



ISSN: 0975-833X

RESEARCH ARTICLE

CARING FOR RELATIVES WITH DEMENTIA IN CHINESE FAMILY SETTING:  
THE DAUGHTER-IN-LAW

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ARTICLE INFO

Article History:

Received 10<sup>th</sup> December, 2013  
Received in revised form  
24<sup>th</sup> January, 2014  
Accepted 19<sup>th</sup> February, 2014  
Published online 25<sup>th</sup> March, 2014

Key words:

Daughter-in-law,  
Family caregiver,  
Dementia,  
Content analysis,  
Chinese.

ABSTRACT

**Introduction:** The traditional role of filial care for frail elderly in Chinese family, the responsibility of caring has typically fallen on women, especially on the daughters-in-law (DILs). To date, little is known about the impact of these DIL caregivers in Chinese society. This study aimed to explore the experiences of DILs on their caregiving involvement for parents-in-law (PILs) with dementia.

**Methods:** A qualitative design of phenomenological methodology was used employing focus group discussion and participant observation with thirteen DILs. Participants were recruited from the psychiatric outpatient department of a hospital in Eastern Taiwan. Content analysis was used to identify themes.

**Results:** Four main themes emerged: (1) care burden with filial obligation; (2) suffering alone; (3) feel powerless; and (4) adaptation.

**Discussion:** The social expectations of DILs as primary family caregiver and lack of effective skill for caring PILs with dementia may lead DILs to feelings of vulnerability with associated physical problems and emotional strain. Family based interventions and educational programmes are recommended as a potential means to alleviate caregiver burden of the DILs.

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INTRODUCTION

Dementia is a serious public health problem which affects a large proportion of aging population worldwide (World Health Organization, 2012). In the Asia pacific region the number of people with dementia is anticipated to escalate from 13.7 million in 2005 to 64.6 million in 2050 (Lim *et al.*, 2011). In Taiwan, over 10,000 new cases are newly identified each year, and the number of older people with dementia is expected to double by 2026 (Taiwan Alzheimer's Disease Association, 2012). Of those, 70-80% of patients with dementia were cared for by their families (Ministry of the Interior, 2010). Global ageing is expected to lead to a dramatic increase in the number of informal, community-dwelling caregivers for older people with dementia (Black *et al.*, 2010; Ferrara *et al.*, 2008; Lei *et al.*, 2011). In Asian societies, adult children are expected to have the obligation care for their sick parents at home because of the value placed on filial piety (Chow, 2004). Filial piety has generally been defined as an expectation on the young to respect the old (Stiens *et al.*, 2006). Cho (1999) found that

when adult children in Taiwan decided to send their frail elderly parents into institutions, they were perceived as being impious. Therefore, institutionalized care are often considered as a last resort when the family caregiver is extremely exhausted or unable to care for their sick parents (Chen *et al.*, 2006).

Daughters-in-law (DILs) comprise the largest group of care providers for older relatives at home in Taiwan (Huang, 2004; Tang *et al.*, 2006). They are viewed as the most appropriate primary family members to provide emotional support for parents-in-law (PILs). The task in this role ranges from doing shopping, providing transportation and to deliver personal care, including bathing and dressing for their parents (Brody, 1990). Moreover, studies indicate that caring for in-laws is viewed as a filial obligation and social expectations, therefore, DILs play a pivotal role as the primary family caregivers of their sick PILs at home (Kim, 2001; Wallhagen and Yamamoto-Mitani, 2006). Kang *et al.* (1999) concluded that Korean families did not share caregiving responsibilities for their own parents and tended to leave all caregiving responsibilities to DILs. Similarly, a study found that of those providing care for older male parents, 17.5% was by the DILs, 14% was by the sons, and 12% was by daughters in Taiwan

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(Chen, 2010). In addition, the same study reported that forty-seven percent of care was given by DILs, 17.5% was by daughters to female parents. Obviously, DILs have considerable primary family care functions to undertake and they appear to bear greatest level of burden in caring for PILs with dementia in Chinese society (Chiu *et al.*, 2004; Choo *et al.*, 2003).

