

Caregiving and Coping Strategies 1

Examining Live-in Foreign Domestic Helpers as Coping Resource for Family Caregivers of People with Dementia in Singapore

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Abstract

In Singapore, the responsibility of caring for persons with dementia falls on family members who cope with long-term caregiver burden depending on available support resources. Hiring foreign domestic workers to alleviate caregiver burden becomes a prevalent coping strategy that caregivers adopt. This strategy allows caregivers to provide home care as part of fulfilling family obligations while managing caregiver burden. This study aimed to investigate primary caregivers' relationship with hired support and its impact on coping with caregiver burden. Twenty in-depth interviews were conducted with primary caregivers who hired live-in domestic helpers to take care of their family members with dementia. The findings revealed that caregivers perceived the normative obligations to provide home care to family members with dementia. They sought support from domestic helpers to cope with physical and mental burnout, disruption of normal routines, and avoidance of financial strain. A mutual-support relationship was built between caregivers and domestic helpers through trust and interdependence. The presence of domestic helpers as a coping resource reveals the positive outcomes of problem, emotional, and diversion focused coping. This study illustrates that coping strategies are employed in different ways depending on the needs of caregivers, access to infrastructure, cultural expectations, and available resources.

Keywords: caregiver burden; caregiving; coping; dementia; domestic helpers

According to Alzheimer's Disease International (2015), over 46 million people live with dementia worldwide and it will become a trillion-dollar disease by 2018. Dementia is characterized by progressive deterioration in cognitive ability and capacity for independent living (Prince et al., 2013). Overtime, persons with dementia will experience memory loss, irreversible brain damage, health deterioration, communication breakdown, and increased behavioral disturbances which leave them completely dependent (Jennings et al., 2015; Prince et al., 2013). Family members have traditionally been responsible for the care of people with dementia and are vulnerable to burdens, health risks, and poorer quality of life (Chan, 2011; Lai, 2010). The World Health Organization (2012) has identified dementia as a major public health issue, calling on governments to improve the care and quality of life of people with dementia and family caregivers.

People with dementia will need increasing levels of care that intensifies burdens for family caregivers (Etters, Goodall, & Harrison, 2008; Jennings et al., 2015). Generally, family caregivers may not have the necessary skills and experience to handle caregiving responsibilities, and thus may experience high levels of stress and burden (Alpert & Womble, 2015). Extant research has documented that family caregivers face constant physical, psychological, emotional, social, and financial stressors leading to burnout, depression, social isolation, disruptions in employment, and decreased quality of life (Brodaty & Donkin, 2009; Lai, 2010). Moreover, as family caregivers struggle to meet the demands of caregiving, their own physical and emotional health is often ignored, and leisure activities, hobbies, time with friends and family are sacrificed (Alpert & Womble, 2015; Brodaty & Donkin, 2009; Chan, 2011; Seow & Yap, 2011).

Substantial proportions of people with dementia are cared for at home. For instance, the Centers for Disease Control and Prevention (CDC) estimated that in 2015 about 80% of people with dementia were cared for at home in the United States. Similarly, in European

countries policies are enacted to incorporate home- and community-based services so that people with dementia can stay at home longer (Verbeek et al., 2012). In Asian societies such as India and China, people with dementia live in extended-family households and are cared for within the home (Chan, 2011). Home care reflects the preference of people with dementia and their family members to stay in their home environment as long as possible (Tew, Tan, Luo, Ng, & Yap, 2011; Verbeek et al., 2012; Wilson & Bachman, 2015). Past research indicates that dementia caregiver burden emerges more often in home care settings, where caregivers deal with the stress and frustration of caring for the patients with less professional aids (Chan, 2011; Eters et al., 2008).

Similarly, in Singapore the family home is considered the ideal caregiving space for older parents while nursing homes become the less desirable institutional space (Huang, Yeoh, & Toyota, 2012). In this Confucian society, filial responsibility bounds children to care for their aged parents (Chan, 2011; Lai, 2010). Thus, admitting one's parents to a nursing home could receive societal disapproval and is perceived as a failure of filial duty (Tew et al., 2011). Accompanying the filial expectations of dementia caregiving are the high costs of institutional facilities and limited options of community-based care in the form of day care centers and home care services by professionals (Tew et al., 2011). Altogether, the cultural and structural environments have led foreign domestic workers (FDWs) to become the de facto mode of providing care at home (Tew et al., 2011; Yeoh & Huang, 2009). Situated in this Confucian context that values filial care and downplays institutional assistance, this study seeks to explore how foreign domestic workers become a support resource for family caregivers of persons with dementia.

Dementia Caregiving in Singapore

In Singapore an estimated 40,000 older adults above the age of 65 (i.e., 10% of the older population) live with dementia and this number is expected to soar to 80,000 by 2030

(Institute of Mental Health, 2015). Seow and Yap (2011) noted that the majority of dementia caregivers in Singapore are middle-aged women. Influenced by the Confucian emphasis on filial piety and family members' mutual obligation to take care of each other (Lai, 2010; Lim, Goh, Chionh, & Yap, 2012; Vaingankar et al., 2013), Singapore's national policies promote family as the principal support system for older adults (Yeoh & Huang, 2009). While home care is the preferred option for persons with dementia and for their family members (Wong, Pang, & Yap, 2014), such a choice also depends on whether caregivers can afford to stay at home full-time and whether they can afford to employ a live-in FDW to share the caregiving responsibilities (Tew et al., 2011).

