

# Coping strategies and social support-seeking behaviour among Chinese caring for older people with dementia

ALMA AU\*, STEVEN M. SHARDLOW\*†, YUE TENG\*,  
TERESA TSIEN\* and CHARLES CHAN\*

## **ABSTRACT**

The study reviewed coping and help-seeking behaviour among Hong Kong Chinese family care-givers of older people diagnosed with dementia. A convenience sample of those caring for family members with dementia (N = 11) was recruited in Hong Kong. Semi-structured interviews were conducted, transcribed and analysed using NVivo. The study found evidence of distinct Chinese coping strategies that focused upon internal self-regulation, forbearance and family obligations. In terms of help-seeking behaviour, these care-givers expressed great concern about bothering their family members. When there is a desperate need for help, they turn to community services. Results are discussed in the context of both traditional Chinese cultural values as well as the modern transformations of the Chinese society. In particular, Eastern philosophical teachings tend to focus on changing personal inner perception and thoughts rather than attempting to change the environment. Although family obligations have been traditionally upheld, many modern Chinese societies are undergoing social and demographic changes, resulting in marked decline in multi-generational households. Our findings can have applications not only for Chinese cities but also may have implications to the West as strong well-established Chinese communities are widespread.

**KEY WORDS** – Chinese, dementia, care-givers, coping, social support, Hong Kong.

## **Introduction**

Dementia, in its various forms, is largely, although not exclusively, a progressive condition that affects older people. Many older people with dementia live with and/or are cared for, in part or entirely, by their families. The early stages of dementia may present relatively few problems for

\* Department of Applied Social Sciences, Hong Kong Polytechnic University, Hong Kong, China.

† School of Nursing, Midwifery & Social Work, The University of Salford, UK.

care-givers. However, as the condition progresses, the challenges of caring for someone with dementia are likely to become more acute and demand increased amounts of time and commitment from care-givers (Alzheimer's Society 2008; Donaldson, Tarrrier and Burns 1998; Pinquart and Sörensen 2003; Sörensen and Pinquart 2005). In the medium term, as the global population of older people increases both proportionately and in absolute numbers, an increasing number of families are likely to face the challenges of providing care for an older person with dementia. In the *World Alzheimer Report* (Alzheimer's Disease International 2009) it was estimated that more than 35 million people worldwide would have dementia in 2010. Global dementia prevalence is predicted to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (Wimo, Winblad and Jonsson 2007).

Dementia care-giving is a stressful task. Numerous research studies have reported a negative association between caring and the physical and mental health of the care-giver (Pinquart and Sörensen 2003; Vitaliano, Zhang and Scanlan 2003). Previous research studies of Western care-giver populations have reported that the use of problem-focused, instrumental coping strategies were associated with lower levels of depressive symptoms among care-givers; while emotion-focused coping strategies were associated with poorer care-giver health (Fingerman *et al.* 1996; Haley *et al.* 1987; Pruchno and Resch 1989; Vitaliano *et al.* 1985; Williamson and Schulz 1993). However, research on coping mechanisms and support-seeking patterns adopted in non-Western populations has been lacking. The current study explored aspects of care-giving by Chinese people in Hong Kong, allowing both comparisons between Chinese and Western care-givers to be made using findings from previous studies juxtaposed with the findings from this study, and also to provide a critique of the applicability of Western research findings to Chinese populations.

#### *Previous research: coping with a family member with dementia*

The burden of providing care for older people with dementia frequently falls upon the family; care may be provided by a single care-giver or may be shared. Within families, poor family functioning (*e.g.* lack of communication and mutual support), has been found to have a direct effect on care-givers' levels of distress and to negatively mediate the perceived impact of providing care (Heru, Ryan and Iqbal 2004; Mitrani *et al.* 2006; Tremont, Davis and Bishop 2006). The quality of family functioning may be even more salient to Chinese than to Western care-givers, as traditional Chinese values, heavily influenced by Confucianism, emphasise the importance of interconnectedness and interpersonal harmony. Published research has examined many

aspects of caring for older people with dementia; selected elements from this body of work were found to be pertinent to this study: coping mechanisms used by care-givers and support-seeking strategies of care-givers, which are reviewed below.

