

CARING FOR CAREGIVERS- A SINGAPORE PERSPECTIVE

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Disclosure

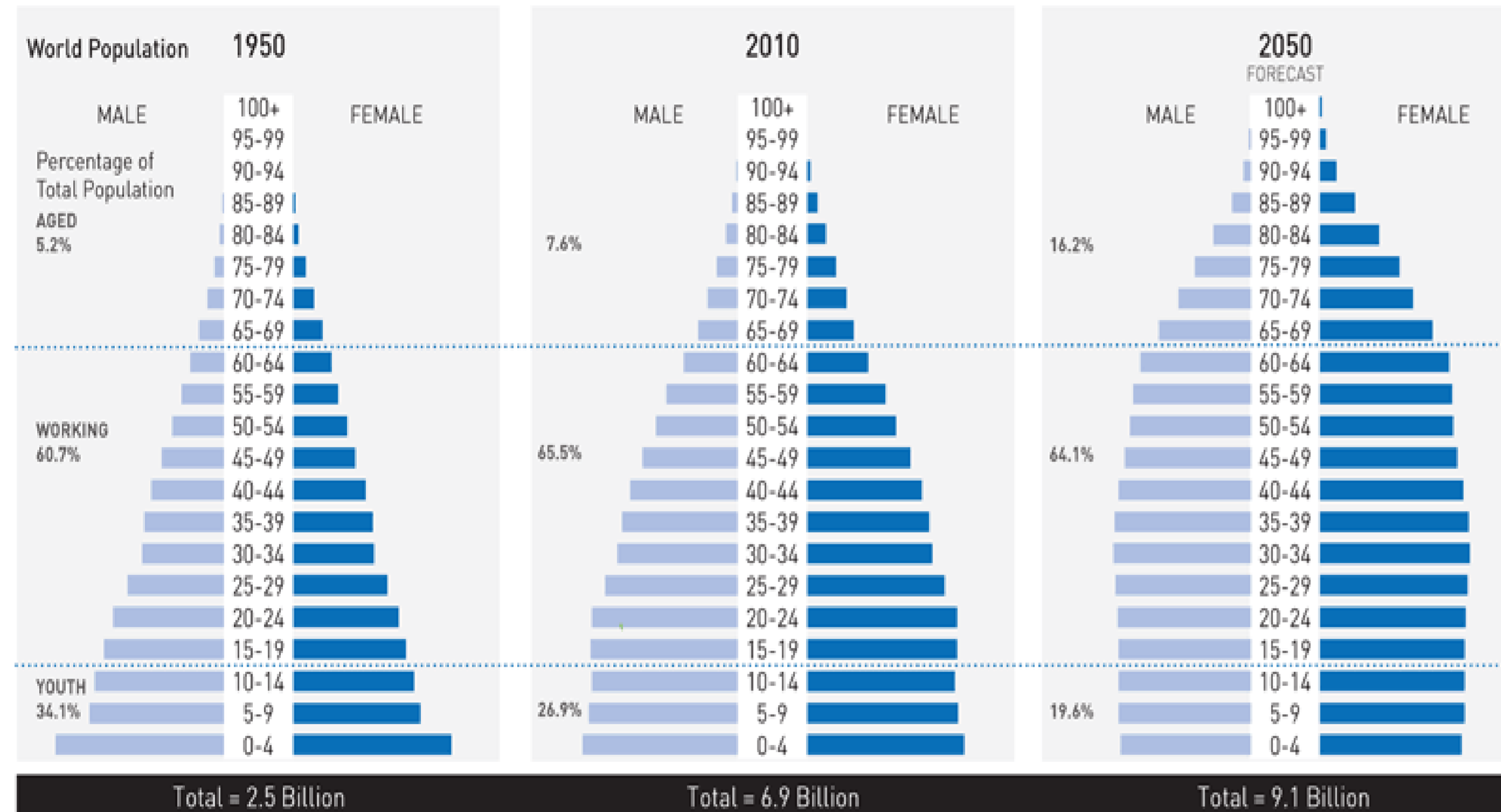
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Population Ageing



- Population ageing is a global phenomenon
- Presents enormous social, economic and political challenges for societies.

The Caregivers: Increasing Need

As people age, even if they have resources, they still need care

- 01 Sudden medical emergencies like – stroke or fall
- 02 Loss of eyesight or unstable gait may necessitate assistance
- 03 Advanced neurodegenerative conditions
- 04 Frailty
- 05 End of life care

Role of Informal caregivers of older adults

- Worldwide, **349 million people** are estimated to be care-dependent, of whom
 - 18 million (5%) are children aged under the age of 15 years
 - 101 million (29%) are older people 60 years of age and over.
- **Informal caregivers** play a crucial role in maintaining the health, well being, and quality of life of older people living in the community
- Augment and support care of older adults at home by
 - helping with transportation, shopping, chores, banking
 - enriching the social and emotional experiences of older people
 - providing an additional layer of monitoring so that necessary interventions can be implemented
 - making sure that appropriate care is in place
- Provide end of life care and emotional support to the older adult

Impact on informal caregivers



Caring for **more than one** older adult at home



About a third had to **give up or cut down on work** to take care of their relative with dementia



Approximately two-thirds of caregivers are **women** and 34% are **65 years or older**