The idea of hiring FDWs to provide care parallels the notion of home care aids in the United States and in Europe in that both emphasize the delivery of health care at home (Ansah et al., 2013). Nevertheless, there are distinct differences between home care aids and FDWs. A FDW is a female migrant worker tied to an individual employer through a regulated work permit system that allows her to work for only a single household (Yeoh & Huang, 2009). The majority of FDWs in Singapore are from Indonesia and the Philippines, while a small number comes from Sri Lanka, Myanmar, India, Thailand, and Bangladesh (Yeoh & Huang, 2009). FDWs as live-in domestic workers are expected to provide 24/7 care for people with dementia as part of their household duties, given the elasticity with which domestic work is treated (Vaingankar et al., 2013; Yeoh & Huang, 2009). In Singapore, more than 50% of households hire FDWs to help care for family members with dementia (Ansah et al., 2013; Huang et al., 2012; Lim et al., 2012). Often FDWs are employed to deliver the practical caregiving aspects such as feeding, dressing, bathing, toileting, administering medication, and getting in and out of bed (Huang et al., 2012; Østbye, Malhotra, Malhotra, Arambepola, & Chan, 2013). Although engaging the services of FDWs has its costs, caregivers reported a reduced financial burden as it allowed them to remain

employed (Østbye et al., 2013). Furthermore, the cost of employing a live-in FDW is much lower compared to home- and community-based services or nursing home placement (Tew et al., 2011). Employing FDWs is a convenient solution to ensuring home care while at the same time covering a range of other household responsibilities such as cooking and cleaning (Yeoh & Huang, 2009).

Similar to other societies, dementia caregivers in Singapore face a range of burdens that include unmet needs for family, social, and institutional support; psychological disturbances; depression; interpersonal problems; physical health problems; financial stress; and lack of access to facilities and social services (Lim et al., 2012; Seow & Yap, 2011; Tay et al., 2014; Vaingankar et al., 2013). While formal health care systems and the government rely on the family to be the main provider of care, the decreased size of families and the increased prevalence of dementia continue to deepen caregiver burden among family caregivers (Thompson, Eberlein, & Matchar, 2012). Alternatively, the availability of hired support allows family caregivers to obtain physical assistance from FDWs as a substitute for resources from the government, health care systems, and other family members. However, despite the extensive involvement of FDWs in elderly care, little is known about how the provision of such hired support affects caregivers in coping with caregiving responsibilities and burdens (Østbye et al., 2013). Thus, the purpose of this study is to explore dementia caregivers' employment of hired support to cope with caregiver burden and the various impacts of this coping strategy.

Coping with Dementia Caregiving

Coping is a key construct in the literature of dementia caregiving (Roche, Croot, MacCann, Cramer, & Diehl-Schmid, 2015; Taylor & Stanton, 2007). It refers to a dynamic process in which caregivers make behavioral or psychological efforts to manage stressful events appraised as exceeding their resources (Kneebone & Martin, 2003; Kristofferzon,

Linqvist, & Nilsson, 2011). From a cognitive psychological perspective, coping as a process involves appraisal and decision making. When encountering a stressful situation, a person may assess the relevancy of the encounter, evaluate whether it is a threat, and bring to mind a potential response to the threat (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984). Then, the person makes decisions to utilize certain strategies to reduce the discrepancy between the stressful demands and personal resources if any (Lazarus & Folkman, 1984). Past research indicates that both positive and negative appraisals may appear during coping and that a stressful situation may evoke mixed emotional arousal (Tew et al., 2011). In this study we focus on caregivers' appraisals and decision making related to the use of hired support as a coping strategy to unveil the dynamic interplay of caregiver burden, filial expectations, and the availability of FDWs in the local cultural context.

Coping strategies adopted by caregivers can influence the ways they respond to stressors and therefore affect the quality of life for both them and the patients (Kristofferzon, Linqvist, & Nilsson, 2011; Taylor & Stanton, 2007). The classical model of coping holds that in stressful situations, individuals may adopt: (1) emotion-based coping strategies to control their feelings and emotions or (2) problem-focused coping strategies to reduce stressors by taking action and seeking support (Lazarus & Folkman, 1984). Studies related to family caregivers' coping have frequently discussed the problem-solving and emotion-focused strategies (Chan, 2011). In recent years, the classical model has been expanded to posit that caregivers may deploy dysfunctional coping strategies to avoid stressful situations through mental and behavioral disengagement and through substance use (Cooper, Katona, Orrell, & Livingston, 2008; Sun et al., 2010). Alternatively, Okabayashi et al. (2008) has also revised the coping model by highlighting the beneficial effects of diversion coping, which refers to caregivers' strategy of carving out personal time away from fulfilling caregiving responsibilities.

Few studies have compared the effects of different coping strategies on reducing caregiver burden and have yielded mixed results (Chen, Huang, Yeh, Huang, & Chen, 2015; Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009; Roche et al., 2015; Sun et al., 2010). A possible explanation of the diverse results is that caregivers might not consider different coping strategies as mutually exclusive options and may use them concurrently to respond to a stressful situation (Kneebone & Martin, 2003; Sun, 2014). In the realm of dementia caregiving, this raises the question of how and what coping strategies caregivers of persons with dementia use to relieve caregiver burden in the studied context. In this study we argue that hired support may represent a new coping strategy that resembles characteristics of problem-focused, emotion-based, and diversion coping strategies. With hired support, caregivers can actively seek physical aids to overcome stressors and at the same time passively manage emotional distress through buying time away from their role obligation. The process and impact of using hired support as a coping strategy are understudied. Little is known about the complex attributes of hired support and their relationship to other coping strategies. Thus, this study aims to understand the reasons underlying caregivers' decisions to use hired support as a coping strategy and the impact on health. The paper serves to fill a gap in the literature and raise important questions for future research and interventions pertinent to the unique functions of hired support. Specifically, we raise the following research question: How does the presence of FDWs influence coping with caregiver burden among primary caregivers of people with dementia?

