

# Singaporean caregivers' experiences of placing a relative into long term care.

Journal:	Clinical Gerontologist
Manuscript ID:	WCLI-2014-0033.R3
Manuscript Type:	New and Emerging Professionals
Date Submitted by the Author:	11-Jul-2015
Complete List of Authors:	Ramanathan, Rajini; James Cook University Singapore, Psychology
Keywords:	caregivers, long-term care, caregiver stress < stress, older adult, placement < interventions

SCHOLARONE™ Manuscripts

CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION

RUNNING HEAD: CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION

Singaporean caregivers' experiences of placing a relative into long term care.

Rajini Ramanathan and Paul Fisher

Author's note: This research project was conducted as part of the requirements for the submission of a Doctorate in Clinical Psychology.

Rajini Ramanathan, Department of Psychology, James Cook University Singapore, 600 Upper Thomson Road, Singapore 574421; email: rajini.ramanathan@my.jcu.edu.au

Dr. Paul Fisher, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ; email: p.fisher@uea.ac.uk

#### **Abstract**

Caregivers experience many difficulties and challenges with the process of providing care particularly at times of transition, such as when the care recipient moves into a nursing home. This qualitative study aims to understand caregiver experiences of this important process. Twelve interviews were conducted with caregivers with an older relative in a nursing home. Thematic analysis identified five themes: Filial and cultural expectations shape caregivers' experience of pre-placement decisions and post-placement; View of the placement decision; Continued impact of caring; Engagement with the institution and Maintaining the relationship. The findings and the post-placement implications are discussed.

Key words: caregiver, older adult, long term care, culture, filial piety, transition.

#### Singaporean caregivers' experiences of placing a relative into long term care.

Caregiving for an older relative is a demanding process that often comes at a high personal cost for the caregiver (Dellasega & Mastrian, 1995). Caregivers experience increased levels of stress, physical and psychological risk, a higher mortality rate and greater social isolation in contrast to their non-caregiving counterparts (Chene, 2006; Friss Feinberg & Goldstein, 2008; Schulz & Beach, 1999; Spector & Tampi, 2005; Vitaliano, Zhang, & Scanlan, 2003). However, despite these repercussions, caregivers also describe positive outcomes of caregiving, including lower scores of depression, burden and increased positive evaluations of their own health (Cohen, Colantonio & Vernich, 2002) better cognitive outcomes such as greater achievements on memory and processing speed tests (Bertrand, Saczynski, Mezzacappa, Hulse, Ensrud, & Fredman, 2012). Relational rewards of the role include companionship, while increased personal mastery leads to a sense of meaningfulness, fulfillment, and the opportunity to perform caregiving duties (Cohen, Colantonio & Vernich, 2002).

Caregiving is a dynamic process often described in the literature as a 'career' marked by "shifts in activities and stresses" (Pearlin, 1992, p.647) with transitions and diverse trajectories (Gaugler & Teaster, 2006). The decision to place the older relative into long-term care (LTC) represents an important transitional phase in which the caregiver is faced with an evolving set of roles and demands (Fleming, 1998; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Skaff, Pearlin, & Mullan, 1996) rather than a termination of their existing duties. However, caregiver outcomes following placement are varied. While there is decreased strain, stress and role overload (Gaugler *et al.* 2010), certain groups of caregivers, such as spouses and daughters, report increased distress (Butcher, Holkup, Park, & Maas, 2001). Other caregivers experience increased depression and anxiety consistent with those continuing to provide care in the community (Schulz et al., 2004) suggesting that not all

difficulties may be resolved by institutionalisation. When faced with the decision to continue, share or relinquish caregiving, caregivers were driven by their one of two caregiving purposes. First, interrelational objectives included protecting or maintaining the care recipient's sense of self and the caregiver-care recipient relationship. Second, pragmatic objectives included providing the care recipient with physical comfort, assuring high levels of care and minimizing the costs of caregiving. Key transitions often denoted changing emphases in each of these areas. For many caregivers, the decision to relinquish or continue caregiving at home was driven by the desire to maintain the relationship with the care recipient and the experience of caregiving is a complex social process with unique meaning for the caregiver (Caron & Bowers, 2003).

Transition to LTC is an emotionally difficult process for the caregiver. Reuss, Dupuis and Whitfield (2005) identified three temporally based transition experiences as well as four continually occurring factors. Critical time points include the wait for admission, preparation for the move, and ease of the move. Four further conditions were relevant throughout the process – namely, the quality of communications, control over the process, support received, and caregiver and care recipient perceptions including the acceptance of the placement.

Nolan and colleagues (1996) also identify four factors important in supporting the placement decision – anticipation of the move through forward planning and conscious decision making, a continuum of participation, exploration of alternate solutions, and ensuring sufficient information to facilitate the decision.

Most of the research to date has been driven by studies based on Caucasian populations in America or Western Europe (Milne & Chryssanthopoulou, 2005). The literature arising from Asian studies is focused on earlier phases of placement such as on decision making (Chang & Schneider, 2010; Park, Butcher & Maas, 2004), but is limited in illuminating the Asian experience in caregiving during the transitionary phase, or on post-

placement caregiving. It is unclear how findings and theories on coping, accessing social support, early identification of increasing needs, and expression of negative effects of caregiving which arise from studies based on Western populations can be applied to other groups such as Asian caregivers (Milne & Chryssanthopoulou, 2005) who possess culturally unique coping and social support resources, experience stressors and appraise situations and outcomes, (e.g. caregiving burden, mental and physical health) differently from their Western counterparts (Kim & Lee, 2003; Knight & Sayegh, 2010; Pinguart & Sorensen, 2005). Different cultural groups also vary in terms of demographic profiles, (e.g. kinship, age, gender) (Pinguart & Sorensen, 2005), and multigenerational living arrangements, suggesting that culture and ethnicity differences are significant factors (Dilworth-Anderson, Williams & Gibson, 2002). Knight and Sayegh, (2010) argue that the importance of cultural values was moderated by coping and social support, rather than serving as mechanism for the appraisal of caregiving burden. However, this was not confirmed in studies of Chinese Americans. Instead, the relationship between culture and coping was unclear. Chang, Schneider and Sessanna (2011) review the decisional making differences between Western individualist societies in contrast to Asian collectivism and reflect on the predictive validity of applying theories cross-culturally. Accounting for cultural beliefs and norms – which determine how a society defines ageing, the caregiving role and expectations of family members – leads to a better conceptualisation of the issue among differing ethnic groups.

