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An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China

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**An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China**

**Keywords:** experimental study, mutual support group, family caregivers, dementia, Chinese.

**Abstract**

When caring for an older relative with dementia, family members experience considerable distress and burden. Literature reviews show that supportive group interventions for these caregivers have significant positive effects on improving their distress and quality of life, but not consistent and conclusive. Limited research is found in Asian populations. This study tested the effectiveness of a 12-session bi-weekly mutual support group program for Chinese family caregivers of a relative with dementia in Guangzhou of mainland China, when compared with standard family support service. An experimental study with pretest and post-test, parallel groups design was conducted. A randomized sample of 78 family caregivers, 39 in each of the experimental and control groups, from one regional dementia care center participated in the study. A protocol was specifically designed by an advanced practice nurse to guide the mutual support group process and the facilitator and peer leader training, based on evidence from the literature on family support group intervention in Western countries. The results of ANOVA tests indicated that the mutual support group participants had significantly greater improvements in distress levels and quality of life than the control group. There were only mild changes in the demands for mental health services in both groups at post-test. These findings support the effectiveness of mutual support groups to offer psychosocial support to Chinese family caregivers in dementia care beyond routine community mental health care.

**Introduction**

In developed countries, the prevalence rates of dementia are estimated to increase from 2% in persons aged 65 to 75 years to more than 30% in those aged 85 and older (Chien 2005; Cummings *et al* 2002).  In 2009, the prevalence rate of dementia in Guangzhou was about 4.2% overall or about 320,000 persons aged 65 years and older (All China Data Center 2010). Dementia is characterized by progressive decline in cognitive and functional abilities, as well as psychological and behavioral disturbances such as psychotic and depressive symptoms and agitated and abnormal behaviors. People with dementia are increasingly dependent upon family members to provide daily care or fully depend on them at the latest illness stage (Heru, Ryan & Iqbal 2004).

Family members often experience a heavy burden and emotional distress in caring for a relative with dementia, which may also contribute psychosocial health problems and higher risks for mortality (Brodaty, Green & Koschera 2003). The negative outcomes associated with care-giving are well documented and involve a wide variety of health concerns. They include psychological disturbances (e.g., depression and anxiety), reduced physical functioning and immunological dysfunction, poor interpersonal relationships, and social activity restrictions (Belle *et al* 2006; Mitrani & Czaja 2000). An accumulation of these pressures can threaten caregivers' ability and self-efficacy in taking care of their relative with dementia at home.

To address the psychosocial health effects of dementia care, different psychosocial interventions were developed in the United States, such as the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program and the Program of All-Inclusive Care for the Elderly (PACE). These programs mainly consisted of supportive and educational strategies in helping these caregivers understand the illness and its care (Belle *et al* 2006). Some of them have indicated preliminary evidence of its effectiveness on improving

caregivers' overall health condition and delaying clients' institutionalization (Schultz, Martire & Klinger 2005; Brodaty *et al* 2003). However, only few indicated significant effect on reducing clients' behavioral problems and thus improving caregivers' distress or quality of life (Schultz & Martire 2004). In addition, most family intervention studies have focused on Caucasian populations and few studies have been carried out with Chinese and Asian populations where great importance is attached to intimate interpersonal relationships with and a need for social support from family members (Chien & Lee 2011). Therefore, this study was to test the effect of a family mutual support group program that incorporated educational, supportive and community mental health care components in a group of family members caring for a relative with dementia at home.

## Literature Review

### Family-centered Intervention in Dementia Care

Among various intervention approaches to dementia care in the community, family focused psychosocial interventions are of utmost importance and more significant effects on both clients' and families' health outcomes (Brodaty *et al* 2003). Skills requisition in behavioral techniques, symptom management and social problem-solving have been commonly used to help these caregivers manage the behavioral problems of their relatives with dementia and improve their ability in care-giving (Chien & Lee 2011). Results of a single-centre controlled trial for home-resided clients with dementia in Hong Kong indicates that supportive family group intervention can improve caregivers' overall health conditions (Fung & Chien 2002), whereas a family psycho-education group program for people with dementia produced positive effects on both clients' and their families' mental health and daily functioning (Chien & Wong 2007).

Not only focused on the community care of people with dementia, the psychological and behavioral reactions of family caregivers towards this chronic and 'incurable' illness such as anticipatory grief, social restriction and their uncertainty about the hardships of long duration care-giving have been of great concerns (Asen 2002). Interventions for family members of people with dementia should focus on important aspects of coping with stress such as the establishment of their effective coping strategies to enhance psychological well being and reduce burnout in care and learning of problem-focused coping for enhancing their self-efficacy in care-giving (Ulstein *et al* 2007).

However, a few limitations of the recent family studies are identified. First, the paucity of controlled trials with cultural sensitive, community-based and family-led interventions and a wide variety of psychosocial outcome measures has been noted (Belle *et al* 2006). Second, there is very small sample size such as 10 to 20 in each study group and insufficient study power (Schultz *et al* 2005). Third, poor adherence to published dementia care guidelines, including under-estimation of family caregivers' health needs (Heru, Ryan & Iqbal 2004; Hinrichsen & Niederehe 1994). Last, the fact that many programs have not involved good partnership between health professionals, caregivers and/or the clients and not been integrated into the community healthcare system (Schultz *et al* 2005).

**Cultural Considerations for Family Support and Care**

Family care-giving refers to activities provided by the family members to those who have established roles and relationships such as wife-husband and child-parent and are not able to provide for themselves, in order to take care of their daily living (McCallion & Toseland 1995). In the Chinese society and other Asian countries, there is an obligation to care for a dependent older relative that is influenced by cultural values and filial responsibility (Chou, LaMontagne & Hepworth 1999; Choi 1993). Recent family studies have shown that

such belief of filial obligation often causes a heavy burden for family caregivers, which can be progressively overwhelming (Li & Bucchel 2007; Almberg, Grafstman & Winbald 1997). These culture factors, together with limited social resources to provide suitable institutional care for elderly, may cause many Chinese families to continue keeping their older people with dementia at home even when they are burnout.

