

Title:

A Randomised Controlled Trial of a Family-led Mutual Support Programme for People with Dementia

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Keywords: controlled trial, mutual support group, family-centred care, dementia

Aim

This controlled trial was to investigate the effectiveness of a family-led mutual support group programme for Chinese people with dementia on caregivers' quality of life, burden and social support and clients' mental state and institutionalisation.

Background

The prevalence rate of dementia in Hong Kong was estimated to be over 430,000 persons (i.e. 7.5% of those aged 65 years and older) in 2008; as in Western countries, it increases from 2% in persons aged 65 to 75 years to more than 27% in those aged 85 and older (Chien & Lee, in press). Local dementia care services mainly include institutional (inpatient and hostel-resided) and daytime and respite care for clients and/or their family caregivers as needed. Family members often experience a heavy burden and emotional distress in caring for a relative with dementia, contributing to physical health problems and immunological dysfunctions, psychological problems such as depression and anxiety, social relationship changes, and social activity restrictions. These may also result in higher risks for mortality. Recognising the personal and psychosocial health impacts of dementia care, different psychosocial interventions were developed in the U.S. such as the REACH programme (Belle *et al.* 2006), which indicate empirical evidence of its effectiveness on improving caregivers' mental health and delaying clients' deterioration of illness condition and institutionalisation. However, a few limitations of recent family studies include: the paucity of clinical trials with comprehensive education, skill training and supportive interventions, broad range of outcome measures, sufficient study power, poor adherence to

treatment protocols, and/or under-estimation of clients' problem behaviours and caregivers' health needs (Belle *et al.* 2006, Brodaty, Green & Koschera 2003).

Among a few effective intervention approaches, a multi-component educational and supportive program may be an effective one in responding to complexity and varying levels of needs and difficulties in dementia care (Brodaty *et al.* 2003). The intervention should involve multiple helping strategies such as information giving, problem solving skills training, social support, and stress management techniques for enhancing caregivers' knowledge and skills in dementia care. Some of these approaches also reported significant impacts on helping caregivers deal with clients' behavioural problems, but few indicated therapeutic effects on improving family caregivers' health condition or mental well-being. A few trials support the benefits of an effective peer-led mutual support group to improve families' general health and to provide them appropriate support services (Chien & Lee 2008).

Most family studies have focused on Caucasian populations and few studies have been carried out with Asian populations where significant meanings of family caregiving and behaviours are attached to intimate interpersonal relationships and preferring collectivistic actions and practical assistance ('actions stronger than words') with family members (Chien & Lee 2008). Thus, little is known about whether a peer-led group intervention that integrate educational, supportive, and open communication and sharing components can be applied successfully to a Chinese family-oriented culture. To address the gaps in quality of care for Chinese people with dementia, a new community-based Family Mutual Support Programme in Dementia Care (FMSP-DC) was developed. This study was to evaluate the effects of the FMSP-DC on Hong Kong Chinese families of clients with dementia on caregivers' quality of life, burdens and social support, and on clients' symptoms and rates of institutionalisation.

Design

This study was a randomised controlled trial with parallel group, pre-test and post-test design to test the effectiveness of a family-led mutual support group for clients with dementia residing in the community on both clients' and caregivers' health outcomes.

Methods

The participants in this study were family members caring for a relative with dementia at home, and they were recruited from one of the four largest dementia care centres in Hong Kong, which consisted of about 500 clients primarily diagnosed with dementia. Eighty of 400 pairs of eligible patients and their primary family caregivers were selected randomly from the client list of the centre, using the computer generated random numbers. They were then randomly assigned into either the FMSP-DC or routine care group (control), each consisting of 40 family dyads. Based on previous studies in both Western and Chinese populations (Brodaty *et al.* 2003, Chien & Lee 2008), this sample size could detect any significant difference between groups at a 5% significance level, with a power of 80% and 20% of potential attrition (Cohen 1998).

The inclusion criteria of family caregivers were those who were: aged ≥ 18 years and living with and caring for the client diagnosed as Alzheimer's type of dementia according to the DSM-IV (American Psychiatric Association, 1994). Those who had a mental illness themselves or cared for their patient less than two months were excluded. This trial was approved by the Research Ethics Committees of The University and the dementia centre. Written informed consent was obtained after the purpose and procedures of the trial had been explained. With consent obtained, the family dyads were assigned randomly to either routine dementia care or the FMSP-DC.