Within Asia, Singapore's unique caregiving context arises from cultural values that are a blend of East and West (Foo, Merrick & Kanzantiz, 2006). Although retaining Asian values of collectivism, interdependence, and familism (Foo, Merrick & Kanzantiz, 2006), greater exposure to the English language (D'Rozario & Romano, 2000), colonial rule and modernisation (Cheung & Kwan, 2009) have differentiated Singaporeans culturally from their counterparts in East Asia. The Singapore government has actively encouraged "ageing

in place" as the primary means of supporting the rapidly growing aging population where the family is the first line of support for the emotional and physical needs of older adults (Ministerial Committee for Aging, 2007). Caregiving largely falls upon family caregivers, specifically second-generation female members (i.e. daughters or daughters-in-law) (Chee, Li, Luo, Wai & Yap, 2010). Most older adults in Singapore live with their children who subsequently take on the caregiving role (Mehta, 2005; Malhotra, Malhotra, Ostbye, Matchar, & Chan, 2012). This is unique as compared to Western caregiving arrangements, where most caregivers are spouses, or children who live independently (Finlayson & Cho, 2008; Bragstad, Kirkevold, Hofoss, & Foss, 2014). As a result, there is a strong social responsibility for family members to perform a caregiving role, and LTC facilities are generally seen as unfavourable options although this opinion is gradually changing (Sitoh, 2003). Indeed, there is specific legislation in Singapore, the Maintenance of Parents Tribunal Act, which requires children to provide for their older parents and allows parents to seek legal redress in the event of failure to do so. Additionally, LTC and other day care support services in Singapore is more expensive than in Western countries (Chee et al., 2010) making it a less viable option for many caregivers.

Using a qualitative methodology, this paper aims to explore how Singaporean caregivers' retrospective experience of the process of placing their older relative into an LTC and their continued involvement post-placement.

#### Method

### Design

A thematic analysis of interview data (Braun & Clarke, 2006) was chosen for the detailed exploration of caregivers' experiences of admitting a relative into LTC. Thematic analysis is defined as a means of "identifying, analysing and reporting" (p.79) trends within a

data set (Braun & Clarke, 2006) where important concepts emerge in the description of the phenomenon in question (Fereday & Muir-Cochrane, 2006).

# **Participants**

A nursing home in Singapore, with approximately 280 older adult residents aged 60 and above, provided the location for this study.

Twelve family caregivers of the residents were recruited. This sample has been shown to be appropriate for a thematic analysis (Braun & Clarke, 2006; Fisher, Johnstone, & Williamson, 2011) as data saturation can be reached within six interviews (Guest, Bunce, & Johnson, 2006). Additionally, as recommended by Morse (2000), the sample size of a qualitative study is influenced by a narrowly defined scope of enquiry and amount of useful data each participant shares. "Caregiver" was defined as the individual with whom the resident had lived and depended on for activities of daily living (ADL) (McConnell, 2001) prior to admission. Potential participants met the following inclusion criteria if they were a) a relative of the care recipient, b) above 18 years of age years upon the care recipient's placement, c) involved in caregiving prior to placement and in the decision to place the care-recipient, and d) could communicate in simple English. Table 1 provides a summary of participant profiles.

< Insert Table 1 about here >

Participants reported differing lengths of time since the placement of the care recipient. While this was derived through convenience rather than purposive sampling processes, this variance among the current participants serves to identify core experiences among the caregivers.

#### Procedure

**Recruitment.** Nursing home staff approached family members to raise awareness of the study and mailed letters of invitation to caregivers. Interested potential participants contacted the first author, who verified their eligibility and explained the study to them.

**Data collection.** Signed informed consent was obtained at the start of each interview. Participants were interviewed in a location of their choosing (e.g. their homes or a private location at the nursing home). Interviews were conducted in Standard English, although some participants responded in colloquial Singaporean English. Interviews, lasting between 45 minutes to 100 minutes, were audio-recorded. The interview focused on the decision to institutionalise. It began with the question "Tell me about the time you decided to put your (relative) in the home" and then progressed following a flexible semi-structured interview schedule, based on the procedure described by Butcher, Holkup, Park and Maas (2001) and Strang and colleagues (2006). Participants were given the lead in the interview to share experiences they felt were pertinent. Prompts were used to clarify responses when necessary (e.g. about making the decision, difficulties and concerns regarding placement). Participants were given a \$\$20 supermarket voucher in appreciation.

**Data Analysis.** The first author transcribed the audio-recordings verbatim. Analysis was performed using NVIVO 9 computer software package (QSR International), which allows for greater auditability of the process and outcomes of the analysis, thereby increasing the credibility of the analysis (Butcher, *et al.* 2001).

The procedure described by Braun and Clarke (2006) was followed. At stage one, after a close reading of the transcripts, the first author identified all relevant quotes as potential data extracts and generated codes to represent the meaning within the data deemed to be significant reflections of the participants' perceptions (Luborsky, 1994). An effective code is one which identifies important 'moments' and reflects the "qualitative richness" (Fereday & Muir-Cochrane, 2006, p.4) of the phenomenon in question. These pieces of data

are given a definition or a description (Boyatzis, 1998). Codes were linked directly to the data rather than to extant theories or the researcher's preconceptions (Braun & Clarke, 2006). Coding entails the categorisation of identifiable topics under headings indicating similarities between quotes. The topics are then named to reflect the information they contained (Huberman, 1994). For example, the quote "My mother is already used to the environment. She agreed to come because she knows I am unable to care for her" was coded under the topic "Acceptance of transition to LTC". The data was coded exhaustively. If found to encompass more than one idea, the quotes were included under multiple codes.

At stage two, the codes were analysed for conceptual similarities and overlaps. The first author categorised them into 'sub-themes', or clusters of related codes conveying corresponding meaning (Chang, Schneider & Sessanna, 2011). The codes and the sub-themes were reviewed for accuracy and relevance.

In stage three, the sub-themes were further refined and integrated into wider overarching themes. A theme is "a pattern of information that minimally describes and organises the possible observations and at maximum interprets aspects of the phenomenon" (Boyatzis, 1998, p. 161). These identified themes, derived through repeated, strict adherence to and careful reading of the raw data, then become the categories for analysis. The codes are then organised into a coherent and meaningful structure, and collapsed together into wider categories with corresponding meanings to form themes. The resultant themes were then further refined (e.g. those with insufficient supporting data may be discarded, other themes combined, or overly complex themes may be further divided).

Validation. Each step of the thematic analysis was validated to ensure the credibility of the data (Bradley, 1993). Exhaustive coding ensures rigour in the analysis (Yardley, 2000). To further ensure transparency and coherence (Yardley, 2000), the entire process of analysis was reviewed by an independent researcher, unfamiliar with the raw data but competent in

thematic analysis. The independent researcher confirmed the validity of the analysis, indicating that the observations could be replicated (Stiles, 1993). The first author and the independent researcher discussed the clustering of the codes into themes and sub-themes (Chang, Schneider & Sessanna, 2011; Stiles, 1993) until 100 percent agreement was reached (Butcher, *et al.* 2001).