In mainland China, as well as in Hong Kong and Taiwan, there are relatively few nursing home institutions, when compared with Western countries such as the United States (Chien & Lee 2011). Families are expected to care for their dependent elders at home. Many Chinese families are dominated by Confucianistic principles, with a belief in showing respect, filial piety and obligation to care for an elder and a strong emphasis on specific roles and proper relationships among the family members (Chou *et al* 1999), are expected to take care of their older family members at home. This is also particularly true for Chinese women such as wife, daughter, and daughter-in-law, because of the culturally defined gender roles in which women are believed to be fully responsible to provide family care (Chien 2005; Fung & Chien 2002). Thus, Chinese families of an elderly client with a debilitating chronic illness such as dementia may need to care for the dependent old aged more often and over longer periods of time, with inadequate social support (Bond 2009).

**Distress and Quality of Life among Family Carers of a Relative with Dementia**

Individual family caregivers can respond differently to the stressors of caring situations and demands. Recent research has identified factors that affect caregivers' demands of care-giving, resulting in burden and distress, mainly including: patient's levels of functional deficits, self-care ability and disturbing behaviors (Almberg *et al* 1997); caregiver's personal characteristics such as age and education (Schult *et al* 2005); and family relationships and social support (Chien 2005). High levels of stress in caregivers have

significantly correlated with the mortality of clients with dementia (Roselands, Van Oost & Depoorter 2008).

Fung and Chien (2002) and Schults and Martire (2004) have indicated that the perceived quality of life of families caring for a relative with dementia or other chronic illnesses in the community is another important factor influencing the family well-being. Quality of life refers to the perceived psychological well-being of an individual in the dimensions of physical, mental, social and financial activities, and has gained significant evidence as an important psychosocial outcome (World Health Organization 1995). Research also suggested that an individual's perceived quality of life is associated with the amount and types of available social support (Schultz & Martire 2004; Donaldson, Tarrier & Burns 1997). As providing care to a relative with dementia often induces social isolation and restriction to family caregivers, their life satisfaction may be much lowered, thus requiring for assessment and intervention.

**Mutual Support Groups for Family Caregivers**

Peer-led mutual support groups have been increasingly used to help not only people with chronic illness enhance self-care and illness management but also their families cope with care-giving. However, the effectiveness of mutual support groups for family caregivers of clients with dementia have been under studied and in a few studies, is found inconclusive (Fung & Chien 2002). Individual and group therapy directed by therapists or health professionals usually have mandatory participation, thus making it difficult to establish empathy and open discussion, or family caregivers have limited choice, sense of control and empowerment during therapy sessions (Mitrani & Czaja 2000; Dunkin & Anderson-Hanley 1998). These difficulties may have been overcome by using mutual support group interventions, which operate on voluntary participation and gather members that have similar

problems and situations of care-giving (Galinsky & Schopler 1995). These support groups

also provide free choice and greater control of the group ideology and processes (Chien, Chan

& Thompson 2006). Perceived benefits for participants in per-led support groups include

openly sharing feelings and experiences about similar concerns in a supportive environment

and informing caregivers of the effects of their relative's chronic disabilities and appropriate

community resources (Fung & Chien 2002; Buckwalter 1996).  Family participants may also

be inspired to initiate new social support network in collaboration with their group members

(Chien 2005).

In addition, mutual support group intervention usually require less intensive training

for health professionals as facilitators than other psychosocial intervention approaches such as

behavioral management programs or cognitive therapy. Support groups can also provide a

flexible, interactive client-directed approach to help families cope with their caring role.

Despite the popularity of support group interventions, there is little research evidence

supporting enthusiastic claims for peer support alone contributes to improve caregivers'

distress and quality of life as well as the care of the neurological and psychiatric symptoms of

clients with dementia.  There is none in mainland China for Chinese families, taking care of a

relative with dementia. Previous studies on support groups were mainly based on qualitative

exploratory, case studies, or cross-sectional descriptive designs (Chien & Lee 2011; Chien

2005; Dunkin & Anderson-Hanley 1998).  Studies by Fung and Chien (2002) in Hong Kong

and Toseland *et al* (1989) in the United States concluded that a supportive group in dementia

care is a potential effective alternative approach of family intervention that deserves greater

attention by mental health professionals in better supporting these families. However, there

are only few studies on the effectiveness of mutual support groups for family caregivers

caring for a relative with dementia, particularly in Asian countries (Chien & Lee 2011).

Therefore, this experimental study reported here was one of a few experimental studies in

Chinese populations to use mutual support group for family caregivers of people with

dementia, with a specifically designed treatment protocol.

**Study Aims and Hypotheses**

This study aimed to evaluate the effectiveness of a mutual support group for Chinese

family caregivers of a relative with dementia, compared with standard family care in the

community.  The main hypotheses were that the family caregivers of community-resided

people with dementia participated in the mutual support group would show significant greater

reduction on their level of distress, greater improvement in their quality of life and more

appropriate service utilization, when compared with those who received usual family support

services only.

**Methods**

**Design**

This experimental study with parallel groups pre-test and post-test design was

conducted to compare the effectiveness of a mutual support group program for family

caregivers of relatives with dementia with that of those who used routine family support

services. The study was undertaken over a period of 24 months, between January 2010 and

March 2011.

**Sample and Setting**

The study subjects were family caregivers of elderly clients diagnosed with dementia

according to the criteria specified in the Diagnostic and Statistical Manual, DSM IV

(American Psychiatric Association 1994).  Operationally defined, this older client had to be,

aged 60 or above, whose attending psychiatrist had diagnosed with dementia (mainly

Alzheimer's type and cerebrovascular diseases), and who lived at home with the family at

recruitment. The caregivers were recruited from a list of people with dementia attending one

of two dementia resources and respite care centers in Guangzhou, Guangdong Province of

mainland China.  The resource center provided daytime physical care, self-care and skills

training for clients, respite care, social and recreational activities, and care-giving resources to

about 3,000 clients with dementia, and their family members.  The clients with dementia were

received to this center from mainly three sources, including: a regional psychiatric center, two

psychiatric outpatient departments, and Social Security and Welfare Department of The

Government.

