Journal of Clinical Gerontology & Geriatrics

www.e-jcgg.com

Original Article

Net informal costs of dementia in Singapore

*Lai Leng Woo[1], Claire L Thompson[2], Yan Hong Dong[3]

[1]Ph.D., James Cook University, College of Healthcare Sciences, Townsville, Australia
[2]Ph.D., The Cairnmillar Institute, School of Psychology, Melbourne, Australia
[3]Ph.D., Department of Pharmacology, National University of Singapore, Singapore

***Correspondence**
Lai Leng Woo, Ph.D
Division of Tropical Health and Medicine, College of Healthcare Sciences, James Cook University, Townsville QLD 4811, AUSTRALIA.
Email: laileng.woo@my.jcu.edu.au

Received 31 May 2017
Accepted 3 September 2017
DOI: 10.24816/jcgg.2017.v8i3.06

Keywords:
Caregiving, dementia, net informal costs, geriatrics

ABSTRACT

Background: To estimate the net informal costs of dementia in Singapore by comparing costs related to caregiving for people with different severity of dementia (mild, moderate and severe) with those without dementia (PWOD).

Methods: Two cross–sectional cost of illness studies were conducted with caregiver-informants of patients with dementia (PWD) from a public health outpatient clinic and with caregiverinformants and PWOD from a tertiary hospital outpatient memory research clinic. The final samples comprised 51 caregivers of PWD and 137 caregivers of PWOD.

Results: The net informal care cost of dementia was estimated at SG$39,053.52 per person per year and rose with severity (Severe: SG$41,774.27; Moderate: SG$ 33,130.81; Mild: SG$8,370.65). The mean annual informal cost of care for PWOD was SG$ 5,477.03, while PWD was SG$44,530.55.

Conclusions: The total net informal cost of care in Singapore was estimated at SG$1.76 billion in 2015 and predicted to increase to SG$4.02 billion by 2030. Given that the number of PWD is expected to increase from 45,000 in 2015 to 103,000 by 2030, this poses a heavy burden on families, national healthcare systems, social services and the Singapore economy.

INTRODUCTION

Dementia is not just a medical problem, it is also a societal problem, where economic and financial resources will be utilised. In Singapore, the proportion of older adults (defined as persons aged 65 years and older) has increased dramatically from 2.5% of the resident population in 1965 to 11.8% in 2015.[1] Given that the incidence of dementia increases after the age of 65 and that the elderly population is growing, the number of Singaporeans with dementia is expected to escalate over the next decade. There are currently 45,000[2] **people with dementia** (PWD) in Singapore and by 2030, that number is expected to more than double to 103,000[2] thus posing a heavy burden on families, national healthcare, social services and the economy. The monetary impact of dementia in terms of future long-term care costs will be significant.[3]

The overall burden of dementia includes not just monetary costs, but also informal costs – the costs beyond those would be incurred if dementia did not exist. Informal care costs represent the time caregivers spend taking care of PWD and are influenced by the caregivers own employment status and, in Singapore, by the common presence of **domestic helpers** (DHs), who often play a major role in the daily care of the family including PWD. By measuring informal costs of care for PWD and **people without dementia** (PWOD), we can calculate the net informal costs of dementia care.

The aims of this study were to 1) quantify the informal cost of care for people without dementia (PWOD) and 2) calculate the net informal costs of dementia, based on severity, by comparing costs of PWD[3] and PWOD. This information can be useful for determining research priorities and has implications for social, health and economic policies for PWD and their families. This study hypothesised that the net informal cost of care increases with the severity of dementia. This study is important as it is the first study to estimate the net informal costs of people with mild, moderate and severe dementia in Singapore including the impact of DHs.

METHODS

Participants

Sample 1: PWD. There were 346 consecutive existing patients attending a follow up consultation with a psychogeriatrician in a government funded public health

institution in Singapore during a four-month period from August to December 2015. Of these, there were 59 patients diagnosed with dementia and thus eligible for this study. Four further PWD were approached but declined to participate while another four PWD did not attend for their follow-up appointments. The remainder of the 287 patients came for treatment of other psychiatric illness such as schizophrenia, bipolar affective disorder, anxiety disorder and depression but did not have dementia. The final sample of PWD was 51.

The inclusion criteria were that all participants had to be aged 60 or above (all 51 patients were actually aged 65 years or above), meet the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IV-TR) criteria for dementia, be accompanied by a reliable caregiver or other informant, and be able to provide informed consent. The informant was required to have adequate language fluency in English, Mandarin or Malay. The exclusion criteria included having other active psychiatric illness and no dementia; and significant physical, visual, or hearing impairment, however no participants needed to be excluded.