Finally, one third of the transcripts were randomly selected and reviewed as a whole.

The first and second authors read these transcripts independently, ensuring that the themes identified were evident in the original text.

#### Results

The analysis led to the generation of five themes. Table 2 presents a summary of the themes and component sub-themes.

< Insert Table 2 about here >

# 1. Filial and Cultural Expectations shape caregivers' experience of pre-placement decisions and post-placement interactions

As the transcripts were analysed, the importance of filial piety as an important framework upon which the participants drew meaning throughout the placement process was evident. It was the basis upon which participants made decisions. Filial piety was a set of expectations shared by both the participants as well as the residents.

Participants constantly re-evaluated role requirements to match their new realities and held different ways of fulfilling these expectations. They responded by doing more for the care recipient, thereby fulfilling the filial role in line with the care recipient's and society's expectations as the participant perceived it. While placement was generally seen as an unwelcomed eventuality, participants attempted to fulfil their obligations in other ways. For example, Participant 10 reviewed her entire time of caregiving for her mother-in-law, and felt that she had sufficiently fulfilled her caregiving commitment. She said:

"We feel so uncomfortable that we were not given a chance to look after her. But it is also very lucky that I looked after her for a certain period of time. I have done my part for that period of time. At least if at that period of time I do not even look after her, I would feel damn bad right now. What am I? Am I a proper human? I did not do my job as a daughter-in-law.... at least I tried."

Participant 2 reported that if she was well she would care for her mother at the nursing home so they could have time together. Although she was unable to provide the care for her at home, she carved out additional roles. She explained, "I will top up all her needs... If I can't go, if I have flu, I will call and check. If she's sick I will ask (staff) to (consult) the house doctor."

For the participants, caregiving was an opportunity to demonstrate their love and appreciation for the care they had previously received. Reciprocity was a key aspect of the decision to provide care for the care recipient. This was evidenced by sentiments such as gratitude. Participant 3 said, "She brought us up [alone], I know. Very hard.... I grateful to her for everything I have." Such feelings of gratitude and reciprocity reflected the quality of caregiver-care recipient relationship. However, this sense of "giving back" persisted even in the face of poor relationships with the care recipient. Participant 9 suggested that "I know she is not a good mother. But what to do? She [is] my mother". While this highlights the role of the relational history between the caregiver and care recipient, it goes beyond just the immediate dynamics of the relationship but speaks of a wider sense of duty which the participant felt.

Participants were typically appreciative of the opportunity to demonstrate filial roles and recognised positive personal outcomes. Participant 3 reflected that caring "makes me positive because when she's around then I can fully show my love for her. I can present myself as a daughter ... I can't be filial to my father because he's already dead...I thank God

for the time we have together." Participant 5 said, "I also happy...I've done my duty,... I treat her well". Although participants never felt that they had achieved their ideals, they expressed their filial piety as a process of continued attempts.

It was also an opportunity to execute their duties in accordance to their own stations in the family. Often participants reflected on their position in the family and what this meant in terms of traditional expectations, such as those for the son. Participant 8 shared that "in the family, I a bit higher education (*sic*)... I have to accept this responsibility.... Usually in Chinese [tradition], the big brother have (*sic*) to take care. Since my big brother cannot take care himself, I have to. Take the responsibility to do everything for them."

Despite how participants interpreted their filial obligations these ideals were reflected by participants regardless of the length of time since placement.

#### 2. View of the Placement Decision

Each participant described having mixed feelings about the placement largely owing to the participants' own sentiments as well as the residents' reluctance. Many initially felt uncomfortable with the idea of admitting their care recipient into LTC and held some ideals of providing care at home. Participant 10 delayed the placement decision because: "I feel bad she have (*sic*) to pass her old age that way. That's really sad because I don't (sic) really expect this ending for her". Participant 5's mother had asked to be put in a nursing home so as to alleviate some of Participant 5's difficulties. However, Participant 5 felt she could still manage: "I tell her no, because right now I still can look after you, I still want to carry on." The sense of duty was a main motivating factor in wanting to continue caregiving.

The notion of patriarchism is strong and the placement of the care recipient without their permission felt like it was going against an authority figure. As a result, gaining the care recipient's agreement to the decision was crucial to majority of the participants. Participant 11 shared: "actually, my sister suggested it but my mother don't want to go... she wants to be

the authority. She made things very difficult". His mother was finally admitted only after she had gone into a delirium and there was no longer any other option. Similarly, Participant 6 felt herself to be in a bind when her father rejected placement. She reported that: "It is important that he agreed ... we have to persuade him until he nod (*sic*) his head."

Eventually, placement came as a relief because of the practical support offered.

Participant 12 shared "A lot of worries are out of my mind. At least I can go to work only thinking about the work... At least I know she is in the good care of the home." She went on to elaborate: My thoughts are to do the best for her, whatever is good for her".

Delaying placement through personal sacrifice. Increasingly unable to cope, participants opted for institutionalisation as a last resort and only after making significant personal sacrifices to keep the care recipient at home for as long as possible. At times the practice of filial caregiving came at great personal sacrifice. Participant 7 who had serious health issues, talked about using his limited funds to buy medication for his father instead of for his own use. He said "I don't take my medicine, I give it to him."

Participants experienced a sense of resignation regarding the placement decision, especially when it was suggested by medical professionals. Participant 6 reported that: "We just made the decision. It's totally helpless... Mama (has) to go nursing home because the doctor (said): discharge her only if she wants to go nursing home... if she doesn't want to go to the nursing home then cannot discharge her from the hospital".

#### Caregiver's changing ability to care leading to unavoidable placement.

Extraneous and caregiver factors presented constraints to continued caregiving at home.

Participant 3 explained that her own disability prevented caring for her mother: "I cannot even bend, squat... That's the reason I cannot bring my mother to stay with me. Because if I bring her back, I have to carry her. And the weight I cannot sustain."

Despite reservations most participants saw the placement as something they had to

accept. Participant 11 said "it was a very clear decision. Although ... we don't like it...there is no other alternative." He said his mother would "definitely fall. There is no shadow of a doubt, and then she will die faster, and it will be a painful one".

They assessed the care recipient's needs against what they were able to do as caregivers. Participant 6 discussed being unable to cope with the demands of caregiving: "her condition, the tube feeding... because we don't know how to feed her we better don't... danger to her life". She said, "I cannot cope..., we are not trained....I cannot take too much." Nine participants reported that they wished they were able to provide the care needed but felt that the best option was formal caregiving in a safer environment.