Inclusion criteria for the family caregivers included those who were: (1) the main

carers for the client, providing care for at least 4 hours per day; (2) their relative with

dementia suffered no co-morbidity of other mental illness during recruitment; (3) free from

any psychiatric disorder themselves; and (4) able to read Chinese and understand spoken

Cantonese or Mandarin language.  They were excluded if they themselves had mental illness

and/or cognitive impairment, or if they had been the primary carers for < 3 months. For

clients with more than one caregiver, the one who had the primary caring role as suggested by

their family members was recruited.

## Sample Size Calculation

A total of 78 family caregivers who fit the study criteria and consented to participate

in the study were randomly selected from 350 eligible caregivers in the center. As reported in

previous studies (Chien & Lee, 2011; Fung & Chien 2002), a sample size of 70 family

caregivers was sufficient to detect the significant differences in caregivers' quality of life and

family service utilization rates between two groups at effect sizes of 0.68 and 0.50,

respectively, with a 5% significance level and a power of 80% (Stevens 2002). The sample

size used in this study (N= 78, 39 in each group) was considered to be sufficient when taking into account 10% of potential attritions. During subject recruitment, another 48 families refused to participate due to time inconvenience and lack of interest.

With written consent obtained, all selected caregivers were then randomly assigned to an experimental (mutual support) group (n= 39), or a control (routine care only) group (n= 39).  The experimental group was then divided into five sub-groups (each with 7 to 8 subjects) with closed membership according to their time of convenience and living districts. Participants in these five small-sized groups attended the support group sessions independently over 24 weeks (i.e., 12 bi-weekly sessions).

**Instruments**

The family caregivers were asked to complete the Chinese versions of three outcome measures listed at below for pre-test (at recruitment) and post-test (at one month after completion of the intervention) to assess the effects of the intervention. The questionnaires were completed in about 25-30 minutes. Demographic data of the caregivers and their relatives with dementia were also collected at pre-test.

*The Neuropsychiatric Inventory-Caregiver Distress Scale (NPI-D)*

The caregiver distress scale, NPI-D was developed by Kaufer *et al* (1998) to assess the caregivers' levels of distress in relation to the neurological and psychiatric symptoms of their relatives with dementia.  The scale consists of 12 items and each item (symptom) is rated for frequency, severity, and degree of caregiver distress produced. The total score for each domain is calculated by multiplying the frequency by the severity and its possible range is from 12 to 144. There is a caregiver distress score for each neuropsychiatric domain (item) and a total distress score is the sum of the 12 individual scores. The internal consistency of

the Chinese version of the NPI was satisfactory (Cronbach's alpha = 0.86) and test-retest

reliabilities were 0.79 for frequency and 0.86 for severity over a 2-week interval (Fung &

Chien 2002).

*World Health Organization Quality of Life Measure-Brief Version [WHOQOL-BREF (HK)]*

The 28-item quality of life measure, WHOQOL-BREF (HK) was modified from the

WHOQOL-100 by the World Health Organization (1995) and translated into Chinese and

validated by Leung, Tay, Cheng and Lin (1997).  Its items are structured in 4 domains:

physical health, psychological, social relationship, and environment (i.e. 7 items for each

subscale), rating on a 5-point Likert scale (i.e., the total score range from 28-144). The

Chinese version of the WHOQoL-BREF (Leung *et al* 1997) had high content validity by

expert review and satisfactory internal consistency (Cronbach's alpha = 0.71) and test-retest

reliability (r= 0.80) over a 2-week interval in Hong Kong Chinese population.

*Family Support Services Index (FSSI)*

The FSSI developed by Heller and Factor 1991 is a checklist to measure formal

support services needed and their usage by psychiatric clients and their families. It was

translated into Chinese and modified into 16 items according to the available family support

services for psychiatric outpatients in mainland China, by checking the service list obtained

from the community mental health team. Each item is rated for whether the family was in

need of the service (Yes/No) and whether they were receiving it (Yes/No).  Inter-rater and

internal reliabilities of the Chinese version were 0.88 and 0.84, respectively (Chien 2005,

Fung & Chien 2002).

*Demographic data sheet*

The data sheet was attached at the end page of the WHOQOL-BREF (HK) scale at pre-test.  The demographic data of caregivers and their relatives with dementia included: caregivers' age, gender, education level, relationship with client, employment, and duration of caregiving; and clients' age, gender and stage of dementia.

**Interventions**

*Mutual support group*

The peer-led mutual support group met bi-weekly, for a total of twelve 1.5-hour sessions.  All group sessions mainly consisted of information giving, sharing and discussion, psychological support, and problem solving; and a group protocol was specifically designed for this study, based on evidence from other mutual support group intervention studies (Fung & Chien 2002; Almberg *et al* 1997; Toseland *et al* 1989). Seven major themes of family support groups formed the basis for group members' interactions and purposive activities in each session, including: (1) information about client's condition; (2) development of group as a support system; (3) emotional impact of care-giving; (4) learning about self-care; (5) improvement of interpersonal relationships; (6) establishing support outside the group; and (7) improvement of home care skills. The protocol of the mutual support group is presented in Table 1.

**[Insert Table 1]**

To foster the use of problem-solving strategy within the group, at least one group members shared personal care-giving problems with other members in each session and these problems were worked on using a six-step model suggested by Zarit, Orr and Zarit (1985). These six steps consisted of defining the problem, generation of alternatives, examining and evaluating each alternative, cognitive rehearsal of action plan, execution of the plan as homework, and evaluation of agreed outcomes.

