The family carers were living with and caring for the patient for  $\geq 1$  year and had a moderate to high caregiving burden ( $>20$  scores of the Family-Burden Interview Schedule).<sup>2</sup> Carers who had recently received family intervention or had a history of a serious mental/medical disease were excluded.

33 families per centre were randomly selected and assigned to the self-learning programme, family psychoeducation group, or usual psychiatric care. To achieve 80% power and 5% significance, 66 patients per group ( $n=198$ ) were needed to detect a medium effect size on family burden (Cohen's  $d=0.32$ ), with expected attrition rate of 15%.<sup>2</sup>

Interventions were conducted for family carers over 5 months. The self-learning programme consisted of five modules in Chinese language and four monthly review/sharing group sessions led by a trained nurse facilitator.<sup>2</sup> Family psychoeducation groups were led by one experienced psychiatric nurse based on the validated protocol of psychoeducation group programme.<sup>4</sup> Usual psychiatric care consisted of usual community mental healthcare services provided by psychiatric outpatient clinics and the community centres under study.

Primary outcomes were carers' problem-solving skills (measured by the 25-item Revised Social-Problem-Solving Inventory) and caregiving burden (measured by the 25-item Family Burden

Interview Schedule), whereas secondary outcomes were caregiving experiences (measured by the 66-item Experience of Caregiving Inventory), psychotic symptoms (measured by the Positive and Negative Syndrome Scale), re-hospitalisation rates, family functioning, and recovery (measured by the Questionnaire about the Process of Recovery). Participants were assessed at baseline (T0) and 1 week (T1), 6 months (T2), and 12 months (T3) after intervention. All tools had satisfactory reliability and validity.<sup>2,4</sup> Four focus-group interviews (3-5 members per group, 15 participants per intervention) were conducted after the 1-week follow-up.

Homogeneity of study groups was examined. Outcomes were analysed based on the intention-to-treat principle. Generalised estimating equations were used to assess the interaction (group × time) effects within and between groups across four time-points (T0-T3), followed by pairwise contrast tests. Missing data were estimated with the maximum likelihood estimation, not having other replacement methods. No co-variance analysis was performed, as there was no significant difference between groups at baseline. Level of statistical significance was set at  $P < 0.05$ . Content analysis was conducted based on group interview data.

## Results

A total of 191 pairs of family carers and patients were included for analysis. The self-learning programme group (n=66), family psychoeducation group (n=66), and usual psychiatric care group (n=66) were comparable in terms of characteristics at baseline (Table 1).

The group × time effect was significant in five outcomes at 12 months after intervention (Wald  $\chi^2 = 9.68-20.61$ ,  $P = 0.02-0.001$ , effect size = 0.10-0.35, Table 2). Improvement was significantly greater after the self-learning programme than family psychoeducation group or usual psychiatric care. At T1 to T3, compared with usual psychiatric care, self-learning programme achieved greater improvement in caregiving burden ( $P = 0.03-0.002$ ), problem-solving ( $P = 0.04-0.005$ ), psychotic symptoms ( $P = 0.05-0.001$ ), and subjective recovery ( $P = 0.04-0.008$ ). At T2 and T3, compared with usual psychiatric care and family psychoeducation group, self-learning programme achieved greater improvement in mean duration of re-hospitalisations (all  $P = 0.01-0.03$ ). At T3, compared with family psychoeducation group, self-learning programme achieved greater improvement in caregiving burden, problem-solving, psychotic symptoms, and subjective recovery (all  $P = 0.02-0.04$ ).

Compared with family psychoeducation group, self-learning programme achieved greater improvements mainly at T3 in psychotic symptoms ( $P = 0.008$ ), insight ( $P = 0.03$ ), functioning ( $P = 0.01$ ), and recovery level ( $P = 0.005$ ).

Over the three follow-up periods, the percentage of patients being hospitalised reduced from 26.6% (n=17) to 12.5% (n=8) after self-learning programme, from 28.6% (n=18) to 23.8% (n=15) after family psychoeducation group, and slightly increased from 25.0% (n=16) to 29.7% (n=19) after usual psychiatric care. Reduction in the percentage of patients being re-hospitalised from T0 to T3 was greater after self-learning programme than after family psychoeducation group or usual psychiatric care ( $P = 0.005$ ). Types/doses of psychotropic medications and participation in other psychosocial interventions did not differ significantly between the three groups ( $P > 0.20$ ). Mean scores of all outcomes did not differ between community centres ( $P = 0.12-0.20$ ) or between non-completers and completers of self-learning programme ( $P = 0.10-0.21$ ).

