**Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore**

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Experience of caregivers of dementia in Singapore

**Abstract**

The prevalence of dementia is increasing, especially in Asia. Caregivers of people with dementia are at greater risk of psychological morbidity; however, most studies on caregiving have been conducted in Western populations. As a caregiver’s experience can be influenced by cultural factors, this needs exploring further. This study explored the lived experience of caregivers of dementia patients in Singapore and the impact of caring on their sense of self. Six Chinese female spousal caregivers were interviewed and their experiences were analyzed using interpretative phenomenological analysis (IPA). Four super-ordinate themes were identified: impact of caregiving, acceptance of destiny, taking control, and view of self. The findings reflected the influence of Confucian values. Clinical implications are discussed, including more culturally sensitive services.

**Keywords***:* caregiver; culture; dementia; interpretative phenomenological analysis

**Introduction**

According to a report by the World Health Organization (WHO) in 2012, 35.6 million people in the world are diagnosed with dementia. It has been predicted that the number will double by 2030 and more than triple by 2050 (WHO, 2012). The prevalence of dementia in Asia is increasing even more quickly due to a rapidly aging population, with Singapore having one of the world’s fastest aging populations (Alzheimer’s Disease International, 2014). A study conducted by Alzheimer’s Disease International (2006) found that the prevalence of dementia in Singapore for those aged 65 years and above was 22,000 in the year 2005. A more recent study by Alzeheimer’s Disease International (2014) projected that this figure will increase to 45,000 in 2015, and 103,000 and 241,000 in 2030 and 2050, respectively. The estimated costs of dementia in Singapore in 2015 is US $1.6 billion, which has made this a key issue for the government. (Alzheimer’s Disease International, 2014).

***Dementia and caregiving***

Kitwood (1997) has introduced a person-focused approach towards dementia. This involves the understanding of individuals with dementia from their perspective and within the context of their family (Brooker, 2003; Cheston & Bender, 1999; Epp, 2003). It has been established that caregivers for individuals with dementia are at greater risk of psychological morbidity, such as depression and anxiety (e.g. Bédard, Pedlar, Martin, Malott, & Stones, 2000; Coen, O’Boyle, Coakley, & Lawlor, 2002; García-Alberca, Lara, & Luis Berthier, 2011; Papastavrou et al., 2011; Waite, Bebbington, Skelton-Robinson & Orrell, 2004), as well as experiencing lower levels of positive affect (Adams, 2008).

Stressors, the challenging situations that negatively impact caregivers’ ability to adapt, are conceptualized as being either primary or secondary (Pearlin, Mullan, Semple, & Skaff, 1990). Primary stressors are associated with symptoms of dementia such as cognitive disorders, functional impairment in activities of daily living (ADL), and behavioral disturbances (Huang, Lee, Liao, Wang, & Lai, 2012; Pearlin et al., 1990). As a result, caregivers may experience somatic symptoms, lack of time for self, loss of social relationships, and emotional burdens such as embarrassment and self-reproach (Aguglia et al., 2004). The management of these challenges impacts their quality of life (Coen et al., 2002).

As the decline in cognitive functioning of individuals with dementia is progressive and non-reversible, it results in the experience of chronic secondary stressors by caregivers. Taking on the caregiving role is a major life event that necessitates readjustment (Pearlin, Menaghan, Liberman, & Mullan, 1981). Role strains, which are difficulties in managing role obligations, highlight caregivers' inability to improve the current situation (Goode, 1960). Role conflicts also arise between the caregiving role and job commitments, as well as when expectations of responsibilities differ between caregivers and other family members (Pearlin et al., 1990). Under these difficult circumstances, caregivers are at risk of losing their self-esteem and sense of mastery, which are defined as the two broad components of the self (Pearlin et al., 1981). Additionally, caregiving activities may increase restriction in the scope of, and eventually take over the life of caregivers. This engulfment of the caregiver role results in a diminishment of the self and loss of identity (Skaff & Pearlin, 1992).

Within the dementia literature, the majority of research studies have been carried out in western populations from the developed world (Chan et al., 2010). While knowledge about the impact of caregiving has increased over recent years, gaps in understanding the impact of racial, ethnic and cultural variations on the experience of these caregivers have been highlighted (Dilworth-Anderson, Williams, & Gibson, 2002; Janevic & Connell, 2001). A review by Janevic and Connell (2001) found differences among caregivers of different racial, ethnic, national, and cultural groups with respect to psychosocial outcomes, experience of the stress process, and service utilization. Hence, to understand more in depth how culture affects the experience of caregiving, there is a need to consider specific cultural contexts.