# 3. Continued Impact of Caring on the Caregiver

Negative aspects of caregiving. Practically, there was significant concern about finances and meeting monthly payments following placement. Participant 11 said "[My sister] has to work. She is the only one that is... fit to work... she has to work... to support my mother". Caregiving led to anticipatory anxiety among caregivers. Participant 11 expressed a sense of ongoing foreboding. She said "I worry about her all the time. What is going to happen to her?" There was also uncertainty about the future in general Participant 10 expressed, "I do feel frightened too. Nobody can predict what will happen next. Illnesses and stuff." Participant 9 said "[I am] 52, how long can I work? Sometimes I sick... [What if] I pass away? [What happens to my] mother?"

Role Transitions. Role transitions, both pre- and post-placement impacted on participants' self-image and self-perceptions. Feeling unable to care for her mother impacted how Participant 3 viewed herself even though the placement decision had occurred 18 years ago: "I feel I'm very incapable of taking care of her.... my mom can take care of me, how come I cannot take care of her?" Placement signified a reduction in the caregiving role which was difficult for the participants to adjust to.

The new role included caring for other family members at home. Participant 4 talked about providing her mother with emotional support after her father was placed in LTC, "Actually, I myself also got this feeling... [but] I need to console her,...how can I do this myself?" Participant 6 had to take on the roles usually performed by her mother prior to her admission and her workload at home increased because she "lost the help of our mother."

Following placement, one new role for the caregiver was as advocate for the resident. Many caregivers kept abreast of the care recipient's health and well-being, and of the medical care received. One daughter said of her father who could not communicate, "I will try to talk to my father, then see what is the response. If he feel[s] sick..., but the nurses didn't observe, we will say today... he's got a fever." Participants were constantly worried that had they not stepped in, the care recipient would have had important needs that were unmet.

#### 4. Maintaining the Relationship

Maintaining the care recipient's personhood extended to the continuity of the relationship. Participants tried various means of maintaining the care recipients' connection to their former lives and identity. Participant 1 said, "occasionally I will bring her home,...

Then she's very happy." He explained "I just want to make her happy that she still got a home." Participant 10 said, "we... speak to her in our own language... We don't want her to forget [her] own language" Participant 3 explained, "There's a relationship... We don't want them to feel that they are abandoned! We can't look after them, but we can visit them...make them happy.... It's the time and the relationship we have with them."Participant 3 said, "I will never abandon her. Unless I am dead. I do to my last breath." Participant 1 shared, "I will come every day,....even tsunami or earthquake I still ... come". He maintained the sense of togetherness by reassuring his mother at the end of each day that he was returning to his bedroom, instead of telling her that he was going home, so that she did not feel rejected by the move to LTC. As one participant said, "They need the love, we give them, they need the

time we spend with them...I do the best of what I can. So my own conscience—so I don't live with regret. If one day she's not around I don't live with regret that I have not been a filial daughter."

Given the care recipient's declining cognitive functioning, the relational bond became even more important. Participant 1 shared that his mother no longer remembered his siblings "because they don't come so often" and that "she only remembers me. I'm the one closer to her."

# 5. Engagement with the Institution

The participants' level of familiarity and comfort with the home was a major influence over the amount of comfort they felt at leaving their relative in their care and how positively they appraised their placement decision.

Dealing with the nursing home. Naturally, the longer the length of the residency, the more familiar participants became with the nursing home practices and staff. Participant 3 said that her mother's nurse "is very close to me because my mom stay here nearly 20 years." She felt confident that her mother's needs would be met adequately, and that her mother was at home there. Participants also took efforts to increase this level of familiarity through communications with the staff. Through continued engagement, participants hoped for improvements in individualised service and care for their relative. However, this was disrupted by staff turnover leading to frustration for the caregiver and concern about the placement decision. Participant 4 said she gets to know the staff at the home and requests that they "take extra care. Then by understanding they will be able to look into [my father's needs]." However, at times, this engagement felt like it was driven mostly by the participants' needs for more knowledge and understanding of the nursing home's practices rather than something independently offered by home staff as a matter of course. This engagement could

also have been a reflection of the participants' need to control processes over which they had limited influence.

At times participants felt disempowered when dealing with the home. This sense of disempowerment stems from a perceived lack of reciprocity in information sharing. Most of the participants felt they were not in a position to provide feedback or that it would not be welcomed. Participant 5 said that things were "still the same. Because... the staff keep on changing, and they do not have a proper training... and they don't really stick to the rules." She also feared repercussions for her mother. She said "I cannot [give] feedback... they ask me to do feedback, ...my mom is here".

Even when it came to engagement with the facility, the participants were motivated by their care recipients' needs. The service rendered by the home was as a proxy for the care they were unable to provide themselves, and the facility as a representative of the caregivers in fulfilling their filial duties. As a result, participants attempted to engage with the home more. They regularly expressed a sense of gratitude towards the nursing home. Participant 10 said "I told my [son], we owe the nursing home. They help me to look after your grandmom."

#### Discussion

This study aimed to explore the experiences and perceptions of Singaporean caregivers spanning the transition process into LTC. Findings revealed important aspects of Asian caregivers' experiences of the transition not previously reported in the literature. The current study presents a unique addition beyond the role of the dyadic relationships in motivating post-placement involvement (Strang et al., 2006). Significantly, this study indicates that filial piety is an added dimension which motivates caregiver involvement and interpretations of the experiences throughout the placement process.

The first theme identified was *Filial and cultural expectations shape caregivers'* experience of pre-placement decisions and post-placement interactions. Filial piety

obligations reported by the participants are key to understanding the experience of placing an older relative in the home and the caregivers' continued involvement. Filial piety represents collectivistic moral duties, attitudes, values and actions of caring for one's elder family members. It is founded on reverence and honour for and obedience towards the elder (Zhan, 2004). As such, filial piety strongly influences the way in which Asian caregivers carry out their roles and is a protective factor in keeping caregivers engaged in the process (Zhan & Montgomery, 2003). It is a powerful and emotive value that persists throughout the caregiving process, and includes concern about the elder's health, financial support, housing and respect for the elders' wishes and authority (Lai, 2010). This is further evidenced by the participants' suggestion that although they derive satisfaction in being able to provide care, the process is an ongoing one that persists even after admission of the care recipient. Adding to previous findings in the literature, such as the importance of filial piety in the placement decision, the findings from this study indicate that filial piety continues to be relevant after placement. The current study shows that caregivers, while describing caregiving as difficult, did not view their role as burdensome. This may be because their caregiving duties were in line with their values of filial piety. Lai (2010) found that filial piety served a protective role in reducing the impact of stressors while enhancing the appraisal of caregiving as being positive and beneficial.