### *Coping mechanisms used by care-givers*

A number of studies have identified adaptive or maladaptive coping mechanisms used by care-givers in response to the challenges of caring. For example, avoidant coping has been found to be associated with depressive symptoms among care-givers (Haley *et al.* 2004); self-controlling and distancing behaviours were found to be associated with care-giver drinking behaviours while positive appraisal and confrontative coping were found to be associated with non-drinking (Mjelde-Mossey, Barak and Knight 2004); and benign cognitive appraisal, religious coping and recognition of perceived benefits of care-giving were more likely to be found in association with care-givers that possessed a strong sense of wellbeing (Powers, Gallagher-Thompson and Kraemer 2002). Support from immediate or extended family members has been found to be predictive of care-givers' resilience (Wilksa and Croomb 2008), reduced secondary stress (Gaugler *et al.* 2008) and reduced perception of care-giver burden (Benson, Fisher and Tessler 1996).

Flexibility in approach to coping has been argued to be especially relevant to Chinese people. This approach is characterised by variability in coping strategies as well as the continuous attempt to find a good fit between the nature of coping strategies and situational demands. This kind of flexibility may be rooted in the dialecticism found in Confucian, Buddhist and Taoist philosophy, all of which emphasise the importance of adopting flexible approaches to handle complex matters in response to changes in the social environment. This is exemplified by the Taoist expression 'using methods appropriate to the current situation' (*yin shi zhi yi* 因時制宜, rooted in the book *Huai Nan Zi*, which was written in the Han Dynasty, 202 BC to 220 AD).

Using Western terminology, coping strategies can be differentiated into two broad types: 'active coping' (problem-focused coping) and 'passive coping' (including avoidant and emotion-focused coping). 'Coping flexibility' refers to the pattern of deploying more problem-focused coping strategies in controllable stressful situations, and more emotion-focused coping strategies in uncontrollable stressful situations. A study, undertaken in Mainland China, found that Chinese care-givers of dementia patients who used both problem-focused coping and emotional coping (*e.g.* acceptance) had lower perceived stress than those who only used problem-focused coping (Meng, Xiao and Liu 2006). The outcomes of a group intervention

programme for dementia care-givers in Hong Kong, which increased use of both active and passive coping strategies, were found to be associated with enhanced self-efficacy (Au *et al.* 2010). As few studies were identified about the coping mechanisms used by Chinese care-givers of family members with dementia, a gap in the research literature was identified; the purpose of this study was to explore aspects of this under-researched domain.

### *Help-seeking behaviours*

Overlapping somewhat with the construct of ‘coping’, social support seeking is another important approach to the reduction of one’s stress. For example, emotional support provided by family members has been found to have the strongest correlation both with enhanced life satisfaction and also decreased depressive symptoms among the care-givers with responsibility for managing patients with dementia (Au *et al.* 2009a, 2009b). In previous studies, Chinese students were found to utilise social support in a unique manner that differs from the social support-seeking patterns typically found in Western cultures. These Chinese students tended to place great value on social support (Pines *et al.* 2003), but were willing to seek it only when they were unable to handle the problems by themselves (Boey 1999). Some studies (*e.g.* Chen 1987; Cheung 1984) have found that Chinese prefer to tackle problems by themselves rather than to seek help from others, as they feel embarrassed and uncomfortable about receiving support; others found that when Chinese *do* seek help, they prefer to approach their family members and friends rather than mental health professionals (*e.g.* Cheung and Lau 1982; Sue 1976). Such patterns in modern societies may be a result of the residual influence of traditional Chinese values to uphold propriety and harmony (Wang *et al.* 2006). As previously, there is a paucity of research literature that concerns Chinese social support-seeking behaviours of dementia care-givers; this theme was explored in this project.

## **Methods**

The study was designed to explore the nature of coping mechanisms and help-seeking behaviours used by Chinese people that were caring for older people with dementia in their family.