The FMSP-DC consisted of eight, bi-weekly, 2-hour group sessions and lasted about six months. Seven themes of family supportive care identified from the literature and found effective in previous studies for dementia caregivers (Belle *et al.* 2006, Brodaty *et al.* 2003, Chien & Lee in press), including: (1) information about client's illness, prognosis and current treatment and care; (2)

development of social relationships with close relatives and friends, and thus a satisfactory extended social support network; (3) sharing and adaptation of emotional impacts of caregiving; (4) learning about self-care and motivation; (5) improvement of interpersonal relationships with family members and the client; (6) establishing support from the community groups and health care resources; and (7) improvement of problem solving skills in family care. To strengthen the problem solving skills within family, one or two experienced family caregivers were invited to share their personal caregiving problems with the families during the third and fourth sessions and, under the guidance of the group facilitator who was an experienced psychiatric nurse.

All participants in both the FMSP-DC and control group received the routine family services provided by the dementia care centre. The services included: (1) medical consultation of client and advice to family on client's illness, treatment plan and effects of medications provided by a psychiatrist; (2) advice and referrals of social welfare services by a social worker; (3) monthly educational talk in dementia care and social and recreational activities conducted regularly by a psychiatric nurse and other centre staff. The programme also used culturally sensitive family care strategies to address the Chinese cultural tenets in respect to family relationships and value orientation, e.g., valuing collectivism over individualism and emphasising filial obligation and kinship ties.

One researcher who was blind to the group assignment administered the outcome measures, including caregivers' burden (Family Caregiving Burden Inventory; Chou, Jiann-Chyun & Chu 2002), quality of life (WHOQOL- BREF; Leung *et al.* 1997) and social support (Six-item Social Support Questionnaire; Sarason *et al.* 1987) at baseline before randomisation and at post-test at one week after intervention. The clients' mental state was assessed using the Mini Mental State Examination (Chiu *et al.* 1994). The Chinese versions of these scales have demonstrated good reliability and validity among Chinese patients and their families in previous studies (Chien & Lee 2008, Chou *et al.* 2002). The frequency and length (days/month) of residential placements or hospitalisations in the previous three months were also measured.

Repeated-measures MANOVA test was performed for the outcome variables to determine the treatment effects, followed by post-hoc Tukey's HSD analysis (i.e., protected Type I error). The data analysis used an intention-to-treat basis that maintained the advantages of random allocation.

Results

The mean age of the 80 family caregivers was 40.63 (SD=8.21) years (range=32-60) and 58 of them (72.5%) had completed secondary school education. Their average monthly household income was HK\$12,510 (UK£1,043). Fifty-two of them were female (65.0%), 30 (37.5%) were children and 32 (40.0%) were spouses. The mean age of the 80 clients was 68.1 (SD=7.95) years (range=60-80) and their average duration of illness was 1.8 (SD=1.0) years. Forty-three of them (53.8%) were male, 50 (62.5%) received cholinesterase inhibitors (e.g., donepezil) or *N*-methyl-D-aspartate antagonists (e.g., memantine) and 42 (52.5%) also received low dose of antipsychotic medications (e.g., haloperidol).

The average contact hours for caregiving per day was 6.0 (SD=1.5; range=3.8-9.0). Sixty-five of the clients (81.3%) were at the early (ambulatory) stage of dementia and presented low to moderate levels of impairments in activities of daily living such as bathing, communication and toileting, whereas 10 (12.5%) were at the late stage.

There were no differences between the study groups with respect to their socio-demographic characteristics, types and dosage of medication, or mean scores of the baseline measures, using Student's or Chi-square test. Thirty-eight (95.0%) of the families completed the FMSP-DC and one client in both FMSP-DC and control group died at post-test. However, no family in both groups dropped out from the study.