Chang, Schneider and Sessanna's (2011) finding that most Chinese adult children regard placement as abandonment of the relative was not wholly reflected here. The caregivers in this study were less exposed to feelings of conflict and ambivalence in making the decision. Interestingly, this was contrary to Chang, Schneider and Sessanna's report that despite recognising the necessity of placement, caregivers described feeling torn in their decision of placement. Instead, current findings suggest that caregivers were better able to adjust to the decision. While participants strongly endorsed the importance of filial piety,

they were not overly distressed. Rather, they sought proactive means of fulfilling their roles. The contextual interpretations of filial responsibilities may also reflect changing filial norms, indicating the caregivers' socialisation to the contemporary environments and demands (Ng, Philips & Lee, 2002). One complication in gaining a better understanding of filial piety is that the delivery and receipt of the practice tends to be situationally driven and shaped by social and economic circumstances (Ikels, 2004).

The findings from this study echo those based on other Confucian populations. In a qualitative study of Taiwanese caregivers, Chou, LaMontagne and Hepworth (1999) reported that filial obligation was inversely correlated to levels of reported burden. This stands in contradiction of findings among American caregiving daughters which indicated that increased levels of filial obligation were related to increased caregiving burden (Cicirelli, 1993). This leads to the suggestion that Asian caregivers may be more likely to experience higher levels of filial obligation as well as lowered levels of burden due to cultural caregiving values. However, although the current study was an exploratory effort, it is revealing there are some major systematic differences at work. The second theme, View of the placement decision, related to caregivers' interpretations of the placement decision. While there was generally a sense of resignation that they had few other viable alternatives in providing care, the move was also followed by a sense of relief for caregivers. Reluctance to arrive at the placement decision was similar to that reported by Grant and Nolan (1993). The decision was easier when care recipients acceded to placement. However, in this study, care recipients at times agreed to the placement despite their preference for remaining with their families. Consistent with findings from other Asian studies, this could be a reflection of how harmony and collectivistic values are emphasised (Lee, 1999). The conceptual model postulated by Reuss, Dupuis and Whitfield (2005) reflects the above findings. This model suggests that acceptance of the placement was important to caregivers. This is also paralleled by the

conceptual order of the placement process suggested by Nolan and colleagues (1996) who state that when both caregiver and care recipient participated in decision making, the experience was deemed to be successful. In this study, it appears that notions of filial piety lead to increased acceptance of placement and their retrospective views of the decision. Additionally, the importance of communal agreement and collectivist good may have contributed to the participants' reflected levels of acceptance. Ironically, while placement may appear superficially as a violation of caregiving obligations, participants did not view LTC as a sign of failure (Lundh, Sandberg & Nolan, 2000). This is a new finding which is in contrast to Chang, Schneider and Sessanna's (2011) report that caregivers continued to feel burdened and distressed by the decision of admission in LTC despite their recognition of the necessity of placement. Engagement with the institution following the placement allowed the participants to evaluate the decision to institutionalise the care recipient. This was consistent with other Asian studies which found that continued evaluation following placement had a strong influence on caregivers' adjustment (Chang & Schneider, 2010). This suggests that increased interactions with LTC staff could serve a positive outcome for caregiver adjustment following placement.

Where Nolan et al (1996) conceptualised Participation in the decision making process and Reuss, Dupuis and Whitfield identified the Control over the Process as the important aspects of the caregiver's involvement, this study found that the need for control persists beyond the initial pre-placement phase into the stage of continued involvement. Caregivers' perceptions of the staff's lack of openness to their inputs and needs was a major factor in how much control the participants felt over the process and their final assessments of the level of person- and relationship-centred care they were receiving (Ryan, Nolan, Reid & Enderby, 2008). This had significant implications for the caregivers' overall satisfaction in dealing with the home and their sense of security for the care recipients' well-being. At times,

participants reflected that communications and cooperation with home staff was insufficient and unsatisfactory – an assessment which affected their post-move adjustment.

The sub-theme, *Delaying the placement process*, comprises the personal sacrifices and perceptions of coping with care recipients' increased needs as caregivers faced deteriorating health and functioning themselves. This theme is consistent with the idea that caregivers often feel under-resourced in their roles (Vitaliano et al. 1991), as well as having to make personal sacrifices to delay placement (Park et al., 2004). In the current study participants were often alone in providing care. Previous research indicates that support from other family members and professionals, while often felt to be lacking (Ryan & Scullion, 2000), was crucial in alleviating caregivers' symptoms of depression and improving physical health (Sorensen & Pinquart, 2005). In striving to provide care for as long as possible, participants endured personal sacrifices of their time. This was in line with findings by Park et al (2004) among a Korean population of caregiving daughters. The third theme, Continued Impact of Caring, highlighted the agreement among participants regarding the impact of caregiving and the role changes experienced as a result of placing their relative in the home (Dellasega & Mastrian, 1995). Caregivers undergo significant changes in their role which may include taking on the care recipient's areas of responsibility, which ultimately increased the caregiver's workload. These changes sometimes caused caregivers to negatively reevaluate their self-image.

Advocating on behalf of the care recipient was another important role that almost all the caregivers developed following the transition to LTC. These new roles are consistent with findings generated from other cultures (Dupuis & Norris, 2001; Stull, Cosbey, Bowman, & McNutt, 1997). Caregivers in this study were faced with uncertainty of their role following placement and lacked knowledge regarding how to better assist the care recipient. While upset by the need for placement, caregivers continued to craft a relevant role for themselves.

This is in contrast to reports that caregivers saw placement as a "caregiving failure" (Smallegan, 1985) and caregivers did not relinquish the bond (Ross, Rosenthal & Dawson, 1993) but rather worked to strengthen it.

The fourth theme, *Maintaining the Relationship* often related to the idea of maintaining the care recipient's identity (Bowers, 1987; Hasselkus, 1998), (e.g. using the care recipient's primary language and offering their favourite foods). Additionally, being able to continue with key aspects of their pre-placement lives was important to caregivers and gave them an opportunity to fulfil roles they perceived as relevant. Such opportunities led to increased caregiver satisfaction. The desire to maintain the relationship and continue with caregiving roles may also be reflective of the perceived conflict between the caregiver's values and the apparent non-filial act of placing one's relative into LTC which has been noted to cause feelings of ambivalence in other Asian studies (Chang, Schneider, & Sessanna, 2011). This theme was also consistent with findings in the wider literature following placement. This finding reflects the theme of deeply bonded relationships and attempts at continuity among caregivers (Strang et al., 2006)

One of the key roles played by caregivers post-placement is in maintaining continuity for the resident. For LTC facilities, taking a relationship-centred stance may improve the involvement and support of family caregivers and of how homes are perceived when it comes to making the placement decision. This is in line with Sussman and Dupuis's (2014) findings that interpersonal interactions with family following placement facilitates the residents' adjustment to LTC. In extension to Sussman and Dupuis's findings, staff may also further the residents' and caregivers' adjustment to the LTC environment by offering relationship-centred support.

