

*Asian Family Conference 2017*

# **In the Face of Vulnerabilities: Informal Caregivers of Dependent Elders from Lower-Income Households in Singapore**

**Leng Leng Thang, National University of Singapore**

**Suen Johan, University of Cambridge**

*With concluding discussion by Wang Jing, Tsao Foundation*

The research was funded by the NUS-Tsao Aging Initiative

# Outline

- Introduction: background context, brief literature review, objectives of the study
- Method and profile of respondents
- Source of income and non-monetary resources
- Caregiving challenges
- Conclusion

# Introduction

- Increasing attention on issues faced by caregivers of older persons requiring long term care in Singapore
- There is still gap in understanding the experiences of members of lower-income households in their efforts to manage the strain imposed on their financial, material, and emotional resources.

# Objectives

- To establish a qualitative account of the **mosaic of support** and **contextual challenges** faced by primary caregivers of dependent elderly who reside in low income households in Singapore
- Seek to shed light on the decision-making processes, socio-economic circumstances, and the socio-familial dynamics that shape the coping strategies employed by caregivers of dependent elderly.

# Existing literature on caregiving for dependent elderly in lower-income households

- National Survey of Informal Caregivers in Singapore (Chan, Ostbye, Malhotra, & Hu, 2013)
  - Financial inadequacy among caregivers from impoverished households causes higher stress
  - Dual role caregiver (conflicting demands of work and caregiving)
  - Lack of option in employing foreign domestic live-in help
- Lower-income caregiving tends to be contributions in kind → Hard to quantify (Fokkema, ter Bekke, & Dykstra, 2008: iv)
- Broad familial network but multiple dependents / needy members within the network of relatives (Brody, 1995)

*==>Overall, caregiving strategies and arrangements with low-income households tend to be complex, diverse and involving multiple actors (Dilworth-Anderson, 1993; Brody, 1995)*

# Method

- Semi-structured interviews with 19 informal caregivers of dependent elders from low-income households.
- Criteria (parallel with indicators on poverty):
  - Residing in 1 to 2 room public housing apartments
  - Have low or no formal education
  - Earning an average monthly household income that does not exceed \$1500

# Caregivers profile

- 14 Female and 5 Male
- 7 Chinese, 8 Malays, 4 Indians
- 9 married, 4 single, 5 widowed, 1 divorced
- Age ranging from 40s to mid-80s (12 are aged 65 and above)
- Care-recipients: 11 spouses, 6 parents, 2 elderly siblings.
- Educational background: 3 completed secondary school, 16 elementary school or less, 9 no formal education.

# Typical routine as caregivers

- Common daily tasks
  - Going to the market
  - Cooking
  - Household chores such as washing and cleaning
  - Ensure dependent elderly takes medication
  - Interactions with DE tends to be emotionally demanding
    - Constant need to watch over DE with dementia
    - Antagonistic relationships between CG and DE
- Challenges faced
  - CGs themselves lacked physical strength to assist with ADLs (due to own health problems)

# Sources of Income and Non-Monetary Resources

## *Strategies for resourcing day-to-day lives*

- ***CPF (Central Provident Fund), Personal Savings, Rent, and Inheritance***
  - CPF payouts (both DE and CG), insufficient to cover living expenses
  - Savings (DE, older CG), work income
  - Those living in 3-room apartments leased out a room  
→ exploitation by errant tenants
  - Not all CG get access to inheritance received by DE due to strained relationships.

“ When my dad passed away... I make sure that I didn't take a single cent. Even though some of my money was left with my dad... she (my mum) felt no confidence. So I said ok, I brought her to the bank to change the account name to hers. Even when the government gave the package once every year... she was so alert... she asked if the government has given money. I told her just bank into my account and I will give it to you...or we can have joint account...she didn't want... the officer at the bank even asked if we wanted to open a joint account. She scolded the officer.. then within 8 months, she swiped clean...the whole thing gone... that time she gambled when she was able to walk... she went to Singapore pools.”

-Caregiver 10, 63 years, Female, Chinese  
(mother-95 years old with mild dementia)  
(caregiver an only child (adopted))

# Sources of Income and Non-Monetary Resources

- ***Assistance from government and non-governmental welfare organizations agencies***
    - Crisis event results in contact with medical social worker to assist with medical-related expenditure.
    - Snowballing effect: Referral to both govt. welfare agencies and Voluntary welfare organizations.
    - Handouts from religious organizations (churches- e.g. S\$350 per month, mosques)
- == alleviated medical-related expenditure.

# Sources of Income and Non-Monetary Resources

- ***Support from family members***
  - Irregular and relatively small sums.
  - Mostly food and small amount of groceries
  - Emotional support
  - Provided physical assistance for ADLs but occasional.
  - Source of temporary respite
  - Proximity and ‘convenience’ of family member important factor
- ***Other informal sources of support***
  - Neighbours for emergencies and urgent situations.
  - Colleagues potential source of short-term loans.