Forty-one percent of caregivers have an **annual household income of \$50,000 or less**



Increased vulnerability of caregivers

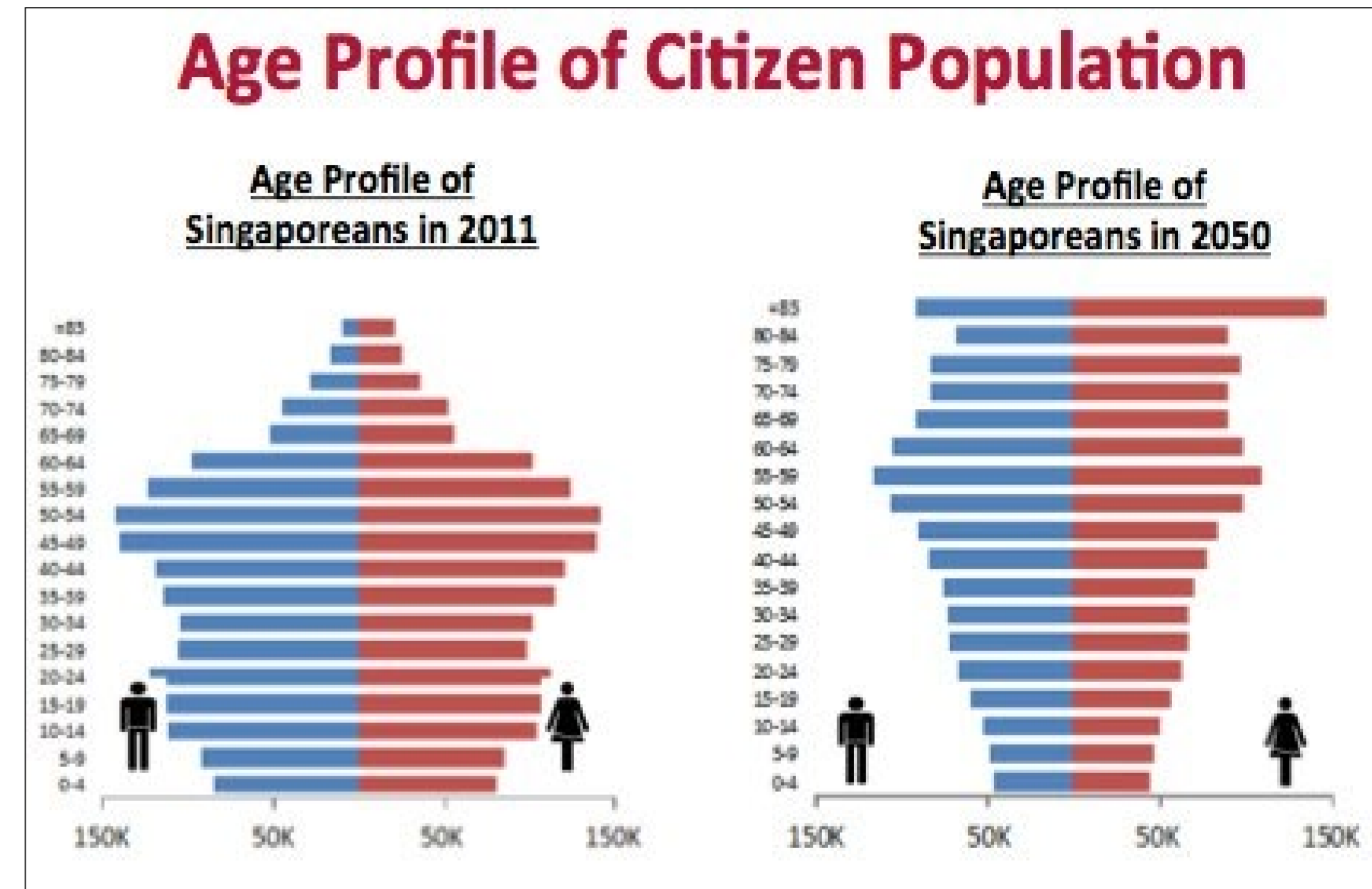


In 2014, friends and family of people with Alzheimer's and other dementias provided an estimated **17.9 billion hours of unpaid care**

SINGAPORE

Singapore's Demographics

- 01 Singapore's population is aging rapidly.
- 02 In 2020, the average life expectancy at birth in Singapore was 83.9 years.
- 03 By 2030, one in four people will be aged over 65 years, and this will rise to almost one in two by 2050.
- 04 When combined with Singapore's decreasing fertility rates and falling population growth, it will have an impact on multiple domains.
- 05 Old age dependency ratio in 2020 was at **21.6 residents aged 65 years and older per hundred residents aged 15 to 64 years.**