***Dementia in an Asian context***

Culture is defined as a collective set of symbols, beliefs, and customs that are internalized by individuals, in turn influencing their beliefs and behavior (Goodenough, 1999). It provides a structure for making sense of individuals' encounters (Dilworth-Anderson & Gibson, 2002).

There is clearly much heterogeneity within Asia with many distinct cultural, ethnic and national groups, therefore subsuming these into one ‘Asian’ culture is rather simplistic (Saw & Okazaki, 2012). However there are a number of values shared by people from many different countries within Asia which can shed light on the experience of dementia and being a caregiver in this region.

When describing how individuals within different cultures define and make meaning of the self – the term self-construal is used. Markus and Kitayama (1991) hypothesized that while there are a number of universal aspects of the self, there are other aspects of the self that may be specific to specific cultures. They identified two self-construals – independent and interdependent. People with a primarily independent self-construal, construe the self as an “autonomous and independent person” and the “cultural goal of independence requires construing oneself as an individual whose behavior is organised by reference to one’s own internal repertoire of thoughts, feelings and action”. In contrast, those with a primarily interdependent self construal see themselves “as part of an encompassing social relationship, and recognizing that one’s behavior is determined, contingent on and to a large extent by what the actor perceives to be the thoughts, feelings and actions of others in the relationship”. While they suggest that individuals within any culture vary on both these dimension, on average individuals in Western cultures are likely to hold more independent self contruals whereas people in non Western cultures e.g. Asia are more likely to hold more interdependent self construals.

 The values and beliefs of people in Asia are also often influenced by Confucian and Taoist ideas, which advocate the responsibility of family members to provide care for ailing elders (Chan, 2010). The Chinese, for example, also believe in heaven’s will by accepting occurrences that happen to them, and high priority is placed on one’s capacity to endure situations that one cannot change (Ikels, 1998; Mok, Lai, Wong, & Wan, 2007). Thus, family members accept the disease, as well as their responsibility as caregivers for the individual with dementia (Mok et al., 2007).

The value of familism is held strongly in Asia. This is a form of social structure whereby the needs of the family as a whole are more important than those of individual members, and emphasis is placed on family harmony (Chee & Levkoff, 2001). In the Korean and Chinese cultures, ‘face-saving’ is a predominant practice, whereby problems are expected to be kept within the family. It is believed that seeking external help may upset the family cohesion, and there is a fear that the individual with dementia will be stigmatized. As a result, caregivers accept the responsibility of providing care and do not often seek help from others or formal services (Chee & Levkoff, 2001; Mok et al., 2007). Thus, it is evident that cultural practices affect the caregiving experience and need exploring further.

 In a typical Chinese family, the order of expectation of a family caregiver appears to be: spouse, daughter, daughter-in-law, and son (Kua & Tan, 1997). Research has found that spousal caregivers present with higher levels of stress and depression and lower levels of life satisfaction (Connell, Janevic, & Gallant, 2001). Due to the decline of the previously established marital relationship, they have a higher tendency to experience loss of self (Skaff & Pearlin, 1992). Furthermore, among spousal caregivers, female caregivers reported more stress and burden (Hooker, Manoogian-O’Dell, Monahan, Frazier, & Shifren, 2000; Mehta, 2005). Caregiving is stereotyped as a woman’s duty owing to the emphasis on care and nurturing; these gender roles in turn increase women’s susceptibility to the stress of being a caregiver (Miller & Cafasso, 1992). The experience of Chinese female spousal caregivers will therefore be important to understand further

***Dementia in Singapore***

Singapore is a culturally diverse society made up of different ethnic groups, with the Chinese forming 74.2% of the population, Malays 13.3%, Indians 9.1% and Others 3.3% (Department of Statistics Singapore, 2014). Up to 95% of all the elderly (i.e. people over the age of 65 years) in Singapore live with their family members (Mehta, 2005).

 As outlined above dementia is becoming an increasingly pressing issue in Singapore as elsewhere in Asia. This has prompted the government to recognise this as a major health priority and outline a three prong strategy to cope with the issue. This involves early identification of dementia patients, more help to caregivers and more services for the elderly in the community (Toh, 2012). Current support for caregivers includes a dementia helpline, respite services, counselling, support groups and caregiver training courses, mainly provided by the Alzheimer’s Disease Association. There is also some financial assistance available from the government including a Foreign Domestic Worker grant and a Pioneer Generation Disability Assistance Scheme.