# Sources of Income and Non-Monetary Resources

- Formal/Informal work income

"Now that my sister is slightly better and I can let her be on her own at home, I can go do more work. I help iron clothes for this family for 2-3 hours a week. I also do simple sewing and altering of clothes. They are referred to me from my friends. My friends asked me if I want to do the work, and then if I say yes, they will put us in contact. "

Caregiver 4, 73 years, Female,  
Malay (single, caring for 68 year-  
old sister with stroke)

# Caregiving challenges: Constant daily care issues

- ***Need for constant care and attention***
  - DE with dementia
  - Fall risks
  - Multiple partially-dependent household members
- ***Transportation issues***
  - Problems with attending medical check-ups and follow-up appointments (especially for themselves)
- ***Dementia and legal transgression***
  - Cases of nuisance calling, illegal bird feeding, complaints from neighbors and housing authorities
  - Financial and administrative problems with obtaining medical certification for the appeals process

"She can call you 120 times a day. Already 3 times I went to the police because they sent me a letter saying that she makes nuisance calls... I quarrelled with the police. They are very rude. I said yes, my mother is wrong, why don't you arrest her? She doesn't know what is going on. I got a police report here... he asked me to cut my [home] phone, but what if there is an emergency?"

Caregiver 2, 58 years, Male, Malay  
(DE 78 year old mother, dementia)

"My father likes to throw things outside, like rice. That's why when we eat, we must watch him... he throws the rice outside to feed the pigeons. Then we received warning by Town Council and AVA\*. I received 3 letters, fines for S\$200, S\$300, and S\$500 because they said my father is feeding bird. I paid S\$200 to get the clinic to post the [medical] report to AVA so they reduced the fine to S\$200 but they gave me warning that if it happens again, it will be heavy penalty already. That's why until now, every minute every second, when he takes his meal, either my mother or me will sit and watch him."

Caregiver 3, 51 years, Male, Chinese, single  
(DE 85 year old father, dementia)

\*Agri-food and Veterinary Authority

# Caregiving challenges: Family tensions

- ***Fractured and antagonistic relationships among family members***
  - Severed/estranged; frequent; and ‘fractured’ → Siblings and children who made irregular contact but were still approached in times of great need.
  - Competing interests and demands of in-laws.
  - Demands of care for dependent elderly weakens relationships between caregiver and their siblings/children and reduces amount of contact due to guilt arising from the failure of filial responsibilities
  - Such dynamics exerted pressure on lines of support
  - CG obligations for lower-income families have more negative impact on familial relations.

# In-laws issues

"My son has no job.. he is 49 years old and has very low self esteem. His wife supports him but doesn't want to support his "issues", which includes us [his parents]."

Caregiver 11, 77 years, Female,  
Chinese (DE- husband 88 years old)

"The problem with my brother's wife still continues... when my brother promised to give us money for my father, she said, 'Why do we need to do that? When we took care of him, did she give us money to support?' It doesn't matter, this is not the first time she has chased him [the dependent elderly father] out."

Caregiver 6, 40 years, Female,  
Malay (Caring for father 87 (bedridden) and husband 58 (ill))

# Caregiving challenges: Family tensions

- ***Care for partially-dependent household members***
  - 6 caregivers had at least one other partially-dependent family member residing with them.
- ***Conflict between parental and caregiving roles***
  - Dual task of looking after both their younger or unemployed children as well as their elderly parents.
  - Scarce resources → Choice to support elderly parents cause conflict with their own children and spouses → Causes (or threatens to) the rupture cycle of filial piety → Resulting in isolation and high stress/anxiety

"They [caregiver's wife and children] come to visit me and my mom only one year once. I tell them if they are not sincere, then forget it. Let me die enough...my children never think. Next time their children see them acting like this, they also won't take care of them. Then how? Who will take care of them when they're old? I have to take care of my mother...

I stay at my mother's house. They stay at my own house. I wanted to bring her to my own house but they not happy. I told them.. hey I still have my mom. They don't think about the old. Only think about themselves... That's why next time, I know what to do. I don't want to live like this... I'm going to skydiving [commit suicide] already."

Caregiver 2, Male, 58 years old, Malay (DE 78 year old mother, dementia)

**"Recently, my son had another son and he wanted me to take care of him [because he and his wife has to work] but I told him his stepfather [her dependent elderly spouse] is sick. I don't have the time...I have to bring my husband in and out of the hospital... where do I have the time. Then something wrong between us... maybe he felt hurt when I said I didn't want to look after my grandson. It hurts me now when I cook and they don't eat."**

**Caregiver 1, Female, 65 years old, Malay (DE-husband 70 years old)**

# Caregiving challenges: Tensions between caregivers and dependent elderly care-recipients, and post-caregiving

- ***Conflicts with dependent elderly***

- Conflict stemming from breakdowns in communication, antecedent animosity, and incompatible personalities.

"He is very hot tempered... will scream at you... that day... Wednesday or Tuesday, he screamed inside the bus. He shouted at me because he was in a bad mood. Because I said to him, when you go up the bus, don't stop. If you stop that means jam because a lot of people behind you. So I hold him to walk fast a bit. Then he jumped and said why you pushing me like that?"