Informal caregivers of older adults in Singapore

Survey of **1190** Dyads in 2010-2011

Care recipients **>75 years of age**

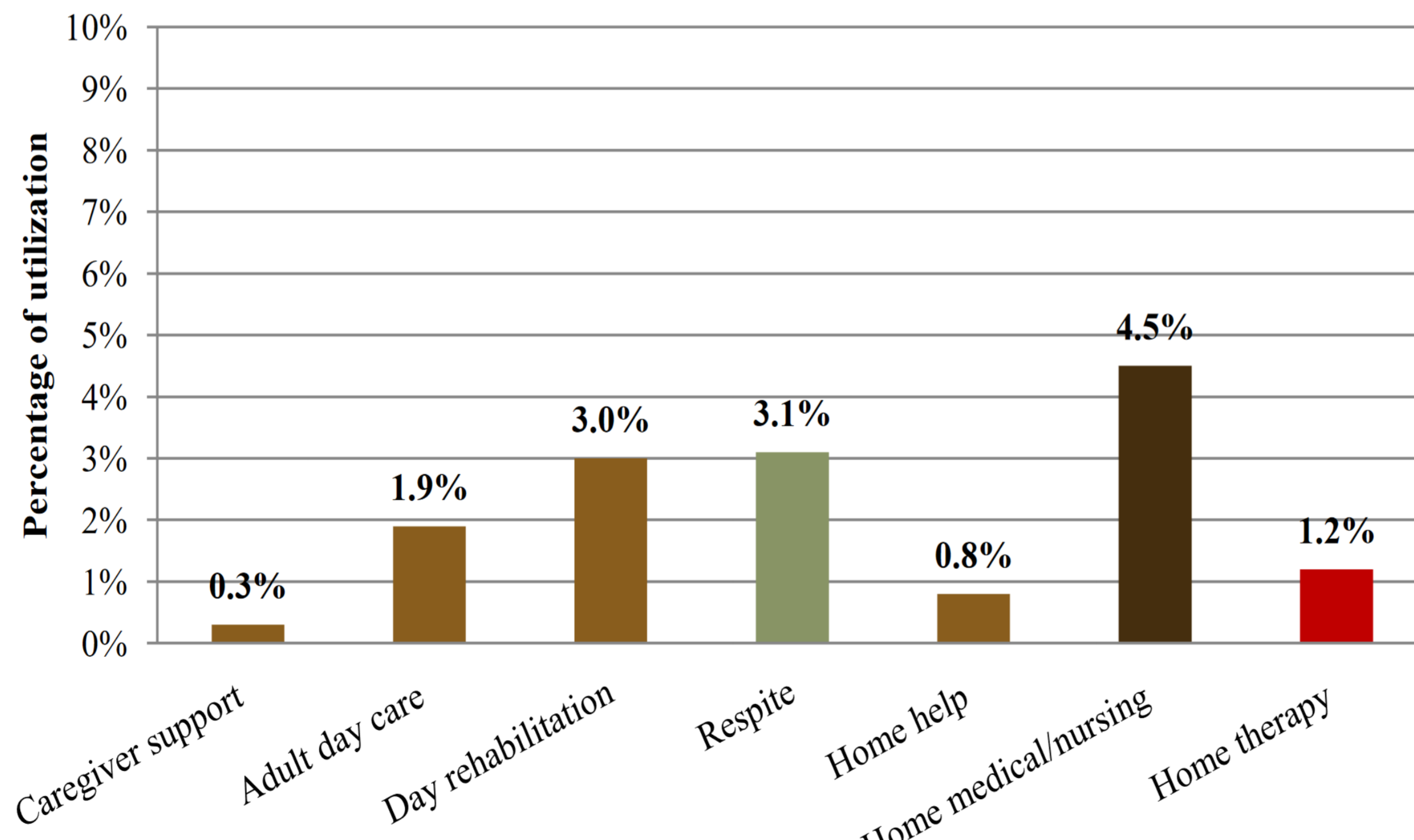
Receiving assistance in at least one area of caregiving