Singaporeans of Chinese ethnicity form the majority of the population and they hold values and beliefs that are strongly influenced by Confucian ideas and familism and ‘face-saving’ practices prevail as described above. As elsewhere in Asia, these factors have been found to have a negative impact on caregivers' receptiveness towards utilization of formal services (Yap & Seng, 2008). Singapore is, therefore, a good context in which to explore the experience of Chinese caregivers.

The objective of this study is to explore the lived experience of Chinese female spousal caregivers of dementia patients in Singapore, as well as to examine the impact of caring on the individual’s sense of self.

**Methods**

***Study design***

A qualitative approach was used to obtain an in-depth account of the caregivers’ experiences. Interpretive phenomenological analysis (IPA) explores how individuals perceive and attach meaning to their experiences (Smith, Flowers & Larkin, 2009). It is phenomenological as it emphasizes the individual’s subjective experience, instead of an objective report of their circumstances. According to symbolic interactionism, the meaning that individuals attach to their experiences is obtained through an interpretative process (Denzin, 1995). Therefore, IPA requires researchers to interpret and make sense of the individual’s report of their experiences (Smith et al., 2009). This approach allows for discovery of underlying themes and constructs that may be currently unknown (Smith & Osborn, 2003).

***Participants***

There were six participants who were all Chinese female spousal caregivers whose husbands had a diagnosis of dementia. The average age of the sample was 61.83 (±7.28). All have children and 2 still have adult children living at home. See table 1 for description of participants.

IPA involves intensive analysis of detailed personal accounts of participants. Therefore a small sample size is recommended to meet the phenomenological, hermeneutic, and idiographic underpinnings of IPA and allow exploration of meaningful similarities and differences between participants without getting overwhelmed by the data (Larkin, Watts & Clifton, 2006; Smith et al., 2009, Smith, 2011). The idiographic nature of IPA means it can be used for in-depth analyses of single cases (see e.g. Bramley & Eatough, 2005) and studies with large sample sizes have been criticised for losing the idiographic focus on the individual (Smith et al., 2009). Qualitative studies that are based on largely homogeneous participants exploring fairly narrow objectives tend to reach rich data saturation within six interviews to twelve interviews (Guest, Bunce and Johnson, 2006) hence data collection stopped after six interviews.

The researcher had no prior relationship with any of the participants, and was not involved in the care of their spouses.

[Insert Table 1 here]

***Procedure***

The study was approved by the ethics committee of James Cook University and the National Healthcare Group, Singapore.

A senior consultant geriatrician from a major general hospital in Singapore assisted in the recruitment of suitable participants. Participants were recruited using purposive sampling according to the inclusion criteria of the study, namely being female spousal caregivers of Chinese ethnicity, living with and providing daily care for their husbands, whom had all been given the diagnosis of dementia for at least six months. As all interviews were conducted in English, participants were excluded if they were not able to speak English well. Six of the initial eight participants approached for the study agreed to be interviewed. No data on those who declined to take part was collected.

Participants who agreed to take part were contacted to arrange a convenient time to be interviewed at the hospital. Informed consent was obtained from all participants. All participants completed a demographic information sheet.

The interview was semi-structured, comprising of open-ended questions, in line with the theoretical framework of IPA (Smith, 1995). The questions were designed to invite participants to narrate and reflect upon their experiences including their day to day life, how caregiving had affected them, and how caregiving had changed how they viewed themselves. The interviews lasted between 45 to 60 minutes. They were audio-recorded and transcribed verbatim prior to analysis.

***Data analysis***

The data were analyzed using IPA (Smith et al., 2009). Each transcript was read by the second author several times in order to become familiar with the data. Three types of comments were noted in the margins of the transcripts. Descriptive comments focused on the content of the narratives, linguistic comments focused on the participant’s use of language, and conceptual comments entails understanding the narratives at a more abstract level (Smith et al., 2009). These notes were then interpreted and classified to form emerging themes to capture the essence of the participant’s account. Thereafter, connections between the emerging themes were examined and a master list of themes and sub-themes was produced for the transcript. This process was repeated for all six interviews. The themes and sub-themes for each transcript were then compared, and recurrent patterns across the six transcripts were identified and consolidated into a list of super-ordinate themes, which aimed to account for the experience of the sample.