An advanced practice psychiatric nurse, who had more than 5 years of experience in dementia care and community mental health services and had experienced group facilitation, was chosen as facilitator for the supportive group.  This nurse attended a 2-day training workshop organized by the research team on facilitation of a mutual support group before the study was started.  During the 24-week group intervention, the audio-taped group sessions were reviewed by the facilitator, together with the research team, to monitor treatment integrity, adherence to the protocol and any questions from group members.

One to two peer leaders, elected by the group members, agreed to coordinate and plan the group sessions with the facilitator's consultation, as suggested by Chien *et al* (2006) and Toseland *et al* (1989).  The elected leaders were experienced in family and dementia care and received three 4-hour training sessions on planning and leading a mutual support group, using the protocol.

*Routine care group*

The control group received the conventional family services provided by the dementia centers.  Similar to the other big cities in Guangdong and other Provinces of mainland China, the services included: (1) medical consultation of client and advice to family on client's illness condition, treatment plan and effects of medications provided on monthly basis by two visiting doctors; (2) advice and referrals of financial aids and social welfare services provided by a social worker; (3) educational talk or seminars in dementia care conducted by registered general nurses; and (4) referrals and advices on medical and social services by the center staff. In other developing cities and sub-urban or remote areas, there is not any dementia care center and the only health care service that those families can obtain is the medical consultation by visiting doctors and their referrals to hospital care whenever necessary.

Participants in the control group were informed about community supporting services for dementia care and referral to appropriate agencies for respite could be obtained from staff in the dementia center.  After post-test, the research assistant asked them whether they would like to participate in a mutual support group specifically organized for them.

**Data Collection Procedure**

When the families attended for social and recreational activities organized by the centre staff, the research assistant invited those who fit the study criteria and were randomly selected from a client list of the center to participate in the study. After obtaining their consent with full explanation of the study, the family caregivers were asked to complete the three pre-test measures and demographic data sheet. They were then randomly assigned into either the mutual support or control group, undergoing 24-week interventions.  The mutual support group was led mainly by peer leaders and supported by the group facilitator (i.e., the trained advanced practice psychiatric nurse). All sessions of the mutual support groups were audio-taped, with the participants' consent. All The center staffs that were blind to the study participation provided usual care to both the treatment and control group.

At one month after completion of the interventions, the participants in both mutual support and control group were asked to complete the three outcome measures again by the research assistant.  They were also asked about whether they had participated in any other structured therapies over the period of intervention.  The group attendance of each subject in the experimental group was recorded by the nurse facilitator. The trained research assistant who was blind to the subject assignment administered the pre-test and post-test questionnaires.

**Ethical Considerations**

Permission to conduct the study was obtained from the resources center and the Human Subjects Ethics Committee of The University. Written consent was sought from the family caregivers for study participation on voluntary basis before randomized group assignment. They were informed of the purpose of the study and what would be expected of them as participants and assured confidentiality of personal identity and data collected. They were also assured of their right to terminate participation at any time.

**Data Analysis**

The Statistical Product and Services Solutions (SPSS; SPSS Inc, Chicago, IL, USA) for Windows version 15.0 was used for analysis of all pre- and post-test data. Quantitative data on demographic characteristics, group attendance, attrition rate, and outcome measures of the families were summarized with descriptive statistics. Analysis of data was on an intention-to-treat basis, thus maintaining the advantages of random sampling and enhancing the validity of the study findings (Montori & Guyatt 2001). A Goodness of Fit Chi-square test was used to test the differences in demographic characteristics between the participants in the experimental and control group.

Group means and standard deviations of the NPI-D and the WHOQOL-BREF (HK) for the pre-test and post-test were generated and compared between groups using the Analysis of Variance (ANOVA) test (Group x Time). Mean values of the total number of mental health service utilization were compared between the groups using the Mann-Whitney U test. As multiple comparisons between the subscales or items of the outcome measures were performed, the adjusted significance level of all analyses was set at 0.01 in order to reduce the type I error, which refers to the possibility of false positive results occurred when the statistical tests rejected the null hypotheses (Tabachnick & Fidell 2001). The audiotapes of the mutual support group sessions were reviewed and the participants' comments on the

strengths and weaknesses of the group program were summarized by the first author to provide additional information about the caregivers' perceived benefits from the support group participation.

## Results

### Demographic Characteristics of Family Caregivers

Seventy-eight family caregivers initially participated in the study, however, six participants (7.7%) withdrew from the study because of their failure to attend 6 or more group sessions (n= 4) or to complete the post-test (n= 2). The overall attendance at group sessions of the 39 participants in the mutual support group ranged from 5 to 12 sessions (42% to 100%; in an average of 82%).

The demographic characteristics of the caregivers and their relatives with dementia are shown in Table 2. About two-thirds of the caregivers were aged between 31-50 years (41%) or 51-70 years (23%). About 59% of the caregivers in the mutual support group and 64% in the control group were female, mainly wife and mother. Also, about half of them had an education level of secondary school and more than one-third were spouses of the clients. More than half (50% - 60%) of the caregivers were in full- or part-time employment. Average durations of client care were 10.3 months (SD= 3.8) and 10.9 months (SD= 3.5) for mutual support and control group, respectively. The clients with dementia were mainly in moderate severity of illness (>70% in both groups) and more than half of them (51% and 54%) were females. More than 80% of them were aged 60 to 90 years (82% and 80%). However, there were no significant differences found between the two groups at baseline assessment when using the Goodness of Fit Chi-square test (p values ranged from 0.10 to 0.28). All of the study participants were found not involved in any family group therapies.