Method

Procedure

A university's institutional review board in Singapore approved the study. Participants were recruited with the help of the Alzheimer's Disease Association (ADA) of Singapore. After acquiring approval from the ADA's board for the study, recruitment emails

were sent to its members stating the specific criteria of being the primary caregivers of person with dementia. Interested participants either replied to the email or called the research team, upon which an interview was set up at their convenience. Before setting up the interview, participants were briefed on the nature of the questions, the interview process, and their right to participate or withdraw any time during the interview.

Data Collection

The interviews were conducted between May and December 2014. Each interview began with an introduction of the study, a briefing on ethical procedures, and a short survey of participants' demographics. Each participant signed informed consent forms prior to being interviewed and received ten Singapore dollars (~ USD\$7) as a token of appreciation regardless of whether they completed the interview. All interviews were completed. The semi-structured interview focused on participants' experiences as primary caregivers, the availability and kinds of support, and the ways in which they coped with and obtained resources to manage caregiving responsibilities. Some of the specific interview questions were: Besides you, who else takes on the responsibility of caring for the patient? What kinds of support do you receive from your helper? What link do you see between the support you obtain from your helper and your health? How does employing a helper allow you to cope with taking care of the patient? The interviews lasted between one to two hours, resulting in 40 taped hours and 627 double-spaced pages of text.

Participants

Initially, 38 participants responded to the recruitment email. During the course of the project, 14 participants dropped out due to various reasons such as incomplete interviews, scheduling difficulties, and lack of interest to set up an interview after discussing the interview protocol. In total 24 primary caregivers completed the interviews, and no two caregivers from the same family/household were interviewed. All participants took care of

the patients in home settings. Among them, 20 hired FDWs to care for the patients and were identified as the research participants of this study. Participants' ages ranged from 23 to 75 years ($M = 50.15$, $SD = 13.14$) with an average length of being caregivers for six years ($M = 5.9$, $SD = 3.30$). With respect to the one 23-year-old participant, she and her father shared caregiving responsibilities and she responded to the call on behalf of her father, and was the only participant below the age of 40. Most participants were female ($N = 18$) and cared for their mothers ($N = 15$). Out of the 20 cases studied, 17 caregivers lived with a person with dementia, while in the three remaining cases the persons with dementia lived with only FDWs. Pseudonyms are used to maintain confidentiality of the caregivers.

Data Analysis

Thematic analysis was utilized to uncover broad themes. The data analysis occurred in six steps, i.e., familiarizing, generating initial codes, searching for themes, reviewing the themes, naming the themes, and writing, as discussed by Braun and Clarke (2006). In the first step, each author read and re-read each of the transcripts to become familiar with the data. Second, each author generated the initial codes by taking notes about patterns that emerged in the transcripts. Third, through discussions, the authors narrowed down the initial codes to potential themes. For instance, the authors discussed emerging patterns in the data such as types of stressors, available resources for caregivers, mutual relationships between caregivers and FDWs, impacts of hired support on caregiver burden, patient needs, and the difficulties that FDWs faced. Fourth, the authors further discussed and refined the potential themes to address the research question. Specifically, we wanted to know what the data revealed about the process of choosing hired support to cope with caregiver burden and its impact on caregivers' assessments of their caregiving responsibilities and well-being. Fifth, through further discussion, the themes were defined and named as: obligations and burdens, caregiver relief, and mutual support. Sixth, the authors selected vivid and compelling

extracts for this article that relate back to the research question and literature. Several techniques were used to validate our data. We compared results between the authors, explored the literature for alternative explanations, and consulted two primary caregivers of people with dementia to get their feedback on the themes. Additionally, attempts have been made to provide sufficient evidence in the results section to allow the readers to judge the reliability of the analysis.

Results

Three themes emerged from the data. The first theme, obligations and burdens, reveals caregivers' appraisal process. Caregivers identified the psychological, social, physical, and financial stressors associated with caregiving. They embraced the idea of home care as a family obligation and strategized to manage caregiver burden through available resources. Accordingly, they identified FDWs as a potential resource to manage the obligations and burdens. The second theme, caregivers' relief, illustrates the problem focus and diversion characteristics of hired support as a coping strategy. Hired support enabled caregivers to better cope with emotional and physical stress as well as to manage their own needs. This coping strategy also allowed participants to reappraise caregiver burden as less stressful and manageable. The third theme demonstrates that the feeling of relief also depended on the mutual support between the FDWs and the caregivers. While the aid primarily flowed from the FDWs to the caregivers, the caregivers also provided informational support, advice, and empathy to the FDWs.

Obligations and Burdens

Participants described providing care to aged parents as a highly regarded practice and belief in the local cultural context. Min summarized her filial beliefs and the cultural expectations of caring for parents at home:

I tell my husband she did this or that today. Then my husband says, “Why don’t you send her to the old folk’s home or nursing home? You just put her there and some people take care of her, then you can go and visit her and you don’t have this kind of problem.” So I said to him I can’t, I don’t know, as a Chinese, we always think that it’s no good to send your parents to the old folk’s home, nursing home.