In keeping with the IPA approach, the validity of the study was assessed by conducting an independent audit trail (Dallos & Vetere, 2005; Smith et al., 2009). This included a thorough examination of the data from the transcripts to the final paper, and was carried out by both the second and third authors, who are experienced qualitative researchers. The initial stages of data analysis (initial comments and emergent themes) were carried out independently by the first and third authors and then discussed with the second author. The master themes were derived by the second author alone and then discussed and reviewed with the first and third author. This was to ensure that the themes were both warrantable and grounded in the data (Smith et al., 2009). However as the focus of IPA is to obtain a subjective rather than objective view of a phenomenon, this particular interpretation represents one of the many possible and acceptable interpretations (Smith et al., 2009). Each theme was endorsed by at least four of the six participants.

**Results**

Four super-ordinate themes emerged from the qualitative analysis: impact of caregiving, acceptance of destiny, taking control, and view of self (see Table 2). In the illustrative quotes, square brackets ([ ]) were used to indicate edited and omitted material.

[Insert Table 2 here]

***Impact of caregiving***

The first super-ordinate theme focuses on the impact of caregiving on the participants. It includes three sub-themes: multiple responsibilities, influence on lifestyle and emotional burden.

*Multiple responsibilities*

Participants reflected on the multiple and varied practical aspects of caregiving, such as assisting in their husbands’ activities of daily living (ADL).

 The multitude of responsibilities that participants had to manage negatively impacted on their role as a mother, such that they were not able provide the level of care to their children that they felt they should. For example: 'Because I have to help the father, so I let go of my son and tell him he has to help himself' (P5).

Some participants noticed the relationship between their husband and children had broken down, often due to a lack of understanding of the father's behavior. Some participants viewed it as their responsibility to try and improve this relationship as the lack of harmony within the family caused feelings of sadness: 'I feel sad, so I [tell them that] daddy is good, he doesn’t take so many medicine already. Because daddy’s brain [is] like that, so you must understand him. But they say "I know, but we all can’t stand him"' (P3). This was seen as an extra responsibility and increased the emotional impact of caregiving.

*Influence on lifestyle*

All participants’ lifestyles were impacted by their caregiving role, affecting their work, social and personal life. They often placed emphasis on how their life was like in the past, which could reflect their yearning for their old lifestyle.

 All participants experienced a lack of time for themselves and not having enough rest: 'Not enough sleep every night. Most of the time [feeling] tired' (P6).

*Emotional burden*

All participants experienced a sense of being overwhelmed with the stress of caring. They also often had to cope with the feeling of embarrassment that accompanied their husbands’ behaviors in public. One participant, for example, shared her feelings that occur at family gatherings:

His relatives will come and ask, everyone wants to show some concern. So, I guess I feel embarrassed, because he will say something inappropriate, then I am also worried that he will say something not nice. [But if] they don’t come, I also feel sorry for him, that he is sitting there looking lost (P6).

Participants found difficulty in managing these negative emotions, and often felt guilty for not being understanding enough: 'I try not to get upset with him. What can I do? I can’t scold him, because I am not supposed to scold a dementia patient. Everything got to be positive' (P5).

Many participants reported a sense of loneliness and a loss of the previous relationship they had with their husband, which further highlighted yearning for the past.

There is nobody else I can share with, anything and everything, and he will understand me. But now it’s not the same anymore. Whatever I can tell him at night, I will talk [to] him, he is like before, he will *[nods head].* But next morning it is gone. It is a complete wipe-out (P1).

***Acceptance of destiny***

The second super-ordinate theme highlighted the submission of the participants to their destiny. It encompassed two sub-themes, namely resignation to fate and fulfillment of the duty of a wife.

*Resignation to fate*

Some participants initially experienced difficulty in accepting their husband’s diagnosis. However, over time, participants appeared to become resigned to and then accepting of their fate that they have to care for a husband with dementia for the rest of their lives. One participant talked about hard this process was: 'I have to change, but the thing is I am not accepting fully yet' (P1).

 Participants dreamt about the future with their husbands; however, the illness had crushed their hopes: 'I always say that when I retire I want to do things together with you, go [travelling] with you. I always think, now I cannot do it already. So I just see myself, I am fated, like that' (P2). It appeared that they were stuck in the current situation: unable to go back to the past they yearn for, or to fulfill dreams about the future.

