



# The effectiveness of manual-guided, problem-solving-based self-learning programme for family caregivers of people with recent-onset psychosis: A randomised controlled trial with 6-month follow-up



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## ABSTRACT

**Background:** Family intervention for psychotic disorders is an integral part of psychiatric treatment with positive effects on patients' mental state and relapse rate. However, the effect of such family-based intervention on caregivers' psychological distress and well-being, especially in non-Western countries, has received comparatively much less attention.

**Objectives:** To test the effects of guided problem-solving-based manual-guided self-learning programme for family caregivers of adults with recent-onset psychosis over a 6-month period of follow-up, when compared with those in usual family support service.

**Design:** A single-centre randomised controlled trial, which was registered at ClinicalTrials.gov (NCT02391649), with a repeated-measures, two-arm (parallel-group) design.

**Settings:** One main psychiatric outpatient clinic in the New Territories of Hong Kong.

**Participants:** A random sample of 116 family caregivers of adult outpatients with recent-onset psychosis.

**Methods:** Following pre-test measurement, caregivers were assigned randomly to one of two study groups: a 5-month self-help, problem-solving-based manual-guided self-learning (or bibliotherapy) programme (in addition to usual care), or usual family support service only. Varieties of patient and caregiver health outcomes were assessed and compared at baseline and at 1-week and 6-month post-intervention.

**Results:** One hundred and eleven (96%) caregivers completed the 6-month follow-up (two post-tests); 55 of them (95%) completed  $\geq 4$  modules and attended  $\geq 2$  review sessions (i.e., 75% of the intervention). The family participants' mean age was about 38 years and over 64% of them were female and patient's parent or spouse. Multivariate analyses of variance indicated that the manual-guided self-learning group reported significantly greater improvements than the usual care group in family burden [ $F(1,110) = 6.21, p = 0.006$ ] and caregiving experience [ $F(1,110) = 6.88, p = 0.0004$ ], and patients' psychotic symptoms

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[ $F(1,110)=6.25, p=0.0003$ ], functioning [ $F(1,110)=7.01, p=0.0005$ ] and number of hospitalisations [ $F(1,110)=5.71, p=0.005$ ] over 6-month follow-up.

**Conclusions:** Problem-solving-based, manual-guided self-learning programme for family caregivers of adults with recent-onset psychosis can be an effective self-help programme and provide medium-term benefits to patients' and caregivers' mental health and duration of patients' re-hospitalisations.

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## What is already known about the topic?

- Recent-onset psychosis is a distressing and disabling mental disorder for both young patients themselves and their first-time family caregivers.
- A few approaches to family intervention in psychosis such as psycho-education have resulted in a few positive patient outcomes, mainly mental state and relapse from illness, but comparatively few caregivers' health outcomes.
- Self-care, coping and problem-solving skills training, which is based on the stress-vulnerability and stress-coping model, have been more frequently adopted in patients with chronic illnesses, as well as their family carers. Nevertheless, more research should be conducted to prove its positive effects as an early intervention for people with recent-onset psychosis.

## What this paper adds

- Self-help, problem-solving-based manual-guided learning programme, or bibliotherapy (in addition to usual care), is more effective to improve family caregivers' and patients' psychosocial health conditions in recent-onset psychosis over 6-month follow-up, when compared to usual family support services only.
- Bibliotherapy, significantly improved caregivers' perceived burden and patients' mental state and risk of relapse over a 6-month follow-up. However, caregivers received usual family support service reported a gradual deterioration in most of the patients' and caregivers' outcomes over the follow-up period.
- This manual-guided problem-solving-based self-learning programme can also enhance families' positive experiences and appraisals of first-time caring for their relative with recent-onset psychosis.

## 1. Introduction

With the advent of de-institutionalisation, more than two-thirds of people with recent-onset psychosis (up to the first 6–12 months of illness) in Western and Asian countries are mainly resided in the community and being taken care by their families; whereas, both patients and family caregivers much depend on access to community patient/family support services (Chan, 2011; Pharoah et al., 2010). Carers of a family member with psychotic disorders, particularly first-episode or recent-onset psychosis, are confronted by varying degrees of physical and psychosocial demands in association with unpredictable and abnormal behaviours

of the patient and social stigma and discrimination regarding mental illness (Chien and Chan, 2013). Recent systematic reviews suggest that psycho-education programmes for patients with psychotic disorders can enhance their knowledge and insight into the illness and coping with their psychotic symptoms, thus improving prognosis (Xia et al., 2011, 2013).

However, there has not yet been adequate care and attention to the family carers' health and well-being while these caregivers are often an important source of support and facilitation for these patients' treatment and rehabilitation. Mental healthcare or psychiatric treatment guidelines in both the US and UK suggest that family-based intervention can be an integral of a community-based rehabilitation programme to produce significant positive patient outcomes in early psychosis whenever their family caregivers can improve in coping with their caregiving role and psychosocial functioning (Lehman et al., 2004; The National Collaborating Centre for Mental Health, NICE, 2009). Research evidence from the West has demonstrated the clinical efficacy of a few approaches to family intervention, especially psycho-education and behavioural or crisis management programmes, in reducing patients' relapses from their psychotic disorders (Berglund et al., 2003; Petrakis et al., 2013).

Recognising that many families may find it difficult to regularly participate in psycho-education or other face-to-face interventions because of time constraints and feeling disempowered or stigmatised by the formal mental health services (Lee et al., 2006), a growing body of research has examined the feasibility of self-help programmes for families caring for a patient with psychotic disorders in Western countries (Edwards and McGorry, 2002; Marshall and Rathbone, 2011). A structured self-help, educational programme may empower caregivers (or service users) to identify their own life problems and needs and minimise professional input, as evidenced in other family support programmes for people with chronic physical and terminal illness such as frailty, stroke and cancer (Foster et al., 2015; Savundranayagam et al., 2011; Valeberg et al., 2013). While there is no practice guideline available in Hong Kong and China for schizophrenia care, the UK Schizophrenia Guidelines (The NICE, 2009) also suggest that ethnically adapted family intervention in psychotic disorders should be designed and evaluated on its benefits to patients' mental health conditions and illness relapse, as well as their caregivers' negative caregiving experiences and distress. This can enable both patients and caregivers to better engage with the intervention. Therefore, more research on an effective approach to family intervention is highly recommended to improve the standard/quality of

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