There was a statistically significant difference between the two groups on the multivariate test of significance for the outcome variables ($F=5.1$, $df=3,78$, $p=0.005$; Wilks' Lambda, $\lambda=0.84$, partial $\{\eta; \eta\}^2=0.23$). The mean scores and results of MANOVA for the

outcome measures are shown in Table 1. The results indicated that there were statistically significant differences between the two groups in the family caregivers' burden and quality of life and clients' symptoms severity and frequency and duration of institutionalisation at the post-test. Post-hoc comparisons indicated that, in the dementia care program, the caregivers' burden and quality of life and length of institutionalisation at the post-test showed significantly greater improvements, compared with routine care only.

Insert Table 1

Discussion

The results provide evidence support for the effectiveness of the FMSP-DC to the psychological distress and quality of life of family caregivers and delay the deterioration of the clients' illness after the completion of the intervention. Consistent with a few trials, the clients with dementia whose family caregivers participated in an educational and supportive group indicated a certain extent of improvements or slow worsening in a few pathological behaviours (e.g., hallucination and aggression), and the number and length of institutionalisation (Brodaty *et al.* 2003, Chien & Lee 2008). Since dementia care has been an increasing burden to families and healthcare services, it is worth to note that the families who underwent this support group reported significant improvements in their caregiving burden and quality of life, with an increase of social support network and satisfaction. This lowering in psychological distress allows for better caregiver coping when providing care for the dementia client. Stress associated with caregiving can be relieved by the psychosocial support from group members in similar family situations and life difficulties together with the professional support, helping caregivers to identify concerns and develop systematic problem solving techniques to resolve them.

The findings also suggest that providing a culturally sensitive and peer-led mutual support group intervention for these families in this trial can improve caregivers' psychosocial

health condition and can reduce clients' rates of institutionalisation. Further research is recommended to examine the net and longer-term effects of the FMSP-DC on improving knowledge and skills in caregiving with reduction of burden and clients' neuro-pathological behaviours (e.g., hallucination). Without any blinding to the study participants, families receiving routine care were recruited as the control group and thus, Hawthorne effect could not be excluded. Further process and outcome evaluation of this group intervention with a larger, diverse samples and a longer follow-up period can provide more convincing evidence applicable to Chinese and/or Asian populations in dementia care.

Relevance to clinical practice

This study supports the family-led mutual support group (FMSP-DC) to be an effective community-based intervention for families of Chinese clients with dementia, as compared with routine care. The group programme was time-limited to six months in one day-care centre in this trial and it can be applied to other community care settings in Hong Kong and mainland China as well as other countries, for further testing on its wider clinical use.

Contributions

Study design: LQW, WTC; data collection and analysis: WTC; manuscript preparation: LQW, WTC.

Funding source and conflict of Interest

The study was funded by the School of Nursing, The Hong Kong Polytechnic University. The authors do not have any conflict of interest with respect to this publication.

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Table 1. Study outcomes and results of MANOVA in family mutual support and routine care groups (N=80)

Instrument	DCMP (N=40)				Standard care (N=40)				F (1,78)
	Baseline		Post-test		Baseline		Post-test		
	M	SD	M	SD	M	SD	M	SD	
FCBI (0-96) ^a	68.2	11.9	55.2	15.0	68.8	16.7	65.0	18.1	7.2**
WHOQoL (28-144)	65.9	13.0	78.8	19.0	67.0	13.5	68.9	15.7	6.5**
SSQ6									
No. of support person	3.1	1.0	4.4	2.0	2.9	1.1	2.9	1.3	3.2
Satisfaction (1-6)	5.3	1.8	6.2	3.1	5.5	1.1	5.6	2.1	3.0
MMSE (0-30)	17.5	4.7	18.1	4.0	17.3	3.9	17.2	4.1	1.9
Rate of institutionalisation									
Number ^b	5.1	0.9	3.8	1.0	5.5	1.2	5.2	1.3	4.3*
Duration ^c	13.8	4.0	10.1	5.1	14.2	3.8	17.9	7.1	5.8**

FCBI, Family Caregiving Burden Inventory; WHOQoL, World Health Organization Quality of Life Scale (Brief H.K. version); SSQ6, Six-item Social Support Questionnaire; MMSE, Mini Mental State Examination.

^a Possible ranges of scores are written in the parentheses.

^b Average number of residential placement/hospitalisation over the past three months.

^c Length of institutionalisation to a residential home or hospital unit in terms of average number of days/month over the past three months.

* p< 0.01; ** p< 0.001.