### *Aim*

The principal aim of this study was to explore the possible differences between the coping mechanisms and help-seeking behaviours deployed by Western (as identified in published literature) and Chinese people

(as identified in this study). This aim was realised through an exploratory manner through findings provided from a qualitative study of Chinese care-givers.

### *Site*

The study was conducted in Hong Kong, where the population is a little above seven million (Hong Kong Government Census and Population Department 2010). The largest population group are Han Chinese, with Cantonese and English as official languages. In Hong Kong, around 60,000 people were living with Alzheimer's disease in 2010 with an estimated prevalence number of 332,000 by 2050. Primary care for these people is generally undertaken by family members (Alzheimer's Disease International 2009; Wimo, Winblad and Jonsson 2007).

### *The sample*

Both female and male care-givers as well as spousal and second-generation care-givers were included in the study. A convenience sample comprising care-givers (N=11) of older people with dementia was recruited. The target had been 12; 11 were identified through the recruitment strategies. The number of participants was deemed sufficient without the instigation of additional recruitment strategies, as the aim was to generate detailed understandings of a limited number of cases. The primary recruitment strategy was to seek willing participants from the families of those that attended a day-care centre for people with dementia. Researchers attended a family support-group meeting at the day-care centre to brief care-givers about the study aims and procedures. Nine participants were recruited from this source. A secondary recruitment strategy was also used; two care-givers, one wife and one daughter-in-law, were recruited through the psychogeriatric unit of a general hospital. Among these 11 care-givers, there were two husbands, two wives, four daughters, two daughters-in-law and one son. The socio-demographic characteristics of these care-givers and those of the care recipients along with health status and prior relationship with care-givers and other family members can be found in Table 1. Some respondents are given the prefixes Mr and Mrs to indicate that they are senior citizens and are spousal care-givers. This is consistent with common practice in Hong Kong.

### *Data collection*

Written consent was obtained from the care-givers after verbal explanation of the study rationale. False names have been used in this discussion of the study to protect the identity of the care-givers. Data were collected by one

TABLE 1. *Socio-demographic characteristics of care-givers (CG) and care recipients (CR)*

CG	CG role	CG age	CG education	CG work and marital status and family structure	CR age/year of onset/ stage of dementia	How CR was perceived by CG
Mr Ching	Husband with a number of chronic illness	83	Secondary	Retired. Living alone but with a live-in domestic helper while wife (CR) living in an elderly home	83/1995/late stage; hallucinations	Committed wife and dedicated mother
Mr Xi	Husband with knee problem	79	Secondary	Retired. Living with wife (CR)	71/2006/mid stage; night waking	Supportive and caring wife and mother
Mrs Leung	Wife with high blood pressure	68	Secondary	Housewife. Living with husband (CR)	74/2004/mid stage; urinating in inappropriate place	Hardworking and dedicated father
Mrs Lo	Wife with back problem	65	Primary	Housewife. Living with husband (CR) and grown-up single son	76/2004/mid stage; calling for attention all the time	Hardworking but somewhat chauvinistic husband
Yang	Daughter-in-law	58	Secondary	Business owner and a volunteer. Living with mother-in-law (CR), husband and a son plus domestic helpers	87/2002/mid stage; agitation	Strong-willed and hardworking mother
Shan	Daughter-in-law	46	Secondary	Housewife. Living with mother-in-law (CR), husband and three school-age daughters plus a domestic helper	84/2006/mid stage; refusal to eat at times	Committed but strong-willed mother
Dan	Son	43	Post-graduate	Employed. Single and living with mother (CR) plus a part-time domestic helper	89/2006/mid stage; delirium	Loving and warm and diligent mother
Wen	Daughter	45	Secondary	Self-employed. Married with two sons and one daughter	83/2000/late stage; depression; multiple physical problems	Warm and committed mother
Hong	Daughter	60	Post-graduate	Retired. Single and living with mother (CR)	90/2004/mid stage; heart problems	Strong, caring and loving mother
Lok	Daughter	45	Secondary	Employed. Single and living with mother (CR) and father	86/2006/mid stage	Caring mother
Ailan	Daughter	51	Matriculation	Retired. Living with husband and one school-age son	74/2004/mid stage	Loving and warm mother

researcher between August 2007 and February 2008 through face-to-face semi-structured interviews, which lasted between 40 minutes and two hours. An interview guide was used to:

1. Examine the extent of disease awareness.
2. Identify challenges faced by families in the care-giving processes, and the coping strategies used, in light of the progression and behavioural manifestation of dementia.
3. Probe the process of family care-giving, *i.e.* to examine the stresses felt, the tasks undertaken, and the support and conflicts emerging between and among family members.
4. Identify the perceived needs of the care-givers, so as to suggest intervention programmes for future help.