Overall, while relationship factors as described were crucial, in addition to findings by Strang and colleagues (2006), it appears that in the current study, filial obligations were an

added social dimension to the demands and expectations perceived by the caregivers. This conjunction of relationship reciprocity and filial obligation is likely to lead to a compulsion for continued caregiving.

Caregivers' participation with the home is reflected in the fifth theme, *Engagement* with the Institution. Over time, participants developed an attachment with the home. Often caregivers felt that such a relationship ensured that the care recipient received better service and closer attention from the home staff. This extension of the role demonstrates how the caregiving role evolves beyond merely being task-based ADLs and includes socio-emotional aspects such as in facilitating the development of the relationship between the resident and LTC staff. As described by Gaugler (2005), few previous studies have delved into this dimension of post-placement caregiving. Caregiver's poor relationships, in particular perceived conflicts, with staff increases caregiver depression rates (Chen, Sabir, Zimmerman, Suitor, & Pillemer, 2007). Furthermore, lack of perceived support also led to feelings of disempowerment for the caregiver. The quality of the relationship with the staff and engagement with the home is important because it leads to a sense of disempowerment as described by the participants. Furthermore, a poor relationship is likely to lead to increased anxiety about the resident's well-being and has been found to lead to decreased family visitations (Port, 2004). The sense disengagement with the home and disempowerment is reflected as the lack of control. This is important because it affords the caregivers an important opportunity to come to terms with the decision made and to maintain ownership of the decision. The relationship between LTC staff, caregivers and residents is central to the adjustment to placement has been found to increase a sense of satisfaction and positive outcomes (Ryan, Nolan, Reid & Enderby, 2008).

Themes four and five were reflective of Sussman and Dupuis's (2014) suggestion that the complexity of adjusting to LTC was shaped by multiple dimensions in the transition of

caregiving. In the current study, the interpersonal relationship between the caregiver and resident was also influenced by the systemic layer of broader social values and culture – filial piety. In order to enhance adjustment, staff need to be aware of how the caregiver and resident may experience their duties and what placement may mean to them personally. *Implications* 

Caregivers require adequate support at key stages throughout the placement transition. Prior to contemplating placement, support is needed in terms of dealing with care recipient behaviours. Appropriate caregiver training may address issues of feeling under resourced when performing ADL such as feeding and bathing. During the decision making phase, support is necessary in terms of explaining the rationale for placement, as well as managing care recipient responses. Following placement, the institution may increase opportunities to engage caregivers. The caregiver's sense of disempowerment or loss of a major role may be countered with preparation for what may be expected. As suggested by Sussman and Dupuis (2014), at the systemic layer, LTC staff may recognise the role of interpersonal interactions and the importance of filial piety. LTC facilities may offer ways in which caregivers may continue with key roles and activities of the pre-placement phase to facilitate their and the care recipients' adjustment. Commending and providing opportunities for caregivers to continue with routine caregiving activities may facilitate adjustment for both the resident and the caregiver, and may alleviate the sense of failing one's filial duties. In treating caregivers as part of the team, and by drawing from their knowledge and expertise on the resident, staff may increase the caregiver's confidence and comfort in the placement decision as well as increase their post-placement involvement.

# Strengths and Limitations

Given the participants' awareness of the study's objectives, it is possible that they may have been responding in a manner perceived to be socially appropriate. Nonetheless, this

is a common issue in caregiver research. Furthermore, participants' regular visits, maintenance of their relationship and the continued involvement in the care recipient's care corroborates their self-report.

While adequately reflecting the view of caregivers who chose to remain involved in their older relatives' lives, the findings from this study do not capture a significant and important subset of the population. As reflected by anecdotal reports from the nursing home staff, a significant proportion of families were less involved with their family member than the participants of this study. Nonetheless, this data provides an opportunity to understand perceptions of family members who continued to care for their relatives after they have been placed into LTC.

This study overlooks the multi-phased nature (Sussman & Dupuis, 2012) of the placement process and reviews caregiver experiences from a retrospective angle. The differing amounts of time since the participants went through the placement process may alter their recall of the experiences. However, we believe that the findings here are still pertinent, especially given the high rate of agreement among the participants, since they add to the literature about caregiver sentiments at the present time.

The findings arising from this study are enriched by the qualitative approach which allows for the caregiver's personal meaning of the experience to be understood. Future studies may take a longitudinal approach and assess how caregiver's experiences change over time through the course of caregiving. Further understanding is also needed to comprehend the unique factors that Singaporean caregivers may face as well as to explore the role of the relationship and culture in caregiving decisions.

#### Future research

A quantitative investigation is needed in order to understand the Singaporean caregiver's appraisal of filial piety, burden and how these factors affect their caregiving

outcomes. Furthermore, previous research indicates that social support and coping styles are the core factors which distinguishes between cultural groups. Further understanding of how caregiver values, coping styles and social support mechanisms operate in a collectivist society is necessary.

#### Conclusion

This study aimed to understand the Singaporean caregivers' experiences and perceptions regarding the placement of an older care recipient into LTC. Cultural values were found to significantly impact on the caregiving experience. Caregivers placed significant emphasis on filial piety which seemed to impact on their caregiving role prior to placement, when making the decision to place their relative into LTC and after placement. Whilst placing a relative into care changed the nature of the caregiving role, it was still fraught with difficulties. Caregivers worked hard to maintain their close relationship with their relatives in LTC whilst also building a new relationship with the facility.

#### References

- Bell, J. (1996). Decision making in nursing home placement. *Journal of Women and Aging*, 8(1), 45-61.
- Bowers, B. J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents.

  \*Advances in Nursing Sciences\*, 9(2), 20-31.
- Bradley, J. (1993). Methodological issues and practises in qualitative research. The Library Quarterly, 63(4), *Symposium on Qualitative Research: Theory, Methods, and Applications.* 431-449.
- Bragstad, L.K., Kirkevold, M., Hofoss, D., & Foss, C. (2014). Informal caregivers'

  participation when older adults in Norway are discharged from hospital. *Health and*Social Care in the Community, 22(2), 155-168.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research* in *Psychology*, 3, 77-101.
- Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, 43(2), 230-241.
- Butcher, H.K., Holkup, P.A., Park, M., & Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing & Health*, 24, 470-480.
- Chang, Y.-P., & Schneider, J.K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in Psychiatric Care*, 46(2), 108-118.
- Chang, Y.-P., Schneider, J.K., & Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies*, 25, 436-444.