 While participants were resigned to their husbands having dementia, some learnt to accept him for who he was: 'Just face it that he is like that, it don’t affect me, I am ok. I understand that he is like that, not that he does it on purpose, that he cannot remember' (P2).

*Fulfillment of the duty of a wife*

Participants highlighted that caring for their husbands was their duty as a wife. Some participants expected themselves to bear full responsibility for their husband, and were worried that their family members would not take up this role in future: 'If I die first, he very poor thing, then no people [take care of him]' (P4).

 While for some this was more of a duty, others still cherished the men who they felt were destined to be their partners for life: 'I am just happy [to be] with him, take care of him, make sure he is well' (P2).

***Taking control***

The third super-ordinate theme describes means by which participants gained control of their lives. It comprised of three sub-themes: active coping, a sense of empowerment, and changing roles.

# *Active coping*

Participants took control of their life circumstances by actively engaging in coping strategies. Many sought support from friends: 'I will arrange for him and my other friend, who is in a similar position as him, we all go out for lunch, then we all talk' (P6). They highlighted that sharing about their lives helped them feel connected with others and more able to cope. Participants were open to seeking formal help, such as attending talks on dementia. Learning more about the illness appeared to provide them with comfort. Some participants also joined formal support groups: 'All the friends, we feel very good. I feel [that things are] not so difficult' (P3). Being in a community setting provided them with opportunities to seek validation for their feelings and actions.

 However, while there were some common ways of coping, there were also differences in the way they coped. Two sought strength from their faith, for example: 'God wants to give you joy, you must get strength from God' (P1). While some participants found focusing on other aspects of their lives helpful. For example focusing on work: 'Focus on your job and [it] should be alright' (P6) or physical activities such as line dancing: '[Even though I am] retired, but I still want to make myself active' (P2).

*A sense of empowerment*

While participants attempted to cope with their current situation, the successful efforts led to the development of a sense of empowerment. This feeling was particularly strong for one participant who shared that her husband used to take charge of everything. She highlighted: 'Nowadays, I learn so many things. Anything that I want to do, I can. I can think over and do on my own, don’t need to suit my husband' (P3).

This sense of empowerment boosted their confidence in managing their own difficulties, as well as taking a step further to help others: 'Why can’t I use my experience and expertise to help other people? If I widen that one, then it will be better' (P6).

*Changing roles*

Participants often experienced changes in roles between themselves and their husbands. It appeared that participants had to assume the position of head of the household, a role that used to be held by their husbands: 'So now, I have to do everything that he used to do for me, just like payback time' (P1). Some participants compared caring for their husbands to caring for a child: 'He is like a baby, have to look after him' (P2).

***View of self***

The fourth super-ordinate theme focused on the participants’ view of themselves and how their sense of self was influenced by how they made sense of their caregiving experience.

 The majority of participants viewed themselves as experiencing positive changes such as 'growing up' (P3), or becoming 'more caring towards others' (P2). Some participants however had more negative views of themselves, for example feeling incompetent and noticing changes in themselves: 'I am not a good person, and not a good caregiver as I should [be]' (P1). 'Sometimes I cannot find myself, I [am] grumpy. I don’t smile as much as I used to. It has changed my personality.'

 The views of others also impacted on the way caregivers viewed themselves. Some participants were happy to accept compliments from friends: 'It is comforting to know that well, [I am] not bad' (P6). However another participant highlighted that she was doubtful about what others had to say about her: 'That is the funny thing, they say I am strong. I am quite surprised you know. I hear from a few people, but inside me I know I am not, I break' (P5).

**Discussion**

This study provides an insight into the caregiving experience of Singaporean wives of Chinese ethnicity whose husbands have dementia. Participants spoke about how taking on the caregiving role has affected them. Similar to other Asian caregivers and caregivers elsewhere in the world they experienced many different types of caregiver burden: objective burdens included a lack of time for self, physical burdens included not having enough rest, and emotional burden included guilt and loneliness (Choo et al., 2003; Huang, Shyu, Chen, & Hsu, 2009; Lim, Son, Song, & Beattie, 2008; Moon-doo et al., 2009).

The caregivers highlighted that the need to manage multiple responsibilities had a negative impact on their role as a mother. For many Asian families, the teachings of Confucius highlights the importance of closeness between parent and child (Park & Chesla, 2007). The analysis suggested that caregivers were not able to give as much time to their children as before. While not mentioned explicitly in this sample, it has been suggested that being unable to uphold values deemed as important can lead to feelings of guilt (Cho, 2000). This is something that would warrant further exploration.