### *Data analysis*

All face-to-face interviews were recorded and transcribed. From these transcripts understandings, meanings and interpretations as constructed by respondents were extrapolated and then interpreted (Granvold 1996). NVivo 8.0 (QSR International 2009) was used to code the information into emergent categories. Text data were carefully read and systematically analysed by investigators to identify recurrent themes derived from research questions. Several researchers read all interviews and the team evaluated the main codes against text samples. The analysis protocol included checks for consistency between codes and coding of interviews, including double coding (by two coders of half of the interviews to ensure consistency). Emergent categories were then refined and reconfigured.

## **Results**

Eleven care-givers described their experiences of providing care for a close older family member with dementia. Two themes emerged from the analysis that were consistent with the dementia care-giving literature, namely coping mechanisms and help-seeking behaviours. Some positive aspects of care-giving were also identified, such as improved relationships and personal growth. These themes in care-giver experiences are presented with selected illustrative quotations. The acronym CR has been used to denote 'care recipient' in the quotations. Given that the interviews were conducted in Cantonese, a spoken dialect of the Chinese language, and that many elderly care-givers used some parochial languages, the translation of the quotations into English has been done to preserve as much of the semantics and localism as possible.

*The challenges of care-giving and care-givers' coping mechanisms at early stages of the disease*

It was not until the behaviours of care recipients rendered independent living impossible and/or significantly disrupted family life that family members sought to find out about the care recipient's problems. This was in accordance with research findings about the Chinese culturally based way of viewing dementia, which sees memory loss of older individuals as a normal consequence of growing old and considers mental illness to be highly stigmatised (Wang *et al.* 2006). Initially, as the condition of the care recipient was still perceived as controllable, there was a tendency for the care-givers to use problem-focused coping strategies (Lazarus and Folkman 1984). Most care-givers looked for information and/or sought professional advice with initial queries about 'unusual' behaviour. Almost all of the care-givers had searched the internet or community libraries for information. For example:

...when the doctor first said that she [CR] had got dementia; we searched for information on the internet. . . . other people talking about their cases, those about care-givers – there are lot of information online. (Hong)

Some proactively contacted the doctor for information and diagnosis: many actively participated in talks about dementia care-giving held by local non-governmental organisations (NGOs). Some care-givers would discuss with their extended family the arrangements and decisions to be made about at-home care-giving. They also tried to elicit help, be it instrumental or emotional, from family members, if there was help available:

Now it [the financial support] is the responsibility of the second and third daughters, the youngest son already hired us a domestic helper. (Mrs Cheung)

And

If the elderly [person] has some problem, I'll call up everyone in my family, I don't need them to take up the actual care-giving responsibilities, but I want them to show concern about the elderly – even making a phone call to her from time to time is good. (Yang)

However, help from family members was not always available. For most of the children care-givers, seeking help from other family members was not a preferred option. Many of the children care-givers found it was not possible to obtain practical support from family members. Some of them did not have any support from siblings, as they had established their own families, and were not willing to take on extra care-giving responsibility for their parents anymore. For example:

[Brother] never gave any money for daily expenses of the family, not even a penny . . . never take them [the parent CRs] to his home for a short stay or visit.