While Min hinted at the burdens of caregiving, she reasoned that her obligation to take care of her mother with dementia, especially at home, outweighed the burdens. Caregivers like Min often rejected the idea of removing their parents from home because it violated their role expectation. Similarly, Su described the obligation to take care of her father at home:

I told my sister it is very hard on me. I discussed the problems with her and then she said, “If that’s the case, then we have no choice.” Then my sister checked out different nursing homes that they have for people with dementia. Yes, there is a limit of tolerance or circumstances that we can face. But I told my sister that as children, we’re obliged to take care of our parents. It’s our obligation to take care of them.

While family members may suggest palliative care as a way to lessen the burdens, the caregivers themselves opposed the idea and chose to take on the responsibilities based on filial beliefs. However, taking care of people with dementia was a full-time job and it took participants away from other aspects of their lives. Jing explained her situation:

I spent a lot of time on my mother. Sometimes I will ask myself, where will the ending be? Because I’m almost 50 years old. Not much time to enjoy myself, I don’t get much time for my husband, I don’t get much time with my children. It affects me, it affects my husband, and it affects my children. I sometimes have only one Sunday to do my housework, to spend time with my family, and sometimes my house can be really messy because I spend a lot of time here.

In addition to the increased disruption of normal routines, Jing's situation highlighted the fact that caregivers could be aged themselves and be at risk of age-related health problems.

Caregivers often sacrificed their personal lives for caregiving and such disruptions could yield tremendous emotional and mental stress. Tan, an unmarried caregiver who lived with her mother, highlighted the lack of social and family life:

You know, I don't have friends. I don't go out and meet people because I can't leave the house. My life and social circle revolves around her. I realized that if my mother is no longer around, I don't have any life. One thing is you don't have your own life. You are tied to her and every minute, every hour, or even every second. There's only you and her and if she's not around, how do I live on? So the last few months, I started to go out on Saturdays when my family [referring to siblings] came to visit. I don't see them but my mother has company and I can go out.

Participants said that as they devoted their lives to taking care of the persons with dementia, the feeling of loneliness and social isolation increased. Tan's example illustrated that caregivers had a desire to reconnect and rebuild their social network, particularly as the patients' condition deteriorated. However, they were often torn between the needs of the patient under their care and that of their own families. Qian, who initially quit her job, described the challenge of balancing her caregiver role obligation and her own life:

Definitely, I lost weight. There is a lack of sleep. I was frustrated. I became very short-fused and temperamental. I got emotional. I cannot go for a movie or just sit down and read a book. Even when I am sleeping I am still thinking about have I prepared the medicine or have I done this and that. But then eventually I told myself, I had to get back to work because I need a distraction. So the work helped to distract, but I could only go back to work because we hired a maid to take over some duties.

Caregivers juggled between their caregiving responsibilities and balancing their family and personal time, careers, and relationships. As Qian noted, the option and ability to hire FDWs presented a way to cope with the burdens. Similarly, Chen, who quit her job and stayed at home as a full-time caregiver, also shared about the challenge of balancing her caregiver role and her personal needs:

I cannot go on like this, you know what I mean? Because I cannot just day in day out, I cannot just care for someone like that because emotionally it affects you. Mentally, it affects you too. And more importantly, I have to care for myself, I have to live you know. Whether we can afford or cannot afford I don't care, I still have to hire someone. Cause somebody has to lift the burden off me.

“I cannot go on like this” was a shared frustration among all caregivers and it explained why participants considered hiring FDWs to share their caregiving responsibilities. To participants, the burdens not only came from emotional and psychological stress but from physical burnout and financial strain as well. Financial concern was an important reason for participants to seek hired support. When participants can earn more money than the amount they paid for the FDWs, they preferred to secure a full-time job so that they can secure more financial resources for the patients. Seeking hired support therefore became a suitable strategy to both keep their job and fulfill their caregiver role. Zhen explained:

Frankly speaking, I really didn't know what to do. If I lose my job, I don't have money to support her at all. Of course, my husband, financially, he's ok, but I cannot depend on my husband because my husband got to support my family right? It's totally different thing. So my worry is that I need income to support my mother.

Loss of income increased financial stress, and could also increase mental anguish.

Caregivers highlighted that having an income was essential in order to manage the financial needs of taking care of people with dementia. Based on filial beliefs and cultural

expectations, caregivers took on the responsibility of caring for family members with dementia at home. To fulfill the role obligation, however, caregivers had to develop strategies to manage stressors such as burnout, disruptions in life, emotional and mental anguish, and financial strain. Accordingly, FDWs became an important coping resource for caregivers to provide home care and at the same time lessen the intensity of stressors.

Caregivers' Relief

Participants described that the coping strategy of seeking hired support provided physical support, emotional and mental relief, and the opportunity to return to normal routine. Caregivers hired FDWs for physical support such as cooking, bathing, feeding, bringing the patients to the toilet, changing diapers, and taking them out. Khun described the shared caregiver roles between her and the hired helper:

The maid cooks for her and takes care of her bathing. The maid will hold her when she needs to go to the toilet or comes out to eat or wants to go outside. When I'm at home or that the maid is on her off day, I do all these. Other than that, I take care of things that she needs, such as doctor's consultation, I'll bring her to these medical appointments. Also, I'll arrange for the medications and watch over her.