[Insert Table 2]

## Treatment Effects

The mean scores of the NPI-D and the results of two-way between groups ANOVA tests are shown in Table 3.  There were a statistically significant (Group x Time) interaction effect [F (1, 76) = 19.09, p = 0.005] and the main effects for groups [F (1, 76) = 17.15, p = 0.01] and for time [F (1, 76) = 23.68, p = 0.001].  The effect size of the NPI-D was large (eta squared = 0.32). The family caregivers of the mutual support group had significantly greater reduction of total scores of NPI-D (Pre-test and post-test mean difference = -9.37) than that of the control group (mean difference = -3.03). The mean scores of four of the 12 NPI-D items in the support group also showed significantly greater reduction than those in the control group at post-test.  These items included delusional ideas [F (1, 76) = 26.92, p = 0.001], hallucinatory behavior [F (1, 76) = 25.12, p = 0.001], agitated and violent behavior [F (1, 76) = 28.81, p = 0.001], and elation and over-excitement [F (1, 76) = 31.33, p = 0.0005]. Therefore, the results indicated that the caregivers in the mutual support group had significant lower levels of overall distress and the distress concerning the four above listed symptoms, when compared with those in the control group.

[Insert Table 3]

Table 4 shows that the overall scores and the psychological and social domains of the WHOQOL-BREF (HK) that were significantly different between the two groups at post-test [F (1, 76) = 22.19, p = 0.001; F (1, 76) = 19.86, p = 0.001; and F (1, 76) = 21.98, p = 0.001, respectively].  The effect size of the overall quality of life score was large (eta squared = 0.38). Therefore, there were significantly greater improvements of the overall quality of life as well as the psychological and social life domains in the mutual support group than those in routine care at post-test.

**[Insert Table 4]**

Frequencies of mental health service utilization for the two study groups are shown in Table 5.  The mutual support group had slightly higher frequencies and average amounts of utilization on five types of mental health services than those in the control group. The five types of services included: outpatient medical consultation, family consultation and financial aids by medical social workers, counseling by clinical psychologists, acute admission and in-patient care, and respite care. However, the results of Mann-Whitney U test indicated that there were no significant differences between the groups on the average units of service utilization in each item of mental health services (i.e., p values ranged from 0.09 to 0.23).

**[Insert Table 5]**

**Participants' Comments on Support Group Program**

Verbal comments from the audio-taped records of the mutual support group sessions indicated that they valued most on: the opportunity to share feelings and concerns in group discussions and gained insights into symptoms and disturbing behaviors among their relative with dementia, as well as positive thinking and facing with the difficult caring situations with the group support.  This helped them reduce their feeling of guilt, discomfort or embarrassment, and distress towards family and client care. They also indicated that they were not alone to their life problems when they recognized that other families in the support group encountered similar care-giving problems. They emphasized the importance of receiving important information during group sessions about how to handle the illness and family problems. Most of the group members mentioned their appreciation about the empathetic attitude of the peer leaders and the group facilitator.  However, a few members indicated that the peer leaders needed to improve their leadership skills such as resolving conflicts between members and better handling the dominant and manipulative members.

**Discussion**

The findings provide preliminary support for the effectiveness of the family-led

mutual support group to improve the psychological distress and quality of life of their family

caregivers at one month after completion of the 24-week intervention The results showed that

the family caregivers in the support group had significantly greater reduction in distress

levels, especially when managing client's symptoms of delusions, hallucinatory behavior,

agitation and violent behaviors, when compared with that of the control group.  This lowering

in psychological distress would give room to the caregivers for better coping with care-giving

and more effective care provision for their relatives with dementia.  Consistent with one

previous controlled trial conducted in Hong Kong (Fung & Chien 2002), the family members

participated in mutual support groups could demonstrate a significant improvement in their

distress and burden in care-giving, health-related quality of life and duration of client's

institutionalizations. With this understanding of the client's illness and condition, the family

caregivers in the support group felt less frustrated when their care-giving efforts were not met

with appreciation, especially from the client.  Toseland and Rossiter (1989) suggested that

mutual support groups could be effective on universalizing and normalizing caregivers'

experiences and instilling hope in providing quality of care for clients with dementia. Since

dementia care has globally been a longer term burden to family members and community

mental healthcare services, it is noteworthy that the families who underwent this mutual

support group intervention reported significant improvements in their care-giving burden and

quality of life, without any noticeable increase in demands for community mental healthcare

services.

The evidence that accumulated psychological and social stressors can impair a family

caregiver's ability to look after a relative with dementia is well documented (Belle *et al* 2006;

Gwyther & Strulowitz 1998). However, stress associated with care-giving to a family member

with dementia can be relieved by the involvement of a peer support group that help caregivers

identify concerns themselves and develop effective problem-solving techniques to resolve

them. Support groups can also provide practical assistance and advices on the community

resources in needs and assure caregivers that their role is vital (Chien 2005; Toseland *et al*

1989).

This is particularly important in mainland China, and other Asian countries, where the

majority of elderly people with dementia rely solely on family members to provide them with

a level of independence not otherwise possible (Chien & Lee 2011).  Mutual support groups

can equip caregivers with knowledge about the debilitating nature of dementia, and provide

them with effective mechanisms to cope with the demands placed on them.  These demands

for care-giving are considerable and cannot be replaced by health professionals. They include

constant monitoring and supervision of the progressive deficits in memory, personality,

cognitive-intellectual functions, and self-care ability in the course of dementia (Chou *et al*

1999).

In addition, the family caregivers in the mutual support group also showed

significantly greater improvement in their perceived quality of life, both psychologically and

socially, than did the control group.  The support group participants believed their quality of

life was better not only because of the techniques they learned from their group participation,

but also because other support group members served as role models of how to cope with

care-giving as well as caring for they themselves and their families (Ulstein *et al* 2007). The

findings also reflected a significant improvement with the mutual support group in the

domain of social life on the WHOQOL-BREF (HK) scale.  Items, such as opportunity to

participate in social and recreational activities, satisfaction on interpersonal relationships,

social support from relatives and friends, and ability to provide care for family members, are

examples of this improvement.  As suggested by McCallion and Toseland (1995), mutual

support groups can produce a greater positive impact on caregivers' social functioning and

establishing informal social networks than that of the conventional family support services in

dementia care.