Caregiver Profile

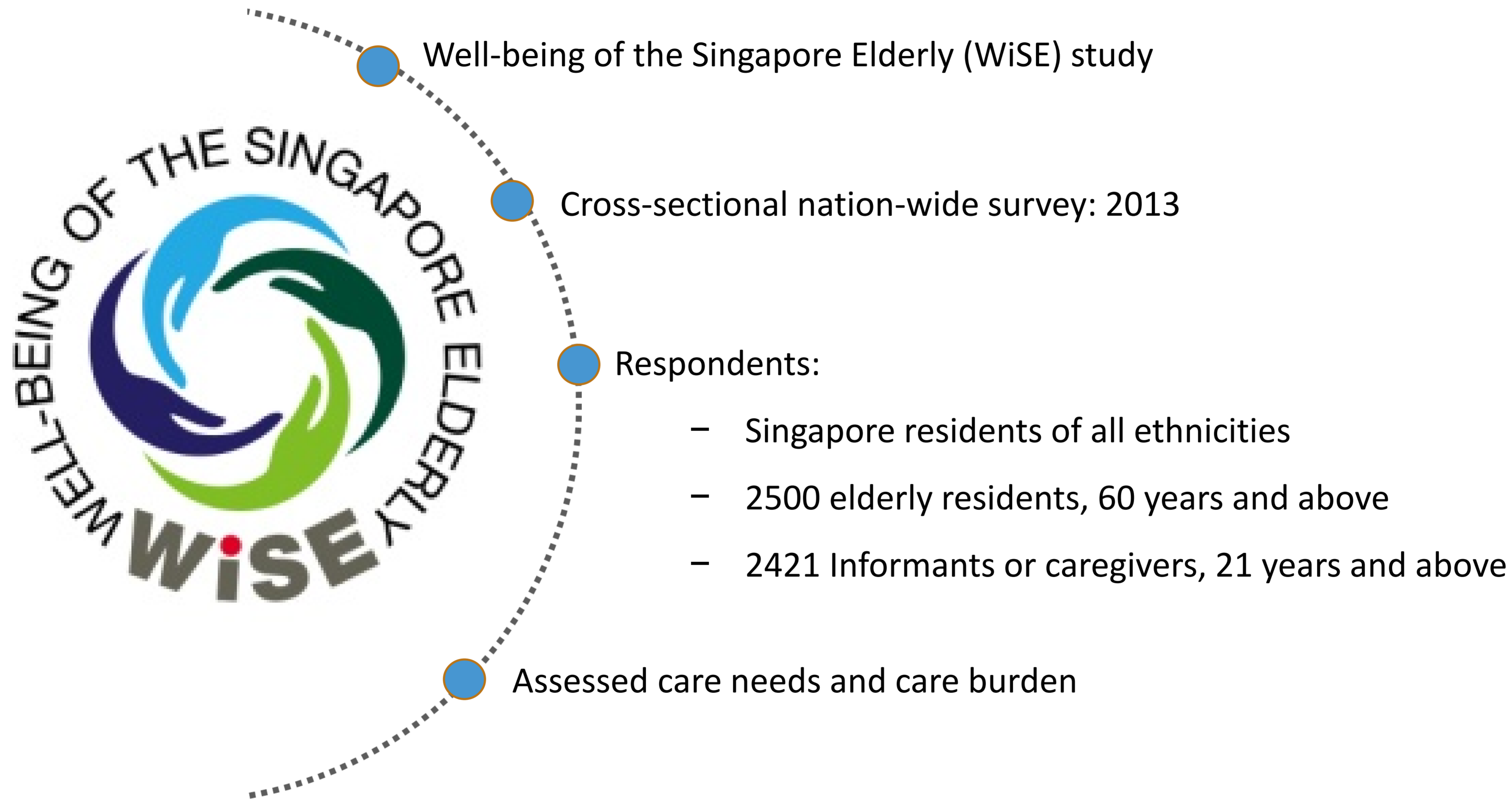
(N= 1,190)	
Caregivers' Gender (%)	
Male	39.8
Female	60.2
Total	100
Caregivers' Age (%)	
19 to 44 years old	14.2
45 to 59 years old	55.0
60 to 74 years old	20.4
75 years old & above	10.4
Total	100
Caregivers' Marital Status (%)	
Married	64.9
Widowed	3.8
Separated/Divorced	5.4
Never Married	26.0
Total	100

Informal caregivers of older adults in Singapore

	Spouse (N= 190)	Children (N= 921)	Others (N= 79)	Total (N= 1,190)
Hiring of Foreign Domestic Worker to Care for Care Recipient*				
Yes	33.7	51.9	53.2	49.1
No	3.7	4.2	3.8	4.1
No FDW Hired	62.6	43.9	43.0	46.8



Informal caregivers of older adults in Singapore



Caregivers of older adults with care needs



68% women



66% age above 50

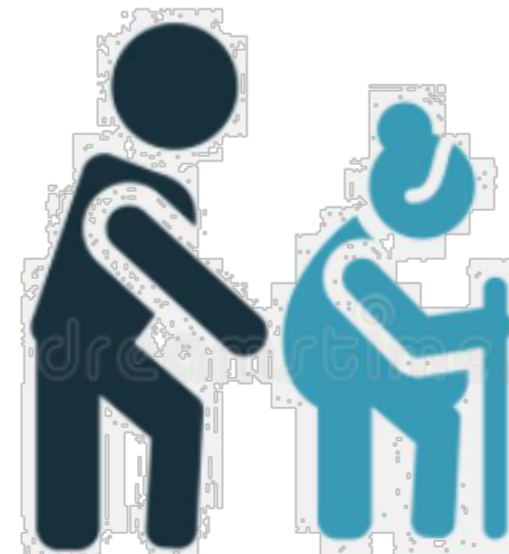


72% below secondary education

Among older adults in their care :



55% had at least one BPSD



40% needed assistance in 3 or more ADLs/IADLs



20% received assistance in care from family/friends



45% had a paid helper

Impact on caregivers



20%

gave up or cut-back on work



46%

had BPSD-related distress



8.8%

had psychological morbidity



24.5%

experienced care burden

Why the Focus on Dementia Caregivers?



Caregivers' burden of those providing care to PWD is high



Care burden among caregivers of older adults with any care need (n=693)

Zarit Burden Interview
Total score >23 = Burden

Older adult characteristics

↑ Age: 60-74y (OR 2.5)

↑ High care needs (OR 2.5)

↑ Any BPSD (OR 3.5)

↑ Dementia (OR 2.5)

Logistic regression analysis



**1 in 4
have Care
Burden**

Older caregivers have higher care burden



Zarit Burden Interview, 22-item scale, higher total score indicates higher perceived burden

The association between caregiver burden, distress, and healthcare utilization among persons with dementia in Singapore

The data of 399 caregiver-PWD dyads were extracted from the WiSe study.

PWD completed the Client Service Receipt Inventory, which provided information on their healthcare utilization (i.e. emergency service use, hospital admission, length of stay in hospital, and number of outpatient visits) within a frame of 3 months.