While FDWs shared some of the primary caregivers' duties by assisting in patients' daily activities, caregivers provided their own physical support to the patients by arranging hospital visits, bringing them to the hospital, communicating with physicians, and making medical decisions. The physical support that FDWs provided helped to alleviate the stress on the caregivers and allowed them to better cope with caregiver burden. Meina explained how hired support became her main coping strategy:

She was very good and she took care of my mom. She was with us for almost seven years; she loves my mom very much. When we got confidence in her, she became the primary caregiver. So I went back to work and my sister went back to teaching.

Everybody was happy because we trusted her to take care of my mom and we were very happy with that.

“Took care of” refers to the day-to-day physical care provided by FDWs for the patients. The ability to share the daily care of the patients provided possibilities to manage the fatigue and exhaustion of caregiving. Moreover, the receipt of hired support also allowed family caregivers to return to the work they had initially quit to become full-time caregivers.

Caregivers like Meina highlighted the importance of trust in this coping process. Trust led to better coping for the primary caregivers due to decreased everyday stress and increased emotional and mental relief. Similarly, Lim explained the significance of a good relationship with her FDW based on trust:

The maid was the one 100% there, so we relied on her a lot. She knows how to manage her time very well and she knows how to handle my mother and she got a good sense of humor. And my mom loves her very much. Surprisingly, even though they may not be able to communicate that much, but she can relate to her quite well. So of course, when you realize that you have this person you can trust, 80% of your burden is relieved.

Lim’s experience illustrated that the ability to acquire relief, both physical and emotional, was linked to the relationship between the FDW and the patient. Language as a barrier may come into play. The elderly patient may speak only Chinese dialects so communication may become problematic. However, when the helper and the patient were able to work through that barrier, it provided additional relief to the caregiver. Fang echoed similar sentiments:

She worked two and a half years for me and she did things perfectly. I mean not 100%, maybe 90%, so I really trusted her. During that two and a half years, no real burden. She even learnt Cantonese, so language wise also no problem.

Trust of FDWs and good relationships between FDWs and the person with dementia allowed for better coping with stressors for the family caregivers. Through the development of trust, caregivers could rely on FDWs as a reliable coping resource, relieving the physical burden. For instance, Pang and Jian mentioned being able to return to their hobbies, jobs, and other routines in their lives.

Pang: I have my helper to help me. We told her that the first priority is my mother. If there's a crisis, I'll be there to manage it. I'm not 100% taking care of her because I still play the ukulele you know? And I like to go running and walking in the gyms.

Jian: I have to care for myself, I have to live you know? I cannot go crazy, someone has to lift the burden off me. I decided to talk to my siblings and hire a maid. It was such a relief. Now I can take a break, go on vacation, spend time with my husband and children.

The ability to return to normal life and pursue their own needs and interests through hired support provided a way to cope with caregiver burden. Live-in hired support allowed family caregivers to fulfill family obligations of home care as well as balance caregiving responsibilities and their own lives. Some caregivers even discussed the presence of an emotional bond between them and the FDWs. Hui explained this further:

I feel that she is a very good companion to me, more like a companion than a maid. I don't treat her like a maid, I treat her more like a companion to make her happy because she's from another country and she's helping me a lot. So we give and take. We are more like friends now. Though we have a little bit of argument here and there, but the majority of the time, we get on very well together.

Hui explained that she did not receive any physical, financial, or emotional support from her children and the helper was her only source of support and companionship. FDWs as a coping resource provided a way to build emotional bonds and trust with the caregivers.

Caregivers hired FDWs as a strategic coping resource, particularly with the expectation of physical support. The physical support revolved around the constant care of the patient, which enabled caregivers to return to normal routines in their lives and reduced their stress and provided mental and emotional relief, which led to better coping with caregiver burden. Trust in the FDWs allowed caregivers to reduce stressors and better manage their own health and well-being. Notably, this support relationship depended on the mutual understanding and support between the caregivers and the support providers. This coping mechanism relied on building a sustainable relationship among the family caregivers, the FDWs, and the patients.

Mutual Support

The interview data revealed that caregiver burden did not disappear but was merely transferred from family caregivers to FDWs. Thus, coping resources were provided by the caregivers to the FDWs. To manage the relationship between the patients and the FDWs, caregivers often switched roles from care providers to moderators who guided FDWs to cope with the stress and responsibilities. Zhen described the importance of providing informational and emotional support to her helper:

I did tell her my dad's temperamental, sometimes angry and sometimes sad. Even then, the first time she saw my dad get angry, she got a shock. She said "ma'am, dad said I am stupid." My sister told me she ended up standing outside because my dad shouted. So when I came home, I sat down with her and I said you don't have to worry, don't take it too hard, don't be sad, because my dad also called me stupid. Then she broke out in laughter.

The support from caregivers to helpers was critical in sustaining relationships among the patients, the caregivers, and the hired support. The shifting of caregiver burden was a matter of expediency. Either the family caregiver or the FDW must deal with the physical and emotional stress coming from patients' cognitive and behavioral declines. Even with the

presence of mutual support, the FDWs might not be able to cope with the intense emotional hardship. Threat of physical violence and uncontrolled outbursts often led to emotional stress that was hard to adapt to. As Chen explained:

She couldn't take it. Very hard for her to take, because it happened that there was once, in the middle of the night, my mother wanted to go out. She just opened the door and went to the coffee shop. The coffee shop was open. My maid just followed her. Then inside the coffee shop, I don't know what happened, I don't know what my mother wanted also, she shouted and scolded my maid. My maid told me she felt so shy, so shameful you know in front of so many people, she was scolded by an old lady so loudly.