About this I'm pretty angry. Maybe it's really because of financial issue – he seldom took our mom out to spend leisure time, even to have tea [a traditional Hong Kong way of getting-together for families and friends] is very rare . . . not once in the last two years. (Wen)

Others gained only minimal support from family members, such as one or two visits per month, or received some financial support. Most of the care-givers interviewed indicated that they were unable to rely on their family members for support, especially in respect of emotional or instrumental support (*e.g.* assistance in solving a problem). At such times, some attended church as a means to obtain social support, while many care-givers often resorted to friends to provide emotional support. For example:

I have a lot of good friends. Before I didn't like it [sharing the experience of care-giving with them], . . . felt like it's talking too much, on one hand it's annoying to the others, on the other those are personal matters. . . . but every family has some sort of trouble, so I'm lucky to have some best friends who can help me at those most critical moments. They all understand, about one taking care of several. . . (Shan)

*The challenges of care-giving and care-givers' coping mechanisms at later stages of the disease*

As the disease progressed, the care-givers reported that situations became gradually harder and harder to control. However, the sampled care-givers still chose to take care of their family members at home, probably due to the influence of traditional Chinese values. As Chinese culture is collectivistic and values social relations, obligations are often bound to an individual's social role and each individual is supposed to perform a spectrum of proper behaviours. This was especially obvious in the family setting. For example, some care-givers care for their parent care recipient because they regard it as a filial responsibility.

Because she is my mother. You know, we have no choice in choosing our family members. I am her son, thus I have to take care of her. It is the reason. (Dan)

Care-givers also do certain things for their family care recipients due to internalising others' expectations. For example, some care-givers in our study expressed the feeling of having a lack of choice in response to being questioned as to why they cared for an older person at home:

I am struggling whether to apply to the rest home for her [CR]. Although it is more feasible for me and for my family, there is a negative stereotype on me if I do so. People usually think you are not willing to take care of the elderly that you put them into the rest home. Thus I am still taking care of her [CR] by myself. (Yang)

As the symptoms worsened the care recipients presented more difficult behaviours; their capability for daily functioning declined and was often combined with increased emotional instability. At such times, the care-givers found increasing difficulty in managing their stress by using active coping. *Passive coping* strategies were reported in the care-giver's repertoire of coping behaviours with higher frequency than previously. These behaviours can be understood as Chinese culturally specific coping mechanisms, which are discussed next.

Ren (忍) can be understood, in a Western context, as a personal attribute 'facing adversity with magnanimity'. As such, Ren is a highly valued virtue in Chinese culture, which originates from the writings of Confucius. Chinese cultural beliefs emphasise the positive value of adversity and people's capacity to overcome adversity (*i.e.* positive beliefs about adversity). Such cultural beliefs are basically shaped by Confucian thoughts where people's inner strengths and virtues, such as perseverance and tolerance, are strongly maintained (Tseng 1973). Many Chinese believe that to embrace Ren, as a virtue, can strengthen their resilience to overcome inadequacies and preserve family harmony, cohesion, and avoid interpersonal conflict (Triandis *et al.* 1988).

At that time, she [CR] did not bathe and change her clothes for a week. I felt uneasiness, and even dare not sit on the sofa she has sit before. It was so dirty! And I was really very distressed at that time. But my husband asked me not to force her to bath because my husband loves his mother [CR] very much. I didn't want to argue with him, therefore I forbore it. (Yang)

And

Every day, when I am back home, she [CR] calls my name over and over for whole night. How can I bear it? I just put up it and let her speak until she feels tired. (Lok)

*Zhi-zu* (知足) can be understood in the Western context as a personal attribute, based on the belief that 'however unfortunate your own situation, there are others worse off than you'; a belief rooted in Chinese culture since the Han and Jin Dynasties (202 BC to 420 AD). Hence, Chinese like to compare their own situations with others. Then, they find comfort by telling themselves that although they are not as fortunate as some, they are more fortunate than some others (Lu *et al.* 2001). This relational concept enables individuals to attribute satisfaction to their own situation by juxtaposition with that of others. The responses of several respondents indicated that *Zhi Zu* was strongly embedded in their approach to coping behaviours, as can be seen from the following abstracts:

I know some other people with dementia would have the symptoms of incontinence, or even throwing objects at their family members. But my father is much better than

them. He would only forget things easily, or just skip bathing. So I feel fortunate about that. (Ailan)