Based on the focus-group interviews, three categories of perceived benefits of the self-learning programme were identified: increased caregiving skills and abilities, more positively hopeful for independent family care and patient recovery, and less perceived social stigma. Of the three categories of perceived benefits, two were for the difficulties in intervention participation (concerns about fluctuating psychotic symptoms and long-term persistent treatment needed) and one was for the challenges/hindrances in self-learning and/or problem-solving practices. Only parts of the perceived benefits (enhancing caregiving skills and positively hopeful for independent family care) could be found in family psychoeducation group. Most participants expressed that sharing and support in group sessions encouraged them to continue engaging in the intervention and seek help/information from mental health staff and professionals.

## Discussion

The professional-supported, problem-solving, self-learning (manual-reading) programme for families of people with recent-onset psychosis is effective to improve both carers' and patients' psychosocial health and well-being. Family carers achieved greater improvement in caregiving burden and problem-solving ability, with moderate to large effect sizes (Cohen's  $d = 0.10$  and  $0.24$ , respectively). Most of these treatment effects of the self-learning programme were significantly greater than those of the family psychoeducation group, especially at the 12-month follow-up.

These findings suggest that self-learning by family caregivers and group-sharing among those with similar caregiving situations, together with resources provided by health professionals, can provide adequate empowerment, skills, and competence to family carers of people with early psychosis in terms of problem-solving and caregiving skills. These

TABLE I. Characteristics of participants at baseline (n=198)

Characteristics	Self-learning programme (n=66)	Family psychoeducation group (n=66)	Usual psychiatric care (n=66)	P value
<b>Family carers</b>				
Sex				0.22
Female	41 (62.1)	42 (63.6)	44 (66.7)	
Male	25 (37.9)	24 (36.4)	22 (33.3)	
Age, y	33.22±8.90	36.10±9.12	37.50±8.13	0.14
20-29	16 (24.2)	14 (21.2)	12 (18.2)	
30-39	25 (37.9)	27 (40.9)	30 (45.5)	
40-49	16 (24.2)	17 (25.8)	18 (27.3)	
≥50	9 (13.6)	8 (12.1)	6 (10.0)	
Education level				0.16
Primary school or below	10 (15.2)	12 (18.2)	10 (15.2)	
Secondary school	43 (65.2)	40 (60.6)	44 (66.7)	
University and post-graduate degree	13 (19.7)	14 (21.2)	12 (18.2)	
Relationship with patient				0.24
Child	12 (18.2)	10 (15.2)	10 (15.2)	
Parent	20 (30.3)	19 (28.8)	22 (33.3)	
Spouse	22 (33.3)	26 (39.4)	24 (36.4)	
Others (eg, sibling)	12 (18.2)	11 (16.7)	10 (15.2)	
Monthly household income, HK\$	16 485±3758	17 985±4233	17 345±3988	0.25
5000-10 000	10 (15.2)	9 (13.6)	9 (13.6)	
10 001-15 000	25 (37.9)	22 (33.3)	21 (31.8)	
15 001-25 000	22 (33.3)	26 (39.4)	26 (39.6)	
25 001-35 000	9 (13.6)	9 (13.6)	10 (15.2)	
<b>Patients</b>				
Sex				0.22
Female	31 (47.0)	30 (45.5)	29 (43.9)	
Male	35 (53.0)	36 (54.5)	37 (56.1)	
Age, y	24.48±5.89	26.43±6.62	28.70±6.98	0.27
18-23	29 (43.9)	27 (41.0)	25 (37.9)	
24-30	28 (42.5)	33 (50.0)	34 (51.5)	
31-38	9 (13.6)	6 (10.0)	7 (10.6)	
Employment status				0.17
Employed (full-time)	31 (47.0)	30 (45.5)	26 (39.4)	
Employed (part-time)	22 (33.3)	25 (37.9)	30 (45.5)	
Unemployed	13 (19.7)	11 (16.7)	10 (15.2)	
Education level				0.12
Primary school	12 (18.1)	10 (15.2)	13 (19.7)	
Secondary school	36 (54.6)	40 (60.6)	35 (53.0)	
University/College	18 (27.3)	16 (24.2)	18 (27.3)	
Duration of illness, m	10.82±5.72	9.72±5.81	11.23±5.85	0.18
1-6	17 (25.8)	15 (22.7)	16 (24.2)	
>6-12	30 (45.5)	31 (47.0)	30 (45.5)	
>12-18	19 (28.8)	20 (30.3)	20 (30.3)	
Services receiving				0.14
Outpatient department	60 (90.9)	58 (87.9)	56 (84.9)	
Day hospital/centre	7 (10.6)	10 (15.2)	9 (13.6)	
Community psychiatric nursing service/ early assessment services for young people	50 (75.8)	45 (68.2)	48 (72.7)	
Counselling and social/recreational service	10 (15.2)	12 (18.2)	15 (22.7)	
Dosage of medication				0.11
High	14 (21.2)	13 (19.7)	15 (22.7)	
Medium	26 (39.4)	29 (43.9)	28 (42.4)	
Low	26 (39.4)	24 (36.4)	23 (34.9)	
Types of psychotropic drugs				0.14
Atypical antipsychotic	25 (37.9)	27 (40.9)	25 (37.9)	
Typical antipsychotic	25 (37.9)	22 (33.3)	26 (39.4)	
Blended antipsychotics	15 (22.7)	16 (24.3)	14 (21.2)	
Antidepressant/mood stabiliser	9 (13.6)	10 (15.2)	10 (15.2)	
Others (eg, anxiolytics)	12 (18.2)	10 (15.2)	7 (10.6)	

