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# **Empowerment in Dementia Care**

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**Thesis submitted in fulfilment of the requirements for the  
degree of Doctor of Health Psychology**

**City University  
Department of Psychology  
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# **SECTION A**

## **Preface**

This portfolio documents my two years training in Health Psychology, from valuing the psychological and behavioural aspects of health prevention, management and treatment of illness, to the application of psychological theories and methods and research findings, with a focus on empowering the Chinese family care givers and individuals involved in dementia care. The journey of developing the skills and knowledge of Health Psychology has deepened my understanding of the issues around dementia within the Chinese community, and how a Health Psychologist could work with the community to achieve better health outcomes.

The concept of Community Health Psychology has inspired me to apply a participatory approach to psychosocial intervention with the Chinese family carers in the research studies. While the research studies were to explore the change in carers' psychological empowerment in the participatory intervention, I have developed a new measurement tool for this specific group.

My experience in teaching and training and in delivering psychological intervention has built up my confidence in these areas, as I appreciated that the quality of life of individuals at an early stage of dementia could be enhanced through a tailored psychosocial intervention, the quality of care delivery could be improved through training family carers and community workers using a person-centred approach to dementia care. In order to explore the effectiveness of training interventions for family carers of dementia, I have conducted a systematic review with an objective to review training programs aiming to improve family carers' psychological strength.

In my consultancy competence, I applied both my knowledge in health promotion and psychological approach in delivering a health promotion program to a Chinese community group. In one of my optional units, a funding proposal was approved to conduct a community research which aimed to address current health issues in the Chinese community. Whereby the results of the community research was disseminated at a policy level in the statutory service, I also appreciated the fact that a Health Psychologist works on different levels to achieve better health outcomes, including that on a policy level to influence health on a community level. I will discuss the major development of my Doctorate in Health Psychology in the following sections.

### **The Participatory and Empowering Intervention**

For many Chinese communities, people with dementia and their carers are stigmatised due to the lay perspective of this illness. The role of stigma has rendered them vulnerable because of the tendency to conceal their problem; as a result they became even more isolated and helpless in dealing with the dementia illness with the lack of support from the community and from the health services. While many people suffering from dementia are increasingly dependent on family

members to provide daily care, caring for someone with dementia is considered a stressful experience due to the patient's difficulties.

The focus of the second research study in this portfolio was to investigate the impact of psychological empowerment on the Chinese family carers using participatory interventions. The third research study sought to explore how the processes of participatory and empowerment has become effective and the lesson learned from adopting a participatory and empowering approach with Chinese family carers living in England.

Study 2 is both a quantitative and a qualitative study adopting a participatory and empowering approach as the framework of psychosocial intervention. The aim of the study was to engage three groups of Chinese family carers of dementia in a five-month participatory intervention during which development of new consciousness on aspects of caring was explored and ways of improving the difficulty in caring were inspired. Each group of the family carers was engaged in forming their groups, deciding on vision and values and each group was to identify a common goal to be achieved during their participation in the research project. Results of the quantitative analysis using the new measurement tool show significant and consistent changes in the carers' psychological empowerment over time. Qualitative analysis of semi-structured interviews with carers using thematic analysis highlighted the importance of building up knowledge base, support from care recipients, family and peers, and the awareness of resources available in the community.

Study 3 is a qualitative study to further explore the processes of the participatory interventions. Results show that in overcoming the barriers to participation, it is suggested that the carers' needs and motivations should be explored in a much deeper sense. During participation, carers' inadequacy should not be a focus, rather, their strengths, interests and motivation. Researchers should work according to their levels and use their language in communication, encourage participation and share responsibility. To effectively empower the carers, establishing support outside the research project is essential. It is particularly true that whereas the research study has a limited project span, relationships built up with peers and community organisations is essential in giving on-going support when the research comes to an end.

### **The Development of a Chinese Sense of Empowerment Scale**

Study 1 is a quantitative study demonstrating the development of a new measurement tool, the Sense of Empowerment Scale in measuring changes in psychological empowerment of the family carers in the participatory interventions over a five-month period. This study gives a detailed account of the process of the development of the new tool, from identifying the concept of

'empowerment' among the Chinese family carers for the basis of establishing and expanding the items of the measurement scale, to piloting the Scale and finally to testing the reliability of the Scale. Results of the reliability test show good internal consistency. Content and face validity tests were also conducted at the early stage of the scale development. The new Scale has provided a measure for assessing psychological empowerment of family carer groups or other disadvantaged groups who come across similar difficulties such as language barrier, lower socioeconomic status and hurdles in accessing culturally-sensitive health services. This study has added to the knowledge of developing a population-specific tool for measuring sense of empowerment which is an abstract variable in both quantitative and qualitative research.

The three research studies also added to the understanding of how to engage family carers who are disadvantaged and isolated in the community and highlighted various factors that can be helpful in improving carers' sense of empowerment as well as sense of well being.

### **Improving Dementia Care Delivery through Training**

Caregiver training is one of the interventions that could lead to positive outcomes for carers of people with dementia. To prepare myself for training and teaching, I did a training course on the person-centred approach to dementia care and became an accredited trainer for the training programme. The aims and objectives of the training programme are to enable learners, including community workers, domiciliary workers and family carers, to learn about the special needs of individuals with dementia, how to meet these needs and to learn new skills in order to deliver a person-centred care. Over the last two years, I have delivered training programmes to five different groups in two settings including community organisations and residential care homes. The case study described my skill development in teaching and training as a trainee health psychologist, from a beginner to a more confident trainer using different media in delivering training according to the learners' needs. The case study also shows that the person-centred approach to dementia care is a meaningful training method which has inspired the faith of the workers and the family carers in their roles of care giving.

### **Exploring the Effectiveness of Training as an Intervention for Family Carers of Dementia**

A systematic review was conducted to examine the effectiveness of training interventions for family caregivers of dementia sufferers. The objectives of this systematic review were to review training programmes aiming to improve family caregivers' psychological strength, such as reducing their distress, depression and sense of burden relating to caregiving; improving their assertiveness, stress and anger management skills, communication and problem solving skills.

The findings of this review were that there is some evidence that psychoeducational and skills training is useful in reducing caregivers' depression, distress, burden and in increasing their coping and self-efficacy. This review has revealed a scarcity of studies on the effectiveness of training interventions for family carers for people with dementia.

Reflection on this systematic review shows that training interventions can be effective; however, there is not enough research to be conclusive about the effectiveness of the types of training designed to meet the family carers' needs. Better research into this field should be a priority for those interested in improving the lives of people with dementia and their carers.

### **Enhancing the Quality of Life of Individuals at an Early Stage of Dementia**

A psychosocial intervention which aimed to discover the strengths and to enhance the well-being of individuals at an early stage of dementia and sensory stimulus are reported in this portfolio. In this case study I worked on the design and implementation of a psychosocial intervention for an individual at an early stage of dementia. The intervention was designed to improve the client's quality of life based on the idea of normalisation, the principle of which is to open up the positive perspective of health that is in search of the individuals' strengths and abilities rather than focusing on their disability or inadequacy. The study demonstrated how normalisation activities have helped to improve the client's psychological well being through reminiscence, story telling, memory training exercise, social activity and sensory stimulus.

### **Improving Health Awareness on a Community Level**

My consultancy case study documented a service delivered to a NHS Partnership Trust. This was a good opportunity to improving health awareness on a community level which encourages people to look at health issues from a psychological perspective. The consultancy role involved planning, designing and delivering a health promotion programme at a community health day engaging the local Chinese residents. A forum theatre approach was used to raise the awareness of psychological health from an everyday perspective. Brief sketches of negative health behaviours were performed to inspire discussions among the members of the audience, who were later encouraged to participate in developing their own scripts and acting out the positive scenarios of health enhancing behaviours. Evaluation of the health event shows that 98% of the audience expressed increase in their understanding of psychological health and the forum theatre approach to conveying health messages was interesting and inspiring. The client's feedback on the consultancy service was positive and further consultancy service was taken into consideration.

### **Improving Health Outcomes on a Policy Level**

To demonstrate how I attempted to improve health outcomes of the Chinese community on a policy level, a case study describes how psychological knowledge addressing current health issues in the Chinese community was disseminated. The study involves a funding proposal for a community research project aiming to examine service users' experience in accessing health services, their needs and expectations. Results of the community research study were reported to the health commissioners in the borough where the research was conducted, and was also disseminated at a national seminar focusing on improving the delivery of health services to ethnic Chinese groups.

## **SECTION B**

### **Research Competence**

## **AREA OF COMPETENCE: Research**

### **Study 1**

#### **The Development of a Sense of Empowerment Scale**

**A scale to measure empowerment among Chinese immigrant family carers for people with dementia and other mental illnesses**

### **Study 2 & 3**

#### **Empowering Chinese Informal Carers for Dementia – A Participatory Intervention**

**SETTING:** Chinese Mental Health Association (not for profit organisation)

**TARGET GROUP:** The Chinese family carers in the community in Leeds, Newcastle-upon-Tyne and London

**DESCRIPTION OF WORK:** Applying the concept of community health psychology, a participatory and empowerment approach to psychosocial interventions was adopted in working with three groups of Chinese family carers. A Chinese Sense of Empowerment Scale was developed to measure psychological change.

## Introduction

Dementia is a group of conditions with different aetiologies that are caused by changes in brain function. Being one of the incapacitating chronic diseases among the older population, dementia is an irreversible condition that leads to progressive deterioration of cognitive, intellectual, physical, and psychosocial functions (Fung & Chien, 2002).

Around the world an estimated 18 million people have developed dementia. Figures obtained from Alzheimer's Disease International indicate that the occurrence rates of dementia in various communities, including the Chinese, are more or less within the range of 4.2% for the age group of 65 or above, 16.7% for the age group of 75 or above, and 23.6% for age group of 85 or above. In the past, the prevalence of dementia among the Chinese population was believed to be lower than their western counterparts. In recent years, surveys and research studies conducted in China, Hong Kong, Taiwan and Singapore have suggested that the rates of dementia among the Chinese are higher than previously believed, and do not differ much from international statistics. Gao, Fang & Pan (1999) reported that the overall rate of dementia in China was 4.2%. In Hong Kong, a study led by Chiu, Lam, Leung, Li, Law, Chung (1998) reported that 4% of those aged 65 and over suffered from dementia-related ailments. Other studies in Taiwan and Singapore in the late 1990s reported that the prevalence rates of dementia in these two cities were between 2 and 7% (Department of Health, Taiwan, 2003; Kua, 1999).

In the UK, little is known about the prevalence of dementia among the Chinese immigrants. However, based on the figures obtained from the UK Population Census for 2001 and the general rates of dementia among the Chinese countries, it can be estimated that around 4% of the Chinese in the UK aged 65-74 and 16% of those aged 75 years and over may also suffer from dementia.

Dementia is one of the most common mental health problems in older Chinese people in the UK, along with anxiety and depression (Yee & Au, 1997). While many people suffering from dementia are increasingly dependent on family members to provide their daily care, caring for someone with dementia is considered a stressful experience due to the patient's difficulties, such as incontinence, challenging behaviours, disorientation in time and place, sleep disturbance, wandering, agitation and immobility. Such stressful experience can render vulnerable and may influence the caregiver's well-being in areas such as coping strategies, quality of the caregiver's relationship with the dementia sufferer and family support (Kua & Tan, 1997).

In the process of undertaking caring tasks, Chinese carers in this country usually experience a higher level of stress resulting from the combination of economic and social factors and their caring

responsibilities (Yee & Au, 1997). This can be traced back to the historical background of the Chinese immigrants in Britain. In addition, while many spouse carers of the afflicted persons are similarly older, isolated and socially disadvantaged, community attitudes towards mental health, the stigma or misinterpretation of dementia and the barriers to accessing services are three other factors that worsen the carer's situation in assuming their caregiving role.

According to the 2001 Census, 6% of women and almost 3% of men in the Chinese community in the UK are aged 65 years and over. The majority of the older people in the community will be those who have migrated from Hong Kong since the mid-1950s. Most of the older women in the community arrived during the 1960s and 1970s as dependants of male relatives – predominantly fathers and husbands. Many have, within their country of origin, experienced extreme hardship and trauma during the Second World War. For those who came from rural areas and farming families to settle in London and other cities, they have had to cope not only with the change in environment, but also the city life that can be as isolating as living in rural areas because of the language barrier and their relatively low level of education (Yee & Au, 1997). About 70-80% of the first-generation immigrants do not speak English (Home Affairs Committee Report, 1985).

Not being able to speak English is the biggest barrier to accessing the predominately English speaking health services. The barrier is reinforced further by difficulties in expressing experiences when a person has a progressive cognitive impairment, even in his/her own language (Forbat, 2003). As a result of the language barrier, similar to other ethnic minority groups who face the language problem in accessing health services, dementia within the Chinese community is underrepresented. Dilworth-Anderson & Gibson (1999) report that older ethnic minorities are underrepresented in memory disorder clinics and other programmes, however, the reasons for their under-representation are not clear.

Chinese community attitudes towards mental health are broadly similar to those found in the general population. People with mental health problems find it difficult to admit these problems because of the stigma attached. Mental illness is no longer a new topic nowadays. It is very common, and happens everywhere and in every community. However mental illness is still a stigma in Chinese culture, mental health issues are an untouchable topic to discuss in the community. In some cases even when medical attention or support is needed, people are reluctant to seek help (CMHA, 2007).

Stigma attached to dementia is perhaps derived from the seemingly undignified translation of the term in Chinese. The term used for dementia in Chinese means 'insane' and 'immobile', and that is the medical term commonly used in South East Asia, except in Taiwan, where a different term

(meaning 'loss of sense') is used to indicate dementia. The role of stigma is more complicated when family members are to manage someone with a diagnosis of dementia, there are multiple layers of concern around the negative impact that this has on the person's identity and quality of life (Forbat, 2003). Like some of the other mental illnesses, as dementia is often associated with behavioural disinhibition, it may be seen as a very visible or obtrusive form of illness which is likely to be stigmatised (Goffman, 1963). In the inner city areas where there are close-knit community networks, Chinese people with mental health problems and their families have a tendency to conceal their difficulties (Yee & Au, 1997).

Lay perspectives of dementia might reflect caregivers' different needs, expectations and beliefs that need to be addressed. A study by Chung (2000) in Hong Kong revealed that when family carers had limited medical knowledge of dementia, they tended to lose their way in the forest of jargon and uncertainties. Hence, to gain control of the disease process and the caring experiences, they are inclined to use external events, personal experiences and building up an illness story to explain the occurrence of dementia. The search for explanation of dementia is a means for family carers to ease their feeling of desperation when coming to terms with a tragic loss of a loved one. Chung suggested for family care of individuals with dementia to be effective, health care professionals must listen to and accept carers' subjective understanding of dementia, rather than insisting them to accept the biomedical explanations as the only causation of dementia. At this juncture, Chinese immigrants in this country might have difficulty expecting such supportive ideas from their health professionals who are predominately western people. Therefore, unless the Chinese carers and the persons with dementia are able to conceptualise their experiences within the western medical frame, they are unlikely to secure the help they need, thereby compounding health inequalities (Forbat, 2003).

Depression is often commonly misdiagnosed as dementia because many of the symptoms are similar (Yee & Au, 1997). Stories of under-diagnosis (with medics assuming symptoms are normal ageing) and over-diagnosis (depression being mislabelled as dementia because assessments are not sufficiently sensitive) were frequently reported. These features are common to the narratives of misdiagnosis in the majority ethnic group (Forbat, 2003).

Another barrier for members of the Chinese community is that they are in a disadvantageous position where systems of support are far from being developed that are tailored to their cultural needs for dementia care. The statutory sector mental health services seldom address the needs of Chinese people adequately (Li, Logan, Yee & Ng, 1999). One of the major challenges for both the statutory and voluntary sectors is the dispersed nature of the Chinese population across the UK (National Statistics, 2001). By definition, mental health problems, whether interpreted as 'mental

illness' or not, affect a relatively small portion of any population. In the UK, planning, co-ordinating and provision of social and health services are almost exclusively carried out at a local level. Chinese people are widely dispersed; the Chinese population in any given area never amounts to a very significant proportion of the population, be it a city borough or county. Therefore, responsibility for arranging services for people with problems in such a small minority, even when they are recognised as needing specialised mental health services, may not be anyone's business (Au & Tang, in press).

Much research has addressed the stress and support needs of caregivers for persons with dementia. Ways of enhancing the caregivers' quality of life involve cultivating a stronger self-efficacy and lowering the individuals' psychological distress through psychoeducation, management skills training, formal and informal support. Studies show that stress associated with caring for a family member with dementia can be relieved by the involvement of support groups that help caregivers to identify concerns and develop systematic problem-solving techniques to resolve them (Fung & Chien, 2002). Support groups can also provide much-needed assistance and advice about community resources and assure caregivers that their role is vital (Mittelman, Ferris, Steinberg, Shulman, Mackell & Cohen, 1993).

Yee & Au (1997) suggested that statutory services should consult widely with Chinese carers about their needs and about how they would like these needs met. National organisations offering advice and support to carers should target Chinese carers, identify their needs, encourage them to recognise their role as being important and inform them of available services to improve their quality of life.

### **Background to the Study**

Based on Yee & Au's suggestion, this research study aimed to explore the practical ways of engaging Chinese carers in finding out their needs and how these needs could be met. It also seeks to encourage them to recognise their role as being important and to improve their quality of life with information about available services that they might not have known of or had access to. In its objectives, the study draws on the assumption that the Chinese, because of their tradition of acquiescence to power and authority, may be reluctant in articulating their demands, and family carers who are suppressed because of their roles and social stigma could be rendered even more vulnerable in a social setting. A participatory and empowering approach based on the concept of community health psychology will be the key element of this research study.

Health psychology emerged from clinical psychology and social psychology in the late 1970s, it branched out from one-to-one clinical interventions into health promotion and disease prevention, but its focus has remained on the individual's determinants of health (Nelson, Pancer, Hayward & Kelly, 2004). While traditional health psychology has tended to have a psycho-centric view of health, in contrast, community health psychology takes a broader view of health and well-being, focusing on the connections between individuals and their social environments. Community health psychologists advanced the idea that health is more than an individual attribute; health also includes community development, equality and social justice (Nelson, Pancer, Hayward & Kelly, 2004; WHO, 1996).

Contextually speaking, community health psychology takes the micro, meso and macro ecological levels of analysis into account (Febbraro, 1994); and distinguishing it from mainstream health psychology is that community health psychology calls attention to the strengths of disadvantaged people and encourages them to gain control over health through active participation in research focusing on their health issues (Tolman & Brydon-Miller, 2000; Nelson, Pancer, Hayward & Kelly, 2004).

Going beyond individuals' health status in terms of ecological and strengths perspectives would mean that community health psychologists engage in interventions that strive to change social conditions that affect the health of disadvantaged people (Febbraro, 1994; Prilleltensky & Nelson, 2002). Community health psychology interventions incorporate activities such as the development of competence and self-efficacy, active participation in multiple settings, and the acquisition of valued resources such as education, housing and income (Nelson, Lord, & Ochocka, 2001; Prilleltensky, Nelson & Peirson, 2001; Nelson, Pancer, Hayward & Kelly, 2004).

When we look at the difficulties that have been encompassing the lives of the Chinese carers and their care recipients culturally, socially and economically, and the more intensive the health service standards to which they are expected to adjust, but it is not yet within their ability to adjust to; it is reasonable to believe that determinants of health of this ethnic group have apparently gone beyond the individual level. The principles of community health psychology and its adaptation in this study can enhance the understandings of the social context of health of this minority group, and how community health psychology intervention can help to build up the carers' competence, self-efficacy and active participation to address the issues that have been affecting their health in a broader social context. To understand the broader social context of the disadvantaged group in discussion and applying the concept of community health psychology into practice, Guareschi & Jovchelovitch (2004) present a framework for psychosocial interventions in primary health care focusing on participation, empowerment and community development.

Guareschi & Jovchelovitch highlight the social psychological dimensions involved in participation and the role it can play in improving conditions of living and thus, health. Their study was located in southern Brazil, a geographical context of extreme social exclusion, where small groups of people started to occupy land illegally and gradually constituted themselves as a community demanding resources in sanitation, education, transport and health care delivery. Guareschi & Jovchelovitch stated that for countries exposed to chronic social inequality such as Brazil, improving these conditions could only happen with pressure from below.

Communities living in a situation of extreme deprivation need to organize themselves and develop the various competences required for effective participation in the public sphere if they are to improve conditions of living and thus enhance health. Participation, empowerment and community development, therefore, become key strategies in reducing health inequalities and in incorporating the demands of the poor into health policy.

Guareschi & Jovchelovitch (2004) p. 312

One of the foci of their work, participatory intervention in the community, was structured and guided by dialogical communication, recognition and critical awareness. They used a number of qualitative methodologies ranging from interviews and group work, to participant observation and filming to enact processes of listening, observing and talking to the community. In their experience, individual interviews, group discussion and the use of video to produce films about the groups they worked with allowed to bring to light the true picture of the community, both at the conceptual and material levels. The process of uncovering knowledge of and about the community allows understanding and making sense of the conditions of living and generating a meaningful theme of the community (Freire, 1972; Guareschi & Jovchelovitch, 2004).

Guareschi & Jovchelovitch concluded that community participation continues to be a key strategy for reducing health inequalities and improving the health of poor populations; developing and sustaining participation for empowerment remains a necessary, although complex, task. Drawing on the experience of Guareschi & Jovchelovitch's framework of psychosocial intervention in primary care, this study sought to engage three groups of Chinese family carers for psychosocial interventions grounded on a participatory approach.

In the following sections three studies will be discussed. Study One is to discuss the development of a measurement scale to assess the psychological empowerment of carers before and after the

participatory psychosocial intervention Study Two and Study Three cover the participatory action research with the Chinese carers.

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## Study 1

### **The Development of a Chinese Sense of Empowerment Scale**

#### **A scale to measure empowerment among Chinese immigrant family carers for people with dementia and other mental illnesses**

##### **1. Introduction**

The concept of empowerment has been examined at different levels of practice in diverse academic disciplines and professional fields (Braithwaite & Lythcott, 1989; Rappaport, 1981; Wallerstein, 1988). Individual empowerment refers to an individual's ability to make decisions and have control over his or her personal life. It is similar to other constructs such as self-efficacy and self esteem in its emphasis on the development of a positive self-concept or personal competence (Israel, Checkoway, Schulz & Zimmerman, 1994).

In this study, a Sense of Empowerment Scale (SES) was designed and developed to assess the change in the Chinese carers' psychological states specifically in the context of caring for family members with dementia. Since exploring the change in Chinese carers' sense of empowerment through participation in a group in which they shared common values and a sense of identity is one of the objectives of the research, the first step in the process is to examine the concept of empowerment and to understand the conceptual framework of the stress process that health educators normally followed in planning health promotion and intervention at a community level. The literature review of this study is mainly drawn from Israel et al. (1994) in their discussion of community empowerment and conceptualising and measuring perceptions of individual, organisational, and community control.

In its most general sense in the context of community psychology, empowerment refers to the ability of people to gain understanding and control over personal, social, economic, and political forces in order to take action to improve their life situations (Zimmerman & Rappaport, 1988). An important aspect for individual empowerment is the inclusion of the establishment of a critical understanding of the individual's social and political context, and the nurturing of both individual and collective resources and skills for social action (Kieffer, 1984). This is particularly relevant to this research study as the Chinese carers are re-examined in these contexts in which minority status, poor education, language difficulty, powerlessness, lack of control and lack of social support are risk factors which might have been affecting their health and well-being. Many of these risk factors, beyond their individual ability to control or change,

are often being overlooked or ignored. In this research study, the understanding of the social, economic and political contexts are just as important as the personal determinants of health such as life-style choices and individual health behaviours.

Empowerment is often defined for different levels of analysis and practice – for example, individual, organisational and community. It is because empowerment at the individual level is linked with the organisational and community levels through the development of personal control and competence to act, social support, and the development of interpersonal, social, and political skills (Kieffer, 1984). For individuals to be empowered in their own community, they would have to come together as a group where they can share a sense of identity and belonging.

In this study, when the individual Chinese carers characterised and identified themselves as a group, the researcher sought to explore some of the common elements likely to emerge which would be useful primarily in understanding the cultural and social background of the Chinese carers. These common elements are: (1) shared emotional connection in that they share a common history as carers for people with dementia, experiences, mutual support; (2) shared culture and languages – Chinese origin, speaking Cantonese or Hakka; (3) shared values and norms; (4) shared history – immigrants from Hong Kong, China, or other Chinese regions. In the process of designing the SES, such understanding is essential to find out the definition of empowerment specific to this group.

There have been numerous discussions of measurement issues and calls for the development of instruments to measure empowerment. However, there are still competing definitions and a lack of clarity on how empowerment is conceptualised at different levels of practice, its relationship to health, its measurement, and its application to health education practice (Israel et al., 1994).

Israel et al. (1994) developed a measurement which draws on research through the Detroit Area Study (DAS), a large, random sample survey conducted yearly at the University of Michigan. In the autumn of 1988, during the planning phase of the DAS, they were involved in a seminar series on empowerment, and were challenged by the lack of measurement instruments consistent with their conceptualisation of community empowerment. Thus, they created a set of twelve questions designed to assess individual perceptions of control or influence at the three levels of analysis; individual, organisational, and community, for inclusion in the DAS survey. Participants were asked about their involvement in numerous organisations including national, neighbourhood or church organisations. A four-point response scale, ranging from 1 = disagree

strongly to 4 = agree strongly, was used for all the items. Some of the twelve items measuring perceptions of control are as follows:

- I can influence the decisions that this organisation makes.
- I have control over the decisions that affect my life.
- By working together, people in my community can influence decisions that affect the community.

Three subscales were created subsequent to a factor analysis of the overall twelve-item community empowerment scale. The three subscales correspond to perceived control at the individual level, the organisational level and the community level. Israel et al. suggested that the community empowerment scale or perceived control indices could be used by a health educator engaged in a community empowerment intervention for both assessment and evaluation purposes. The measurement instrument could also be used in a survey to gather baseline data on perceptions of influence and control within a community or to investigate basic research questions to further understanding of the community empowerment concept.

However as the authors suggested, since the perceptions of control were assessed by the use of a survey instrument with closed-ended items, they are not able to capture the richness and complexity of the community empowerment concept, and the use of more in-depth, semi-structured interviews, focus groups, and community observations throughout a community empowerment intervention is needed to better assess empowerment as both a process and outcome. Another limitation of the scale the authors point out is that since the definition of community was not incorporated into the questionnaire, respondents answered the questions using their individual and undetermined conceptions of community. The authors suggested that the instrument would be most useful for intervention purposes if all respondents within a particular community were asked to answer the questions with the same community in mind. Furthermore, the instrument was developed and tested with respondents from a large urban area involving a diverse population, therefore, the concepts of community, control, and empowerment may differ across cultures and regions, and these variations need to be taken into consideration when adapting the scale to other areas. An alternative approach, consistent with the definition of empowerment, as the authors proposed, would be to involve community members actively in the generation and testing of the questionnaire items.

In his chapter on empowerment theory, Zimmerman (2000) gave an account on the development of appropriate measurement devices:

A significant barrier for studying psychological empowerment (PE) is the development of appropriate measurement devices. The development of a universal global measure of PE, however, may not be feasible or conceptually sound, given that the specific meaning of the construct is context and population specific. This suggests that measures of PE need to be developed for each specific population with which one is working. Similarly, measures of PE in one life domain may not be appropriate to other settings of an individual's life. Measurement development must include the research participants to help create measures and to test and refine them. The research may also require intense observation and involvement with a particular population in a particular context as a first step in the research process. In-depth study of the research setting and population would not only add to our understanding of PE, but would also add insight into the organisational and community settings in which it develops.

Zimmerman (2000), p. 51.

Based on the lessons learned from above literature reviews, the current study endeavours to develop a Sense of Empowerment Scale specific to the Chinese immigrants who assume the role of family carers for people with dementia in the United Kingdom. Since there is no single scale to date developed to measure this specific population, the SES is particularly developed to measure the change in psychological empowerment of this group of carers in the process of the participatory psychosocial intervention of the current research.

## **2. Devising the items and content validity**

For many Chinese communities, especially people from the older generation, the code of conduct based on Confucianism, which reflected a hierarchical social system, still exists as a social norm which requires respect for people of a higher order, such as younger generations respecting their elders, wives respecting their husbands, and all citizens should respect authority. For thousands of years, this social hierarchical system has been practiced and handed down from generation to generation in China. It has a vast impact on the social, cultural and political life of all Chinese societies regardless of where these societies are based. Grounded on the influence of Confucianism, Chinese people are culturally reverential to authority (Mental Health: Culture, Race and Ethnicity, 2001).

It is reasonable to believe that the concept of 'empowerment' would be totally foreign and new to the older Chinese generation, even more so to a group of family carers, presumably mostly females who are expected to be subservient in the family and the social setting. While it is impossible to endorse any explanations or meanings about all aspects of the interpretation of the

term 'empowerment' in relation to caring of this specific group, the previous scales (Israel et al., 1994) was used as a helpful guidance at the beginning of this study, and in order to cover a domain of empowerment among the Chinese family carers, the researcher was motivated to develop a population specific new tool so that specific factors of empowerment could be addressed.

As Streiner & Norman (2003) indicated, new items can come from five different sources: the patients or subjects themselves, clinical observations, theory, research, and expert opinion. In scale development, patients and potential research subjects are an excellent source of items. In this study, a sample of 35 participants in the Chinese community was used as the source of devising the items of the new measurement tool. For the purpose of establishing the content validity of this measurement scale, that is, the extent to which the design and structure of the scale reflects the particular purpose for which it was developed (Rust & Golombok, 1999), this selected sample of family carers of dementia and mental ill health, health professionals and community workers from the Chinese community was used because they were most justifiable to give opinions on the issues around dementia care. The opinions collected from this selected sample was used as reference in constructing the framework.

## **2.1 Method**

### *2.1.1 Participants*

The source of items was people from the Chinese community who were all of Chinese origin and who had lived for at least ten years in the UK. Participants included fifteen family carers for people with mental illness including dementia; ten health professionals including medical doctors, counsellors, psychotherapists; five community workers in the area of carer's and patient's support; five people from other professions such as accounting and media. More than half of the carer participants did not reach secondary school level, whereas all the participants from professional background reached university level or over. The participants were service users and affiliates of a Chinese mental health charity based in London.

### *2.1.2 Procedures*

Four open-ended questions were devised to ask the participants their general opinions and interpretations on the term 'empowerment'. The answers collected would be further analysed for the generation of themes that can be used to phrase the items themselves.

The four questions are as follows:

1. What is your opinion about empowerment?
2. In what ways will you feel you are being empowered?
3. In what situations would empowerment take place?

Question four is for health professionals and community workers only:

4. If you work with patients, carers or service users, in what ways do you think they could be empowered?

The fifteen family carers were interviewed on the telephone by the researcher, whereas the twenty professionals replied and sent the questions back to the researcher via email.

In Chinese, there is not a single equivalent term for the English noun 'empowerment'. The direct translation of empowerment in Chinese is 'being given power or authority to act'. At the beginning most carer participants had difficulty understanding the terms empowerment because they had not much experience relating themselves to the situation where they are given power to act.

To conceptualise the meaning of empowerment and look at it from the carer's perspective, the researcher spent the first 30 minutes in each phone interview with the carer exploring the connotation of empowerment through discussing and understanding their difficulties in caring and in turn scenarios that would make them feel being empowered. The closest description of empowerment in Chinese, in the carers' way of expression is 'making them feel more powerful and having more strength'.

When the term empowerment in Chinese was clear to the carer participants, the researcher then went on asking the open ended questions. At this point, the researcher placed emphasis to the participants to consider specifically the situations relevant to their role as a family carer when they answer the questions.

All the twenty professionals had no problem in identifying the term empowerment. All of them preferred answering the questions in their own time to a phone interview. They all gave detailed explanation of their understanding and opinion on empowerment in writing and sent them back via email to the researcher.

### *2.1.3. Data analysis*

The researcher recorded and transcribed the carer participants' phone interviews in Chinese and translated the Chinese transcripts into English. As for the email replies, data was all in English. Thematic content analysis was used to code the data. By using

the thematic analysis, both types of theme, the manifest themes of the data and the more latent meaning of the manifest themes, would be observed and interpreted. Basically data from the transcription was coded by categorisation; that is, taking the repeated appeared texts, grouping them together, and labelling them as falling into certain categories, in a way that allows for later retrieval and analysis of the data (Mark & Yardley, 2004).

#### 2.1.4 Results

The data collected was divided into two sets, one from the carers and one from the professionals. The two sets of data were used to compare and contrast opinions from the two groups of participants, who were distinctive in their educational and socioeconomic backgrounds. Quotes were included in the initial data sheet when over 50% of the same and similar phrases from the participants were collected. Data before thematic content analysis is shown in Table B.1.

**Table B.1.** – Summary of the carers’ and professionals’ views on empowerment

Carers’ views on empowerment	Professionals’ views on empowerment
<p><b>Empowerment is...</b></p> <ul style="list-style-type: none"> <li>● To have support available from an organisation.</li> <li>● To have a supportive network of friends.</li> <li>● To have a supportive family.</li> <li>● To have the courage to speak to the authority</li> <li>● To be given help &amp; support.</li> <li>● To be able to speak better English.</li> <li>● To be given a space to speak.</li> <li>● To be listened to and be respected.</li> <li>● To see real change in health services.</li> <li>● Have a feeling that ‘help and backup’ is out there.</li> <li>● Knowing where to get help, information &amp; advice.</li> </ul>	<p><b>Empowerment is...</b></p> <ul style="list-style-type: none"> <li>● To be able to assert oneself.</li> <li>● To be independent.</li> <li>● To be able to make decision.</li> <li>● To be given authority over certain matters or people.</li> <li>● To enable people to do what they could not do before.</li> <li>● A sense of control over one’s life.</li> <li>● Being able to contribute.</li> </ul>

*Continue...*

Empowerment could happen...	Empowerment could happen...
<ul style="list-style-type: none"> <li>● Though sharing experience with people from the same background.</li> <li>● Through supporting each other.</li> <li>● Through communication and interaction with other people.</li> <li>● Through participation and user involvement.</li> <li>● Through attending consultation event.</li> <li>● When my care recipient accepted my help.</li> <li>● When my care recipient trusted me.</li> <li>● When one is able to make good use of the health services.</li> <li>● When one has acquired enough knowledge about one's rights in the health system.</li> <li>● When one has enough knowledge of the disease.</li> <li>● When one acquired the right strategy to communicate with the authority.</li> <li>● When one knows how to complain.</li> </ul>	<ul style="list-style-type: none"> <li>● Through participation.</li> <li>● Through training and a learning environment.</li> <li>● Through gaining knowledge of the issue in discussion.</li> <li>● Through opportunity given to acquire knowledge and skills.</li> <li>● Through encouragement.</li> <li>● Through support from other people.</li> <li>● Through guidance and advice.</li> <li>● When one has the right to decide what they want and to execute the decision.</li> <li>● When the lobby-group is strong enough to be heard by the authority.</li> </ul>

Looking at the quotes from the two groups, although some similarities are found, statements from the carers are much more explicit in demonstrating a picture of what empowerment meant to them. Themes were formed mainly from the quotes from the carer participants and some from the professionals. Table B.2. shows the themes arise from the thematic content analysis.

**Table B.2. – Themes of empowerment from the telephone interviews**

**Theme One: Social support as a source of empowerment**

- To have a supportive network of friends.
- To have a supportive family.
- To have support available from an organisation.

**Theme Two: Empowerment through participation and sharing**

- Through participation in attending consultation events.
- Through user involvement.
- Through sharing experience with people from the same background.
- Through supporting each other.

*Continue ...*

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**Theme Three: Organisational support as a source of empowerment**

- To be offered help and be supported.
- To have a feeling that 'help and backup' is out there.
- Knowing where to get help, information and advice.

**Theme Four: Getting one's voice heard by the authority**

- To be given a space to speak.
- To see real change in health services.
- To be listened to and be respected.

**Theme Five: Ability to speak and to communicate**

- To be able to speak better English.
- To know how to complain.
- To have the right strategy to communicate.
- Through communication and interaction with different people.

**Theme Six: Knowledge of the health service system**

- When one has acquired enough knowledge of his rights in the health service system.
- When one is familiar enough about the rules and regulations of the health care system.
- When one is able to make good use of the health services.
- When one has enough knowledge of the disease.

**Theme Seven: A trusting relationship with the care recipient**

- When my care recipient trusted me.
- When my care recipient accepted my help.

**Theme Eight: To be given the right to make decision**

- Have the right to make decision.
  - To be entrusted to make decision.
  - When one has the right to decide what they want and to execute the decision.
- 

*2.1.5 Phrasing the items*

Based on the eight themes arising from the thematic content analysis, the first eight items of the SES were formed. The eight items are shown in Table B.3.

**Table B.3.** – The first eight items of the Chinese Sense of Empowerment Scale

- 
1. I have a supportive network of friends.
  2. I like sharing experiences with carers from a similar background.
  3. A strong link to community organisation is helpful.
  4. I feel enabled when I have the chance to speak to the authority.
  5. I know what I should when I have to talk to the health authority.
  6. The person for whom I care accepts my help.
  7. I am familiar with the health service system.
  8. In general, I feel in charge because I have decision making power.
- 

The eight items were first constructed in Chinese, based on the transcripts of the phone interviews, and were translated into English for reporting purposes. Streiner & Norman (2003) suggested that except for scales that are aimed at a selected group whose educational level is known, the usual rule of thumb is that the scale should not require reading skills beyond that of a 12-year-old.

#### *2.1.6 Face Validity*

To evaluate the acceptability of the test items (Rust & Golombok, 1999) and to ensure that the respondents' interpretation of the questions is the same as the researcher's, two family carers were invited to read through the eight Chinese items. They shortened and simplified some of the wordy items, making them read more straightforward. They said that since carers are mostly older people from a lower education background, the items should be set out as easy to understand as possible. No jargon was used in the questions. Face validity was measured again when the scale was expanded to a 48-item scale and will be discussed in the next section. A sample of the Chinese eight-item scale can be found in Appendix B.1.

### **3. Expanding the items**

At this point, the items had not yet been fully established to represent the eight themes. When the researcher went over the themes again, it was noticed that although the two to four statements under each theme were describing a similar aspect, they were relating to different situations that different respondents might encounter; therefore expanding the items to cover more than one situation in each theme was necessary. Another objective of expanding the items was to rule out the tendency to say 'yes', also called acquiescence bias. This is the

tendency to give positive responses to a question (Couch & Keniston, 1960). At most extreme, the participant responds in this way regardless of the content of the item, sometimes even for mutually contradictory statements (Streiner & Norman, 2003). Whether or not this tendency really exists, Rorer (1965) acknowledges that some people are more prone to answer 'true' than 'false' when ignorant of the correct answer. Krosnick (1999) reports that there is an average acquiescence effect of about 10 per cent in favour of answering 'True' or 'Yes'. To minimise acquiescence bias, mutually contradictory statements were added throughout the questionnaire, for example, a negative item like 'I don't have many friends' was added to contradict its positive item, 'I have a supportive network of friends'. After expanding the items, each theme now consisted of six items, totalling 48 items. The 48-item is shown in Table B.4.

**Table B.4.** – The 48 items formed

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**Theme One – Social support as a source of empowerment**

- I have a supportive network of friends.
- I can get support from the community centre when I need help.
- I can deal with stressful situations because I have a supportive family.
- My family is unable to support me when I am under stress.
- I don't have many friends who could support me when I need help.
- I don't think the community organisation can help much when I need support.

**Theme Two – Empowerment through participation and sharing**

- I like sharing experiences with carers from a similar background.
- I enjoy the supporting relationship with other carers.
- Being involved in a group is empowering.
- Attending a consultation event made me feel more confident.
- I don't think a consultation event would make me feel more confident.
- I don't like sharing experiences with people from a similar background.

**Theme Three – Organisational support as a source of empowerment**

- A strong link to community organisation is helpful.
- The community organisation has the right information for me whenever I need it.
- It's good to know that help is out there even though I may not need it now.
- I don't think going to community organisation is helpful.
- I don't think community organisation can give me help.
- The community organisation I go to is not supportive.

*Continue...*

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#### **Theme Four – Getting one’s voice heard by the authority**

- I feel enabled when I have the chance to speak to the authority.
- Giving opinion to the authority without restriction is empowering.
- To see real changes in statutory health services is empowering.
- I feel respected when I am listened to.
- I don’t think speaking to the authority is useful.
- I feel okay even when people don’t listen to me.

#### **Theme Five – Ability to speak and to communicate**

- I have the right strategy to talk to the health authority.
- I have the right words to complain in English.
- I have the courage to speak to the authority.
- I can’t find the right words to talk to the authority.
- I don’t have the courage to talk to the authority.
- I don’t have the ability to complain in English.

#### **Theme Six – Knowledge of the health service system**

- I have enough knowledge about the illness of the person I care for.
- I am familiar with the health service system.
- I know where to get the right health services.
- I don’t have enough knowledge about the illness of the person I care for.
- I don’t know much about the health service system.
- I don’t know what health services the patient is entitled for.

#### **Theme Seven – A trusting relationship with the care recipient**

- The person I care for trusts me.
- I have a supporting relationship with the person I care for.
- The person I care for accepted my help.
- The person I care for does not trust me.
- The person I care for does not accept my help.
- I feel discouraged because I don’t have rapport with the person I care for.

#### **Theme Eight – To be given the right to make decisions**

- I feel in charge because I have the right to make decisions.
  - I feel in charge because I can delegate things to other people.
  - The person I care for trusted me to make decisions on his/her behalf.
  - I don’t have the power to make decisions most of the time.
  - I have to do all the things on my own. nobody helps me.
  - The person I care for doesn’t want me to make decisions on his/her behalf.
-

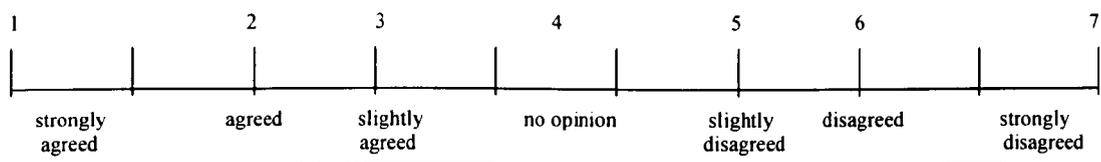
The expanded 48 items were first constructed in Chinese and were translated into English for reporting purposes. A sample of the Chinese 48-item is in Appendix B.2.

To evaluate the suitability of the test, two carers were invited again to read through the 48 items to make sure that the items are short and clear, although not so short that clarity is lost. The 48 items appeared on the questionnaire to be administered to the participants in random order, so that mutually contradictory items would not be read immediately one after the other. The term 'care recipient' in the questionnaire was replaced by 'the person I care for' according to the carers' opinion that 'care recipient' sounded too formal that the respondents might relate their care experience in some formal setting.

#### 4. Scaling the responses

After a set of items have been devised, the next step is to choose a method by which responses will be obtained. As the nature of the items stated, for example, 'I am familiar with the health service system' does not determine simply a 'yes' or 'no' response but a continuous judgement, the use of a more refined technique may be required in order to provide more choices of response levels.

A Likert scale (Likert, 1952) was constructed to measure change in the psychological empowerment of the participants in this research study over a period of three to six months. Likert scales are bipolar, as in Figure 1. In this measurement scale, agreement with the items is tapered from 'strongly agree' to 'strongly disagree'.



**Figure B.1.** Example of the Likert scale.

A seven-point Likert scale, ranging from 'strongly agree' to 'strongly disagree' was constructed to obtain responses in each of the 48 items. A sample of the measurement scale (both Chinese and English) can be found in Appendix B.3.

#### **4.1. Scoring the questionnaire**

The scores are allocated to response options according to the continuous scale that has been constructed; strongly agree = 7; agree = 6; slightly agree = 5; no opinion = 4; slightly disagree = 3; disagree = 2; strongly disagree = 1. For the reversed items, to revise the scoring in order that each item is scored in the same direction; strongly agree = 1; agree = 2; slightly agree = 3; no opinion = 4; slightly disagree = 5; disagree = 6; strongly disagree = 7.

The score on each item was added up to obtain the total score for the questionnaire. In this measurement scale, the higher the total score, the greater the presence of sense of empowerment is measured.

#### **4.2 Standardisation**

With the aim of interpreting the score of an individual participant, that is, whether or not his or her score on the questionnaire is characteristic, this step was to standardise scores obtained in this pilot study of the questionnaire. Rust and Golombok (1999) referred to these scores as norms are possible to interpret the score of an individual respondent. It is important for the current research study to determine how an individual family carer's psychological empowerment has changed in time; thus standardisation will be computed to compare the individual score. Standardisation will be presented in terms of the mean and standard deviation (Rust & Golombok, 1999) for this pilot study group. Statistical analysis of the standardisation will be presented section 5.1.3.4.

#### **5. Piloting the measurement scale**

At this stage a pilot study was to be conducted. The data collected from the pilot study would be used to analyse and select the best items of the final version of the measurement scale. The pilot study would engage Chinese carers for whom the measurement scale was intended. Rust & Golombok (1999) suggested that if the questionnaire is intended for a specific group of people one might carry out the pilot study with people who are representative of that population group. Rust & Golombok also suggested that the respondents who take part in the pilot study should differ in terms of demographic characteristics such as age, sex and social class, while if the questionnaire is intended for both sexes; there is little meaning in piloting a questionnaire only with men. Therefore, when deciding the group of participants for this pilot study, both men and women were invited to take part, and they were varied in terms of age, education level and social class, although they were all carers in the Chinese community.

## 5.1 Method

### 5.1.1 *Participants*

Pilot study participants were 108 Chinese carers (73 women and 35 men). The participants were obtained from three Chinese community organisations in London, Leeds and Newcastle-upon-Tyne. Participants who were family carers but did not rely on services in Chinese community organisations were also obtained through contacts. Chinese carers for people with dementia and other mental illnesses were surveyed from different cities and social backgrounds to increase the demographic diversity of the sample and thus a pattern of the normal contribution of this sample population and the generalisability of the results. Participants ranged in age from 18 to 89 years, with a mean age of 52 years. All of the participants were of Chinese origin. In terms of regions where they came from before they migrated to this country, there were 73 (68%) from Hong Kong, 25 (23%) from Mainland China, and 10 (9%) from Malaysia. The length of residence in the UK ranged from 9 years to 33 years with a mean of 29 years.

### 5.1.2. *Procedure*

The researcher administered the questionnaire at a community centre in London, and cooperating instructors administered the questionnaire to the participants in community centres in Leeds and Newcastle. The participants were informed the purpose of the research study was to explore the views held by Chinese carers for people with dementia and other mental illnesses and their responses were anonymous. No financial reward was offered as an incentive to participate. Twenty-two participants who were obtained by contacts filled out the questionnaire and returned via email to the researcher, whereas all the rest of the participants filled out the questionnaires at the community centres with the presence of the researcher or the instructors. Completed questionnaires from Leeds and Newcastle were sent by post to the researcher in London.

### 5.1.3. *Data Analysis*

Descriptive data analysis, Cronbach's alpha coefficient, factor analysis were conducted using the SPSS statistical package to measure the standardisation, the internal consistency and the factor loading of the new scale.

#### 5.1.4. Results

##### 5.1.4.1. Internal consistency

Based on data from all 108 participants, the internal consistency value established by means of Cronbach's alpha coefficient among the 48 SES items was 0.893. The item-total correlation showing the product-moment correlation coefficient of each item is shown in Table B.5. The items which have lower correlations (below 0.2) with the total items are items 39 (0.077); 43 (0.097); 2 (0.152); 15 (0.171) respectively.

**Table B.5.** – Corrected Item –Total Correlation

Item description	Total correlation
1. I have a supportive network of friends.	0.411
2. I can get support from the community centre when I need help.	0.152
3. I have the right strategy to talk to the health authority.	0.551
4. My family is unable to support me when I am under stress.	0.530
5. I don't have many friends who could support me when I need help.	0.473
6. I have a supportive relationship with the person whom I care for.	0.252
7. I like sharing experiences with carers from a similar background.	0.322
8. I enjoy the supporting relationship with other carers.	0.344
9. I have enough knowledge about the illness of the person whom I care for.	0.490
10. Attending a consultation event made me feel more confident	0.303
11. I don't like sharing experiences with people from a similar background.	0.442
12. A strong link to community organisation is helpful.	0.458
13. Being involved in a group is empowering.	0.291
14. The person I care for accepted my help.	0.388
15. I don't think community organisation can give me help.	0.171
16. The person I care for does not trust me.	0.348
17. I can deal with stressful situations because I have a supportive family.	0.464
18. I don't have enough knowledge about the illness of the person I care for.	0.420
19. I don't think a consultation event would make me feel more confident.	0.443
20. I know where to get the right health services.	0.347
21. The community organisation I go to is not supportive.	0.399
22. I feel okay even when people don't listen to me.	0.269
23. I don't know what health services the patient is entitled for.	0.421

*Continue...*

24. I don't think community organisation can give me the right information and advice.	0.354
25. I have the right strategy to talk to the health authority.	0.409
26. I feel in charge because I have right to make decision.	0.402
27. I feel enabled when I have the chance to speak to the authority.	0.401
28. To see real changes in statutory health services because of my opinions is empowering.	0.438
29. The person I care for doesn't want me to make decision on his/her behalf.	0.204
30. Giving opinion to the authority without restriction is empowering.	0.328
31. I have to do all the things on my own, nobody helps me.	0.488
32. It is good to know that help is out there even though I may not need it now.	0.301
33. The community organisation has the right information for me whenever I need it.	0.263
34. I don't think speaking to the authority is useful	0.362
35. I don't have the courage to talk to the authority.	0.371
36. The person I care for does not accept my help.	0.460
37. I have the right words to complain in English	0.372
38. I don't have the power to make decision most of the time	0.524
39. I feel respected when I am listened to.	0.077
40. I don't know much about the health service system.	0.473
41. I have the courage to speak to the health authority.	0.376
42. I don't think going to community organisation is helpful.	0.309
43. The person I care for trusted me to make decision on his/her behalf.	0.097
44. The person I care for trusted me.	0.325
45. I feel in charge because I can delegate things to other people.	0.414
46. I am familiar with the health service system.	0.428
47. I feel discouraged because I don't have rapport with the person I care for.	0.254
48. I don't have the ability to complain in English.	0.364

#### 5.1.4.2. Exploratory Factor Analysis

Factor analysis yielded five factors with Eigen values greater than one. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy is 0.756. After reading the factor and item analyses, a six-factor combination was judged the best. This yielded a 26-item questionnaire with factors accounting for 50% of the total variance. Factor loading for six factors and 26 variables is presented in Table B.6. A list of items of the six factors structure is presented in Table B.7.

**Table B.6.** – Factor loading matrix for six factors and 26 variables

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
46	.792					
20	.726					
3	.682					
25	.676		.424			
9	.667					
37	.659					-.415
41	.602					
7		.876				
8		.865				
12		.729				
32		.710				
13		.646				
10		.636				
28			.734			
30			.678			
27	.435		.626			
45			.610			
26			.605			
1			.483	.401		
2						.732
33						.682
44		.402			.821	
43					.810	
17				.725		
6				.712		
14				.471		
Eigenvalue	3.507	3.535	2.542	1.415	1.330	1.173
Variance	13%	13%	9%	5%	5%	4%

**Table B.7.** – Items of the six factors structure of the SES

Subscale name	Items
1. Confidence in pursuing one's rights because his/her knowledge	<ul style="list-style-type: none"> <li>● I am familiar with the health service system.</li> <li>● I know where to get the right health services.</li> <li>● I have enough knowledge of the illness of the person I care for.</li> <li>● I have the right strategy to talk to the health authority.</li> <li>● I have the right words to complain in English</li> <li>● I have the courage to speak to the health authority.</li> </ul> <p style="text-align: right;"><i>Continue...</i></p>

2. Recognising the importance of social support	<ul style="list-style-type: none"> <li>● I like sharing experience with carers from a similar background.</li> <li>● I enjoy the supporting relationship among other carers.</li> <li>● A strong link to community organisation is helpful.</li> <li>● Attending a consultation event made me feel more confident.</li> <li>● Being involved in a group is empowering.</li> <li>● It is good to know that help is out there even though I may not need it now.</li> </ul>
3. Confidence in being assertive	<ul style="list-style-type: none"> <li>● It is good to know that help is out there even though I may not need it now.</li> <li>● Giving opinion to the authority without restriction is empowering.</li> <li>● I feel enabled when I have the chance to speak to the authority.</li> <li>● I feel in charge because I can delegate things to other people.</li> <li>● I feel in charge because I have the right to make decision.</li> </ul>
4. Recognising support from care recipient and family	<ul style="list-style-type: none"> <li>● I feel in charge because I have the right to make decision.</li> <li>● I have a supportive relationship with the person I care for.</li> <li>● The person I care for accepts my help.</li> <li>● I can deal with stressful situation because I have a supportive family.</li> </ul>
5. Recognition from the care recipient	<ul style="list-style-type: none"> <li>● The person I care for trusted me and let me make decisions on his/her behalf.</li> <li>● The person I care for trusted me.</li> </ul>
6. Awareness of resources from the community	<ul style="list-style-type: none"> <li>● I can get support from the community centre when I need help.</li> <li>● The community organisation has the right information for me whenever I need it</li> </ul>

#### 5.1.4.3. *Standardisation*

The score of each participant of this pilot study was computed. Minimum score is 100, maximum 263, mean is 186.33 and standard deviation is 25.851.

#### 5.1.4.4. *Improvement on the scoring of the questionnaire*

A design problem was noted in the middle position of the scale labelling 'no opinion'. As this middle position may imply that the item does not apply, or the person does not understand the item, or the person is unable

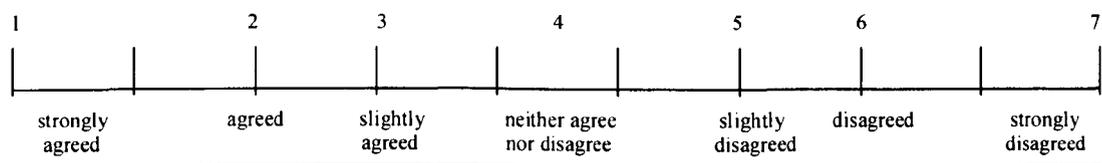
to make up his/her mind, it was decided that scores of the middle item were to be discarded.

The scores were re-allocated on the scale as follows:

strongly agreed = 6; agreed = 5; slightly agreed = 4; no opinion = 0; slightly disagreed = 3; disagreed = 2; strongly disagreed = 1. For the reversed items, strongly agreed = 1; agreed = 2; slightly agreed = 3; no opinion = 0; slightly disagreed = 4; disagreed = 5; strongly disagreed = 6.