After adjusting for significant correlates such as dementia severity and multimorbidity,

- ✓ **caregiver distress from responsive behaviours was positively associated with emergency room utilization**
- ✓ **caregiver burden was positively associated with length of hospital stay**

Societal cost of Dementia

The annual cost of dementia per person in 2013 in Singapore was estimated at **S\$10,245 (US\$7,881, using 2013 exchange rate of 1US\$ = 1.3S\$)**

The total cost of dementia for the population of Singapore was **S\$532 million (US\$409 million)** per year

The main costs driver was from the social care component, which contributed **76%** of the societal costs. The costs of unpaid care represented 60% of social care costs.

The Societal Cost of Dementia in Singapore: Results from the WiSE Study

Edimansyah Abidin^{a,1,*}, Mythily Subramaniam^{a,1}, Evanthia Achilla^b, Siow Ann Chong^a, Janhavi Ajit Vaingankar^a, Louisa Picco^a, Rajeswari Sambasivam^a, Shirlene Pang^a, Boon Yiang Chua^a, Li Ling Ng^c, Hong Choon Chua^d, Derrick Heng^e, Martin Prince^f and Paul McCrone^b

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Abstract.

Background: There is currently limited evidence on the economic burden that dementia exerts on multi-ethnic Asian populations.

Objective: The present study aimed to estimate the economic cost of dementia in Singapore.

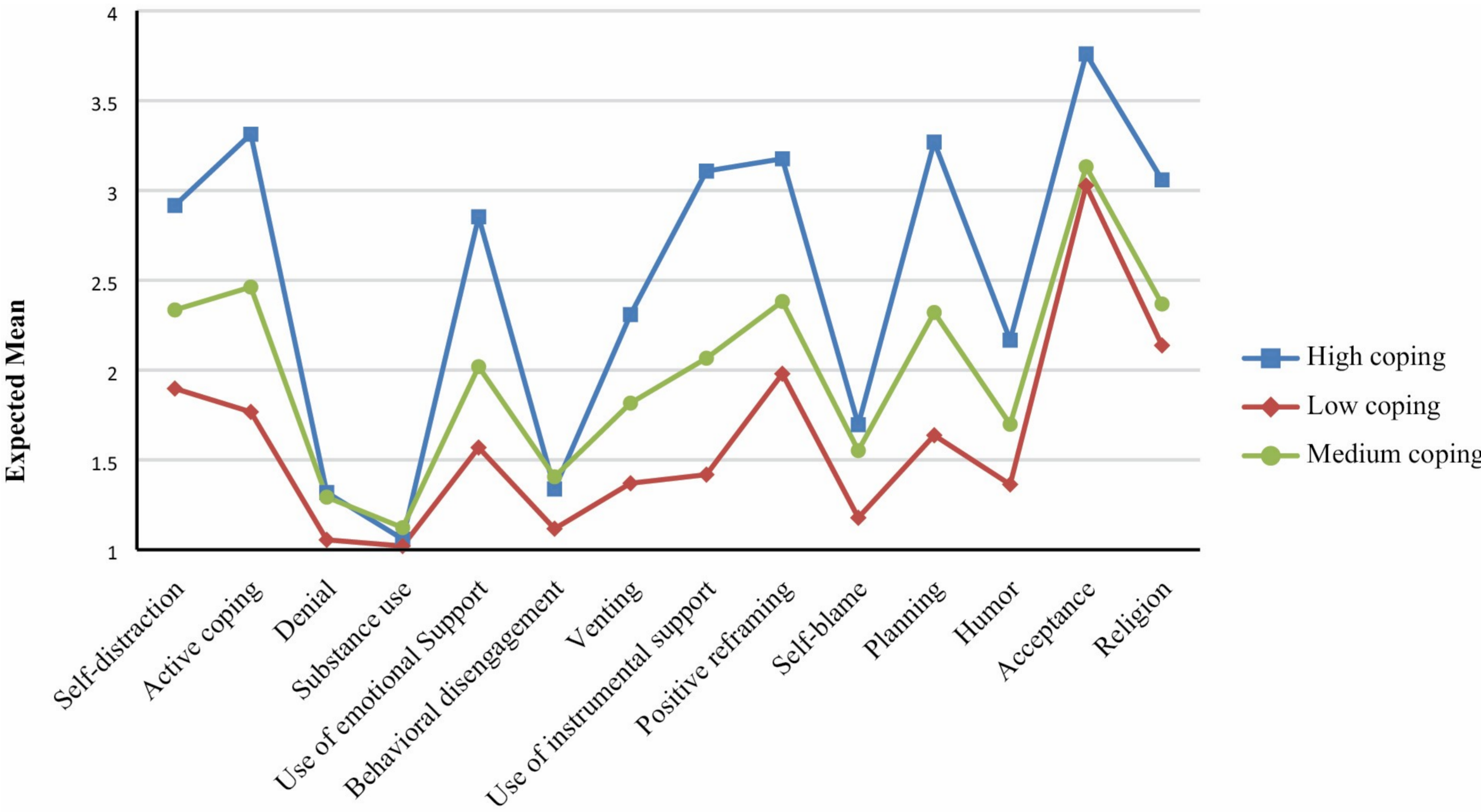
Methods: We used data from the Well-being of the Singapore Elderly study, a nationally representative survey of the older Singapore Resident population aged 60 years and above. Generalized linear modeling was used to estimate factors associated

How do Caregivers Cope?