TABLE 2. Outcome measure scores of the three groups at baseline (T0) and 1 week (T1), 6 months (T2), and 12 months (T3) after intervention (n=191)

Outcome measure	Self-learning programme (n=64)	Family psychoeducation group (n=63)	Usual psychiatric care (n=64)	Group effect $\beta$ (95% CI)	Time effect $\beta$ (95% CI)	Group $\times$ time effect $\beta$ (95% CI)
Mean $\pm$ standard deviation (95% confidence interval [CI])						
Family Burden Interview Schedule				0.55 (0.30-0.80), P=0.01	-0.66 (-0.96 to -0.36), P=0.001	-2.01 (-3.50 to -0.39), P=0.005, Wald $\chi^2=17.61$ , effect size=0.24
T0	29.13 $\pm$ 5.01 (23.89-34.43)	29.98 $\pm$ 6.18 (23.51-36.60)	29.90 $\pm$ 5.76 (22.10-36.74)			
T1	27.03 $\pm$ 4.98 (22.11-32.08)	27.40 $\pm$ 6.01 (21.40-33.45)	30.01 $\pm$ 6.03 (23.98-36.08)			
T2	25.41 $\pm$ 5.81 (19.52-31.14)	27.04 $\pm$ 5.95 (21.12-32.52)	29.63 $\pm$ 7.12 (22.01-38.05)			
T3	21.82 $\pm$ 5.02 (16.02-28.12)	25.13 $\pm$ 7.02 (18.21-32.50)	31.94 $\pm$ 8.01 (23.63-40.05)			
Experience of Caregiving Inventory				0.40 (0.20-0.60), P=0.04	-0.44 (-0.80 to -0.08), P=0.05	-0.68 (-1.43 to 0.07), P=0.05, Wald $\chi^2=8.12$ , effect size=0.05
T0	131.22 $\pm$ 17.11 (114.11-148.32)	127.98 $\pm$ 18.91 (109.05-148.85)	123.71 $\pm$ 16.81 (106.90-140.65)			
T1	127.21 $\pm$ 16.43 (110.80-143.92)	123.22 $\pm$ 16.52 (107.52-140.83)	130.02 $\pm$ 18.42 (111.60-148.52)			
T2	119.23 $\pm$ 18.04 (101.20-137.32)	125.83 $\pm$ 20.04 (105.82-145.42)	129.52 $\pm$ 22.02 (107.40-153.54)			
T3	118.84 $\pm$ 16.41 (102.52-135.33)	120.53 $\pm$ 18.81 (101.72-139.05)	130.81 $\pm$ 19.21 (111.60-150.42)			
Social Problem Solving Inventory-Revised: short version				0.40 (0.12-0.68), P=0.03	0.45 (0.20-0.65), P=0.01	0.80 (0.30-1.30), P=0.01, Wald $\chi^2=9.68$ , effect size=0.10
T0	48.33 $\pm$ 8.56 (39.80-56.90)	50.11 $\pm$ 7.93 (42.31-58.05)	50.08 $\pm$ 6.80 (43.30-56.95)			
T1	52.22 $\pm$ 8.46 (43.82-60.83)	52.23 $\pm$ 7.03 (45.11-59.28)	49.02 $\pm$ 8.04 (41.08-57.26)			
T2	55.23 $\pm$ 9.02 (46.24-63.35)	53.02 $\pm$ 9.16 (43.89-62.36)	50.01 $\pm$ 9.51 (40.50-59.62)			
T3	58.85 $\pm$ 8.43 (50.43-65.39)	54.82 $\pm$ 9.05 (44.80-63.89)	49.83 $\pm$ 10.23 (39.70-60.16)			
No. of re-hospitalisations				0.21 (0.10-0.32), P=0.09	0.23 (0.15-0.29), P=0.08	0.46 (0.10-0.72), P=0.10, Wald $\chi^2=2.07$ , effect size=0.02
T0	1.72 $\pm$ 1.10 (0.60-2.84)	1.70 $\pm$ 1.01 (0.70-2.73)	1.57 $\pm$ 0.92 (0.63-2.54)			
T1	1.58 $\pm$ 0.98 (0.60-2.58)	1.52 $\pm$ 1.01 (0.50-2.54)	1.79 $\pm$ 0.90 (0.89-2.70)			
T2	1.63 $\pm$ 0.81 (0.81-2.34)	1.65 $\pm$ 1.00 (0.65-2.65)	1.60 $\pm$ 1.14 (0.48-2.75)			
T3	1.34 $\pm$ 0.86 (0.50-2.21)	1.70 $\pm$ 1.22 (0.49-2.93)	1.50 $\pm$ 1.31 (0.18-2.82)			
Duration of re-hospitalisation, d				-0.38 (-0.60 to -0.26), P=0.04	-0.50 (-0.84 to -0.16), P=0.01	-0.87 (-1.30 to -0.30), P=0.02, Wald $\chi^2=9.71$ , effect size=0.10
T0	16.98 $\pm$ 6.01 (10.82-23.11)	19.78 $\pm$ 7.52 (12.12-27.44)	17.85 $\pm$ 7.90 (9.87-25.55)			
T1	14.02 $\pm$ 5.85 (8.20-19.91)	16.33 $\pm$ 6.44 (10.00-22.74)	15.91 $\pm$ 7.12 (8.79-23.03)			
T2	12.08 $\pm$ 6.21 (5.90-18.32)	17.21 $\pm$ 9.02 (8.21-26.25)	17.83 $\pm$ 9.51 (8.32-27.14)			
T3	14.15 $\pm$ 8.53 (5.62-22.65)	18.02 $\pm$ 9.04 (9.00-27.10)	18.55 $\pm$ 10.11 (8.45-28.66)			