The strong kinship systems that constitute the extended Chinese families, and the

traditional beliefs of obligation, respect for elders and inter-dependent relationships (Chien &

Lee 2011; Li & Bucchel 2007) may result in self-blame and guilty feeling of family members

for any deterioration in their relatives' illness condition. In such circumstances, family

caregivers would be progressively less able to cope with the increased deficits and

dependence of the ill relative. This strong traditional family culture is also evident in Latin

American families (Ellis, 1998) and consequently, family members when caring for a relative

suffering dementia are eager to obtain up-to-date information, emotional support, and social

companionship from other people in similar situations. Meeting other support group

members, and health professionals, may enable them to strengthen hope and social support

that would probably reduce the anxiety and feelings of responsibility they harbored and has

been noted in previous studies on family caregivers of people with mental illness (Chien *et al*

2006).

Nearly two-thirds of the family caregivers in this study were female.  As previous

studies indicate, Chinese society expects women (e.g., wives and daughters-in-law) to assume

the role of primary carers and nurture dependent older people every day for about four to five

hours per day (Chou *et al* 1999).  The burden for women in particular, and the distress

resulting from expectations that they assume the role of primary carers, has become a

pervasive problem in Chinese societies.

In contrast with previous studies (Belle *et al* 2006), the attrition rate in this study was

very low (i.e., about 7.7%). This may be explained by the fact that the clients with dementia

had the illness over a short period (i.e. mainly 6 months to 2 years) and the families might

have been enthusiastic and motivated about the potential for change or coping well with the

illness (Roselans *et al* 2008; Fung & Chien 2002). Previous studies also indicated that

psychosocial benefits of a family support group significantly correlate with the level of group

members' involvement and participation (Chien *et al* 2006; Luke, Roberts & Rappaport

1993). The high group attendance of the caregivers in this study might contribute to the

significant positive effects in their quality of life and distress level. Nevertheless, the level of

support received and provided by peer group members that may strongly contribute to

perceived benefits by group members was not examined in this study.

A protocol was established to guide the group process and the facilitator and peer

leader training. According to Toseland et al (1989), a clearer and specific guideline for a

support group can influence the group process and promote positive outcomes. In addition,

well-trained group leaders can result in optimal benefits in mutual support groups. It was

therefore important and essential to perform regular review of the audiotape recorded sessions

of the support groups and discussions about the progress of the support group between the

facilitator and the researchers, in order to assure consistency in the protocol implementation

as well as the treatment integrity in this study.

It is also interesting to note that mental health service utilization by the family

caregivers in the mutual support group was only slightly more frequent than those in routine

family care. Montogomery and Borgatta (1989) suggested that an increase in service

utilization is influenced by caregivers' mutual sharing of information within groups,

therefore, increasing knowledge of available community resources. Nevertheless, the results

of this study did not support this, as the frequency of service utilization did not significantly

differ between the mutual support and routine care group. This can be explained, as

suggested by Chien *et al* (2006) and Fung and Chien (2002), that it might be due to the

families' increased knowledge of the illness and its care, improvements in problem-solving ability, more effective communication between people in their increased social network, and enhanced competence in handling the stress and demands for care-giving, since these knowledge and skills could be learnt in the support group participation.

**Limitations of the Study**

A few limitations are noted in this study. The caregivers in the mutual support group might be particularly susceptible to the influences of social desirability when responding to outcome measures.  They were reluctant to give responses indicating difficulties because they were concerned about whether they might be perceived by the group members and facilitator as problematic families that required special attention and care.  Even though the outcome assessor (research assistant) and center staff were blind to the group assignment and participation of the family caregivers in this study respectively, this might raise questions about the internal validity of the findings based on the family caregivers' responses to the questionnaires.  An in-depth investigation of caregivers' individual appraisals of their situations by using process evaluation (e.g., observation of group sessions and qualitative interviews) may reflect specific changes in attitudes and behaviors that may have been learned in the support group (Chien & Norman 2009; Buckwalter 1996).

The sample size in this trial was relatively small, comparing with the dementia population in mainland China.  The results might not be able to generalize to the total population of families of home-resided clients with dementia in different geographical regions of China, indicating varied cultures and community care services.

Family caregivers frequently engage in multiple roles in family care and they are not free or time convenient for group participation.  This might be an important reason for some of the caregivers to refuse to participate in the mutual support group and/or the study.

Therefore, a comprehensive family support service should be considered to relieve caregivers from multiple family roles so that they are available to receive additional psychosocial support and care, such as participation in a support group.  Nevertheless, the caregivers in this study included only those who were willing to participate and their strong motivation and desires to participate and co-operate in the group intervention might represent only those who had time and were enthusiastic in client care.

As is the case with most psychosocial interventions, it is difficult to have a well-defined treatment protocol used in other trials of structured family programs (e.g., family behavioral management program). Similar to other support groups, the protocol established by the caregivers in this study was flexible and agreed by all group members to allow the exercise of their autonomy, self-help and empowerment. Processes of interactions and the skills required by peer leaders to coordinate a support group may not be easily standardized during intervention. Adherence to the protocol and the skills of leading a support group should be examined, to enhance replication and further investigation of the group program.

**Implications for Clinical Practice and Research**

The family-led mutual support group is found to be more effective in improving family caregivers' burden and quality of life due to clients' symptoms in dementia, than routine care in Chinese families. The support group, which was managed by a self-developed group protocol, the trained peer leaders and the family caregivers, were closely monitored by the facilitator (advanced practice nurse) and nurse researchers.  The support group with better information giving and psychosocial support in care-giving, therefore, has resulted in better health outcomes among the family caregivers.  The findings indicated that mutual support groups, which have been commonly used in Western countries, can be applied to a Chinese family context in caring for people with dementia at home. Family caregivers can act as group

leaders while the advanced practice nurse can serve as a group facilitator, or a resource person, to empower the group members' (caregivers') mutual psychological support and practical assistance in the group process.