And

She [CR] always argues with us repeatedly and repeatedly. Although it is annoying, the situation is much better than some people [with dementia] who cannot move and can just lie in the bed and wait for death to come. When I think in this way, I can feel happier. (Hong)

By comparing their situation with others that are worse off, they felt gratitude for what they had. This is consistent with a Taoist philosophy that all things in life are only relative in nature. Nothing is absolutely good or bad – the belief that no absolutes exist: a common passive coping strategy that Chinese use as consolation. Nonetheless, even during this stage emotion-focused coping was the dominant strategy, active (problem-focused) coping was also found. Some care-givers solved some of the care recipients' problematic behaviours successfully:

One time she [CR] excreted in the rubbish bin. Then I think of a solution – buy a chamber pot for her. I chose the chamber pot seriously, in terms of its height, shape, whether there is a cover on it . . . and I discussed with my family members seriously. (Yang)

And

She [CR] likes arguing so much. In the past, I can stop her by playing the video of Chinese opera. But now it is not useful at all. Therefore, I use another method now – ask my eldest son to take care of her, especially when she is having her meals. Because she is afraid of my eldest son, she would eat quietly only when he is present. (Wen)

In addition, these care-givers utilised the previously described emotional coping methods to enhance their own wellbeing. This way of alternating between the two types of coping strategies illustrates that some of the care-givers demonstrated a certain level of coping flexibility.

### *Help-seeking behaviour used by care-givers*

On account of concerns about loss of 'face', Chinese often refuse to seek social support in order not to lose face in social relationships. 'Lose face' simply means saying or doing something inappropriately in front of other people (usually not within the family). In Chinese perceptions, loss of face does not only result in a loss of one's own social standing but also in bringing embarrassment to one's family (Ho 1994; Hwang and Han 2010). As having dementia is still highly stigmatised in Chinese societies, Chinese care-givers were unwilling to disclose their family problems to people who were not their

family members. In some sense, face preservation was more important than utilising social support among Chinese (Ow and Katz 1999):

I can't tell anyone about my strain and burden. It is useless to tell other people, even my daughter, my relatives, and my friends . . . I am afraid they will look down on me, you know, I am a man [stereotyped as strong and tough]. (Mr Ching)

Another factor that prevented the care-givers from seeking help, especially from their immediate family members, was that they did not want to burden their adult children as they thought it might have caused undue stress for them:

I would not tell my daughter and my grandson about our [the care-giver and CR] situation. I don't want to bother them. They are very busy, my daughter has to work all day, and my grandson is studying for his PhD . . . There is no need to tell them. (Mr Ching)

Why bother telling the younger generation? They do not have the patience to hear and bear all this anyway. (Mr Xi)

Initially, these Chinese care-givers tended to seek help from a family member, but when no help was available or when they were unwilling to bother their children, individuals with high concern about face turned to different community services, such as NGOs or other helping professionals. Practical problems concerning the older people with dementia were usually tackled after consulting professionals. For these care-givers, emotional support was sought from social workers or self-help groups.

## **Discussion**

The present study analysed care-givers' views about caring for older family members with dementia, using a framework derived from notions of Chinese coping and social support-seeking behaviours. Despite a small sample size, meaningful results worthy of further explanation and discussion were found. Consistent with previous findings about Chinese people, participants in the present study showed the presence of distinct patterns of flexibility in coping and social support-seeking – some patterns that have not been previously reported. The results provide a new perspective to help understand how traditional Chinese culture influences the affection, behaviours, and cognition of Chinese care-givers in modern society in the context of providing care for older family members with dementia. Distinct from Western culture, Eastern philosophy, an amalgamation of Confucian, Taoist and Buddhist thinking, encourages the management of stress and emotional distress by changing inner thoughts and desires instead of attempting to effect overt changes to the environment (Cheng, Lo and Chio 2010).

