

## **Appendix 1 Details of the development of the Family-led **Peer Support** Group and its research evidence**

We developed a 12-session family-led **peer** support group program for Hong Kong Chinese caregivers of people with schizophrenia and found in our first small-scale clinical trial for 24 and 38 families of outpatients with schizophrenia that they reported significantly greater improvement in both family and patient functioning and number of re-hospitalizations, when compared with standard psychiatric care over a three-month in 2004(1) and a 12-month follow-up in 2008(2), respectively. The findings with a short-term follow-up have provided preliminary evidence that **peer** support groups could be an effective family-initiated, community-based intervention for Chinese patients with schizophrenia in Hong Kong.

Further controlled trials of the support group program (provided with more emotional and practical assistance and coping skills training for family members) indicated longer-term effects (i.e., 12-18 months) on two major family outcomes (e.g., family burden and distress), compared with either family psycho-education group or standard care(3,4). The interventions were delivered at outpatient clinics over a 6-month period and the **peer** support group program consisted of 12 bi-weekly (every two weeks) group sessions, each lasting about 2 hours. **Peer** support consistently produced greater improvements in patient and family functioning and caregiver distress over the intervention and follow-up periods, compared with the other two intervention modalities. Nevertheless, the number of re-hospitalizations and symptom severity did not decrease significantly in the three groups.

Based on the findings of our four previous clinical trials mentioned above, the family **peer** support group program (**FPGP**) was expanded from 12 to 14 group sessions (from six to nine months), including more problem-solving and care-giving practices, specific Chinese

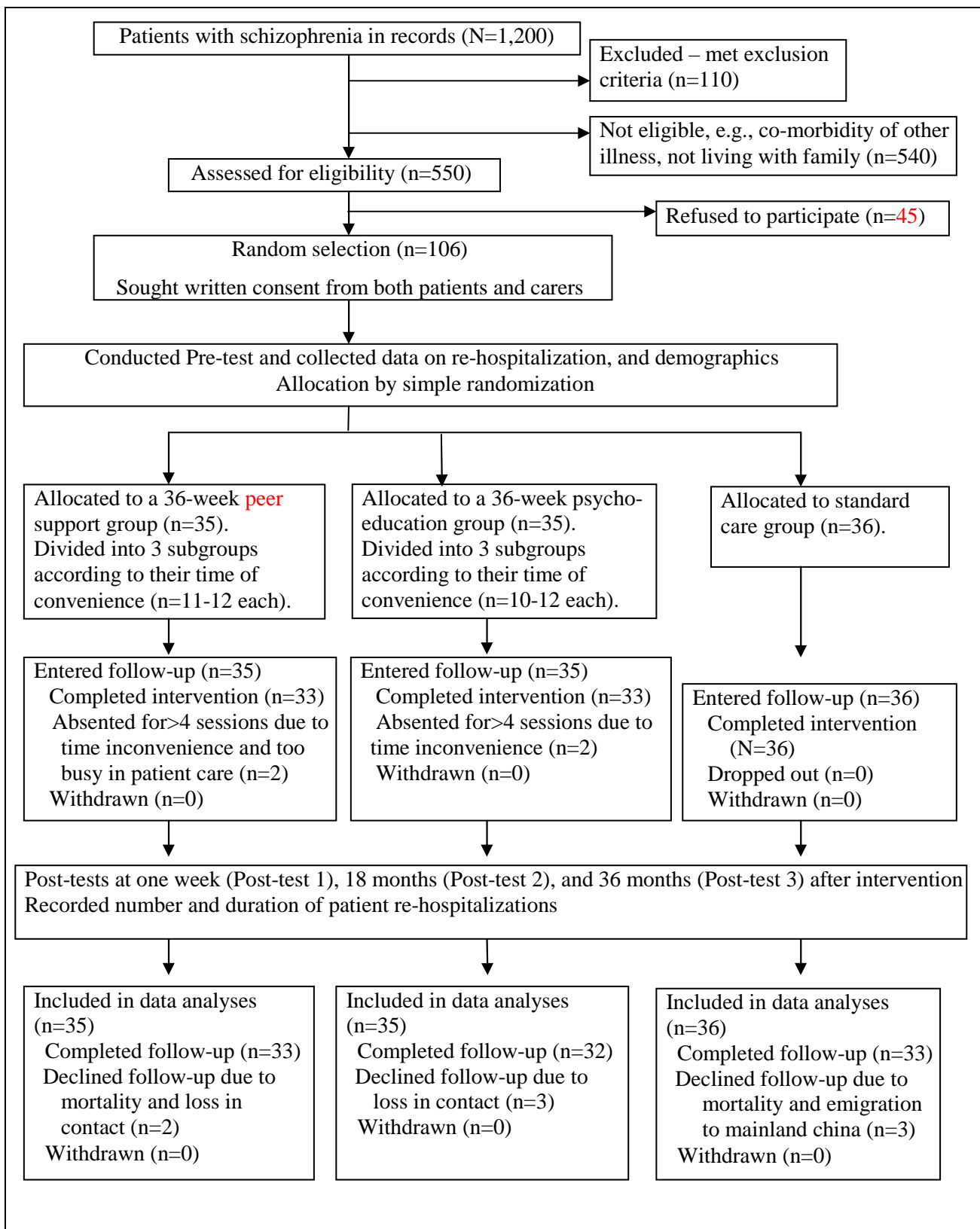
cultural issues (e.g., discussing stigmatization toward mental illness and practical assistance outside group sessions) and patient participation in some sessions. A peer-leader (elected by group members and trained by researchers with a 2-day leadership workshop) coordinated and led all of the group sessions and he/she worked closely with a group facilitator (first author) who acted as a resource person and provided support for the group development at its early stage.