- Chee, Y.K., & Levkoff, S.E. (2001). Culture and dementia: Accounts by family caregivers and health professionals for dementia-affected elders in South Korea. *Journal of Cross-Cultural Gerontology*, 16, 111-125.
- Chee, W.T., Li, F.T., Luo, N., Wai, Y.N., & Yap, P. (2010). Why family caregivers choose to institutionalise a loved one with dementia. A Singapore perspective. *Dementia and Geriatric Cognitive Disorders*, 30, 509-516.
- Chen, C.K., Sabir, M., Zimmerman, S., Suitor, J., & Pillemer, K. (2007). The importance of family relationships with nursing facility staff for family caregiver burden and depression. *Journal of Gerontology: Psychological Sciences*, 62B(5), 523-260.
- Chene, B. (2006). Dementia and residential placement: A view from a carer's perspective. *Qualitative Social Work*, 5(2), 187-215.
- Cheung, C.-K., & Kwan, A.Y.-H. (2008). The erosion of filial piety by modernisation in Chinese cities, 29(2), 179-198.
- Chou, K.-R., LaMontagne, L.L., & Hepworth, J.T. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research*, 48(4), 206-214.
- Cicirelli, V.G. (1993). Attachment and obligation as daughters' motives for caregiving behaviour and subsequent effect on subjective burden. *Psychology and Aging*, 8(2), 144-155.
- D'Rozario, V. & Romano, J.L. (2000). Perceptions of counselor effectiveness: A study of two country groups. *Counseling Psychology Quarterly*, 13(1), 51-63.
- Davis, S., & Nolan, M. (2003). 'Making the best of things': Relatives' experiences of decisions about care-home entry. *Ageing & Society*, 23, 429-450.
- Dellasega, C., & Mastrian, K. (1995). The process and consequences of institutionalising an elder. *Western Journal of Nursing Research*, 17(2), 123-140.

- Dilworth-Anderson, P., Williams, I.C., & Gibson, B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review. *The Gerontologist*, 42(2), 237-272.
- Duncan, M.T., & Morgan, D.L. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *Gerontologist*, 34(2), 235–244
- Dupuis, S.L. & Norris, J.E. (2001). The roles of adult daughters in long-term care facilities: Alternative role manifestations. *Journal of Aging Studies*, 15, 27-54.
- Fereday, J., &Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development.

  \*International Journal of Qualitative Methods, 5(1), Retrieved 12 May 2012 from http://www.ualberta.ca/~iiqm/backissues/5 1/pdf/fereday.pdf
- Finlayson, M., & Cho, C. (2008). A descriptive profile of caregivers of older adults with MS and the assistance they provide. Disability and Rehabilitation, 30(24), 1848-1857.
- Fisher, P., Johnstone, L., & Williamson, K. (2011). Patients' perceptions of the process of consenting to Electroconvulsive Therapy. *Journal of Mental Health*, 20(4), 347-354.
- Fleming, A.A. (1998). Family caregiving of older people with dementing illnesses in nursing homes: A lifeline of special care. *Australasian Journal of Aging*, 17(3), 140-144.
- Foo, K-H., Merrick, P.L., & Kazantis, N. (2006). Counseling/Psychotherapy with Chinese Singaporean clients. *Asian Journal of Counselling*, 13(2), 271–293.
- Friss Feinberg, L. & Goldstein, C. (2008). Family caregiver needs: Assessment. *The Encyclopedia of Elder Care*, 2nd. ed. New York: Springer Publishing Company, 2008.
- Gaugler, J.E. (2005). Family involvement in long-term care: A synthesis and critical review. *Aging and Mental Health*, 9(2), 105-118.

- Gaugler, J.E., Mittelman, M.S., Hepburn, K., & Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine*, 8(85), 1-14. doi:10.1186/1741-7015-8-85
- Gaugler, J. & Teaster, P. (2006). "The Family Caregiving Career". *Journal of Aging & Social Policy*, 18(3/4), 141-154. doi: 10.1300/J038v18n03 10
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Hasselkus, B.R. (1998). Occupation and well-being in dementia: The experience of day-care staff. *American Journal of Occupational Therapy*, 52, 423-434.
- Hermanns, M. & Mastel-Smith, B. (2012). Caregiving: A qualitative concept analysis. *The Qualitative Report*, 17, 1-18, http://www.nova.edu/ssss/QR/QR17/hermanns.pdf
- Hurberman, M. (1994) *Qualitative Data Analysis: an expanded sourcebook.* London, Beverley Hills.
- Ikels, C. (2004). Introduction. In C. Ikels (Ed.), Filial piety, practice and discourse in contemporary East Asia, 1-15. Stanford: Stanford University Press.
- Lai, D.W.L. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging*, 32(2), 200-223.
- Lee, D.T.F. (1997). Residential care placement: Perceptions among elderly Chinese people in Hong Kong. Journal of Advanced Nursing, 26, 602-607.
- Lundh, U., Sandberg, J., & Nolan, M. (2000). 'I don't have any other choice': Spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32(5), 1178-1186.
- Kim, J., & Lee, E. (2003). Cultural and non-cultural predictors of health outcomes in Korean daughter and daughter-in-law caregivers. *Public Health Nursing*, 20, 111-119.

CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION

- Knight, B.G., & Losada, A. (2011). In *K. Warner Schaie and Sherry L. Willis* (Eds.), Handbook of the Psychology of Aging (7<sup>th</sup> ed., p. 353-365). Elsevier Inc. doi: 10.1016/B978-0-12-380882-0.00023-1
- Knight, B.G., & Sayegh, P. (2009). Cultural values and caregiving: The updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences*, 65B(1), 5-13.
- Malhotra, C., Malhotra, R., Ostbye, T., Matchar, D., & Chan, A. (2012). Depressive symptoms among informal caregivers of older adults: Insights from the Singapore survey on informal caregiving. *International Psychogeriatrics*, 24(8), 1335-1346.
- Mehta, K. (2005). Stress among family caregivers of older persons in Singapore. *Journal of Cross Cultural Gerontology*, 20, 319-334.
- McConnell, E.S. (2001). The effects of nursing home placement on family caregivers of patients with Alzheimer's Disease. *The Gerontologist*, 41(6), 819-826.
- Milne, A. & Chryssanthopoulou, C. (2005). Dementia caregiving in Black and Asian populations: Reviewing and refining the research agenda. *Journal of Community & Applied Social Psychology*, 15, 319–337.
- Ministerial Committee for Aging, (2008). Committee on Ageing Issues: Report on the Ageing Population.
- Morse, J.M. (2000). Determining the sample size. *Qualitative Health Research*, 10, 3-5.
- Nolan, M., & Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1994). Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24(2), 265-274.