Scores on each item from each participant were amended and reliability and factor analysis tests were run again. Results of the two tests were identical to that of the first data analysis, showing no effect of change on the results due to the alteration of the scores.

The revised scale is as follow:



**Figure B.1.a** Revised scaling of responses

## 6. Discussion

The role of family carers for people with dementia is demanding and a great deal of both physical and psychological strength is required. It could be even more difficult for immigrants living in a foreign country to take up this crucial caring role because health and social care services may not be designed in such a way that are culturally fitted for the purpose of the ethnic groups. In the essence of working on the carers' sense of empowerment, it would suggest that they may be able to gain a sense of control over their caregiving role and their psychological well-being would be promoted. The current study describes the empirical procedures which were used to establish a Chinese SES as a tool for assessing the psychological empowerment in Chinese immigrant family carers for people with dementia.

The SES showed good internal consistency (coefficient alphas of 0.893). The Kaiser-Meyer-Olkin measure of sampling adequacy (0.756) suggested that the value falls into the range of

being good (Field, 2000); therefore, it could be positive that the factor analysis is appropriate for this sample of data. Furthermore, the results of an exploratory factor analysis investigating the factor structure underlying the SES showed a 6-factor structure encompassing 26 of the 48-item of the full-scale instrument.

The factor analysis shows a structure which is similar to the themes that have emerged at the early stage of devising the items for the measurement scale. Within this 108 sample, the first factor which yields 7 items being 'confidence in pursuing one's rights because of one's knowledge' and the second factor which yields 6 items being 'recognising the importance of social support'; the third factor (5 items) is about 'confidence in being assertive'; the fourth factor (3 items) is 'recognising support from the person I care for and family'; the fifth factor (2 items) is 'recognition from the person I care for' and the sixth, 'awareness of resources from community'. The factor structure suggests that there are 17 items loaded consistently on 'confidence', 'assertiveness' and 'social support'. This might be due to the fact that being confident and assertive to pursuing their rights and equality in health services in a western country is essential to the Chinese carers who are hardly ever heard by the authority because of a language barrier. In this dilemma, social support, be it from other carers with similar background, or from organisations which provide community service, or from groups that carers can identify themselves with, becomes another important factor to promote their psychological empowerment.

Zarit, Reever & Bach-Peterson (1980) found that the quality of the relationship between the carers and their care recipients with dementia plays a role in moderating the caregiving burden (Fuh, Wang, Liu & Wang, 1999). Another study conducted by Heok & Li (1997) in Singapore also found that daughters-in-law who had relationship conflicts with their mothers-in-law before the onset of Alzheimer's disease complained more about the burden of caring for their mother-in-law. In this current study, another six items loaded on 'carer & care recipient relationship' suggested recognition from and a trusting relationship with the care recipient is another factor (the fourth and fifth factors) which supports a sense of empowerment. Carers who shared their views on empowerment emphasised their feelings of frustration and worthlessness when their help was not being acknowledged or their ability to perform the caring role was questioned by their care recipients. A number of carers experienced a change in power relationship, especially when the husband who used to be the head of the family, now vulnerable and frail, has to rely on his wife who, in the past, had no power or say in the family. In such a situation, the relationship between the wife-carer and the husband-care recipient can go sour, when both parties are trying to fight for their own corner in the family. I will discuss this aspect of care

relationship within Chinese families more in my following studies with carers who participated in the action research projects.

As mentioned in the result section, four items of the corrected item-total correlations are below 0.20:

2. I can get help from the community centre when I need it.
15. I don't think community organisations can give me help.
39. I feel respected when I am listened to.
43. The person I care for trusted me and lets me make decisions on his/her behalf.

When the contents of items 2 and 39 are examined, it is expected that the majority of respondents would give an 'agreed' or 'strongly agreed' scoring to them, whereas for item 15, a 'disagreed' or 'strongly disagreed' response would likely be endorsed. Since the majority of responses of items 2 and 39 are inclined to the positive direction and item 15 in the negative direction, these items are not in effect yielding an unbiased response in the sample. Since the majority of respondents were members of their local Chinese community centres, it is obvious that when opinions were asked, positive feedback would be obtained. Even when respondents do not attend nor need the service in these centres, they still hold high recognition for their function in the Chinese community.

When it comes to get a score, item 43 is an uncertain item for most of the respondents, mainly because it requires two decisions at the same time:

1. Whether or not the carer is trusted by his/her care recipient.
2. Whether or not the care recipient allows the carer to make decisions on his/her behalf.

Many respondents expressed that even if their care recipients allowed them to make decisions on their behalf; they would not execute this freedom because they respect the patients' choice for decision. In fact care recipients like to have the choice for decision making, and respecting the patients' rights is a way to gaining trust from them. Many respondents said most of the time they would inform them of the choice rather than making a decision on behalf of the patient, except when the care recipient is still a child. Item 43 yielded high on the middle score, which indicated that respondents were unsure of how to handle the question. Its mutually contradictory item (29) however does not have the same issue in response because it focused on decision making and it is read as:

The person I care for does not want me to make decisions on his/her behalf.

This design problem of item 43 could be resolved by taking out its first part to read as 'My care recipient accepted me to make decisions on his/her behalf.' Item 39 which has the lowest corrected item total correlation (0.077) is to be discarded, whereas items 2 and 15 could be revised to specify more clearly the help one could get from a community centre. Examples of the revised items can be read as follows:

2. Joining the activities in the community centre can help to relieve my stress in caring.
15. Joining the activities in the community centre cannot help to relieve my stress in caring.

Although item 43 obtained the second lowest corrected item total correlation (0.097), it correlates strongly (0.774) with item 44 ('the person I care for trusted me') in the correlation matrix. Therefore the two items became one of the factors within the factor structure. As the two items are not mutually contradictory, the very close distance between the two items (43, 44) might have an immediate effect on prompting the respondents to draw a consistency in scoring the next item after the first, which is similar in context. Since a trusting relationship between the carers and their care recipients is essentially an acknowledged theme in the context of family care, item 44 would serve a correlated item in the scale. However, more in-depth understanding will be necessary to discover the idea of decision making for the care recipient and its effect on the carer's sense of empowerment.

Another design problem which has already been discussed in the Results section is the terms used for the middle item. Better terms would be 'Neither agree nor disagree', or 'Neutral' (Streiner & Norman, 2003). A sample of the revised 47 items can be found in Appendix B.5.

As discussed earlier, empowerment, in the Chinese family carers' terms, is specific to their struggle in the family and the community from which they seek to gain support and confidence. Empowerment is also specific to the struggle for equality in health service as an ethnic group in this country. In this Chinese SES, items in the first and third factors which involve 'confidence in pursuing one's right' and 'confidence of being assertive' are exclusive to situations when health services are favourable towards the group in discussion. In Canada, where Chinese immigrants are particularly impressed by the availability and extent of the culturally sensitive health services offered, the 'confidence' factors in this Chinese SES may not be applicable because of the difference in service provision for the migrants.

When Zimmerman discussed the primary issue for the development of locally relevant measures for empowered outcomes, he set out a conceptual definition of empowerment that is consistent with the empirical literature that helps to delineate the boundaries of the construct, although conceptualisations of empowerment might differ at different levels, some themes should be expected to be part of the definition because research on empowerment has consistently found these variables to be central to the construct. These themes are; mastery and control, resource mobilization, and socio-political context and participation. When we look at the SES, it is found that items on the scale have covered all of these themes. Here are examples of the items that describe each theme:

*Mastery and control*

- I feel in charge because I can delegate tasks to other people.
- I can make a complaint in English
- I have the courage to speak to the authority.

*Resource mobilization*

- A strong link to community organisation is helpful.
- I can get support from the organisations in my community.
- I am familiar with the health service system.

*Socio-political context*

- I don't think speaking to the authority is useful.
- Seeing real change in health services is empowering.

*Participation*

- Being involved in a group adds more power to me.
- Attending a consultation event made me feel more confident.
- I like to share experiences with other carers from a similar background.

A limitation of the SES is that in devising the items, only 35 Chinese carers and professionals were surveyed to identify the meanings of empowerment that were considered to be common among Chinese family carers for people with dementia and other mental illnesses. Kim, Atkinson & Yang (1999), in their development of the Asian Values Scale, highlighted that value dimensions that distinguish first-generation Asian Americans from European Americans may vary with education, age, and other characteristics, also endorsement of individual items and the scale may vary from one to another. The difficulty in obtaining representative values might have been due to a diverse survey sample which subsequently yielded varied opinions. In this study, however, there was a more specific survey sample in terms of its education, age and care

characteristics; a larger sample could be used to obtain more fruitful source of items. As to the size of the survey sample, Streiner & Norman (2003) suggested that there is no set number of people who should be interviewed, and the criterion often used is 'sampling to redundancy'; that is, interviewing people until no new themes emerge.

At this stage, validity of the SES has been assessed in terms of its content and face validity. A number of validity assessments should be administered to examine to what extent it is representative of the relevant questions that could have been asked (McDowell, 2006). To examine the content validity on a broader level, McDowell suggested that patients and experts in the field critically review the content of the scale, alternatively more formal focus groups and in-depth interviews may be arranged to explore whether the questionnaire covers all aspects of the topic relevant to the patients. Following content validation, more formal statistical procedures of validity testing should be administered. Among the various validity tests, criterion validity considers whether scores on the instrument agree with a 'good standard' measurement of the same theme. However, since criterion validity as an option for validating a measure typically occurs when a new instrument is being developed as a simpler and more convenient alternative to an accepted measurement (McDowell, 2006, p.31), it may not be the best choice to test the validity for this SES which did not develop for that purpose. McDowell suggested that for variables such as pain, quality of life, or happiness, gold standards do not exist and thus validity testing is more challenging (p.34); empowerment as an abstract variable will be falling into the same category. Construct validity would be appropriate to measure the conceptual definition of the topic, indicating the internal structure of its components and the way it relates to other constructs (p.34). It is suggested that additional construct validity testing of the SES is needed to further confirm its predictability in relation to other constructs such as self efficacy, social support or psychological well being. This can be done by running the SES in parallel with another scale (such as self efficacy). Construct validity would be established if a consistent pattern of response across the two tests has been observed.

## **7. Conclusion**

Community researchers have highlighted the need for measures of psychological empowerment to be developed for each specific population with which one is working (Israel et al., 1994; Zimmerman, 2000). The development of the SES is the first attempt to introduce a new tool for community psychology research. After the construct validity has been established at a later stage, the SES could be useful for researchers who may want to assess the psychological empowerment of their participants in action research or project in a community setting. Research study which involves other ethnic carer groups who might

come across similar difficulties such as language barrier, lower socioeconomic status and difficulty in accessing the right health service may try to adapt this tool for examining the relationship between psychosocial intervention and change in the sense of empowerment.

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## Study 2 & 3

### **Empowering Chinese Informal Carers for Dementia – A Participatory Intervention**

#### **Abstract**

Dementia is one of the most common mental health problems among the older Chinese population in the UK, along with anxiety and depression. While many people suffering from dementia are increasingly dependent on family members to provide daily care, caring for someone with dementia is considered a stressful experience. Not being able to speak English, community attitudes towards dementia, the stigma attached to the illness and the lack of resource and support for the Chinese community are factors that have rendered carers vulnerable. This study aimed to explore the practical ways of engaging Chinese carers, based on the concept of community health psychology and participatory action research. A series of participatory interventions using the empowerment approach were conducted with Chinese family carers recruited from three community organisations in London, Leeds and Newcastle. A Sense of Empowerment Scale (SES) was developed to measure the change in the sense of empowerment of the Chinese carers over a period of five months. Both quantitative and qualitative data analysis were administered to measure the impact of the interventions. Results show that family carers' psychological empowerment had improved significantly. Knowledge of dementia gained and skills developed in caring are two major factors associated with the successful outcomes and sense of well-being of the carers. The collaborative organisations involved also experienced positive improvement in building up new skills and resources during the participatory processes; their role as an empowering agent also proved to be helpful in the participatory processes.

#### **1. Introduction**

The importance of participation in the process of improving health and healthcare delivery has continuously been highlighted and its implementation process encouraged (World Bank, 1996). Although consensus about the importance of individual participation in healthcare is endorsed, it has not resolved the widespread disagreement on the definition of participation, why it should be encouraged and how it can be implemented and assessed. Among many other debates, two different and contrasting perspectives on participation can be identified; the utilitarian and the empowerment approach (Guareschi & Jovchelovitch, 2004).

The utilitarian approach to participation is seen as meaning when external agents invite communities to participate in order to use local resources legitimately to offset costs (Morgan, 2001). The utilitarian approach can be applied in five forms of participation, namely, manipulative participation, passive participation, participation by consultation, participation for material incentives and functional participation. These types of participation do not involve participants in decision making while using them instrumentally to justify allocation of resources (Pretty, 1995). And these participatory approaches do not essentially mean sharing in power (White, 1996; Guareschi & Jovchelovitch, 2004).

When we look at the instrumental and nominal nature of the utilitarian approach, it was obvious that when researchers are to use these types of participatory approaches, it would imply that they go into the community, do the field work for data collection, and then go away analysing the data and publishing the report. Participation is nominal because these approaches do not require individuals or communities to have a level of involvement in the research processes as high as the researchers who are identifying the problems 'for' the participants to be investigated. The effectiveness of using these approaches to improve carers' psychological empowerment is questionable because during the research process, although the researchers might be able to identify problems faced by the carers, opportunities are limited in terms of giving them the space to develop the various aspects of empowerment, such as, to think actively about the issues, to take ownership of the problems, and to build up a consciousness over the issues as well as the skills to challenge their problems in a broader social context.

The second approach to participation is the empowerment approach, which views participation as a set of empowering practices. It seeks to achieve a real re-balancing of power structures while developing the consciousness and citizenship of socially excluded communities (Guareschi & Jovchelovitch, 2004). Individuals in an empowering participatory approach are to be involved actively in identifying their own problems such as health issues, and the role of the researchers is to identifying the problems 'with' them.

The empowerment of local communities to improve health outcome, as Guareschi & Jovchelovitch define, is the centre of the empowerment approach; and in order to achieve real social change, the tendency is to adjust participation to specific local, cultural and political contexts with the clear goal of empowerment for the communities. In these specific contexts, individuals in the communities, usually the most disadvantaged groups are given the autonomy and opportunity to design and to plan their own agenda, according to their own needs. This process is one that allows individuals and communities to develop a new awareness about their conditions of living and construct strategies for improving them. It reframes the relationship

between individuals, community and the political arena. It is also empowering, developing citizenship and building spaces for the presence of grassroots in the institutional structures of the state (Guareschi & Jovchelovitch, 2004).

In psychosocial interventions, participation for empowerment is a similar process in that participants are encouraged to take on an active role in identifying their problems, finding out possible solutions, and building up skills to deal with their problems, with the help of the researchers. It is noteworthy that the role of the researchers in a participatory and empowering approach to intervention will be more facilitating than directing throughout the whole research process.

On the questions of what would be the conditions for setting the scene of an environment for a participatory action research, Nelson, Pancer, Hayward & Kelly (2004) demonstrated an exemplar of community health psychology in their study. They applied the empowerment and partnership theory into action research which involved citizens from low-income communities in planning promotion and prevention programmes. The focus of their research was to enhance the health of children, families and the community and to prevent cognitive, social and health problems of children. To develop value-based partnerships for prevention, Nelson et al. adopted a three-step model that had been set out in an earlier research study (Nelson, Amio, Prilleltensky & Nickels, 2000).

The three steps are (1) forming the partnerships; (2) deciding on the vision and values of the partnership; and (3) identifying and merging the strength of the different partners. With respect to the first step, Nelson and colleagues created a forum where residents could come together to form a partnership, and within the partnership, residents have a say in interventions that are of value to them and take part in decision making on issues that are of their real concern. Nelson and colleagues elaborated the second step as clarification of vision, values and working principles. In their research, a shared vision and value was developed for getting the participants 'on the same page' and as a guide for partnership activities. The third step was to identify and merge the strengths of the different participants. As disadvantaged people bring experiential knowledge, including an understanding of their local context, all types of knowledge are valuable and need to be pooled in an equal partnership (Kress, Cimring, & Elias, 1997; Nelson et al. 2004).

Empowerment at the individual level combines (1) personal efficacy and competence, (2) a sense of mastery and control, and (3) a process of participation to influence institutions and decisions (Israel et al., 1994). In the context of empowerment, to what extent the Chinese carers

in this study can be empowered would be dependent on what perspectives they hold on personal efficacy, competence, sense of mastery and control. As it makes little sense for the researcher to speculate on a definition for empowerment specific to the participants, Study 1 has identified the empowering factors and hence, a possible way to measure them. In this study, a Chinese Sense of Empowerment Scale was used to assess the change in the carers' sense of empowerment in the participatory interventions over time. In effect, empowerment at an individual level is linked with the organisational and community levels through the development of personal control and competence to act, social support, and the development of interpersonal, social and political skills (Israel et al., 1994). For empowerment to work more effectively at an individual level, it is therefore reasonable to link up individuals with the organisations from which they can gain support. The organisations could also be places that provide opportunities for individuals to develop interpersonal, social and political skills.

One of the challenges that researchers face is the declining value of expert knowledge, especially to young people (Beck, 1997). This is perhaps a reflection that this current study can take into perspective, although young people are not the focus of our research. Beck called for the experiences of ordinary people which provide the bedrock of understanding and a way to access the real knowledge behind the young people. In a similar way, understanding the family carers' experience would be an important aspect in this current study.

Bradley, Deighton & Selby (2004) reported an action research project aimed at increasing the capacities of young people at risk in a rural Australian town, which was drawn on an 'experience-based' approach to risk assessment and the concept of collective efficacy. Their intervention used the voices, skills and experience of young people themselves to help create and direct the research-intervention. This collaborative and participatory action research would avoid benefiting only from the perspectives of professional researchers (Bradley, Deighton & Selby, 2004). This concept of defining and matching the strength of the participants coincides with step (3) in the principle of participation that was discussed above (Nelson et al., 2004).

With the framework of participatory and empowering intervention in mind, this study primarily sought to explore the impact of empowerment on the individuals. The research questions of these studies are: Study 2 – Did a participatory psychosocial intervention lead to an increased sense of empowerment in the Chinese carers for family members suffering from dementia? Study 3 – If the participatory process has taken place that benefited the Chinese carers, how did the processes of participatory and empowerment became effective? And finally the lessons learned from adopting a participatory and empowering approach with Chinese family carers living in England will be discussed.

## **2 Methodology**

### **2.1. Methodological Assumptions**

In this study, a participatory and empowering approach was adopted as the framework of psychosocial intervention as its goal was to explore the psychological empowerment among the Chinese carers for family members suffering from dementia. It would be inspiring to see how carers develop a new consciousness about the difficulties in their caring role and develop ways for improving them through participation.

The research study was carried out in three cities and three Chinese community organisations were invited to act as collaborative organisations in London, Leeds and Newcastle respectively. The purpose of this arrangement, apart from obtaining venues for the research activities, was to facilitate an environment with which participants were familiar and in which they felt safe to share and discuss their issues. The collaborative organisations would also be the places that provide opportunities to the carers to develop their interpersonal and social skills, with the support of the organisations' workers with whom they are familiar.

In this current study, the three step approach of Nelson et al. (2004) was used as a guiding principle in forming a meaningful partnership with the Chinese family carers. The three steps are (1) forming the partnerships; (2) deciding on the vision and values of the partnership; and (3) identifying and merging the strength of the different partners. After forming a partnership, carers were encouraged to decide on vision and values of the groups based on their skills and experience. The decided vision and values of the groups would also set forth the goals and direction of the psychosocial interventions.

### **2.2. Researcher**

The researcher in this study entered the three collaborative community organisations mainly as an academic psychologist working within the framework of the empowerment approach to participatory intervention. Her role ranged in a number of ways, from facilitating, researching, and standardising the experience to providing resources and expertise. She facilitated an empowering process that adhered to the definition of 'empower', that is, to enable others, or to enhance others' abilities in order that they may obtain power through their own efforts. During the process, the researcher actively reflected on the concept that health education cannot 'give' power to people, but can enable others to strengthen skills and resources to gain power over their lives (Israel et al., 1994). Before the research project started, the researcher conveyed message of participatory action research and the concept of empowerment to the co-facilitators

to ensure that they would work with her under the same underlying principle in their facilitation in all of the research activities.

### **2.3. Co-facilitators**

The researcher invited one or two workers in each of the three collaborative organisations to act as co-facilitators during the whole process of the participatory interventions. This arrangement was to build up a stronger rapport between the carers and the workers in the collaborative organisations where the carers had been and would continue to be supported after the study was finished. On the other hand, since the workers had known the carers longer and knew them better, it would be helpful for them to co-facilitate in the research activities, as this would make the carers feel more comfortable to share their experiences and problems with someone they were already familiar with. At the beginning of the research, the three co-facilitators received the same instruction from the researcher; that their role was to recruit carers from their organisations, to organise meetings for the research activities with the carers, to remind carers to come to the meetings, and to encourage discussions and participants during the meetings. The co-facilitators were also encouraged to speak the carers' dialects if they felt that would be easier for them to express themselves in their own dialects. In this situation, the co-facilitators would interpret for the researcher so that she could follow up with the discussion.

In Leeds, two female workers helped to schedule and coordinate the meetings; they also participated and co-facilitated the group throughout the project. They were from the same cultural background as the carers and spoke the same dialect of Hakka. The two workers were also carers to older family members with dementia. The co-facilitators mostly communicated in Hakka with the carers and interpreted for the researcher throughout the research activities.

In Newcastle, a community leader and two workers in the collaborative organisation helped to organise meetings, co-facilitate and to support the group throughout the research. The community leader had a good connection in the community and helped to identify and to encourage carers who might be suitable to join the research.

In London, a volunteer in the collaborative organisation who had been actively involved in supporting and befriending the older people in the community helped to arrange meeting schedules, transport the participants to the meeting place, and participate and facilitate in the research activities.

## 2.4. Collaborative Organisations

### 2.4.1. *The Women's Group (WG) – Leeds*

The Cantonese speaking community is the oldest and poorest Chinese community in Leeds, with the largest number of people of retirement age. The 2001 Census showed a Chinese population of just under 3500 people in Leeds; of these 230 people were aged over 60 years.

Before WG was set up in 1988, there was a small group of parents; the majority of them were women who brought their children to a Sunday Chinese school. Over a period of time, chatting and sharing of the group in a small room at the Sunday school uncovered problems that Chinese immigrants faced in common. Added to their common issue such as not being able to speak English or to communicate with the society outside the family, other psychosocial barriers were lack of confidence and feeling incapable to work because of the limited skills they had. The parent group then highlighted the need for setting up a charity organisation to support each other, especially for the women's needs in the community.

At the beginning, there were only a few members in WG. The size of membership grew gradually until in 1998 WG hired an office at the Leeds city centre. Several core members who joined WG since its inception are still with them, and today the number of people registered as members exceeds 300. In the late 1980s, members of WG were mostly Hakka women from the new territories, the village side in Hong Kong. Recently the members are more of a combination of people from Hakka, those from Hong Kong city who speak Cantonese, and new immigrants from mainland China who mainly speak Mandarin.

A team of three workers in WG has been active in looking after the welfare of Chinese families. Although their beneficiaries are primarily women, they also provide services that are fitted for the women's families, such as out-of-school play schemes for children, luncheon clubs for older people, picnics and celebration events at Chinese festivals. The training programmes they run, including setting up business, building life skills and preventative health workshops, are popular among the women in the community, while, English classes, being their core training programme, are provided on an on-going basis regardless of the availability of funding resources.

In November 2005 when the researcher approached WG for the possibility of working together in this research, her ideas were welcomed and supported by the WG centre coordinator who saw this as an opportunity to raise awareness about caring for family

members suffering from dementia. Since cases of dementia and carers needing support were close at hand, the centre coordinator was confident that she would be able to invite participants to join the research group. The first research organisation was identified. Six carers agreed to join the research group in February 2005.

#### *2.4.2. The Health Club (HC) – Newcastle*

According to the Census of 2001, the Chinese population for Newcastle upon Tyne was around 3100. The Chinese community representatives nevertheless insisted that around 6000 Chinese people are living in the city, with over 2000 Chinese students studying at the universities in Newcastle. The Chinese community in Newcastle is relatively young in comparison with other major British cities. Most family members did not arrive much before 1967 to support their family businesses, while the number of immigrants in the North East was increased in the 1970s because of the influx of Vietnamese refugees. The Chinese community in Newcastle in recent years is a combination of immigrants from the New Territories and the city of Hong Kong, from Vietnam and from mainland China.

In 1996, in a workshop at a consultation event where health workers and members in the community discussed issues around community care, the needs of a health association dedicated to serve the Chinese community in Newcastle came into view. A particularly influential Chinese woman, 'SF', then supported the development of the HC in response to the expectation of the community. HC was set up in 1998 by a group of like-minded people in the community, with the support of SF, a Chinese community development worker in a statutory service.

Since 1989 when SF was working in the minority ethnic support at a statutory service based at the city centre in Newcastle, she served mainly clients from the Chinese community and her work mainly involved giving advice on welfare rights and developing health services. At that time, she was the only Chinese community worker in Newcastle. Because of her passion in developing health services for the community, SF's role at the statutory service was maintained until she retired in 2005. SF's relationship with the Chinese community went back to 1979 when the community was extremely lacking in resources for health services. Over the years SF became a link person and an influential leader because of her working relationship and networks in Newcastle.

HC is a relatively young organisation. Its aim is to provide and to promote health information and activities to the Chinese community with regards to healthy lifestyle.

Today there are about 200 members attending services and activities in their organisation. HC was the collaborative organisation of this research in Newcastle supported by SF. Six carers agreed to join the research group in February 2005.

#### 2.4.3. *The Mental Health Service (CMHA) – London*

There are about 80,201 Chinese people residing or working in the capital city (Census 2001). London has the largest Chinese population compared with any other cities in Britain. CMHA, based and working mainly for the Chinese community in Hackney, was interested to collaborate in this research. The Chinese population in Hackney is around 2373, with 5% of them over 65; a slow tapering to an older age reflects the economic migrants from the 1950s and 1960s.

CMHA was established following the success of a Chinese Counselling Service piloted to provide counselling, support and advocacy services to meet the mental health needs of the Chinese community in east London. This initiative uncovered the complexities of mental health issues among Chinese people of all age groups. The outcome of this project drew attention to the need for a London-wide organisation to work alongside with the mainstream mental health services, making sure that services were more accessible to the Chinese community. In 1993, CMHA secured funding to run the first direct mental health service in London.

Due the nature of their service and activities, which cater specifically for people recovering from mental illness, they chose an office location away from Chinatown, the centre of the community, aware of the fact that service users might not want to be seen in a highly concentrated Chinese area as they try to seek help from a mental health service. Due to the nature of their service, unlike the other two community organisations in Leeds and Newcastle, CMHA is not open to membership.

In 2005 the researcher approached one of the project coordinators in CMHA to carry out the research in their centre. The idea was taken forward and in February 2005, three carers from the community agreed to join the research group.

## 2.5. Participants (Family carers)

A total of ten carers took part in the participatory interventions, the carers' demographics are summarised in Table B.8.

**Table B.8.** Carer characteristics (n=10)

Mean length of time caring	9 years		
Mean age	62.6 years		
Gender	7 females, 3 males		
Relationship to care recipient	5 spouses, 2 children, 3 other		
Education	4 primary, 5 secondary, 1 university		
Occupation	3 pensioner, 2 run own business, 3 home duties, 2 labourer		
	<b>Leeds</b>	<b>Newcastle</b>	<b>London</b>
Mean length of time caring	7 years	8.5 years	11 years
Mean age	60	56	81
Caring status	4 current carers	2 ex-carers, 2 current,	1 ex-carer, 1 current
Gender	4 females	3 females 1 male	2 males
Relationship to care recipient	3 spouses, 1 other	2 children 2 other	2 spouses
Education	5 years	13.5 years	12 years
Occupation	1 run own business 3 home duties	1 run own business 1 pensioner, 2 labourer	2 pensioner

### 2.5.1. Family carers – Leeds

At the beginning, six participants were recruited from the collaborative organisation. All of them were females; all of them had a caring role for a family member with dementia at the time of the research. Four of them were spouses of the recipients of care, the other two were daughters-in-law. They had all migrated from the New Territories in Hong Kong and they all spoke Hakka dialect. The educational level of this group of carers was around four to six years on average, except the youngest carer who was a daughter-in-law and had 13 years of education. Age ranged from 56 to 70, except the youngest carer who was in her thirties. This group of carers all carried on their caring role for between five and ten years. Two participants, including the youngest carers, withdrew from the research group at the first two group meetings. The other four carers stayed on with the group until the end of the research.

### 2.5.2. Family carers – Newcastle

Six participants were recruited through contacts by the community leader, SF, as mentioned in the collaborative organisation above. Three of them were ex-carers; the other three were existing carers at the time of the research. Three were females, two of whom were ex-carers, one was the granddaughter and other was the daughter of the deceased care recipients. The existing carer was looking after her mother-in-law. Of

the three males, two were existing carers who were caring for their mothers, and one had cared for his mother-in-law until her death.

This group was a combination of immigrants from Vietnam and Hong Kong; they all used Cantonese as their daily dialect. Their education level was around 12 years, except the youngest who was a graduate. The age of this group ranged from 55 to 70 years, except the youngest, who was in her late thirties. Years of caring were around eight to ten years. One of the carers, aged in his seventies, withdrew from the group in the middle of the research due to deterioration of his mother's health condition.

### 2.5.3. *London*

Three carers were recruited through contacts by a volunteer (the co-facilitator) in CMHA. Two were males and one female. One was an ex-carer who cared for his wife for over ten years before she passed away. The other two were existing carers looking after their wife and husband respectively. Both care recipients were in the early stages of dementia. Age ranged between 73 and 89. Years of education were between ten and twelve. The two existing carers had taken up their caring role in the last three years. Two of them came from Hong Kong and one from Vietnam. They all spoke Cantonese. The female carer withdrew from the research after the first group meeting, the other two male carers stayed on throughout the whole the project.

## 2.6. **Ethics**

This participatory research project involved a phase of five months of psychosocial intervention with each group of the carer participants. The research project had three stages: an 'exploration', 'confidence building' and 'implementation'. Prior to the commencement of undertaking the stage one intervention, the researcher had gone through a series of procedures to make sure that ethical practice was observed and planned.

### 2.6.1. *Ethics Application*

For the purpose of seeking ethics approval to undertake this research study with Chinese carers in the three different cities, the researcher approached for advice each of the three Research Departments at the Mental Health Trusts where the research field work was to take place. It took a while to obtain feedback from the Research Departments as to who should be consulted regarding this ethics application. In response to her request, a Director of Research from one of the Mental Health Trusts came into contact with the researcher to discuss the details of the research project. After having a more specific idea about the research methodology, the recruitment of

the participants, the type of intervention and the procedure of carrying out the intervention, he concluded that application and approval from their Trust for this particular research would not be necessary according to the following points:

1. Since the activities are not going to take place in any of the Trust's buildings, rather, in a non-governmental office such as the community centre, ethics approval from the Trust to carry out the research is not required;
2. If the research is to involve the Trust to identify carers, it would be necessary to have the Trust's approval and a requirement to adhere to their confidentiality policy. However since the carers are to be identified and recruited through contacts from the local Chinese community, ethics approval from the Trust to carry out the research is not required;
3. Since no NHS staff will be recruited or be involved in the research, again, ethics approval from the Trust is not required;
4. For an intervention to be carried out in the form of discussion, meeting and focus group, ethics approval would not be required.

The researcher took the view that, although ethics approval was not required from the Trust, the Code of Conduct, Ethical Principles and Guidelines of the British Psychological Society were to be observed. Ethics approval from the City University was obtained.

#### *2.6.2. Information sheet and consent form*

An information sheet describing the aims, procedure and a consent form were devised in both English and Chinese and were written in simple, non-technical terms which would be easily understood by the participants. All participants and workers involved in the research were given a copy each of the information sheet and the consent form about two weeks before the first time the researcher met with them (see Appendix B.6.).

In the first meeting the researcher met with the research group which consisted of the carers and the workers (also the facilitators), the workers went through the contents on the information sheet again with the carers line by line, and when all of them understood the purpose of the research, they were to sign on the consent form and to tick the box on the consent form stating that they were happy to take part. The participants were also assured that they have the right to withdraw from the research group if they so requested.

### 2.6.3. *Confidentiality*

The researcher complied with the confidentiality policy in the organisation which sponsored the research. Personal data was not recorded on the questionnaires or notes that related to the interventions. Personal data subject to the confidentiality policy referred to full name, telephone number, email address, postal address, postal code and health condition of the care recipients of the participants. Throughout the process of the research, when contact with the participants was necessary, the researcher would retrieve their personal data which was stored on a computer to which only she had the password for access. Verbal consents were given to the researcher for keeping of their personal data. Whenever the researcher would have to contact them by telephone, an appointment would be scheduled in advance by the workers in their centres.

During the course of the research, participants were requested to keep confidentiality of any personal issues they came across within the group (including group meetings, focus groups, training sessions and any group activities). Conversations in any of the research activities were not to be discussed with anyone outside the group. This was to ensure that everyone in the group feel safe to express themselves on issues that might appear to be sensitive. The researcher, however, could not guarantee confidentiality in the research group because it was still up to the participants to follow the request and maintain confidentiality once they left the venue of the research activities.

### 2.6.4. *Data protection*

Data generated from the research was being stored in the researcher's personal computer to which only she had password for access. Hard copies were stored in a locked filing cabinet in the workplace, where only the researcher and her line manager would have access to them. These two persons had control of and acted as the custodian for the data generated by the study.

### 2.6.5. *Potential risk*

This research study was basically safe and one would not expect the participants to suffer any harm or injury because of their participation. However, there could be some emotional distress when carers talked about experiences which related to their or their family member's health condition. The researcher has the relevant training in identifying potential risk of emotional distress during the course of the interventions. In the situation when a participant was distressed, the researcher would ask whether he/she would like to take a break, or change the topic of discussion. When further

support was required, the workers in the collaborative organisations would help to follow up and make referral to other counselling service as and when it was necessary.

## **2.7. Implementation of Intervention**

The researcher worked on a period of five months with each collaborative organisation to carry out the participatory interventions. During the five months' time period, the participatory carer groups, based on their own experiences, were encouraged to set out achievable goals that they viewed as meaningful. The carer groups also set out learning objectives to enhance their skills and confidence in order to achieve the goals that they had set forth.

As mentioned, the researcher worked in collaboration with three Chinese community organisations in Leeds, Newcastle and London respectively. Carers were recruited from the three organisations by the workers (later being the co-facilitators in the participatory interventions) in each of the organisations. They were familiar with the carers, their interests and their personal backgrounds. Research activities were carried out at the centres of these three organisations where the researcher, the workers and the participants met regularly for the purpose of the research projects.

The participatory interventions were a series of regular group meetings initiated with the principle: 'Engaging the carers, establishing what mattered to them, listening to them and validating their knowledge and experience.'

Meetings were designed as a cycle of activities according to carers' aspirations. The three stages of interventions and the groundwork before interventions are described as follows:

### *2.7.1. Pre-intervention groundwork*

In Leeds, having discussed the idea of the research project with the centre coordinator of a Chinese community organisation, the researcher paid an initial visit to the organisation two months before the project started. The coordinator arranged a time at another venue when and where their members, mostly older people, were having a regular luncheon club. At that gathering place the researcher was introduced to the workers and those members who would potentially be invited to participate in the research project. The luncheon club was a friendly environment, most people spoke Hakka, including all the workers who came from the office to join the club at the lunch hour.

The centre coordinator talked to the researcher about the statutory services which currently only provided personal care for older people, such as helping them to take a

bath. The statutory service no longer provided a service or commissioned voluntary groups to provide service for everyday chores such as shopping, cooking and cleaning for the older residents. As she saw the family carers for people with dementia, on top of their household chores, have to deal with loads of stress from the patients whose behaviours were challenging; being a carer herself, the coordinator understood how difficult it was for the carers to deal with the situation. When the researcher discussed ideas of empowering the carers, the coordinator thought the concept of empowerment was positive, as long as ways of empowerment were fitting to the carers' background and level. The initial visit was important for the researcher to understand more about the carers' situation in this community, also, to build up a common goal and rapport with the centre coordinator who was to work closely with the participants in the next five months. Introduced by the centre coordinator, the researcher also talked to each of the potential carer participants about the research and initially invited them to take part in the study.

In Newcastle, the research group was convened by a retired community worker, SF, who had strong connections with the community and with the collaborative organisation that was going to provide venue and support for the research project. At the time of the research, carers in the research group were not members of the organisation but they knew SF and the workers in the organisation well, as the latter had been involved in organising social and health events for the community over many years. Most of the carers met the researcher as she was invited to deliver a health talk in Newcastle two years ago. Unlike the carers in Leeds who had links with the organisation on a regular basis, the links for the carers in this group was not with the organisation but with SF. The carers, although not very familiar, had known one another as acquaintances in many other community events before.

The researcher had a working relationship with SF and the organisation in the past, was well informed and was supported when she proposed the research initiative. Prior to the first meeting, coordination of the first meeting was efficient; because of the direct and indirect link to one another, group members including the carers, the workers and the researcher got along quickly soon as they met in the first meeting.

The researcher was linked up to the collaborative organisation in London because of her work training over the last two years. The manager in the organisation was supportive to the research initiative and a volunteer, 'CH', was assigned to help in the project. CH had supported the two carers for many years and soon as she mentioned that she was finding people to join the research team in London, they agreed to come

along. The two older carers did not have direct links to the collaborative organisation before they came to join the research project. Research meetings took place at the office of the collaborative organisation.

### 2.7.2. *Stage One*

According to Nelson's creation of a value-based partnership for prevention which involves a three-step programme model, as mentioned earlier, the researcher set out steps 1 & 2 – forming the partnership and deciding on the vision and values of the partnership at this stage of the research project.

The first month was the beginning of the intervention and was a time for exploration of the carers' experiences, needs and expectations. At this stage, carers agreed to come together as a carer research group, with the presence of the co-facilitators in the collaborative organisations where they usually gathered for social activities and support services. The co-facilitators organised group meetings for the researcher to meet with the carers regularly over the next five months.

The first month was to let the carers to get to know one another more and to build up trust and rapport among them, also, building up trust and rapport with the researcher. The researcher encouraged the carers to share their experiences and the issues they came across in caring, started off by acknowledging their efforts in participating in the research and that it was a good opportunity for all that were involved to work together in the following five months.

Adopted from the participatory appraisal methods which are commonly used in community development projects, the aim of these methods were to empower the carers to share and to analyse their own knowledge of life and conditions and to further define their own strategies and actions (within their abilities) to realise improvement in their situations (Mason, 2005).

The idea of using a participatory appraisal method in group facilitation is a growing family of approaches and methods to encourage people to share, enhance and analyse their own experience in life and condition, and to plan, act, monitor and evaluate (Chambers, 1994).

The visual form of brainstorming and discussion aimed to raise awareness about the issues involved in the life of the carers group, it also aimed to help identify issues and stimulate individuals to move from ideas on paper into achievable and actionable initiatives (Mason, 2005).

The researcher and the facilitators discussed the idea of empowerment with the carers, followed by encouraging them to think of a goal, or a task that they would like to do together as a group.

To visualise the concept of a shared goal, the researcher used visual aids such as a flipchart to draw diagrams and charts to brainstorm ideas, for example, in a flipchart paper, each participant was asked to write or to draw on a 24-hour planner what they usually do to assist their care recipients, the planners would then represent each of the carers' typical daily life. The carers then shared and discussed their ups and downs in a day. Having visualised how a typical day of a carer was like, they became more aware of their needs for support. They also realised that their problem was not at all an individual one, rather a problem shared by the group.

In a 'happiness' and 'sadness' map, carers were to share their experience of caring, both happy and unhappy, and the facilitators were to write and group what they said onto a flipchart paper.

With the help of the researcher and the co-facilitator, the carers were encouraged to identify a goal, a particular task or tasks that they would do together as a group. They were encouraged to decide together on the shape of the outcome of the project. The task(s) would have to be something that they enjoyed doing, something meaningful and that was within their abilities to achieve. . For example, the task could be producing an article about Chinese carers, producing a video clip, or organising a campaign to fight for better health services.

#### *2.7.2.1. Leeds*

All activities took place in the meeting room at the centre of the community organisation. The researcher had two meetings with the carer group on the first month. In the first meeting after the briefing on the overall objectives of the project, without setting out an agenda, the researcher went on encouraging the group to discuss things that they would like to raise around caring. At the beginning the group was quiet. The co-facilitator then started the conversation by raising the group's interest on the issue of caring.

Once the conversation was opened up, the carers started to join the discussion. At this point, the researcher and the co-facilitator stepped back and let the carers to take charge of the discussion. The carers' frustration

and queries became clear as the discussion went along and the carers' needs were gradually defined.

The carers had a lot of queries about the attitudes and behaviours of their care recipients which they found confusing and difficult to deal with. The researcher then responded to the many queries the carers raised by explaining the difficulties faced by people with dementia because of the illness caused to them. In response to the carers' queries on dementia, the researcher suggested to running a carer skills training course for the group. The carers welcomed this idea.

At the end of the first meeting, the researcher suggested the group think about a task that they could work on together, something that is interesting, meaningful and within their abilities to do so.

In the second meeting, discussion was about the piece of joint work that the group would have to decide to do. The decision was to be based on their needs and expectations, although the researcher and the co-facilitator had helped to brainstorm a lot of ideas.

The group had no idea what to do at the beginning and they were interested to know what the other two research groups had decided to do for their projects. The first group that had come up with a decision was the London group. Their idea was to make a photo album. Along the same line the co-facilitator suggested a booklet and let the group to carry on with the discussion.

The researcher maintained that this should be a piece of work shared by the group. When carers were silent for a while, the co-facilitator then suggested the idea of making a booklet. The co-facilitator assured the carers that she and the researcher would support them throughout the work, although they would have ownership of the booklet because that was their joint work. The purpose of the booklet was to bring out experiences of the Chinese carers for dementia.

The group decided to produce a booklet containing two carers' stories, two original healthy recipes for patients, and some useful local service information.

Apart from the group work in producing the booklet, the co-facilitators and the carers also suggested a series of activities including a stress management workshop and a skills training day delivered by the researcher. Seeing the needs of knowing more about available services, the co-facilitator suggested arranging a talk to be given by the Social Services on carer's allowance.

According to their time schedules, the carers also agreed to have nine meetings altogether with the researchers throughout the project.

At the end of the first stage, a work plan for stage two was set up by the co-facilitator and jobs were allocated to each carer in the research group.

#### *2.7.2.2. Newcastle*

Research meetings were held in a hall at a community building. Since the time the majority of the group could commit was limited, only one meeting took place on stage 1. In the first meeting after briefing on the objectives of the project, the researcher started to seek the carers' feedback and views on the project. At the beginning, the carers were not sure what they could do and worried about the time and commitment required. The researcher assured the carers that the commitment level would be dependent on the goal they were going to set out for; therefore the group was encouraged to define a goal that was suitable for their level of commitment for the research project.

The group started to discuss conditions in the care homes, since two ex-carers and one existing carer had experience in placing their care recipients into care homes; they had a lot to share and had a lot of frustration over the issue. During the discussion, the researcher responded at times when questions were raised as to what could be a better service for people with dementia.

The researcher pointed out that the approaches to care for dementia were very important. A person-centred approach to dementia care was seen as a more effective way of delivering care which improves the quality of life of the patients. Carers were interested to understand the current conditions of the care homes. Having heard the discussion among the carers, the researcher tried to define an area the carers would be interested to pursue

based on their experiences and their doubts about the health service for people with dementia.

At this juncture, the carers set out a goal to produce a booklet to include four stories, information about dementia illnesses, information on social benefits, and useful information on both voluntary and statutory organisations that provide services and support for people with dementia and their carers. The group decided to meet once a month. Three of them had to take time off from work to attend the research activities. However, since they were interested to participate they agreed to commit one half day a month for the research. The group was to meet in the following month to discuss the set goals and work plan in the next stage. The researcher had six meetings with the research group over the five month period.

Apart from producing the booklet, a carer suggested organising visits in stage two. The target of the visits was two residential care homes, one in the neighbouring city of Newcastle-upon-Tyne and one in another city.

#### 2.7.2.3. *London*

The researcher had two meetings with the carers and the co-facilitator CH for stage one. The first meeting was to open up discussion and conversation with the two carers. After welcome and briefing, the researcher started to chat with the carers about their experience in caring and at the same time defining the area where empowerment might be suitable in accordance to their background. The carers were not talking much.

The researcher then started to do a mapping exercise, using flipchart papers to draw a clock with 24 hours and encouraged the carers to fill in the activities which representing a typical day in their life as a carer. The ex-carer (B) was to recall the time when he was caring for his wife.

When they had finished filling out their daily schedule, it was apparent that the two carers were at totally different stages. B had experienced all that a carer would have to experience, while the other carer (A) was just picking up his role of caring. The researcher and CH then started to motivate discussion on the ups and downs in caring. The meeting was finished by setting a date for the next meeting.

In the second meeting, the researcher tried to define a common goal which the group could share to achieve. When the two carers thought about the question of what they could do together to make them more empowered, B suggested making a photo album picturing the life of carers for dementia. He was a poet, and before that he had already published a few poetry books. B suggested producing a photo album in remembrance of their stories, as both carers were interested in taking pictures.

The group then decided to produce a photo album. The two carers were to take pictures or to provide old pictures that could represent the theme of 'caring' and their stories were to be narrated in the album. The group also decided to have six research meetings in the period of five months.

It was noted that the spouse (the care recipient) of A came along from the first meeting. At the beginning the researcher arranged other colleagues to run some activities for the care recipient. Later on, considering that both the care recipient and carer A might become anxious when they could not see each other, the researcher then decided to keep the care recipient together with the group.

Although this arrangement might be hindering A from sharing his experience in caring, the researcher and the co-facilitator thought that if the circumstance was not in favour of A or that it would make his wife worried, it could actually be defeating the purpose of empowerment, so considering that A would be more comfortable to have his wife at hand, the researcher decided that having the care recipient in the group would be a better arrangement.

The researcher noticed that A was not very engaged in the discussion, up until this point; he did not seem to be sure of the purpose of his presence in the group. This was found out later from the co-facilitator, who told the researcher about A's queries each time after the research meeting. The researcher decided that in stage 2, she would try to explore something out of the project which would eventually be of benefit to carer A. Knowing that the researcher was an accredited trainer for dementia care, the carers and the co-facilitator suggested having a carer skills training workshop in the following month. Therefore, going onto stage 2, the plan was to produce the photo album and to deliver the carer skills training workshop.

### 2.7.3. Stage 2

Once the task was defined, the group was to draw up an action plan for the second stage. While stage 1 involved steps 1 and 2 of Nelson's creation of the programme model, stages 2 and 3 in this research project involved what the step 3 of the model set forth – identifying and merging the strengths of the different partners. The aim of this stage was to encourage the carer to implement the goals that they had set out at Stage 1.

In the second and third month, the researcher worked according to the action plans as set forth by the groups. In these two months, researcher met regularly and worked closely with the groups. Together with the co-facilitators, the researcher gave a lot of support and advice, and provided resources whenever it was needed by the group to fulfil their goal. The purpose of stage 2 was to empower the carers to build up their confidence, skills, knowledge and interests on subjects or areas that they thought were inadequate and would like to be strengthened.

#### 2.7.3.1. Leeds

The researcher had four meetings with the carer group in two months on stage 2 of the project. The meeting schedule included group work on compiling information for the carer's booklet; a stress management workshop; a care skills training workshop and; a group discussion and interim evaluation day.

This stage was focused on team building and skill development. In the process of producing the stories for the booklet, interviews were conducted with the two carers who volunteered to share their stories. The purpose of sharing stories on the booklet would be an experience for them to realise the value and purpose of their roles as carers in the family. The two carers were pleased that their stories were represented in the booklet. Through the interview, when one of the carers was asked about the stress in caring, she started to realise the importance in finding ways to relieve her stress. Other carers wrote recipes for healthy eating and prepared foods for the group. They all enjoyed the group work on the day. At the end of the meeting the carer who was interviewed by the researcher, suggested having a stress management workshop.

Therefore, in the next meeting, the researcher conducted a stress management workshop with the group, using deep breathing, muscle relaxation technique and light music. This was the first time the carers

had come across this kind of relaxation exercise. They found it new and interesting and the music relaxing.

The co-facilitator was inspired to arrange a more suitable venue for this kind of stress management exercise and other outdoor activities for the carers.

The researcher delivered a carer skills training course focusing on communication. The researcher conceptualised and drew each topic into colourful cartoon images on flipchart pages, with short and punchy (one or two words) descriptions besides the images. The flipchart pages were decorated and pasted with cut papers in different shapes.

The delivery of the training course was simple and user friendly. All the carers were interested and involved in discussion. They were delighted when they saw the cartoon images on the flipchart. The method of delivering the training had raised the carers' interest in the topics of caring; they then asked questions and shared their experiences in daily caring. When the carers were asked to feedback on the usefulness of the training at the end of the session, they said it was interesting, joyful, and they learned a lot on the day, especially the style of communication. They suggested having some role plays but they were also aware of the time limitation on the day of training.

By this stage, the carers had built up trust and rapport with the workers at the centre and the researcher. Apart from the co-facilitator, other workers in the centre sat in on the research meetings from time to time to support the carers. From then on, the carers started to talk about their issues with the workers. They usually arrived at the centre early, before the research meeting started, for the purpose of talking to the workers on a one-to-one basis.

#### *2.7.3.2. Newcastle*

The group met twice in the two months with the researcher. They also arranged a visit to two residential care homes, one care home and one care centre based in Newcastle. In the two visits the researcher stayed back and left the group to work on their own.

In the first meeting at this stage, they set up a work plan to implement the booklet. The researcher brainstormed ideas with the group about the components of the booklets. At the beginning the carers, having no ideas of what and how the booklet should be compiled, were not confident in discussion. The researcher and co-facilitator encouraged and assured the carers that support would be given to them whenever they needed. One of them started to think about telling their experience in the past, others started to bring out the poor conditions of the residential care home they came across. Two carers volunteered to conduct interviews for the stories.

This was a fast-action group, two of the carers put in a lot of effort in conducting interviews, transcribing the audiotapes and translating the transcription; the carers' stories were soon furnished.

The co-facilitator helped to search for service information and the researcher also helped to find information on dementia. At this stage, the group was enthusiastic to take action.

All group members joined together to visit two projects and a carer wrote a report explaining what they experienced in the visit.

The highlight in stage 2 for this carer group was the feedback on the care home and new project which they had visited. They gained understanding and insight into the current services which were provided by a specialised dementia care organisation in Newcastle. The residential care home they selected to visit was an award-winning project that provided a non-institutional care service to empower the tenants. This award-winning project consisted of five bungalows and a care centre. Within the care centre, leisure, learning, beauty and therapeutic treatment, and sporting facilities were available to tenants and were also open to the community. While the bungalows were only available to residents of Newcastle, respite-care service in the care centre was open to all.

At the care centre, they were well received by the centre manager and three other officers who gave talks on different aspects of their services. They were also provided with a fresh and professionally cooked lunch.

The carer group was very impressed with the buildings that were purposely designed for people with dementia. The bungalows were

bright and spacious. They were very pleased with the 24-hour services being offered to cater for individuals' needs. Most of all, they were informed that Chinese service users could share a bungalow together.

The group was impressed with the improvement of the conditions of the care homes and they were hoping that a care home for Chinese people with dementia could be built in the future. They were putting this wish forward in the booklet they were going to produce.

#### 2.7.3.3. *London*

Two meetings were held at this stage of the research project. One was a care skills training workshop, and the other meeting was for discussion of the contents of the photo album.

On the day of the training workshop, four other volunteers at the collaborative organisation joined in with the two carers. The four volunteers were very interested to have learned new concepts and knowledge of caring for people with dementia. They also mentioned that the training raised their awareness of the right attitude towards people with dementia. The two carers, however, were not engaged throughout the training workshop.

The co-facilitator suggested that although the training materials had been simplified to suit the family carers' level of education, they might still find the content too difficult to understand. Carer A might be too shy to share his experience in front of a whole group of volunteers whom he had not met before.

The researcher suggested the co-facilitator to have a drink with the two carers thereafter to follow up with what might have been missing in the training. This arrangement was probably more effective in understanding the carers' views onto this research project.

The co-facilitator reported back to the researcher that in general, carer A was actually anxious about the communication breakdown between him and his wife. The training workshop might be useful for him eventually, however he was puzzled by the message that was conveyed to him in the workshop, that dementia was a degenerative disease and once people got the disease it was unlikely to recover. It was perhaps not his style to

accommodate his wife's challenging behaviour, as in the past his wife had never been a difficult person to deal with in any aspect. It was too early for him, and even more so for an older person to accept this reality, that his wife's illness was not going to get better. In his plight he found himself confused and frustrated, because he was expecting information on ways for his wife to adjust her challenging behaviour. It was hard for him to believe that he was the one who was to adjust to this change.

The researcher and the co-facilitator discussed the way in which they could engage carer A more and to achieve the aim of empowering him in the intervention. As it was clear that he was going through a difficult moment when he needed to accept his wife's illness, the focus should be on helping him to see the positive aspect of the relationship between him and his wife. The researcher, however, did not set out an agenda on how to help carer A, rather, observing carer A more for the best possible agenda through the following research activities.

In the following meeting, the researcher was to construct a story line for the photo album, the researcher and the co-facilitator used the form of story telling to facilitate the group.

On the day the researcher used flipchart pages and drew cartoon images to represent two stories which was going to be narrated by carer A, carer B and carer B's wife. The purpose of story telling was to motivate the carer recipient's long term memory and to bring out the appreciation of her life. The carers started to tell about their stories, carer A's 40 years marriage and the shared history with his wife had been valuable and memorable.

Moving on to stage 3 of the project, the researcher and the co-facilitator continued to work on the photo album based on the materials and the stories that the two carers had given. After this meeting, carer A became more relaxed in talking about his wife's challenging behaviours as he realised that it was the illness that has caused to the change in her character and her frustration.

The two carers provided some old pictures from when they were young. They treasured their pictures very much and they would like their photos and their stories to be compiled in the photo album as a remembrance of

their past and present, hoping that their stories would inspire many other carers that although the process of caring might be difficult, remembering the life of the care recipients as valuable individuals was still important.