This trial evaluated the effectiveness of this modified 14-session **FPGP**, a psycho-education group program and standard psychiatric care (lasting about nine months) for Chinese patients with schizophrenia on both patient and family health outcomes and functioning over a 3-year follow-up.

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## Appendix 2 Flow diagram of clinical trial for three study groups



### **Appendix 3 Psycho-education Group Program for Family Caregivers**

The psycho-education group program contained 14 bi- or tri-weekly sessions, each lasting around 2 hours. The treatment program consisted of four stages: orientation and engagement (two sessions), educational workshop (4 sessions), therapeutic role and strength re-building (6 sessions), and termination (2 sessions), based on the family group programs by **Chien and Wong and the research team conducted in Hong Kong (1), Ran et al (2) and Li and Arthur (3) conducted in mainland China**. The program topics and contents were also selected and prioritized on the basis of the results of a needs assessment of families of Chinese people with schizophrenia in Hong Kong (1,4). Patient participation was essential and important at least within a few sessions in which the concepts, prognosis and course of schizophrenia and its treatment and services available, effects of the illness to patients and their families, medication use and its compliance, and improvement of family environment and support thoroughly taught and discussed. In addition, patients were also highly encouraged to attend other sessions if preferred and invited by their family caregivers. This was because some family caregivers might feel embarrassed and distressed in discussing about their patient's problem behaviors and their intense and negative feelings towards the patient during open discussion and practice rehearsals on their care-giving. This arrangement, which was found practical and effective in previous clinical trials on family psycho-education intervention (1,2,5,6), could facilitate the choices made by the family caregivers on patient participation and discussion about some difficult and patient-blaming family situations and thus provided the most comfortable and open environment for family participation in the group sharing, discussion and skills training.

The length of the psycho-education group program (i.e., nine months) was shorter than those suggested by Ran et al (2), McFarlane et al (7) and Xiong et al (6), which lasted about 12 months. A shorter duration needed in this program was due to highly accessible family participants who were living in non-dispersed or clustered residences and preferred to or requested for receiving specific advice, support and information in a shorter period of time. Despite having a shorter duration, the participants in this group program had more frequent group meetings (bi- or tri-weekly) and the number of topics or amount of content of this program was very similar to those with a longer duration.

Based on the psycho-educational family approach **used by our research team (1,2,6)** and the vulnerability–stress model (8), an interactive psycho-educational family group program was developed and accentuated the improvement of families' beliefs and attitude toward

mental illness, sharing of experiences of caring for patient, care-giving role adoption and strengths re-building, learning effective communication with patient and family members, and enhancing problem-solving and coping skills in caregiving.

The program also used a culturally sensitive family intervention model, which had been found successful and effective in Hong Kong Chinese families of outpatients with schizophrenia (1), and some cultural tenets that were based on the principles of Confucius (e.g., high values of collectivism over individualism and beliefs in family inter-dependence and harmony and strong kinship ties), were carefully considered when building trust relationship between therapist and participants and discussion about family care-giving issues and situations.