Part of the emotional struggle for the FDWs came from the uncertainty of coping with the patients' behavior. The person who cared for the patient, either the FDW or the family caregiver, had to tolerate the frequent physical outbursts of the patient. The threat of physical harm and emotional hardship added stressors to sustaining the mutual support relationship between the caregivers and FDWs. Shun explained the difficulties she faced:

What caused her to leave was because my mother beat her. And then my mother spit on her face. She couldn't stand it. It would be good if my mother doesn't behave like that. If she doesn't beat people, if she doesn't spit saliva on peoples' face, maybe the maid won't ask for transfer.

Caregivers were aware of their responsibility to provide support to the FDWs so that the latter could manage the shifted caregiver burden and maintain their own well-being. Meina observed similar challenges caused by her father's behavior, which affected her relationship with her FDW and in turn her decision making:

If he is going to behave the same way as with my past maid like shouting, using words of abuse, causing the maid to be emotionally disturbed that she says "ma'am, I

cannot take it anymore,” then I have to opt for nursing home for him. I did tell my sister. I was asking her how she feels about putting dad in a nursing home.

To continue the provision of home care to the patients, providing support to the FDWs is essential, particularly to manage outbursts of the patients. Putting a parent in a nursing home was seen as the last resort because family obligation dictates home care as a sign of love and respect. Accordingly, communicating mutual support was essential in the burden-shifting process. Min described the support she provided to her helper:

We told my maid the condition my father is facing – not to frighten her off but she is aware. I explained to her that I have a dad who has dementia and what that means in terms of taking care of him. I also told her don’t worry I will send you for different courses. She attended some training in the hospital because the maid needs to know to handle them because they’re a bit temperamental.

Caregivers sought to provide support to FDWs through empathy and advice. In addition, support was provided through registering them in training programs and seeking community support. Ang described how her helper acquired emotional relief after receiving community support:

I sent my maid there [ADA training programs]. After that, she came back and told us happily, “Por por [granny in Chinese] is not that bad, other maids’ por por worse.” I was like “so you feel lucky right, por por is not that bad?” After the course, she understood more or less that actually por por cannot control herself. Ya she cannot control her temper and there’s no reason why she just behaves like that, just no reason. The reason is that it’s dementia and that’s all.

Caregivers noted FDWs’ need for knowledge to care for the patients and to come to terms with the changes in behavior. While our participants counted on hired support to care for the patients, they sought community support to provide resources for the FDWs. The caregivers

can tap into training grants meant for persons with dementia who are Singaporeans or Permanent Residents. The Singapore government allocates SGD\$200 (~USD\$140) to people with dementia every financial year which the caregivers can use to pay for FDWs to attend training programs organized by institutes such as the ADA. Qian described the benefits of receiving community support from the ADA:

I feel that letting maids attend such things [ADA training programs] is a good thing, because at least, even if you didn't really learn anything you can see things, it gives you some sort of mental preparation regarding the situation, so she won't think it's funny that the patient does all sorts of things.

The ability to hire live-in FDWs allowed the primary caregivers to maintain their own health mentally, physically, and emotionally. While FDWs were hired to provide physical assistance to the caregivers, they also inherited the emotional stress and the need for support. Thus, to sustain this coping mechanism, caregivers also need to provide support back to the FDWs. Participants used resources such as those from the ADA to provide informational support to FDWs so that the latter could cope with the shared caregiver burden. Participants also provided emotional support to the FDWs through talking about the patients' health conditions and possible threats from the patients' cognitive and behavioral disorders. The mutual support relationship illustrated the bond of sharing caregiving responsibilities and ways to cope with emotional and psychological stressors. Providing mutual support allowed caregivers to deepen their relationship with FDWs.

Discussion

Caregivers of family members with dementia face financial strain, emotional and physical burnout, and disruption of their normal routines as a result of the long-term demands of caregiving. In particular, in the context of Singapore, there is a cultural emphasis on providing home care by family caregivers to fulfill family obligation. The filial expectations

of family caregiving, coupled with a lack of current infrastructure, prevent caregivers from tapping into home and community care services. Although plans are under way to increase the availability of institutional care facilities by as much as 50% in the next 10 years (Tew et al., 2011), government policy and cultural norms currently expect family members to take care of the person with dementia at home (Huang et al., 2012). Situated in this context, caregivers turn to FDWs to manage their obligation, all the while ensuring the provision of home care. Caregivers consider seeking hired support as a useful coping strategy in reducing physical strain, relieving stress, and carving out personal time for leisure, social activities, and work. The shift in caregiving responsibilities, however, also requires caregivers to provide support to FDWs in the form of educational training, empathy, and advice so that the shared caregiver burden can be managed. The relationship between caregivers and FDWs thus is interdependent. Findings from this study suggest that the sustaining of this coping strategy is rooted in trust, bonding, companionship, and mutual support. When family caregivers must respond to the situation of providing continual and increasing care to people with dementia, their use of hired support reflects their understanding of the sociocultural environment, the available institutional and familial resources, and their personal needs. Caregivers have to constantly adjust their assessments and manage their decision making in response to new challenges emerging from the dynamic interactions between them, the FDWs, and the patients. Findings from this study demonstrate a culturally situated approach to coping with dementia caregiver burden in a context where strong filial expectations and weak institutional support interact.