*Coping mechanisms*

In the present study, different coping strategies were deployed by the care-givers. At the early stages of the disease, when practical issues were the major concern, most care-givers reported a tendency to deploy problem-focused active coping behaviours, for example to search for information online and consult professionals. As the disease progressed, the care recipients' behaviour became more unmanageable, the care-givers perceived their situation to be less controllable due to the deteriorating perceptual, communication and functional abilities of the dementia patients. Constant disruptions and adjustments to meet the changing health needs of care recipients made the experience of care-giving an overwhelming and uncontrollable task for them. In this situation, care-givers interviewed tended to use passive coping strategies. These care-givers did not internalise only the unique Chinese virtue of forbearance, but also comforted themselves by comparing themselves with others that are worse off as well as resorting to moral obligations. By deploying different coping strategies, care-givers in the study showed coping flexibility that was consistent with previous studies, which indicated that Chinese were more likely to deploy problem-focused coping strategies in controllable situations while utilising emotion-focused coping in uncontrollable situations (Cheng and Cheung 2005). These Chinese ways of coping reflect the influence on people's choice of coping strategies of traditional Chinese philosophies. As placement of a family member in a nursing home was still widely considered a failure of filial piety in most Chinese societies, for many the provision of at-home care was seen to be the only choice. Under such situations, the emotional coping strategies evidenced in the study may help the care-givers to regulate their mood and provide some protection against emotional burn-out (Elliott *et al.* 1996; Jones 1995). However, an overemphasis on family role responsibility and sense of obligation may be linked with care-givers' distress (Losada *et al.* 2010).

*Support seeking*

For social support, participants demonstrated patterns of behaviour typical of the Chinese collectivist culture, in which social and interpersonal relations are highly valued (Hwang and Han 2010). In the Confucian paradigm, all parties need to fulfil roles and obligations in respect of defined social relations (*e.g.* husband–wife, mother–daughter, *etc.*) in order to maintain harmony. Group concerns override individual needs (Triandis *et al.* 1988). Consequently, people have an overwhelming concern about others' appraisal of themselves (Ho 1994), and there was a tendency for them to

worry about others' opinions and to meet others' expectations in order to obtain social acceptance, maintain relational harmony, avoid social sanctions, and save face (Yang 1981). Interdependence between family members was valued and taking care of elder parents or parents-in-law was considered a responsibility of adult children (Wang *et al* 2006). Thus, the Chinese care-giver may be hesitant about disclosing information and seeking help unless there is an urgent need as observed in the study.

When having to seek support in the face of urgent needs, Chinese were found to prefer to approach their family members and friends over and above helping professionals (Chen 1987; Cheung 1984). A study completed in Mainland China about care-giving for those with dementia also found that female care-givers would seek help and support from within the family as the preferred choice over aid from outside the family (Tang 2006). However, a more complex pattern was found in the present study. For informational support such as consultation, the care-givers interviewed tended to approach professionals directly. This may be explained by the nature of dementia; the difficulty for family members to manage the behavioural and emotional problems posed by this disease made professional help necessary and indispensable. However, with respect to emotional support, these care-givers may still prefer to seek help from family members. But unfortunately for many of them, support from family members was not always available or was insufficient most of the time, and some of them did have concerns and wished not to bother their children or close friends. Hence, ultimately, many of the care-givers either sought emotional support from self-help groups or often just tackled the stress on their own. Miscommunication between family members can place additional extra strain on the Chinese care-giver, as Chinese have typically a more collectivistic set of social values than members of Western societies (Triandis *et al.* 1988). Several care-givers gave up their own full-time or part-time job to become a full-time care-giver. However, when such sacrifices were not appreciated by other family members, the care-giver may feel abandoned and helpless, especially at times when major decisions about care-giving have to be made. Indeed, a growing number of studies have shown that filial obligation related to a sense of increased care-giver burden and distress among Chinese care-givers (Wang *et al.* 2006).

### *Limitations of methodology*

Due to the modest sample size and convenience sampling methodology employed, the findings are not generalisable to the whole population of at-home dementia care-givers in Hong Kong. It should be noted that Hong Kong Chinese, though sharing the same traditional cultural traditions with Mainland Chinese, have been influenced by Western cultures and thus are

grounded in both Western and Asian values about family and interpersonal relationships. However, this exploratory study revealed interesting findings about the unique coping and help-seeking mechanisms used by the care-givers in dealing with the day-to-day demands of care-giving. Future investigations with larger sample size and different sampling methods could provide more conclusive evidence and further insight into Chinese ways of coping and help seeking.