Sample 2: PWOD. The sample of PWOD were recruited following a previous study of cognitive screening of 1,082 patients in public primary healthcare clinics (polyclinics), with 309 of these further assessed for signs of cognitive impairment, of which 243 were diagnosed as having no cognitive impairment (CDR = 0).[4] Sample 2 for the present study was recruited from these 243 patients-informant dyads, with 137 agreeing to participate in the current study. The inclusion criteria were that all participants had no cognitive impairment. Other than cognition, the inclusion criteria remained the same as the PWD in Sample 1.

Measures

The Resource Utilization in Dementia[5] (RUD) systematically considers caregiver time used in assisting with activities of daily living (ADL), instrumental activities of daily living (IADL) and providing general supervision. Caregivers were asked to state the number of hours and days on a typical day they had assisted the patients in ADL, IADL and supervision during the last four weeks. This study assessed monthly informal care time based on time spent in assistance with (1) ADL, (2) IADL, and (3) casual supervision, for the PWD at a single point of time in a month. Caregivers were also asked about their work status and hours of work lost due to caregiving.

The Chinese Mini-Mental State Examination[6] (CMMSE) was used to screen PWD general cognitive abilities. The possible CMMSE score ranges from 0 to 28, with lower scores indicating more severe impairment (0-10: Severe, 11-20: Moderate and 21-24: Mild).

Subjective Level of Function Test measured the participant's ability to live independently, encompassing both ADL and IADL. The score ranges from 1 to 4. The scores of 1 and 4 indicate complete independence and complete dependence, respectively, while 2 represents some assistance is required for basic ADL and 3 represents assistance is required with IADL.

Procedure

Ethics approvals were obtained from both health service Institutional Review Boards and the university Human Research Ethics Committee before any data was collected. Informed consent for the study was taken from the patient and caregiver. The collection of data was conducted in two public hospital clinics in Singapore in two separate studies. Sample 1 (PWD) were attending a scheduled treatment consultation and Sample 2 were attending for a research assessment. The RUD was administered by the same researcher to the caregiver-informants of both samples. The CMMSE was administered with the PWD; and Subjective level of Function was administered with the PWOD.

Design and Analysis

The two samples were collected separately, but using identical methodology. The analysis of both samples adopted a cost of illness approach. The informal care cost was estimated by multiplying the informal care time spent taking care of patients with the "price of labour" (i.e., average wages based on government published wage data). To best reflect reality, this study used the replacement cost approach[7] for caregivers' supervision of ADL and the opportunity cost approach[8] for IADL. The net informal costs of dementia were then calculated by subtracting the costs relevant to PWD from the costs for PWOD.

Valuation of caregivers' time is calculated for three subgroups of caregivers: employed people, retirees and DHs. For employees, indirect costs are calculated in terms of productivity losses, i.e. missed days or part-days of paid work due to caregiving responsibilities. Cost-estimates are based on the median gross monthly income of full-time employed workers in Singapore in 2014, which was SG$3,770.[9] Time taken from paid employment was valued by using the 2014 census median income data from the Singapore Department of Statistics, where SG$21.42 represented the median wage earnings of the Singaporean population, with an assumption of a 44-hour work week.

For retired caregivers, this study evaluated the time spent on caregiving (i.e., informal care) as indicated on the RUD. Daily hours of assistance with ADL and IADL was maximized at 8 hours per day and multiplied by SG$6.25 per hour as the base rate (based on the minimum monthly salary of SG$1,000 in Singapore).

The cost of employing a live-in paid DH, including fixed costs (administrative fees, agency fees, security bond, medical insurance, personal accident insurance, medical examination, cost of attending/settling in program) and variable cost (monthly food, basic necessities, lodging cost, foreign worker levy and gross monthly salary) was calculated with each caregiver individually and averaged to be SG$1,314 per month.[9] DHs typically work 96 hours per week or 384 hours per month (on 16 hour days with one day weekly off). This gives an hourly rate of SG$3.42. The cost of employing a DH is not applicable to sample 2 as the participants in this sample did not have dementia. As these participants were not cognitively impaired and did not have dementia, they were capable of performing ADL independently and IADL with minimal supervision.