- Ng, A.C.Y., Philips, D.R., & Lee, W.K.M. (2002). Persistence and challenges to filial piety and informal support of older persons in a modern Chinese society: A case study in Tuen Mun, Hong Kong. *Journal of Aging Studies*, 16(2), 135-153.
- Park, M., Butcher, H.K., & Maas, M.L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long term care facility. *Research in Nursing & Health*, 27, 345-356.
- Pearlin, L.I. (1992). The career of caregivers. *The Gerontologist*, 32(5), 647.
- Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45(1), 90-106.
- Port, C.L. (2004). Identifying changeable barriers to family involvement in the nursing home for cognitively impaired residents. *The Gerontologist*, 44(6), 770-778
- QSR International Pty Ltd (2010). NVivo qualitative data analysis software. Version 9.
- Rasmussen, L.J., Sander, M., Wewer, U.M., & Bohr, V.A. (2011). Aging, longevity and health. *Mechanisms of Ageing and Development*, 132(10), 522–532.
- Ryan, A.A., & Scullion, H.F. (2000). Nursing home placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing*, 32(5), 1187-1195.
- Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the Sense Framework to achieve relationship-centred dementia care services: A case example. *Dementia*, 7(1), 71-93
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282(23), 2215-2229.
- Schulz, R., Belle, S.H., Czaja, S.J., McGinnis, K.A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *The*

- CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION
  - *Journal of American Medical Association*, 292(8), 961-967. doi: 10.1001/jama.292.8.961.
- Sitoh, Y.Y. (2003). Nursing homes in Singapore: A quiet revolution. *Singapore Medical Journal*, 44(2), 57-59.
- Skaff, M.M., Pearlin, L.I., & Mullan, J.T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and Aging*, 11(2), 247-257.
- Spector, J., & Tampi, R. Caregiver depression. *Annual Long-Term Care: Clinical Care Aging*, 13, 34-40.
- Stiles, W.B. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593-618.
- Strang, V.R., Koop, P.M., Dupuis-Blanchard, S., Nordstrom, M., & Thompson, B. (2006). Family caregivers and transition to long-term care. Clinical Nursing Research, 15, 27-45.
- Stull, D.E., Cosbey, J., Bowman, K., & McNutt, W. (1997). Institutionalization: A continuation of family care. *The Journal of Applied Gerontology*, 16(4), 379-402.
- Sussman, T., & Dupuis, S. (2012). Supporting a relatives move into long-term care: Starting point shapes family members' experiences. *Canadian Journal on Aging*, 31(4), 395-410.
- Sussman, T., & Dupuis, S. (2014). Supporting residents moving into long-term care: Multiple layers shape residents' experiences. *Journal of Gerontological Social Work*, 57(5), 438-59.
- Vitaliano, P.P., Russo, J., Young, H.M., Teri, L, & Maiuro, R.D. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and Aging*, 6(3), 392-402.

- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129(6), 946-972.
- Yardley, L. (2000). Dilemmas in qualitative health research. Psychology and Health, 15, 215-228.
- ed lens.

  \*\*Jof Women & As

  \*\*A.J.V. (2003). Gender an

  \*\*Cutral constraints. Gender and So. Zhan, H.J. (2004). Through gendered lens: Explaining Chinese caregivers' task performance
- Zhan, H.J., & Montgomery, R.J.V. (2003). Gender and elder care in China: The influence of

# CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION

Table 1. *Participant profiles*.

Participant number	Relationship to Resident	Sex	Age	Employment status	Care Recipient's Age & Gender	Length of Residence in LTC	Primary reasons cited for placement
1	Son	Male	55	Part-time	84, Female	4.5 years	Unable to care
2	Daughter	Female	63	Unemployed	84, Female	2 months	Unable to care
3	Daughter	Female	54	Part-time	77, Female	18 years	Unable to care
4	Daughter	Female	38	Full-Time	71, Male	1 year	Unable to care
5	Daughter	Female	51	Full-Time	78, Female	2.5 years	Unable to care
6	Daughter	Female	40	Part-time	73, Male /74, Female	3.5 years/ 3 years	Unable to care

(Table 1 continues)

# CAREGIVERS' EXPERIENCES OF INSTITUTIONALISATION

(Table 1 continued)

	Relationship				Care		
Participant	to Care	Sex	Age	Employment	Recipient's	Length of Residence	Reasons cited for placement
number	recipient				Age & Gender	in LTC	
7	Son	Male	52	Part-time	82, Male	5 years	Relationship factors
8	Brother	Male	59	Full-Time	64, Male	2.5 years	Unable to care
9	Daughter-in-	Female	46	Unemployed	70, Female	2 years	Unable to care
	law						
10	Son	Male	51	Full-Time	71, Male	3 months	Unable to care
11	Son	Male	70	Unemployed	100, Female	7 months	Unable to care
11	5011	iviaic	70	onemployed	100, 1 cinaic	, months	ondoic to care
12	Daughter	Female	65	Part-time	100, Female	10 months	Unable to care

Table 2. Summary of Codes, Themes and Sub-Themes

Themes	Sub-Themes	No. of participants
		endorsing
Filial and Cultural expectations		12
shape caregivers' experience		
View of the placement decision	Delaying placement through	12
	personal sacrifice	
	Caregivers' changing ability to	12
	care leading to unavoidable	
	placement	
Continued Impact of caring	Caregiver's shifting role	12
	Difficulties in providing care	12
Engagement with the institution	Dealing with the home	11
	Perceptions of nursing homes	9
Maintaining the relationship	Continuity of the relationship	11
	Concerns for the relationship	12
	Protecting the care recipient	12
	Caregiver's continued	11
	involvement	

# **Statement of Ethical Approval:**

Ethical approval for this project was granted by the James Cook University Human Research Ethics Committee (Application Id: H4219D).

# **Statement of funding:**

No external funds were received for the conduct of this project.

#### **Statement of conflict of interests:**

There are no known conflicts of interests which arose in the conduct of this research paper.

# **Declaration of the contribution of authors:**

Rajini Ramanathan and Dr. Paul Fisher contributed towards the (a) the conception and design, analysis and interpretation or validation of the data; (b) the drafting of the article or revising it critically for important intellectual content and (c) approval of the version to be published.

Address correspondence to Rajini Ramanathan, Department of Psychology, James Cook University Singapore, 149 Drive Sims, Sims Dr, 387380. 6709 3888; email: rajini.ramanathan@my.jcu.edu.au