#### 2.7.4. *Stage 3*

In the fourth and fifth months, the researcher stayed back from the group to let them finalise the tasks by themselves. The co-facilitators in each research site continued to support their participants to implement their tasks. The purpose of this move was to test whether the groups were able to use their skills acquired from the second stage and sustain them to work on their own initiative. When the tasks were completed, the researcher met up with each of the groups for a reunion, acknowledging and celebrating their contribution and success and sharing experiences of the participatory interventions.

##### 2.7.4.1. *Leeds*

The carer group started to meet without the presence of the researcher. In the last two months of the project, they had three meetings. The co-facilitator arranged a meeting for the carers to meet with a member of staff from the Social Services to explain the entitlement of carer's allowance. The group was pleased to know about the carer's holiday allowance to which they were all entitled. At this stage they were empowered through the awareness of the support for them from the community organisation. The rapport between the carers and the workers was further strengthened. On the second meeting, they engaged in group work to compile a draft of the carer's booklet. The co-facilitator and the researcher then followed up with the final production of the booklet at a later stage.

In the last meeting, the researcher had a reunion with the whole group for a final evaluation. By this stage, the carers were much more open in expressing their wishes.

The research project has led on to the development of a walking group for carers, including carers for people with other mental illnesses. The organisation has applied for funding to continue and expand the group. The centre coordinator maintained that this was the first time they had been involved in supporting carers for dementia and they found it beneficial, now that they have gained experience in running this kind of

project, and with the carers from the research group as core members, they would like to keep the group going.

#### 2.7.4.2. *Newcastle*

The carers, especially the more active ones, with the support of the co-facilitator, had compiled the first draft of the booklet between meetings with the researcher. Although this group only met with the researcher once a month, the group members had taken things forward much earlier than scheduled. At this stage the researcher was supposed to stay in the background and leave the group to work on its own, however, since the carers had already done a lot, the researcher thus went back to the group to discuss the post-production such as the printing arrangements for the booklets. Meanwhile, the carers learned a lot in the process of post-production.

The researcher met up with the group three times over a period of three months on stage 3 of the project. The co-facilitator had linked up support from the local health authority to distribute the booklet when it was mass printed. The researcher encouraged the carers to make decisions on the size, colours, title, layout, design and sequence of contents in the booklet, and the final printing arrangement was handled by the researcher.

In the final meeting, the researcher had a gathering with the carers. They continued to share what they saw on the day of the visits to the projects. They also talked about ideas for improving services for people with dementia, especially for the Chinese community.

The carer group continued its action after the end of the research project. One month later, they organised another visit to a Chinese housing scheme in Birmingham and one of them took the initiative to write a report on the visit. Their view was broadened as they were impressed by the design structure of the scheme. They were more positive about change in the future and they also exchanged ideas with the manager of the scheme. After the visits, the core members of the group were keeping in contact with their colleagues in Birmingham.

Two months after the end of the research project, two carers were invited to present the work of the booklet at a national health conference. When the first draft of their booklet was produced, two carers, with the support of the

co-facilitator presented their involvement in the research project and their teamwork on the booklet for their community. They were also interviewed by a journalist from the local radio station.

At the same time, the co-facilitator was invited to attend a meeting at the local authority, in which she expressed all the views and opinions which were collected from the research group meetings. The opinions from the research group were then to become part of the considerations to be included in the local authority's ten-year plan.

#### *2.7.4.3. London*

The research group still met to see the researcher and the co-facilitator, although not in a structure as it had originally planned. The two carers, instead of working on their own to produce the album, now came to give feedback and to provide more materials adding on to the production of the album. The researcher and the co-facilitator worked together to make a draft print of the album.

Towards the end of the research project, carer A asked the researcher if there could be any activities suitable to engage his wife so as to keep her more in harmony with the social world. The researcher then designed a series of psychosocial interventions for the purpose of motivating the care recipient's interest in her daily life, such as scheduling a daily routine, making phone calls, singing, etc. The whole group stayed on after the end of the project for another three months of the psychosocial intervention programme with the care recipient.

## **2.8. Data analysis**

There are three main components to the research:

### *Study 2*

1. A quantitative outcome component focuses on the change in the carers' sense of empowerment. A Sense of Empowerment Scale was developed as an assessment instrument to measure psychological outcome over a period of five months of participatory interventions.

2. A qualitative component focuses on the change in the carers' sense of empowerment based on semi-structured interviews with the carers and the co-facilitators at the end of the participatory interventions.

### *Study 3*

3. Another qualitative component focuses on the strengths and weaknesses of the processes of the interventions. Field notes, minutes of group meetings and tape recordings of group meetings were used for data analysis to examine the processes associated with the results of the interventions.

#### *2.8.1. Data collection and quantitative analysis*

A Sense of Empowerment Scale, as discussed in Study 1, was developed to measure outcomes of the intervention. When the researcher met with the carers in the first month of the project, a simple 8-item questionnaire (see Table B.3.) was used to assess the carers' sense of empowerment at baseline. At this stage the full scale 48-item questionnaire was still under construction. In the third and fifth months, when the 48-item questionnaire was statistically tested, it was then used to measure outcomes.

The comparison of psychological outcomes at baseline, time two and time three was based on the carers' responses on the original 8 items at baseline (time one), and their responses on the 8 items which remained in the 48 expanded items at time two and time three.

Repeated measures ANOVA was run to compare the mean scores of the carers' sense of empowerment at time one, time two and time three, based on the first 8-item scale.

A paired-samples *t*-test was run to compare the mean scores of the carers' sense of empowerment at time two and time three based on the 48-item scale.

#### *2.8.2. Data collection and qualitative analysis on the participatory interventions*

Data collection was accomplished through one semi-structured interview with each carer and co-facilitator. The interview was guided by five open-ended questions and each with follow-up probes which were set out to investigate different aspects of their participation:

- 1) Understanding their role and commitment level in the intervention group (e.g. 'What did you usually do in the group?')

- 2) Understanding their motivation of joining the group (e.g. 'What made you decided to join this carer group?')
- 3) Understanding their experiences throughout the intervention (e.g. 'What was the most interesting thing you found in the group? And why did you find that interesting?')
- 4) Understanding the benefit of intervention (e.g. 'Did you learn or find anything helpful to you in your role as a carer? If yes, please explain what was that you learn or find; and why was that helpful.')
- 5) Understanding the meaning of the intervention with regards to empowerment (e.g. 'What has this group meant to you? Did you feel any difference before and after joining the group?')

Interviews with the carers from London and Newcastle were conducted in Cantonese and the interviews with the carers from Leeds were conducted in Hakka. Each interview took approximately from 45 minutes to 1 hour and 30 minutes each. The semi-structured interviews occurred at the end of each of the interventions, that is the fifth of the research projects.

All the interviews were audio-taped and transcribed. In order to minimise the discrepancies in meaning due to language difference, transcription of the semi-structured interviews was carried out in Chinese and was translated into English for reporting purpose.

Due to the small sample size of this study, a thematic analysis method was used for thematic coding of the transcription of the semi-structured interviews. As Marks & Yardley (2004, p.66) suggested:

... On a small sample size, only the descriptive use of thematic coding is advisable, since it is meaningless to assign numbers to a data set that is too small to meet the usual minimum requirements for statistical analysis; as it may be misleading to report the frequencies of codes, as this would seem to imply that the frequency of occurrence in the sample was in some way representative of the likely frequency of occurrence in the wider population.

By using the thematic analysis, both types of theme, the manifest themes of the data and the more latent meaning of the manifest themes, would be observed and interpreted.

Basically data from the transcription was coded by categorisation; that is, taking the repeated appeared texts, grouping them together, and labelling them as falling into certain categories, in a way that allows for later retrieval and analysis of the data (Marks & Yardley, 2004). More specifically, theoretical ideas that were drawn from Study One were used as a source to constitute the themes and to extend previous results. The theoretical ideas were the six factors derived from the Sense of Empowerment Scales. Boyatzis (1998) suggested that theoretically derived themes allow the researcher to replicate, extend or refute prior discoveries. The six factors are as follows:

- 1) Confidence in pursuing one's rights because of one's own knowledge.
- 2) Recognising the importance of social support.
- 3) Confidence in being assertive.
- 4) Recognising support from the care recipient and from the family.
- 5) Recognition from the care recipient.
- 6) Awareness of resources available in the community.

Apart from establishing themes based on the six factors, new and additional themes would also be explored. As Marks & Yardley suggested, although it is advantageous to hold a model of 'testing' in mind, counter-evidence has to be taken seriously. A coding frame was designed to keep the recordings of the codes, description and examples derived from the transcription. The coding frame was set up for a more systematic comparison between the set of texts which helped the researcher to make further analysis and to make sense of the data (Marks & Yardley, 2004).

An example of the coding frame is presented in Figure B.2.:

Code Name	Description	Examples
<i>Confidence in being more assertive</i>	Social interaction	They (the carers) became more outspoken in their daily interaction with other people in the centre. They didn't talk to many people, just one or two friends whom they really knew well.

Figure B.2. Example of the coding frame (adopted from Joffe & Bettega, 2003, in Marks & Yardley, 2004).

The range of codes in the first column would be further divided into a sub-category or sub-categories when the latter become apparent. When there is a conceptual link between the codes and the sub-categories, the sub-categories will be regarded as the lower order sub-categories, however, if the sub-categories are too distinct or are entirely new, they will be taken from the codes and new codes will be created.

A reliability test was applied by coding the transcription again two weeks after the first coding.

### 2.8.3. *Data collection and qualitative analysis on the process of participatory interventions*

Data collection was accomplished through reading the field notes, minutes of group meetings, transcription of tape recordings of group meetings and activity reports. Thematic analysis method was used to code all the documentations collected.

A reporting framework designed by Nelson, Pancer, Hayward & Kelly (2004) was adopted as the theoretical guidelines for constituting themes. The framework is shown in Figure B.3.:

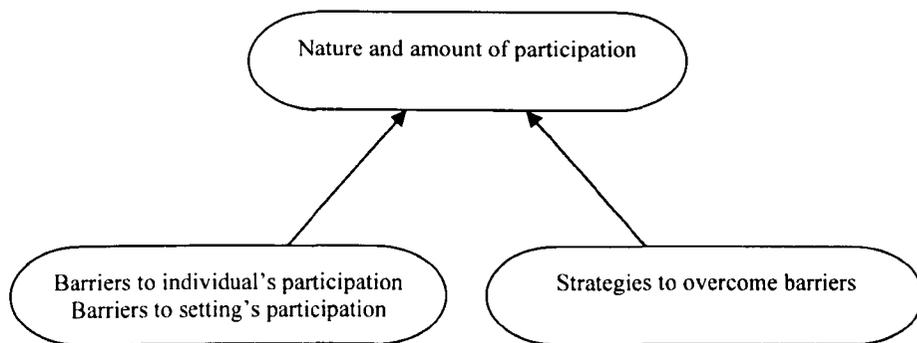


Figure B.3. Reporting framework of the process of participatory intervention, adopted from Nelson et al. (2004).

The three headings in the framework were used as the range of categories and sub-categories were to be constituted under each category. Each category and sub-categories were to be coded and labelled as theme and sub-themes to represent the collective conceptual idea they carried.

Sub-categories which were new and distinctive from the range of codes would be created as new codes and thus labelled as new themes. The same coding procedure and reliability test as mentioned in 2.8.2 were to be used to analyse the process of the participatory interventions.

## 3. Results

### 3.1. Outcomes assessed by the Sense of Empowerment Scale

### 3.1.1. Comparison at T1, T2 and T3 using the 8-item scale

The 10 carers completed an initial 8-item questionnaire at baseline (T1). Carers' responses on the same 8 items in the expanded 48-item Sense of Empowerment Scale (SES) at month 3 (T2) and month 5 (T3) were used to compare changes at T1, T2 and T3.

Results were obtained from a repeated measure ANOVA to assess changes in each group. There is a significant effect of change on the overall level of sense of empowerment among the 10 carers. Table B.9. shows the results of the repeated measures ANOVA.

**Table B.9.** Mean Scores, Standard Deviations and *f*-ratio of overall sense of empowerment at T1, T2 and T3 (n=10)

Variable	T1	T2	T3	
Sense of empowerment of Carers in the three cities (n=10)	Mean (SD)	Mean (SD)	Mean (SD)	<i>f</i> -ratio
Descriptive Statistics	16.8 (6.56)	18.1 (3.87)	23.7 (2.4)	
Bartlett's Test of Sphericity				$f(5) = 0.013, p < 0.05$
Tests of Within-Subjects Effects – Greenhouse-Geisser estimate				$f(1.5) = 0.002, p < 0.05$
Tests of Within-Subjects Contrasts				$f(1) = 0.006, p < 0.05$
Multivariate Tests				$f(8) = 0.007, p < 0.05$

### 3.1.2. Comparison at T2 and T3 using the 48-item scale

The 10 carers completed the 48-item SES questionnaire on the third (T2) and fifth months (T3) and responses were assessed. Results were obtained from paired sample *t*-tests. There was a significant change in the overall level of sense of empowerment of the 10 carers ( $t(9) = -6.831, p < 0.05$ ). Table B.10 shows the mean scores and standard deviations of the overall sense of empowerment scores at T2 and T3.

**Table B.10.** Mean Scores, Standard Deviations & *t*-ratio of overall sense of empowerment at T2 and T3 (n=10)

Variable	T2		T3		<i>t</i> ratio
	Mean	(SD)	Mean	(SD)	
Sense of empowerment	154.20	(11.56)	193.10	(10.268)	$t(9) = -6.831, p < 0.05$

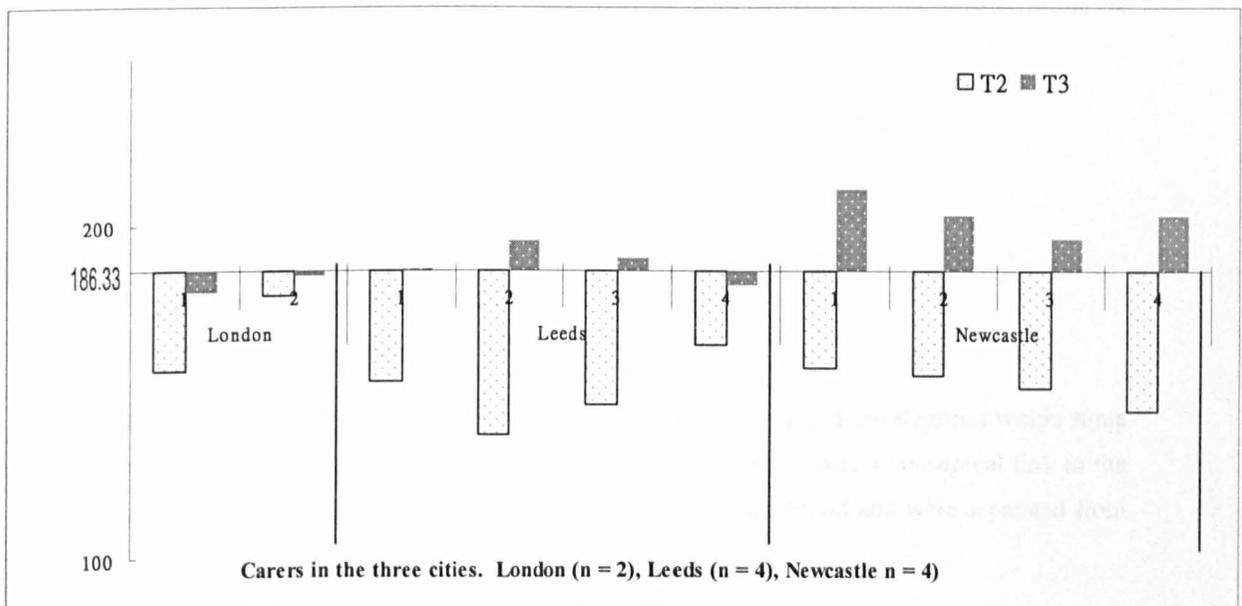
Significant changes were also found when paired sample t-tests were run separately in each group. Table B.11. shows the mean scores and standard deviations of the change in sense of empowerment of the carer groups in the three different cities, the t-ratios are also reported.

**Table B.11.** Mean Scores, Standard Deviations & *t*-ratio of each of the three groups at T2 and T3 (n=10)

Variable	T2		T3		<i>t</i> ratio
	Mean	(SD)	Mean	(SD)	
Sense of empowerment of Carer group in London (n=2)	167.50	(16.26)	182.50	(3.53)	$t(1) = -1.67, p < 0.05$
Carer group in Leeds	150.00	(11.40)	188.25	(5.66)	$t(3) = -4.52, p < 0.05$
Carer group in Newcastle	151.75	(5.74)	203.25	(6.13)	$t(3) = -16.49, p < 0.05$

In study one, the standardised score of the SES as obtained from statistical analysis is to be 186.33 which set out the middle standard of sense of empowerment on the scale, therefore a total score on the questionnaire below 186.33 would indicate that psychological empowerment is likely to be on the lower side, while scores above 186.33 would indicate a higher sense of empowerment. Figure B.4. shows the trend of each carer's scores at T2 and T3 which crossed on the middle standard on the SES.

**Figure B.4.** Carers' SES scores at T2 & T3 intersecting the standardised SES score.



Using the six factors as derived from the factor analysis in study one, scores of each sub-scale were computed for paired sample *t*-tests. Significant changes were found in all factors except in factor two – ‘Recognising the importance of social support’. Table B.12. shows the mean scores, standard deviation and of the six factors as interpreted as variables and the *t*-ratios of the statistical analysis.

**Table B.12.** Mean Scores and Standard Deviations of 6 variables at T2 and T3 (n=10)

Variable	T2		T3		<i>t</i> ratio
	Mean	(SD)	Mean	(SD)	
F1. Confidence in pursuing one’s rights because of one’s own knowledge	16.00	4.78	23.30	4.57	$(t(9) = -4.379, p < 0.05)$
F2. Recognising the importance of social support	31.70	1.34	30.90	2.03	$(t(9) = 1.037, p > 0.05)$
F3. Confidence in being assertive	10.20	4.05	12.50	3.92	$(t(9) = -2.501, p < 0.05)$
F4. Recognising support from care recipient and family	9.50	2.01	12.30	1.25	$(t(9) = -3.500, p < 0.05)$
F5. Recognition from care recipient	8.50	2.41	10.10	0.32	$(t(9) = -2.182, p < 0.05)$
F6. Awareness of resources from community	9.10	2.23	10.30	0.48	$(t(9) = -1.724, p < 0.05)$

### 3.2. Semi-structured Interviews

Categories drawn from the semi-structured interviews were based on the components of the six factors developed from the Sense of Empowerment Scale:

1. Confidence in pursuing one’s rights because of one’s own knowledge;
2. Recognising the importance of social support;
3. Confidence in being assertive;
4. Recognising support from the care recipient and from the family;
5. Recognition from the care recipient;
6. Awareness of resources available in the community.

Themes were generally fitted into the categories of the six factors. Sub-categories within some themes were found and were labelled as sub-themes when there was a conceptual link to the main theme. New themes which were entirely new were also found and were separated from the original categories.

Main themes and sub-themes are reported within each factor and new themes are reported separately.

### ***3.2.1. Confidence in pursuing one's rights because of one's own knowledge***

Only one carer made reference to this theme. A carer in Newcastle who was the youngest and had the highest level of education among all other carers stated that she was more confident to pursue her rights because of the knowledge she had gained about dementia illness. She was also the only carer who spoke fluent English. In the past, regardless of language ability, she found it difficult to articulate her needs due to the limited knowledge of her rights as a carer. After participating in the research project, she was pleased with her noticeable improvement in the knowledge of dementia; more knowledge had helped her to advocate for her and other carers' needs more confidently.

### ***3.2.2. Recognising the importance of social support***

Carers in Leeds and Newcastle appreciated the opportunities for networking and making new friends. Some of them made new friends in the research project and after the end of the project they were continuing to see one another for meals. They experienced the importance of social support, especially in associating with people from the same background.

Carers in Leeds all felt the benefit of social and peer support from the other carers and the workers. All of them enjoyed attending the group because of the opportunity of sharing with other carers and the mutual support which built up gradually among them. They enjoyed the space of time when they could chat, make jokes and share stories in the research group. One of the carers stated that before joining the group she felt no sympathy from other people whenever she tried to talk about her husband. The mutual understanding on the same issue had established support and empathy towards one another.

In recognising the importance of social support, some of the carers in Leeds expressed that their sense of well-being was also improved. A sub-theme is described as follows:

#### ***3.2.2.1. Increased sense of well-being because of social support***

Three carers highlighted the benefit of social support in that it brought about an improvement of their sense of well-being. Talking about the burdens in daily care routine was a good way to release negative emotion which had been bottled up for a long time. The interaction and encouragement from the group was a temporary relief to the carers, especially those who were facing a demanding role because of the health

condition of the care recipients. Some carers said that they were happier, more relaxed, and less frustrated than before.

### **3.2.3. *Confidence in being assertive***

Carers in Leeds and Newcastle were more confident and more assertive in different aspects of their daily life after the end of the research project.

In general, the carers in Leeds used to be quite passive and isolated. During and after the research, they became more open in communication with other carers and people outside the group. Their confidence level had increased moderately, as a worker observed that at the beginning when the carers came to the group meetings, they were very reluctant to speak up. Gradually they became more confident, not just within the research project, but in other activities. They were more relaxed in talking to people with whom they were not very familiar.

The carers in Newcastle became more confident in being assertive, although in a different way. Two carers mentioned their experience of making a presentation at a national health conference. They were interviewed by a journalist from the local radio as well as going up to the stage to present their involvement in this research project. They were both fascinated by the fact that they could take on the challenge. One of them said that it was difficult to talk in front of the public, especially the first time being interviewed by a journalist. She took the courage to talk as she felt sure that what she had done in the project was a good job. When asked to express her opinions on the carers' presentation, a worker expressed that the carers' involvement in the research project had built up their confidence and they took pride in what they had done, hence they felt more assertive in representing issues on dementia in the community.

### **3.2.4. *Recognising support from the care recipient and from the family***

In Leeds, the carers' relationship with their care recipients had improved because of their change in attitude after the care skills training workshop. One stated that she was getting along better and more easily with her husband and the atmosphere at home was much better. Another carer from Leeds, who appeared to be the most frustrated and stressed when she came to the group, emphasised the importance of her involvement in producing the carer's booklet. She was one of the carers who shared her story in the booklet. She was pleased because her story was printed on the booklet and she felt that her role as a carer was recognised. She showed the booklet to her family and they came to realise that she had really attended a meaningful research project for carers.

This was recognition from her family and she rejoiced over her involvement in the project.

**3.2.5. *Recognition from the care recipient***

No reference was made to this theme as previously formed in Study 1.

**3.2.6. *Awareness of resources available in the community***

A worker in Leeds expressed that the booklets produced by carers had raised the awareness of the resources available among the group as well as other carers in the centre. The carers in the research project found the booklet useful and they all took a copy home. Involvement in the production of the booklet made them aware of the useful services and the contact details. Apart from the booklet, a seminar on Social Security benefits for carers also helped them to understand the resources that they were entitled to. All of the carers appreciated the opportunity to get practical support that they had not known before. All carers were pleased that they were entitled to the carer's holiday allowance.

Carers in Newcastle appreciated that through discussions in the research meetings, they learned about the Social Security benefits and services that were already available in the community. They also appreciated the fact that they could now utilise the resources and support more, both from the statutory and voluntary sectors (one example was the resource on social benefits for carers). A carer expressed that knowing where to get help was important because carers could be so busy in their daily caring routine that they might overlook the fact help was just out there in the community.

The carers were pleased that one of them helped in organising visits to two residential care homes. In general, the carers in Newcastle had bad experiences of the conditions of residential care homes. They felt more assured and positive after the visits when they saw that the facilities and conditions of the care home had improved a lot in recent years.

New themes are reported as follows:

**3.2.7. *Benefits of knowledge gained***

This theme was the most prominent theme that was coded throughout the semi-structured interviews across the three carer groups. In Leeds, carers unanimously agreed that they had benefited most from the carer skills training workshop. They

learned how to look after their care recipients better. They learned to adjust their communication with the care recipients, for in the past carers did not realise that certain behaviours were due to the illness. Carers found it useful when they became more considerate towards, and able to communicate differently with, their care recipients. One stated that before joining the group, she did not know how to deal with her husband. Each time when he showed his temper, she would confront him, or just ignore him. She said the most meaningful thing to her in the research group was the correct attitude she learned to care for her husband.

In London, carers benefited from the knowledge of dementia illness obtained through group discussion, a one-day carer skills training workshop delivered by the researcher and their informal discussion with the volunteers after the group meetings. Although the carers did not seem to be engaged during the training, one of the carers later in his own time read the notes and handouts of the handouts which he found useful.

In Newcastle, carers frequently mentioned the knowledge expanded through group discussion in the meetings where they were given advice by the researcher on facts about dementia, difficulties faced by people with dementia illness and ways of communication. The carers also gained knowledge from the process of producing the booklet when they were to conduct interviews with one another and to read the draft of the booklet in order to give feedback and comments to the group. The carers stated that they learned a lot more about how to care for people with dementia. One recalled that when her grand mother with dementia was alive, she was frustrated at not knowing how to look after her. She felt more confident now that if anyone in the family has the same problem, she was sure that she would be able to look after and to help them.

#### ***3.2.7.1. Improved sense of well-being because of knowledge gained***

Carers in Leeds expressed that they were feeling better and were in a better mood. One of them admitted that having a depressive mood all the time was really not good as it would affect one's physical condition. The carer who appeared to be the most stressed and frustrated emphasised the benefit of the stress management workshop. She took up her caring role 10 years ago and wanted to find ways to release her stress. She learned the deep breathing exercise for the first time in the research project and after that she still kept on doing the relaxation exercise when she was stressed.

A carer in London was more able to let go of his frustration about his wife's behaviour. He expressed that, before he came to the research project, he

was quite unhappy because he did not understand that people with dementia could not control their own behaviour. He used to feel frustrated but after he understood more about dementia from the research project, he found it easier to let go of his frustration. He also understood that it was beyond his ability to control his wife's behaviour that was due to dementia. He felt more relaxed about the situation and was more willing to get help as it could help to improve his sense of well-being.

#### **3.2.7.2. *Motivated for further learning***

One carer was especially conscious of her knowledge gained about dementia and building on what she had already learned, she was interested to learn more about dementia. She attended a health conference and she particularly chose a workshop on dementia in the afternoon session of the conference. She expressed that this was very much due to her participation in the research project. In the workshop a lot of the information discussed was familiar to her, thus she came to realise that she had really learned something. She was interested and motivated to learn more about dementia. She said that the research project had broadened her view on the issue.

#### **3.2.8. *Sense of contribution and achievement***

Carers in Newcastle who were actively involved in the production of the carer's booklet had developed a sense of contribution and achievement. This theme repeatedly appeared in the transcription of the semi-structured interviews. They took pride in their involvement in producing the booklet and they saw this piece of work as meaningful and worthy of their time spent because the booklet would become a valuable resource for the community.

They saw the booklet that they had produced as a useful tool for the community, especially for carers for dementia when they sought service information and real-life stories about dementia. The carers also felt empowered because of their involvement in the research group in general. One carer was proud of joining the research project, she was pleased to share with her friends that she had been involved in this meaningful project.

#### **3.2.9. *Recognition of one's caring role***

As mentioned in 3.2.4., a carer in Leeds who shared her story in the booklet was pleased that her story was printed on the booklet. Her story in the booklet was a form

of evidence of her contribution as a family carer and she felt that her role as a carer was finally recognised. In Newcastle, all the carers received a certificate in appreciation of their role in caring on the day of a conference. They were pleased that the organiser of the conference, being thoughtful, had reminded them to recognise and appreciate their role and the efforts they contributed as a family carer.

#### **3.2.10. *Empowerment through valuing one's own past***

In London, the two carers' idea of producing a photo album, unlike the other two groups, was to have a piece of work that was meaningful and valuable to see and to remember. Although much work was done by the co-facilitator, the carers were happy that the album was going to be published. They were pleased when they heard the researcher and the co-facilitator's admiration of their beautiful pictures. One carer said that at the beginning he did not want to share his wife and his old pictures with us; those beautiful black and white photos of his wife that he treasured so much. After a while he took them to the research group as he also wanted the album to be worth remembering. He would like to include his and his wife's pictures in their twenties and in their sixties, both young and old, and their stories which were all parts of their lives. The co-facilitator expressed when she saw their pictures that she appreciated the value of life that not even illness could take away.

#### **3.2.11. *Learning through role modelling***

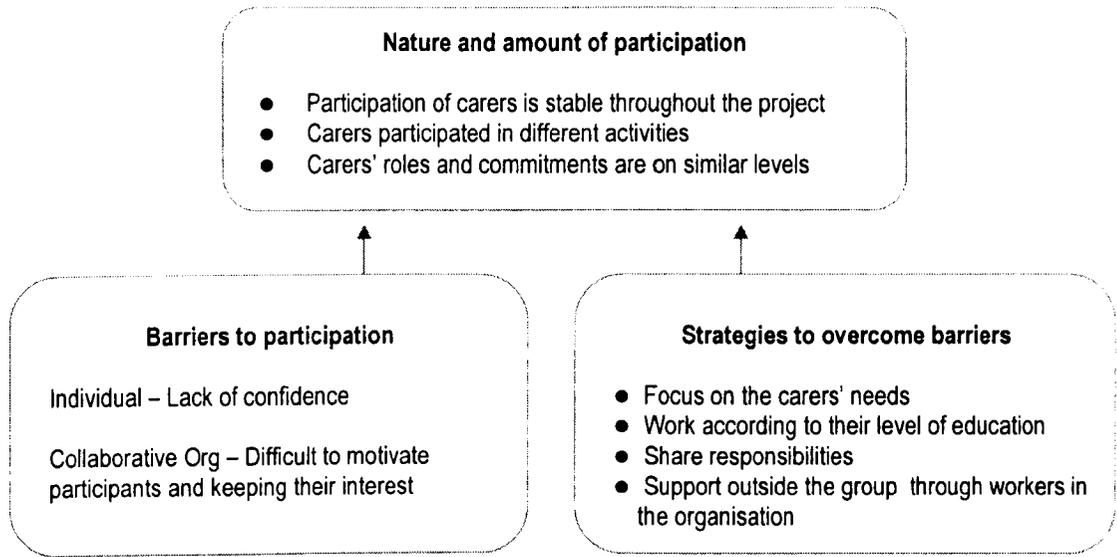
Another source of learning is to learn from a role model. In London, an existing carer learned a lot from an ex-carer B whom he much admired. The carer said that he had learned a lot from B as he heard how much B had loved and cared for his wife, especially on those days when her health condition was deteriorated badly. He realised that B had put in a great deal of patience and love in caring. He expressed that he would like to try to do what B did in the past. The co-facilitator observed that, learning from the other carer; he was becoming more considerate to his wife.

### **3.3. Participatory processes**

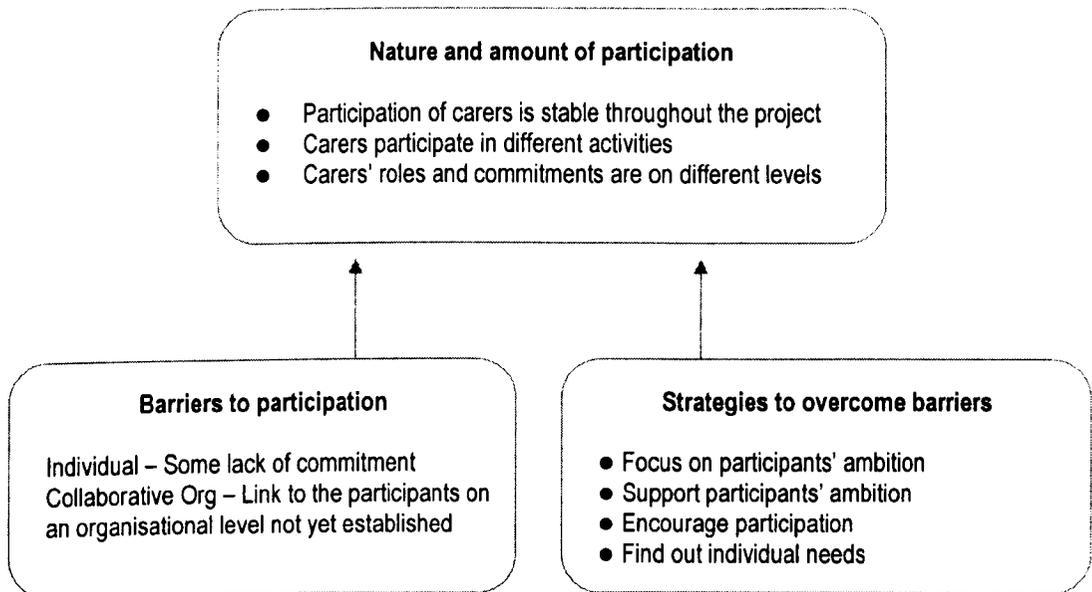
Categories drawn from the field notes, minutes of group meetings, transcription of tape recordings of group meetings and activity reports to analyse the intervention processes were based on the reporting model of Nelson et al. (2004) in their participatory research study.

An overview of the results of the participatory processes in Leeds, Newcastle and London are presented respectively in the following figures:

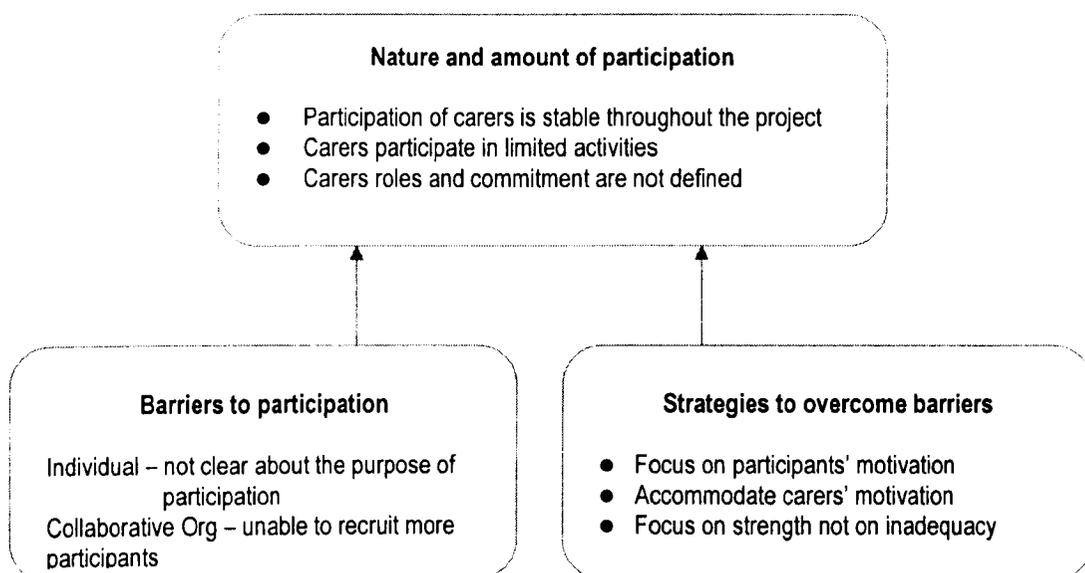
**Figure B.5. Group in Leeds**



**Figure B.6. Group in Newcastle**



**Figure B.7. Group in London**



The emphasis in analysing the data collected and report of the results in this section is on the processes of the interventions. Themes are reported within each component of Nelson et al.'s participatory reporting model.

### **3.3.1. Nature and amount of participation**

#### **3.3.1.1. Stable participation**

It was shown that all the carers in the three groups were stable in their participation in the interventions. All carers in Leeds and London attended all the meetings and activities as scheduled. In Newcastle, three of the four carers had full attendance throughout the project, the other missed two meetings. All carers were punctual in attending the research meetings, and stayed until the end of the meetings. The carers in Leeds usually arrived 15 to 20 minutes earlier. They were particularly committed to coming to the meetings, as was evident once when the researcher was half an hour late, and in a friendly way, they commented that the researcher was not keeping to time.

### **3.3.1.2. *Active participation***

The carers in Leeds and Newcastle had been involved in different activities initiated by their needs and expectations. Team work on producing carer's booklets was their main goal and they all became involved in the tasks on different levels. Other activities ranged from stress management workshop, carer's skills training workshop, seminar on carer's benefits, site visits to residential care homes and day centres and attending and presenting at a national conference. The nature of their participation suggested that during the process of interventions, carers started to build up their knowledge and skills in caring. Participation was also an opportunity to be informed (visiting care homes) and to inform (presenting at conference) on services and experiences. The activities were viewed as new, useful and interesting to the carers.

#### ***Passive participation***

The carers in London had limited involvement and were more passive in their participation. From the minutes of the research meetings and field notes, it appeared that the researcher and co-facilitator had to spend time in encouraging discussions. Feedback and quotes from the carers were limited.

### **3.3.1.2. *Carers' roles and commitments***

#### ***Factor of education level***

As records of the field notes had suggested, although producing carer's booklets was viewed as a meaningful task, most of the carers were concerned about their inability to fulfil the task. Some carers in Newcastle and all in Leeds expressed that their literacy level was not even enough to write a simple article. The carers however were pleased to contribute whatever they could in the production of the booklet. The co-facilitator was very encouraging and ensuring that every little effort would help in the process. The carers were enthusiastic, involved and joyful in the group work.

On the other hand, a carer in Newcastle who had a higher education level was motivated and was making every effort in compiling the contents of the booklet. Due to difference in educational levels, it was apparent that the more educated carer in Newcastle took up more responsibilities, and hence

more satisfaction when the tasks were achieved. In Leeds, carers' educational levels were very similar and their roles and responsibilities were also on the same level.

### **3.3.1.3. *Barriers to participation from the carers' perspective***

#### ***Lack of confidence***

Many carers were lacking confidence at the beginning of the intervention, especially when they were encouraged to contribute on a piece of joint work. As mentioned above, while some carers were on a lower education level, they also lacked confidence that they were to do something which required skills and knowledge. Although they were assured that the purpose of the research project was just to build up their confidence in their experience as a carer, at the beginning they did not seem to be convinced.

#### ***Lack of commitment and motivation***

Commitment both in attending the meetings and in dedicated to the goals of the project was seen in Leeds, when enthusiasm and interest was manifested in each meeting report and field note. Carers expressed that they looked forward to meeting the researchers in the next meetings. Two carers expressed that they would like to have the meeting every week. Although most of the carers were committed to attending the meetings, one carer in Newcastle group was not very committed to the purpose of the research project. This carer was not committed or engaging well in meetings or in the responsibility shared on the joint task. In several points on the meeting minutes, it was noted this carer had raised practical support needs for his care recipient. Unlike the carers in Leeds who could get practical support from the collaborative organisation, carers in Newcastle were not in any way getting direct help from the collaborative organisation. When such needs were not addressed, commitment in the research project was seen to be impeded.

In London, level of commitment and motivation was low due to the difficulty in defining the carers' goals and expectations.

#### ***The concept of participation in research***

In London, the reason for the lack of commitment and motivation might be due to the lack of understanding of the concept of participation in research.

The focus of the group was on the existing carer because the other, an ex-carer, was already highly empowered in his background as an active volunteer in the community. Reports from the co-facilitator revealed that the carer viewed research as a process of interview and interrogation to uncover issues of the participants. He was concerned about not being able to help the researcher because at the beginning he was still unsure what to disclose and what not to disclose about his experience in caring. The co-facilitator took time to explain the concept of participation in research in the carer's language. This method of research was viewed as new and lacking structure, as the carer said to the co-facilitator that he was unaware that chatting and sharing could also mean that research was already in progress.

#### **3.3.1.4. *Barriers to participation from the organisations' perspective***

##### ***Unable to recruit carers***

Records of the pre-intervention groundwork suggested that recruiting carers in London was difficult. Chinese community organisations providing home care service to older people were always under a heavy workload. Workers of the organisations were unable to spare extra time in coordinating with the project. On the other hand, perhaps because of the more sufficient resources for older people and job opportunities for carers in London, community organisations found it hard to introduce the concept of empowerment to carers. As one of the workers stated, it was difficult to reach the carers because they all were very busy working and caring at the same time; and having the opportunity to work and earning a stable income was regarded as empowering in itself from the carers' point of view.

##### ***Lack of rapport with the carers***

As mentioned above, in Newcastle one carer's support need had not been addressed. From the organisation's point of view, it was difficult because its service, which had just developed in the recent years, was new to the community. When the researcher fed back this particular carer's need to the organisation, a worker expressed that unfortunately at that moment, they had not yet developed a service to support family carers in the community. It was found from the field notes, that the collaborative organisation in Newcastle was more helpful in coordinating with tasks than building up rapport with the carers. An example was the amount of tasks in the minutes

which recorded the help enlisted from the organisation in support for the paperwork such as translation and editing the booklet at the later stage, meanwhile, direct contact with the carers was limited.

#### ***Difficult to motivate and maintain the carers' interests***

Co-facilitators in Leeds and London found it difficult to motivate and maintain the carers' interests in the interventions, although the carers were committed to attending the meetings. From the organisation's point of view, keeping the carers' interest as well as fitting their interest to the purpose of the research might be a difficult task. A co-facilitator maintained that change in time schedule, care commitment and other social activities were potential distractions to maintaining the carers' interests in the process. During the whole process, the co-facilitators were seen making a lot of efforts in motivating the carers to attend the meetings and sending constant reminders before each meeting.

#### **3.3.1.5. *Strategies to overcome barriers***

##### ***Explore the carers' needs and motivations***

It was found that the researcher and the co-facilitators tried to define goals and objectives with the carers based on their needs, motivations and strengths. Needs and motivations were defined through the process of discussions. The researcher and the co-facilitators followed the flow of discussion among the carers. On many occasions, carers might not realise in which area they would need to be supported. An example was that, when the researcher asked the carers a direct question, 'What are our needs as a carer?' an answer might not be given straight away. However, through listening to the discussion among the carers, their needs and motivation were uncovered. In Leeds, the carers' discussion was mostly focused on difficulties in communication with their care recipients. Fitting into this particular need, the researcher accordingly suggested a carer's skills training workshop. In London, focus was on a carer who had recently assumed a caring role. The researcher and the co-facilitator spent time to explore what the carer truly needed at the time he joined the research project. The carer gradually built up a greater conscious awareness in his caring role through knowledge and support gained both within and without the research group.

### ***Work according to the carers' level and language***

It was found that participation and empowerment were enhanced when the researcher used the same language and a learning style suitable to the carers' level of understanding. In London, carer's skill training was delivered but it was not successful in engaging the carers. The co-facilitator reflected that the materials might be a little difficult for the carers to understand. Learning from this experience, the researcher used a more visual form of learning method to inspire the carers in Leeds. Feedback from the carers this time was positive. It was evident that three months after the training course, minutes of the meetings still recorded carers' recollection of some of the skills picked up from the training. Another empowering factor was the use of the carers' own language in the intervention. The carers in Leeds felt relaxed and free to talk about their issues in Hakka among themselves. They were pleased with the research environment and appreciated the fact that the researcher was respecting their use of language. On many occasions, some carers volunteered to interpret for the researcher, checking whether the researcher would have been left out in the midst of Hakka conversation to make sure that she was feeling just as comfortable in the meetings. The co-facilitator stated that the carers expressing themselves in their own language was empowering.

### ***Focus on strength, not on inadequacy***

The co-facilitators and the researcher had been promoting a sense of partnership throughout the process of interventions. It was reflected that they emphasised a collaborative approach to ensure that carers would not feel inadequate because of their limitations in carrying out some tasks. They emphasised the carers' contribution in their every little effort that made a difference. To encourage the carers to look at their strength more than their weakness, the co-facilitator in London stated in the discussion of the joint work with the carers that their stories and experiences were valuable and meaningful. Toward the end of the intervention, a change in the level of participation and commitment was shown when the carers were pleased to share their old pictures for the compilation of their carers' photo album. At that stage, the carers started to realise a sense of worth and they were looking forward to seeing the album completed. The process of producing a booklet, although beyond the carers' ability would it have

seemed at the beginning, had become a series of learning experience which had empowered them as they all shared the contribution of developing a useful resource for their own community.

#### ***Support established outside the group***

Carers in Leeds were directly supported by the workers (the co-facilitators) in the collaborative organisation. The support that the organisation could practically offer had helped to build up rapport with the carer participants during the intervention. In some occasions, when the researcher made contact with the co-facilitator on her way to the centre for a meeting, she was assured that the carers were all right. Before the researcher arrived, the workers were usually helping the carers in resolving their issues, listening to their problems and giving emotional support. The support from the organisation had further strengthened the carers' confidence in taking more initiative to seek help when they were in need.

#### ***Encourage participation and share responsibility***

Although carers might be limited in taking up roles and responsibilities due to their level of education, some of them were seen to be motivated to participate in the process. The carers in Leeds had shown their commitment on the day when they were to compile materials for their booklets. One carer prepared refreshments on the day, she expressed that she was not able to write, but she was pleased to help out. Another was pleased to write her own recipes which would be included in the booklet. The atmosphere was joyful and pleasant and their participation was harmonious. After all, the carers were not at all discouraged by a task that might appear to be beyond their abilities. They enjoyed the participation, the companionship and the group dynamic throughout the process.

## **6. Discussion**

In these three studies, I examined psychological empowerment using participatory interventions with three groups of Chinese family carers. Study one is the development of a Sense of Empowerment Scale (SES) to measure the change in the carers' psychological empowerment over time. Study two makes use of the SES to understand the impact of a participatory

intervention, and Study three depicts processes of the participatory interventions with carers in a voluntary organisation setting.

Zimmerman (1990) identified a multilevel construct of empowerment that integrates perceptions of personal control, a proactive approach to life, and a critical understanding of the socio-political environment. Empowerment in this multilevel construct takes place at three levels; the individual, the organisational and the community, in which each level of analysis is interdependent with the others. The empowerment of carer groups in this study, if placed in Zimmerman's (1990) multilevel construct of empowerment, could be identified as empowerment at the individual level (psychological empowerment).

Psychological empowerment may be distinguished from organisational or community empowerment, however, it could be interlinked with empowerment on other levels of analysis (Zimmerman, 1990). In the current study, it is shown that empowerment was found at both an individual level and an organisational level. Carers' individual level of empowerment could be influenced or enhanced on an organisation level when they worked with an organisation that provided an environment for empowerment to happen. In order to study the psychological empowerment of the family carers, understanding of empowerment at an organisational level and how these organisations became one of the sources of empowerment to the carers is necessary.

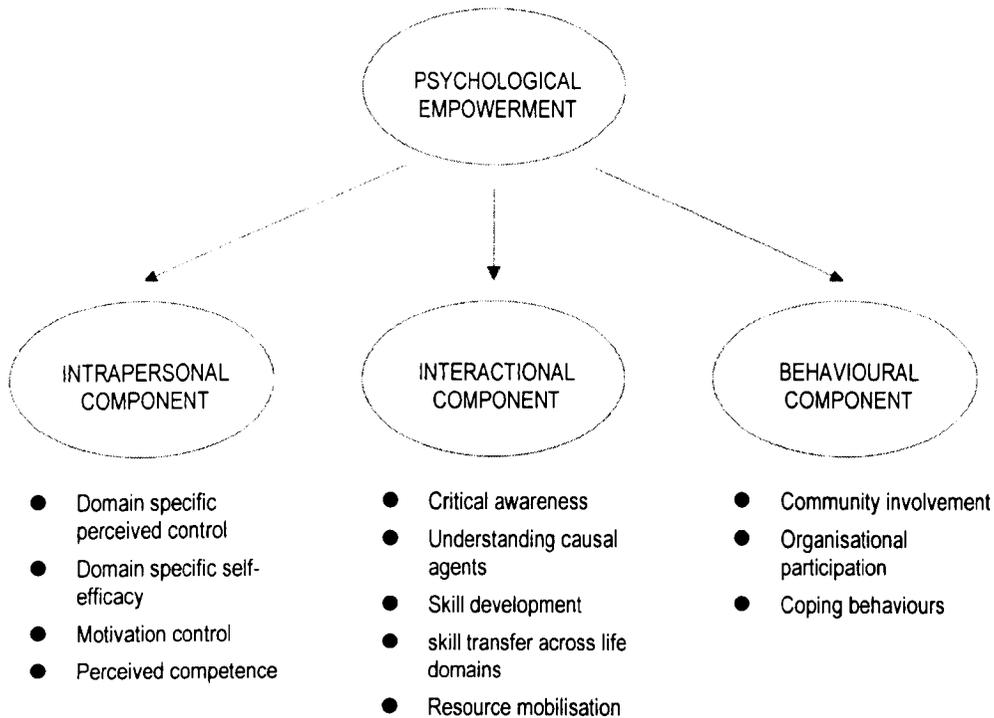
Zimmerman (1990) suggested that when an organisation can incorporate processes and structures that enhance members' skills and provide them with the mutual support necessary to effect community level change; it can be considered as an empowerment organisation. In the current study, empowerment at an organisational level is also shown when the organisations have improved their capacity in competing for resources and networking with other organisations, as a result of the developmental skills learned from the process of this research study. Therefore, empowerment in this study is revealed at both the individual and the organisational levels.

With regard to the first research question on the participatory psychosocial intervention which is aimed at leading to an increased psychological empowerment among the Chinese family carers for dementia, a Sense of Empowerment Scale (SES) was developed which is context- and population-specific to measure the empowered outcomes. As mentioned in study one, items on the SES encompassed the themes of mastery and control, resource mobilisation, and socio-political context and participation that would be expected in the conceptual framework of psychological empowerment, as Zimmerman (1990) suggests. The outcomes measured for the

participatory interventions using the SES, therefore, should also have represented the impact of the interventions encompassing these major elements in the construct of psychological empowerment.

Looking at the third research question, about how the participatory processes have taken place that were effective and helpful to the carers, four aspects are observed on the basis of evaluating the fundamental aspects of empowering processes. Zimmerman (1995) suggested that when professionals are working to enhance empowered outcomes of others, an empowering process would mean (a) involving community members in the development, implementation, and evaluation of interventions; (b) developing an identity whereby professionals become part of the community to some extent; (c) working with community members as co-equal partners; and (d) creating opportunities for community members to develop skills so that they do not have to be dependent on professionals. The current studies have demonstrated how these aspects of processes have empowered carers, particularly on the aspects of developing and practising skills such as communication and knowledge of dementia; learning about resource development such as developing the carer's resource booklets; working in a team on a common goal such as sharing tasks among the group members to producing the booklets; and expanding their social support network such as meeting carers from a similar background and having more involvement in joining social activities organised by their community organisations.

Apart from the four aspects of which evaluation of the impact of empowering process can be discerned, another framework, a nomological network for psychological empowerment set up by Roesch & Golding (1980), suggested that elements relevant to psychological empowerment can be observed within an open-ended construct. Roesch & Golding (1980) indicated that in general, open-ended constructs may include observational terms and rules; however, they may not need to capture any one specific operation because these constructs are used to analyse different forms in different populations, contexts, and times. Psychological empowerment may therefore be considered an open-ended construct because it takes on different contexts, population, and developmental time (Zimmerman, 1995). In psychological empowerment, a necessary first step is to identify the observational terms and conditions that are relevant within its open-ended construct. I will discuss the evaluation of the empowerment processes based on the results of the qualitative analysis of the current studies and whether or not the processes have achieved development of the components as they are represented in fundamental aspects of the nomological network of psychological empowerment (Zimmerman, 1995). The framework is presented in Figure B.8.



**Figure B.8.** Nomological network for psychological empowerment (Zimmerman, 1995).

### 6.1. Empowered outcome

In general, results of the quantitative analysis show that the Chinese family carers had achieved a significant increase in their psychological empowerment over the five months' participatory interventions. Results of the repeated measures ANOVA using the initial 8-item scale indicate that the comparison of psychological empowerment of the ten carers as group from baseline to three months and five months is significant over time ( $p < 0.05$ ).

Paired sample *t*-tests using the expanded 48-item scale was further administered to test the pattern of change at three months and five months. Results of the paired sample *t*-tests also show a significant effect of improvement of the carers' sense of empowerment ( $p < 0.05$ ). When the paired sample *t*-tests using the 48-item scale was administered to test the pattern of change for each group of carers separately, significant results are also observed. Among the three groups, the carers in Newcastle show the most significant change ( $t = -16.49, p < 0.05$ ), followed by the carers in Leeds ( $t = -4.52, p < 0.05$ ), and London ( $t = -1.67, p < 0.05$ ).

When the six factors of (1) confidence in pursuing one's rights; (2) recognising the importance of social support; (3) confidence in being assertive; (4) recognising support from care recipient and family; (5) recognition from care recipient; and (6) awareness of resources from community, are used for measurement of observable changes in the aspects of psychological empowerment, a pattern of steady increase is found across five aspects, and a very slight decrease in one aspect.

Results of the paired sample *t*-tests show that the factor which has the most significant effect is 'confidence in pursuing one's rights' ( $t = -4.379, p < 0.05$ ), the second most significant is 'recognising support from care recipient and family' ( $t = -3.5, p < 0.05$ ), the third is 'confidence in being assertive' ( $t = -2.501, p < 0.05$ ), followed by 'recognition from care recipient' ( $t = -2.182, p < 0.05$ ) and 'awareness of resources from community' ( $t = -1.724, p < 0.05$ ).

The factor 'recognising the importance of social support' did not yield a significant result ( $t = 1.037, p > 0.05$ ). This is probably because of the fact that social support has already been recognised by the carers as an important source of empowerment at the beginning of the study; therefore the change in perception of this aspect would not be as significant as it would have been for the other five aspects, and self ratings for this aspect stayed at a steady level over time.

In study one, a scale score was developed by summing across and standardising the measures for each item on the SES, as a result, a standardised score of 186.33 is a score which sets out an average level on the SES. When this standardised score was used for evaluating the level of psychological empowerment, it is suggested that on the third month in the study, all ten carers were below the average level (186.33) when the SES was administered to measure the empowered outcome.

On the fifth month when the SES was administered again, seven carers reached scores above 186.33, the average standard. Significant improvement is shown particularly on the carers in Newcastle, where all four carers had increased in their sense of empowerment from a below- to an above-average level. Two carers in Leeds also reached scores above the average level on the fifth month. Although four other carers in London and Leeds remained on a below-average level, they all departed from the lower side, reaching closer to the higher end on the SES.

It is noted that some workers (co-facilitators) who participated in group activities were also family carers, and some other carers joined irregularly in group activities, so that the

sizes of the groups were actually around five to eight from time to time. In order to obtain the most consistent and reliable data, these workers were not overlapped as participants in the interventions, and only data from those family carers who were truly committed throughout the course of the interventions were used and reported in this study.