Given that nearly 70%–90% of older people with dementia exhibit some degree of behavioural and psychological symptoms during the course of the disease (Chang *et al.*, 2008), it creates even greater stress and burden on the primary family caregivers to care for a family member with dementia (Black, 2010; Gallicchio *et al.*, 2002). In relation to the provision of care to older relatives with behavioural problems and functional impairment, it was found that DILs provided care for the longest period of time and have demonstrated more negative feelings of distress than other caregivers (Hong and Kim 2008). Literature indicated that family disagreement of caregiving-related situations (such as giving help, doing a share, spending time, showing appreciation, showing respect, visiting or telephoning, having patience, and giving unwanted advice) may increase the burden on caregivers (Casado and Sacco, 2012). Meanwhile, older people with dementia and their family members rarely appreciate the extent of the role of the caregiver as they assume this work as the caregivers' obligation (Kim and Lee, 1999; Lee and Sung, 1997). These perceptions can lead to unhappiness and feeling unfair in primary family caregivers (Wu, 2006). Studies have previously reported that DILs perceived even greater emotional and physical burden in comparison to other caregivers if family support is lacking (Hong and Kim, 2008; Evci *et al.*, 2012). To date, little is known about the experience and roles of the DILs who provide care for their PILs with dementia in the sociocultural context in Chinese society. The aim of this study was to explore the experience of DILs on their caregiving involvement for PILs with dementia, perceptions of role stress and coping strategies. Increased understanding of the experience of the DIL caregivers may help health professionals understand the situations, and be in a better position to develop feasible and suitable intervention program to support DILs caring for PILs with dementia.

## METHODS

### Design

The methodology for this study was hermeneutic phenomenology with a qualitative design. According to Van Manen (2001), the facts of lived experience are always already meaningfully experienced and conveyed through language; that are descriptive and interpretive process. Focus group discussions (FGD) with process recording and participant observations were conducted for data collection. The FGD began with "tea party" atmosphere and set a friendly and open discussion.

### Participants

A total of 13 DILs who cared for their PILs with dementia at home were recruited from the psychiatric outpatient

department in a local hospital in Eastern Taiwan. The DILs were self-identified as filial caregivers to provide direct and most responsible for the day-to-day caregiving to their PILs with dementia at home. They aged from 35 to 60 years, with an average age of 47.8 years. The mean time they had been engaged as primary caregiver for their PILs was 6.1 years, ranging from 10 months to 30 years. The average of caregiving time was more than 70 hours per week, ranging from 32 hours to 98 hours/wk. Eight participants actively cared for their mothers-in-law (MILs) and five participants cared for their fathers-in-law (FILs).

### Data collection

This study was approved by the ethics committee of a regional hospital in Eastern Taiwan and informed consents were obtained from all participants. Data collection was conducted by FGD and was guided using a semi-structured question about caregiver experience. Three focus group sessions were held in a meeting room in the hospital and each lasted from 2.5 to 3 hours until no new data was forthcoming. FGD were initiated by a researcher who has qualitative interview training. In the process, the participant was invited to describe (1) the caregiver's role of DIL with filial obligation (2) challenge of caring process and (3) coping strategies. The discussion was started with a broad question: "would you describe how you perceive your role as a primary caregiver in the family?" The discussion then moved to issues of individual caring experience and focused on the how they deal with the disturbance behaviours of PIL and associated challenges. Questions included: "what do you encounter in your caregiving involvement and how do you response?" The last part of the discussion explored the caregiver's process of adaptation, "please share with us what specific experience or effectively mastering strategies that affect you as a confident caregiver?" During the focus group, DIL caregiver could also feel free to share any concerns related to the caregiving issues. Audiotapes from FGD were verbatim in Chinese/Taiwanese, and recordings were fully transcribed.