RESULTS

Demographic Data

The mean age of the caregiver-informants for PWOD was older at 61.65 (*SD* = 12.45) compared to the PWD at 53.24 years (*SD* = 14.22). Females were the majority caregivers for both the PWD and the PWOD (Table 1). Spouses were the main caregiver for PWOD while children were the main caregivers for those PWD. A few DHs (1.96%) were the primary caregivers for PWD but there was none for those PWOD. A third (33.58%) of the caregivers for PWOD was gainfully employed while about half of the caregivers for PWD were gainfully employed. Majority of these PWOD (83.21%) stayed at home with their families and lived in their own homes (96.67%). Slightly more than half of PWD (54.90%) stayed with their families and less than half of them (47.06%) lived in their own homes. More than half of the caregivers (51.09%) were sole caregivers in taking care of PWOD while almost half (49.10%) of the primary caregivers had one other caregiver in helping them to care for PWD. Less than a third (28.47%) of the primary caregiver spent 21- 40% of their time taking care of PWOD, while a third (33.33%) of them spent 1-20% of their time in caring for PWD. A minority of primary caregivers employed DHs (14.60%) in their households for PWOD. These DHs were mainly to do housekeeping chores for them. However, more than half of the households (58.82%) employed DHs for PWD. The time spent by caregivers on ADL, IADL and supervision for PWOD were much lesser compared to PWD. This was mainly because PWOD had fewer problems in their daily activities and hence required less supervision compared to PWD.

Table 1. Baseline demographic details of caregivers for people with and without dementia

	Patients without dementia (*n* = 137)	Patients with dementia (*n* = 51)
Age (years) (SD)	61.65 (12.45)	53.24 (14.22)
Gender (% female)	62.04	70.59
Relationship to patient (%)		
Spouse	67.15	27.45
Sibling	1.45	1.96
Child	28.47	41.18
Other	2.92	9.80
Domestic Helper	0.00	1.96
Residential Care Facility (%)	0.00	17.65
Currently working for pay (%)		
Yes	33.58	47.06
No	66.42	35.29
Living with patient (%)		
Yes	83.21	54.90
No	16.79	45.10
No of other caregivers (%)		
0	51.09	9.80
1	25.55	49.10
2	15.33	15.69
3	5.11	3.92
4	2.92	3.92
Level of contribution of caregiving by primary caregiver with other caregivers involved		
1-20%	13.86	33.33
21-40%	28.47	21.57
41-60%	27.74	9.80
61-80%	12.41	1.96
81-100%	17.52	15.69
Presence of domestic helper (%)	14.60	58.82
ADLS (hours) (SD)	0.45 (1.80)	2.48 (3.32)
IADL (hours) (SD)	3.28 (3.19)	3.31 (2.90)
Supervision (hours) (SD)	0.03 (2.99)	2.36 (3.75)
Mean annual informal cost of care (SG$)	5477.03	44530.55
Net informal cost of care (SG$)		39053.53

Informal Costs of Care

The mean annual informal cost of care for PWOD was SG$ 5,477.03 while the mean annual cost for PWD was SG$ 44,530.55.[3] The median annual costs of informal care for PWD were SG$13,847.68 for patients with mild dementia, SG$38,607.84 for moderate dementia and SG$47,251.30 for severe dementia.[3] There was a significant negative correlation of cost and CMMSE scores, r = -0.37, p = 0.02, with the median annual cost of care being the highest when the patient had severe dementia (Figure 1).

Net Informal Costs of Care

The annual net informal cost of care per person was estimated to increase with severity of dementia (Severe: SG$41,774.27; Moderate: SG$ 33,130.81; Mild: SG$8,370.65). The total annual net informal cost of care for PWD was estimated at SG$ 1.76 billion in 2015 and projected to SG$4.02 billion by 2030, based on the current 45,000 and projected estimate of 103,000 PWD.[2]

DISCUSSION

Caregiver Contributions

More than three quarters of the caregiver-informants (83.21%) lived with PWOD. In Singapore, close to 95% of older people co-reside with family members, highlighting the importance of community support by family caregivers.[8] About a third of the primary caregivers of PWD spend only up to a fifth of their time in caregiving, whereas majority of the caregivers for PWOD spent between 20% and 60% of their time in caregiving. This apparently contradictory result may be explained by the role of DHs, who had a much greater role in looking after PWD than in assisting PWOD. More than half of the families of PWD had DHs assisting them, compared with a minority of DHs assisting families of PWOD.