The results of the empowered outcome from the qualitative analysis further bring in a better understanding of what practical aspects the interventions have achieved to make the carers feel more empowered. In this study, carers among the three groups emphasised the knowledge learned in the understanding of dementia. This marked an important aspect for them to gain confidence in asserting their rights, and to gain a sense of control in the role of caring. One carer also became more motivated in further learning in dementia as a result of the knowledge gained.

The carer group in Leeds expressed the benefit of improved communication and relationship with their care recipients as a result of the skills learned in the training workshop conducted as part of the interventions. The improved communication and relationship with the care recipients, in turn, brought the carers an improved sense of well being. On the other hand, self-care training, such as a stress management workshop, also played a part in improving carers' sense of well being. On a multilevel construct of empowerment, it is suggested that the carers have gained a greater sense of mastery and personal control as a result of the knowledge gained in the research groups. The participatory action research was in itself a therapeutic process.

Participatory intervention is also a means to access social support, to practise team work, to develop skills and to achieve collective goals. The carers in Newcastle highlighted the sense of achievement and contribution as they accomplished the production of a carer's resource booklet for their community. In London, participatory intervention has built up a carer's critical awareness of his role as a carer and his understanding of dementia as a progressive degenerative disease.

Zimmerman suggested that empowering processes are a series of experiences in which individuals learn to see a closer correspondence between their goals and a sense of how to achieve them, gain greater access to and control over resources, and where people, organisations, and communities gain mastery over their lives (Cornell Empowerment Group, 1989; Mechanic, 1991; Zimmerman, 1990, 1995). The current study initially created an empowering environment that provided opportunities for carers to experience and to develop their skills, to explore a group identity and to participate in achieving meaningful tasks. The carers in Newcastle had taken a more proactive approach to

learn about new resources and to evaluate how they could achieve the resources. This has demonstrated that the carers had learnt to see a closer link between their goals (a residential care home for the Chinese) and a sense of how to achieve them. It might be too early for the carers to have built up the know-how of achieving such goal. In this study, the co-facilitator had helped the carers to feed back their opinions to the local authority. This partnership approach between the carers and the co-facilitator became empowering as their voices were being heard and their opinions being valued.

Psychological empowerment was manifest in different skills, interests, abilities and behaviours among the three groups in this study. In Leeds, the carers were more focused on building up their skills and social support, whereas in Newcastle, the carers were more concentrated in finding out resources in residential care homes and in pursuing better services for the community. In London, one carer became the mentor of the other who had just taken up his caring role.

In examining empowered outcome, it is reasonable to expect that interesting a positive correlation between the carers' demographic backgrounds (e.g. educational level) and the potential for change in their psychological empowerment would be observed. On a general view, the descriptive analysis could give some idea of the relation between the carers' demographic background and its potential improvement in the sense of empowerment. When the mean ages and the years of education of the three groups are compared, it is found that the group in Newcastle which has the highest education level and the youngest carers among the three groups, is also the group most empowered and, empowered to a higher level, by the intervention, whereas the carers in Leeds and London, older in age and lower in education, were empowered but to a lower extent. However, in achieving to empower the carers who were older and from a lower education background, these research studies had made a contribution in bringing knowledge and skills to the carers who were most deprived to the learning resource which could have been tailored to their cultural needs and level. It is important to consider the concept that outcomes of a participatory action research could not be evaluated in terms of the magnitude of the change achieved on the action undertaken, because participatory action research often makes its input as a process of ongoing learning and awakening (Kock & Kralik, 2006).

In sum, results of the current studies show that participatory interventions have led to an increased psychological empowerment among the Chinese family carers for people with dementia. The outcome of the participatory interventions is positive in that the carers

show a consistent improvement in feeling more empowered. Family carers were more confident because of the knowledge built up in the understanding of dementia, while some had improved in their communication and relationship with their care recipients, others experienced a better sense of well being, feeling less stressed, and some of them were motivated to learn more about dementia. Carers were also more confident in being assertive and became more aware of the resources available in the community. Carers in the participatory interventions were empowered at different levels and all moved towards a positive level.

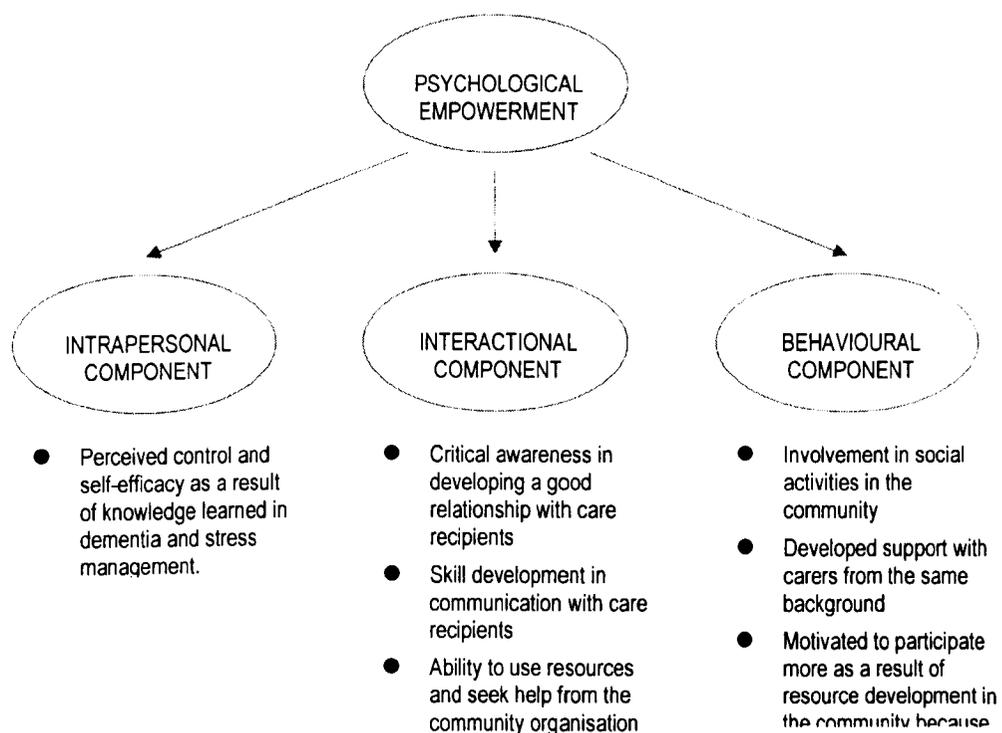
## **6.2. Empowering processes**

As mentioned earlier, populations may be differentiated in age, socio-economic status, sex and level of education, and the distinguishing characteristics one chooses may influence the meaning of psychological empowerment for one's research (Zimmerman, 1995). In this study, the meaning of psychological empowerment also differed from one group to another, depending on the characteristics of the group in discussion. It could be unrealistic to expect a group of carers from a lower educational background to demonstrate the same skills or motivation for increasing their psychological empowerment as the carers from a higher educational background. Carers from a lower educational background may take more time to develop their confidence, support, and communication strategies to be helpful carers, whereas carers from a higher educational background may need to develop the motivation for acquiring new skills and knowledge, and advocating for better resources for their community.

Zimmerman stated three underlying assumptions in empowering processes. The first one is to identify the characteristics of the population to be empowered. The second assumption is that empowerment takes different forms in different contexts, therefore it is important to understand the culture of the organisation (or structure of the setting) that provides the environment for the participants to undergo the empowering processes. The third assumption suggests that psychological empowerment may vary across different life domains, for example, work, family, social network. It is important to identify which life domain the intervention is targeted. In these studies, it is also evident that features of the empowering processes were subject to the characteristics as defined from the three underlying assumptions.

In Leeds, the distinguishing characteristic of the group is a group of existing female carers who had long been isolated and deprived of resources from their families and from

the community. In spite of the fact of being carers for people with dementia, they had very high needs for support and resources to deal with their everyday life. However, their awareness of their need for support was low because of their limited language capacity in English and lack of confidence in pursuing their needs, admitting to a sense of helplessness developed from the male-dominated society which rendered them more vulnerable. These are the intrapersonal variables which are expected to correlate negatively with psychological empowerment (Zimmerman & Rappaport, 1988). When the four carers in Leeds from a similar background came together, it was not difficult to define a common goal and a common life domain of which empowerment could be built upon. The nomological network for psychological empowerment, when applied to this group, could be presented in Figure B.9.



**Figure B.9.** Leeds carers group – Adapted from Nomological network for psychological empowerment (Zimmerman, 1995)

It is observed that when carers were able to discuss and share freely their experience in caring, their frustration was revealed and their needs were also defined. They were frustrated and had queries over difficulties in caring for their husbands with dementia,

this aspect was most central in their life domain. They needed to gain control in their caring role. Therefore the objectives of the carers were unanimous – building up carer skills. This was also a process of conscious awareness raising which enabled the carers to share a sense of identity when they became aware of their problem as a group.

It is suggested that building up carer skills was the most empowering process for this group, whereas producing the booklets together might not be as effective in building up their sense of empowerment. This outcome was clear in the semi-structured interviews, when they revealed their appreciation of the training workshops more than the team work of producing their carer's booklet.

Carers had all teamed up in working on the booklet, regardless of the very small tasks they took; they were committed to offer whatever they could to do the job, although they were also conscious of the fact that much of the work would have to be accomplished by the researcher and the co-facilitator. They did not feel, however, that they were contributing much in the team work as compared to the benefits of the training workshops. This is consistent with the idea that psychological empowerment is the indication of *perceived* control, competence and efficacy (Zimmerman, 1995), and these form the intrapersonal component because they are a basic element that provides people with the initiative to engage in behaviours to influence desired outcomes (Strecher, DeVellis, Becker & Rosenstock, 1986; Zimmerman, 1995). In the participatory intervention in Leeds, it was also the case that the carers did not believe that they had the competence to produce the booklet, but they could be motivated to experience and to learn how to accomplish this goal. The process of producing the booklet however, had encouraged the carers to take one big step out forward for an adventure which might be empowering within a safe and supportive environment. In this instance, working with the carers and to be 'with' them as a co-worker was an important factor that could ease out their feeling of being incapable. The carers were assured of their commitment and they felt relieved to enjoy the process of participation.

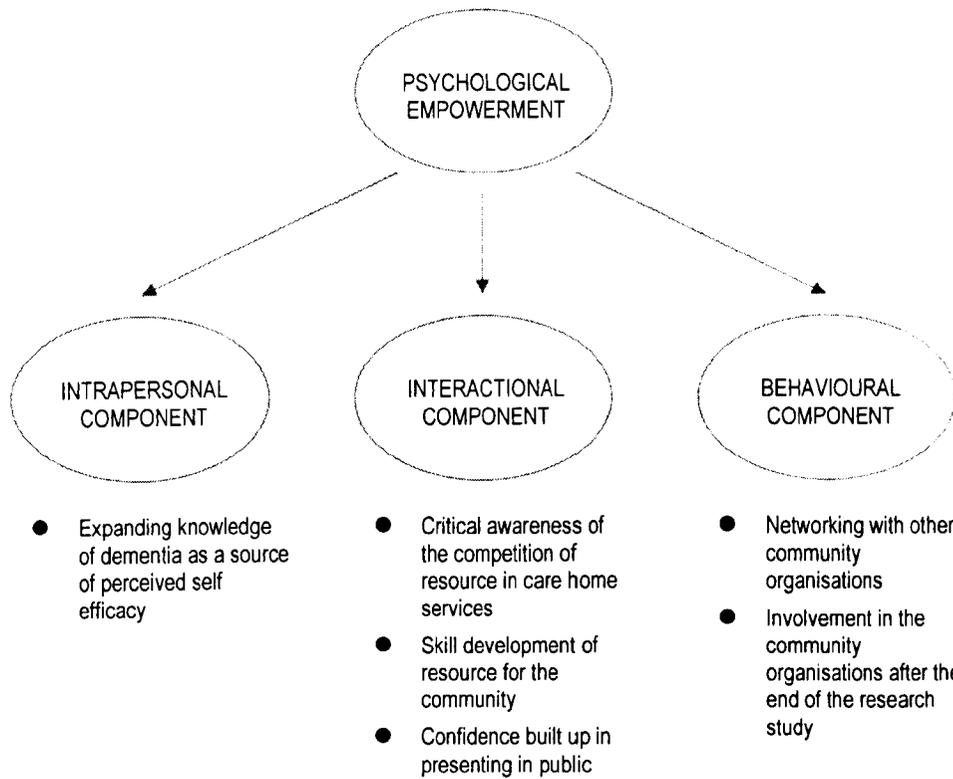
Learning from this group, it is suggested that for empowering processes to be effective in a participatory intervention, assembling individuals of a similar background (all existing carers), educational level (lower educational background), problem (frustration in caring), and needs (skills development in caring) at the time of interventions is important in that it renders a more coherent empowered outcome to the group collectively. In Leeds, no individual felt they were being left out or had to compensate for other members' inadequacy, due to the difference in motivation, educational level or caring status.

When the characteristics of the carers in Newcastle were examined closely, it is shown that carers in this group were from a similar background in terms of their roles as carers who all experienced the difficulty of limited resources for their care recipients and for themselves from the statutory services. On the other hand, this group was also diverse in terms of their cultural background, and more so, in their caring status, which later affected individuals' motivation in achieving the common goal of the group at the time of the participatory intervention.

Two carers in Newcastle were ex-carers whereas the other two were existing carers. During the first two meetings, when the researchers were trying to define the carers' needs, the ex-carers, who were also the more outspoken participants, overshadowed the other two carers in the discussions. It is apparent that while communication and carer skills are no longer so much of a concern for the ex-carers, issues they raised were naturally focused around the insufficient services they had experienced in the care homes where their care recipients were admitted when they were no longer able to be cared for at home. The two ex-carers, and one existing carer whose care recipient was already placed in a care home, came up with a goal of developing a carer's resource booklet for the community, together with the mission to find out about good care homes in other cities.

It was understandable that the existing carer, who had needs for practical support, was swayed in the direction set forth by the majority of the group. This carer was not without commitment in his involvement in the participatory activities, because his involvement in exploring new care homes, even though not as immediate, was still considered to be beneficial to his care recipient in future. The empowering process was therefore not in favour for this carer in comparison with the other three carers in this group.

In general, the carers in Newcastle were more inclined to develop their strength on the interactional aspect when the nomological network is applied to explain the psychological empowerment of this group collectively. The nomological network of this group is presented in Figure B.10.



**Figure B.10.** Newcastle carers group – Adapted from nomological network for psychological empowerment (Zimmerman, 1995)

The carers in Newcastle were more proactive in exploring resources that could be helpful to themselves and to the community. Their action in visiting the newly developed care home projects and culturally sensitive homes for Chinese residents indicated that they were beginning to learn more about the service environment and to understand what sort of resources are needed in order to achieve their goal. Their new experience enhanced their knowledge of what would be a good model for a care home and their wish for having similar standard of care home for the Chinese community in their city was subsequently included in the resource booklet they produced. The participatory process was also a conscious raising process as they were brought to a greater awareness of what they could possibly do as a carer group. The process helped them to re-define their capacity and to re-define themselves as a carer who could also do something for their own community.

‘Interactional’ component of psychological empowerment refers to the understanding people have about their community and related socio-political issues (Zimmerman, 1995).

Individuals may need to develop a critical awareness of their environment, understanding the resources needed to achieve a desired goal, knowledge of how to acquire those resources, and skills for managing resources once they are obtained (Kieffer, 1984; Freire, 1973). Zimmerman refers to this ability to mobilise resources as an essential aspect of the interactional component of psychological empowerment because it suggests environmental mastery.

In the empowering processes, it is suggested that carers in Newcastle took the initiative in developing a critical awareness of the resources available in the community, and trying to learn how better resources could be achieved in the long run. This first step of action was beginning to build up the ability to mobilise resources in order to gain mastery over future well-being in the community.

The participatory intervention had created an environment where this group of carers came to work together to solve problems. The team work of producing a carer's resource booklet, the vision of advocating better service for the community, their vision documented in the booklets that were to be published, and their experience in representing carers' voices in the community at a national conference were all empowering outcomes that have led to a sense of achievement and confidence after the participatory interventions. The research process guided the carers to explore their experiences that connect their past and future together and thus gave them a sense of continuity. Their role as a carer (especially those ex-carers) did not just stop when their carer recipient had passed away. In search of new experience in this research, they gained a sense of contribution which was validating their role as a carer.

It must be noted that not all carers in Newcastle would feel that they became more assertive, or more confident, or were empowered in the same way at the same level, but for those carers who were empowered most were those who were involved and contributed most in the project. Their working relationships with the researcher and the co-facilitator were more mutually supportive.

For the carer who was not engaged as much as the others, the researcher and the co-facilitator might not have been observant enough to address his motivation and what challenges he was facing. The empowering processes which oriented almost entirely in one direction might not have allowed him to build up the area where he needed to be empowered. This was reflected in the semi-structured interview, where his focus was around the knowledge of dementia gained from the group, but that his concern about the

support for people with dementia and their carers had not been addressed. His concern had brought up the question that, while the community organisation (the health club) was providing an interpreting and advice service for the Chinese community, these services were not targeted for people with dementia; no support service has as yet been developed for people with dementia and their carers.

It would have been more effective, had the challenges faced by each individual been more carefully defined, in order that the actions that followed could be fitted into a more coherent purpose of participation as a group, that is, getting the participants on the same page. On the other hand, consideration has to be taken carefully on the crucial variables which could affect the empowering processes. In this participatory intervention, one of the crucial variables was their caring status, which influenced their interests and motivation when they joined the group.

For a participatory intervention which is time limited, handling different interests and motivation at the same time would mean the empowered outcome would also be divergent, or the interest and motivation of some individuals would have to submit to the interest of the majority voice. In future studies, it is suggested that depending on the time scale of the project, careful consideration has to be taken on the composition of the group for participatory interventions which aim for empowerment.

A participatory process promotes sense of ownership in what Kelly (1988) called a participative ownership process. Kelly described several steps to help community members to take up an active role in projects affecting their lives, including involvement in defining the problem, developing a relevant programme, implementing the programme, and evaluating its process and outcomes.

In the facilitation of these participatory interventions, the researcher in the current studies tried to define the areas of empowerment through discussion with the carers. The areas of empowerment defined might or might not have been in-depth enough to cover the carers' various needs, but then again, due to time limitation, the researcher and the co-facilitator made a choice on the surface of the needs based on the carers' feedback and observation, took it from there, and led on to develop a relevant programme for the groups. In this way, the carers and the researcher had not yet reached to a level where they are equal partners in working together.

Although it might be difficult to expect isolated and powerless carers, such as those in Leeds, to become coequals in a short period of time, and the approach of empowerment should take place wherever it fits the levels of the participants; the co-facilitators and the researcher worked together in partnership with the carers by giving them more support particularly at the beginning of the studies. They gradually stayed back when the carers were capable to take on more responsibilities in the groups; interventions in this study did achieve empowered outcomes to a great extent.

Zimmerman recommended that a goal of participatory action research is to help communities develop the knowledge they need to improve their quality of life and influence relevant policy, and in some instances, a consciousness-raising experience may need to take place before participants can begin to be empowered. Reflecting on the current studies, it is particularly true that the whole participatory process, e.g. the Leeds carer group, could have been a consciousness-raising experience rather than a complete empowering process.

Before empowerment comes into realisation, carers need to develop an awareness of what has been affecting their health, their well-being and their life in order to be able to make sense of their participation and to develop the knowledge they need to influence relevant policy. It was just the beginning of the journey of empowerment at the end of the intervention project in Leeds, but it was encouraging to hear one of the carers who, at the beginning felt very helpless and found no sympathy from her neighbourhood in support of her burden in caring, say:

‘We should let the authority know that a care home for our community is important, for at this stage when we are still not too old, we should say it. We should hope for the future that when we need to go to a care home, it will be a home suitable for us.’

In a similar way, regarding the carers in Newcastle who were going a step further in an attempt to improve the quality of life, not just for themselves but also for the community, more time is needed for them to gain skills in leadership, and hence for developing a suitable programme, implementing it and to evaluating its process and outcomes.

It might have been difficult to engage the carers in London because, apart from the small number of participants (2 carers), they were older and one of them was very vulnerable when he first joined the research study. Most difficult of all, the care recipient (the

spouse) of one of the carers, due to health and safety reasons, also attended the group from the third meetings until the end.

Even though the size of the group was small, the characteristics of the two participants were considered to be on two opposite poles in terms of their sense of empowerment. While the older carer was abundantly empowered, the other felt powerless and isolated. In terms of the caring status, the older participant was an ex-carer, whereas the younger one was an existing carer. They were both aged over seventy, from a similar background and spoke Cantonese. The difference in caring and empowerment status was a barrier to defining a common concern between the two, and with the presence of the care recipient, it was difficult to define the problem faced by the younger carer, an area where empowerment could possibly be worked on.

The younger carer, with or without the presence of his spouse, was quiet during the research meetings especially at the beginning of the project. Discussion in the first two meetings, which aimed at defining the carers' problems, their interests and motivations, was naturally dominated by the contributions of the older carer, who had a great deal of experience in caring for people with dementia.

As an active member in the community, he had published three poetry books, with one of the books published in remembrance of his deceased wife. He was a poet, a teacher of calligraphy, a volunteer in charity fundraising events and was honoured with a senior citizen award. It is not surprising that the ex-carer's motivation in joining the research group was to offer help to the community rather than looking at the objective of being empowered as a family carer. His idea of producing a photo album of carers for dementia as a team work would be more a process of self-actualisation rather than a process of empowerment.

In this instance, one could realise that the focus of empowerment should be on the younger carer, rather than on the older carer, who already had a good sense of well-being, was highly empowered and was well linked to and supported by the community. The idea of producing a photo album was not the younger carer's aspiration, nor did he believe in developing skills through that team work in order to be empowered. At that stage, he might need to raise his consciousness of his role, and to develop the confidence, skills and behavioural strategies in being a carer.

Producing the photo album in this intervention did not in itself achieve the aim of empowerment through the process of skill development and team work, rather, it was a means to facilitate an environment where the younger carer could come into terms with his wife's illness, to be conscious of his role as a carer, and to reconcile the misunderstanding with his wife during the session of story telling. Therefore, a little indirect as it seemed, the empowering process was intertwined within a goal which might not appear to be empowering to the younger carer in the first place. The process of story telling was therapeutic because it reminded the carer of his and his wife's self value. The story of the ex-carer was also affirming the value of caring for a love one.

As mentioned earlier, empowering processes may occur at all levels of analysis. Empowering individuals might include mentors who help adolescents learn about adult roles (Zimmerman, 1995). In the intervention in London, the mentoring function naturally came into place and subsequently empowerment took place in the process when the older carer and the co-facilitator helped the younger carer to learn about carer roles.

It is worth mentioning that the process of producing the photo album could be a useful approach in psychosocial interventions for people with dementia and their carers, as it includes reminiscence, story telling and picture viewing, similar to the concept of the Memory Group used for people at an early stage of dementia and their carers. Whereby the Memory Group aims to combine the benefits of peer support by gaining insight into each other's experiences, thoughts and feelings (Carek, 2004), support is seen to be the key product of this interaction and the driving force for achieving the group's aims of increasing self esteem (Carek, 2004).

Apparently the care recipient and the carer both benefited from gaining insight and experience from the story narrated by the older carer. The strength of remembering the past was also empowering for the care recipient because the experience of life in her prime was still in her memory. The memory reminded her and her husband of her success and contribution to the family and to the community. The sign of recognition of his wife was underlined as the carer joined in contributing the old photos of him and his wife that he valued so much for compilation of the photo album. Empowered outcomes were evident in the younger carer's expression of knowledge gained in dementia, his acceptance of his wife's illness, and a more relaxed attitude towards to his wife challenging behaviour due to the illness.

The empowering process for the carer in London, similar to the other two groups, was just at the beginning phase. More time and effort will have to be continued in order to promote a greater psychological empowerment through a longer on-going learning and awakening process.

### **6.3. Empowering organisation**

While the focus of this study was not directly associated with the psychological empowerment of the three voluntary service organisations, it would be helpful to understand how the involvement of the three collaborative organisations had contributed to the advancement of empowered outcomes revealed in the individual carers. When empowerment is related to an organisational level, two conditions need to be distinguished: (1) an empowering organisation and (2) an empowered organisation. The distinction is explained by Zimmerman (2000, p.51):

Organisations that provide opportunities for people to gain control over their lives are empowering organisations. Organisations that successfully develop, influence policy decisions, or offer effective alternatives for service provision are empowered organisation. Although a distinction between empowering and empowered organisations is made, organisations may have both characteristics.

Furthermore, Maton and Salem (1995) described four vital characteristics of an empowering organisation: (1) a culture of growth and community building; (2) opportunities for members to take on meaningful and multiple roles; (3) a peer-based support system that helps members develop a social identity; and (4) shared leadership with commitment to both members and the organisation.

In contrast, empowered organisations are those that successfully thrive among competitors, meet their goals, and develop in ways that enhance their effectiveness. They may extend their influence to wider geographical areas and more diverse audiences, and are also expected to mobilise resources such as money, facilities, and members effectively (Ferree & Miller, 1985; Jenkins, 1983; McCarthy & Zald, 1978; Zimmerman, 2000).

In the current studies, the community organisation in Leeds, which has the longest history of service among the other two organisations, has established a good support

system that helps their members integrate into the mainstream society. They provide training opportunities for members to building up life skills to be able to live independently. In a city where the Chinese are a small minority group, their role in building up and supporting the community is essential. If this organisation is to be reviewed in accordance to Maton and Salem's four characteristics, it is suggested that they have some but not all of the characteristics that an empowering organisation is expected to manifest. Although looking at their capacities, they have as yet reached the phase that they could be considered an empowered organisation.

Having thorough knowledge of the community and a long-standing relationship with the members, they recruited the appropriate participants and had secured the trust from the carers who agreed to commit to the research study. The support and commitment that this organisation has offered in co-working and taking initiatives to achieve the aim of empowerment is worthy of mention. Throughout the study, the workers in the organisation met with the carers, listened and helped to solve their problems, within and outside of the research meetings. This initiative had strengthened the carers' level of commitment in the research, and also developed a support system for the carers.

The participatory interventions in the current studies had further achieved an empowered outcome at an organisational level, in that the collaborative organisation in Leeds had developed competence in developing a new project, a carer project through supporting this participatory intervention. As a result, the workers developed the skills of how to assess resources when later on they worked on a fundraising project for a new service for the carers.

The collaborative organisation in Newcastle was a relatively young organisation, which has been around for nine years. Similar to the organisation in Leeds, the aim of its service and the way it was set up had been progressing towards the characteristics of an empowering organisation as set forth by Maton and Salem.

The carers in Newcastle in the current studies, however, were not as closely linked to the empowering organisation as they were linked to the true empowering agent, SF, a community leader, a retired development worker at the statutory service, and a link person in the community for over 20 years. In her sixteen years of service at the statutory department, SF had done a great deal in developing health services for the community, and because of the advantage of being able to mobilise statutory resources for the benefit

of the community, SF had built up a strong rapport with many people and with colleagues in the voluntary service organisations.

It is not surprising that, as an individual, SF was performing a similar role as the organisation in Leeds. What made it impossible for the organisation in Newcastle to establish a role as an empowering agent to the carer group was that before the research study took place, the carers had no history of constant involvement in the organisation other than occasionally attending its festivals and celebration events jointly organised with the other community groups.

When examining the impact of an individual as an empowering agent, SF was considered to be significant because of her connection with the local health authority, her knowledge of the socio-political control and assessing resources, her knowledge of the operation within the statutory services and her leadership skills.

In the participatory intervention, her role as an empowering agent had helped in coaching not only the carers but also the workers by transferring her skills to the organisation. In other words, empowerment took place at an organisational level through the effort this community leader as well as the researcher. SF also utilised her connection with the health authority by feeding back the carers' expectations on future health services for the community. Her involvement had enhanced the empowered outcomes, also, strengthened the carers' confidence with a more rewarding participation by seeing that their views were eventually heard by the authority.

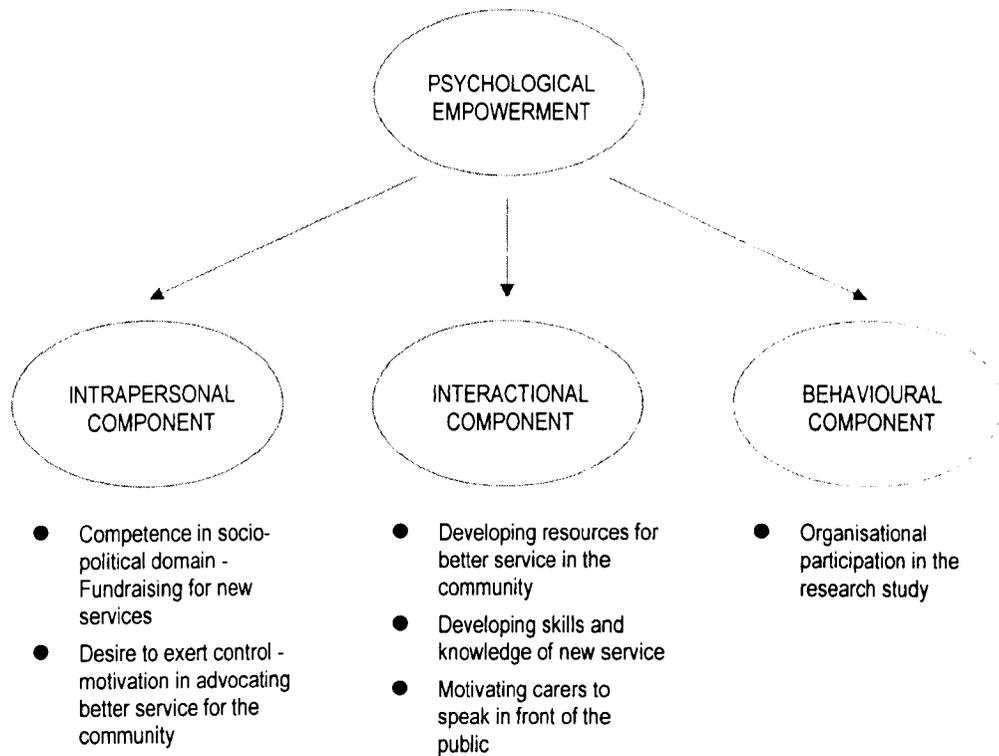
In comparison with the other two organisations, empowerment at an organisational level was not as significantly shown in the collaborative organisation in London. Where other community organisations in the neighbouring areas opened their centres to their local Chinese community, this organisation only opened by appointment to Chinese people with mental health issues. This organisation, due to its aim of delivering mental health services, was perceived as a clinical service provider more than a community organisation. At the time when the research study took place, it was difficult to recruit participants because carers from their previous project had dissipated due to the funding having come to an end a year ago. When carers were contacted for the purpose of this study, many of them could not commit to participating because they were either busy at work or were engaged in a very tight schedule caring for family members.

The carers who were recruited later on were not directly connected with the organisation but were familiar with a volunteer who had been befriending the older people in the community. In the absence of the characteristics of an empowering organisation, or alternatively, an influential individual as an empowering agent, the researcher mainly worked with support from the volunteer (the co-facilitator) and did not have direct association with the team of workers in the organisation. In this situation, the organisation was mainly a venue which the researcher used for meetings and activities.

The participatory intervention, however, had indirectly brought about empowerment at an organisational level when the idea of service development was recommended to the organisation. This included the idea of developing new services such as psychosocial intervention as it was used for the care recipient during the course of the research study. The organisation in London then later applied for funding to develop this new service as suggested by the researcher.

As several researchers have identified, settings such as voluntary organisations are vital to the development of psychological empowerment (Zimmerman & Rappaport, 1988; Prestby, Wandersman, Florin, Rich, & Chavis, 1990). Organisations in such settings are usually involved in community services helping the disadvantaged and vulnerable groups who are deprived in society. However, due to the non-profit making nature of their operations, these settings are in constant struggle because the lack of resources or the skills in capacity building.

In the current studies, the empowering processes for individuals might also have been helpful in empowering the organisations to some extent. Applying the nomological network of psychological empowerment, some changes could be seen in the organisations with regards to the three components of the network. Figure B.11. presents some observable empowered outcomes from the three organisations collectively.



**Figure B.11.** The collaborative organisations – Adapted from nomological network for psychological empowerment (Zimmerman, 1995)

It can be concluded that the organisations had also been empowered to some extent, outcomes of which were obtained from the self-reported accounts of the co-facilitators who represented the collaborative organisations and the observations of the researcher.

Maton and Salem (1995) suggest that empowering organisations should have a belief system that inspires growth and focuses on strengths; they provide opportunities for member participation and contribution; they are the source of social support and they have the organisational power to effect community change. It is shown that in the current studies, the research organisations were committed to the value of their users' participation and this had also created some positive changes in the carers as well as in the organisations themselves.

#### 6.4. Challenges in participation and lessons learned

This participatory intervention study was an exercise to put the psychological empowerment theory developed by Zimmerman (1990, 1995) into practice. The participation of the Chinese family carers and the involvement of the community organisations had allowed a great deal of learning about the participatory and empowering approach to psychological intervention. It has also led to a numbers of challenges related to participation and psychological interventions with this seldom heard and disadvantaged group.

##### *Dual roles of the researcher – co-partner & professional*

In their study with the very poor and marginalised communities in Brazil, Guareschi & Jovchelovitch (2004) pointed out that the most difficult aspect of participation is perhaps the development of a common language between the various actors and stakeholders in the participatory process.

In the current studies, the absence of common language might not be due to the difference in perspectives on the issue to be discussed but the lack of trust from the participants. Developing a common language between the researcher and the carers was a barrier, especially at the beginning of the participatory process when the latter had doubts about the purpose of the study and the researcher's proficiency in dementia disease. To overcome this barrier, the presence of the co-facilitators helped to ease out a lot of potential mistrust and tensions between the researcher and the carers. Although in a participatory action research, a researcher is to enter as a co-equal partner, one must also possess the professional skills and knowledge of the area of discussion so as to ensure the participants that he/she has the expertise and resource to help on the problems they come across. The researcher in these studies conveyed knowledge of dementia and carer's burden to establish the carers' confidence and trust in joining a project, which they were assured, would be helpful to their problems.

##### *Support from the collaborative organisations*

Obstacles to participation provide further evidence of the complexity of participatory processes, especially in countries where there is a strong tradition of authoritarian politics (Guareschi & Jovchelovitch, 2004). Apart from the subservient culture that might have been influencing the Chinese people to be less articulate in public, another obstacle to

motivating participants to talk about their problems was the fact that discussing personal and family problems in a social setting is not a custom in the Chinese tradition.

One can envisage that it would be even more unlikely that the carers would talk about something they might believe to be shameful within the family in front of people whom they did not know well. This, however, did not discourage those carers when they were with the organisation or an agent whom they trusted; for the carers who were new to the researcher, time was necessary to cultivate a trusting relationship before they could open up for discussion.

To overcome this barrier, participants should be encouraged to see the importance of participation and how this capacity for producing pressure from the users' perspective could improve their health and lives, and of that of their care recipients. When they became vocal, each began to emerge as more of an actor of their own problem – for example, the carers in Newcastle was later empowered to a point that she was willing to present the carer resource booklet they had jointly produced at a national conference.

Furthermore, it takes time for the participants to create a sense of identity with the project, and in accommodating this climate; empowering organisations should spend time encouraging them to stay on and to take on higher level functions (Nelson et al., 2004).

#### *Consciousness raising experience*

As Zimmerman suggested, in some instances, a consciousness-raising experience may need to take place before participants can begin to be empowered. Stage one in the process of this research could have been a period when the carers started to think about their caring experience and how it had affected their lives. One month for this consciousness-raising experience period might have been too short for some carers, for example, the carer in London who eventually came to terms with his wife's dementia illness.

A open-ended structure for developing this consciousness-raising experience and the assessment of on what level participants' consciousnesses are raised, and hence are more ready for empowerment to take place, can be useful for this kind of participatory intervention. Guareschi & Jovchelovitch (2004) maintained that in participatory processes, individuals who retain higher levels of consciousness are capable of reflecting about the set of factors that frame their everyday life and devise appropriate practices to

intervene in these factors. Further research studies to explore the development and understanding of this area would be helpful.

#### *Getting carers onto the same page*

Kelly and van Vlaenderen (1996) have pointed to the importance of taking into account the imbalances and power asymmetries that shape communicative processes in participation. These asymmetries have become visible in the interaction between carers from different status, hence bringing with them to the group different motivations for participation. In this instance, consolidation of the carers' values was difficult and the result of such imbalance was the minority's submission to the stronger ones who finally shaped the communicative processes. Learning from this lesson, the facilitator should recognise and validate the values and expectations of each individual, encourage the group to set out priorities and plans, and to consolidate strengths of individuals to achieve different priorities.

The constraint of not being able to accommodate carers' different priorities may be due to the timeframe of the short five-month study, and an initial set strategy which had potentially shaped the participation process – the three stages of participation as discussed earlier. The time constraint and the pre-set strategy might have been the withholding factors which limited the full potential for empowerment to take place in the processes; for there is not one particular strategy that is important, but rather a cumulative process of creating an empowering climate that is intentionally designed to maximise participation (Guareschi & Jovchelovitch, 2004). Although the level of psychological outcomes across the three carer groups was significant, more effort could be taken in nurturing each individual's potential for empowerment by looking more deeply into each of their experience and support needs.

In any case, psychological empowerment should be a continuous process in which participants move through a series of stages in their involvement with a project, they are often motivated to volunteer in order to gain personal benefits such as the opportunity to meet others, gain or learn new skills, then they begin to identify with the project, and eventually they begin to take on more roles (Nelson et al., 2004).

In the current studies, participants were not immediately able to take on roles; neither could many of the participants take on more roles at three months or at five months before the end of the project. Reflecting on this, it appears that, for individuals to be

empowered to a greater extent, the timeframe and strategy of the project should be dependent on the individuals, rather than on the empowering organisation. It would take longer for the participants to define what they would really want to set out by way of strategy and timeframe for a project, however, whenever they were able to do it, it would be the goal which they would truly like to achieve.

The Leeds carer group is a good example of showing the limitations of time constraint and goal setting by the empowering agent. While decision had been made to produce a resource booklet, the carers would have learned more had their wishes of building up carers' skills been closely followed through. In such situation, the researcher and the organisation were overshadowed by the goal of achieving a piece of work which was more tangible, rather than on the training workshops, which were actually more useful for the carers. Although in effect, the carer's booklet was empowerment in a sense that it has become the representation of the outcome of the project that brought about positive changes (e.g. evidence of needs for future funding resource for the community organisation) and this success was shared by the carer group and the collaborative organisation.

#### *Six factors of empowerment specific to Chinese carers in the UK*

The aim of the current studies is to examine the effect of psychological empowerment using a participatory approach; hence, factors enhancing the empowered outcomes in the processes are crucial. These lessons learned can be helpful for organisations which are interested in empowering individuals using the participatory approach.

The six factors developed from the Sense of Empowerment Scale in Study One indicated that recognising the importance of support from society, support from the care recipient and the family, and realising the resources available in the community are the three major factors of psychological empowerment.

Results of the qualitative analysis in Study Two and Three have further explained the impact of these three factors. When the carers were brought together as a group, they started to share their burdens and experiences in caring. They started to realise that their feelings were validated when they found empathy from other carers and voluntary workers on burdens that had been weighing them down on a daily basis. They started to build up rapport among themselves and they enjoyed the friendship in the group.

Recognition of the importance of support took place when carers had come across the benefit of being supported in a social setting; a benefit of social support was an increased sense of well-being as a result of the interaction and encouragement from the group and the workers in the collaborative organisations. While many carers may not be confident enough in taking the initiative to set up a carer group for the benefit of supporting each other, community organisations could be an appropriate third party to create an environment for the carers; and the environment for building up social support should be safe for individuals to share and to express their concerns in confidence with one another.

Support from the care recipient and from the family is another important factor of enhancing the carers' psychological empowerment. In the current studies, bringing the carers through recognising the support from the care recipient and from the family was by means of education and evidence of involvement in the research project. Carer skill training workshops were useful in helping the carers to deal with and to communicate with their care recipients in a better way. As a result, carers experienced a better relationship with the persons they cared for and better atmosphere in the family. They then came to realise the importance of a supporting relationship with the care recipients and the family.

Involvement in the research project was another source of gaining recognition from the family. In Leeds, a carer was pleased to show her family that her story, which was part of her involvement in the project, was included in a booklet produced by the carer group. Through the production of the booklet, this carer experienced the recognition from the family and she was also more assured of her role as a carer. In addition, participation in implementing a task has built up a sense of achievement and contribution. With regard to this outcome, it is suggested that empowerment could be enhanced when carers are to take up tasks that are within their potentials and skills to achieve. The group in Newcastle is a good example of carers with certain abilities and knowledge to take on achievable goals. The outcome of matching the carers' abilities with the tasks developed a greater sense of achievement, as was expressed by the carers in Newcastle.

These are a few ways to encouraging family carers to recognise the support from their care recipients and from the family. It would be helpful to explore other ways of enhancing family carers' recognition in this particular aspect in future research studies.

It would also be helpful to explore ways of increasing the carers' awareness of resources available in the community. The awareness of available resources in the community was

raised when the carers were engaged in producing their carer's booklets, and in the process they started to search for information on health services and carers' needs and experiences. Both the process and outcomes were positive. Either taking a more active role or just contributing according to their own capacities in compiling the booklets, all carers who had participated in the work saw the resources they produced as valuable. While written materials are more tangible resources, community organisations are another source of support from which the family carers could gain resources. In the current studies, awareness of resources from the community organisations could be traced back to the awareness of the importance of social support from peers as well as from the workers.

Building up family carers' knowledge about dementia is seen as the most important factor of increasing their psychological empowerment. All the carers expressed the value of knowledge gained during the course of their participation in the current research study. The carers learned new skills and knowledge through training workshops delivered by the researcher, discussions in group meetings with peers, discussions with the co-facilitators and the workers in the collaborative organisations out of research meetings, and the talk from Social Security on carers' allowance arranged by the co-facilitator, and site visits to residential care homes arranged by the carers.

The effort of building up the family carers' knowledge base in dementia had brought about different outcomes in different groups. A carer in Newcastle, who was already confident before joining the research, became more confident in pursuing her rights in health services as she became more knowledgeable of the illness, the health service system and the resources available in the community. She was also motivated for further learning in the area of dementia-related illnesses. The knowledge gained in approaches to care had improved the sense of well-being of the carers in Leeds. Carer skills training and the stress management workshop had contributed to better self-care and better relationships with the care recipients, hence a better sense of well-being of the carers.

Building up knowledge of care approaches can appear in different form. It is suggested that for knowledge to be built up effectively, ways of delivery should be based on the carers' learning styles, level of education and motivation. Sometimes, creativity in making use of the immediate resources available in the research groups could be a way to resolve the difficulties in engaging participants. An example is the difficulty in engaging the older carers in training workshops, be it in a taught style or a discussion workshop, mainly because they had difficulty in keeping concentration on a tutor, and were also

keeping quiet during group discussion. In reviewing this situation, the researcher tried to build up learning through role modelling and mentoring, with the older carer sharing experiences in caring. The outcome was seen as positive in that the younger carer had gained a lot more through an informal yet more practical way of learning.

#### *Participatory intervention as a therapeutic process*

The process of a participatory intervention was in itself a therapeutic process, while storytelling is as one of the methods commonly used in participatory action research (Koch & Kralik, 2006). Producing the photo album through story telling created an empowering environment where the carers could regain confidence through reminiscence. 'Valuing one's own past' emerged as an outcome of empowerment in this carer group. Engaging family carers from different age groups, different education levels and different life experiences in a participatory intervention may not be straightforward, however, it is suggested that engaging older carers, although longer time is needed to build up the support, also longer time to explore their consciousness of the issues, it could be equally empowering to use a storytelling approach because the process helps them to review themselves, their care recipient and the world around them in a more positive way. People's stories and life experiences are always valuable and inspiring; when the older carers looked back for appreciation of their own lives again it would become empowering and reassuring.

#### *Focus on strengths*

In overcoming the barriers to participation, it is suggested that the carers' needs and motivations should be explored in a much deeper sense. During participation, carers' inadequacy should not be a focus, rather, their strengths, interests and motivation. Researchers should work according to their levels and use their language in communication, encourage participation and share responsibility. To effectively empower the carers, establishing support outside the research project is essential. It is particularly true that whereby the research study has a limited project span, relationships built up with peers and the community organisations are essential in giving on-going support when the research comes to an end.

#### *The Chinese Sense of Empowerment Scale*

Another important lesson learned from this study is the development of a Sense of Empowerment Scale which was used to assess the change in the sense of empowerment

of the carers in the process of the participatory interventions. The formulation of this measurement was based on opinions surveyed from a specific population which was also the subject of discussion, the Chinese carers for family members with dementia in Britain. As it is believed that psychological empowerment manifests itself in different perceptions which are influenced by the quality of health services, in this case, the environment of service equality for ethnic minority population such as the Chinese community, development of a measurement scale should be based on their specific experiences, behaviours, concept of caring duties and perspectives on relationship with care recipients. The development of this tool is an effort of contributing to the context- and population-specific measures of psychological empowerment.

As Zimmerman suggested, a tool as such may help further develop empowerment theory, study how it changes over time, learn more about how settings may be empowering or disempowering, and evaluate interventions designed to enhance individuals' control over their lives. Zimmerman's nomological network for psychological empowerment which consists of the three components, the intrapersonal component, the interactional component, and the behavioural component, would be a useful underlying principle for the improvement of the Sense of Empowerment Scale for the Chinese carers. Further studies in improving the structure of the scale will be useful.

The SES has contributed in adding to the knowledge of measuring psychological empowerment which needs to be developed for each specific population with which one is working (Israel et al., 1994; Zimmerman, 2000). The SES focused on the Chinese family carers has explored the factors of psychological empowerment relevant to this ethnic minority population in Britain. The development of the SES brought in a new tool for community psychology researchers who are interested in investigating empowerment in this ethnic group, and also other ethnic communities who are facing similar difficulties in the process of caring. Issues such as language barrier, lower socio-economic status, lack of awareness of health resources and lack of confidence in gaining access to the right service are reflected in the scale in order to measure the various aspects of empowerment relevant to these ethnic communities in Britain and in other countries where similar issues are observed. Once the construct validity of the SES is established at a later stage, it will be a useful tool for examining the relationship between psychosocial intervention and change in the sense of empowerment among family carers, and a reference for developing new tools when working with other disadvantaged groups.

## 7. Conclusion

In this research study, I have sought to contribute to the knowledge of measuring psychological empowerment of a specific group, the Chinese family carers for people with dementia in Britain. The 48-item Sense of Empowerment Scale which was developed through a procedure grounded on the actual experiences of the Chinese family carers indicated six factors of psychological empowerment pertinent to this particular group. These six factors have helped to resolve the difficult aspects of measuring empowerment, an abstract variable in both the quantitative and qualitative research studies.

The reliability of measuring changes in the psychological empowerment using the new tool is seen as positive, when consistent patterns of improvement and significant results are observed across all statistical tests for quantitative analysis at T1, T2 and T3 in participatory interventions with the carers in the three groups. The SES has further proven its consistency as the six factors were used as the theoretical derived themes in the process of analysing the qualitative data. The results of the qualitative analysis showed that improvement in psychological empowerment was linked to five of the factors and processes of empowerment were explored and explained.

The SES presented in this research study has demonstrated a scientific procedure of developing a measuring tool and it could be a useful reference for researchers who are interested in this area. Further research is needed to test and re-test the validity of this scale when it is administered with a parallel scale in other psychological interventions.

In this research study, the knowledge and experience enabled the understanding of carers who live in a system of support with scarce resources which was hardly tailored to meet their cultural needs, and that service providers would be considered as 'outsiders' who seldom looked closely into their needs. This study achieved the identification of the important aspects of psychological empowerment for this disadvantaged group. Building up skills and knowledge, recognising the importance of support from the care recipient, the family and from the community, alongside awareness of community resources available, has led to improvement in psychological empowerment and sense of well being.

Further research studies would be useful in setting up a structure of participatory interventions with longer timeframe in order to explore more in-depth factors that enhance psychological empowerment and components that encompass the interpersonal, interactional and behavioural aspects of the empowered outcomes.

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# **SECTION C**

## **Professional Practice**

**AREA OF COMPETENCE: Generic Professional Development**

**Practicing Health Psychology in a Voluntary Service Setting**

**SETTING:** Chinese Mental Health Association (CMHA)

**TARGET GROUP:** The staff team and the service users in CMHA

**DESCRIPTION OF WORK:** To apply the knowledge of health psychology in the workplace.

## **Background**

My trainee practice for the Stage Two Training in Health Psychology was working with a voluntary service organisation (the Organisation). During my two years of trainee practice, the Organisation was undergoing development in community research and preventative health service. This presented a good opportunity to introduce health psychology, to apply it at a practical level, and to build up learning and knowledge of my generic professional competence. My work with the Organisation involved setting up and managing a mental health helpline (the Helpline), conducting community research studies, delivering a training programme, delivering psychosocial intervention and health promotion related consultancy projects. This case study will discuss how my development as a health psychologist has also helped the Organisation to set up and to maintain services to professional standards. The following discussion is structured around the sub-headings provided by the BPS guidelines for completion of the Case Study on Trainee Practice in Health Psychology

### **Establish, maintain and review systems for the security and control of information**

Before the Helpline was in operation, it was important to set up a comprehensive system and security procedures for keeping and retrieving confidential information. The Helpline was a confidential service for people from Chinese communities to talk about their emotional issues. I started to collect information about policies and procedures, making sure that the Helpline would operate according to a system that safeguarded both the workers/volunteers and the callers. Three major policies were set up: 1) Data Protection; 2) Complaints; and 3) Confidentiality. The Data Protection Policy ensured that no personal data of callers was recorded unless details were needed for the purpose of service referral. With regard to the Confidentiality Policy, team members had different views on social ethics and at what stage the workers should break the boundary of confidentiality. Mutual agreement was obtained with the input of the management. The Confidentiality Policy ensured that the Helpline worked to protect children at risk of abuse and also was prepared for situations where immediate medical attention was necessary for the callers. New policies and procedures were to be established to make certain the team was clear about their roles and responsibilities on particular issues, for example, a policy on 'Handling of Caller at Risk of Self Harm' was set up at some point when the workers was seeking clear line of intervention for callers at risk. All policies and procedures were reviewed on a half-yearly basis. Team members who observed the policies and procedures in practice on a daily basis were also involved in reviewing and revising them.

### **Ensure compliance with legal, ethical and professional practices for self and others**

To establish and implement comprehensive systems for maintaining and monitoring professional practice, I sought to promote the quality and confidence for callers to the Helpline by undertaking an accredited quality standard assessment to be conducted by a professional association. The quality standard contained sets of criteria, many of which were based around the process of the call itself. It also placed great emphasis on review, monitoring and evaluation to try to ensure that those helplines accredited to the quality standard were committed to ongoing improvement. Since the process of quality standard assessment had involved the Helpline team as well as all the other members in the Organisation, this was a good opportunity to obtain relevant advice from experienced colleagues on the issues about professional practices, and to identify issues that might affect legal, ethical and professional practice. The process of the assessment also raised the awareness of the concept that it was everyone's responsibility to carry out professional practice in the Organisation.

### **Establish, implement and evaluate procedures to ensure competence in psychological practice and research**

Establishing a work boundary was important for the Helpline workers who provide emotional support so that they understand the limits of their role. In the Helpline training programme, setting up work boundary was a topic I set out for the workers to define clearly the boundaries of competences for working with callers. Professional, personal and emotional boundaries were the three main aspects that were to be discussed in the training. I specified that the role of the Helpline was not to be a friend nor was the role a reciprocal one; callers were not there to listen to the workers' issues. While it was natural that at times callers might trigger a range of emotions with which the workers could identify, developing understanding of one's own emotional reactions so that they could handle them during a call, and using appropriate support from the Helpline supervisors, would be an important part of development in carrying out psychological work. Emphasis was also placed on the role of the Helpline workers who fulfil a function of providing emotional support and empowerment to the callers. I also highlighted that we should be aware of our own limitations and unresolved issues within ourselves so that we would not be involved emotionally when similar issues were identified from the callers. A list of good practice guidelines for setting up work boundary with callers is attached in the Appendix C.1.

### **Establish, evaluate and implement processes to develop oneself professionally**

Throughout the two years of Stage Two Training, I found the supervision meetings with my University supervisor were helpful and important in identifying professional development needs by evaluating strengths and weaknesses of my practice. At the beginning, my personal experiences and knowledge of health psychology were influenced by the nature of my work with the Organisation focusing more on project management and development. Applying theories of health psychology at work was a process of learning that enhanced my work in the Organisation in a more professional way. Examples are using psychological assessment tools to assess the effectiveness of some intervention projects. This established an evidence base for the effectiveness of the projects and raised the funding bodies' confidence in the grant that had been offered.

### **Elicit, monitor and evaluate knowledge and feedback to inform practice**

During my Stage Two Training, I was keen to learn whether my practice had enhanced the work of my colleagues and the well-being of the clients in the Organisation. I sought feedback from colleagues and my supervisor at work about the new systems and training that I set up and the advice that I had given. For my work with the clients (two clients from the psychosocial interventions I conducted and one client from the health promotion consultancy project), I usually sought feedback through informal discussion.

### **Organise, clarify and utilise access to competent consultation and advice**

During the two years of Stage Two Training, the supervision arrangement of the University was my main source of consultation and advice. I met with my supervisor once a month. I made use of these meetings to clarify with the supervisor areas that were not fully understood. Consultation and advice covered each competence of the training, for example, advice on conducting a systematic review was practical and inspiring. The clarification of deciding on the topic of the review on health psychology rather than clinical psychology was important. Apart from supervision meetings, consultation and advice was received in the workshops and group supervisions arranged by the University. Help from other contacts in the University was also extremely helpful. The workshops and group supervisions provided good opportunities in building up skills in psychology practice, sharing ideas and experiences with my fellow course mates and networking.

### **Develop and enhance oneself as a professional applied psychologist**

In my workplace, I tried to extend and develop professional competence by applying funding to carry out community services based on the framework of health psychology; for example, a funding proposal was submitted to run a psychosocial intervention project which aimed to work with elderly people at an early stage of dementia. In order to work more effectively with individual service users who come across psychological issues such as stress management, sleeping disorder and caring for people with dementia, I also attended training to enhance my skills and knowledge of counselling such as Cognitive Behavioural Therapy, Motivational Interviewing and the Person-Centre Approach to Dementia Care.