### Data analysis

Content analysis was used to systematically identify and count themes (Joffe and Yardley, 2004). All key points were listed and then clustered into groups to form initial categories. These categories were used to recode the transcripts which were clustered into groups based on similarity and overlap. To ensure rigor, during open coding two qualitative research experts, was asked to code these transcripts to compare data bits with data labels, and mutually agreed to assign them a category. Similar incidents were labeled and grouped together in to the main themes. Coding and analysis were interactive processes until no new themes were identified. Rigor (reliability of this study) was based on trustworthiness of data, as proposed by Lincoln and Guba (1985), to maintain objectively. We further sought for participants verification by sending the themes identified to a representative of three DILs for comments. The effective percentage agreement was 95%. This study generated a context in culture-specific on DILs as primary caregivers and their caregiving situation for PILs with dementia.

## Findings

Through an inductive content analysis, four key themes emerged from group discussion. These were named and defined as: (1) care burden with filial obligation; (2) suffering alone; (3) feel powerless and (4) adaptation.

### Care burden with filial obligation

Due to cultural acceptance of memory loss as normal aging and traditional respect for elderly, from the social expectation of family-centered caregiving in Chinese culture, the DIL caregiver is seen as the non blood-tied victim of filial obligation. She has primary responsibility to care for the older relative and to meet their needs at all times. There is no alternative to this arrangement.

*"My MIL relies on the eldest son very much therefore I have heavy load for caring MIL than others. We divided properties equally but why is always the eldest son taking most of the responsibility of caregiving and the responsibility extended to me. (caregiver 7)"*

*"My sister-in-law said to me 'you've been taking care of my mother all the time, you must know how to care her very well...,it is not an easy work to take care for dementia elder and you are the best person for caring my parents'. (caregiver 1)"*

*"I have no idea how long will this situation continue. It has been thirteen months since my MIL got dementia. I have been losing weight. As a role of daughter and DIL, I feel double stress under filial obligation. (caregiver 3)"*

*"I quitted job to care for PILs. Because my husband said "Our parents used to treat us well, and we must do the same to them. We should do". (caregiver 4)"*

### Suffering alone

PILs with dementia who displayed behavioural and psychological symptoms sometimes could embarrass families and provided a real challenge for DILs. Moreover, DILs highlighted that they lacked the cues or skills to deal with such behavioural disturbance. They mentioned that they had to learn these skills from scratch by themselves. Additionally, DILs found that they had little time for dealing with their own emotions and frustrations, which were often related to stressful events associated with caregiving.

*"My MIL doesn't trust me. She lent me something but told others I stole it. I'm already fully occupied with work; it's driving me crazy! (caregiver 5)"*

*"MIL has problems synchronizing what she said, she thought and acted. I asked her if she wants to eat something and she said yes. Sometimes she spewed on me or threw the bowl to me. It's great challenge for me to take care of her. (caregiver 9)"*

*"Everyone says my MIL is a dementia patient, but I wonder if that's completely true. She definitely knows what she's doing. She hits me much heavier than she hits her son, and she scratched my hands where I had injuries (She shows her injuries to other participants....). (caregiver 13)"*

*"One day, when I was showering MIL, suddenly she grabbed my hair and kicked me. I didn't think too much I just hit back. Do you know what she said? She said 'you are my DIL, you*

*can't hit back!' (What could you do? Would you defense for attack? Shake her head.....). (caregiver 9)"*

*"My FIL was always a gentleman, but everything changed nowadays. Sometimes he wanted to touch me or exposure his private sexual organ even I knew he was sick but it still made me feel uncomfortable and embarrassment. (caregiver 10)"*

*"The most obvious symptoms were wearing clothes inside out; wanted to head out without wearing pants properly, ate eggs with shell and ate fruit with skin. A doctor told me 'you'd gone mad before your FIL, because I have no clue how to take care of him'. (caregiver 2)"*

*"My FIL always moved aimlessly here and there that make me nervous. My eyes couldn't take away from him. My job is 24 hours. I am totally tied by my FIL. (caregiver 6)"*

*"I can hardly sleep at night because I have to take care of MIL who sleeps next to my room. I can smell even she urinates.....I feel exhausted. (caregiver 7)"*

### Feel powerless

All participants indicated that they felt a high level of emotional strain associated with their caregiving role. They found it difficult to accept the negative feelings placed upon them through the expectation of other family members. When participants tried to seek family agreement to share the workload of caring with other family members they often encountered negative response even abandoned by other family members.