One Confucian ideal often mentioned in relation to caring for elderly family members is filial piety (Park & Chesla, 2007). Interestingly despite all the participants having children, no themes emerged within the results relating to either praising their children for supporting them as caregivers or lamenting the lack of their support. This may have partly been an artifact of the interview schedule, which, in line with the aims of the study, focused on the participants’ experiences as caregivers and their sense of self. Alternatively this may have been because the value the participants placed on their role as a mother to look after their children outweighed any expectations they had of their children to look after them.

Two of the themes that emerged, namely acceptance of destiny and taking control, were related but also appeared to contradict one another. Given this, these themes will be discussed together.

Much of the caregivers’ experience centered around the theme of accepting their destiny and their duty as a wife to care for their husbands. The terms ‘acceptance’ and ‘resignation’ are passive in nature, implying a sense of helplessness towards their situation. Interestingly, this finding did not emerge in other qualitative studies conducted in Asia (Chan et al., 2010; Chee & Levkoff, 2001), and this therefore represents a novel finding. This finding is understandable given that a significant value within Chinese culture is the acceptance of heaven’s will; this takes the form of accepting what happens in one’s life and places high priority on enduring situations that cannot be changed (Ikels, 1998; Mok et al., 2007). The value of duty is also significant in Confucian family ethics (Park & Chesla, 2007). Thus, while caregiving may be a duty that caregivers are obligated to fulfill, this role may have been accepted and assumed as part of their lives (Holroyd, 2005). Theoretically, the passiveness may have caused participants to feel that they lacked control over their lives (Ikels, 1998). However, the results suggested that feelings of acceptance and duty could sit alongside a feeling of being in control.

In Asian culture, there are clear role divisions and power imbalances between husbands and wives, whereby husbands make important decisions (Hurh & Kim, 1990). In the process of caring, taking over the husband’s role indicated a change in the role of a wife; resulting in new identities for themselves and their husbands (Perry, 2002). With a new identity as head of household, the caregivers demonstrated a new sense of empowerment. Empowerment is the process by which one develops a sense of competence to exert control over one’s life (Zimmerman, 1995). While the caregivers were forced into a difficult life situation; this was accompanied by opportunities to take action and make decisions. These empowering processes are significant contrasts to the idea of passiveness: while caregivers may not strive to change their situation, they take control by conquering the obstacles that they face.

Feelings of emotional burden and loneliness were common. The caregivers had lost someone whom they could share with and confide in. They experienced relational deprivation, whereby they suffered a loss in reciprocity of the relationship (Adam, McClendon & Smyth, 2008). As well as losing someone to confide in, the caregivers expressed views of their change in relationship with their husbands and seeing them as now being like a child. Some however still talked about being happy to be with their husband.

While participants did not link these ideas explicitly, according to attachment theory, caregivers change their attachment model to take on the role of a protective caregiver and preserve the emotional bond between them and their husbands (Bowlby, 1980; O’Shaughnessy, Lee, & Lintern, 2010). This is suggested as a form of active coping with the changing relationship: the new way of viewing the relationship allows for feelings of affection to remain albeit being in a new form such as that between parent and child. Thus, with the loss of a husband-wife relationship, replacing it with something akin to a parent-child relationship may be a way of caregivers coping with this change, and warrants further investigation.

Within the theme of coping there were many similarities in the ways the caregivers coped with their situation. The caregivers noted that informal support from friends and family helped them cope with their difficulties. This has also been endorsed by other Asian caregivers (Au et al., 2009; Choo et al., 2003). In addition, the caregivers were open in seeking formal help. This contradicts findings in other studies where caregivers were put off from seeking help due to ‘face-saving’ or fearing the stigma associated with dementia (Chee & Levkoff, 2001). While this finding requires further exploration and replication, it might represent increasing awareness and openness towards mental health issues in Singapore. Being more willing to seek help may also have been linked to the education level of the sample (all had completed secondary school).

There were however some differences in coping between the participants, for example some turning to faith, with others focusing more on other aspects of their lives such as work or physical exercise. This would suggest the need for a larger sample to explore further what influences coping. The fact that all the participants were actively trying to cope with their situation may be linked to the length of time they had been caring for their husbands. The caregivers had on average been caring for 6.33 years (range 3-9 years). Therefore it could be hypothesised that all the caregivers had had time to process the initial shock of their husband’s diagnosis, and come to terms with what they needed to do to cope with the situation.