Working in an Organisation that provided mental health services could give people an impression that the training I was undertaking was on the clinical side. I was also feeling confused at the beginning of the training. Consultation and advice received from my supervisor had been very useful to ensure my capabilities and seeing myself as a psychologist, and that theories and models of health psychology had to be applied in my competences. I regularly up-date my résumé of additional capabilities, qualifications and competence obtained as a result of the Stage Two Training.

### **Incorporate best practice into one's own work**

In my workplace, the concept of health psychology was useful for the development of preventative mental health services. The concept of community health psychology was a new area that I introduced to the Organisation in promoting the well being of the community. The framework of participatory and empowering approach was identified in funding proposals for community research studies. This built up a stronger working relationship between the Organisation and the service users, and stages and structures of empowerment were to be explored. I also worked with a team to identify a project model for family learning using a combination of social work and psychology practices. The sharing and comparing of practices promoted the professional standard of the project, which in turn would be more beneficial to the service users who received the service.

### **Assess the opportunities, need and context for giving psychological advice**

At times, other institutions such as universities would seek advice from the Organisation on psychological issues from the Chinese cultural perspective when they were to work with Chinese students. In such occasions, colleagues in their counselling departments were the key people as recipients of advice. With the help of one of my colleagues, a literature search was conducted on journal articles and reference books focused on Chinese cultural values, social structure and learning

style, and Chinese perspectives on counselling and family values which might be useful for the Western counsellors.

### **Provide psychological advice**

I had written an interesting paper which I used as a script at the presentations. In the first two presentations with the universities' counsellors, I gave a detailed description of the social structure and the cultural values which shaped the characteristics of the Chinese in general. These included self esteem, self image, social relationships, filial piety, and language barrier as overseas students, financial pressure, coping strategies for stress, traditional Chinese medicine and health concepts, and knowledge of counselling. In the presentations I also quoted anonymous case studies as examples for discussion.

### **Evaluate advice given**

Comments were favourable but suggestions were made to give more time in discussion. I realised that the contents of the presentation might not have brought the advice given to a practical level. In other words, the presentation might not have covered all that the audience would like to know.

### **Evaluate feedback needs of clients**

I attended a workshop on 'Giving Feedback to Clients' using the Case Formulation Model of Cognitive-Behavioural Psychotherapy (Bruch, 1988). Five phases were discussed in the application of this model:

Phase 1 – Statement of Problem

Phase 2 – Exploration

Phase 3 – Formulation

Phase 4 – Intervention

Phase 5 – Evaluation

In this model, it shows that a feedback situation would not be established until a growing awareness and a shared concern was identified (Bruch, 1988). At the beginning when the statement of problem was to be explored, the presence of sensitivity from the therapist was needed. I adopted this model in the training for the Helpline team. Evaluating feedback needs of callers was a process of formulating accurate information about their concerns, their emotional needs and to what extent the feedback would be helpful to them.

### **Prepare and structure feedback**

Following the first phase of the case formulation model, preparation and structured feedback could be done through the second phase of 'exploration' and the third phase of 'formulation'. Again using the Helpline service as the background of practice, in training sessions with the workers, this stage of organising the content of feedback to meet callers' needs would mean collecting data from the callers. The purpose of collecting data from callers was to build a description of the problem behaviour (or emotional distress) including the before and after effect of the problem. Workers were to practice skills in counselling, for example, interviewing and observation techniques such as those in the cognitive-behavioural psychotherapy (the downward arrow and eliciting negative automatic thoughts (Neenan, 2006), etc) and motivational interviewing (Williams, 2006). As data collected were sufficient to formulate a case, the workers should be able to pace the presentation of information in response to the callers' needs.

### **Select methods of communicating feedback**

Working with the callers on the Helpline would mean that verbal communication over the telephone was the only method of delivering feedback. In this situation, what was of most concern would be the style of delivery of feedback to meet the needs of clients rather than the communication media and formats. In communicating feedback, workers were to use an approach which was collaborative, evocative and affirming the caller's right and capacity for self-direction and facilitated informed choice. Workers were to take up a non-judgemental approach. They were to avoid confrontation with the caller which meant imposing a new idea with which the client would not agree. They were not to assume that the client was lacking in knowledge or insight necessary for change and they were not to tell callers what they must do (Miller & Rollnick, 2005).

### **Present feedback to clients**

This included reflecting the dimensions of change, looking back and forward; and exploring goals and values with the clients. The client was encouraged to recognise the advantages of positive change as well as expressing optimism about and intention of achieving change.

**Reflection:**

The person-centred approach to dementia care training, stress management training and communication skills with clients, counselling skills trainings in CBT and motivational interviewing have improved my confidence in working with service users, consultancy clients and people in the workplace.

Over the two years training and work placement, I came across service users and carers who faced difficulties in dealing with stress or problems because of their circumstances and the care recipient's illness; outcomes of introducing new perspectives in communication, such as the person-centred approach to dementia, skills in stress management, motivating changes in behaviour to improve health, were positive. I became confident in applying the skills and knowledge of working on aspects of people's psychological health and well-being which is important in enhancing my professional development as a health psychologist.

Throughout my training, I found that evaluating my own knowledge and practice to establish effectiveness was important. This involved getting feedback from clients and people whom I worked with. An example was that of a colleague who organised social activities for clients who found that the weekly psychological assessment (the Faces' Scale) was too frequent so that clients started to feel the procedure was tedious. Her feedback inspired the development of a more user-led and free style assessment within a psychological framework. For example, we set out structured questions for users to interview one another; in outdoor activities such as visiting museums, we encouraged them to each draw an object that they most liked in the visit, and then gave a rating to represent their level of satisfaction on the day.

These assessment methods have also provided useful documentation to show the service users' lively participation in the project. As I looked at how seriously the service users had engaged in these participatory evaluations, evaluating my own knowledge and practice through gaining feedback from others has inspired me to see the impact of user involvement. Evaluation of my knowledge and practice will be an important aspect of practice as a health psychologist.

It was important to know where to get support throughout the training because health psychology was a new area to the colleagues and management in my workplace. The University was a helpful place, making use of the supervision arrangement and the resources in the University helped me to understand the skills and knowledge required for a health psychologist. One of my colleagues in the University helped me a great deal when I was struggling to develop a psychological assessment tool. To date I have already developed the new tool for my research study. Getting support from

colleagues is important. In my future career development I will continue to share my knowledge and network with people in the same field.

With regards to providing psychological advice to the University counsellors and evaluating advice given, I came to realise that the contents of the presentation might be interesting to the audience because of the new knowledge and information on Chinese perspectives. However, evaluating the comments given by the audience, I re-structured the format of the presentation to become more interactive with the audience. This would have been more challenging to me because I might come across questions that might be out of my knowledge. At this point, I spent more time in researching information on Chinese values and how they affected the dynamic in counselling. I started to use the more interactive approach in the presentation with the university counsellors and recently I found this approach was more inspiring to them. Although issues that I did not cover before were mentioned in discussion, the interactive approach was a more productive of giving advice to the counselling colleagues. On-going evaluation of the psychological advice given to clients therefore will be another aspect to strengthen my practice as a health psychologist in future.

With regards to evaluating feedback needs of clients, I believe that making assumptions and drawing conclusion too early and quickly would not be helpful in establishing a good therapeutic relationship. On the Helpline in the workplace, when callers discussed an existing concern or emotional distress, they might sense that something has gone wrong but might not be aware that a problem exists. This might have to come from feedback from the Helpline worker. At this stage the worker was to help the callers to spell out the elements of emotions in distress. Adopting Bruch's discussion of the case formulation model, feedback at this stage was to help the caller to identify problems in his/her language.

During the second and third phases when we tried to formulate a case in order to be able to give feedback to the clients, it was important to verify the hypothetical case with the client. If the hypothetical case did not meet the client's need, workers were advised to stay on the early phases instead of stepping up to the next phase. Workers should make use of the supervision and case management meetings if they felt stuck with the callers. Although providing emotional support was more of using listening and befriending skills, in many cases, giving feedback to clients helped them to look at their problem in a different perspective.

The style of communicating feedback could be empowering when a right approach was adopted. Although a case formulation model of the cognitive-behavioural psychotherapy was used at the early stage, motivational interviewing was even more suitable to use on the Helpline because it is a way of communicating rather than a set of techniques such as cognitive-behavioural therapy. On the Helpline where callers called up at their own discretion and workers were not able to follow up with

them on a regular basis, a structured therapy such as the CBT might not be appropriate. The concept of the case formulation model however was a useful tool in guiding the workers to work with the callers.

The success of the feedback to be presented to clients was dependent upon the earlier stages when communication was much about helping clients to see their problem and to reinforce balanced thinking or positive behaviours. As Bruch maintained, an individual's success at the process depends upon obtaining accurate information, getting a valid explanation, choosing an appropriate plan of action and monitoring and receiving positive feedback for their efforts in a supportive environment. These skills are also important to a health psychologist in practice, not only in therapeutic settings, but can be applied in other working relationships with clients such as consultancy, teaching and training and management.

The two years of training has broadened my knowledge of health psychology and how to apply the theoretical base into research, teaching and training, consultancy and psychological intervention. The concept of health psychology in improving health and well-being is empowering and I much appreciated the scope of health psychology that can reach out to different settings and to different client groups.

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**AREA OF COMPETENCE: Teaching and Training**

**A Person-Centred Approach to Dementia Care**

**SETTING:** Chinese Mental Health Association (CMHA)

**TARGET GROUP:** 1. CMHA direct service staff team  
2. Chinese family carers in the community  
3. Domiciliary workers in residential care home

**DESCRIPTION OF WORK:** To teach the target groups about the person-centred approach to dementia care.

## **Background**

Last year as I was reviewing journal articles for the preparation of the research protocol on empowering Chinese carers for family members suffering dementia, the overwhelming stress in the process of caring for sufferers of this progressive and degenerative disease, both within the family and in the residential care home, captured my attention. In one study, a combination of direct observation and video filming was used to explore communication and care in residential care homes. It highlights the fact that one of the distinct skills needed for dementia care is communication (Ward, Vass, Aggarwal, Cybyk, Garfield, 2002). However family carers or domiciliary workers may not have the communication skills to care well for a person with dementia, and often their choice is to avoid communication.

I learnt that training to build up the psychological knowledge, skills and practices for family carers and care workers is necessary. Although there is not much that medical advancement could do to cure dementia, carers can at least help to minimise the effects caused by environmental, social, and people factors. Carers can take time to talk to people, consider their feelings, respect them, and help them feel included in the social world. To help people with dementia lead a better quality of life, and to help carers to build up better communication skills, I decided to learn more about the person-centred approach to dementia care, because of its inspiration of valuing a person as a person and getting to know their life but not focusing on their problem.

To prepare myself for training and teaching, from October 2005 to December 2005 I undertook a training course, 'A person-centred approach to dementia care', delivered by the Dementia Training & Consultancy Services, a voluntary organisation which was funded to deliver this training for trainer course free to other statutory and voluntary services. In March 2006, I became an accredited trainer for a three-day training programme on a person-centred approach to dementia care.

I delivered the training course to four different groups between March and June 2006 which included domiciliary workers from two residential care homes, a group of six Chinese family carers and volunteer workers in London, a group of eight front-line mental health workers in the Chinese Mental Health Association (CMHA), and a group of family carers from a Chinese community centre in Leeds.

## **Case Study One – Training with a group of front-line mental health workers**

### **Assess training needs**

Knowing that I had completed a training course on dementia care, the helpline supervisor in my workplace, the Chinese Mental Health Association, asked me if I would like to deliver a dementia skills training course to the staff, especially the front-line workers, the helpline workers and the volunteers. She was keen for all the workers who have direct contact with users to receive some dementia awareness training so that they could learn about caring for the service users and the carers. I suggested to her the three-day training programme and the course outline, encompassing factors which can cause difficulties in dementia and guidelines for good communication in responding to challenging behaviour.

### **Identify training programme structures and content**

The supervisor found the three-day training programme very interesting, suitable and important; however, her concern was that the staff might find a three-day programme too long, that their work schedules might not allow them to spare the three whole days for the training. Ideally, a one-day course would be more suitable for their schedule. I suggested bringing the course outline back to the team of workers who were likely to attend the course and let them decide together which topics should be included in the one-day course. After consulting the staff, the helpline supervisor advised me that they would like to have the original three-day programme.

The training course was then scheduled between 31 May and 2 June 2006, from 10 am to 4 pm at my workplace. Training facilities such as flipchart and overhead projector were all available.

### **Select training methods and approaches**

The main aims and learning objectives for this three-day training programme were to:

- enable participants to learn about the special needs of people with dementia and
- how to meet these needs;
- enable participants to learn new information, skills and ways of working with people with dementia.

I used a combination of learning methods including group discussion, brainstorming, role play and feedback, and exercise for case study to motivate a greater participation from the learners.

### **Use appropriate media to deliver training materials**

I prepared the transparencies of the presentation, photocopied all the handouts and exercise sheets before the day of the training. I prepared some flipchart pages for brainstorming and feedback, group discussion, exercise and role play. I also pre-wrote and pre-cut all the papers that I would need for games and ice-breaking exercises with the participants.

### **Implement training methods**

The training course delivered by the Dementia Training & Consultancy Services I had attended provided a standard set of materials for the three-day training programme including handouts, transparencies, exercise sheets and course structure. Expanding on this set of materials, I added some case studies which are more relevant to the Chinese community and transparencies of some topics that were not covered in the set.

Observation and evaluation of the training was conducted by my course supervisor, Dr Catherine Sykes, on 31 May 2006 (the first day) at the office in CMHA where I was delivering the training to in-house staff and volunteers. Dr Sykes came to the office at around 12.30 pm, an hour before the start of the session, to assess the training materials. On this preliminary assessment, Dr Sykes commented:

Plenty of evidence of excellent preparation; very neat course handouts. This was a well-thought training that had been tailored to meet the needs of busy professionals and volunteers with limited time. Rebecca had decided to design the training so that the specific learning outcomes of each day were obvious. Attendance on all 3 days was not compulsory; trainees were able to decide which days they felt they could attend. The practicalities of managing this were discussed prior to the training. Rebecca was advised to avoid references to previous days, to recap on learning and to manage people who had lots of questions by informing them that there are comprehensive handouts for all of the training.

I started off by explaining how I came to be running this course and introducing to the group my course supervisor, who had come to observe and videotape the training. During a short break my supervisor gave me some feedback outside the training room. She advised me to engage the audience by more participation, apart from that, when I was asking the group a question, if someone said something wrong, I should not be giggling at them. I said I did not mean to giggle or laugh at them, but that I was a little nervous. We went back to the room, taking my supervisor's feedback on board, I became more comfortable in delivering the training. Dr Sykes' written comments were:

*At first Rebecca seemed not to be engaging her audience. For example she asked the audience what they wanted to achieve from the training but then went on to recite what she aimed to achieve without any reference to what the audience had said. This was discussed in a break then Rebecca went on to engage more with her audience and as time went by she seemed more comfortable and went on to build a rapport. It was also pointed out to Rebecca that she should avoid giggling if a member of an audience got a question wrong. Rebecca is aware of this and is something that is related to nerves rather than an intention to giggle. Rebecca needs to work more on this when providing training.*

Further comment on the training by Dr Sykes:

Other points to note and work on in future:

*Rebecca needs to pay attention to the time given to the audience to do an exercise. For example, five minutes was supposed to be given to do an exercise however she went on to discuss the exercise after two minutes. She should have noted the time when the exercise started. If the audience seemed to have finished, she should have highlighted that only two minutes had passed and asked if they needed more time or if they were all happy to go onto the discussion. Rebecca needs to work on striking an even balance between information giving and group exercise.*

*On the whole, this was a good training. The strength of the training was in the preparation and the material presented. Although the delivery was eventually good and Rebecca did establish a connection with her audience, the delivery of training does need some more reflection and practice.*

On the second and third day of training course, I made sure that the learners had sufficient time to do the exercises. When the learners gave feedback in discussion, I made sure that I responded and validated their feedback appropriately.

Reflecting on my supervisor's feedback, I came to realise that when I am delivering a person-centred approach to dementia care, the training must be person-centred too. I need to create an atmosphere which optimises learning. I should be open and genuine to developing relationship with the audience. I have to understand their 'reality' which means their day-to-day concerns, and how I could link up the training with their experiences and thoughts. I should also listen well to participants and be supportive, also, value each person's contributions and encourage them to recognise the importance and value of their work.

## **Plan and implement assessment procedures**

Before delivering this training course, I had delivered a one-day training course at a residential care home in March. I devised an assessment form for the learners to fill out at the end of the training. The questions were in general more about the benefit of the training, the adequacy of the learning resources, the content and the progress of the course and two open questions about how the audience would make use of the learning back in their day work. The learners had returned the questionnaires and the feedback was very good. I emailed the assessment form to my supervisor for advice.

My supervisor suggested that I add some questions related to the learning objectives rather than concentrating too much on training style and delivery. I thought about the way I structured the learning outcomes, which was looking at each topic in the training on each day, to set out the learning objective for each topic, for example:

*Learning objective – to help learners to understand the experience of dementia;*

*Learning outcome – learners would be able to understand the experience of dementia.*

I devised the assessment questions according to the learning outcomes for each day of the training programme and set out different questionnaires for the three days. The assessment questions now became more specific to assess how much the learners feel they have achieved each learning outcome in relation to each learning objective. The assessment sheet was passed out to the learners at the end of each training day. A reflective report of the training programme was also designed for learners to fill in after the training.

## **Evaluate training programmes encompassing psychological knowledge, skills and practices**

The reflective report completed by the learners helped me to understand whether the training programme was able to build up the psychological knowledge, skills and practices in a person-centred approach to dementia care. Questions in the reflective report are about the structure, content and delivery of the training programme; which part of the training they thought was most helpful; how much did the learners learn from it, and how could the training be done differently and in a better way. Here are some extracts from the reflective reports:

*I would definitely apply the training onto my work, say if someone calls our Helpline for dementia related problem, I know how to support the caller, for example, a helping and partnership approach with the patient, what could really help a patient is to maintain their abilities by letting them to do whatever they could still do.*

*What you could [do] differently is that, because we do not deal with dementia patients on a daily basis, it would be helpful to show us some videos so that we can have an idea how they react, talk and respond etc.*

The reflective reports suggested that the training programme in the future could be delivered separately in either Cantonese or English because language seemed to be a minor problem during discussion sessions. Video presentations about dementia patients, their life and experience, could be presented in the training so that learners who do not have much contact with people with dementia could have a better idea of their problems and how it is affecting their lives. The learners found role plays most useful, as they strengthened their understanding about dementia when putting themselves in that position.

### **Case Study Two – Training with a group of Chinese family carers**

The two groups of Chinese family carers with whom I was working on a psychological intervention in my other research study were very keen to learn more caring and communication skills to cope with the spouse or in-law for whom they care. In the first of these training courses, I intended to use the same materials for informal carers adopted from the Dementia Training & Consultancy Services. As the original handouts and transparencies are in English, I translated them into Chinese before the training. On the day, two male elderly carers in their seventies and eighties, together with four middle-aged volunteers who were interested in the topic, attended the session. The whole training course was conducted in Cantonese. This was a simplified version of the three-day training programme. I initiated more discussion and sharing amongst the carers rather than going into too much detail on the concept of the person-centred approach to dementia care.

Since the approach of this training course was rather informal, assessment was conducted in the form of feedback and sharing at the end of the training. The four volunteers were very fascinated to have learned new concepts about the person-centred approach and knowledge about caring people with dementia. They also mentioned that the training raised their awareness of what was the right attitude towards people with dementia. The two elderly carers, however, were very quiet during the training; one of them fell asleep half way through.

One of the volunteers, who knew the two elderly carers well, suggested that, although the training materials had been simplified to suit the family carers' level of education, they might still find it too difficult to understand. Topics that tackle immediately the problems in their daily caring, such as coping with memory loss and living with dementia, would be more appropriate. The male elderly carers might also be too shy to share their negative experience because this might be viewed negatively.

The feedback from the first training course was very helpful for me to prepare the second. As the participants were going to be a group of female family carers in their fifties and sixties, and all came from a lower educational background, I decided to use a totally different medium to deliver the training. I adapted several topics (such as coping with memory loss, communicating better, etc.) from a booklet entitled *Helping to Care*, published by Lundbeck Limited (2004) as the source of the materials. I conceptualised and drew each topic into colourful cartoon images on flipchart pages, with short and punchy (one or two word) descriptions besides the images. The flipchart pages were decorated and pasted with cut papers in the shapes of flowers. I invited a worker from the three-day training course (Case study 1 above) to co-facilitate and talk about managing financial matters.

Nine participants, including three workers, attended the second of these training courses for carers in Leeds. From my observation, the carers were very interested during the whole training. They were delighted when they saw the cute cartoon on the flipchart. They were also interested in the topics of the training, they asked questions and they shared their experiences in caring. From time to time, I conveyed the concept of the person-centred approach throughout the training. When they were asked to provide feedback on the usefulness of the training at the end of the session, they said it was interesting, joyful, and they learned a lot on the day, especially the style of communication. They suggested having some role plays but they were also aware of the time limitation in a one-day session.

Two samples of the records of the evaluation and reflective reports for all training courses in this case study can be found in the Appendix C.8 & C.9.

## **Conclusion**

The two case studies above highlighted my development in skill in teaching and training as a trainee health psychologist. At the beginning, when I delivered the first training course, because I was not familiar enough with the training material (although it was well put together), I put a lot of effort in reading to the learners all that was scripted during the course. After delivering a few more training programmes, I became more confident in presenting and relating the principles of the care approach to the learners' experiences rather than reading from the script. I think it is important to learn from the learners about their care experiences. Giving them space and time to talk and give feedback during the course can also enhance a supporting relationship between me and the learners. In order to encourage the learners to enjoy the training, materials should be designed according to the learners' background and educational level. As a trainer, one has to be flexible and creative.

This is a well-meaning care approach which aims to improve the quality of life for people with dementia. Throughout the training courses, I realised that the person-centred approach to dementia

care is also a worthy psychosocial intervention. It inspired the faith of the workers and the family carers in their roles of care-giving, that people with dementia are not at all someone who is just going to get worse. Their ability to communicate may be limited, but their feelings are not limited, caring with respect for the patients and preserving their dignity are ways to strengthen their lives, which are powerless and vulnerable.

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**AREA OF COMPETENCE: Consultancy**

**A Health Promotion Project Using a Forum Theatre Approach**

**SETTING:** A Primary Care Trust in North England

**TARGET GROUP:** The Chinese community in a city at North England

**DESCRIPTION OF WORK:** To plan, design and to deliver a health promotion event using a Forum Theatre Approach

## **Assessment of requests for consultancy**

In late September 2006, the Health Improvement Officer of a Primary Care Trust (PCT) called the London-based organization with which I work, the Chinese Mental Health Association (CMHA), to discuss a health promotion event on psychological health he was planning to organise for the Chinese community in their area. This was going to be an event jointly organised by a Chinese association and the PCT in northern England. The Chinese population there is small but cohesive as a group. Social events such as festivals, health talks and seminars were well supported by the community. As the organiser of the health promotion event, the Health Improvement Officer was keen to work with a Chinese organisation specialising in this field, so that the social and cultural aspects of psychological health could be addressed in an appropriate way. Therefore, he requested the CMHA to take part in planning and delivering the health promotion programme, in a format that would be best to raise the public awareness and interest of positive psychological health. I was allocated this task. The Health Improvement Officer was the only person with whom I came into contact and communicated throughout the project, so I identified him as the contact client in this piece of consultancy work.

In the United Kingdom, almost a quarter of the population frequently experience insomnia (health information extracted from the website of Bupa). The development of insomnia can be due to stress and health related issues. Interestingly, in many cases, worry about sleeplessness itself is a potential mechanism related to the development of insomnia (Jansson & Linton, 2006). Combined treatment methods emphasising both psychological and medicinal contributions have long been recommended (de Koninck & Godbout, 1985). A recent research study (Oosterhuis & Klep, 2006) also suggests that psychological and behaviour therapeutic interventions for sleeping problems yield positive results. This is an example of how the psychological aspect of individuals could possibly affect their physical health. This health promotion event intended to bring the audience to view health from an everyday life experience; and issue as common as insomnia can be resolved when the psychological aspect of health is taken care of.

For the purpose of the Doctorate in Health Psychology, this case study will focus on the work done on health promotion by empowering the audience to explore new solutions to maintaining a healthy lifestyle and dealing with sleeping problems from a psychological perspective.

In this health promotion event, I used the method of 'Forum Theatre' developed by Boal in the 1970s (Fursland, 2001) as a means to communicate with the audience. Forum Theatre is a type of interactive drama composed of sketches that depict situations requiring change. Actors and actresses first act out the situation and then a facilitator helps the audience to explore new options through improvisation (Seguin & Rancourt, 1996). Members of the audience can make suggestions about what could have

been done differently, take on the role of a character and replay it. The audience can test new ideas and experiment with changes in the behaviour of the characters in complete safety to produce a different or better outcome (Fursland 2001). The use of Forum Theatre was also suggested to be an effective problem-solving exercise between children and families (Houston, Magill, McCollum, & Spratt, 2001).

I made a suggestion of using brief pieces of drama/sketches to illustrate psychological and mental health topics such as sleeping problem, depression, dementia, schizophrenia and obsessive compulsive disorder. The sketches set out situations when families experienced difficulties in dealing with a member who is suffering from emotional or mental distress. After viewing the performance at the end of each scene, a member of staff would briefly explain the subject issue. Then the audience would be invited to give feedback on the characters, the scenarios and the topic issue. They would also be encouraged to write their own scripts for the purpose of improving the characters' relationship in the sketches, and participate in acting the new script. The purpose of the audience participation was to inspire creative solutions for dealing with psychological health issues which were reflected in the sketches. The Forum Theatre approach would also help the audience to identify themselves with the characters in the sketches and inspire creative and effective problem solving to deal with the psychological issues within their families.

Having heard about this idea, the Health Improvement Officer and the Chair of the Chinese Community Association were enthusiastic about the suggestions I made. The PCT agreed a figure of £500, including materials and travel expenses for the delivery of the event. In this consultancy, I consider that I used both the expert and the collaborative model to work with my client.

### **Plan consultancy**

This consultancy work was to plan, design and deliver the programme at the health promotion event through sketches and audience participation. The aim of the project was to raise awareness of psychological health among the Chinese community in a city at northern England, with the following objectives:

- Demonstrate common psychological issues in daily life;
- Demonstrate situations when a family member suffers from a psychological or mental health problem, how other family members could help to support him/her, e.g. improve communication, changing health belief, seeking medical attention or counselling, etc;
- Identify appropriate communication styles when dealing with people with psychological or mental distress;

- Involve audience to give feedback, discuss and reflect on the characters, scenes and the themes of the sketches;
- Involve audience to improvise on creating new scripts for the scenes after viewing the performance.

The theoretical framework of the consultancy was based on the idea of Forum Theatre approach and brief sketches were performed. In this project, the outcome criteria for each stated objective above were to:

- Write a script for five sketches which defined some of the common psychological and mental health issues; the five sketches described the most common communication problems within Chinese families with which the audience could identify themselves.
- Explain to the audience ways of appropriate communications when dealing with people suffering psychological and mental distress;
- Facilitate discussion;
- Listen to, feedback, and validate the audience's views on the subject issues;
- Encourage members of audience who were willing to share their views and were able to participate in the performance.

The abovementioned aims, objectives, theoretical framework and outcome criteria were to make sure that the ultimate clients, the audience from the Chinese community, could benefit from the project. The contact client was relying on me to identify the most relevant topics of the sketches to be played in the event. The client would like me to take cultural sensitivity into account and find the best way to convey the message to the Chinese audience. The client was expecting me to take on an expert role in this aspect.

Soon after the client confirmed that we could go ahead with the work, I produced a work plan for internal organisation use. The work plan included an itemised action plan, schedules and job allocation to implement the jobs. A detail work plan is attached in the Appendix C.12 to this case study.

### **Establish, develop and maintain working relationships with clients**

This was a two-month project between September and November 2006. The Health Improvement Officer was working to a tight schedule. He had to do a lot of preparation for the community event, such as producing flyers and posters and press releases, booking a venue and catering, and liaising with the Chair of the Chinese Community Association who was working with him in the event. He had to finish everything within these two months. Since the target audience of this event was the Chinese community, apart from planning, designing and delivering the health promotion performance,

it was important for the client to have a good understanding of the Chinese cultural perspective of health. My role was to also give advice on the graphic design and appropriate language to be used on the publicity materials, such as the promotional flyer, the poster, the programme in Chinese print language and furthermore, the evaluation of the event.

The PCT where there was client based was far from London, it took time for me to travel to his office for meetings. The absence of face-to-face meetings did not jeopardise the communication between myself and the client, although a lot of details had to be followed up with him during the two-month period. To resolve any potential problem that might be caused by a communication gap, I appointed a staff member in my team to follow up with the contact client so that whenever he needed support, a designated colleague would be able to attend to his queries either through email or by phone.

Contact and communication with the client had been well established. The client exchanged at least two emails with my colleague each week during the two months. My colleague developed a good working relationship with the client. She gave advice and support through email very promptly to the client. She was also professional and helpful in responding to the client's queries and was proactive in searching out information and resources for him, such as the information about sleeping problems, gambling issues and emotional health issues in the Chinese community, etc. I was able to monitor the progress of the project and evaluate the working relationship with the client because each time my colleague and the client sent an email to each other, I would receive a copy of it. My colleague reported to me regularly, and when decision or further advice was required, she would involve me to discuss with the client. From the email exchange, I could see that the client was satisfied with our support and advice.

We offered to send the scripts of the sketches to the client; however he did not require the scripts before the event because he felt that we were the best judges to decide the content of the sketches as we were familiar with the mind-set of the Chinese community and their emotional health issues.

In this consultancy, we did not draw up a formal contract with the client; however the cost of the consultancy, the aims, objectives, methods, timeframe and delivery of the health promotion were clearly set out in the email exchange between the client, my staff who coordinated the event and me. For the purpose of practising setting up a consultancy contract, I produced a sample contract relevant to this piece of work. The sample contract is attached in the Appendix C.11.

## **Conduct consultancy**

When I was considering the process to deliver the planned activity, the first and foremost thing I did was to make sure that the key stakeholders of the event were consulted. The major planned activity to be delivered in this project was the performance of the sketches. Although the contact client gave me a free hand to decide the topic of the sketches, I thought it was important to involve the client in the planning. Therefore I explained the purpose of the sketches to highlight the effect of psychology on health. Following my suggestion, the contact client had a discussion with officers at the PCT about the topics of the sketches.

Consultation with the client was useful because I was informed that the clients' superior, who knew the community well, considered that problem gambling, a topic that I intended to use, was a big issue there but would be too sensitive to be discussed in the event.

After I explained the purpose of the sketches, the clients expressed that they liked the idea of raising people's concern of how negative emotions could affect one's physical health, and that living a healthy lifestyle, having positive emotions, good communication, and having social and family support, were very important in keeping one's well being. The clients also appreciated the fact that inspiring people to think about psychological health issues from their everyday life perspective was essentially what they would like to achieve in the health promotion event.

When the topics of the sketches were mutually agreed, the next step was to make sure that the scripts were written to portray the psychological aspects of health. When it comes to psychological health, many Chinese people consider it as purely a medical issue. In this project I wished to encourage the audience to look at health from a holistic point-of-view, for example, a sensible communication and family relationship, which for quite some time has been neglected within the families, was actually important in improving the aspect of people's psychological health.

To implement the planned activity, I wrote five scripts. A brief description of one of the topics is as follows:

**Sleeping problem** – A daughter was suffering from a sleeping problem. Three scenes were to portray how the daughter was causing trouble to her mother on three consecutive days and nights. The mother, although concerned about her daughter's problem, was overlooking the real cause behind her sleeping problem, which the daughter had mentioned in one occasion – her work stress. At the end of the sketch, both the mother and daughter were on the verge of nervous break down. At this point, one of the staff would explain some common causes of insomnia such as ineffective stress management, poor preparation for sleep, overly worrying about insomnia, trying too hard to get to sleep, and excessive

procrastination of some unfinished business that runs through one's mind as he or she tries to get to sleep. At the end of the scene, members of the audience were invited to give suggestions for the mother to deal with the daughter's problem.

On the day of the event, a gentleman volunteered to act as the father in the sketches. This male audience member took time to talk, listen to and understand the daughter's real problem. He suggested the daughter take positive steps to deal with her situation, setting a realistic schedule to finish each task one after the other. The gentleman's participation was greatly appreciated by the audience with a big round of applause.

Another good example was a sketch depicting an elderly woman with dementia and her frustrated daughter-in-law. One of the audiences talked to the person who played the elderly woman, saying that her husband's mother who passed away seven years ago, had behaved exactly the same way as in the sketch. She regretted that there was no similar event back then, to show people the symptoms of dementia; and how the understanding of the illness could help to support the patient and the caregiver in a better way. We assured the audience that after the event, should they have further need for support, they could contact our organisation for help.

### **Monitor the process of consultancy**

This was a health promotion activity using performance art, monitoring the process of consultancy would have to do with helping the client at each stage of the preparation of the event, making sure that the client's needs and expectations were fulfilled.

In November, three weeks before the activity, the client maintained again that when it came to psychological health, the dilemma within the Chinese community was not only the lack of understanding but also the difficulty in opening up conversation to talk about it. So to speak, the lack of support and understanding in the community and family has been very unhelpful for people who experience emotional or mental health problems... He would like to make sure that the intention of the sketches was to include these factors whenever it appeared to be appropriate. I confirmed to the client that that was actually our aims for the performing sketches. I went through the scripts with my colleagues (who also helped in acting on the health promotion event) again to strengthen the effect of positive communication and a supportive family relationship. The team rehearsed the sketches to make sure that they remembered the scripts well and their performance would be good on the day of the event.

The client also asked for my advice and guidance on the publications on mental health, because he would like to arrange some Chinese language information to be distributed to the audience, and such information should reflect the issues discussed in the sketches. Fortunately CMHA had produced some Chinese publications on all the topics. I also suggested the client order copies of other booklets which would be relevant to the Chinese audience, such as 'How to deal with anger', 'How to cope with sleep problems' etc. In the end, the client ordered 210 copies of the Chinese information booklets.

A week before the event, my colleague followed up with the client to make sure that the booklets would be available on the day. Other arrangements such as display boards, posters, and audio-visual equipment for the sketches would also be prepared.

### **Evaluate the impact of the consultancy**

A week before the event took place, the client and I discussed and agreed the need to set up an evaluation to assess the impact of the event. We would like to evaluate whether the event had achieved its aim and objective based on the audience's feedback.

The client considered that the questions on the evaluation form should be consistent with the messages we were putting across in the sketches. The client initially drafted some evaluation questions and I made comments on the appropriateness of the questions.

I developed a self-report questionnaire to record the audience's perceptions of improvement in:

- Their understanding of psychological health issues;
- Their knowledge of seeking advice regarding psychological health problems;
- Their willingness to discuss the issues with other people;
- Their attitude to being more supportive towards people with psychological health problems.

The questionnaire contained six items on a 5-point scale ranging from 'strongly agree' to 'strongly disagree'. At the end of the six items, an open-ended question was set out for the audience to give comments. The questionnaire was first produced in English and was translated into Chinese.

In designing the questionnaire, I used the skill I learned when I was designing an assessment form for the training programmes of my Training and Teaching Competence. When I first created the questions, I listed each learning outcome of the training programme. Each question was then set out in terms consistent with each learning outcome; therefore questions were able to instigate an opinion on whether each learning outcome was fulfilled. The questionnaire should be brief and succinct.

With regard to the stage at which the audience should be given the form during the day, I suggested to the client that it would be best to distribute it after the last sketch performance. This was because, after viewing the performance, it could also be the time when the audience were most fascinated and excited about the acting, the characters and the subjects, and they should be pleased to offer some help back to us. The client accepted my point-of-view and the evaluation forms were given at the time I had suggested on the day.

Apart from the completed evaluation forms we collected, of which the client and I both kept a set, informal evaluation was carried out during the time for networking and chatting with the audience. In an email the client sent me a week after the event; he mentioned that the event was a big success. The members of the Chinese Association informed him that they were very pleased with the event and that people enjoyed the day as well as finding it interesting and informative. Results of the evaluation indicated that 98% of the audience reported that their understanding of psychological health issues was increased after the event.

## **Conclusion**

The client's continued communication with me might indicate that the outcome of the consultancy had been fulfilled. To evaluate the outcome of the consultancy, one can refer to the press release (enclosed in the Appendix C.15.) that the client was going to issue in the PCT's magazine; the client's intention to publish a report about the success of the event; the client's intention to identify further possible work and activities following this event; and his intention to enter this event for relevant Health Awards. This was a small piece of consultancy work, and because there was only one client involved in all the work and communication, things I needed to plan and handle were straightforward and specific. This was a good opportunity for me to build up confidence and skill in undertaking consultancy work.

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**AREA OF COMPETENCE: Optional: Implementing Interventions to Change  
Health Related Behaviour**

**A psychosocial intervention to improve the well-being of an individual at an  
early stage of dementia**

**SETTING:** Chinese Mental Health Association (CMHA)

**TARGET INDIVIDUAL:** A service user in CMHA

### **Assess the suitability of client for health-related behaviour intervention**

My idea of designing a psychosocial intervention for people at an early stage of dementia came after several research activities I undertook with a group of family carers for people with dementia in London between March and July 2006. One of the carers, in his 70s, brought his wife along each time he attended the research meeting. His wife's diminished memory capacity has been a disappointment to him although he was aware that this is due to degeneration of her brain. Communication has also been a problem between the couple as the wife's attitude and temperament became aggressive and unpredictable.

As I had completed an accredited training on the person-centred approach to dementia care, by observation, I recognised the wife's frustration because of her declining memory capacity. She felt insecure and lacked confidence due to the problems caused by dementia. She was sensitive of being judged that she has dementia, however, lacking the insight into her problems, her husband's confrontational dialogue constantly irritated her.

I thought that psychosocial intervention might be helpful to improve the client's quality of life. The initial idea of psychosocial intervention with the client was to include activities such as reminiscence, maintaining daily social interaction and further skill learning. In June, I started to search for materials in this area and I had found an activity book which looked useful. I decided to plan the intervention based on this guidebook - the 'Activity Guidebook on Care for Dementia' published by the Department of Health in Hong Kong in 2004. I would like to borrow ideas from this guidebook because the range of activities suggested have a cultural background which is tailored for Chinese people.

At the end of August 2006, in the last research meeting, I discussed the idea of intervention with the carer and the client, in the presence of two other carers who were their close friends. They all welcomed the idea. Starting September, they would continue to work with me in a different arrangement once a week for the psychosocial intervention. The client had a slight concern whether or not she could manage to learn the things that I would like her to do, and I assured her that was going to be a failure free intervention, and that we would be there to support her.

Since the Activity Guidebook is in Chinese, I translated it into English so that my supervisor could comment on whether or not it is suitable for the intervention. My supervisor read through the activities and suggested that they are suitable for the intervention; however, activities which are more assessable for psychological outcomes should be more preferred. The activities are divided into six main categories:

- Reminiscence – childhood memory, career, wedding ceremony, public transport
- Sensory stimulus – music, tasting fresh fruit, touching, smell and guess
- Memory training – making phone call, matching exercise
- Arts – Chinese art festival, self expression and art
- Socialisation – discussion, picnic
- Sport – gardening, Tai Chi

### **Identify and negotiate the behaviour change goals of the client**

I invited the client, her husband and her two friends for a discussion of the potential psychosocial intervention. To let the client have a better idea of the intervention, I showed her the Activity Guidebook explaining what I could work with her in each activity, and the purposes of the activities. The activities mainly involved memory practice, social interaction and skill building through leisure interest. The client's main concern was not being able to fulfil the tasks. I assured her that she did not have to worry because the activities would be designed according to her own interests and needs. When I asked if she understood the aims of the intervention, she said that the activities were to help her to remember things. She also thought that the activities would be interesting and she would like to try them.

This type of intervention is based on the idea of normalisation which describes family carers' reactions to their care recipients who suffer from any forms of disability due to physical or mental health problem. Putting normalisation into the context of psychosocial intervention and care approach, the principle of which is to open up the positive perspective of health that is in search of the individuals' strengths and abilities rather than focusing on their disability or inadequacy (Robinson, 1993). For an individual with dementia, he or she would lose some of the daily functions such as memory loss or language skill. However, some of the functions still remain such as singing or even making a joke. When caregivers try to normalise the way in which they see their care recipients, they no longer concentrate on the disabilities, rather, they focus more on their strengths so as to preserve the care recipients' abilities, confidence and dignity in their daily lives. Health professionals and family carers also recognised that normalisation is a good care approach which could enhance problem solving in the process of caregiving (Knafl & Deatrck, 1986).

The purpose of using activities as a way of intervention is built on the idea that 'occupation' is a good way to maintain health, a meaningful life, and is a source of the improvement of quality of life (Bowe, 1990). To strengthen the effectiveness of the activities, it has to be voluntary, failure free, and designed in a way which is meaningful and appropriate to the participants' social and cultural background. Activity programme using the concept of normalisation (normalisation activity) was

introduced in the 90s to improve the quality of life of people with disability (Hellen, 1992). In this intervention, the normalisation activities were aimed to maintain the client's cognitive ability and well-being through reminiscence, story telling, memory training exercise, social activity and sensory stimulus etc.

Before the first session of intervention, I ran through the topics in the Activity Guidebook with my client. I suggested her to choose the activities that she liked to work on. She liked most of them. However when she saw the one which involved learning to bath and get changed, she maintained that she was not yet that severely ill, she could still manage to take bath by herself; that activity was for people whose cases are more severe. At that point, her husband, her two friends and I looked at one another – this was the first time that she unambiguously talked about and admitted her problem. Her husband agreed and also supported that she could manage to look after herself in terms of personal hygiene. The other activities were interesting to her and she chose to do most of them.

When I asked the client what other expectations she had for the new activities, she said she would like to talk to, and hear from the group. She would like to have support in the group where she felt it was safe and comfortable to talk. The negotiation brought about a mutual understanding of the goals of the client who was taking part in the intervention:

- Possible improvement in performing daily tasks, such as making phone calls;
- Possible improvement in emotional well-being;
- Be able to enjoy social interaction;
- Be able to share her feelings in the intervention sessions and;
- Be heard and be supported in the intervention sessions.

We agreed to have six intervention sessions starting early September. I set up a simple consent form stating that the client agreed to take part in the psychological intervention. I read through the consent form, the client understood, signed and dated the form.

In negotiating the behaviour change goals of the client, I considered that working with clients with dementia is different from working with those without. Since behaviour change for clients with dementia is largely contingent on a supportive relationship and communication with those that surround them, facilitating a supportive environment in the intervention would be more important than working on the cognitive level of the clients.

### **Assess the cognitive, behavioural and situational determinations of and influence on relevant current behaviour**

As it was deemed too sensitive to discuss with the client, her problems with dementia; therefore, assessment of her cognitive, behavioural and situational determinations of, and influence on her relevant current behaviour was mainly through observation and discussion with her husband and friends. On a cognitive level, the client has shown signs of disorientation in time, place and people due to dementia. She has a different sense of perceived reality which made her dialogue incoherent with the existent account of reality. Unaware that it was due to dementia, the client's cognitive disorientation and subsequently her incomprehensible speech was rebuked by her husband at times and gently challenged by other people in some occasions. It was obvious that she was being frustrated particularly by her husband's criticism. Being frustrated and confronted, her current behaviour is both aggressive and challenging.

Using significant others for the assessments of patients' health conditions and care needs were carried out in neuropsychological and social care research studies. Combining assessments by the clients, their family members and named nurses of the quality of long-term care leads to a more comprehensive picture of the quality of the service (Kahanpaa, Perala, Raikonen, 2006). Clients should be the main source of information for health assessment; however, when clients are not able to express their opinions, other sources of assessment such as involving the significant others, are necessary. A research study using significant others for assessment showed that a high degree of consistency was found between significant others and patients' self ratings on the measures of their everyday memory dysfunction (Olsson, Wik, Ostling, Johansson, Andersson, 2006).

Since the client's decline in cognitive capacity is non-reversible, I believed that in the intervention sessions, ways to work on her current behaviour should focus on facilitating an environment where she could experience people's acceptance of her cognitive decline, especially from her husband. Looking from a behavioural perspective, the client was verbally aggressive and challenging to people around her. Aggressive behaviour in people with dementia is another way of communication. The client's aggressive behaviour was possibly a message that has not been heard, or a need that has not been addressed, therefore during intervention, I would explore the message and need that was channelled through aggressive behaviour.

At a situational perspective, disorientation of places and the loss of sense of direction had been a great frustration to the client. She was embarrassed by her own vulnerability. Sometimes she rejected helping hands offered to her and was sceptical about people intention to help her. Again, the client would experience difficulty in her every day life because of the problem dementia might have caused her. I believed that to compensate for the problems that she encountered in her daily life, building up

trust in other people and the willingness to receive help would minimise her frustration due to situational influence.

### **Develop a psychosocial intervention based on the client's needs**

This psychosocial intervention was aimed to discovering the client's strengths and enhancing her well-being, a series of activities such as reminiscence, memory training, arts, social activities and sensory stimulus would be developed. I did not set out the programme of the intervention all by myself but involved the client, her husband and her friends to decide the activities which were found to be interesting, helpful and could improve the client's emotional well-being. I had run six sessions with the client. The six sessions were around reminiscence and memory training exercise.

The intervention was a process of developing trust, building up a sense of achievement, improving communication and sense of well-being. During the whole process, I have learned ways of working with people at an early stage of dementia. At the beginning I tried to identify the client's motivators for adapting new skills. It was simply the client's own interest and her practical needs that could motivate her in doing and enjoying the activities in the intervention. I usually started the sessions by chatting to the group about things in their past; that could be their life history, traditional foods, festival and movie stars from their youth, etc.

In the first session, the client was to practice making phone calls step by step. At the beginning, she could not remember the steps. Sometimes she started to talk before the line was connected. After a few runs practice with hints from me and other people, she could manage to make a phone call to me in another room and talked to me for a minute. I commended her and she smiled and was pleased. One of her friends suggested to practice taking phone message when her husband was not around. The client said she could try and was willing to learn. The client tried a few times but had difficulty in passing on message to her husband. The group suggested creating a board which she could pick and choose pre-made name tags and message strips for posting phone message. The client was pleased with the result.

In the next session, I presented the phone board I made for the client. We tried to practice using the board a few times. However the client found the new board difficult to use. She could only use the board when assistance was available. I assured her that this was just an exercise and she could try to play round with it in her own time. The session went on without any pressure placed on the client.

The first two sessions made me realised that the chatting at the beginning of the activity was useful in bringing the group together. It served two purposes, firstly, by remembering the past, the client and the group talked through once again their joys and achievements. Secondly, it helped to create a more

relaxed and friendly atmosphere. The client did not have to feel that she was coming for a test or something serious. During the chatting, I observed that the client's literacy levels were quite high. She could read and recognise all Chinese characters. In the following sessions I focused more on her strength – her reading skills so that she could use this skill more often. The presence of her friends was very important in giving her support and making the session dynamic and fun.

The next three sessions involved memories of Chinese movie stars and songs in their 20s and 30s. I printed out pictures of popular movie stars in the 60s. When I showed her the pictures, she could not recognise them but then I realised the movie stars were not her generation. She mentioned a few names of movie stars and titles of Chinese operas. Then I asked my colleague to help print out the lyrics of the operas. She sang with one of her female friends in the group. She still remembered most of the lyrics and found singing the opera a joyful experience.

I ran a session using nutritious fruits to inspire the client's sense of taste and smell on the day of the Chinese Moon Festival. One of the client's friends bought a box of moon cake. This session was a session of sharing and eating together. The client's husband started to talk about that in the past, his wife used to make moon cakes and sell them to the Chinese takeaway shops and community centres. He commended her that she was clever and honest. For many years she kept the selling price of the moon cake the same, she was such a kind person who did not think about making more profit. This was a very touching moment because for the first time, the client's husband commended her rather than rebuking her in front of the other people. His appreciation and recognition for her achievement in the past was very encouraging.

The conclusion of the six intervention sessions was that the client enjoyed coming for the sessions, although she might forget what was taught, shown and said in just a few seconds. She enjoyed the time she was there with me, her husband and her two friends. After the second sessions, the client started to feel more comfortable sharing stories with me. The client was nice and cheerful during the sessions without expressing any aggressive language. I thought the intervention had been successful in that it facilitated a supportive environment where the client could experience acceptance, a non-judgemental communication and a sense of achievement.

## **Ensure monitoring and support for behaviour change plan**

Before the start of the intervention, I designed the method for monitoring behaviour and mood change with the guidance of my supervisor.

For the memory training sessions, I assessed the client's possible improvement in performing daily tasks by the following criteria, for example, making phone calls:

- Observer's criteria
  1. Picking up the phone
  2. Dialling the number
  3. Saying hello to the person on the other side of the phone
  4. Starting the conversation

I asked the client to demonstrate making a phone call step by step and then ticked on each criterion that the client achieved in order to assess the improvement of her memory function as a result of the intervention. The assessments were conducted at the first 'making phone call' session; and at the last second session when I asked the client to perform the same task again. Observations were recorded in the practice log book.

For the reminiscence sessions, I would assess the client's mood and confidence level by the 'Faces Scale'. The 'Faces Scale' would be conducted before and after each session. At the second last session, I would use the 'Faces Scale' to assess the overall emotional outcome. Assessments were recorded in a separate evaluation sheet.

## **Evaluate Outcome**

With regard to the improvement in making phone calls, one of the client's daily tasks, she had shown a little improvement at the second last session when I asked her to perform the task again with lesser hints than she needed in the first session. With reference to the observer's evaluation criteria, before the intervention, the client was unable to coordinate making a telephone call. At the end of the intervention, she was able to pick up the phone and dial the number by herself. Although she started saying 'hello' before the line was through, when the line was really through, she started the real conversation again and chatted joyously with the person on the other side of the phone for about 2 minutes.

For the message board which was created for assisting her to take phone message at the third session, at the beginning I was unsure whether or not she was using it at home. One of her friends at the

intervention group called to test her when her husband was not around. The friend said that she did not pass his message back to her husband. We discussed this at an intervention session. The client said that taking messages had not been something important to do on a daily basis, on the other hand since she was retired, not many people would call in apart from her children.

The conclusion was that although the purpose of the message board was to motivate her to learn new skills and to assist her daily tasks, unlike making phone calls, there seemed to be no urgent need or personal interest there to motivate her to use the new board. I discussed this outcome with my supervisor and she suggested that the board might be too complicated, or had too many steps for the client to follow. I also considered the simpler the design of the board, the better, I will continue to modify the design of the message board for the future use.

With regards to mood and confidence levels, the outcome of the assessment using the Faces Scale' (see Appendix C.17 & C.18) was good. The client chose a happier face before and after each session. In the first session she chose number 4 face which was a face showing no emotion. At all the following sessions, she would choose number 5 or 6 faces which were happy and quite happy to start with, and at the end of the sessions she usually chose a happier face. The assessment suggested that the intervention sessions had improved her emotional well-being, at least, during the intervention.

When I asked if she thought she was more confident after the intervention, the client did not understand the term 'confidence'. Therefore, assessment of the client's confidence level was not established. Next time, I will get advice from the client and his/her significant others in the intervention to make sure that the choice of words and use of language for the terms in my assessment criteria and expected outcomes are within the client's level of understanding and can be comprehended when asked again in the evaluation at a later stage.

When I asked the client what were the activities she liked most over the last few sessions, she said she was very pleased with the activities. She might not remember what was taught, discussed or learnt, once she stepped out of the therapy room, however she felt she was happy in the sessions. She remembered that people were nice to her and cared for her. She was listened to and being cared for whenever she came to the session. She said it was very important for elderly people to have someone to talk to, those elderly people who were not cared for would be miserable.

Based on the assessments and the verbal accounts of the client, the outcome of this psychosocial intervention was positive. The outcome met the client's goals which were discussed at the beginning of the intervention. The intervention had achieved an improvement in the client's emotional well-being; she enjoyed the activities; she shared her feelings and she felt that she was heard and supported in the sessions. The unexpected and one of the most encouraging outcomes was that her husband

started to show appreciation and support to her during the intervention. The client was shown to be pleased and contented.

### **Negotiate completion, follow-up or referral as appropriate**

The intervention finished in the middle of October. Since there is no such psychosocial intervention as such for Chinese people at an early stage of dementia in London, I referred the client to the weekly social group at my workplace. She and her husband had joined once for an outdoor activity which they both enjoyed. The client has also been joining weekly elderly luncheon club at another Chinese association where she could meet friends.

Towards the end of the intervention, I was approached by a NHS run memory clinic in South London. I was invited by their worker to visit their clinic and shadow the work of their clinical psychologist. This would be a good opportunity for me to develop the skills in this area. The visit will be arranged next year.

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**AREA OF COMPETENCE: Optional: Disseminate Psychological Knowledge to  
Address Current Issues in Society**

**A community engagement research study showing the health needs and  
experiences of the Chinese community in North London**

**SETTING:** Chinese Mental Health Association (CMHA)

**TARGET GROUP:** 1. The Chinese community in North London  
2. The Primary Care Trust in North London

**DESCRIPTION OF WORK:** 1. To apply funding for a community engagement research project  
2. To conduct a community engagement research exploring the health  
needs and experiences of the Chinese community in North London  
3. To disseminate the research results to the statutory health services

### **Identify current social issues and review appropriate literature and information sources**

I currently work in a charity which was set up to provide community mental health services for the Chinese community. The purpose of our services, such as befriending and running social activities, is to offer social support for people who are recovering from mental distress and for isolated elderly people. Apart from these direct services, the charity has also been involved in health promotion campaigns aimed at breaking down stigma attached to mental ill health. A few years ago, a range of products were developed to convey accurate and positive messages about mental health. These included a television documentary, user newsletters, an animation, a newspaper column, a service directory and a bilingual website. Much work has been done to raise the awareness of the community to look at mental health in a positive way. As a direct consequence, more people have approached the charity for help at an earlier stage, whereas many others have been referred by statutory organisations for cultural support.

In many situations, service users who came in for help expressed their difficulties in accessing statutory services when they needed medical attention. In general, their difficulties were as a result of language difficulties, cultural barriers and the lack of information provision. These difficulties gave rise to stress and feelings of dissatisfaction and inequality. Many of these difficulties have been identified in research studies looking at the mental health needs of this ethnic group over the last ten years in Britain (Cowan, 2001; Li, Loan, Yee & Ng, 1999; Li & Logan, 1999). Although problems in accessing health services by the Chinese community have long been discussed, service users' experiences as revealed by the charity indicated that the problems seem to have remained the same as they were ten years ago.