*"I recommended my husband to send my MIL to daycare during daytime, and take care of her at night by rotation. Then we had a family meeting, I didn't expect to be attacked by three of my sisters-in-law. They said, 'you are so cold-hearted, sending mother to mental institution. She will not be treated nicely. I tried to explain to them: 'it is daycare for elders, not mental institution. I visited there couple times. If you disagree, then we will need to take care of her by turns.' Nobody ever thanked me for what I've done for past twenty years. (caregiver 9)"*

*"I don't know whom I can talk to. I hope my family member could share the load; it is too much burden for me" (caregiver 6)"*

### Adaptation

Some of DILs indicated that changing their state of mind helped them to face the challenge and to find more balance in their situation. This could possibly relate DIL caregivers who can adapt and are more confident in their ability to find solutions to handle stressful situation effectively associated with caring for their PILs.

*"I'm confident to say that I'm good with taking care of MIL. My advice is not to see it from a negative point of view. No matter how bad the situation may come, or how peculiar PIL' behaviors may appear, we have to treat them like our own parents and believe that we have the capability to keep on loving them. (caregiver 11)"*

*"Demented elderly repeat question often. Of course sometimes you are out of patience. I figured out a way to solve this. I write down her frequent questions and answers to those questions. No matter she asks, there will only be standard answer and*

which satisfied her. Don't to serious to treat elders with dementia, you just please and play with them. (caregiver 13)"

"Looking after dementia PIL isn't easy. I think only us who have been through this can tell what it's like. I'm willing to share my experiences, hope this helps. (caregiver 8)"

"Care for elder with dementia should avoid any irritation. Talk slowly and try it couple more times, they would understand. (caregiver 12)"

"In my opinion, sometimes you have to follow what demented elders ordered you to do. If he misunderstood, then you have to try it another way. Make sure he's not offended. (caregiver 4)"

## DISCUSSION

In summary, our study findings from DILs provide greater insight into the experience and roles of DILs being the primary caregivers for PILs with dementia. This study highlights the following issues: DILs are often overwhelmed by the burden of their caregiver role under filial obligation of culture norm (Hong and Kim, 2008; Kim, 2001; Stiens *et al.*, 2006) special for the eldest DILs because of traditionally responsibility (Kim, 2001; Wallhagen and Yamamoto-Mitani, 2006). Previously published literature has reported that DILs maintained their role as caregiver based on social expectation and filial sacrifice rather than affection (Kim and Lee, 1999; Lee and Sung, 1997). However, DILs do not only work for their own benefits, they are willing to gain assurances from others, but many of them feel let down and disappointed. Often DIL caregivers feel they have little control the situation by themselves. Their emotional well-being may be quite complicated and contradictive while taking care of older people with dementia and there is no appropriate way of releasing pent up negative emotions, this may potentially lead to feelings of antipathy towards their PILs. In addition, older people and their family members rarely show any form of appreciation for what their DILs has done for them because they assumed that this work is part of their caregivers' obligation (Hong and Kim, 2008; Kim, 2001). These obligations have lead to feelings of depression and upset in DIL caregivers and cause them to have a negative relationship with other family members (Chiou *et al.*, 2002; Hong and Kim, 2008; Wu, 2006). When DIL caregivers start to think if other family members should share the responsibilities, as non blood-tied caregiver, it will change the relationships among all family members, if members' opinions differ from each other; it will bring a conflict to the family structure and make DIL caregivers depressed (Chou *et al.*, 1999; Casado and Sacco, 2012). These feelings appeared exacerbated in our study, DIL caregivers have previously be seen to feel isolation and abandonment by other family members that failed to provide any meaningful recognition of their efforts (Lane *et al.*, 2003). PILs with dementia who displayed behavioural and psychological symptoms may cause embarrassment to themselves or those around them; this factor appears to be the source of a great challenge for the DILs who were primary caregivers. In general, the high level of stress experiences by caregivers can result in a number of negative outcomes, including feelings of depression and overburden (Chiu *et al.*, 2004; Kim, 2001; Zarit and Zarit, 2007). Consistently, research indicated that DIL caregivers experience caregiver burden at higher rate of sons or daughters (Ingersoll-Dayton *et al.*, 1996; Evcil *et al.*, 2012), this was fully supported in our study.