The results also suggested that the experience of caregiving has unique influences on an individual’s sense of self which are discussed below.

Some caregivers expressed a sense of incompetence, both as a caregiver and as a person. Self-esteem and sense of mastery are defined as the two broad components of the self; an inability to meet the duties of one’s role has an adverse influence on these two components (Pearlin et al., 1981). When caregivers feel that they are not a good caregiver to their husbands, it may imply that they do not see themselves as fulfilling their duty as a wife. Additionally, the caregivers experienced the caregiving role as having a negative impact on their role as a mother. Collectively, these experiences may lead to a global loss of their self-esteem and sense of mastery as a person.

It could be hypothesised that they viewed themselves more negatively due to a failure of upholding their roles as wives and mothers, as this conflicts with the cultural values of Confucianism (Park & Chesla, 2007). This also fits with self-oriented theories of aging, for example Self discrepancy theory proposed by Higgins (1987). This postulates that when there are discrepancies between the actual and hoped for self, there can be feelings of dissatisfaction and disappointment. In this case the model of the ideal self is based on the cultural values espoused by Confucianism.

However these results may also be linked to gender. Researchers (e.g. Kashima et al, 1995) have built on the concepts of the independent and interdependent self construals and further categorised the interdependent self-construal as having different aspects: relational (the extent to which people define themselves in terms of close relationships) and collective (the extent to which people define themselves as part of larger social groups). They suggested that women are more likely to interact with others in dyads or close relationships, whereas men tend to interact more in larger groups. Having a spouse with dementia causes a major change to the caregivers relationships, and as women define themselves in terms of relationships this change would have a greater impact on their sense of self that it may do for a man in the same situation, regardless of culture.

However, some found that caregiving made them become a better person. Serpe (1987) stated that changes in the self are viewed as a reflection of changes in one’s environment. As caregivers experience empowering processes and take control of their circumstances and environment, this influences the way they view themselves. Caregiver mastery is defined as the 'positive view of one’s ability and ongoing behavior during the caregiving process' (Lawton, Kleban, Moss & Rovine, 1989, p. 62). Thus, the new-found sense of empowerment has a positive influence on their sense of self.

These findings may link to theories of successful aging which emphasise personal control (Sneed & Whitbourne, 2005). For example Heckhausen and Schulz’s (1995) life span theory of control discusses the importance of two types of control: primary and secondary. Primary control is where people seek to change the external environment, whereas secondary control is where people shape their internal processes to minimize losses in, maintain or expand existing levels of primary control. Many of the caregivers were still able to exert primary control over their environment, and as a result able to view themselves more positively in their role as a caregiver. As these caregivers age and there may be less possibility for taking active control over their environment, it may be that secondary control and changing how they view themselves as caregivers becomes more important.

# Limitations

# While all participants were able to converse well in English, some indicated that they were more comfortable to speak in Mandarin or other dialects. This may have detracted slightly from their overall fluency in expressing ideas.

No data regarding the age of the husbands, their stage of dementia or the families’ socio-economic status was collected. This information may have allowed more understanding and discussion of the themes to be developed.

 While the aim of the study was to explore the areas of interest in depth with a small sample, the sample size may have limited the scope of issues that arose.

**Conclusions and Recommendations**

The present study showed how cultural values influence the experiences of caregivers of individuals with dementia. Confucian values influence female Chinese caregivers’ beliefs about their roles as wives and mothers. This results in feelings of loss, guilt, and resignation to fate. However, these caregivers also experienced a sense of empowerment, which seems to represent an opposite to passive acceptance. These contrasting feelings have varying and distinct influences on their sense of self, which may be linked to culture as well as gender.

The results suggest the need for caregivers to be better supported with interventions specifically tailored to their cultural background. Discussions pertaining to beliefs about their various roles such as issues of loss of the previous relationship with their husbands, guilt for neglecting their role as a mother, and difficulties in managing these multiple roles could be addressed. Assisting caregivers with the process of empowerment and taking control by actively coping, rather than just resigning themselves to their fate would be important.

Future research with larger samples would be useful to explore the impact of some of the cultural factors in more detail and the whether these cultural issues change over time with different cohorts of caregivers. Studies using a sample of male caregivers would allow exploration of the impact and interplay of cultural factors and gender on caregiving, the self and identity.

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