Caregiver 8, 60 years, Female, Chinese  
(DE 72 year old husband, Parkinson's disease)

# Caregiving challenges: Tensions between caregivers and dependent elderly care-recipients, and post-caregiving

## *Post-caregiving anxiety*

- After death or relocation of DE
- Anxiety over deterioration of health (both CG and DE)
- Fear of losing home (need to sell in order to pay for LTC)
- Some homes of CG under name of DE

# Caregiving challenges: Seeking formal help and perceptions

- ***Reluctance for seeking assistance from social welfare organizations/agencies***
  - Believed there were more “deserving” recipients / Reluctance to accept being in the direst of circumstances
  - Means-testing issues: further strains with children, Patronizing, invasive, insincere, made them feel like they were “begging”
  - Those who did paid work faced Catch-22 situation (ineligible for full assistance because of work, but can’t stop work because need to maintain livelihood; work is insufficient to cover all expenditures)

"There was once, some officers from the CDC\* came down...she said she can't give us any monthly form of help but they will consider the utility bill subsidy. She even said, if my situation is too difficult, **why not I just sell my house. As if I had no feelings...I told her once I sell, where would I stay? At the mosque or under the bridge? I was very frustrated... She told me to sell my house back to HDB and I will get around S\$600 or S\$700 each month for spending. But what happens after 30 years? My sister is younger than me, what happens to her if I'm gone and 30 years have passed? Ever since that officer spoke to me, it has made me bitter, and so I didn't want to ask for anymore help. They did ask me to try and ask Jamiyah... but hearing the way the CDC officer spoke to me, I don't want to."**

Caregiver 4, 71 years, Female, Malay

"It was not always easy to get payslips from my children [for means-testing]...We have to give reasons like we lost contact with some of our children... then they will decide whether to accept or not... They don't seem to understand... or act like they don't understand. We applied for financial support and waited... but no response...no reply.

This officer from the CDC...told me that I have to be the one to go and work, and that I should ask my brothers to take care of my father. But the problem is that my brothers have already pushed the responsibility to me. If I could have done that, I wouldn't be coming to you for help!"

Caregiver 6, 40 years, Female, Malay  
(caring for father and husband)

# Caregiving challenges: Seeking formal help and perceptions

- ***Preference for non-government over government welfare agencies***
  - Voluntary welfare organizations (VWOs) more compassionate and accommodating process of means-testing
  - Conveniently located medical services, shorter waiting times, and better services by doctors

"They [Tsao Foundation] called me one day and wanted to interview me. I said I don't need, I don't want... They wanted to see my husband because he is sick, so they wanted to help me... I had nobody to talk to until this Tsao Foundation came... and I felt a bit easier because I could let my feelings out. I feel peaceful and sleep peacefully. They told me to go see their doctor and they give me medicine, which has subsidy so I don't have to go to the usual GP."

Caregiver 1, 65 years, Female,  
Malay, DE 70 years old husband

# Discussion: Two Main Types of Caregiving Strategies among Lower-Income Caregivers

- Caregiving strategies are a combination of informal and formal sources of support
- Negotiation of caregiving strategies depend upon various decision-making processes and socio-familial conditions.
- Continuum with 2 types of strategies on opposite ends:  
*Integrated support and diffused responsibilities (ID)*  
*Isolated support and focused responsibilities (IF)*

- ***Integrated support and diffused responsibilities (ID)***
  - Tend to be informal with more support in kind/emotional support
  - More permanent relationships of social support (certain family members, religious groups, informal support relations)
  - Relatively more equitable sharing of CG burden, receive support beyond caregiving
- ***Isolated support and focused responsibilities (IF)***
  - Tend to be more formal but little or no long-term sources of support (case-oriented)
  - CG burden is borne almost totally by primary CG with little options for support
  - The caregiving burden further isolated them from socio-familial relationships as they tend to be overloaded

- Paradoxically, as the narratives of IF caregivers revealed an **identity** based on **strength, independence, dignity, pride, and a notion of being 'undeserving' of assistance**, the decision to seek help becomes extremely difficult as it would involve subjecting themselves to the processes of means-testing, which due to demeaning and derogatory experiences, tend to elicit meanings and emotional responses that are antithetical to those very character traits that allow them to **endure** the great emotional demands of caregiving.

# CONCLUSION

## Light at the end of the tunnel?

### 1) Call for strengthening of throughcare and home-directed resource networks

- Caregivers overwhelm with information and little guidance on different services => Need for throughcare support
- Availability of consistent and stable forms of support provided in the form of a 'middle-person' or care 'agent' with knowledge about history and situation of CG and DE → reduce fragmentation, breakdown of communication, and service frustrations

### 2) Enhancing preparedness for post-caregiving and expansion of aftercare support for caregivers

- **Facilitate independence** and mitigate effects of role disruption → caregiving respite, caregivers support group, financial management, re-entry into workforce
- **Counselling** to deal with uncertainty about future, emotional loss or any feelings of guilt over institutionalization
- **Needs of caregivers to be assessed independently** and in **addition** to that of their care-recipients' (instead of delivering assistance/services to CG only in the name of/through the CR).