Moreover, research reported that blood-tied caregivers have higher filial love and feeling of greater filial obligation to care for impaired parents than in-law caregivers (Stiens *et al.*, 2006). From this perspective, it is more challenge for DILs to care for PILs with behavioural problems, and they may feel powerless and helpless (Davidhizar, 1992; Kang *et al.*, 1999).

In this study, the participants were mostly willing to share with others from the positive attitude of caregiving role. This finding supports earlier research in reporting that despite high caregiver burden, self-efficacy as positive gains required the actual challenges and difficult problem solving experiences (Tedeschi and Calhoun, 2004). It is important to point out that through this challenging process, some of the DIL caregivers became stronger and found a sense of confidence. Meanwhile, some DILs were positive about their role and expressed a sense of personal worth and fulfillment from successful mastering in behavioural disturbance and coping strategies, these findings are consistent with previous research findings (Cheng *et al.*, 2012). Meanwhile, Westphal *et al.* (2011) reported that quality of life in elderly dementia is influenced by the care culture and associated with care burden and caregiver's own knowledge, attitude, values and perspectives. Therefore, the individual caring experience and coping strategies employed by DIL's affected their perceived care burden and quality of care for dementia clients. It is suggested that interventions be developed to target coping strategies and provide group support to reduce care burden on DILs and enhance care recipient quality of life (Casado and Sacco, 2012; McConaghy and Caltabiano, 2005; Lim *et al.*, 2011).

## Limitations

This study used a qualitative design could reflect various perspectives of DIL caregivers, and, thus, may reflect subjective biases. Firstly, there were some variations among the participants which may affect their experiences and feeling for caring for PILs with dementia, such as length of caregiving, education and health condition of DILs, relationship quality with their PILs. Secondly, a small sample from eastern Taiwan may limit the generalizability. Caution must be taken when interpreting the study finding. Future studies may use a larger sample of participants to enrich the qualitative data.

## Conclusion

The study findings indicated that DILs as primary caregivers of their PILs with dementia perceived high levels of caregiver burden, low family agreement and low family support network in their Chinese family. This may be because sons rely solely on their wives to provide direct care for their older parents with dementia. Filial obligation and culture norms appear a heavy burden for DILs to carry. One of the noticeable points is that DILs have several roles and are expected to take on these roles in the Chinese families. If they have no enough supports from family network, especially their husband, it is more likely they will suffer alone and feel burden associated with this role. Additionally, DILs expressed frustration and hopelessness arising from a lack of access to appropriate services, information on how best to deal with PILs' behavioural

problems may also influence the caregiving burden felt by DILs. This may include respite time or alternative forms of care, skills to manage behavioural problems and the availability of health professionals for consultation. In order to alleviate DILs' burdens, family agreement involved with caregiving support is also needed. Our findings may have potential implications for health professionals to develop appropriate interventions and support groups to help DIL caregivers to face the complicated and conflicting process and maintain normal family functions to relieve DILs' care burden and promote quality of life in older people with dementia as well.

### Acknowledgement

This research was supported by grants from Mennonite Christian Hospital. The authors would like to thank the participants of the DIL caregivers in the community for their help in collecting the data for this study.

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