How do Caregivers Cope?

- Two hundred eighty-one primary informal caregivers of persons with dementia (PWD) were assessed.
- Coping strategies assessed by the Brief Coping Orientation to Problem Experienced inventory.
- A latent class analysis was performed to explore caregivers' coping patterns



Qi et al., 2021

How do Caregivers Cope?

Caregivers had three mutually exclusive coping patterns :

High, Medium and Low Coping

- Caregivers in the **Low** Coping Group
 - relied mainly on acceptance coping strategies and very minimally on any other coping strategies.
 - Highest probability of not using coping strategies of behavioral disengagement and denial.
- Compared to **High** Coping Group, caregivers in the **Low** Coping Group had the following features
 - More male & with an education level of degree or above
 - Caring for PWD with more memory and behavior problems
 - Less caregiving burden
 - Lowest CES-D score among the three groups but not significantly lower than high coping group

Does caregiving have any positive aspects?

Are there any gains or satisfaction resulting from the caregiving experience?

- Studies have reported that despite the stress, almost 80% of caregivers experienced positive caregiving (e.g., personal growth, sharing activities, strengthened relationship with PWD, increase in self-esteem, and spirituality)
- The PAC is a 9-item validated instrument designed to measure the perceived positive aspects of caregiving. Informal caregivers were asked to indicate their agreement with 9 statements about possible positive experiences associated with the caregiving.

Each item began with the sentence "Providing help to [care recipient] has...", followed with specific items such as

- ❖ "made me feel useful"
- ❖ "enabled me to develop a more positive attitude toward life"

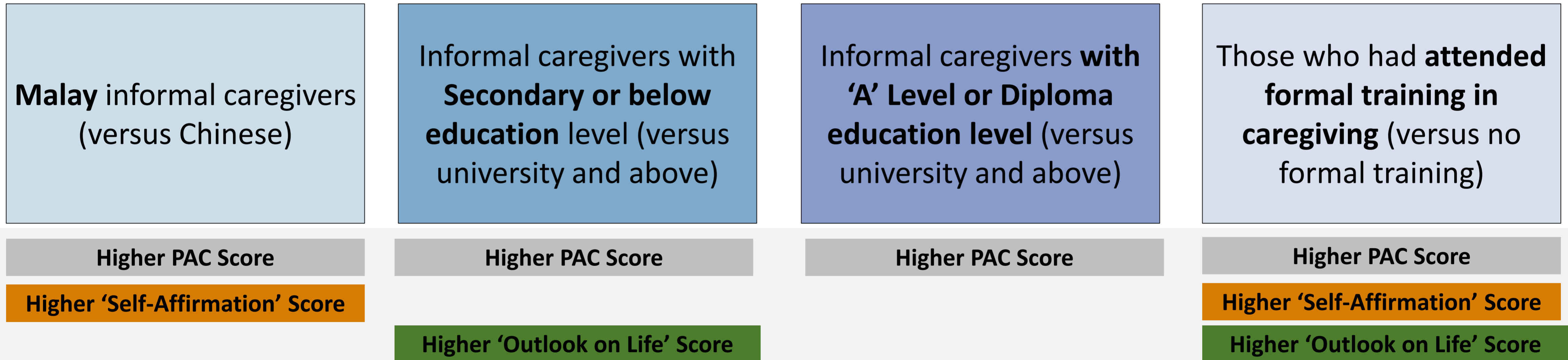
Does caregiving have any positive aspects?

Factor Structure of PAC

The first factor consisting of 6 items was labelled as 'Self-Affirmation'

The second factor consisting 3 items was labelled as 'Outlook on Life'.

The results showed that



Caregiver's self-efficacy in caregiving

Revised Scale for Caregiving Self-Efficacy

Caregivers are asked to rate their confidence at overcoming difficulties, ranging from 0 to 100, or not applicable. The RSCSE has a 3-factor model, namely self-efficacy in obtaining respite (SE-OR), responding to disruptive behaviors (SE-RDB) and controlling upsetting thoughts (SE-CUT)

Self-efficacy in obtaining respite

Social support
Outlook on Life

Responding to disruptive behaviors

Dementia knowledge
Outlook on Life
Average weekly caregiving hours

Caregivers who had a helper had significantly higher scores on SE-RDB, whereas caregivers who were living with the care recipient had significantly lower scores on SE-RDB.

Controlling upsetting thoughts

Social support
Outlook on Life

Tan et al., 2021

Conclusions

- 01 Overall profile of Singapore caregivers similar to global caregivers
- 02 Depend on FDWs more and less on services
- 03 1 in 11 had psychological morbidity and 1 in 4 perceived care burden
- 04 Caregivers cope in different ways - Low coping strategy group associated with lower depression
- 05 Demographic factors associated with positive aspects of caregiving (PAC)
- 06 Training associated with PAC.
- 07 PAC domains associated positively with caregiver's self-efficacy

Coming back to FDWs

Does engaging FDWs specifically for caregiving of PWDs truly moderate caregiver stress?

What are caregivers' experiences of engaging FDWs?

A multi-method study design with a quantitative and qualitative arms.

- Quantitative - 282 informal caregivers of PWDs
- Qualitative study, 15 informal caregivers with FDWs were interviewed.