Comparison of Informal Cost of Care for PWD and PWOD

It was found that the mean annual informal cost of care for PWOD was SG$ 5,477.03 while those PWD was SG$ 44,530.55. This difference was not unexpected as PWD generally required more time in taking care of them due to

their cognitive impairment and functional disability compared to PWOD. Despite a difference in costs between the two samples being expected, the magnitude of the difference is striking. Whilst acknowledging the limitation of recruitment from different sources for the two samples, this data provides clear evidence of the high costs of informal care for PWD as compared to PWOD.

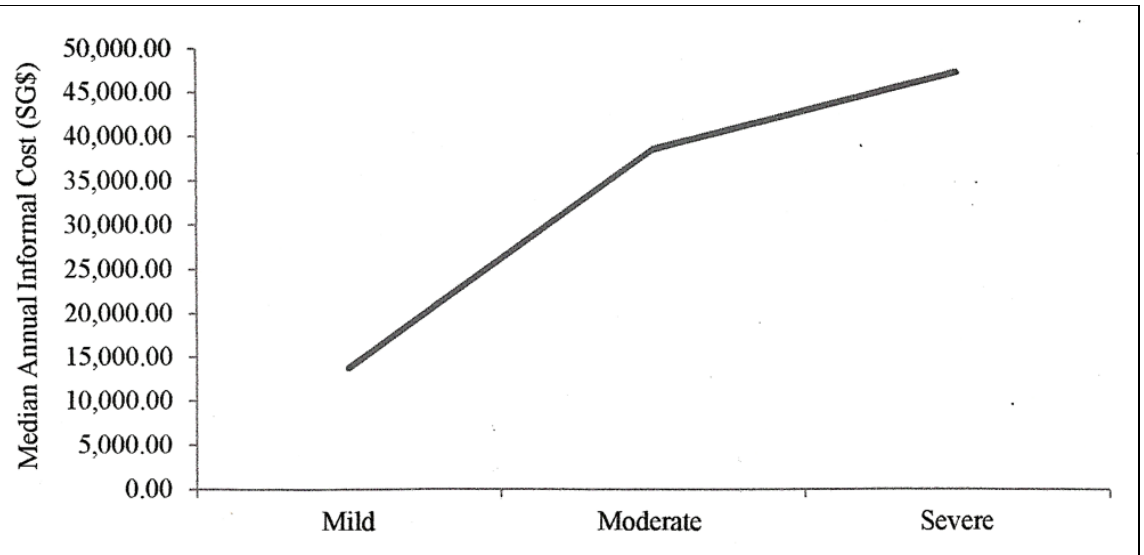

Figure 1. Relationship between median annual informal cost and disease severity

Annual Net Informal Cost of Care

Using the cost per person (per capita) estimate which is then multiplied by the number of people estimated to be living with dementia in that country, this study estimated that it will cost Singapore at least SG$1.76 billion annually in net informal costs based on the current 45,000 PWD in Singapore and the prediction that this number will escalate to almost triple to SG$4.02 billion by 2030.[2] This estimate is likely to be low since it is based on several conservative values and does not account for the significant costs of the patient's reduced quality of life and the emotional stress and burden on family and friends.

However, the findings of this paper should be interpreted in the context of some limitations. The two samples were collected from different sites and so were not suited to direct statistical analysis of the significance of differences between groups and generalisability of the results cannot be assumed. Despite a high response rate of 92.73% for Sample 1, the small size of this sample constrains statistical power to conduct more complex analyses of costs. Also, all data presented here is cross sectional and therefore cannot predict whether the current type and cost of care for PWD (i.e., cared by DHs) will change over time, depending on new methods of diagnosis or treatment of the disease.

There are other possible influences on costs that may be useful directions for future research. PWD are likely to have more co-existing chronic health problems than PWOD because certain diseases (e.g., stroke and depression) are more common in PWD.[11] Thus, adjusting for the presence of these comorbid conditions may be important in estimating the costs due to dementia alone.

Our findings indicate that the annual net informal cost of dementia in Singapore was at least SG$1.76 billion in 2015. The most significant component of the net informal cost was the assistance with ADL, IADL by DHs, family and friends in the community for PWD.

CONFLICTS OF INTEREST STATEMENT

The authors declare no conflicts of interest.

FUNDING/SUPPORT STATEMENT

The authors declare no funding and support.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the Memory Ageing and Cognition Centre at the National University Hospital, Singapore, and the Institute of Mental Health, Singapore, for their assistance with access to participants and collecting demographic and diagnostic data.

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