The findings suggest further investigation of this mode of community-based, family-centered intervention, with families from different socio-cultural backgrounds in Chinese population and across cultures.  As the psychosocial needs of family caregivers have been met by the support group, they could effectively cope with the demands for care-giving and provide high quality care for their relatives with dementia.  However, the impact of this group intervention on clients' illness symptoms and health condition and longer term effects of this group intervention (e.g., one year) to both the clients and families were not examined. Randomized controlled trials on this model of care with a larger and more diverse sample with different socio-economic backgrounds are recommended.

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Table 1. Protocol of the Mutual Support Group Established by Group Participants

| Stage | Goals | Main Themes |
|---|---|---|
| Engagement (1 session) | Establishment of trust and respect as well as agreed goals and objectives | • Orientation to the mutual support group and establishing trust and mutual acceptance<br>• Negotiation of goals, rules, roles and responsibilities in the group<br>• Initial discussion about dementia, its effects to family, issues in caregiving and family care, and family members' reactions towards the illness |
| Recognition of carers' own psychological needs (3 sessions) | Understanding about individual psycho-social health needs and cultural issues within family | • Empowerment on individual self-efficacy and regulation of caregiving and decision making within group<br>• Sharing of intense emotions and feelings about caregiving; discussion of ways to deal with negative emotions<br>• Information sharing about dementia and its care<br>• Discussion of Chinese culture and beliefs of family and mental health problems such as dementia |
| Dealing with bio-psychosocial needs of self and family members (3 sessions) | Understanding about most important health needs for themselves, client and family | • Understanding each other's health needs regarding caregiving<br>• Information about medication, illness management and other psychological treatments, home affairs and family care, and available mental health services<br>• Learning of effective communication and interpersonal skills with client and family members and seeking support from people or group members |

| Adopting positive role and challenges for caregiving (4 sessions) | Learning effective coping and caregiving skills | • Enhancing mutual support, coping with stress and problem-solving skills by working on each member's client care situations<br><br>• Performing behavioral rehearsals of interactions with client and family members within group<br><br>• Evaluation of the real life practices (in-between sessions) of the coping and problem-solving skills learned in group sessions |
| Termination of group (1 session) | Preparation of ending the group or continuation by group members | • Psychological preparation and discussion of issues in relation to group termination, e.g., separation anxiety and more independent future life<br><br>• Evaluation of the learning experiences and achievement of goals and sharing of experiences and satisfaction with utilization of community resources<br><br>• Discussion about a continuation of the support group after intervention |

Table 2.  Demographic Characteristics of Family Caregivers and Their Relatives with Dementia (N=78)

| Characteristics | Mutual Support (n = 39) f (%) | Routine care (n = 39) f (%) |
|---|---|---|
| *Caregivers* | | |
| Gender | | |
| Male | 16 (41.0) | 14 (35.9) |
| Female | 23 (59.0) | 25 (64.1) |
| Age range | | |
| 18 – 30 | 14 (35.9) | 13 (33.3) |
| 31 – 50 | 16 (41.0) | 17 (43.6) |
| 51 – 70 | 9 (23.1) | 9 (23.1) |
| Education level | | |
| Primary school or below | 10 (25.6) | 11 (28.2) |
| Secondary school | 20 (51.3) | 18 (46.2) |
| Tertiary [a] | 9 (23.1) | 10 (25.6) |
| Relationship with client | | |
| Spouse | 15 (38.5) | 14 (35.9) |
| Parent | 11 (28.2) | 10 (25.6) |
| Sibling | 7 (17.9) | 8 (20.5) |
| Children | 6 (15.4) | 7 (17.9) |
| Employment | | |
| Full-time | 13 (33.3) | 10 (25.6) |
| Part-time | 10 (25.7) | 10 (25.7) |
| Unemployed | 16 (41.0) | 19 (48.7) |
| Duration of caregiving [b] | | |
| 6 – 12 | 14 (35.9) | 15 (38.5) |
| 13 – 24 | 16 (41.0) | 17 (43.6) |
| 25 – 36 | 6 (15.4) | 5 (12.8) |
| 37 – 48 | 3 ( 7.7) | 2 ( 5.1) |
| *Relatives with Dementia* | | |
| Gender | | |
| Male | 19 (48.7) | 18 (46.2) |
| Female | 20 (51.3) | 21 (53.8) |

| Age range | | |
|---|---|---|
| 51 – 60 | 7 (17.9) | 8 (20.5) |
| 61 – 70 | 18 (46.2) | 17 (43.6) |
| 71 – 80 | 10 (25.6) | 9 (23.1) |
| 81 – 90 | 4 (10.3) | 5 (12.8) |
| Stage of dementia [c] | | |
| Early (mild) | 6 (15.4) | 5 (12.8) |
| Intermediate (moderate) | 28 (71.8) | 29 (74.4) |
| Late (advanced) | 5 (12.8) | 5 (12.8) |

*Note.*  f: frequency; %: percentage.

[a] Tertiary level of education represents the diploma and degree qualifications from university, technical school, and professional institutes.

[b] This duration of caregiving denotes the length of time in months in which the clients had been receiving care from the caregivers.