Quantitative Insights

- Support received from FDWs was associated with lower depression symptom scores of informal dementia caregivers (marginal effect = -3.35, $p = 0.0497$).
- However, such support did not affect caregivers' caregiving burden, self-efficacy, and perceived positive aspects of caregiving.

Qualitative Themes

Support

- support on daily caregiving tasks
- emotional support.

Challenges

- finding and maintaining suitable FDWs
- FDWs' lack of caregiving skills and proper attitudes
- training of FDWs
- challenges in managing the FDWs
- dependence on FDWs

Qualitative Themes

‘But my helper is good because she said that if your father knows that he has dementia, he will not behave in this manner. It’s because he doesn’t know, this is dementia she said. And she’s the one who taught us how to manage our temper.’-- P01

‘[...] after the first 2 years they (FDWs) have to go for medical examination right, the chest X-ray, my helper also. Her x-ray showed that there was a shadow in her lungs. Then the X-ray clinic called us to come back again [...] The result went back to her GP, and her GP said she had to go for a scan [...]. The scan showed that she had a growth ... mediastinal mass in her lungs [...] and the growth was quite big [...] she is a good helper and now she is sick, then I have to be her caregiver right, I mean that’s only fair. So, I told her, ‘Ok, I will find a surgeon here in Singapore to do it and I will settle my mom’ [...] I don’t know why I never go into depression [...]’ – p05

Solutions?

What do caregivers need

- Access to affordable paid caregivers
- Day Care, Respite Care
- Subsidized Medicines, care costs – a one stop centre for all their medical needs that is dementia friendly
- Caregiver training, support groups
- Dementia friendly communities
- Deeper understanding of palliative care.....

Culturally Adapted Interventions



Design and Pilot-test of an Innovative Mobile-based Intervention to Promote Mental Health of Informal Dementia Caregivers through User-Centered Design