Other studies (Ma, 2000; Wong, 1999) in America and Canada looking at Chinese immigrants also indicated that cultural and socioeconomic factors were found to be strongly associated with access to and the use of health services. As immigrants sought health care, they often faced cultural dilemmas such as communication difficulties, different beliefs about health and illness, lack of knowledge and information about the Western concept of mental health, and mistrust of Western health care.

### **Formulate psychological and social issues appropriately**

A funding proposal (see Appendix C.22.) was submitted to the Department of Health in order to conduct a community research study which would aim to explore and understand Chinese service users and carers' experiences, feelings, health-seeking behaviours and cultural values which might be the factors affecting them in the process of accessing health care services. The research study was carried

out in the Chinese community in North London where there is the largest population of Chinese residents in comparison with any other area in the U.K.

One of the purposes of this research grant was to help the NHS to deliver race equality in mental health care; therefore, this research study was also expected to make recommendations to the health authority of ways to improve the equality of service, experiences and outcomes in mental health services for the Chinese ethnic group. A grant was secured in May 2006 to conduct a 10-month research project.

### **Consult relevant others**

At the beginning of the research project, I set up a steering group inviting the Diversity and Equality Specialist, the Joint Commissioning Manager, and the Manager of Advice and Information of the Primary Care Trust where the project took place. The steering group met once every two months to discuss the progress of the research and to give advice and support to the research team.

In this research study, I intended to lead a focus group and semi-structured interviews. After I made the first draft of the semi-structured interview schedule, the next thing to do was to meet up and consult with the steering group members for their feedback on the research tool. In the meeting the members explained the structure of the referral pathway within the health services. In the referral pathway, they were particularly interested to know details such as the waiting time for a user to get a GP appointment, the waiting time to be referred to the specialist services such as a psychiatric hospital, community and voluntary units that were culturally appropriate, etc. Other factors such as sufficiency of information provision and awareness of information were also to be explored. Apart from recruiting fifteen service users as research participants, they also suggested including five elderly people, five carers and five people from the general public so that the research could cover opinions from a wider range. Based on the suggestions of the steering group, I revised the semi-structured interview schedule. The amended semi-structured interview schedules then included some questions which steered towards the areas the policy makers would like to explore and improve.

### **Reflection:**

The function of the steering group was important. Since formulating psychological and social issues in this research included a responsibility to find out what was missing and what needed to be changed in the health services, it would have been difficult to find the right angle without the input of the stakeholders. The steering group helped me to crystallise the areas which the policy makers would be more interested in knowing about so that they could use the results and findings of the research to plan for a better service in future. The involvement of the steering group members also developed a sense of their commitment to take ownership of and contribute towards this research project.

### **Analyse, evaluate and disseminate psychological components of current social issues**

The semi-structured interview schedule (see Appendix C.24.) was about the perceptions and experiences of race equality from the perspective of Chinese users of health services. The final interview schedule consisted of seven parts as follows:

- Demographic data
- Mental health awareness in general and perception of one's own mental health problem
- Opinion about the accessibility of services
- Opinion about hospital admission
- Awareness of services and support
- Awareness of information provision
- Needs and expectations of health services

Except for the demographic data, the other parts of the questions were structured for the purpose of quantitative data collection, with open-ended questions at the end of each section for the purpose of obtaining more in-depth qualitative data. A focus group session and four questions (see Appendix C.24.) were established to discuss issues about race equality and experiences in mental health services. The interviews took place and the focus group met and data analysis was completed in January 2007.

The results of my research were consistent with previous research studies (Yee & Au, 1997; Li & Logan, 1999), in that they showed that a language barrier still exists and is a major problem for Chinese service users when trying to access health services in primary and mental health care. The interpreting service did not seem to be solving users' language difficulties when they used primary and mental health services because, even when an interpreting service was available, very often the quality was not good or reliable. This had led to service users feeling frustration, stress, disappointment and that they were being treated unfairly.

### **Apply appropriate psychological frameworks and paradigms to the analyses**

In this research, there was a call for a more united community to preserve cultural understanding and language capacity for the younger generation. This was perhaps the first time that research had reflected the weakness of its own community. The participants suggested that if they wanted to have a culturally appropriate health service, they should also take responsibility for making it work by starting with their own families, nurturing more Chinese speaking health professionals to join the mainstream services.

**Reflection:**

The above finding has led me to consider recommending to the community and policy makers the idea of developing a collective action towards improving health within the Chinese community. The first possible step in this process is to introduce the concept of community health psychology. When helping a disadvantaged group to take control over their health, the most effective approach is to involve people in 'taking ownership' of the problem collectively. Community health psychologists place strong emphasis on the importance of participation in collective action in increasing the likelihood that people will act in health-enhancing ways, and in lobbying for the creation of community contexts that will enable improved health (Campbell & Murray, 2004).

Based on the participants' opinions, the development of human resources for health professions in the community might help to resolve the difficulty in accessing services. Considering that both existing knowledge (barriers and difficulties) and new knowledge (challenges and solutions) are needed to motivate change, I think new projects using a participatory and empowering approach can be applied to facilitate such movement. In the process of reflecting on existing knowledge, the experience of participation empowers by drawing upon existing knowledge and constructing new knowledge (Guareschi & Jovchelovitch, 2004). This process may be helpful in empowering the Chinese community to create better living and thus better health.

**Identify and select audiences for presentation**

I started to plan for the dissemination of the results and findings of this research study. I considered that my supervisor and the board of management committee at work would be the first group of audiences that this piece of work should be presented to. As they had a wide connection with people in the health services at a policy level, they could give me directions to help identify and select the right audiences for further dissemination.

The second group of audiences was the steering group members; as mentioned before this included the Diversity and Equality Specialist, the Joint Commissioning Manager, and the Manager of Advice and Information of the Primary Care Trust who gave advice and guidance to me and to the research team. As the research project was helping to find out the needs and experiences involved in the process of using health services, they were interested in the findings, results and recommendations, as this could possibly enhance their work. In the steering group, one of the most important members was the Joint Commissioning Manager because he was the person who made decisions about the allocation of budgets in the areas under his management.

I also made contact with the health promotion specialist for the local area who was a link person for all public health conferences and events, mentioning to her that should there be any opportunity for future appropriate conferences and events, I would be interested in delivering a presentation about the research.

I had to consider disseminating the findings and results of the research at appropriate national conferences. The grant for this community research was under the 'delivering race equality' scheme of the Department of Health. Each year the Department of Health has a national conference about the 'delivering race equality' scheme. At these conferences, some of the selected community research studies under the scheme are disseminated. The conference took place in February 2007. Unfortunately it was too much of a rush for me to meet the deadline for the submission of the poster presentation or to offer a workshop at the conference.

At the time of writing, another national seminar on delivering race and equality for the Chinese and Vietnamese communities will take place in June 2007, organised by the Department of Health. The major target audiences of this seminar are the health commissioners in the NHS. The foci of the seminar, much in line with the research focus of this case study, are improving the equality of access to services and the experiences of people with mental ill health. I got in touch with the organiser of the seminar regarding the dissemination of this research study. I also planned to organise a launch for this dissemination inviting the wider Chinese community, the media, service users, volunteers and people who have an interest in the research, e.g. researchers and health professionals. A press release with a summary of the research was sent to Chinese newspapers and mainstream health magazines.

### **Select presentation media appropriate to the clients' needs and requirements**

In the first presentation, I used a data projector to deliver a PowerPoint presentation to the steering group at the end of January 2007. The PowerPoint presentation consisted of 62 slides encompassing the data analysis of all the seven parts of the semi-structure interview, the focus group discussion and the recommendations. The presentation lasted for one and a half hours. The members of the steering group were very interested in knowing about every detail of the research findings and posed questions throughout the presentation. However considering that this presentation would be too long for dissemination on other occasions, I have since shortened the PowerPoint presentation to 15 minutes, covering only the major findings, results and recommendations. I have also prepared a set of slides printed on transparencies because some conference venues did not provide a data projector.

For the conference in June 2007, I have planned an A-1 poster of the research because stalls and panels will be set up on the day for organisations who are interested in promoting their services. I have

decided to use graphs and tables rather than putting too many words on the poster. I will also put the contact details on the poster for people who were interested in learning more about the research. I have also planned to produce a research report to be distributed to the statutory units and voluntary organisations.

Apart from delivering the presentation, I have also prepared a set of materials just in case the organiser of the conference or seminar should request me to run a workshop. On such an occasion, I would use about 10 minutes to present the research and the rest of the time for feedback and discussion. Depending on the topic of the conference, or the requirement of the organiser, I would set out some questions to guide the discussion of the people participating in the workshop. I consider that questions about the implementation plan for the recommendations of the research, eliminating the cultural barriers to accessing health services and cultivating a supportive community might be helpful.

For those people who have limited knowledge of English but are interested in learning about the research study, I have produced a Chinese version of the report so that they can read it in their own language.

### **Reflection**

During the first presentation, although the members of the audience (with a policy maker involved) were interested in every aspect of the research study, I think the time was not managed well enough to allow discussion about the more important aspects, such as the recommendations and the psychological approach that might help to improve health at a community level. As the presentation was too lengthy, people started to lose their attention especially towards the end when the recommendations, one of the most important areas, were discussed. I would have to summarise the content more and make a better presentation next time.

### **Present psychological analyses appropriately**

Findings and results were disseminated to the Commissioning Manager and his colleagues at a conference room in a primary care trust building. This was a PowerPoint presentation using data projection; the group posed questions and gave feedback throughout the whole course of the presentation.

Results and findings of this research suggested that although the mental health problem was seen as a common issue, most of the participants (19 out of 28 participants) did not feel they were being accepted by their own community in terms of the problems they came across. There was no obvious

link between participants' religious affiliations and their feelings of acceptance by their community. This suggested there was still stigma attached to, and lack of social support for, people who suffered from mental ill health.

The lack of social support and stigma might have an impact on people when they were coming to terms with their mental health problem, and might be a hindrance for people who actually needed intervention and support. In this research, all of the participants reported that they had suffered from at least one or two forms of mental distress such as depression and anxiety; however, only three of them would identify themselves as mental health service users.

Other research findings (Watt, Howel & Lo, 1993; Green, Bradby, Chan, Lee & Eldridge, 2002; Cowan, 2001) have also found that language barriers, the lack of good quality interpreting services and the lack of specific Chinese information are major barriers to accessing health services. In this research, it was further explained that these difficulties had given rise to the feelings of being ignored, being treated unfairly and being discriminated against because of the lack of quality communication between the health professionals and the Chinese service users. Participants in this research expressed their opinion that using health services could be another source of stress and helplessness, in addition to the stress of the health problem they already suffered from. Another disabling factor which had not been revealed in previous research was that even when culturally appropriate information was available, some Chinese people did not have sufficient time to seek proactively for the information because of long and unsociable working hours in the catering business.

Suggestions from the participants of ways to improve access to services were practical. They suggested that the resources for providing quality interpreting services were strengthened; that specialised Chinese mental health organisations were sustained to bridge the gap between the statutory service and the service users; that training about cross cultural mental health for health professionals should be strengthened; and that Chinese traditional medicine and acupuncture should be integrated into mainstream services. Participants maintained that more partnership work between the statutory units and the Chinese community organisations was important.

To highlight a significant viewpoint that had not been discussed in previous research studies, participants in this research reflected on the weakness due to a cultural factor they were aware of: the fact that Chinese people were not very cohesive as a community. They were often seen as silent and invisible when it came to a call for action as a group. They suggested that creating a more supporting community spirit was needed. On the other hand, they should try to maintain their culture and language by motivating their children to learn Chinese, as well as encouraging them to become health professionals so that they could support their own community when they grew up. One of the participants said, *"It would be so helpful if we could have more Chinese doctors and health*

*professionals. I mean the real Chinese - you know sometimes you meet some Chinese doctors or nurses, but surprisingly they just don't speak Chinese at all."*

### **Reflection**

The participants identified the weakness of their own community, echoing their expectation of creating a more cohesive community: they realised that an individual's health status was determined by a wider perspective. In response to the urge for the development of self efficacy and competence of the community collectively, as mentioned earlier, approaches such as participatory and empowerment in community health psychology may help to facilitate such a change. Community health psychology goes beyond health status in defining health in terms of an ecological and strengths perspective. It emphasises the strengths of disadvantaged people and encourages their active participation and control in research and action that focuses on their health issues (Tolman & Brydon-Miller, 2000). In addition to the policy makers who may improve the delivery of health services after this research project, I think dissemination of the study to the wider Chinese community is important as it may help people to look at health and the ability to take control of health from a different and broader perspective.

### **Evaluate message impact using valid and reliable methods**

The feedback of the first presentation I delivered to the members of the steering group was positive. I considered that it would be more appropriate to evaluate the message impact through discussion because of the working relationship with the steering group members. This audience was supposed to be the group that had the most insight into the research since they had been working together with me from the beginning of the project. Evaluation through discussion would enable me to obtain more qualitative information. I set out some questions to guide the discussion and the questions were as follows:

1. Did the presentation help you to understand more about the mental health needs and experiences of the Chinese community identified by this research?
2. Referring to question 1, would the findings and results help you in any way in your work?
3. Did the presentation help you to understand more about the psychosocial and cultural factors which hindered the Chinese people in accessing health services?
4. Referring to question 2, would the knowledge help you in any way in your work?

5. Would you consider using or quoting the results and findings of the research in any future occasion such as preparing a presentation or report relevant to the Chinese community?
6. Did the presentation have an impact on you in any way, especially at a policy level? If yes, could you explain how?
7. Which part of the presentation would you consider was most helpful and unhelpful?

The discussion did not follow exactly the order in the list, but most of the questions were covered. The group suggested that barriers to accessing health services such as language difficulties were the same for any other ethnic groups. The cultural and psychosocial factors which affected health belief and help-seeking behaviour were most interesting because these could help to improve training for the health professionals in exploring ways to work with the Chinese community. The Commissioning Manager also mentioned the possibility of recruiting a link worker to develop support services for the Chinese community in the area.

A week after my presentation, two of the steering group members attended and presented at a conference on Ethnic Minority Health Improvement. One of my colleagues who also attended the conference mentioned that the two members, in their presentations, expressed their opinion that the research we had done was impressive and informative. They both maintained that it was well worth supporting the research study as such and how useful it was for them to identify knowledge and service gaps. For another occasion such as a dissemination event, presentation, seminar, or workshop where the audiences would be people from the public, I would use an evaluation form to assess the impact of the message. I have designed a questionnaire to assess the impact of the message to be disseminated (see Appendix C.25 for a sample of the questionnaire).

## **Conclusion**

The language barrier was seen to be one of the major stumbling blocks to Chinese immigrants trying to access health services. This situation was almost identical in different English speaking countries such as America, Canada, and Britain. However, the language barrier was only a problem on the surface, and this research study tried to look at the issue from the community, cultural and psychological perspectives and their impact on people when they came to terms with their health problems. These were more inspiring to me and hopefully also inspiring to other health professionals as it did not just identify the issue but instead brought out the psychology behind it. Working with the Health Commissioner and disseminating the research findings and results were useful ways of highlighting the need for service improvement at a policy level, and most of all, the allocation of resources for better services. Dissemination of this piece of research needs to be brought forward at a community

level; more work needs to be done to counter stigma attached to mental health so as to promote a supporting community; and constant health promotion campaigns, education and participation from the community are all needed if we are to achieve better health.

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# **SECTION D**

## **Systematic Review**

**AREA OF COMPETENCE: Systematic Review**

**The effectiveness of coping skill-training intervention for family caregivers of dementia**

## **Abstract**

*Objective:* To review the effectiveness of training interventions for the family caregivers of people with dementia.

*Methods:* A systematic review search was conducted for randomised controlled studies and comparison studies published from 1994 to 2005 using CINAHL (1994-2005), PSYINFO (1994-2005), MEDLINE (1994-2005) and CDSR (1994-2005). Studies that focused on training as a means of intervention for family caregivers of people with dementia who received care at home are included. A general Internet search using a standard search engine (Google) was also carried out. Manual searches were carried out in the *Journal of Dementia Care* and the *Journal of Gerontological Nursing*. Reference lists were examined for additional references. Leading researchers in the current area of studies were contacted. Five studies fulfilled the inclusion criteria of the review. A scoring sheet was developed to evaluate the range of quality of the papers.

*Results:* There is some evidence that psychoeducational and skills training is useful in reducing caregivers' depression, distress, and burden and increasing their coping and self-efficacy. One study, using a combination of cognitive behavioural principle, social learning theory and behavioural approach in building up the structure of training intervention, yielded positive effect sizes.

*Conclusion:* Little can be concluded about the effectiveness of training interventions for family caregivers for people with dementia. Further research studies focusing in this area are recommended.

## 1. Introduction

Dementia is one of the most common diseases among older persons and it leads to progressive deterioration of cognitive, intellectual, physical and psychosocial functions (Fung & Chien, 2002). The prevalence rate of dementia increases with age, with numbers approximately doubling for every five years up to the age of 90 (Audit Commission, 2000; Longshaw & Perks, 2000).

Regardless of the difficulties faced by family carers, about one-third of those with severe dementia remain at home (Audit Commission, 2000; Longshaw & Perks, 2000). Caring for a person with dementia is believed to be a stressful experience because the person is increasingly dependent on family members to provide daily care (Fung & Chien, 2002). For many caregivers, the effects on their well-being were detrimental (Cossette, Levesque & Laurin, 1995). It is noteworthy that since many of the family caregivers are overloaded with care responsibilities on a daily basis, appropriate training in the chronic-care management of dementia is essential. It is particularly important in improving the quality and effectiveness of care at home, whereby skill training for caregivers to cope with their own stress and self-management is considered an important aspect of caring for the carer's own health needs (Hepburn & Lewis, 2002).

Due to the particular stress faced by those who care for persons with dementia, caring for carers is also considered an important aspect of providing health and social care. Support for carers appears in many forms. First, ensuring that the patient has appropriate assessment, treatment and care is the precondition of reducing carer stress (MacLennan, 1998). Recent developments in the NHS and social care services for dementia are documented in the National Institute for Health and Clinical Excellence guideline (NICE Clinical Guideline 42, 2006), which set out support for carers as a key priority for implementations.

Criteria for care plans for carers in NICE Clinical Guideline 42 was developed by the National Collaborating Centre for Mental Health, which is a partnership of the Royal College of Psychiatrists and the British Psychological Society. The Collaborating Centre worked with a group of health and social care professionals (including consultants, GPs, nurses and social workers), representatives of the Royal Colleges and professional bodies, patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations (NICE Clinical Guideline 42, 2006).

It is suggested that those providing care for people with dementia are one of the most vulnerable groups of carers and often have high levels of stress, feelings of guilt, depression and other psychological problems. They often ignore their own health needs in favour of those of the person for whom they care. They may become exhausted, have poor physical health and feel isolated. Recommendations on support for carers include tailored interventions such as individual or group psychoeducation; peer-support group; information and support and training courses about dementia, services and benefits, and dementia-care problem solving (NICE Clinical Guideline 42, 2006).

Current research suggests that psychological interventions may be effective, but there is insufficient evidence to establish cost effectiveness. The promotion of good mental health in older people (many carers are the spouses of people with dementia) – included in standard 7 of the National Service Framework for older people – is vital, especially because the proportion of people with dementia will rise in line with our aging population. Support for carers in general has been given priority in England and Wales through Carers' Strategy documents. Further research is urgently needed to generate a better evidence base for updating this guideline (NICE Clinical Guideline 42, 2006). Therefore, the current systematic review aims to generate a better knowledge of the effectiveness of training as a means of intervention for family carers for people with dementia.

Carer support groups are generally perceived to be beneficial and helpful, however a review by Eccles, Livingston, Freemantle & Mason (1998) suggested that carer support groups do not seem to reduce the burden or change the stress of looking after a person with dementia. Provision of information is seen as valuable by carers and is best given in a standardised way; however, it does not alter outcomes. In the same review, there is some evidence that formal training for carers may reduce their psychological morbidity and may delay institutionalisation of the dementia sufferer (Eccles et al., 1998).

Prior to the study by Ghatak (1994), which tested the hypothesis that better caregiver training will lead to positive outcomes in caregivers and patients with dementia, no previous studies had ever looked at the relationship between caregiver training as a determining variable and caregiver coping as an outcome variable (Ghatak, 1994).

During the last fifteen years, training for family carers and group interventions have increasingly been used as a means of relieving the caregiver's burden, but it remains unclear which types of training interventions are most helpful (Gendron, Poitras, Dastoor & Perodeau,

1996). Training interventions can be in the form of one-to-one sessions, group sessions, telephone-based, educational package and CD-ROM.

In many training interventions for family carers, the aims are stress management, building up coping skills and assertion. Some of these training programmes use cognitive-behavioural techniques to enhance caregivers' abilities to cope with the stress of their challenging role and reduce depression (Gendron et al., 1996; Donaldson & Tarrier, 2000; Hepburn, Tomatore, Center & Ostwald, 2001).

At three months follow up, Donaldson & Tarrier (2000) found that fewer caregivers in the family of the CBT intervention group met the criteria for psychiatric caseness compared with those in the control groups. Gendron et al. suggested that caregivers in the cognitive-behavioural group were more assertive and able to talk more easily about their difficulties, however, ratings of marital adjustment and marital satisfaction by the cognitive-behavioural group was lower than that of the comparison group.

Other studies devised training interventions, which help caregivers to focus on building up their skills in coping with the care recipient's behavioural and psychological symptoms (Dicker, Chawla & Preston, 2005; Martin-Cook, Davis, Hynan & Weiner, 2005).

Dicker et al. (2005) found that carers demonstrated statistically significant learning gains in self-perceived knowledge of dementia and its behavioural and psychological symptoms following delivery of the training. Carers were less stressed in comparison with the control group. However, carer stress had returned to near pre-intervention levels after twelve months post-training, which indicated that the training intervention has an immediate effect on reducing carer stress.

In a randomised control study of a caregiver skills training programme, Martin-Cook et al. (2005) devised a four-week programme of skills training sessions to teach caregivers how to break tasks into smaller steps and to offer cues to assist care recipients with tasks that could benefit care recipients as well as their carers. Results of the study showed no increase in congruence over time between caregiver expectations and care recipients' abilities to perform a series of structured tasks.

Given the use of training as a means of intervention for dementia caregivers, which shows some positive outcomes, the present systematic review aims to review the effectiveness of training interventions for family carers of those suffering from dementia in building up their coping

skills and reducing their psychiatric morbidity. This review included training programmes that aimed to improve family caregivers' psychological strength, such as reducing their distress, depression and burden relating to caregiving; improving their assertiveness, stress and anger management skills, communication and problem solving skills. Apart from psychological interventions, information giving type of training was included. Since these types of interventions (including information giving) are included as recommendations for the support for carers in the NICE clinical guideline 42 as mentioned earlier, this systematic review may help to generate a better evidence base for the update of the guideline particularly on the delivery of a training intervention programme for family carers.

## 2. Methods

The search aimed to identify all literature relating to training programmes for family caregivers for people with dementia. Training programmes including psychoeducational training for coping skills, stress management, anger management, cognitive restructuring of carer role, and information learning such as community resources were defined as any training interventions for caregivers in the form of one-to-one session, group session, telephone training or training package including CD-ROMs.

This review is based on searching the following databases from 1994 to 2005:

- CINAHL (1994-2005)
- PSYINFO (1994-2005)
- MEDLINE (1994-2005)
- Cochrane Database of Systematic Reviews (CDSR) (1994-2005)

The year 1994 was used to continue from the first study of the effects of an intervention programme on dementia patients and their caregivers, by Ghatak (1994). A general Internet search using a standard search engine (Google) was also carried out. Manual searches were carried out in key journals (*Journal of Dementia Care* and *Journal of Gerontological Nursing*) and reference lists were examined for additional references. Leading researchers of the current area of studies were contacted to ascertain whether a paper relating to their study was scheduled for publication during the production of this review. A combined free-text and thesaurus approach was used.

- (i) 'Subject' search terms included: dement\$, alzheimer\$, memory disorder\$.
- (ii) 'Caregiver' search terms included: famil\$, carer\$, caregiver\$.
- (iii) 'Training' search terms included: training\$, program\$, intervention\$, psychoeducation\$, education\$, communication\$, cognitive behavi\$, skills\$, coping\$, stress, management\$, effective\$, efficacy\$.

Two reviewers assessed the literature for inclusion. A quality assessment form was developed to include studies in the review, with the maximum score of 17. The form assessed the following: (1) methodological quality of study including the study design (RCT *versus* comparison), study sample and selection, the description of the training programme and the trainer; (2) intervention including follow up duration; (3) drop out rates; (4) results and outcomes including the assessment of the training programme using validated measurement tool(s), the measurement of satisfaction with the training programme, the cost benefit of the training programme. Combining the results of the three search terms 'Subject', 'Caregiver' and 'Training', 60 results were yielded. Abstracts of the 60 results were read for relevant review. Full-text copies of eight relevant articles were obtained (List in Appendix 1).

## 2.1 *Study selection*

The following inclusion criteria were used.

### 2.1.1 *Participants*

- Family caregivers for persons with dementia involved in studies where training was a means of intervention.
- Family caregivers for persons with dementia who were receiving care at home.

### 2.1.2 *Training Interventions*

Training programmes for family caregivers, which were designed for any, or a combination, of the following purposes were included:

- Reducing family caregiver burden, distress and depression.
- Improving caregiver abilities to manage the functional decline, psychological and behavioural symptoms.
- Improving caregiver's assertion, stress management, anger management, communication and problem solving skills.
- Using the cognitive behavioural model to help caregivers to assume a more realistic belief about their role as a carer.
- Provide education and information to help with access to services.

The following articles were excluded in the study:

- Discussion papers describing training intervention for dementia care.
- Qualitative research using the form of case study to describe the effectiveness of training intervention for family carers.
- Training interventions for formal carers such as nurses and residential care home workers.
- Training interventions that were carried out at nursing homes.

### *2.1.3 Outcomes*

All measures using validated measurement tools and structured interview schedules to evaluate the effectiveness of the training were considered. The main measure for the review was the change in caregiver coping skills and psychological well being before and after attending the training interventions and the comparison with a control group or an alternative group, such as a group given information only.

### *2.1.4 Study design*

Randomised controlled trials and comparison studies were included.

### 3 Results

Eight out of the 60 articles fulfilled the inclusion criteria. The full references of the eight included papers can be found in Appendix D.2. Some of the articles were discussion papers, although excluded, were informative and useful as they discussed the theoretical background of training for caregivers of people with dementia. Three of the eight studies (Donaldson et al.'s, Smith et al.'s and Ghatak's) on training for family caregivers were further excluded as there was not enough statistical information available for the data analysis of the current review. Finally, five studies met the inclusion criteria. Details of the eight studies are described in Table D.1 and D.3.

To assess the quality of the included studies, a scoring system was developed (Table D.2). The studies were scored according to their methodological quality, intervention, analysis, results or outcomes. The maximum score was 17 points. There were differences between the scores on two of the studies and a third person helped to review the studies, scores were adjusted and a mutually agreed score was obtained finally. Table D.1 gives the total quality scores for each paper. The quality scores of the papers are between 10 and 13; one paper scored 13, whereas three scored 12.

#### 3.1. *Participants*

Participants were all family caregivers aged over 50; the age range of the participants across the five studies was between 60 and 75. The caregiver had to be in an informal caregiving role for a person who had a physician-determined diagnosis of dementia. Of the five studies, four used Mini-Mental State Examination as a tool to assess the care recipients' mental state at the time when the studies were conducted. Care receivers of the participants in all these studies were living in a community setting but not in a nursing home.

Participants were recruited from the community via a wide range of channels including geriatric and medical clinics, retirement and assisted living facilities, social agencies, the Alzheimer's Association, senior centres and churches. A range of recruitment methods were used including newspaper and radio advertisement, television announcements and targeted mailings.

Table D.1.  
Summary of review studies

	<i>n</i>	Time points of testing	Satisfaction with intervention	Age group (mean)	Control/comparison group arrangement	Mode of delivery	Cost benefit calculation	Drop out rate (intervention group) (%)	Quality scores
Donaldson et al. (2000)	42	Baseline & 3 months follow up	not measured	77	No interview control group	Group	not measured	<25%	10
Hepburn et al. (2001)	117	Baseline; 5 months follow up	not measured	65	Waiting list	Group	not measured	<25%	11
Gendron et al. (1996)	35	Pre- and post-testing; 3 & 6 months follow up	42.9% very satisfied 57.2% satisfied	66.5	Information support	Group	mentioned but not measured	<25%	13
Davis et al. (2004)	34	Baseline, 3 months & 6 months follow up	>25%	66.7	1 friendly call group; 1 in-home training	Individual	mentioned but not measured	>25%	11
Martin-Cook et al. (2005)	73	Baseline; 7 weeks & 17 weeks follow up	not measured	73	Waiting list	Group	not measured	<25%	12
Smith et al. (2005)	96	Baseline & 6 months follow up	not measured	62	Urban group	one-to-one	not measured	<25%	12
Coon et al. (2003)	169	Pre- and post- testing; 4 & 3 months follow up	not measured	<50	Waiting list	Group	not measured	<25%	12
Ghatak, R. (1994)	36	Pre- and post-testing; 3 & 6 months follow up	not measured	65-79	not mentioned	Group	not measured	<25%	11

Table D.2. The scoring sheet used to assess the quality of the papers

	Maximum score
Methodological quality of study	
Study design (RCT = 2, comparison = 1)	2
Study sample and selection (good sample, well described = 2, poor sample, well described = 1, low sample = 0)	2
Method of training well described (yes = 1, no = 0)	1
Trainer described (yes = 1, no = 0)	1
Intervention	
Follow up duration (6 months and more = 4, 3 – 5 months = 3, 1 month = 2, immediately after intervention = 1)	4
Analysis	
Drop out rate (<25% = 2, >25% = 1)	2
Results/outcomes	
Validated assessment tools used to measure outcomes (yes = 1, no = 0)	1
Satisfaction with intervention (>70% = 2, <70% = 1, not measured = 0)	2
Cost benefit (mentioned and calculated = 2, mentioned not calculated = 1, no = 0)	2
Maximum total	17

### 3.2. *Intervention group*

All participants of the intervention groups were placed on training programs that aimed to build up caregiver's coping strategy and improve their psychological well being including anger management, depression management, assertion, problem solving skills and cognitive restructuring of caregiving role. The purposes of each training intervention, the type of trainings and the assessment tools used in each study is summarised in Table 3.

### 3.3. *Control group*

Three studies used randomised controlled trial and they were Hepburn et al. [2], Martin-Cook et al. [5] and Coon [7]. Participants of all the control groups were placed on a waiting list that would be scheduled for the same intervention. Hepburn et al. [2] scheduled their wait-list control to attend the intervention group in five to six months time. Martin-cook [5]'s caregivers were placed on a waiting list for intervention group and provided information about community services and resources. Coon [7]'s participants received an initial assessment and then a second complete assessment 3 to 4 months later. During that time, brief phone calls were conducted periodically by research assistants to maintain caregivers' interest in the study and to maximise retention for later interventions.

Table D.3  
Summary of training intervention and assessment tools of review studies

Study	Purpose of training intervention	Duration of training	Type of training	Measurement tools used for Initial assessment with care recipients	Measurement tools used for outcome measures with carers
Donaldson et al. (2000)	To test whether cognitive behavioural intervention reduce psychiatric morbidity in caregivers.	14 sessions family intervention	A combination of carers education, stress management & coping skills training	DSM-11 IR criteria for primary degenerative dementia of Alzheimer type	Beck Depression Inventory (BDI)
Hepburn et al. (2001)	Test whether role-training intervention could help carers appreciate and assume a more clinical belief about caregiving.	7 weeks of 2 hours workshop each per week	Using the Minnesota Family Workshop to provide carers with knowledge, skills & caregiving outlook	Lawton ADL Scale (ADLs), Mini-Mental State Examination (MMSE), Revised Memory & Behavioural Problems Checklist, 20-item Center for Epidemiologic Studies Depression Scale, 22-item revised Zarit Burden Scale.	Beliefs about Caregiving Scale (BACS)
Gendron et al. (1996)	To test whether cognitive behavioural training could help in cognitive restructuring & build up carer's assertion & problem solving skills	8 weeks of 90 min session each per week	Assertion training to help carers deal more with spouse, service agencies, health professionals. Problem-solving training helps managing daily living. Cognitive restructuring builds up ability to recognise & reduce negative thoughts.	Memory & Behavioural Problems Checklist	45-items of Hopkins Symptom Checklist, Automatic Thoughts Questionnaire, Jalowiec Coping Scale, Rathus Assertion Inventory, Dyadic Adjustment Scale 22-item Burden Interview Scale, Structured Interview of self-report for opinions on interaction with extended family & friends.
Davis et al. (2004)	To test whether telephone-based skill training could reduce carer burden, distress & depression, also improving abilities to manage the functional decline of care recipients	12 weeks training sessions	General problem solving skills, appraisal of behaviour problems, written behavioural programs for managing specific problems, strategies for handling affective responses to difficult situations.	8-item Independence in Activity of Daily Living (IADLs), 6-item Physical Independence (PSM); Mini-Mental State Examination (MMSE)	Caregiver burden (SCB-A); Caregiver burden (SCB-B); Satisfaction with the project questionnaire.
Martin-Cook et al (2005)	To test whether skills training could improve quality of relationship between carers and care recipients by decreasing the gap between carer's expectations and patient's actual functional abilities & by teaching supportive skills	4 weeks training sessions	Teaching carers to break tasks into smaller steps & to offer cues to assist patients with tasks. Interactive program to help carers objectify patient's functional abilities & to instruct carer by demonstration & practice.	Mini-Mental State Examination (MMSE); 70-item IADLs; Parallel Informat version for carers to rate a patient (ILS/I); 24-item Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory (ADCS-MCI); Texas Functional Living Scale (TFLS) - Performance-based measure of IADL.	Neuropsychiatric Inventory (NPI); 43-item Finding Meaning through Caregiving Scale (FMTCS); 10-question General Self-Efficacy Scale (GSE); 8-item Relationship Attribution Measure (RAM); 15-item Geriatric Depression Scale (GDS) - self administered version.
Smith (2005)	To test whether the Savvy Caregiver Program could benefit carers in rural areas.	12 hours training sessions	Using the Minnesota Family Workshop Model. Training consisted of knowledge of disease, developing emotional tolerance & taking control. CD-ROM and printed manual included.	20-item Epidemiological Studies Depression Scale	20-item Epidemiological Studies Depression Scale; SCP questionnaire assess the effectiveness of the training, client intake form; Self report of carer's health.
Coon et al. (2003)	Skills training interventions to compare the effectiveness of an anger management group, a depression group with a wait list group.	3 to 4 months training sessions	Psychoeducational & skill training ground on cognitive behavioural theory to help carers practise distinct self-management skills.	Mini-Mental State Examination (MMSE); Lawton ADL Scale (ADLs)	Revised Scale for Caregiving Self-Efficacy; State-Trait Anger Expression Inventory (STAXI); Multiple Affect Adjective Checklist (MAACL); Ways of Coping Checklist - Revised (WCCL-R); STAXI Anger Expression Out Scale (AX-O)
Ghatak (1994)	Test the hypothesis that better training will lead to positive outcomes in carers	6 months training	Awareness Training Program (ATP) comprises lectures, interactive discussions, sensitivity training, and video-assisted instruction.	Short Portable Mental Status Questionnaire (SPMSQ); Behaviour Profile Scale	Care Management Stress Scale

### 3.4. *Comparison group*

Both Gendron et al. (1996) and Davis et al. (2004) used comparison groups in their studies.

Gendron et al. used information support for their comparison groups. The groups were led by two experienced animators. Each session began with a presentation (live or on videotape) of different topics dealing with health and aging, dementia, community resources, social and leisure activities, nutrition, respite services and legal issues. Presentations were followed by a question period. Speakers included a social worker, lawyer, nutritionist, and psychologist. Socialisation of participants was a key element of this comparison group; therefore, the second part of each session involved an extended non-structured discussion among participants over coffee and cake.

Davis et al.'s comparison group received friendly calls as opposed to their in-home and telephone training counterparts. Caregivers in the comparison group received an initial home visit by a research staff member trained in supportive social interactions. Friendly callers made an initial home visit to introduce themselves. At the time of each phone contact, friendly callers enquired about the caregiver's past week as well as any changes in their general health and medication regimen. If the caregiver identified caregiving problems, friendly callers encouraged the caregiver to discuss those problems with their family, their physician or minister.

### 3.5. *Training intervention*

Three studies including Hepburn et al. (2001), Davis et al. (2004), and Coon et al. (2003) delivered the training intervention in the form of weekly workshop sessions over a period from four weeks to four months. One study conducted the training on a one-to-one basis with telephone and in-home visit (Davis et al.). Trainers of these studies came from a range of health and psychology backgrounds including nursing, education, family therapy, occupational therapy, cognitive behavioural therapy, research and clinical psychology. Students such as clinical interns, graduates and Master's students were involved in delivery of training in Coon et al.'s study.

#### 3.5.1. *Cognitive Behavioural Approach*

Two studies, Gendron et al. and Coon et al. adapted the cognitive behavioural approach to deliver their training interventions. Gendron et al.'s training intervention emphasised assertiveness, problem-solving and

cognitive-restructuring such as dealing with negative automatic thoughts. Coon et al. adapted a training intervention grounded in cognitive behavioural principles. Their anger management intervention emphasised coping with frustration, teaching basic relaxation skills, generating positive self-talk, monitoring unhelpful thoughts. Their depression management intervention was based on social learning theory and followed the cognitive behavioural principles in its structure, with a greater emphasis on behavioural components.

### 3.6. *Effect sizes*

Effect sizes were computed for each individual randomised controlled study because the three studies used different assessment tools for outcome measures on their training interventions. Effect sizes were calculated according to the available data using the reported sample sizes, means and standard deviations (see Tables D.4, D.6 & D.8). Effect sizes equal to or smaller than 0.20 were considered as a small effect. Effect sizes equal to or larger than 0.50 were considered medium and effect sizes equal to or larger than 0.80 were considered a large effect.

Martin-Cook et al. showed small and medium effect on their participants' self-efficacy using the General Self Efficacy Scale to administer changes at seven weeks follow up (0.30) and at seventeen weeks follow up (0.24). A small effect on decreased depression was observed in the intervention group at seven weeks (-0.18) and at seventeen weeks (-0.48) follow up. The negative effect sizes indicated a decrease in depression as a positive effect.

Hepburn et al. (2001) showed medium effects on their participants' nurturing (0.37) and monitoring (0.31) beliefs using the Beliefs about Caregiving Scale (BACS) before and after the intervention. A large effect on a decrease in the belief about burden among the intervention group (-1.00) was found.

Coon et al. showed significant effects across all outcome measures in both anger management and depression management groups respectively (State of anger -1.6, -2.13; Hostility -3.09, -2.13; Depression -1.15, -0.85; Positive coping 1.41, 1.05). Negative effect sizes in State of anger, Hostility and Depression indicated a positive effect in the reduction of anger, hostility and depression. Large effects were further demonstrated in the cognitive behavioural group (Self-efficacy in managing problem behaviours 2.79; Controlling thoughts 0.89).

Effect sizes of individual randomised controlled study and results of the each comparative study computed in this systematic review were consistent with the results reported in each of the included articles.

### 3.7. *Results of the comparative studies*

Changes before and after interventions and differences between intervention and comparison groups were computed using the reported means and standard deviations. Higher means indicated larger changes and improvement before and after interventions within the same group. Groups with higher means between comparisons also indicated larger effects of the interventions on the group participants. Two studies using different groups to compare the effects of their training interventions were reported (see Tables D. 9 and D.10).

Gendron et al. showed no significant effect in the cognitive behavioural group participants on the overall outcome measures on assertion, marital adjustment, psychological distress, negative thoughts and coping styles before and after intervention within the same group. Changes in the mean scores indicated that, although insignificant, some improvement was observed in some of the outcome measures:

- Assertion in communication with extended family (10.9 → 11.2).
- Psychological improvement in sensitivity (10.9 → 11.1).
- Psychological improvement in lessening somatization (17.8 → 16.7).
- More palliative in caregiving (29.7 → 31.3).
- More use of services (1.2 → 1.5).

Compared to the cognitive behavioural group, mean scores from the information group were generally higher on marital adjustment, psychological distress and automatic thoughts but lower on assertion, perceived burden and services received.

In the comparative study of Davis et al. between the telephone, the in-home training and the friendly call groups, reduction in caregiving burden within the in-home training was observed before and after intervention, and even at three months follows up, same improvement was also shown in the friendly calls group immediately as after the intervention. There was no significant reduction in caregiving burden in the telephone training group before and after or at three months follow up. When the three groups were compared, improvements in caregiver distress across the telephone, in-home and friendly call groups immediately after the interventions were found, with significant effect showed particularly in the in-home group (telephone 14.2 → 12.8; in-home training 21.4 → 15.2 effect size 0.47; friendly calls 18.2 → 15.6).

Table D.4.

Change in means and standard deviations in the intervention and control groups at 7 weeks follow up

Study	Effect size	Intervention Group		Control Group	
		Before	After	Before	After
Martin-Cook et al.					
<i>Neuropsychiatric Inventory (NPI)</i>	0.05	13.29 (13.90)	12.58 (12.40)	12.48 (11.33)	11.95 (12.67)
<i>Geriatric Depression Scale (GDS)</i>	-0.18	1.79 (1.56)	1.67 (2.25)	3.00 (3.26)	2.09 (2.3)
<i>Finding Meaning through Caregiving – Loss/Powerlessness (FMTCS LP)</i>					
	0.08	63.87 (12.23)	62.14 (8.11)	56.70 (10.72)	61.52 (7.78)
<i>Finding Meaning through Caregiving – Positive Meaning (FMTCS PM)</i>					
	-0.18	74.96 (11.96)	74.00 (10.32)	78.65 (9.25)	75.82 (10.08)
<i>General Self Efficacy</i>	0.30	31.71 (4.18)	32.54 (4.17)	29.83 (3.74)	31.27 (4.27)

Change in means and standard deviations in the intervention and control groups at 17 weeks follow up

	Effect size	Intervention Group		Control Group	
		Before	After	Before	After
<i>Neuropsychiatric Inventory (NPI)</i>	0.02	13.29 (13.90)	10.63 (12.40)	12.48 (11.33)	10.41 (12.67)
<i>Geriatric Depression Scale (GDS)</i>	-0.48	1.79 (1.56)	1.58 (2.25)	3.00 (3.26)	2.68 (2.3)
<i>Finding Meaning through Caregiving – Loss/Powerlessness (FMTCS LP)</i>					
	-0.50	63.87 (12.23)	58.71 (7.63)	56.70 (10.72)	62.61 (7.78)
<i>Finding Meaning through Caregiving – Positive Meaning (FMTCS PM)</i>					
	-0.03	74.96 (11.96)	75.75 (9.65)	78.65 (9.25)	76.09 (10.08)
<i>General Self Efficacy</i>	0.24	31.71 (4.18)	31.79 (4.17)	29.83 (3.74)	30.77 (4.27)

Table D.5

Change in means and standard deviations in the intervention and control groups at 3 months follow up

Study	Effect size	Intervention Group		Control Group	
		Before	After	Before	After
Donaldson et al. <i>Met criteria for psychiatric caseness</i>	no information	no information		no information	
Ghatak <i>Caregivers' outcomes</i>	no information	no information		no information	

Table D.6

Change in means and standard deviations in the intervention and control groups at 5 months follow up

Study	Effect size	Intervention Group		Control Group	
		Before	After	Before	After
Hepburn et al. <i>Beliefs about Caregiving Scale (BACS)</i>					
Nurturing	0.37	N/A	27.46 (6.95)	N/A	25.07 (6.37)
Monitoring	0.31	N/A	61.39 (9.98)	N/A	58.28 (9.9)
Behaviour Frequency	-0.07	N/A	6.52 (5.44)	N/A	1.73 (1.80)
Response to Behavior	-0.38	N/A	4.15 (4.36)	N/A	5.79 (4.37)
Depression	-0.45	N/A	12.00 (7.67)	N/A	16.01 (9.11)
Burden	-1.00	N/A	53.87 (12.40)	N/A	59.45 (5.58)

Table D.7

Change in means and standard deviations in the intervention and control groups at 6 months follow up

Study	Effect size	Intervention Group		Control Group	
		Before	After	Before	After
Ghatak <i>Caregivers' outcomes</i>	no information	no information		no information	
Smith et al. <i>Caregivers' outcomes</i>	no information	no information		no information	

Table D.8

Change in means and standard deviations in the intervention and control groups immediately before and after

Study	Effect size	<u>Intervention Group (Anger Management)</u>		<u>Control Group</u>	
		Before	After	Before	After
Coon et al.					
<i>State anger (STAXI)</i>	-1.60	13 (0.84)	12.1 (0.75)	11.5 (0.84)	13.3 (0.75)
<i>MAACL Hostility subscale</i>	-3.09	9.2 (0.85)	7.1 (0.94)	8.5 (0.85)	10 (0.94)
<i>MAACL Depression subscale</i>	-1.15	16.4 (1.3)	15 (1.3)	14.6 (1.3)	16.5 (1.3)
<i>Negative Coping (WCCL-R)</i>	0.50	28.1 (2)	28.9 (2.1)	29.1 (1.9)	27.9 (2)
<i>Positive Coping (WCCL-R)</i>	1.41	52.1 (1.9)	56 (1.8)	54.1 (1.8)	53.6 (1.7)
<i>Self-efficacy</i>					
<i>Managing behaviours</i>	2.79	57.3 (3.6)	70 (3.3)	62.5 (3.6)	60.8 (3.3)
<i>Controlling thoughts</i>	0.89	59.6 (3.8)	67.3 (3.7)	68.8 (3.8)	64 (3.7)
	Effect size	<u>Intervention Group (Depression Management)</u>		<u>Control Group</u>	
		Before	After	Before	After
<i>State anger (STAXI)</i>	-2.13	13.7 (0.85)	11.7 (0.76)	11.5 (0.84)	13.3 (0.75)
<i>MAACL Hostility subscale</i>	-2.13	11 (0.88)	8 (0.97)	8.5 (0.85)	10 (0.94)
<i>MAACL Depression subscale</i>	-0.85	17.8 (1.4)	15.4 (1.3)	14.6 (1.3)	16.5 (1.3)
<i>Negative Coping (WCCL-R)</i>	1.05	33 (2)	30 (2.1)	29.1 (1.9)	27.9 (2)
<i>Positive Coping (WCCL-R)</i>	0.47	55 (1.9)	54.4 (1.8)	54.1 (1.8)	53.6 (1.7)
<i>Self-efficacy</i>					
<i>Managing behaviours</i>	-0.30	55.5 (3.6)	59.8 (3.3)	62.5 (3.6)	60.8 (3.3)
<i>Controlling thoughts</i>	-1.16	52.5 (3.7)	59.7 (3.6)	68.8 (3.8)	64 (3.7)

Table D.9

Change in means and standard deviations in the intervention and comparison groups immediately before and after

Study	Intervention - Cognitive-Behavioral Group		Comparison - Information-Support Group	
	Before	After	Before	After
<i>Gendron et al.</i>				
<i>Structured Interview</i>				
Assertion				
Ext. Family	10.9 (2.1)	11.2 (2.0)	10.1 (2.1)	8.8 (1.3)
Children	11.0 (2.5)	10.5 (2.4)	10.6 (2.6)	10.1 (2.3)
Friends	9.5 (1.4)	9.6 (1.8)	9.2 (1.1)	8.8 (1.7)
<i>Rathus Scale</i>	4.1 (38.1)	0.1 (33.3)	3.7 (21.8)	0.1 (20.3)
<i>Dyadic Adjustment Scale</i>				
Marital Adjustment				
Global	96.9 (16.5)	93.9 (21.4)	97.3 (17.4)	101.3 (11.6)
Satisfaction	34.3 (7.0)	33.6 (7.6)	34.2 (5.9)	36.4 (5.3)
Consensus	45.9 (5.6)	43.4 (8.6)	44.9 (8.9)	45.2 (6.5)
Expression	9.1 (3.2)	9.2 (3.5)	10.7 (1.8)	10.7 (1.1)
Cohesion	7.6 (5.5)	7.6 (5.6)	7.6 (4.8)	9.1 (4.1)
<i>Hopkins Symptom Checklist</i>				
Psychological Distress				
Somatization	17.8 (6.1)	16.7 (4.0)	17.9 (4.3)	18.4 (3.2)
Obsessive-comp.	12.4 (3.9)	12.3 (3.2)	12.6 (3.1)	12.6 (2.1)
Sensitivity	10.9 (2.5)	11.1 (3.6)	12.3 (3.1)	13.1 (3.6)
Depression	18.4 (5.5)	19.3 (7.3)	20.8 (5.0)	22.1 (5.5)
Anxiety	10.3 (2.5)	10.9 (3.3)	10.4 (3.4)	9.9 (2.4)
<i>Automatic Thoughts Questionnaire</i>				
Negative Thoughts				
Perception of Maladjustment	7.2 (1.5)	6.9 (2.2)	9.1 (2.9)	9.2 (2.2)
Neg. Self-concept	9.2 (2.6)	9.2 (3.1)	11.2 (2.7)	10.9 (3.5)
Low Self-esteem	2.1 (0.5)	2.1 (0.5)	2.4 (0.9)	2.4 (0.9)
Helplessness	2.6 (0.8)	2.2 (0.5)	2.9 (1.1)	2.7 (1.1)
<i>Jalowiec Coping Scale</i>				
Coping Styles				
Confrontive	39.8 (8.9)	37.4 (9.4)	39.0 (10.1)	37.0 (7.8)
Emotive	18.6 (3.4)	18.2 (3.8)	18.9 (4.7)	17.6 (3.4)
Palliative	29.7 (6.2)	31.3 (5.3)	32.9 (6.9)	31.4 (7.3)
<i>Burden Interview Scale</i>				
Perceived Burden	1.3 (0.6)	1.6 (0.6)	1.0 (0.5)	1.3 (0.6)
<i>Structured Interview</i>				
Services received	1.2 (1.2)	1.5 (0.9)	0.9 (1.2)	0.8 (1.2)

Table D.10

Change in means and standard deviations in the intervention and comparison groups immediately before and after

Study	<u>Intervention 1 – Telephone Training</u>		<u>Intervention 2 – In-Home Training</u>		<u>Comparison – Friendly Calls</u>	
	Before	After	Before	After	Before	After
Davis et al. (SCB-A)	26.9 (9.8)	29.9 (7.8)	39.8 (12.0)	30.0 (10.9)	37.0 (12.1)	35.0 (12.0)
Caregiving burden (SCB-B)	14.2 (6.6)	12.8 (6.3)	21.4 (13.5)	15.2 (9.6)	18.2 (10.6)	15.6 (12.0)
Caregiving distress						

Change in means and standard deviations in the intervention and comparison groups at 3 months follow up

	<u>Intervention 1 – Telephone Training</u>		<u>Intervention 2 – In-Home Training</u>		<u>Comparison – Friendly Calls</u>	
	Before	After	Before	After	Before	After
(SCB-A)	26.9 (9.8)	27.4 (7.2)	39.8 (12.0)	31.7 (12.0)	37.0 (12.1)	37.0 (11.8)
Caregiving burden (SCB-B)	14.2 (6.6)	11.2 (8.3)	21.4 (13.5)	12.8 (9.5)	18.2 (10.6)	20.5 (16.3)
Caregiving distress						

### 3.8. *Satisfaction with the training intervention*

Of the five studies, only the two comparative studies measured the participants' satisfaction with the training interventions. In Gendron et al.'s study [9], participants reported a high degree of satisfaction with the intervention programme. They found the intervention interesting (97.1%), realistic (100%), useful (85.7%) and practical (100%). They felt the intervention had fulfilled many of their needs (77.1%) and found that it helped them cope with their situation more efficiently (97.1%). In Davies et al.'s [4] study, mean scores of satisfaction were reported but no further description was mentioned.

### 3.9. *Age, gender and years of education*

Participants from the five studies were all aged between 60 and 75. Of the participants across all the studies; 83% were female, and 90% were either spouses or daughters. They had received around 12 to 15 years of education. Most of the participants (90%) were white. All five studies reported no difficulty for the participants in attending the interventions.

### 3.10. *Depression*

Of the five studies, four measured participants' level of depression before and after their training interventions. Three studies, Martin-Cook et al., Hepburn et al. (2001) and Coon et al. showed small to large effect sizes of outcome measures on depression respectively. Gendron et al. showed no significant change in their participants' level of depression after the training intervention.

### 3.11. *Caregiving distress*

Outcome measures for distress specific to caregiving were only found in Davis et al.'s study. Changes in mean scores across the three comparison groups indicated some effect of intervention in reducing caregiving distress.

### 3.12. *Caregiving burden*

Outcome measures for the burden specific to caregiving were used in three studies – Gendron et al., Davis et al. and Hepburn et al. (2001). Gendron et al.'s study showed no change in the reduction of caregiving burden, whereas Davis et al. showed positive changes and Hepburn et al. indicated large effect in the reduction of perceived caregiving burden.

### 3.13 Coping

In their studies, Gendron et al. and Coon et al. measured caregivers' coping capacities. Gendron et al. showed small change over a palliative coping style in their intervention group, whereby Coon et al.'s anger management group showed large effect in outcome measures on participants' use of positive coping and medium effect on reducing the use of negative coping. In their depression group, medium effect on the use of positive coping and large effect on reducing the use of negative coping were found.

### 3.14 Self-efficacy

Martin-Cook et al. and Coon et al. both measured participants' self-efficacy. Small effects were shown in Martin-Cook et al.'s study at seven weeks and at seventeen weeks follow up. Coon et al.'s study showed large effect in their anger management group, whereas in their depression management group, effects were found within the group before and after intervention, however no effect was indicated when compared to the control.

### 3.15 Cognitive Behavioural Approach

The two studies, Coon et al. and Gendron et al., using cognitive behaviour approach in their training interventions showed contrasting results. Coon et al.'s study showed the largest effect sizes in comparison with all the other studies, whereby Gendron et al.'s showed the least significant result among the five included studies.

## 4. Discussion and conclusion

### 4.1. Discussion

Based on the data from the five studies in this systematic review, there is some evidence that psychoeducational and skills training is useful in reducing caregivers' depression, distress and sense of burden, and in increasing their coping and self-efficacy. This systematic review has revealed a scarcity of studies emphasising the effectiveness of training intervention for family carers for people with dementia. Only three randomised controlled studies and two comparative studies were included, covering different training interventions to provide family carers with knowledge, coping skills and caregiving outlook. Small to medium effects were demonstrated in each individual study, and because the sample sizes (see Table D.1) of the three randomised controlled studies were good, consideration can be given to the statistical

power of each of these study. However, as the overall effect size of the three randomised controlled studies was impossible to obtain because of the different outcome measurements used in each study, little can be concluded about the effectiveness of training interventions for family caregivers of dementia sufferers.