Coping Strategies

A key finding of our study unveils how one coping resource, i.e., FDWs, could encompass multiple strategic traits. Appraisal of the caregiving situation as stressful prompted caregivers to tap on FDWs as a way to manage the stressful situation. The decision

to hire FDWs, therefore, became the main coping strategy for caregivers of persons with dementia in Singapore. Hiring FDWs can be considered as a problem-focused coping strategy because it allows caregivers to manage the physical aspects of caregiving – such as assistance with feeding, bathing, toileting, and walking – and to reduce daily caregiving stressors. This hired support strategy, however, also resembles emotion-based coping in that it provides a buffer for caregivers to manage their emotions, mental anguish, anxiety, and the feeling of being overwhelmed. In some cases, FDWs are the only source of companionship such that caregivers form an emotional bond with them and exchange emotional support reciprocally. Furthermore, caregivers' reliance on hired support provides some benefits of diversion coping that allow them to return to normal routines, have more time for themselves and for other family members, and reconnect with friends, career, and hobbies. While most past studies take a quantitative approach to classify coping strategies into discrete categories (Kneebone & Martin, 2003; Okabayashi et al., 2008), our findings suggest that in complex and prolonged stressful situations like dementia caregiving, the use of only one coping strategy might not be sufficient for caregivers to continuously respond to and manage the situation. Our findings resonate with past studies in that they suggest coping is a dynamic process, and caregivers rely on simultaneous coping strategies depending on their needs and available resources (Kneebone & Martin, 2003; Okabayashi et al., 2008). Thus, this study illustrates that problem, emotion, and diversion focused coping are used simultaneously as strategies to lessen and resolve caregiving burdens.

While the presence of FDWs presents a unique circumstance to explore and understand support mechanisms in caregiving situations, it should not detract from the discussion of establishing systems of care and support for both the person with dementia and the family caregiver. Caregivers discussed being able to fulfil obligations, provide home care, balance caregiving and their own needs. However, what is missing in this discussion is

the provision of and access to emotional and psychological support, particularly from family. While emotional coping allowed caregivers to attain emotional and mental relief, it however does not address the emotional and psychological stress derived from prolonged caregiving, the patients' cognitive and behavioral declines, financial strain, and the feeling of losing loved ones. The cultural context may deter caregivers from relying on or seeking formal support systems that would remove the patient from their care; nevertheless, a concerted effort should be made in encouraging caregivers to supplement home care with existing hospice and nursing care, especially counseling services or support groups such as the ones run by the ADA. Innovative ways of reaching out to and encouraging caregivers to use external social services are necessary. Especially for those who are not able to afford hired support, structured programs that specialize in caring for people with dementia will help both the caregiver and the person with dementia.

Limitations and Conclusion

Three limitations need to be acknowledged when interpreting the results of this study. First, sampling through the ADA implies that all participants in our study had the experience of seeking community support to some extent. While this sampling technique allowed us to systematically reach more potential participants, it remains unclear whether differences exist between those we interviewed and those who never sought community support. Future research should address this issue by including caregivers who do not seek external support for themselves or for the FDWs. Second, in this article we report findings from caregivers who worked with FDWs. In the overarching project, we interviewed all caregivers qualified for our sampling criteria and noticed that a small number of them did not seek hired support for various reasons. In this study we only presented narratives of hired support seekers with an aim to advance knowledge of the dynamics of caregivers, FDWs, and the shifting of caregiver burden. Researchers in the future may consider comparing differences between

hired-support seekers and non-seekers in their appraisal process and coping strategies, with a particular focus on those who are unable to afford live-in support. Third, as the overarching focus of our research project is on primary caregivers of dementia patients, we only interviewed the family caregivers. Future research may consider conducting paired interviews with FDWs and caregivers or with FDWs only to further understand the process and impacts of coping with shifted caregiver burden from the domestic helpers' perspective.

In conclusion, the findings reveal coping strategies situated in a local structural and cultural context that emphasizes family obligation and the provision of elderly care at home. While caregivers cannot change the stressful situation, namely, the deterioration of the patients' behavioral, communicative, and cognitive capacity, hired support nevertheless offers an alternative resource that allows caregivers to cope with the stressful situation, to reduce burden, to take control of their financial situation, to relieve worry, to temporarily block out stressors, to avoid loss of employment, and to buy time for themselves. Thus, the insights provide an understanding of the dynamic and pragmatic coping strategies of long-term caregivers of people with dementia. Specifically, the findings provide an understanding of the impact of hiring FDWs on different coping strategies employed by family caregivers during the caregiving process. Caregivers apply multiple strategies to manage the stressful situation where each strategy can provide for specific physical and emotional needs, and diversion from being a caregiver. Thus, this study illustrates that coping strategies are employed in different ways depending on the needs of caregivers, access to infrastructures, cultural expectations, and available resources.

References

- Alpert, J. M., & Womble, F. E. (2015). Coping as a caregiver for an elderly family member. *Health Communication, 30*, 714-721.
- Alzheimer's Disease International. (2015). *World Alzheimer Report*. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
- Ansah, J. P., Matchar, D. B., Love, S. R., Malhotra, R., Do, Y. K., Chan, A., & Eberlein, R. (2013). Simulating the impact of long-term care policy on family eldercare hours. *Health Services Research, 48*, 773-791.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology 3*, 77-101.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*, 217-228.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267-283.
- Centers for Disease Control and Prevention (2015). *Spotlight on: Caregiving for people with Alzheimer's disease or other dementia*. Retrieved from <http://www.cdc.gov/aging/caregiving/alzheimer.htm>
- Chan, S. C. (2011). Family caregiving in dementia: The Asian perspective of a global problem. *Dementia and Geriatric Cognitive Disorders, 30*, 469-478.
- Chen, C., Naidoo, N., Er, B., Cheong, A., Fong, N. P., Tay, C. Y., ... & Lee, K. K. (2013). Factors associated with nursing home placement of all patients admitted for inpatient rehabilitation in Singapore community hospitals from 1996 to 2005: A disease stratified analysis. *PloS one, 8*(12), e82697.