### *Practical implications*

Despite these limitations, the study has implications for rethinking aspects of care for people with dementia and also older people in general both in Hong Kong and other Chinese societies. Chinese societies are witnessing massive demographic, social and cultural transformation. As a result of increasing urbanisation and the erosion of multi-generational households, older people are living with their spouses rather than with their children and an increased proportion of older people live in institutions (Fung and Cheng 2010). In a recent study about care-givers that provided care for physically dependent parents or parents-in-law in Mainland China, Zhan (2006) found that care-givers reported higher levels of satisfaction if they had some form of employment, reported better physical health and were caring for parents with pensions. In the present study, cultural values influenced the care-giving experience in two dimensions. First, care-givers' depression was linked to their report of filial responsibility. Second, perception of low social reward was associated with self-report of social pressure. Although passive coping may occasionally lead to adaptive outcomes (Jose and Huntsinger 2005), there is a need to create more options for care-givers. To assist care-givers to have a greater sense of the process of dementia-related deterioration may help care-givers to gain more direct control over their care-giving. Information and assessment services could be provided to the care-giver more proactively.

As some Chinese care-givers were reluctant to seek help from outside the family, health and social care agencies could consider reaching out to care-givers to assess their needs and introduce services accordingly. Similar policies have been established elsewhere in the world (*see e.g.* in respect of the United Kingdom, Department of Health 2005), which have helped care-givers not known to social services to have better access to available information and social services. As some of the care-givers preferred not to seek help from family members or friends, emotional support can be best provided by peers that have shared the same experience. Mutual support groups may be effective in providing emotional support. Government or NGOs should consider establishing more mutual support groups for care-givers.

Finally, stigma towards those with dementia was found to be a concern. Research in some non-Chinese societies in the West such as the United States has found stigma to be a factor that negatively affects the support and quality of care provided to people with dementia and their caretakers (Jolley and Moniz-Cook 2009; Werner 2008). The current study did find that care-givers experienced misunderstandings of others about dementia and discrimination throughout their care-giving career. The majority of care-givers thought that there was a lack of knowledge about dementia among the general public. Therefore, along with other stigmatising illnesses, public education about dementia should be a government priority. Furthermore, better access to services by enhancing levels of integration between specialised services and primary care requires careful consideration (Mak and Chen 2010).

## **Conclusion**

The study has set out to explore the possible differences in coping mechanisms and help-seeking behaviours deployed by Western and Chinese people. The findings from the study strongly suggested that there was evidence of some informative patterns of coping and support seeking in Chinese people, lending support to the research question about whether there were differences in the coping mechanisms and help-seeking behaviours employed by Chinese and Western care-givers of older family members with dementia. Chinese tend to adopt flexible coping strategies, adopting problem-focused coping in controllable situations and emotion-focused coping in uncontrollable situations. In particular, traditional cultural values of *Ren* and *Zhi Zu* were highlighted in the care-givers' responses. Moreover, Chinese care-givers value social support but were willing to seek it only when they could not handle the problems by themselves. This exemplifies the Confucian paradigm of the requirement to fulfil social obligations, which has been underscored by care-givers in the research. However, the erosion of multi-generational households due to increased urbanisation in many Chinese societies has implications for the continuance of traditional values. To help care-givers more effectively it is necessary to provide more information, instrumental resources and outreach services in the community. Furthermore, better integration between specialised services and primary care is needed to reduce the stigma of help seeking. Hence, for the governments of modern cities and nation states, around the world, there is a need to generate responses to the increased prevalence of dementia through policies that balance state and family responsibilities for care. Our findings have implications not only for

Chinese cities but also for some countries in the West, as strong well-established Chinese communities are widespread across the globe.

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*Address for correspondence:*

Alma Au, Department of Applied Social Sciences,  
Hong Kong Polytechnic University, Hung Hom,  
Hong Kong, China.

E-mail: [ssalma@inet.polyu.edu.hk](mailto:ssalma@inet.polyu.edu.hk)