The five studies all provided similar skill training but varied in timeframes and approaches of delivery of their interventions.

In Martin-Cook et al.'s study, four-week training sessions aimed to engage caregivers, particularly in breaking tasks into smaller steps, as well as other visual, auditory, tactile, or multimodal cues and prompts to facilitate improved performance. In their study, many caregivers underestimated or overestimated their care recipient's level of function. As they came to have a more realistic idea about their care recipient's actual abilities, it might also be distressing for them to face the reality. The need for cognitive readjustment in coming to terms with the care recipient's progressive illness is beyond the interventions due to the brevity of the four-week training sessions.

Similar issues may also be relevant in the study conducted by Gendron et al. that showed no effect when a cognitive behavioural approach was used. Gendron et al. suggested that the significantly lower ratings of global marital adjustment and marital satisfaction by their cognitive behavioural group may be due to the cognitive restructuring component that helped spouses to become more aware of unrealistic ideas in their thinking. The cognitive restructuring element may have led the caregivers to view their situation more realistically. As a result, caregivers developed a heightened awareness of the progressive impact of dementia on their marriage (Gendron et al. 1996).

Training intervention using a cognitive behavioural approach was not at all ineffective, as it was revealed in Coon et al.'s study that yielded the best results in this systematic review. Grounded in the cognitive behavioural principles in its structure, they used a combination of social learning theory, cognitive and behavioural approaches to design their training interventions.

In their study, Coon et al. stated that mediators and moderators are two important factors that built up the evidence of the impact of their study. In terms of mediation, changes in caregiver self-efficacy for controlling upsetting thoughts accounted for changes in hostility and depression. These results indicated that changes in caregivers' perceived competence to handle their caregiving situations because of the intervention was even more decisive in yielding outcome than the skills learned in the interventions (Coon et al.). In terms of moderators of their study's interventions,

caregivers with fewer depressive symptoms before intervention were more likely to reduce use of their negative coping strategies. The implication here is that depressed people must first learn intervention strategies and add positive coping strategies until the depression is more effectively managed; only then can they reduce their reliance on their familiar negative coping patterns (Coon et al.). Coon et al.'s well-designed study has identified an important research question that is worthy of further exploration. Personal characteristics and individual differences can be elements that help to structure a more defined and specific intervention for the caregivers.

Among the other four studies that delivered training in the form of workshop sessions, Davis et al. used a one-to-one approach in their comparative study with three groups of caregivers. There were significant changes in caregiving burden and distress among the in-home one-to-one training participants in comparison with the telephone and the friendly call group participants. This might be due to the fact that more time was spent with the in-home training group, who averaged 65 minutes per contact, whereby the telephone training contacts averaged 37 minutes and friendly call group contact averaged 16 minutes per contact. The significant effect of the in-home training may be due to the convenience the intervention offered to the participants, which saved their time travelling to the training venue. It is noted that the caregiving burden rating in the telephone training group was higher after the intervention and at three months follow up. The rating in this group was the only group that showed a negative effect after the intervention. In addition, dropout rate was predominately high in the telephone training group.

The implication is that one-to-one training through telephone may not be an effective way of delivering intervention for family caregivers. It is noted that the mean age (76.7) of this group of caregivers was the highest in comparison with the other two groups and with all the other four studies. Further research study using a younger sample may be helpful in finding out whether there is an age factor linked to the suitability of delivering telephone training to caregivers. As Davis et al. commented, despite the absence of caregiving information and skills training, 67% of the caregivers in the friendly call comparison group found the benefits of a brief, social phone call sufficient incentive to remain in the 24-week study. These findings suggested that social contacts are a necessary part of effective caregiver interventions. In their study, Gendron et al. maintained a weekly telephone contacts with participants in between group sessions and the provision of financial assistance to settle both transportation and sitter costs. The weekly contacts might have contributed to maintain group attendance (Gendron et al.).

#### **4.2. Implications for future empirical research**

The paucity of studies on the effectiveness of training intervention for family carers for people with dementia calls for the need for more research, especially well-designed randomised controlled studies to further investigate the limitations identified in this systematic review.

Assessment of each carer's self-efficacy level might be useful prior to training intervention. Coon et al. suggested that self-efficacy might have a mediating effect on determining the effectiveness of the training intervention, that is, the higher a carer's level of self-efficacy, the more she/he can learn and benefit from the training. More research studies on building up self-efficacy as a component when designing training intervention for family carers will be useful.

Personal characteristics of the participants, for example, depressive symptoms, may first be addressed by teaching depression management skills before they are allocated to other skill building and coping interventions. Future researchers could explore the impact of personal characteristics as the intervention mediator and moderator effects.

Limitations were found in studies using a purely cognitive behaviour approach in the training intervention. As Martin-Cook et al. suggested, feelings relating to this type of awareness of loss and relationship issues may be better served with some form of counselling and ongoing support. More research on the use of a combination of skill training, cognitive behavioural approach and social support may be useful.

It was found that most of the participants in the five studies in this systematic review were mostly white (over 90%). Further research studies exploring the effectiveness of training intervention are important to address the cultural factors that may or may not have an impact on non-white caregivers.

As already mentioned, further research study using a younger sample may be helpful in finding out whether there is an age factor linked to the suitability of delivering telephone training to caregivers.

#### **4.3. Implications for practice**

It is difficult to make any specific recommendation on implications for practice because of the small number of studies included in this systematic review. In addition, of the five studies, only one study showed strong evidence, whereas the

other four studies showed some evidence to suggest that training interventions for family caregivers reduced their level of depression and their caregiving burden and improved their self-efficacy.

In following the methodological approach to this systematic review, it has been necessary to abandon several potentially useful articles on the basis that statistical information was not available for the computation of the effectiveness of the studies (Donaldson, 2001; Smith & Bell, 2005; Ghatak, 1994).

Coon et al. identified the importance of considering caregivers' personal characteristics before intervention as that might determine whether the caregivers are suitable or ready for the training intervention. In this regard, training interventions designed for family caregivers should be more individually targeted. From the five included papers that were reviewed, it became clear that a combination of psychoeducational training and social intervention would have been helpful, suggesting that a more comprehensive approach in interventions for family caregivers is recommended.

#### **4.4. Conclusion**

Support for family caregivers of people with dementia is a key priority for the UK Department of Health (NICE clinical guideline, 2006). Reflection on the current systematic review shows that training interventions can also be effective; however, there is not enough research to be conclusive about the effectiveness of the types of training designed to meet the family carers' needs. Better research into this field should be a priority for those interested in improving the lives of carers for people with dementia.

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# **APPENDICES**

## Appendix B.1.

### Research: The Chinese 8-item Scale

1. 我有一班支持我的朋友
2. 我喜歡和一些同我背景差不多的照料者分享經驗
3. 和社區中心有緊密聯繫是很有幫助的
4. 我有機會向政府醫療機構發表意見，感到自己很有能力
5. 我知道用什麼字眼來和醫療機構對話
6. 我所照顧的人接納我的幫助
7. 我熟悉醫療服務系統
8. 我有權力作決定，我感到我是能作主的

## Appendix B.2.

### Research: The Chinese 48-item Scale

1. 我有一班支持我的朋友
2. 我需要幫助時可以到社區中心
3. 我有一個正確的策略和政府醫療機構對話
4. 當我有壓力的時候，我的家人都不能夠給我支持
5. 當我需要幫助時，也沒有多少個朋友可以給我支持
6. 我和我所照顧的人的關係是互相支持的
7. 我喜歡和一些和我背景差不多的照料者分享經驗
8. 我喜歡和其他照料者彼此支持的關係
9. 我對我所照顧的人的病有足夠的認識
10. 參加研討會議令我感到更有自信
11. 我不喜歡和一些和我背景差不多的人分享經驗
12. 和社區機構有緊密聯繫是有幫助的
13. 在一個小組裏能加添我的力量
14. 我所照顧的人接納我給予的幫助
15. 我不認為社區機構能夠給予我幫助
16. 我所照顧的人不信任我
17. 因為我有一個很支持我的家庭，所以有壓力時我能應付
18. 我對我所照顧的人的病認識不多
19. 我不認為參加研討會議能提高我的自信
20. 我知道到何處找到適當的醫療服務
21. 我所到的社區機構並不是很支持對我
22. 別人不聽取我的意見我也沒有所謂
23. 我不知道我所照料的人應該得到何等的醫療服務
24. 我覺得社區中心是不能夠提供適當的資料和提議的
25. 我有一個正確的策略和醫療機構對話
26. 我有權力作決定，我感到我是能作主的
27. 有機會向政府醫療機構發表意見，會感到自己有能力
28. 因為我所提供的意見而看見醫療服務有真正的改變，會增添我的能力
29. 我所照顧的人不接受我為他／她作決定
30. 我向政府醫療機構說什麼都可以，令我感到我是有能力的
31. 我需要擔當所有的事務，沒有人幫助我
32. 即使現在沒有需要，但知道在那裡可以找到幫助總是好的
33. 當我有需要時，我可從社區機構取得適當的資料
34. 向政府醫療機構發表意見是沒用的
35. 我不敢和政府醫療機構提出我的意見
36. 我所照顧的人不接納我的幫助
37. 我能夠用正確的英語來投訴
38. 很多時候我都沒有權力作什麼決定
39. 有人聽我說的意見，令我感到被尊重
40. 我對醫療服務不很了解
41. 我有膽量同政府醫療機構對話
42. 我覺得去社區中心是沒有幫助的
43. 我所照顧的人信任我，並讓我為他／她作決定
44. 我所照顧的人信任我
45. 我可以將事務交給別人處理，令我感到我是有話事權的
46. 我了解醫療服務
47. 我所照顧的人不信任我，令我感到挫敗
48. 我沒有能力用英文去投訴

Appendix B.3.

Research: The measurement tool with scaling in Chinese

根據您的個人經驗和感受，請用一至七為以下的句子評分，一代表極之不贊同，七代表極之贊同	極之不贊同	不贊同	些少不贊同	沒有意見	些少贊同	贊同	極之贊同
1. 我有一班支持我的朋友							
2. 我需要幫助時可以到社區中心							
3. 我有一個正確的策略和政府醫療機構對話							
4. 當我有壓力的時候，我的家人都不能夠給我支持							
5. 當我需要幫助時，也沒有多少個朋友可以給我支持							
6. 我和我所照顧的人的關係是互相支持的							
7. 我喜歡和一些和我背景差不多的照料者分享經驗。							
8. 我喜歡和其他照料者彼此支持的關係							
9. 我對我所照顧的人的病有足夠的認識							
10. 參加研討會議令我感到更有自信							
11. 我不喜歡和一些和我背景差不多的人分享經驗							
12. 和社區機構有緊密聯繫是有幫助的							
13. 在一個小組裏能加添我的力量							
14. 我所照顧的人接納我給予的幫助							
15. 我不認為社區機構能夠給予我幫助							
16. 我所照顧的人不信任我							
17. 因為我有一個很支持我的家庭，所以有壓力時我能應付							
18. 我對我所照顧的人的病認識不多							
19. 我不認為參加研討會議能提高我的自信							
20. 我知道到何處找到適當的醫療服務							
21. 我所到的社區機構並不是很支持倒我							
22. 別人不聽取我的意見我也沒有所謂							
23. 我不知道我所照料的人應該得到何等的醫療服務							
24. 我覺得社區中心是不能夠提供適當的資料和提議的							
25. 我有一個正確的策略和醫療機構對話							
26. 我有權力作決定，我感到我是能作主的							
27. 有機會向政府醫療機構發表意見，會感到自己有能力							
28. 因為我所提供的意見而看見醫療服務有真正的改變，會增添我的能力							
29. 我所照顧的人不接受我為他／她作決定							
30. 我向政府醫療機構說什麼都可以，令我感到我是有能力的							
31. 我需要擔當所有的事務，沒有人幫助我							
32. 即使現在沒有需要，但知道在那裡可以找到幫助總是好的							
33. 當我有需要時，我可從社區機構取得適當的資料							
34. 向政府醫療機構發表意見是沒用的							
35. 我不敢和政府醫療機構提出我的意見							
36. 我所照顧的人不接納我的幫助							
37. 我能夠用正確的英語來投訴							
38. 很多時候我都沒有權力作什麼決定							
39. 有人聽我說的意見，令我感到被尊重							
40. 我對醫療服務不很了解							
41. 我有膽量同政府醫療機構對話							
42. 我覺得去社區中心是沒有幫助的							
43. 我所照顧的人信任我，並讓我為他／她作決定							
44. 我所照顧的人信任我							
45. 我可以將事務交給別人處理，令我感到我是有話事權的							
46. 我了解醫療服務							
47. 我所照顧的人不信任我，令我感到挫敗							
48. 我沒有能力用英文去投訴							

**Appendix B.4.**

**Research: The measurement tool with scaling in English**

Based on your own experiences and feelings, please rate the following statements using a 7-point scale when 1 is strongly disagreed and 7 is strongly agreed.	Strongly Disagree	Disagree	Slightly Disagree	No Comment	Slightly Agree	Agree	Strongly Agree
1. I have a supportive network of friends.							
2. I can get support from the community centre when I need help.							
3. I have the right strategy to talk to the health authority.							
4. My family is unable to support me when I am under stress.							
5. I don't have many friends who could support me when I need help.							
6. I have a supportive relationship with the person whom I care for.							
7. I like sharing experiences with carers from a similar background.							
8. I enjoy the supporting relationship with other carers.							
9. I have enough knowledge about the illness of the person whom I care for.							
10. Attending a consultation event made me feel more confident.							
11. I don't like sharing experiences with people from a similar background.							
12. A strong link to community organisation is helpful.							
13. Being involved in a group is empowering.							
14. The person I care for accepted my help.							
15. I don't think community organisation can give me help.							
16. The person I care for does not trust me.							
17. I can deal with stressful situations because I have a supportive family.							
18. I don't have enough knowledge about the illness of the person I care for.							
19. I don't think a consultation event would make me feel more confident.							
20. I know where to get the right health services.							
21. The community organisation I go to is not supportive.							
22. I feel okay even when people don't listen to me.							
23. I don't know what health services the patient is entitled for.							
24. I don't think community organisation can give me the right information & advice.							
25. I have the right strategy to talk to the health authority.							
26. I feel in charge because I have right to make decision.							
27. I feel enabled when I have the chance to speak to the authority.							
28. To see real changes in statutory health services because of my opinions is empowering.							
29. The person I care for doesn't want me to make decision on his/her behalf.							
30. Giving opinion to the authority without restriction is empowering.							
31. I have to do all the things on my own, nobody helps me.							
32. It is good to know that help is out there even though I may not need it now.							
33. The community organisation has the right info for me whenever I need it.							
34. I don't think speaking to the authority is useful.							
35. I don't have the courage to talk to the authority.							
36. The person I care for does not accept my help.							
37. I have the right words to complain in English.							
38. I don't have the power to make decision most of the time.							
39. I feel respected when I am listened to.							
40. I don't know much about the health service system.							
41. I have the courage to speak to the health authority.							
42. I don't think going to community organisation is helpful.							
43. The person I care for trusted me to make decision on his/her behalf.							
44. The person I care for trusted me.							
45. I feel in charge because I can delegate things to other people.							
46. I am familiar with the health service system.							
47. I feel discouraged because I don't have rapport with the person I care for.							
48. I don't have the ability to complain in English.							

**Appendix B.5.**

**Research: The revised 47-item scale**

<p><b>Based on your own experiences and feelings, please rate the following statements using a 7-point scale when 1 is strongly disagreed and 7 is strongly agreed.</b></p>	Strongly Disagreed	Disagreed	Slightly Disagreed	Neutral	Slightly Agreed	Agreed	Strongly Agreed
1. I have a supportive network of friends							
2. Joining the activities in the community centre can help to relieve my stress in caring							
3. I have the right strategy to talk to the health authority							
4. My family is unable to support me when I am under stress							
5. I don't have many friends who could support me when I need help							
6. I have a supportive relationship with the person whom I care for.							
7. I like sharing experiences with carers from a similar background.							
8. I enjoy the supporting relationship with other carers.							
9. I have enough knowledge about the illness of the person whom I care for.							
10. Attending a consultation event made me feel more confident							
11. I don't like sharing experiences with people from a similar background.							
12. A strong link to community organisation is helpful.							
13. Being involved in a group is empowering.							
14. The person I care for accepted my help.							
15. Joining the activities in the community centre cannot help to relieve my stress in caring							
16. The person I care for does not trust me.							
17. I can deal with stressful situations because I have a supportive family							
18. I don't have enough knowledge about the illness of the person I care for.							
19. I don't think a consultation event would make me feel more confident.							
20. I know where to get the right health services.							
21. The community organisation I go to is not supportive.							
22. I feel okay even when people don't listen to me.							
23. I don't know what health services the patient is entitled for.							
24. I don't think community organisation can give me the right information and advice							
25. I have the right strategy to talk to the health authority.							
26. I feel in charge because I have right to make decision.							
27. I feel enabled when I have the chance to speak to the authority.							
28. To see real changes in statutory health services because of my opinions is empowering							
29. The person I care for doesn't accept me to make decision on his/her behalf.							
30. Giving opinion to the authority without restriction is empowering.							
31. I have to do all the things on my own, nobody helps me.							
32. It is good to know that help is out there even though I may not need it now.							
33. The community organisation has the right information for me whenever I need it.							
34. I don't think speaking to the authority is useful							
35. I don't have the courage to talk to the authority.							
36. The person I care for does not accept my help							
37. I have the right words to complain in English							
38. I don't have the power to make decision most of the time							
39. I don't know much about the health service system.							
40. I have the courage to speak to the health authority.							
41. I don't think going to community organisation is helpful.							
42. The person I care accepted me to make decision on his/her behalf.							
43. The person I care for trusted me.							
44. I feel in charge because I can delegate things to other people.							
45. I am familiar with the health service system.							
46. I feel discouraged because I don't have rapport with the person I care for.							
47. I don't have the ability to complain in English.							

## **Appendix B.6.**

### **Research: Information sheet & consent form**

#### **Participation, community empowerment of Chinese carers of Dementia**

##### INFORMATION LEAFLET

Thank you for reading this leaflet. We are conducting a research with Chinese carers for Dementia. The objective of the research is to build up Chinese carers' confidence and skills through group participation. Ideas of participatory activities will be discussed and decided by carers in order to empower them in the process of care giving. The researcher will work with the Chinese carers which involve a period of five months. In the first month, the researcher will help the carers to identify a clear goal for participation and the idea of empowerment. The researcher will then facilitate the group to identify their needs and expectations as a carer, followed by setting out outcomes, priorities and action plan.

The researcher will apply different participatory appraisal methods such as Time Trends Analysis (constructing a visual image on a flipchart the historical and future mapping of the topic in discussion), Diagrams (the use of flow chart, causal diagram or pie charts etc. to represent the group's opinions), Mapping Techniques (a visual tool for mobility mapping and social mapping, e.g. a map to show a carer's typical day of life). The aims of the first month of participation are to build up trust between the research and the group and amongst the carers themselves; and to let the carers to decide the agenda of the activities in the following two months. Carers will be asked to fill out a questionnaire which works as a baseline measurement of their sense of empowerment.

In the second and third month, the researcher will work according to the action plan set forth by the group. In these couple of months, researcher will carry out intervention with the group by its participation in achieving the action plan. At the stage, the researcher will work closely with the carers as a facilitator and a resource provider who helps them in achieving their goals. The purpose of these two months is to enable or empower the carers to build up their strengths in the areas where they identified as needed to be empowered. At the end of the two-month period, carers will be asked to fill out again the same questionnaire which they were asked to fill out in the first month of the research. The same questionnaire will measure the sense of empowerment after the intervention takes place. The researcher will conduct a focus group to explore the process of empowerment and the lessons learned from the process.

After the researcher has worked with the carers to achieve their goals through facilitation, support and advice, the researcher will then stay back from the group. The researcher's goal is to testing whether she has built up the carers' skills to sustain and maintain the group to work on its own. The same questionnaire will be used to measure the carers' sense of empowerment at the end the research study. A focus group will be conducted to explore the process of empowerment and the lessons learned from the process.

This research study is basically safe and do not expect the participants to suffer any harm or injury because of their participation in it. However, there could be some emotional distress when interviewing the participants especially when they talk about experiences which relate to their or their family member's illness. The research is a trainee health psychologist has the relevant education background and experience in identifying potential risk of emotional distress during the course of group discussion and one-to-one interview. In the situation when the participant is distressed, or upset, the researcher will ask the participants whether they wish to take a break, or stay back from the group, or change the line of questioning in case of one-to-one interview. If further support is required, the person will be asked if they would be referred to CMHA counselling service where he/she can receive counselling support.

Personal details – we will need to keep your personal details on file. This will be stored in a locked filing cabinet. Only Rebecca Tang from CMHA & Catherine Sykes from City University will have access to this data. The result of the evaluation will be published in reports, journal articles and conferences; all data will be anonymous.

If you decide to join, please sign on the following consent form. However in any situation you think you would like to withdraw from the research, you have the right to do so at anytime. If you would like more information about this research and evaluation, please contact Rebecca Tang.  
Version 1 – January 2006

**CONSENT FORM**

**Title of Project:** Participation, community empowerment of Chinese carers of Dementia

**Name of Researcher:** Rebecca Tang

**Please initial box**

- 1. I confirm that I have read and understand the information sheet dated .....for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 copy for participant; 1 copy for researcher

## **Appendix B.7.**

### **Research: Interview schedule**

#### **Understanding the carer's participation in the research group**

1. You have been attending the carers' group for a few months, in the group meetings, what did you usually do?
2. Did you help out in the group meeting, such as buying food stuff etc.?
3. What made you decided to join this carers' group?

*Following the reason she joined the group...*

4. Do you think the group in the last few months has fulfilled the reason for your joining the group?

#### **Understanding the carers' experience during the participation process**

5. In the group, was there anything that you like most? And why?
6. In the group, was there anything that you did not like most? And why?
7. What was the most interesting thing you found in the group? And why?
8. What was the most difficult thing you came across in the group? And why?
9. Did the group help you in anyway? If yes, please explain.
10. Did the group help you in anyway as a carer? If yes, please explain.
11. Did the group help you to build up a better relationship with the workers in the women's group? If yes, please explain.
12. Do you feel more confident after joining the group? If yes, please explain.
13. What is meaning of this carers' group to you?
14. Do you think this carers' group can do more for the benefit for you as a carer? If yes what is that?

## Appendix C.1.

### General Professional Development:

#### Code of good practice – Setting up Work Boundary with Helpline Caller

##### 1. Personal details

**DO NOT** give the caller personal details about yourself or your colleagues, such as surname, personal address, phone number or other details about yourself or your colleagues. Preserving a helpline worker's own anonymity is a protection against a caller who might otherwise intrude on your personal or family life.

##### 2. Focus on the caller

Your focus as a helpline worker should be on the caller. Talking about your own experiences – such as what you found helpline in such a situation – changes the dynamic of the call. It interferes with your ability to focus on the caller. This might be appropriate for a self help support group but not on a mental health helpline.

##### 3. The limits to your knowledge

It is not what you know that matters but your willingness to assist callers to find things out. For example a new helpline worker on an information service may feel uncomfortable about their lack of experience and want to be seen as an expert. Honesty is important in any relationship including that of helpline worker and caller. If you don't know something then it is better to say so and be willing to find out or provide the caller with details of a more appropriate service.

##### 4. Medical and Legal advice

As only those who are qualified to provide medical advice or legal advice i.e. doctors or lawyers, are entitled to give the relevant advice. We are **NOT** entitled to give medical and legal advice on the helpline. If you give information about mental health problems or provide legal rights information, you need to ensure that callers understand your role and its limits. You need to tell them that you are not medically or legally trained as appropriate to the situation and that you cannot give medical or legal advice.

##### 5. Quoting the sources of information

It is good practice to quote the source of any information you provide over the phone to emphasise the role you are performing.

##### 6. Professional indemnity insurance

A caller could sue our service for giving bad advice. Standard 4.6 of the MHHP Quality Standard states: *If the helpline gives callers information and/or advice, signposts or makes referrals on which they might rely to make significant decisions, and the decisions could involve the caller in expense or distress for which they might want to recover damages or costs, then the helpline carries professional indemnity insurance and keeps records as required according to the insurance policy.* Our helpline service carries professional indemnity insurance, and it is very important that helpline workers accurately record and log all calls on the call logging data system or record on a log sheet.

## **Appendix C.2.**

### **Training: Course outline**

## **A PERSON-CENTRED APPROACH TO DEMENTIA CARE**

### **Day One**

- Introductions and purpose of the course
- The experience of dementia
- Facts about dementia: types, symptoms and their causes, statistics, risk factors
- Factors which can cause or contribute to difficulties in dementia
- Establishing guidelines for good practice
- Compensating for difficulties caused by dementia
- Making the most of remaining strengths
- Caring in partnership
- Key points and action planning

### **Day Two**

- Basic principles of communication
- Non-verbal communication
- Guidelines for good communication
- Meeting the needs of the whole person
- Individual responses to dementia
- Developing knowledge about people with dementia as individuals
- Responding to different realities of people with dementia
- Understanding messages behind challenging behaviour
- Responding to strong feelings
- Key points and action planning

### **Day Three**

- Reasons behind challenging behaviours
- Understanding and preventing aggressive behaviour
- Responding to challenging behaviour and meeting needs
- Understanding and responding to walking ('wandering')
- Well-being in dementia
- Identifying and monitoring well-being
- The purpose of occupation for people with dementia
- Suiting occupations to individual needs
- Key points and action planning

## Appendix C.3.

### Training: Sample handouts used in the training program

#### WELL-BEING AND ILL-BEING

In spite of their failing mental powers, it is possible for many people with dementia to be in a state of well-being. This can happen when the person with dementia is receiving care which meets their psychological needs as well as their physical needs.

Since people with dementia are often unable to tell us exactly how they are faring, we need to use sensitive observation to assess their well-being. There are particular signs we can look for (which have been identified through research) which let us know if a person with dementia is in a state of well-being. An individual's personality and life history will influence the degree to which these signs are expressed, but the crucial fact is that all these signs can be present even in people who have severe dementia.

#### Signs of Well-Being

- \* Making wishes known (non-destructively)
- \* Making contact with other people
- \* Warmth and affection
- \* Self-respect
- \* Being helpful
- \* Sense of humour
- \* Bodily relaxation
- \* Creative self-expression
- \* Showing pleasure or enjoyment
- \* Responding appropriately to other
- \* Expressing appropriate emotions
- \* Holding his/her own socially
- \* Alertness, responsiveness
- \* Using remaining abilities
- \* Using remaining abilities
- \* Being purposeful

In contrast, the following signs indicate that a person is in a state of ill-being:

#### Sign of Ill-Being

- \* Depression or despair
- \* Intense anger or aggression
- \* Anxiety or fear
- \* Agitation
- \* Apathy and withdrawal
- \* Physical discomfort or pain
- \* Unresolved grieving over losses
- \* Bodily tension
- \* Boredom
- \* Distress
- \* Easily walked over by others
- \* Being an outsider / cultural isolation

A state of ill-being might occur because a person's psychological needs are not being met. It might also represent a long-standing pattern of depression or be related to physical health problems or neurological impairments. Most of the time, ill-being is not an inevitable symptom of dementia. Anyone who is in a state of ill-being needs special attention in order to do everything possible to meet their needs.

**Bradford Dementia Group**

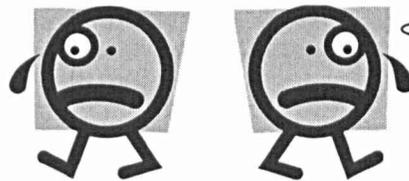
## THE OLD & NEW CULTURES OF DEMENTIA CARE

	Old	New
<b>Attitudes</b>	Dementia care is a backwater, suited to staff of low ability, little inspiration and few qualifications.	Dementia care is one of the richest areas of human work, requiring high levels of ability and resourcefulness.
<b>General View</b>	The primary dementias are devastating illnesses in which personhood and identity are progressively dismantled.	Dementing illnesses should be seen primarily as forms of disability. How the person is affected by their disease depends crucially on their quality of care.
<b>Source of Knowledge</b>	Brain scientists and doctors know most about dementia and its progression.	The most reliable, valid and relevant knowledge is gained by very skilled practitioners of care.
<b>Research</b>	We can't do much until there is a medical breakthrough, therefore more research is needed.	There is a great deal we can do now, simply through insight and skill. This is the most urgent matter for research.
<b>Us and Them</b>	Persons with dementia are significantly different from the rest of us; therefore it is legitimate for staff to have different styles of clothing, cups, chairs, etc.	Persons with dementia are equal members of the human race. We are all, in the most fundamental sense, in the same boat.
<b>What Caring involves</b>	Care is about providing a safe environment, meeting basic needs and giving physical care.	Care is primarily concerned with the maintenance of the personhood of each individual. Basic care is only a part of that.
<b>Priorities in Understanding</b>	It is important to understand a person's impairments clearly and accurately.	It is important to have a clear and accurate understanding of a person's abilities, interests, values, tastes. The focus is on the uniqueness of each person.
<b>'Problem' Behaviour</b>	'Problem' behaviour must be managed skilfully and efficiently.	'Problem' behaviours are attempts at communications, related to need. They almost always make sense in the context of a person's life and the resources they have available.
<b>Caregivers' Feelings</b>	In the process of giving care, we should set aside our feelings, concerns and vulnerabilities and get on with the job.	It is crucial to be in touch with our own feelings and vulnerabilities and transform these into positive resources for our work.
<b>Personhood of Staff</b>	Staff is the servant of the organisation. The organisation's agenda does not include engaging with staff's psychological needs.	Direct care staff is as much in need of respect, nourishing and nurturing as are the persons with dementia for whom they are.

## How would you feel if...

Someone approaches me in the street and starts speaking to me in a foreign language. I tell them that I don't understand, but they keep on repeating themselves.

I'm sitting an exam and I find I can't answer a single one of the questions.



I open my front door to a stranger who tells me that it's time I had a bath.

I am at work when I start to get a stomach ache. Suddenly, without realising it's going to happen, I defecate in my clothes.

Appendix C.5.

Training: Internal organisation script of the training program (the first 2 pages)

A person centred approach to dementia care – 3 day training course

Day before preparation checklist

Handouts photocopied	✓
Exercise sheets photocopied	✓
Evaluation sheet photocopied	✓
Assessor evaluation (if applicable) photocopied	✓
Course outline photocopied	✓
File folders for participants arranged	✓
Flipchart ready	✓
Overhead projector ready	✓
Refreshment arranged	✓
Room set up arranged	✓

Time Keeping	What to say and do	Visual & handouts
<p><b>Day One</b></p> <p>Before it starts</p> <p>1.30 pm</p>	<p>Place the 'course outline' on chairs.</p> <p>Introduce myself.</p> <p><b>Explain how I've come to be running this course:</b> I attended a 10-day training for trainer course run by the 'dementia training &amp; consultancy service last year and became accredited as a trainer for this 3 day course.</p> <p>Shall we introduce ourselves, each in turn to say our name and something you are hoping to get from attending this course?</p> <p>This course was created by Buz Loveday, who ran the course I went on. The purpose of the course is to help staff develop a person centred approach to dementia care...</p>	<p><b>Transparency 1: purpose of the course</b></p>
<p>1.40 pm</p>	<p>The course I am leading contains a lot of materials and information designed to achieve the purpose of the course, but you are not going to be a passive audience, you also need to play a part in order for the purpose of the course to be achieved.</p> <p>Here is a learning contract. I would like you to work together as a group to draw up this contract in order to achieve the purpose of the course.</p> <p><i>Start writing some points on the flipchart and let the group to contribute until all major points are covered, e.g. attending all sessions, starting and finishing on time, paying attention, participating, sharing your experience, keeping confidentiality, being prepared to try out new ideas, being honest, reinforcing content with each other.</i></p>	<p><b>Write on the flipchart – Learning Contract</b></p>
<p>1.45 pm</p>	<p>I would like you to do an exercise which looks at your own feelings. Get yourself into 2 groups as you are going to have the discussion together. Here there are a few situations and your task is to imagine how you might feel if these situations happened to you. You should not imagine you have dementia, just think about how you would feel in each situation if it happened to you today. One of you to write down everyone's</p>	<p><b>My additional handouts (2 pages) to each of them: How do you feel if...</b></p> <p><b>Groups have different</b></p>

	<p>feelings in response to each situation.</p> <p><i>When they have finished, I read out each situation in turn and ask the group which worked on that situation to shout out their feelings. Write down on the flipchart. When a word is repeated, underline it rather than writing it again.</i></p> <p>What do you think is the purpose of doing an exercise like this?</p> <p>These are the types of situations which people with dementia face every day – both as a result of their symptoms, e.g. not recognising the person who has come to give them a bath; and as a result of how others may communicate with them, e.g. a careworker not introduce herself because she assumes the person will remember her.</p> <p>Doing this exercise can be quite an eye-opener about how service users might feel.</p> <ul style="list-style-type: none"> <li>• Although people with dementia may have lost certain mental abilities, they can still experience all the feelings we do. They might lose their memory, but they do not lose their feelings.</li> <li>• We must try to see things from their point of view, and make sure that we are not causing them to experience difficult feelings by the way we approach them.</li> <li>• Some of their strong feelings are caused directly by how they experience dementia (eg frustration about not being able to do things) and we need to develop skills in supporting people with these feelings, I shall come back to this later in this course.</li> </ul>	<p>page</p> <p><b>Flipchart – write the feelings on.</b></p>
1.50 pm	<p>Now I am going to ask you to work in pairs, spending about 5 minutes to do a quiz. This is not a test. It's just a way of getting some facts about dementia.</p> <p>Here you can see an illustration of how Alzheimer's Disease affects the brain. In addition to the shrinkage evident in the picture, there are also plaques and tangles in the structure of the brain and chemical changes. Each of the different types of dementia damages the brain differently, but many of the symptoms are similar.</p> <p><i>Q 5 – discuss; Q 7 – discuss; Q 8 – discuss with T5; Q 9 –14, discuss.</i></p>	<p><b>Q 1 – T 2</b> <b>Q 2 – T 3</b> <b>Q 3 – T 4</b></p> <p><b>Q 4 – T 5 with handout 4; go on to T 6;</b></p> <p><b>Q 6 – T 7 with handout 5</b></p> <p><b>Handout 6 – 7</b></p>
2.15 pm	<p>Dementia is a disability, and like any disability the person is influenced by a number of factors in addition to the disability itself; say for example, the way people with dementia are treated by other people can be a key factor in influencing their difficulties.</p> <p>Let's say this is John, he doesn't have dementia, but a physical disability. He has been involved in a car accident, his spine has been badly damaged and he is paralysed from the waist down.</p> <p>Due to his disability, he is affected by other factors which make the experience of his disability even more difficult. Dementia is like this too. The person is disabled by their brain damage but other factors influence just how disabling this is – environment, other people, sensory problems, physical health and personality/life history.</p> <p>Let us look at how these other 4 factors can contribute to a specific difficulty.</p> <p>Environment – Let say a person with dementia has problem in incontinence; an environmental factor could be a lack of signs on toilet</p>	<p><b>Transparency 8</b></p> <p><b>Transparency 9</b></p> <p><b>Transparency 4</b></p>

## **Appendix C.6.**

### **Training: Learning outcomes**

After the first day of the training, learners would be able to...

1. understand the experience of dementia
2. understand the facts about dementia: types, symptoms and their causes, statistics, risk factors
3. understand factors which can cause or contribute to difficulties in dementia
4. establish guidelines for good practice
5. understand how to compensate for difficulties caused by dementia
6. understand how to make the most of remaining strengths of the patients
7. understand the caring in partnership

After the second day of the training, learners would be able to...

1. understand non-verbal communication
2. understand principles and guidelines of good communication
3. meet the needs of the whole person
4. understand responses to dementia
5. develop knowledge about people with dementia as individuals
6. respond to different realities of people with dementia
7. understand messages behind challenging behaviour & respond to strong feelings

After the third day of the training, learners would be able to...

1. understand and prevent aggressive behaviour
2. respond to challenging behaviour and meeting needs
3. understand and respond to walking ('wandering')
4. understand well-being in dementia
5. identify and monitor well being
6. understand the purpose of occupation for people with dementia

In general, learners would be able to...

1. have a general idea about a person-centred approach to dementia care
2. learn about the special needs of people with dementia and how to meet these needs
3. recognise their power and influence over the lives of people with dementia and learn how to use this to positive effect.
4. learn new information, skills and ways of working.
5. share their ideas, skills and experience and to give and receive feedback

## Appendix C.7.

### Training: Evaluation form

#### Training course – A Person-Centred Approach of Dementia Care – day one

Thank you for attending the training course conducted by Chinese Mental Health Association. In order to help us improve our future training programme, we would like you to complete the following questions as FULLY as possible. Where appropriate, circle a word or number. Thanks for your help.

---

1. **The training has increased my understanding of the needs of people with dementia:**  
Very much so    5       4       3       2       1       Not at all
2. **I understand more about the facts about dementia and their cause to difficulties in dementia:**  
Very much so    5       4       3       2       1       Not at all
3. **I understand more how I can help / care for people with dementia in practical ways?**  
Very much so    5       4       3       2       1       Not at all
4. **I feel that our practices will improve as a result of the training :**  
Very much so    5       4       3       2       1       Not at all
5. **I have a better understanding about a person-centred approach to dementia care:**  
Very much so    5       4       3       2       1       Not at all
6. **I have learned new information, skills and ways of working:**  
Very much so    5       4       3       2       1       Not at all
7. **I was able to share my ideas and experience and to give and receive feedback today:**  
Very much so    5       4       3       2       1       Not at all
8. **As a result of the training, my attitude / approach to people with dementia has changed:**  
Changed a lot    5       4       3       2       1       Not at all
9. **I will use what I learnt to in the training sometimes:**  
Very much so    5       4       3       2       1       Not at all
10. **I enjoyed the training:**  
Very much so    5       4       3       2       1       Not at all
11. **To what extent was the course motivational?**  
Very much so    5       4       3       2       1       Not at all
12. **I think the course met its aims and objectives:**  
Very much so    5       4       3       2       1       Not at all
13. **If you think the course met its aims and objectives, how will you make use of this learning back in your day to day work / care?**
14. **Is there anything that you want to know more about or you would like to discuss further in the course?**

## Training course – A Person-Centred Approach of Dementia Care – day two

Thank you for attending the training course conducted by Chinese Mental Health Association. In order to help us improve our future training programme, we would like you to complete the following questions as FULLY as possible. Where appropriate, circle a word or number. Thanks for your help.

---

15. **The training has increased my understanding in principles of good communication with people with dementia:**  
Very much so    5       4       3       2       1       Not at all
16. **I understand more about meeting needs of the whole person of people with dementia:**  
Very much so    5       4       3       2       1       Not at all
17. **I have developed a better knowledge about people with dementia as individuals?**  
Very much so    5       4       3       2       1       Not at all
18. **I understand how to respond to different realities of people with dementia:**  
Very much so    5       4       3       2       1       Not at all
19. **I have a better understanding of messages behind challenging behaviour & respond to strong feelings:**  
Very much so    5       4       3       2       1       Not at all
20. **I have learned new information, skills and ways of working:**  
Very much so    5       4       3       2       1       Not at all
21. **I was able to share my ideas and experience and to give and receive feedback:**  
Very much so    5       4       3       2       1       Not at all
22. **As a result of the training, my attitude / approach to people with dementia has changed:**  
Changed a lot    5       4       3       2       1       Not at all
23. **I will use what I learnt to in the training sometimes:**  
Very much so    5       4       3       2       1       Not at all
24. **I enjoyed the training:**  
Very much so    5       4       3       2       1       Not at all
25. **To what extent was the course motivational?**  
Very much so    5       4       3       2       1       Not at all
26. **I think the course met its aims and objectives:**  
Very much so    5       4       3       2       1       Not at all
27. **If you think the course met its aims and objectives, how will you make use of this learning back in your day to day work / care?**
28. **Is there anything that you want to know more about or you would like to discuss further in the course?**

## Training course – A Person-Centred Approach of Dementia Care – day three

Thank you for attending the training course conducted by Chinese Mental Health Association. In order to help us improve our future training programme, we would like you to complete the following questions as FULLY as possible. Where appropriate, circle a word or number. Thanks for your help.

---

29. **The training enabled me to understand aggressive behaviour of people with dementia:**  
Very much so    5       4       3       2       1       Not at all
30. **I understand more how to respond to challenging behaviour and meeting needs:**  
Very much so    5       4       3       2       1       Not at all
31. **I understand more how to respond to walking (wandering):**  
Very much so    5       4       3       2       1       Not at all
32. **I have a better understanding about the well-being in dementia:**  
Very much so    5       4       3       2       1       Not at all
33. **I have a better understanding about identifying and monitor well being:**  
Very much so    5       4       3       2       1       Not at all
34. **I understand better about the purpose of occupation for people with dementia:**  
Very much so    5       4       3       2       1       Not at all
35. **I was able to share my ideas and experience and to give and receive feedback:**  
Very much so    5       4       3       2       1       Not at all
36. **As a result of the training, my attitude / approach to people with dementia has changed:**  
Changed a lot    5       4       3       2       1       Not at all
37. **I will use what I learnt to in the training sometimes:**  
Very much so    5       4       3       2       1       Not at all
38. **I enjoyed the training:**  
Very much so    5       4       3       2       1       Not at all
39. **To what extent was the course motivational?**  
Very much so    5       4       3       2       1       Not at all
40. **I think the course met its aims and objectives:**  
Very much so    5       4       3       2       1       Not at all
41. **If you think the course met its aims and objectives, how will you make use of this learning back in your day to day work / care?**
42. **Is there anything that you want to know more about or you would like to discuss further in the course?**

**Appendix C.8.**

**Training: A worker's reflective report on the training session**

**Reflection report on the training Person-centred approach to dementia care training**

**Discussion with:**

**Date: 5<sup>th</sup> June 2006**

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*'The content of the training programme is very comprehensive, you covered a lot of knowledge and skills of how to provide a good dementia care. You engaged the participants a lot, we felt exciting, especially in the role plays when we put ourselves into the situations of someone with dementia. It made us think, act and involve and this is very inspiring.'*

*'I particularly like the ice breaking exercises (which you purposely made the exercises to be related to the content of the training) on the second and third days, although you did it to warm up the class, it was meaningful.'*

*'I would definitely apply the training onto my work, say if someone calls our Helpline for dementia related problem, I know how to support the caller, for example, a helping and partnership approach with the patient, what could really help a patient is to maintain their abilities by letting them to do whatever I could still do.'*

*'What you could differently is that, because we do not deal with dementia patients on a daily basis, it would be helpful to show us some videos so that we can have an idea how they react, talk and respond etc.'*

## Appendix C.9.

### Training: A carer's feedback report on the training session

#### Carer's feedback form

#### Person-centred Approach to Dementia Care Training

**Carer's Name:**

**Date:**

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**1. Was the training needs being met? Why?**

Yes! My need for this kind of training has been met because I have learned a lot about caring a person with dementia.

**2. Have you learned what you expected to learn in the training?**

Yes.

**3. If yes, what have you learned in the training?**

I have learned how to communicate with my husband with dementia, this is most important.

**4. What was the most beneficial section, and why?**

Understanding the cause and effect of the illness made me realised that my husband did not mean to be difficult. It was his illness that caused him difficult. Then I realised that I should be considerate to him and be more patient with him.

**5. What additional topics should be included (if any)?**

Some carers are caring for in-law which is quite different from caring a spouse, would be helpful if caring from this aspect will be included in the future.

**6. How could the training be improved in the future?**

If time allows, do more role play.

## Appendix C.10.

### Training: A sample of the Chinese handout

## 面對壓力 (Coping with Stress)

- 支持 (Support):** 當遇到困難時，或你需要提點，或需要資料，又或者需要找人傾訴時，別害怕表達你所需要的。你身旁有些人願意幫助你，不要讓自己一個人面對問題。
- 善待 (Treat):** 善待自己，照顧自己。確保自己有足夠的休息和消閒的時候。
- 緩解 (Respite):** 每個人都需要間中休息一下。就算是一小時也好，一個下午，一天，一個星期，兩個星期，有時間便盡量休息。
- 表達 (Express):** 向一些可以聽你傾訴的人表達你的情緒。這也許是一個社工，朋友，親屬，或者是其他照料者。你難於向患者表達你的情緒，但如果你不开心或生氣時，別忍耐太久，嘗試定時舒解你的情緒。
- 停止 (Stop):** 停下來想想，是否有更好的方法處理現在的情況？有些壓力是你可以控制的- 例如：你是否同一時間想處理幾件事呢？如果患者為你製造很多麻煩，可能意味著他們正想傳達一些訊息給你？也許你可以尋找一些方式滿足他們的需要，情況也許會有所改變。
- 設定 (Set):** 定下可行的目標。別嘗試完成或達成太多目標。別對自己或你所照料的人期望太多。你需要接納一個事實，便是作為照者，你要對患者不斷重復做和重復講某些事，你會感到煩厭，但仍需接納。

**Appendix C.11.**

**Consultancy: Contract for the delivery of a health promotion event**

**Background**

The \_\_\_ Primary Care Trust (PCT) is planning in collaboration with the xxx a health promotion event for the Chinese community on 21<sup>st</sup> November 2006. PCT would like to commission an organisation who is specialised in Chinese health promotion to deliver the main programme at the event.

**Aims of the Consultancy**

- To give professional advice on raising the awareness of psychological well being among the Chinese Community.
- To give professional advice and support on the cultural sensitivity and knowledge of engaging the Chinese community in the health promotion event.
- To recommend an appropriate format of delivery of the health promotion event.

**Requirements from the Independent Consultant**

- Write up a script for five sketches which well defined some common mental or psychological issues; the scenes described those most common communication styles within Chinese families that audience could themselves with.
- Deliver the performance on the event.
- Facilitate discussion with the audience about health and support services that are available for the Chinese community to cope with mental health or psychological problem.
- Expand on the advice and recommendation on the health promotion event.

**Method**

A project lead and a project coordinator will be appointed from CMHA staff team to be the main contact persons for the coordination of the project. CMHA will produce the script of the sketches, the performers and will deliver the performance on the event. Following the performance, the staff team will facilitate feedback discussion and audience participation. Regular email exchanges and phone calls will be set up to follow up and monitor the progress of the project. CMHA will also help in developing the evaluation framework of the event.

**Cost**

£500.00

**Payment**

An invoice will be sent to the \_\_\_ Primary Care Trust at the end of the health promotion event.

**Time Frame**

From September 2006 to November 2006

**Code of Conduct**

The consultant will carry out the service in accordance with the British Psychological Society.

**Confidentiality**

During the course of the health promotion project, CMHA staff may come into contact with members of the audience who may disclose issues of a confidential nature. In signing this contract, the CMHA will not disclose to any unauthorised person or organisation any such disclosure of personal information unless CMHA staff have strong reasons to believe that the audience or someone else is actively suicidal and / or is at risk of serious harm / or a child is at risk of abuse.

Signature:..... Date:.....  
Client – Primary Care Trust

Signature:..... Date:.....  
Consultant

Appendix C.12.

Consultancy: Implementation plan

Chinese Health Day - November 21<sup>st</sup> 2006 – Work Plan

Main Task	Action	Schedule	Job allocation
General Coordination	To appoint SY to be the coordinator	26 September	SY to: 1. follow up details and email exchange with contact client; 2. arrange all pops and materials on stage; 3. arrange all info flyers and marketing materials to be arranged, carried and distributed on the day; 4. arrange video-recording on the day; 5. book train tickets for the team; 6. coordinate with the team schedule of the trip
Appointing Actors/Actresses	Identify staff and volunteers who are interested in this project.	26 September to end of September	SY to speak to colleagues about this project, checking their schedules and confirm me by end of September.
Script writing	To produce the scripts of the sketches	First draft to be ready by 1 <sup>st</sup> week of October	I am to produce the 1 <sup>st</sup> draft. AC to follow up by brainstorming and discussing with the team. A revised script to be ready by 2 <sup>nd</sup> week of October. Final version by 2 <sup>nd</sup> week of October.
Rehearsal	The team started practicing the sketches.	From the 2 <sup>nd</sup> week of October until 21 <sup>st</sup> November.	SY to call up rehearsal with my presence.
Debriefing	Preparation for debriefing of each of the psychological health sketches.	2 <sup>nd</sup> week of October.	I am to prepare for the information of the 5 health topics is accurate; will double check with AC the content of the debriefing.
Evaluation	To give advice to the client.	One week before the event.	I am to revise the evaluation form produced by the client, making sure that all questions and outcomes of the event are covered.
Evaluation of the consultancy	To seek feedback from the client	Within a week after the event.	I am to ask the client his feedback on this consultancy work either through email or phone.
Payment	To send out invoice to the client	One week after the event.	SY to send out the invoice of the payment for this consultancy work.

**Appendix C.13.**

**Consultancy: Evaluation questionnaire**

**Be Friends with Your Mental Health**

Thank you for attending today's event.

We would be grateful if you could answer the questions below. You do not have to tell us your name.

The answers you give us will help us to evaluate today's event.

	Strongly Agreed	Agreed	Uncertain	Disagreed	Strongly Disagreed
1. Today's event has increased my understanding of emotional health issues.					
2. Today's event has increased my knowledge of who to contact for advice regarding emotional health problems.					
3. Today's event has made me feel more open to discussing emotional health issues with other people.					
4. Today's event has made my attitude towards people with psychological health problems more supportive and understanding.					
5. Overall today's event was useful.					
6. <i>The venue was suitable for the event.</i>					

7. Do you have any other comments either good or bad to make about today's event?

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**Appendix C.14.**

**Consultancy: Publicity of the health promotion event**

The \_\_\_\_\_ Chinese Association and \_\_\_\_\_ County PCT invite you to a

**HEALTH PROMOTION EVENT**

(Including Entertaining Sketches and Free Lucky Draw)

Mental Health Day with the Chinese Mental Health Association

**'Be Friends with Your Mental Health'**

*TUESDAY 21 NOVEMBER 2006 AT \_\_\_\_\_*

- |                   |   |
|-------------------|---|
| 11.30am – 12 noon | Registration and Welcome  |
| 12 noon – 12.30pm | FREE HOT CHINESE LUNCH  |
| 12.30pm – 12.45pm | Introduction to day   |
| 12.45pm – 1.45pm  | Short entertaining sketches about mental health issues  |
| 2.00pm – 2.15pm   | Refreshment Break   |
| 2.15pm – 3.30pm   | Question and Answer session for you to ask Chinese Mental Health Association questions on mental health on a one-to-one basis |

**AND**

2.15pm – 3.30pm Information stalls and Videos

Please come along and join us for a happy and relaxed day.

## Appendix C.15.

### Consultancy: Press release of the health promotion event

#### **'Be Friends with Your Mental Health' Chinese Mental Health Event**

Around 70 members of the Chinese community recently attended an information event in Chesterfield on mental health, at which \_\_\_\_\_, the Chair of the \_\_\_\_\_ Chinese Association and \_\_\_\_\_, \_\_\_\_\_ County PCT's Chair made the welcome speeches.

The aims of the event included increasing understanding of mental health issues within the \_\_\_\_\_ Chinese community and also encouraging discussion of mental health problems by the local Chinese community.

The planning and delivery of the event was an equal partnership between \_\_\_\_\_ County PCT's Public Health Directorate, the \_\_\_\_\_ Chinese Association and the Chinese Mental Health Association, with support also from the \_\_\_\_\_ Mental Health Services NHS Trust. The event comprised of various information stalls from which Chinese language information was available, a hot healthy Chinese lunch and sketches on a number of mental health related topics followed by interaction and discussion with the audience regarding what they had seen. In addition, members of the Chinese community had an opportunity to speak with a Chinese mental health professional on a confidential one-to-one basis.

According to Rebecca Tang of the Chinese Mental Health Association, "There is a social stigma attached to mental health problems in the Chinese community that prevents Chinese people from accessing help and advice and leads to people hiding things from family and friends as well as misunderstanding around mental health issues".

The PCT Public Health Directorate's \_\_\_\_\_, who was responsible for the overall organisation of the event, explained because of the above issues it was decided jointly by the PCT, \_\_\_\_\_ Chinese Association and the Chinese Mental Health Association that to break down barriers and to promote understanding around mental health in the local Chinese community an innovative approach was needed. Regarding the aforementioned, it is believed that the event in Chesterfield is the first time the arts, in terms of performing sketches, have been used to deliver messages relating to mental health to a Chinese community in the UK.

Public Health's \_\_\_\_\_ emphasised that it was essential that the content of the event was culturally appropriate and said that, "Without the hard work of the \_\_\_\_\_ Chinese Association and the expertise of the Chinese Mental Health Association the event would not have been possible". Commenting on the event the \_\_\_\_\_ Chinese Association Chair, \_\_\_\_\_ said, "The event was an enormous success and the \_\_\_\_\_ Chinese Association are looking forward to further close partnership working with the new \_\_\_\_\_ County PCT in the future."

It is intended by the partners involved that over the next few months that Public Health, the \_\_\_\_\_ Chinese Association, the Chinese Mental Health Association and \_\_\_\_\_ Mental Health Service NHS Trust will identify and discuss ways in which the work relating to mental health and the Chinese community can be taken forward.

## **Appendix C.16.**

### **Optional 5.1: Samples of the activity manual for the psychosocial intervention**

#### **Activity two: Memory training activities - How much can you remember?**

##### **Aims**

1. to provide a chance to train visual memory
2. to stimulate the ways of thinking
3. to encourage participant's social contact
4. to bring fun and joy to participant

**Group style:** Open

**Number of participant:** 6 – 8 (the group can be greater if participants are better at remembering.)

**Number of staff:** 1

##### **Materials**

1. Daily used objects, for example, keys, cups, pens, coins, watches, etc.
2. trays or plates
3. a piece of cloth (it must be able to cover the whole tray or plate.)

##### **Instruction**

1. Put all the objects on the tray (start with 3 objects, and then gradually add on.).
2. Let participants say what the objects are on the tray, raise and briefly introduce every object, which helps participants to remember.
3. Cover up the tray by the cloth.
4. Let participants to say the objects that they can remember.
5. Get one score with one correct answer, the one has the highest score wins.

### Activity three: Matching the happiness

#### Aims:

1. to provide a chance to train visual memory
2. to stimulate the ways of thinking
3. to encourage participant's social contact
4. to bring fun and joy to participant

**Group style:** Open

**Number of participant:** 6 – 8 (the group can be greater if participants are better at remembering.)

**Number of staff:** 1

#### Materials

Two sets of the same pictures or photos (and randomly numbered at the back), cellatape and a white board.