- Chen, H. M., Huang, M. F., Yeh, Y. C., Huang, W. H., & Chen, C. S. (2015). Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics, 15*, 20-25.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929-936.
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners, 20*, 423-428.
- Huang, S., Yeoh, B. S., & Toyota, M. (2012). Caring for the elderly: The embodied labour of migrant care workers in Singapore. *Global Networks, 12*, 195-215.
- Institute of Mental Health. (2015). *Study establishes prevalence of dementia among older adults in Singapore*. Retrieved from https://www.imh.com.sg/uploadedFiles/Newsroom/News_Releases/23Mar15_WiSE%20Study%20Results.pdf
- Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., Chodosh, J., Tan, Z., & Wenger, N. S., (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of American Geriatric Society, 63*, 282-289.
- Kneebone, I. I., & Martin, P. R. (2003). Coping and caregivers of people with dementia. *British Journal of Health Psychology, 8*, 1-17.
- Kristofferzon, M., Lindqvist, R., & Nilsson, A. (2011). Relationships between coping, coping resources and quality of life in patients with chronic illness: A pilot study. *Scandinavian Journal of Caring Sciences, 25*, 476-483.
- Lai, D. W. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on*

Aging, 32, 200-223.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.

Lim, J., Goh, J., Chionh, H. L., & Yap, P. (2012). Why do patients and their families not use services for dementia? Perspectives from a developed Asian country. *International Psychogeriatrics*, 24, 1571-1580.

Okabayashi, H., Sugisawa, H., Takanashi, K., Nakatani, Y., Sugihara, Y., & Hougham, G. W. (2008). A longitudinal study of coping and burnout among Japanese family caregivers of frail elders. *Aging and Mental Health*, 12, 434-443.

Østbye, T., Malhotra, R., Malhotra, C., Arambepola, C., & Chan, A. (2013). Does support from foreign domestic workers decrease the negative impact of informal caregiving? Results from Singapore survey on informal caregiving. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 68, 1-13.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia*, 9, 63-75.

Raccichini, A., Castellani, S., Civerchia, P., Fioravanti, P., & Scarpino, O. (2009). The caregiver's burden of Alzheimer patients: Differences between live-in and non-live-in. *American Journal of Alzheimer's Disease and Other Dementias*, 24, 377-383.

Roche, L., Croot, K., MacCann, C., Cramer, B., & Diehl-Schmid, J. (2015). The role of coping strategies in psychological outcomes for frontotemporal dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, 28, 218-228.

Seow, D., & Yap, P. (2011). Family caregivers and caregiving in dementia. *The Singapore Family Physician*, 37, 24-29.

Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family

- caregivers of persons with dementia. *Dementia*, 13, 803-818.
- Sun, F., Kosberg, J. I., Kaufman, A. V., & Leeper, J. D. (2010). Coping strategies and caregiving outcomes among rural dementia caregivers, *Journal of Gerontological Social Work*, 53, 547-567.
- Tay, K. C. P., Seow, C. C. D., Xiao, C., Lee, H. M. J., Chiu, H. F., & Chan, S. W. C. (2014). Structured interviews examining the burden, coping, self-efficacy and quality of life among family caregivers of persons with dementia in Singapore. *Health Services Research*, 48, 773-791.
- Taylor, S. E., & Stanton, A. L. (2007). Coping resources, coping processes, and mental health. *Annual Review of Clinical Psychology*, 3, 377-401.
- Tew, C. W., Tan, L. F., Luo, N., Ng, W. Y., & Yap, P. (2011). Why family caregivers choose to institutionalize a loved one with dementia: A Singapore perspective. *Dementia and Geriatric Cognitive Disorders*, 30, 509-516.
- Thompson, J. P., Riley, C. M., Eberlein, R. L., & Matchar, D. B. (2012). Future living arrangements of Singaporeans with age-related dementia. *International Psychogeriatrics*, 24, 1592-1599.
- Vaingankar, J. A., Subramaniam, M., Picco, L., Eng, G. K., Shafie, S., Sambasivam, R., & Chong, S. A. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. *International Psychogeriatrics*, 25, 1605-1619.
- Verbeek, H., Meyer, G., Leino-Kilpi, H., Zabalegui, A., Hallberg, I. R., Saks, K., ... & Hamers, J. P. (2012). A European study investigating patterns of transition from home care towards institutional dementia care: The protocol of a RightTimePlaceCare study. *BMC Public Health*, 12, 68.
- Wilson, K., & Bachman, S. S. (2015). House calls: The impact of home-based care for older adults with Alzheimer's and dementia. *Social Work in Health Care*, 54, 547-558.

Wong, G. H., Pang, W. S., & Yap, P. (2014). A paradigm shift in regulating and running nursing homes in Singapore. *Journal of the American Medical Directors Association, 15*, 440-444.

World Health Organization (2012). *Dementia: A public health priority*. Retrieved from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

Yeoh, B.S., & Huang, S. (2009). Foreign domestic workers and home-based care for elders in Singapore, *Journal of Aging & Social Policy, 22*, 69-88.