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YUAN Qi

Institute of Mental Health

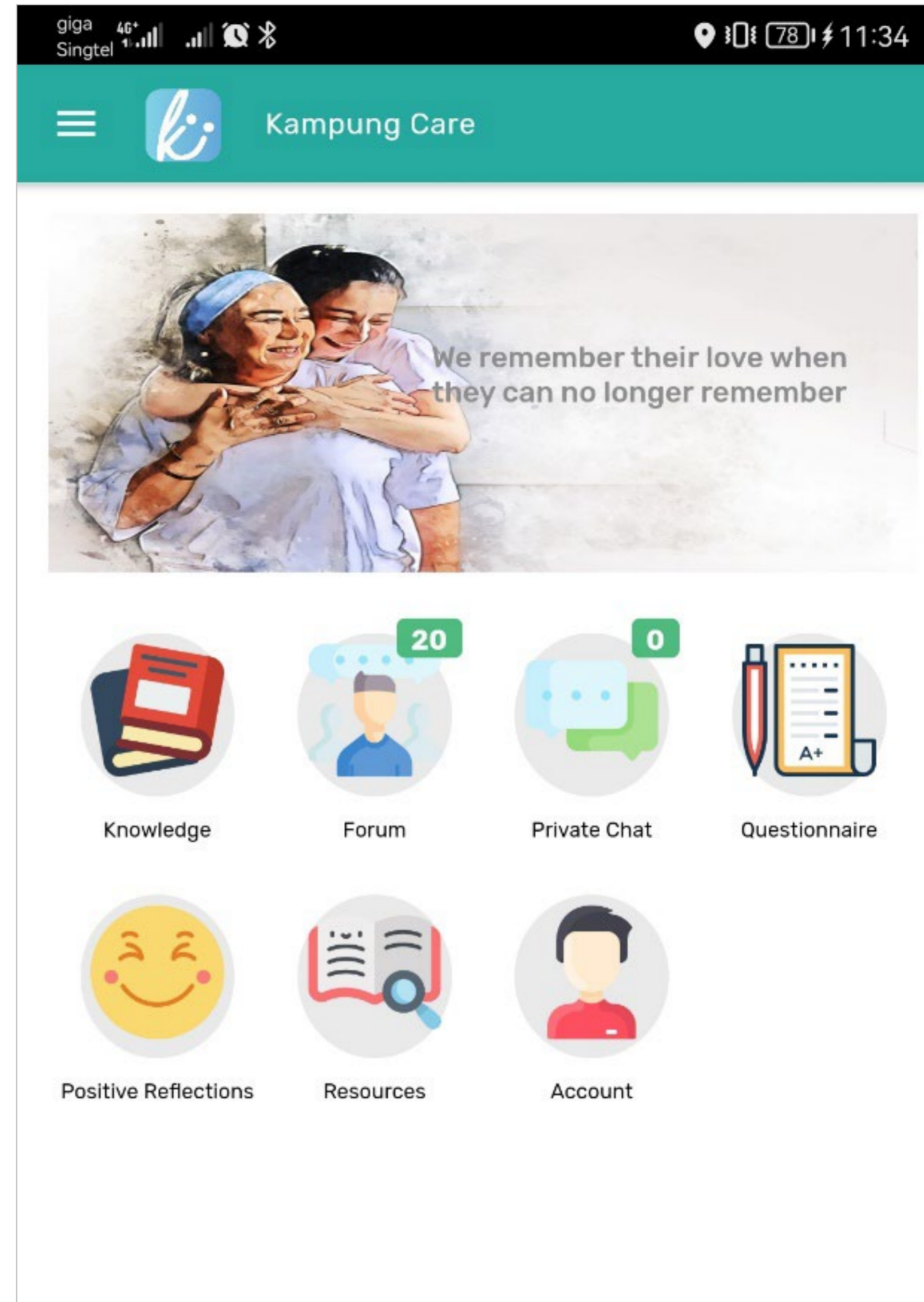
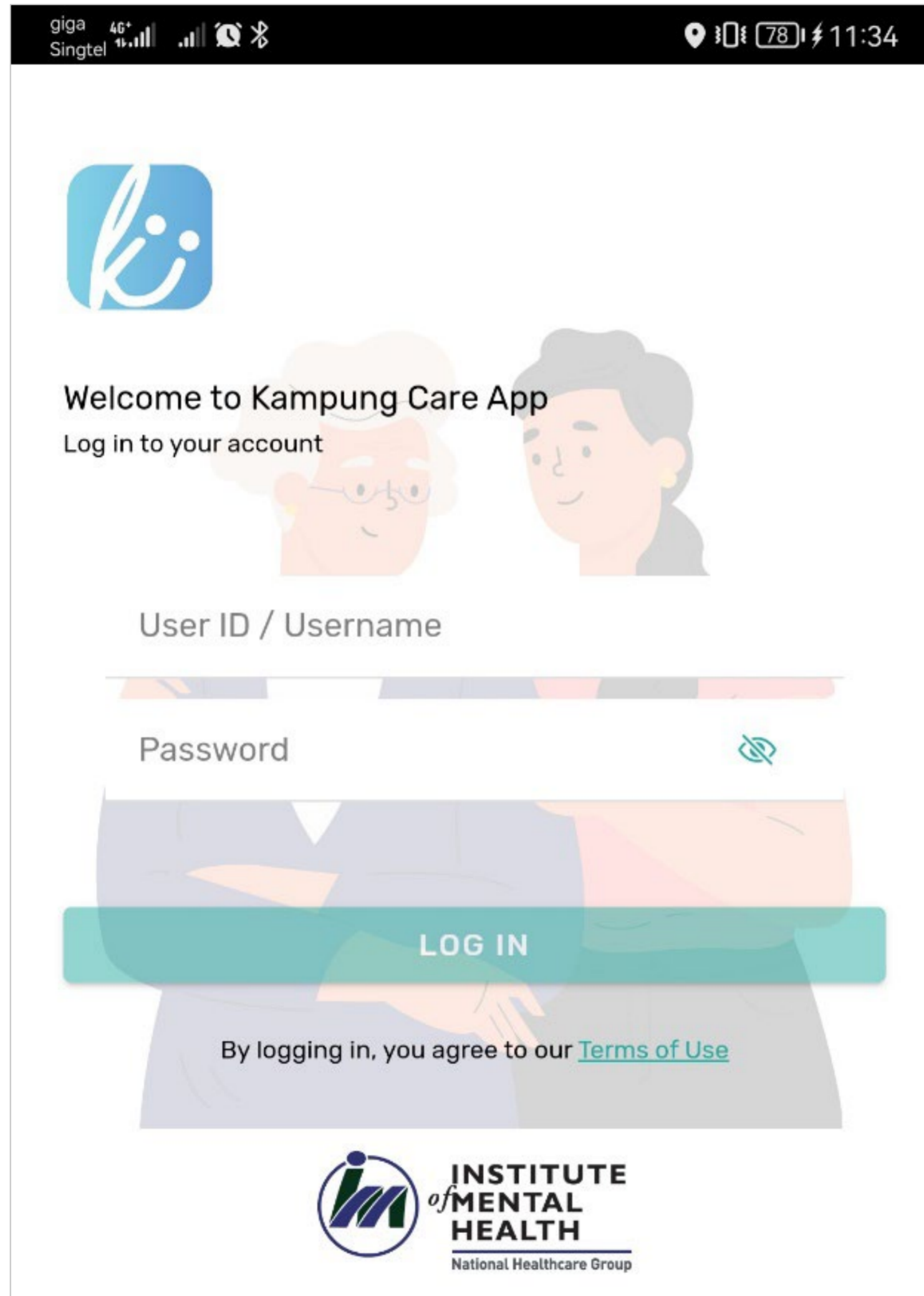
Gaps to Address

- Lack of user-centered design in App development as well as rigorously designed studies based on clear theoretical framework for dementia caregivers (Rathnayake et al., 2018)
- None of the existing evidence-based mobile Apps for supporting dementia caregivers is Singapore-based
- Mobile-based intervention developed with culturally relevant knowledge, support and resources are needed for local dementia caregivers

Objectives

- To design and develop a mobile-based multi-component intervention (i.e. an App) to promote mental health among informal caregivers of individuals with dementia in Singapore
- To pilot-test the effectiveness of the App among a convenience sample of local informal dementia caregivers

Kampung Care – An App based solution



“

Caregiving is a marathon and not a sprint. Equipping yourself for the long haul is essential. You shouldn't walk the caregiving journey alone.

LISA MAYFIELD, FOUNDER &
PRINCIPAL, AGING WISDOM