TABLE 2. (cont'd)

Outcome measure	Self-learning programme (n=64)	Family psychoeducation group (n=63)	Usual psychiatric care (n=64)	Group effect $\beta$ (95% CI)	Time effect $\beta$ (95% CI)	Group $\times$ time effect $\beta$ (95% CI)
Mean $\pm$ standard deviation (95% confidence interval [CI])						
No. of patients being hospitalised						Kruskal-Wallis test=7.81, P=0.005
T0	17	18	17			
T1	14	14	16			
T2	12	15	19			
T3	8	15	17			
Positive and Negative Syndrome Scale				-0.68 (-0.98 to -0.38), P=0.005	-0.72 (-1.13 to -0.29), P=0.002	-1.35 (-1.96 to -0.74), P=0.001, Wald $\chi^2=20.61$ , effect size=0.35
T0	130.56 $\pm$ 17.01 (112.40-147.68)	133.85 $\pm$ 20.29 (113.51-123.63)	132.78 $\pm$ 22.30 (110.51-155.13)			
T1	116.53 $\pm$ 17.82 (98.52-135.53)	117.22 $\pm$ 14.71 (102.51-131.83)	128.12 $\pm$ 9.81 (119.01-137.93)			
T2	99.64 $\pm$ 19.24 (80.03-119.02)	108.81 $\pm$ 12.21 (96.60-121.02)	129.21 $\pm$ 17.10 (112.10-146.32)			
T3	88.22 $\pm$ 17.05 (71.03-106.25)	100.11 $\pm$ 19.51 (80.10-119.73)	130.82 $\pm$ 19.81 (111.01-150.65)			
Questionnaire about the Process of Recovery				0.62 (0.23-1.01), P=0.008	0.58 (0.25-0.91), P=0.01	1.20 (0.89-1.51), P=0.003, Wald $\chi^2=17.10$ , effect size=0.28
T0	38.89 $\pm$ 9.04 (29.83-37.95)	39.12 $\pm$ 9.03 (30.08-48.26)	37.89 $\pm$ 9.12 (28.77-37.22)			
T1	41.92 $\pm$ 9.01 (32.91-40.94)	39.21 $\pm$ 9.10 (30.11-48.22)	38.12 $\pm$ 8.50 (29.88-36.62)			
T2	43.57 $\pm$ 9.82 (33.75-43.34)	40.81 $\pm$ 8.21 (32.60-49.02)	37.08 $\pm$ 9.81 (22.27-46.89)			
T3	46.24 $\pm$ 11.05 (35.19-57.39)	42.50 $\pm$ 9.22 (33.28-51.73)	39.02 $\pm$ 8.31 (30.21-47.33)			