<b>Phase/ Session</b>	<b>Goals</b>	<b>Main content</b>	<b>Responsible staff</b>
<u>Phase 1</u>		<u>Orientation and engagement</u>	
<i>Sessions 1 – 2</i> (patient included in session 1)	To orientate to the program and establish trust relationship between participants themselves, and between participants and instructor(s)	Orientation to the program and introduction of group instructors and members to one another; Negotiation of goals and roles and responsibilities; ensuring confidentiality; and An overview of the topics and their relevance to group members.	Research nurse and researchers
<u>Phase 2</u>		<u>Education workshop</u>	
<i>Session 3</i> (patients included)	To understand schizophrenia, short- and long-term effects to patients and their families	Presentation of a video of one family caring for a person with schizophrenia, with descriptions of symptoms and illness behavior of the patient; Discussion about the importance of knowledgeable involvement by family members to patient and the whole family; Discussion of the mental illness and its effects to family; and Sharing of individual problems in symptom management and practice problem solving in a few family situations.	Research nurse

<i>Session 4</i> (patients included)	To understand the theoretical concepts, risk factors, prognosis, and course of schizophrenia	An overview of theories of schizophrenia from a bio-psychosocial perspective; Discussion of the psychiatric conceptualization of schizophrenia and a review of etiology, symptoms, treatment, and prognosis; and Sharing of experiences in observing and managing illness in social situations.	Research nurse and one psychiatrist
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<i>Sessions 5-6</i>	To recall and share about major symptoms of schizophrenia and their effects on family life	Information sharing about illness-related behaviors and problems and discussion about their effects to family lives; Sharing of intense emotions toward patient and suggestion on how to deal with negative emotions to patient; and An overview of treatment and rehabilitation programs.	Research nurse
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*Phase 3* *Family's therapeutic role and strength rebuilding*

<i>Session 7</i> (patients included)	To realize the effects of medications and its compliance	Explanation of positive and negative effects of medications for schizophrenia; Discussion about the importance of drug compliance and maintenance; Discussion of the specific problems related to the side-effects; and Role playing and discussion about strategies in supporting and enhancing patient's medication adherence; and home assignment for practice.	Research nurse and one psychiatrist / community psychiatric nurse
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<i>Sessions 8-9</i>	To openly share and better understand about individual concerns and cultural issues	Discussion about Chinese culture of family and mental illness; Sharing of intense emotions and feelings about patient care provision and family interactions; Information sharing about schizophrenia and its related illness behaviors and individual management strategies; Role play and discussion about the ways to deal with negative emotions to patient; and Home assignment for practice in emotional management and constructive, open expression of feelings in family.  * Review home practice in-between sessions and discuss about difficulties encountered and strategies in solving their problems	Research nurse and one researcher
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<i>Session 10</i> (patients included)	To improve the family environment and social support	Introduction of the role of environmental stress as a risk factor for acute exacerbations of schizophrenia; Discussion about the importance of family as a source of social support and its role and responsibility within the social environment of patient; Among group members and invited experienced caregivers, sharing of family stress and expressed emotion; and Discussion about some effective ways for improvement of family relationships and emotional environment.	Research nurse and one researcher
<i>Sessions 11-12</i>	To manage psychosocial needs for themselves, patient and family and to cope with stress in care-giving	Discussion about each member's psychosocial health needs; Information about medications, illness management, and available community mental health services; Effective communication skills with patient and seeking social support from others; - Practicing communication skills under supervision by the research team and clinical staff (4-5 members per group). Exploration of home management strategies e.g. finance and budgets, environment and hygiene; Sharing of coping skills used and Enhancing problem solving skills by working on some individual patient management situations; and Practicing coping skills learned during the sessions to real family life (in-between group sessions) and evaluate the results. * Review home practice in-between sessions and discuss about difficulties encountered and strategies in solving their problems.	Research nurse and a clinical psychologist
<u><i>Phase 4</i></u>		<u><i>Preparation for termination</i></u>	
<i>Sessions 13-14</i>	To review the previous learning and to prepare for group termination	Crisis intervention conducted for managing attempted suicide, aggressive and destructive behaviors; Review and summary of their learning in previous sessions; Finalizing their problem-solving, coping and home management strategies learned and information shared among group members; Preparation and discussion on termination issues e.g. separation anxiety, independent living and use of coping skills learned; Evaluation of learning experience and goals achievement; and Explanation of post-intervention assessment and follow-up.	Research nurse and researchers

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*Note.* The psycho-education group program was held bi-weekly or tri-weekly for nine months. Patients were invited to attend at least five sessions as indicated in the above table and encouraged to attend the remaining nine sessions as their family caregivers preferred.

## References

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