[c] Stage of illness is categorized and recorded on the progress sheet of outpatient clinic written by attending psychiatrist

Table 3. Results of NPI-D Item Scores in Family Mutual Support & Routine Care Group (N = 78)

| Items of NPI-D | Mutual Support (n = 39) | | | | Routine Care (n = 39) | | | | F(1,76) | P |
| | Pre-test | | Post-test | | Pre-test | | Post-test | | Group x Time | value |
| | M | SD | M | SD | M | SD | M | SD | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Delusional ideas* | 4.20 | 0.72 | 2.05 | 0.40 | 4.30 | 0.80 | 4.00 | 0.65 | 26.92 | 0.001 |
| Hallucinatory behavior* | 4.10 | 0.53 | 2.85 | 0.60 | 4.00 | 0.47 | 3.95 | 0.60 | 25.12 | 0.001 |
| Agitated and violent behavior* | 3.88 | 0.60 | 2.89 | 0.51 | 4.10 | 0.67 | 3.77 | 0.70 | 28.81 | 0.001 |
| Depression | 3.60 | 1.58 | 3.18 | 1.32 | 3.70 | 0.76 | 3.52 | 0.63 | 4.35 | 0.092 |
| Anxiety | 4.18 | 1.12 | 3.61 | 1.06 | 4.13 | 0.79 | 3.71 | 0.51 | 2.47 | 0.216 |
| Elation and over-excitement* | 4.63 | 1.02 | 2.50 | 0.76 | 4.41 | 0.59 | 4.01 | 0.41 | 31.33 | 0.0005 |
| Apathy and low initiative | 3.65 | 1.00 | 3.48 | 0.70 | 3.75 | 0.61 | 3.60 | 0.38 | 2.91 | 0.118 |
| Disinhibited and impulsive behavior | 3.80 | 0.45 | 3.49 | 1.00 | 3.90 | 0.80 | 3.58 | 0.72 | 2.37 | 0.204 |
| Unstable emotion and anger | 3.91 | 0.78 | 3.51 | 0.92 | 3.80 | 0.54 | 3.50 | 0.80 | 2.19 | 0.172 |
| Abnormal behavior (e.g. wandering and restlessness) | 3.82 | 0.48 | 3.49 | 0.72 | 3.70 | 0.54 | 3.58 | 0.83 | 2.53 | 0.110 |
| Insomnia | 3.57 | 0.63 | 3.31 | 0.56 | 3.61 | 0.64 | 3.38 | 0.50 | 2.46 | 0.105 |
| Eating & appetite | 3.50 | 0.63 | 3.11 | 0.76 | 3.51 | 0.54 | 3.28 | 0.70 | 2.05 | 0.125 |
| Total score* | 46.84 | 8.11 | 37.47 | 9.68 | 46.91 | 9.68 | 43.88 | 13.56 | 19.09 | 0.005 |

*Note.* M: mean value; SD: standard deviation.

Mean item scores based on a 1 to 5-point distress level scale, with 5 being the highest.

Mean total scores of the NPI-D range from 0 to 60; 36 or higher being in a moderate to high distress.

* Items indicate a significant difference of mean scores between the two groups.

Table 4.  Results of the Overall and Domain Scores of WHOQOL-BREF (HK) in Study

Groups (N = 78)

| Domains of WHOQOL-BREF(HK) | Mutual Support (n = 39) | | | | Routine Care (n = 39) | | | | F (1, 76) Group x Time | P value |
|---|---|---|---|---|---|---|---|---|---|---|
| | Pre-test | | Post-test | | Pre-test | | Post-test | | | |
| | M | SD | M | SD | M | SD | M | SD | | |
| Self [a] | 6.45 | 0.93 | 8.19 | 0.70 | 8.09 | 0.54 | 7.27 | 0.47 | 0.36 | 0.570 |
| Physical [b] | 27.78 | 4.03 | 28.08 | 3.68 | 27.21 | 3.27 | 24.91 | 3.28 | 0.71 | 0.432 |
| Psychological [c] | 26.68 | 5.52 | 33.51 | 3.36 | 27.41 | 3.04 | 28.78 | 2.29 | 19.86 | 0.001 |
| Social [d] | 10.08 | 2.23 | 13.73 | 1.74 | 10.50 | 1.53 | 6.75 | 0.80 | 21.98 | 0.001 |
| Environmental [e] | 27.90 | 4.28 | 30.51 | 5.12 | 28.50 | 5.04 | 26.48 | 6.70 | 0.28 | 0.618 |
| Total score | 97.89 | 14.11 | 114.02 | 13.98 | 103.71 | 9.28 | 88.19 | 7.56 | 22.19 | 0.001 |

*Note.*  Mean item scores are based on a 5-point Likert-type scale, with 5 indicating the highest value.

Mean total scores of the WHOQOL-BREF (HK) range from 28 to 140, the higher value denoting higher quality of life.

[a]  This domain consists of 3 items and its total scores range from 3 to 15.

[b]  This domain consists of 7 items and its total scores range from 7 to 35.

[c]  This domain consists of 7 items and its total scores range from 7 to 35.

[d]  This domain consists of 4 items and its total scores range from 4 to 20.

[e]  This domain consists of 7 items and its total scores range from 7 to 35.

Table 5.  Mental Health Services Utilization for Mutual Support and Routine Care Group (N = 78)

| Service item | Unit(s) of Service | Mutual Support (n = 39) | | Routine Care (n = 39) | |
|---|---|---|---|---|---|
| | | f | M (SD) | f | M (SD) |
| Outpatient medical consultation | 1 attendance | 80 | 3.17 (0.98) | 78 | 3.08 (0.78) |
| Home visits by community psychiatric nursing | 1 visit | 73 | 2.88 (0.71) | 74 | 2.89 (0.56) |
| Family and financial support by medical social worker | 1 attendance | 39 | 1.36 (0.45) | 34 | 1.19 (0.43) |
| Counseling by clinical psychologist | 1 visit | 9 | 0.31 (0.10) | 7 | 0.28 (0.12) |
| Day center | 1 day | 322 | 12.59 (2.10) | 324 | 12.62 (1.91) |
| Inpatient hospital care | 1 day | 22 | 0.86 (0.12) | 21 | 0.84 (0.20) |
| Respite care | 1 day | 60 | 2.31 (0.87) | 57 | 2.28 (0.80) |
| Home care and meal service | 1 visit | 98 | 3.85 (0.93) | 100 | 3.87 (0.88) |
| Information hotline (mental health) | 10 minutes | 24 | 1.54 (0.21) | 27 | 1.62 (0.20) |

*Note.* f: Total number of units used for individual mental health service.

M: Mean; SD: Standard Deviation.