self-learning and guided practices can be more helpful than the didactic education or information giving in psychoeducation programmes.<sup>1,5</sup> These findings are echoed by the perceived benefits of the self-learning programme identified by focus-group interviews. Furthermore, self-learning and mutual sharing of illness management, together with effective problem-solving, are increasingly important in family intervention for severe mental illness, particularly for first-time carers.<sup>1-5</sup>

The self-learning programme (and family psychoeducation group) had a very high completion rate and a low attrition rate over the 12-month follow-up. The self-learning programme is more structured than other self-help or mutual support groups that combines social support and family psychoeducation principles and materials with problem-solving and stress management approaches.<sup>2,5</sup> The self-learning programme has favourable effects on various

psychosocial health outcomes over a long term; it is user-friendly and less costly in terms of manpower and resources. Our self-learning programme is more successful than other family interventions that have 40% to 90% of completion rate and 12% to 50% of attrition rate.<sup>1,5</sup>

There are limitations to the present study. Participants were volunteers and thus were likely to be more motivated for intervention engagement; they were not blinded to the intervention allocation and there may be expectation or response bias. The carers and patients recruited had relatively high education level, above average household income, and short duration of illness, and were from only six of 25 community centres in Hong Kong. Thus, generalisability of the findings may be reduced. The self-learning programme only involved one primary carer and minimal participation by patients. Thus, the family-dyad effect was limited. The extent of

engagement and consistency of module learning and/or problem-solving practices were not known and thus further study of these co-variant effects is warranted.

## Conclusion

The professional-supported self-learning programme for family carers of people with recent-onset psychosis is effective to improve both carers' and patients' psychosocial health and mental well-being and hence to reduce patient relapse from psychosis. Future longitudinal study is warranted to investigate associations between perceived benefits, skills performance (mediator), and therapeutic mechanisms of the self-learning programme, using structural modelling and qualitative interviews/observations.

## Funding

This study was supported by the Health and Medical Research Fund, Health Bureau, Hong Kong SAR Government (#15161091). The full report is available from the Health and Medical Research Fund website (<https://rfs1.fhb.gov.hk/index.html>).

## Disclosure

The results of this research have been previously published in:

1. Chien WT, Bressington D, Lubman DI, Karatzias T. A randomised controlled trial of a caregiver-facilitated problem-solving based self-learning program for family carers of people with early psychosis. *Int J Environ Res Public Health*

2020;17:9343.

2. Chien WT, Yip LK, Lubman DI. A randomized controlled trial of a nurse-assisted problem-solving-based self-learning program for family caregivers in recent-onset psychosis. *Int J Adv Sci Eng Technol* 2019;7(S2):23-7.

## Acknowledgements

We would like to express our gratitude to all staff in the six integrated community centres for mental wellness for assisting in sample recruitment, and all participants (people with psychosis and their family caregivers).

## References

1. National Collaborating Centre for Mental Health. *Schizophrenia: Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care*. Leicester: London: British Psychological Society/Royal College of Psychiatrists; 2016.
2. Chien WT, Thompson DR, Lubman DI, McCann TV. A randomized controlled trial of clinician-supported problem-solving bibliotherapy for family caregivers of people with first-episode psychosis. *Schizophr Bull* 2016;42:1457-66.
3. McCann TV, Lubman DI, Cotton SM, et al. A randomized controlled trial of bibliotherapy for carers of young people with first-episode psychosis. *Schizophr Bull* 2013;39:1307-17.
4. Chien WT, Bressington D. A randomized controlled trial of a nurse-led structured psychosocial intervention program for people with first-onset mental illness in psychiatric outpatient clinics. *Psychiatry Res* 2015;229:277-86.
5. Bosnjak Kuharic D, Kekin I, Hew J, Rojnic Kuzman M, Puljak L. Interventions for prodromal stage of psychosis. *Cochrane Database Syst Rev* 2019;11:CD012236.