#### Instruction

1. Stick the picture in the following order on the white board.

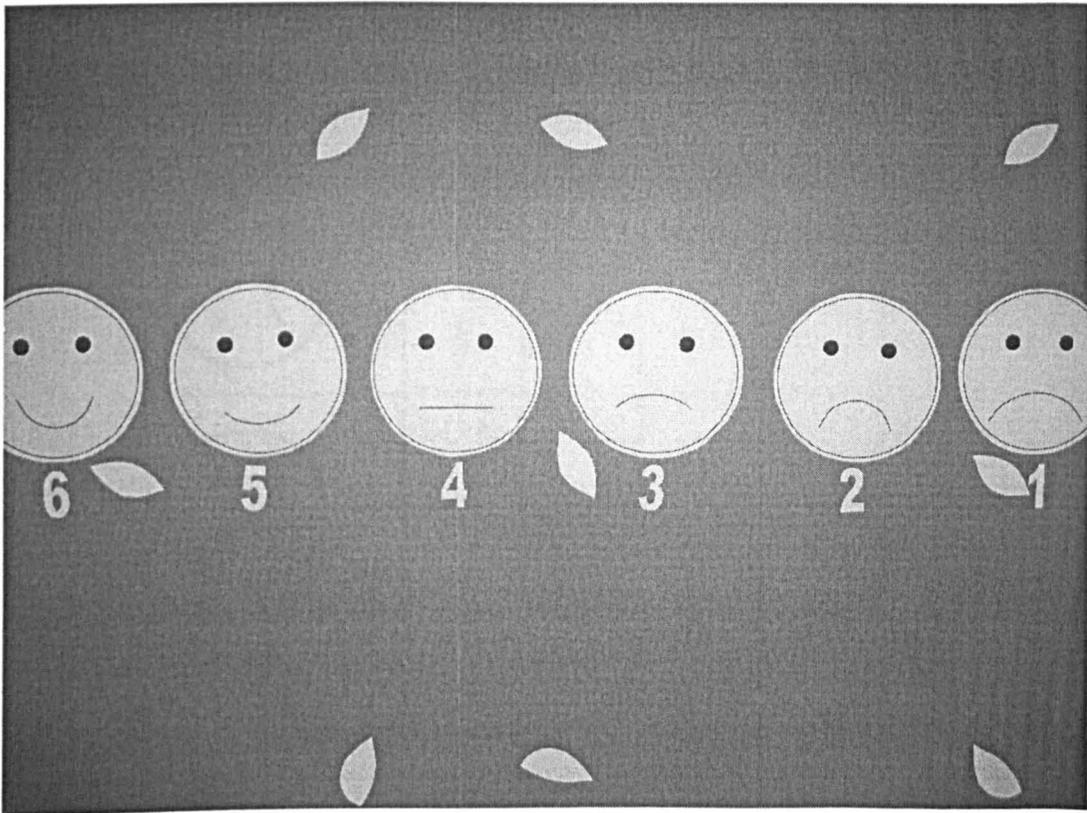
1	2	3
4	5	6

2. Divide participants into two groups.
3. Each member to represent their groups and play the game in turns.
4. Representative chooses two numbers every time, to see whether they can find out the same pictures or photos.
5. One mark will be scored if the same pair is found.
6. If the two photos do not match, then turn them around and put them back.
7. If the same pair cannot be found, then it's the next group's turn; if the same pair is found, the group continues.
8. The game is finished as all the pictures are shown.
9. The group has the highest mark wins.

\*The difficulty of the game can be adjusted by the number of pictures/photos.

Appendix C.17.

Optional 5.1: Faces Scale board used as assessment tool in the intervention



Appendix C.16  
Optional 5.1: Evaluation form

Evaluation form

Participant's name: \_\_\_\_\_

Participant's age: \_\_\_\_\_

Participant's gender: \_\_\_\_\_

Participant's occupation: \_\_\_\_\_

Participant's education level: \_\_\_\_\_

Participant's marital status: \_\_\_\_\_

Participant's income level: \_\_\_\_\_

Participant's health status: \_\_\_\_\_

Participant's social support: \_\_\_\_\_

Participant's coping strategy: \_\_\_\_\_

Participant's stress level: \_\_\_\_\_

Participant's anxiety level: \_\_\_\_\_

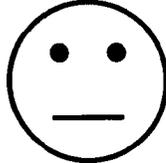
Participant's depression level: \_\_\_\_\_

Participant's life satisfaction: \_\_\_\_\_

Participant's overall well-being: \_\_\_\_\_

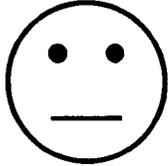
**Appendix C.18.**

**Optional 5.1: Evaluation form**

Emotional well being							
	7	6	5	4	3	2	1
September 5 <sup>th</sup> Making phone calls S1. Before After							
September 14 <sup>th</sup> Outing S2. Before After							
September 26 <sup>th</sup> Taking messages S3. Before After							
October 3 <sup>rd</sup> Singing opera S4. Before After							

**Appendix C.19.**

**Optional 5.1: Assessment report**

Emotional well being							
	7	6	5	4	3	2	1
Session 1 September 5 <sup>th</sup> Making phone calls		After		Before			
Session 2 September 14 <sup>th</sup> Outing	After		Before				
Session 3 September 26 <sup>th</sup> Taking messages		Before After					
Session 4 October 3 <sup>rd</sup> Singing opera		After	Before				
Session 5 October 10 <sup>th</sup> Tasting & Smelling Fruits	After	Before					
Overall assessment On emotional well being		5 weeks later		5 weeks ago			
Session 6 October 17 <sup>th</sup> Traditional Chinese foods, snacks & Chinese folk songs	After	Before					

## Appendix C.20.

### Optional 5.1: Internal organisation manual script for the 1<sup>st</sup> intervention session

#### Session One – Making Phone Calls (Duration: 30 minutes)

##### Content

##### Tools and Materials

##### **Start**

1. Each member of the group, including staff and other members to say their names one by one, and say hello to the member on the next seat.
2. Briefly introduce the target of the session again. Invite one 'smarter' elderly to repeat once, and then invite other members to repeat once altogether.

##### **Learn**

1. Recap the content of last lesson: counting Arabic numbers from 0 to 9.
2. Illustrate the relationship between the numbers and making a phone call.
3. Introduce the formation of telephone numbers.
4. Introduce the way of how numbers from 0 to 9 are configured on general buttons of telephone keyboard.
5. Explain the methods and steps to use this type of telephone.
6. Teach the members to make phone call
7. Remind the members what needs to be paid attention to when making a phone call.

Arabic number cards

Telephone number stripes

Big telephone

##### **Provide 'the information of ...'**

1. The 'reality...' trainer firstly reads out the information of ... on the board.
2. Again, invite one 'smarter' elderly to read out the information on the board.
3. Then invite other members to repeat the information again altogether.

information board

##### **Finish**

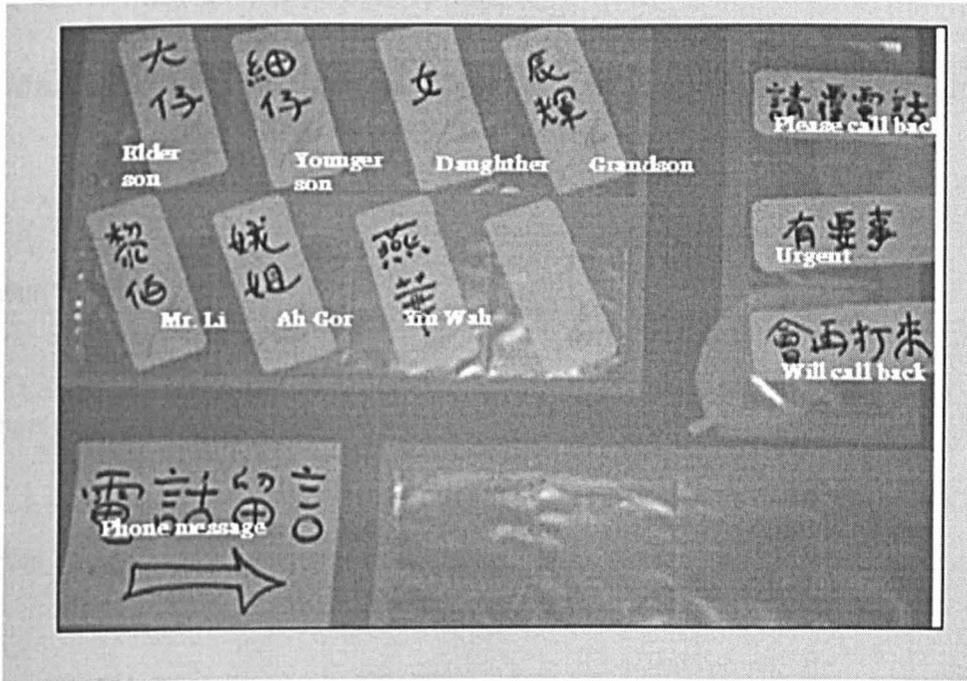
1. Conclude the content of this particular group, and give out the date and time of next meeting.
2. Encourage all the members to greet each other again.
3. Have some tea and coffee, encourage the members to start conversations freely in the relaxing atmosphere.

group schedule

tea sets and biscuits

Appendix C.21.

Optional 5.1: Material designed for the 2<sup>nd</sup> session – A tailored made telephone message board



## **The National Institute for Mental Health in England Community Engagement Programme (2005/6)**

**Managed and Supported By the Centre for Ethnicity and Health,  
University of Central Lancashire**

### **Section 1: Contact details**

Name of organisation applying: **Chinese Mental Health Association**

### **Section 2: About your group/organisation**

**2.1 Please describe your organisation (When was it formed? Why was it formed? What kinds of activities are you involved in?). Please feel free to enclose any leaflets, booklets or reports that you feel will help us get a better picture of what you do).**

The Chinese Mental Health Association (CMHA) was set up in 1993 in response to the success of a Chinese Counselling Service in Tower Hamlets. CMHA was formed to safeguarding and maintaining the mental well being of the Chinese community in the UK. Currently CMHA provides community mental health services to Chinese people with a mental distress and their carers. A range of direct services include a supporting people scheme in \_\_\_\_\_, advocacy, befriending, carer's support, youth counselling and family therapy, oral history research project and weekly user social group. Apart from the supporting people scheme which is particularly for the Chinese residents in \_\_\_\_\_, all the other services operate at a regional level across London. At a national level CMHA runs a Chinese mental health helpline which offers information, advice & emotional support to callers. CMHA also engages in a national mental health promotion & education project, which has produced a range of bilingual resources to raise mental health awareness and combat stigma. Resources include mental health information booklets, a service directory, videos, a weekly newspaper column, a website and a user-led newsletter. With regard to research and development, CMHA is currently conducting a participatory research on Dementia with the Chinese community in the UK.

## 2.2 What kind of organisation are you? (Are you a registered charity, a voluntary sector organisation etc.).

Chinese Mental Health Association is a registered charity

## 2.7 Why are you interested in undertaking this project with us?

The Chinese Mental Health Association (CMHA) is dedicated to preserve and primarily safeguard the mental well-being of Chinese people in the UK. Over the last twelve years, we aim to do this by lobbying for better mental health services for Chinese people in the UK; to improve the quality of life amongst the Chinese users and their carers; to help users and carers access services that are already provided through statutory and voluntary organisations; to promote mental health education in the Chinese community and to raise awareness amongst mainstream service providers. CMHA conducted a nation wide survey with the Chinese community to assess its mental health needs in 2003 and subsequently written and produced a recommendation document for a Department of Health report entitled the 'Inside/Outside' which is currently being implemented by the National Institute for Mental Health in England.

Over the last few years we have involved service users in many different forms of consultation organised by statutory departments. These consultations have proved useful in gaining users' opinions about their experiences in the mental health service system but lacking in terms of sustaining their involvement in the longer term. We believe that community engagement, on the other hand, is an approach that can bring people together to develop social support networks which will result in positive health outcomes in significant ways.

We are very interested in undertaking this project because this would be a great opportunity to engage the Chinese community in \_\_\_\_\_, a seemingly hard to reach and silent group, so as to **strengthen their capacity** to deal with their own health and social needs. Although \_\_\_\_\_ **has the largest Chinese population in the United Kingdom**, community engagement and link to mainstream services with this community has never been established and has been overlooked so far. This project, if funded, will enable the said Council to explore the needs of the community and lead the way in engaging their full participation.

\_\_\_\_\_ is also well placed to carry out the proposed work as it is a **focus implementation site for delivering race equality in mental health care**.

In terms of sustainability, this project will potentially have a continuing impact on the Chinese community in \_\_\_\_\_ as it involves statutory partnerships, training, on-going support and guidance which will greatly strengthen the building block of the support networks.

CMHA has established good links with the Chinese community in \_\_\_\_\_. It has the required skills and cultural understanding to carry out the work and make this project a success.

## Section 3: About the community in which you are based?

**3.1 Please describe the community/communities in which you are based (e.g. geographically, mix of Black and minority ethnic groups, religions, languages, refugee and asylum seekers, economic indicators, levels of wealth/deprivation)**

## **Mix of black and minority ethnic groups**

Between 1991 and 2001, the population in \_\_\_\_\_ raised by 5.4% - more than twice the average rate for England and Wales. The total population in \_\_\_\_\_ is about 314, 564, in which 188,301 residents are white British, 72,188 (26%) are mix of black and minority ethnic groups. The largest ethnic groups are Indian (27,130), Black African (13,651), and Chinese (6,379) respectively. Chinese people form nearly 2% of the population in \_\_\_\_\_. In addition, \_\_\_\_\_ has the largest number of Chinese residents of any London borough.

## **Religion**

According to the 2001 census, Christians are the largest group (over 47%), followed by Jewish (14.8%), Hindu (6.7%), Muslims (6.2%), Buddhist (1.1%) and over 12% of people described themselves as having no religion. The 2001 census confirmed that religion is an important aspect of ethnicity.

## **Language**

With a total population of 314,564 people, \_\_\_\_\_ is the most multicultural community in Europe. A language survey conducted by the Minority Achievement Project (formerly the Multilingual and English Language Support Service) in 1997 revealed that apart from English, about 140 other languages were being spoken in the secondary schools in \_\_\_\_\_. Amongst those 31% of the students who spoke a language other than English at home, two thirds of them were fully competent in English.

## **Numbers of refugees and asylum seekers**

According to the Greater London Authority, the number of refugees and asylum seekers in London are approximately between 350,000 and 420,000, in other words, one in twenty of the city's resident would be a refugee or an asylum seeker. This is a proportion around 30 times greater than the UK in average.

A current survey on health services found that:

- Amongst 83% of the refugees and asylum seekers who were registered with a GP, half of which were not sure if they were registered as a temporary or permanent patient;
- 20% reported offensive or racist attitudes and behaviour from their GP;
- more than 80% had problems with their housing such as overcrowding, damp, or lack of heating;
- half said that their housing was having an adverse impact on their health nearly 80% said that the level of support they received was not sufficient to meet their basic needs;
- problems were consistently worse for people in receipt of vouchers rather than benefits;
- 41% of people on vouchers said that the low level of support they received was affecting their physical health;
- 41% of people on vouchers said that they were suffering from depression or anxiety as a result of the low level of support that they received;
- The voucher system fails to meet the needs of disabled asylum seekers.

## **Levels of wealth/deprivation**

According to the census 2001, the most deprived areas in \_\_\_\_\_ also tend to be areas with the highest number of Black and Minority Ethnic population, such as Underhill, Coppets, West Hendon, Colindale and Brunt Oak. Whilst deprivation and ethnicity generally share the same areas, some areas in \_\_\_\_\_ such as West Finchley who have a high BME population suffer from very little deprivation. Conversely, in Underhill where there is very high deprivation it consists of the lowest BME population. However it is still clear that there is a distinct isolation of deprivation and high BME population especially in West Hendon, Colindale and Brunt Oak.

In general, a substantial amount of research from London and around the UK has shown that people from minority ethnic communities are over-represented in economically and environmentally poor areas. Many people from BME communities tend to be more likely to be in low paid and less desirable jobs or will experience longer periods of unemployment compared to their counterparts from the majority population (Nazroo 1997).

### 3.2 Which of the above communities do you have the strongest and best links with?

We have the strongest and best links with the Chinese community in \_\_\_\_\_.

### 3.3 What kind of links do you have with them? How have these been developed?

*In December 2002, CMHA worked together with the \_\_\_\_\_ and \_\_\_\_\_ on a Chinese Health Day which attracted over 100 Chinese people in \_\_\_\_\_. As a result, CMHA became known to the Chinese community in \_\_\_\_\_ as a service specialist in community mental health care.*

CMHA's connection with local Chinese people in \_\_\_\_\_ was highlighted again in December 2003, subsequent to a launch event of a research report entitled "The Supported Housing Needs of Chinese Mental Health Service Users in London" 2003. The launch event was highly supported by the local MP and the \_\_\_\_\_ Council. Since then CMHA has been working very closely with the \_\_\_\_\_ Council for a mental health service for the benefit of the Chinese community.

CMHA was commissioned to run a supporting people scheme in \_\_\_\_\_ this year. With all the other existing direct services such as befriending, counselling, carer's support and social group which provide supports across London, the supporting people scheme is a service particularly set up for the Chinese community within \_\_\_\_\_. Since the start of the supporting people scheme, CMHA has built up a strong link with both Chinese community, the statutory and other voluntary sectors in \_\_\_\_\_ as a service provider specialised in mental health care for Chinese.

## Section 5: Your Proposal

### 5.1 What will the focus of your work be? (What kind of research do you want to carry out? What is the key issue or question that you want to address? Why? How does what you want to do relate to the aims and objectives of 'Delivering Race Equality in Mental Health Care'?)

The focus of our research is to explore the need for mental health care by the Chinese community in \_\_\_\_\_, and their ability to benefit from mental health care. We shall use a **participatory and community empowerment approach** which seeks to engage the Chinese community who do not appear to be a vocal minority group. The application of participation intends to **develop community competences for both the individuals and the community** to achieve real gains in areas deemed essential for mental health.

When it comes to the issue of mental health, the general perception is Chinese people do not seem to have higher rates of psychiatric disorder but are under represented in service uptake on account of poor access (Cowan 2001). In general, research studies conducted over the last 10 years show that this is due to insufficient linguistic support in communication with mainstream professionals, a lack of culturally experienced practitioners and poor community awareness of issues related to mental illness. Information for service users and their carers in accessible Chinese is very limited.

While most of the issues mentioned above have been addressed by NIMHE in their DRE in Mental Health Care, promotion campaigns by voluntary organisations (such as Chinese Mental Health Association) to raise awareness of mental health have helped tackle the problems to a certain degree over the last 4 years.

To review the current situation in terms of equal access to services, starting in the borough of \_\_\_\_\_ where there is the largest number of Chinese residents, the proposed research is to:

- Review the need and the unmet need for mental health care of the Chinese community;
- Explore their ability to benefit from and to mobilise the mental health services that are already available to them.

The proposed research relates to the aims and objectives of 'DRE in Mental Health Care' in its initiatives to engage the Chinese community in identifying their needs for mental health care, build up support networks between the community and the service providers. A participatory approach will be applied to involve the Chinese community in \_\_\_\_\_ (including **service users and carers**) to form a partnership to be facilitated by **one researcher and five volunteers**. The timeline of the research will be **12 months**. The researcher and volunteers will engage the partnership in a series of group discussions, focus group meetings, interviews and help build up links with local service providers such as PCT, PAL, Social Services and Mental Health Trust. Different **participatory appraisal methods** such as Time Trends Analysis, Diagrams, Mapping Techniques and Ranking Techniques will be applied in the different forms of discussions as mentioned. Evaluation will be carried out at the last stage of the research.

### Work Plan – 2006

February:	Recruitment of researchers and volunteers
March:	Training and workshops Recruitment of carers and users participants in _____
April to October:	Design questionnaires to measure the base-line, mid-term and final stage of the project. Fieldwork involving Chinese carers and users in the participatory research in _____. Write up the first draft of the report.
November:	Submit draft report to UCLan.
December:	Final draft re-submitted to UCLan and dissemination of findings.

**5.2 Who will you recruit as your 'researchers'? What makes you sure you can recruit them? How will you be able to support the people you recruit as researchers through the lifetime of this project? What kind of support do you think they will need? [Please make sure that you have read the paper enclosed with this application form entitled 'The Centre for Ethnicity and Health's Model of Community Engagement' before answering this question]. Note: the people you recruit as researchers will need to attend the six day workshop programme provided by the University (usually delivered in blocks of two days in the North, Midlands or South of England) and you will need to be able to retain them for the lifetime of the project.**

We shall recruit researchers who are ethnic Chinese themselves. They should have experience in working with the Chinese community, speak the same language, share the same cultural background and should be able to facilitate the group with basic understanding of the issues around mental health in the Chinese community in Britain.

We are sure that we can recruit them because as a well established specialist mental health organization, we already have a strong team of freelancers and volunteers who have appropriate working experience and education background to carry out research work under supervision. Besides we have strong links with

Universities across the country where we can recruit new graduates and students who would like to work as a placement.

In CMHA, we have a strong management team, members of which are experienced researchers, university lecturer and psychologist who would be able to support and supervise the people we recruit as researchers through the lifetime of this project.

The researchers of this project would need training, especially community engagement and participatory appraisal methods in order to facilitate in the research activities. They will also need on-going supervision, guidance and administrative support throughout the lifetime of the project.

**5.3 Who do you think your key respondents are likely to be? (Who do you want to consult with? How many people do you think you will be able to talk to? How will you go about consulting with them? What makes you think that you will be able to do this?)**

Our key respondents of this research would be service users, carers, community workers in the Chinese community in \_\_\_\_\_. We are expecting to talk to at least 30 to 50 people. Our existing service users, carers and community workers are the immediate group of people we shall consult with. Building on our network in \_\_\_\_\_, we shall also work with other Chinese community organisations such as Chinese schools and churches as they are the places of social gathering and points of assembly. Since most of the organisations in \_\_\_\_\_ are familiar with our work because we have already built up connections with them through joint partnership work and mental health promotion, it will not be difficult for us to out reach to them and to work with them again in this project.

**5.4 Have you ever been involved in a project like this before? If yes, please give details. What did you learn from it that will help you with this project?**

We had led a research and development project with the aim of establishing the first Chinese supported housing scheme for recovering psychiatric patients. The report entitled "The Supported Housing Needs of Chinese Mental Health Service Users in London" was published and launched in 2002 in London. Commissioned by the Department of Health, we conducted a nation wide survey with the Chinese community to assess its mental health needs in 2003 and subsequently written and produced a recommendation document for a Department of Health report entitled the 'Inside/Outside' which is currently being implemented by the National Institute for Mental Health in England. Although we have never been involved in a project similar to this before, our skills and experience in community consultation project and research would be very helpful for us to carry out this project.

**Section 6: Money**

**6.1 How much money will you need to allow you to do what you are proposing?**

£20,000

**6.2 How much money do you need from us? (Note the maximum you can ask us for is £20,000).**

£20,000

**6.4 How will you spend the money? (e.g. paying staff, volunteers, room hire, events, management costs, incentives for respondents, dissemination of the findings, travel costs, telephone costs etc.)**

Description of item	How much money
One freelance researcher, rate = £10/hour, 7 hr/day, 3 days/wk x 52 wks	£10,920
Project costs: <ul style="list-style-type: none"> <li>• Travel expenses £50 per month x 12 mths</li> <li>• Stationery – printing cartridges, photocopy, and paper (including stationery for dissemination event).</li> <li>• Telephone, fax and internet use</li> <li>• Training – books and research materials</li> <li>• Volunteer expenses £11 per day 5 volunteers a week x 52 wks = £2,860</li> <li>• Refreshment, venue, room hire and misc. expenses for research activities</li> </ul>	£600 £1,500  £300 £600 £2,860  £1,270
Time for management and supervision 1½ per week x 52 wks	£1,950
<b>Total</b>	<b>£20,000</b>

### Section 7: Declaration

I declare that the information contained in this proposal is accurate and truthful to the best of my knowledge

**Optional 5.8: Grant offer letter of the community research project**

Date: 25<sup>th</sup> April 2006

Rebecca Tang  
 Chinese Mental Health Association  
 2/F Zenith House  
 155 Curtain Road  
 London  
 EC2A 3QY

Dear Rebecca Tang

**Re: CSIP Black and Minority Ethnic Community Engagement Programme**

Thank you for attending interview for the above programme. I am pleased to inform you that your application has been successful. This letter sets out a number of points in relation to how we envisage things working over the coming months.

The main points that were raised at interview with you are summarised below:

Name of group – Chinese Mental Health Association		
Area of discussion	Group answers	Notes
Project activities/aims and links to DRE	<ul style="list-style-type: none"> <li>• A community based mental health service for Chinese people.</li> <li>• Research sample will be older Chinese people.</li> <li>• Research will focus on the needs of Chinese elders and their carers in relation to dementia.</li> <li>• The research will enable services which are more responsive &amp; culturally sensitive.</li> <li>• Increase access leading to</li> </ul>	<ul style="list-style-type: none"> <li>• Context – demographics of Chinese community is changing with a quarter aged 50 &amp; over.</li> <li>• Context – Chinese people are significantly under represented in rates of admission to hospitals for mental illness compared to the national average.</li> <li>• Context – to</li> </ul>

	<p>reduction in fear and greater satisfaction.</p> <ul style="list-style-type: none"> <li>Chinese community will be engaged in helping to develop provision which fits in with cultural values and beliefs.</li> <li>Workforce development.</li> </ul>	<p>investigate the barriers in relation to above services.</p>
Research question/methods/ethics	<ul style="list-style-type: none"> <li>Research will focus on the needs of Chinese elders and their carers in relation to dementia.</li> <li>Mix of semi-structured interviews, focus groups: more emphasis on qualitative data.</li> <li>Carers will be involved.</li> <li>15 respondents from Hackney 15 from Tower Hamlets.</li> </ul>	<ul style="list-style-type: none"> <li>Profile of researchers need to fit research sample.</li> <li>To review respondents total numbers from each borough.</li> </ul>
Who will they employ/service user involvement	<ul style="list-style-type: none"> <li>5 researchers from own database &amp; networks.</li> <li>Volunteers to be supported</li> <li>Lead researcher/ co-coordinator will be Rebecca Wong.</li> </ul>	<ul style="list-style-type: none"> <li>CMHA to provide details of research team.</li> <li>Systems to recruit, support &amp; motivate staff are in place.</li> <li>Incentives to retain &amp; professionally develop staff are in place.</li> </ul>
Training – who will attend and numbers	<ul style="list-style-type: none"> <li>Staff development is already encouraged.</li> <li>Uclan workshops will be used as an incentive for professional development e.g. employment opportunities.</li> <li>All researchers will attend.</li> </ul>	<ul style="list-style-type: none"> <li>Attendance is compulsory</li> <li>Will be delivered regionally with other groups in same region.</li> </ul>
Outcomes and sustainability	<ul style="list-style-type: none"> <li>Work will be linked into PCTs older people services and mainstreamed into the work of other health agencies.</li> <li>Support accessed through Steering Group and CDW.</li> </ul>	<ul style="list-style-type: none"> <li>Supported by FIS rep as key area of concern.</li> </ul>
Other issues?	<ul style="list-style-type: none"> <li>The group will need to be linked to other groups (past and present) that have done work around the needs of the Chinese community</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>
Immediate Priorities	Recruitment of researchers.	

## **Support**

You will be allocated a Support Worker employed by Uclan who will visit you once a fortnight. Your Support Worker has not yet been allocated to your group but someone should make contact with you in the next two weeks, if you have not heard from your support worker please let me know by ringing \_\_\_\_\_ and asking for \_\_\_\_\_. Your Support Worker will help you to work through the above points and any questions you have about the programme should be discussed with them in the first instance.

Your Support Worker will assist and support you to deliver this project by offering advice and guidance about: research methods; the target group for your research; data analysis; report writing; budgetary allocation; pulling together a steering group for the project; and maintaining links with your local stakeholders. They will also offer academic advice to any members of your project team who enrolls for the University Certificate that runs alongside this project.

## **Finances**

You have been allocated £20,000 to complete this project; payments will be made by the CSIP Regional Development Centres. You will receive payment in three equal instalments; I will write to you again to give you details of how to claim your first instalment of funding which will be paid in May. Further payments will be made to you upon receipt by the University of a completed Financial Monitoring Form (copy attached) showing expenditure to date, together with a project report indicating key project activities. Financial monitoring forms should be sent to \_\_\_\_\_ by **18<sup>th</sup> August and 17<sup>th</sup> November 2006**. These will be monitored by the project team at Uclan and subject to satisfactory work progress being made against the work plan agreed with your Support Worker authorisation will be given for further payments to be released by CSIP approximately 4 weeks from the above dates. Please note that you should discuss any major change in your proposed spending, (+/-10%) as against the budget agreed at interview, with your Support Worker who will have to grant approval for any budgetary changes.

## **Project Timetable/Milestones**

The following is a guide to the key timetable milestones that you will be required to work to in order to keep your project on target:

### **May**

- Recruitment of researchers should take place in May. You should recruit local people aged 17 or over from the target community to act as researchers to undertake the work. These people should be paid wherever possible (e.g. except where payment may affect a participants' entitlement to receive state benefits and such payment would leave them financially worse off). The budget for your project should reflect this.
- You should establish contact with your regional Race Equality Lead and Focus Implementation Site Representative with a view to establishing a steering group. We want the outcomes from this project to be sustained beyond the lifetime of the funding that we are able to allocate. For this reason it is essential that you notify key groups in the community about the work that you intend to do and establish a Steering Group for this project. Your support Worker and the CSIP Race Equality Lead for your region will be happy to assist you in deciding who to contact and who to include on your steering group. It should however include representatives from local mental health service providers and planners/commissioners (e.g. Primary Care Trusts, Mental Health Trusts, Joint Commissioning Teams, Local Implementation Teams, Voluntary Sector Forums, and Service User/carer Representatives). Experience tells us that projects with effective Steering Groups

are far more likely to be sustained and to achieve change in the longer term. Key roles for the Steering Group include:

1. ensuring that the work that the groups undertake is relevant and important and fits in with key local priorities (e.g. fits with documents such as '*Delivering Race Equality in Mental Health Care: An Action Plan For Reform Inside And Outside Services*')
  2. acting as a resource for groups in the delivery of their projects (e.g. providing information to groups)
  3. helping groups to shape their recommendations such that they can be picked up and implemented locally at the end of the project
- You will need to familiarise yourself and your researchers with the key aims of the five year action plan for achieving equality and tackling discrimination in mental health services in England contained in '*Delivering Race Equality (DRE )in Mental Health Care*' (especially with reference to pages 19 and 39 of the report). I enclose a copy of the report for your information.
  - If you are planning to interview people who are clients of statutory services and you require the help of statutory services to enable you to do so (e.g. by referring people to you or allowing you to use their premises) you will also need to get ethical approval from your Local Research Ethics Committee. This can be a lengthy process, so if this is the case, speak to your support worker NOW to get this started.

## **June**

Your researchers should be ready to attend the first of seven workshops over the lifetime of your project (see information on training above). I will be writing to you again to confirm the dates for your workshops.

## **July**

You will need to work with your Support Worker to develop a work plan detailing what you intend to do and how you intend to do it. You will need to submit this in the form of an ethics approval form to the University to gain approval for the work to be carried out. The objective here is to ensure that no one is put at risk of any harm as a result of this work. Your work plan will need to address issues such as: who you will get to do the work; what work they will do; where they will undertake the work; who they will undertake the work with; how they will be supervised; how you will ensure that participants in the project have given consent; how you will ensure confidentiality; how you will identify and manage any risks. The University may require you to stop or amend any work plan if it feels that what you are doing or are proposing to do is unethical.

If you have already received Local Research Ethics Committee approval you will already have covered and dealt with most, if not all, of what the University requires you to address.

## **August 2006**

Your researchers should complete their draft research tool and/or arrange focus groups at which it can be piloted. As your group is part of a National Programme, although it is important that you should have flexibility to develop your work such that it fits with local priorities it is also important that we are able to pull together the reports that each of the pilot sites produce at the end of the project into one composite report. To this end, we will require you to incorporate a core set of questions in to any questionnaire that you may design, or any monitoring tool that you use to record participants in, say, a focus group. A copy of the core questions will be given to you by your support worker and your researchers will cover this requirement as part of their research training.

**September/October 2006**

Researchers will undertake the fieldwork.

**November/December 2007**

Researchers will undertake the analysis of the data collected in the fieldwork.

**January 2007**

A final report should be submitted to us (one hard copy and one electronic copy in word).

**February 2007**

We will review your report, and may require amendments or further work to be carried out prior to you disseminating or launching the work more widely.

**March 2007**

Work to be completed.

This letter forms the basis of our agreement with you. A signed copy of this document indicating your acceptance of these terms should be returned to me by 8<sup>th</sup> May.

I trust that the above information will answer many of the questions that you may have, any further information you require should be directed to your Support Worker in the first instance. I look forward to working with you over the next year, and hope that this will be the beginning of an enduring and productive partnership between us.

Yours sincerely

(Directors of Community Engagement)  
Centre for Ethnicity and Health



Questions	Strongly agreed	Agreed	No comment	Disagreed	Strongly Disagreed
1. I have enough knowledge to recognise mental illness and symptoms of myself/ or the person whom I care for.	1	2	3	4	5
2. Mental health problems are very common in Chinese community.	1	2	3	4	5
3. If I had mental health problem, I would seek help.	1	2	3	4	5
4. I feel accepted by the community in terms of mental health problems I came across.	1	2	3	4	5

**2. Have you or the one whom you are caring ever experienced from the following mental health problem? (Please tick those which applies)**

Depression	[     ]	Anxiety	[     ]
Mood Swing	[     ]	Intrusive thoughts	[     ]
Suicidal thought	[     ]	Suicidal attempts	[     ]
Flashbacks	[     ]	Difficulties in sleeping	[     ]
Poor concentration	[     ]	Emotional withdrawal	[     ]
Memory loss	[     ]	Hearing voice	[     ]
Delusions	[     ]	Paranoid	[     ]
Loss of appetite	[     ]	Other: _____	

**Part Three – Accessibility of services**

- 1. If you need to seek for mental health support, would you know where to get help from?**  
If yes,  
1a. Where would you get help from?  
1b. If you have accessed help, which services did you access?  
1c. Did you experience any difficulties? Please explain.  
If no, how did you cope?
- 2. How long does it take you to make an appointment with your GP?**
- 3. If you need an interpreting service during the appointment with your GP, is it available?**
- 4. If you have chosen not to use the interpreting service, please explain the reason why.**
- 5. Did your GP provide you with any information about voluntary services in the Chinese community?**  
If yes,  
5a. What was the information given to you?  
5b. At which stage did the GP provide you with that information?
- 6. Have you been referred to other specialist mental health services, such as Community Mental Health Team, a Psychiatrist, and the Chinese Community Organisation?**  
If yes,  
6a. How long did it take you to be referred to?  
6b. Did you feel that this was adequate / appropriate time?

**Part Four – Hospital Admission**

- 1. Have you or anyone you know ever been admitted into hospital for any mental health problem?**  
Yes \_\_\_ No \_\_\_
- 2. If yes, during hospital admission, was there any information provided to you in Chinese?**  
2a. If yes, what was the information given to you?  
2b. If no, do you think you would have liked to have had some information?
- 3. Did the hospital provide interpreting service to you if you so needed them?**

4. With regards to medication, were you given any translated information which could help you to understand the medication and its possible side effects?
5. Are you familiar with the legal aspect of mental health such as the following:
  - Mental Health Acts
  - Sectioning
  - Your rights
  - Complaint Procedure
  - Other \_\_\_\_\_

**Part Five – Awareness of service and support**

1. Do you know of any of the following statutory or voluntary services in the \_\_\_\_\_ area providing mental health support?

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> Community Mental Health Team</li> <li><input type="checkbox"/> Acute Services</li> <li><input type="checkbox"/> Alzheimer's Society</li> <li><input type="checkbox"/> Carer's Network</li> <li><input type="checkbox"/> Advocacy Services</li> <li><input type="checkbox"/> Chinese Mental Health Association</li> <li><input type="checkbox"/> Psychiatry services through your GP</li> <li><input type="checkbox"/> Counselling Services</li> <li><input type="checkbox"/> Other _____</li> </ul> | <p>How did you hear about them?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> |
|---|--|

**Part Six – Awareness of information**

1. Do you think that there is sufficient information available for you to access mental health services in your area?
  - 1a. If yes, what is the most effective method of providing information to you?
  - 1b. If not, could you suggest what the service provider could do to improve the information provision?
2. Have you seen any information around mental health issues in your own language?
 

Yes\_\_\_ No\_\_\_
- 2a. If yes, was there enough information in Chinese?
- 2b. If no, is there any information about mental health issues that you think might be helpful in your own language?

**Part Seven – Needs and expectation of mental health services**

1. What other treatments do you think might be helpful to you? (for example, acupuncture, Chinese herbal medicine, Tai Chi)
2. What other services do you think might be helpful to you? (for example, Chinese counselling, befriending, social group)
3. (This question for service user only) If you had an opportunity to choose your own treatment and services, what would you prefer?
4. (This question is for carer only) If you are caring for someone at home, what kind of service or support you are hoping to receive?

## **FOCUS GROUP QUESTION**

The focus group was structured for participants to discuss the following four areas:

1. How did participants view race equality in relation to mental health services for the Chinese users?
2. How did participants feel they had been treated as a service user when accessing mental health services?
3. What would they like to see for any changes or improvement of mental health services?
4. How could service users and the Chinese community be engaged by the statutory services for the improvement of mental health services?

**Optional 5.8: Evaluation questionnaire**

**Community research looking at the mental health needs and experiences of the Chinese community.**

Thank you for attending this conference/seminar/workshop. In order for us to learn about your opinions about our research, please take 5-minutes to answer the following questions. Thanks for your help.

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Please circle the number which most described your opinion.

- 1. The presentation has helped you to understand more about the mental health needs and experiences of the Chinese community identified by this research.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 2. The findings and results of the research have helped you in your work with the Chinese community.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 3. The presentation has helped you to understand more about the psychosocial and cultural factors which hindered the Chinese people in accessing health services.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 4. Referring question 3, the knowledge has helped you in your work with the Chinese community.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 5. You would consider using or quoting the results and findings of the research in any future occasion such as preparing a presentation or report relevant to the Chinese community.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 6. The presentation has an impact on influencing the health service at a policy level.**

Strongly agreed      5      4      3      2      1      Strongly disagreed

- 7. Which part of the presentation would you consider was most helpful and unhelpful?**

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- 8. Any other comment?**

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## Optional 5.8: Executive Summary, Discussion & Recommendation of the community research report

### Executive Summary

In 2006, the Chinese Mental Health Association (CMHA) received funding from the National Institute for Mental Health in England to conduct a Community Engagement Research Project in \_\_\_\_\_. The project, guided by the Centre for Ethnicity and Health at the University of \_\_\_\_\_, who developed the model of community engagement, gave CMHA their full support and guidance throughout the research study.

This was a great opportunity for CMHA to engage with the Chinese community in \_\_\_\_\_ which has the largest Chinese population in comparison with any other area in the country. This research project aimed to explore the service users and carers' experience in the mental health service system and their mental health needs.

Delivering Race Equality in Mental Health Care (DRE) is an action plan for achieving equality and tackling discrimination in mental health services in England for all people of Black and minority ethnic (BME) status. The vision for DRE is that by 2010 there will be a service characterised by 12 areas (DoH, 2005). The aims of our research project are to address the action plan which will contribute to the delivery of race equality for the Chinese community in \_\_\_\_\_.

Results and findings of the research study show that language barriers still exist as a major problem for Chinese service users to access health services in primary and mental health care in \_\_\_\_\_. Interpreting service did not seem to be solving the language difficulty in using primary and mental health services. This unmet need has led to frustration, stress, disappointment and feeling of being treated unfairly among the service users and carers.

To improve the current situation, recommendations were made to increase mental health awareness in the community, increase the provision of information resource in Chinese language and enhance cultural training for the health professionals. Traditional Chinese Medicine and acupuncture is highly recommended as alternative treatments in the mainstream services. Furthermore it is suggested that culturally appropriate mental health services provided by the Chinese community organisations are ideal for the support of the users and carers.

### Discussion

Our research results show that language barriers still exist as a major problem for Chinese service users to access health services in primary and mental health care in \_\_\_\_\_. Interpreting services, do not seem to be solving the language difficulty in using primary and mental health services because, even when interpreting services are available, very often the quality is not good and reliable. This led to frustration, stress, disappointment and feeling of being treated unfairly amongst the service users.

This is a small research sample, with only 28 participants including 13 service users, 5 carers, 5 elderly people and 5 people from the general public. However when we look at the Office of National Statistics of Psychiatric Morbidity Survey which shows a one year prevalence rate of 0.5% for psychotic illness, it can be deduced that about 31 (0.5% of total 6,379 Chinese population) Chinese residents in \_\_\_\_\_ may suffer from psychotic illness. In this research, it can be deduced that we have recruited about 42% (13/31) of the Chinese residents in \_\_\_\_\_ who are vulnerable to psychotic illness.

Almost all of the participants (27 out of 28) were born outside the U.K., work in the catering industry, and more than half of them do not speak English (table 7). When we look at how the participants view their mental health issues, only 3 of them reported that they suffer from severe mental illness. However, when they were to identify from a list of mental health problems such as anxiety, depression etc., all of them reported that they suffer from at least one to two problems. Anxiety, mood swing, insomnia and depression are the most common issues, these

together with the other 12 issues on the list, 102 responses were made by the 28 participants (Table 15). This is in line with the fact that 50% of the participants in this research agreed that mental health problems are very common in the Chinese community (Table 12), nevertheless more participants would disagree to the statement that they feel being accepted by the community in terms of the mental health problems they came across (Table 14).

Mental illness is no longer a new topic nowadays. It is very common, and happens everywhere and in every community. However mental illness is still a stigma in Chinese culture, mental health issue is an untouchable topic to discuss in the community. In some cases even when medical attention or support is needed, people are reluctant to seek help.

One of the participants said, *"If you ask me how I deal with my psychological issues... yes I was and am stressed, very stressed, really depressed, I wouldn't think of going to see a doctor because I don't have mental health problem... but how to sort out my emotion... I just go out and walk."* – A quote from a female respondent.

It is apparent that due to the small number of participants in this research, their issues may not be significant enough to represent the wider picture of the mental health issues in the Chinese community, they are, however, significant in representing the most disadvantageous and vulnerable group who experience stigma and difficulty in accessing health service due to language barrier and cultural factor and the lack of sufficient resources in the statutory services to help overcoming these problems.

Level of mental health awareness is relatively high (Table 11) and in general participants know where to get help from if they need to seek mental health support (Table 17). The majority of participants (89%) expressed that they would seek help if they had mental health problem (Table 13). In reality, when we look at service referral, 11 out of 28 participants had the experience of being referred to other specialised mental health services (Table 24), and the length of time for referral arrangement varied from on the same day to more than a year (Table 25). Results of this research suggested that the time for referral arrangement to specialised mental health service is longer than booking for the GP appointment.

GPs are the first point of contact for participants to seek help, followed by CMHA (Table 18). Most participants booked for a GP appointment on the day or about three to four days (Table 19). For those who need interpreting at their GP appointment, service is often available to them when requested (Table 21), however time for booking interpreting service varied, 7 participants said it was unpredictable when they recalled the time it took for service. In general, participants felt that the existing interpreting service is not good and unreliable; interpreters sometime do not keep the appointment which caused a lot of inconvenience to the participants. Feelings of disappointment, frustration and stress arise because of the inefficiency of interpreting service which limited the already limited time for each GP consultation. A participant said, *"I feel more stress out whenever I have to see my GP, it's not good for my mental health."*

Furthermore, participants' health problems are not fully conveyed in an accurate way or misinterpreted that they feel being misunderstood and not treated properly. Some participants give up using interpreting service and turn to friends and relatives for help, whereas other tolerate with the problem in silence.

On the other hand, when we look at the three participants' experiences during their hospital admission, the situation was not any better. Interpreting service was not available to them even upon request, besides no Chinese information about the admission, the medication or its side effect had been provided in the hospital. A participant who was admitted to the hospital said,

*"The information given to me by the nurse was in English. I was never told about the side effects of the medication, but from my experience I knew I would probably get drowsy after taking the medication, whereas if it is injection it should be fine. It would be really helpful if I could have information in Chinese about my mental health condition, the treatment and its side effects."* – A quote from a male respondent.

However, based on the opinions of the three participants we had in this study, it is not clear how long ago the participants were admitted to the hospital, we maintain that this is not a representation of the overall and current

condition of the hospitals in \_\_\_\_\_. In one case when language barriers are not an issue, a professional practice was reflected in the communication between the doctor and the patient. A carer participant described the situation when his grandson was admitted to the hospital,

*"They didn't provide translated information but each time the doctor called up our family to discuss the medication with us. He also let my grandson know that as a patient he has the choice whether or not to take the medication." – A quote from a male carer respondent.*

Information provision is an important aspect of improving awareness and hence access to mental health services. Results of this research show that mental health information in Chinese at GP surgeries and hospitals to help the community access services in \_\_\_\_\_ is far from sufficient (Table 28, 29, 30). We consider that for people to get the information they need, it also depends on how proactive they are to search for them. So we asked 10 service users and carers whether they have tried to actively search for service or mental health information, none of them did due to the long working hours in the catering industry. One of the participants said,

*"You know the working hours are so long that when you are off, it's already after mid-night when the GP surgeries are closed. And life is tough here; I don't really have time to care about other issues including my health." – A quote from a male carer respondent.*

Voluntary organisations such as Chinese Mental Health Association have been providing community services and information, publicising via a wide ranging media outlets from bus advertisement, newspaper column, press release and mailing, became the major information source and support for the most hard to reach group in the community. A participant highlighted that,

*"CMHA is an important service because what they provide are exactly what we need – Chinese information, cultural and language support, counselling, and giving us a channel to say what we need, just like in this research project. They have to continue and ideally expand their existing services for the benefit of the Chinese community." – A quote from a female respondent.*

Language barrier and the issue of interpreting service at GP surgery were raised most of time during the semi-structured interviews and the focus group, besides the prolonged waiting time for appointments, not related to mental ill health but for physical problems in the hospital was also one of the most painstaking experiences for the participants. Feelings arise from these problems, when summed up, are strongly linked to the sentiment of discrimination as far as equality of health service and experiences are concerned.

The Chinese community in the U.K. is unique in its historical and cultural background, and people's concepts of health and well-being has long been influenced by the traditional Chinese medical model which aims to maintain a holistic sense of balance of the human body. Until today, people still prefer to use the traditional Chinese herbal medicine as a way to counteract imbalances that are regarded as the source of illness, including mental illness. In this research when we asked our service user and carer participants what other treatments they thought would be helpful, most of them preferred Chinese herbal medicine, Tai Chi and acupuncture.

In addition to the Chinese traditional medicine, a culturally sensitive way of medicine treatment, when asked even more specifically what treatments and services the participants would prefer if they had the choices, the expectation of a more culturally appropriate approach for treatment and service in all aspects has emerged. Ideally participants prefer to have Chinese GPs, Chinese counselling service, an integrated Chinese and Western medicine, a financially sustainable Chinese mental health organisation to provide more comprehensive services, and a Chinese link worker to assist in information and advice for the community. Furthermore, strengthening cultural training for health professionals is suggested. A participant quoted an example of the cultural difference between Chinese and Western ways of looking at mental well-being:

*"My psychiatrist suggested me to take a holiday break because I was down, but you know, having a break or not is no big deal for us Chinese. I was down because my children were leaving me as they have grown up. The western psychiatrist thought this was normal to meet children just once a year and it was not something worth upsetting about. They just didn't understand me, as a Chinese parent this is saddening. If they understand our*

*cultural value more, they would be able to know our psychological needs more." – A quote from a female respondent.*

In this discussion so far, we have brought out the issues of language barrier and interpreting service; the insufficient provision of information and the participants' expectation of a culturally sensitive service. All these findings are in consistent to that of the research studies (Yee & Au, 1997; Li & Logan, 1999) in the last ten years.

In this research, we heard the call for a more united community to preserve the cultural understanding and language capacity for the younger generation. This is perhaps the first time we hear the reflection of the weakness of our own community, that if we want to have a culturally appropriate health service, we also have the responsibility to make it work by starting from our families, nurturing more Chinese speaking health professionals to join the mainstream services. One of the participants said,

*"It would be so helpful if we could have more Chinese doctors and health professionals. I mean real Chinese, you know sometimes you bump into a Chinese doctor or a nurse, you thought you're being lucky to have found someone who speaks your language, but surprisingly he or she doesn't speak Chinese at all." – A quote from a female respondent.*

Whereby voluntary organisations such as CMHA have been engaging the community by promoting and providing access to mental health information, signposting and referring service users to statutory services, let alone the voluntary organisation to deal with the problems, the question of equality of outcome and access to mental health service could hardly be resolved. The following section will set out the recommendations of improving the situation of the existing mental health services for the Chinese community in \_\_\_\_\_.

## **Recommendations**

Chinese interviewees not only discussed their experiences of using the mental health services, they also provided useful opinions of what they would like to see in terms of changes or improvement of mental health services.

### *Improve mental health awareness in the community*

The statutory service should place more efforts in promoting mental health awareness, eliminating stereotypes and discrimination in the Chinese community. Statutory service providers should work closely with local Chinese voluntary organisations such as CMHA in different ways to organise awareness campaigns such as seminars, talks and health events. A workforce consisting members from the statutory service and the Chinese voluntary organisation is suggested to set up to discuss the partnership work and implementation of this point as soon as possible.

### *Creating a helping community*

Chinese people, especially the first generation immigrants, face language barriers in this country. The idea of developing a helping community would help to improving health from within the Chinese. The second Chinese generation or simply, British Born Chinese should keep learning their own language and culture in order to contribute to their own community.

The first possible step in its process to create a helping community is to introduce the concept of community health psychology. Projects using a participatory and empowerment approach can be developed to involve people to 'take ownership' of the problem collectively. The project can be facilitated by a health psychologist for the purpose of increasing the likelihood that Chinese people will act in more health-enhancing ways and in lobbying for the creation of community contexts that will enable improved health (Campbell & Murray, 2004). CMHA will source for funding in the near future to pursue this idea.

### *Increase information resources in Chinese*

The relevant authority should translate more information into the Chinese language. The information can include an introduction of mental health services and the way of accessing the service. They could also give financial support to the Chinese voluntary organisation such as CMHA to do the translation. A team consisting members from the statutory service and the Chinese voluntary organisation is suggested to set up to discuss the partnership work and implementation of this action point as soon as possible.

### *Training for professionals and family carers*

Provision of training for a wide range of workers in statutory services of cross cultural awareness is important. Chinese may have very different life perspectives if compared to other ethnicities. Thus cross cultural awareness training would be beneficial for both Chinese and service providers. The quality of interpreting service should also be improved by proper training. Provision of support, training and information for carers and family members in terms of mental health knowledge and understanding of mental illness is also essential. Meeting should be set up between CMHA and the relevant unit in the statutory service to discuss how this could be implemented in the near future.

### *Culturally sensitive medical treatments*

There are about 20 practitioners registered under the member of The British Medical Acupuncture Society in London. They are legally practicing acupuncture in mainstream hospitals. Despite that, the service is still very limited among the Chinese community. Hence, it is recommended that Chinese acupuncture and Chinese herbal medicine could be widely practiced in mainstream services in the near future.

### *Strengthening service support for Chinese users*

The statutory services like hospitals and all GP surgeries should work, cooperate more closely with CMHA to strengthen the support for the Chinese community. CMHA can act as a bridge between the statutory services and the Chinese community to support the Chinese service users. A Chinese Community Development Worker based in CMHA would be the most effective way to provide support and service to the community in \_\_\_\_\_.

## Appendix D.1.

### Systematic Review: Quality Assessment Tool

Table D.2. The scoring sheet used to assess the quality of the papers

	Maximum score
Methodological quality of study	
Study design (RCT = 2, comparison = 1)	2
Study sample and selection (good sample, well described = 2, poor sample, well described = 1, low sample = 0)	2
Method of training well described (yes = 1, no = 0)	1
Trainer described (yes = 1, no = 0)	1
Intervention	
Follow up duration (6 months and more = 4, 3 – 5 months = 3, 1 month = 2, immediately after intervention = 1)	4
Analysis	
Drop out rate (<25% = 2, >25% = 1)	2
Results/outcomes	
Validated assessment tools used to measure outcomes (yes = 1, no = 0)	1
Satisfaction with intervention (>70% = 2, <70% = 1, not measured = 0)	2
Cost benefit (mentioned and calculated = 2, mentioned not calculated = 1, no = 0)	2
<b>Maximum total</b>	<b>17</b>

## Appendix D.2.

### Systematic Review: Reference list of the 8 included research studies

1. Donaldson, M.A., Tarrier, N. et al. (2000) *A cognitive behavioural family intervention reduced psychiatric morbidity in caregivers of patients with Alzheimer's disease*. Evidence Based Mental Health. 50 Vol 4 May 2001.
2. Hepburn, K.W., Tornatore, J., Center, B., & Ostwald, S.W. (2001) *Dementia Family Caregiver Training: Affecting Beliefs About Caregiving and Caregiver Outcomes*. Journal of American Geriatrics Society. 49-450-457, 2001.
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4. Davis, L. L., Burgio, L. D., Buckwaltr, K. C. & Weaver, M. (2004). A Comparison of In-Home and telephone-Based Skill Training Interventions with Caregivers of Persons with Dementia. Journal of Mental Health and Aging, Vol. 10, No.1, Spring 2004.
5. Martin-Cook, K., Davis, B.A., Hynan, L., & Weiner, W.F. (2005) *A randomized, controlled study of an Alzheimer's caregiver skills training program*. American Journal of Alzheimer's Disease and Other Dementias. Vol 20 Nov 4 July/Aug 2005.
6. Smith, S. & Bell, P.A. (2005). Examining the effectiveness of the Savvy Caregiver Program among rural Colorado residents. *Rural and Remote Health*. Available from <http://rrh.deakin.edu.au>
7. Coon, D. W., Thompson, L., Steffen, a., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and Depression Management: Psychoeducational Skill Training Interventions for Women Caregivers of a Relative with Dementia. *The Gerontologist*. Vol. 43, No. 5, 678-689.
8. Ghatak, R. (1994) *Effects of an Intervention Program on Dementia Patients & Their Caregivers*. Caring Magazine. August 1994.

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