

# Brief Report

## Expert estimates of caregiver hours for older Singaporeans with dementia

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**Aim:** *To obtain experts' estimates of the number of non-medical care hours required by older Singaporeans at different stages of ageing-related dementia, with low or high behavioural features.*

**Methods:** *Experts on dementia in Singapore attended one of two meetings where they provided estimates of the number of care hours required for individuals at mild, moderate and severe levels of dementia with either low or high behavioural features. The experts were shown the collated responses, given an opportunity to discuss as a group, and then polled again.*

**Results:** *The estimated mean care hours varied by dementia severity and the level of behavioural features. There was no interaction between dementia severity and behavioural features.*

**Conclusion:** *Estimated care hours needed by individuals with dementia is independently influenced by severity of dementia and behavioural features. These estimates may be useful for policy-makers in projecting the impact of caregiving.*

**Key words:** *ageing, caregiving, dementia, expert estimate, Singapore.*

### Introduction

Ageing-related dementia is usually progressive and irreversible, and as symptoms progress, the care needs of the individual change [1]. Whereas those with mild dementia may

only require assistance with complex tasks (e.g. handling personal finances), individuals with severe dementia are likely to be incontinent and unable to feed themselves, necessitating total care [2].

In order to plan care options for individuals with dementia, it is necessary to have a general understanding of the number of care hours required by individuals at different levels of impairment. Although some estimates exist for people in North America [1,3,4] and Europe [5], there are few studies on the number of caregiver hours required for individuals with dementia in Asia, and none in Singapore. While studies from elsewhere may be useful as starting points from which to make informed estimates, Singaporean culture differs significantly from that of North America and Europe. Social tenets such as filial piety are pervasive in Singapore [6], and neglecting to provide care for an older family member could be stigmatised to a greater degree than in Western countries. In fact, negligent children can be sued by their parents for not being supportive financially [7]. Due in part to these norms, as well as the fact that caregivers in Singapore are more likely to cohabit with care recipients [8], it is hypothesised that the number of care hours Singaporeans provide may be different from that in the West. The objective of this study was to produce a better understanding of the number of care hours older Singaporeans with ageing-related dementia require.

A panel of experts on dementia in Singapore was convened and polled about the non-medical care needs of Singaporeans at different stages of ageing-related dementia, with and without non-cognitive features (hereafter called behavioural features). Because the care needs of dementia can change greatly from stage to stage [2], panel participants were asked how the number of care hours would differ for people at mild, moderate and severe stages. In addition to differences in care due to severity level, how behavioural features such as pacing, wandering, and physical or verbal aggression might affect care needs was also investigated [9]. When discussing care requirements, it is important to consider behavioural features because the presence of some types of behaviours (e.g. aggression) requires active management from the caregiver [9] and have been associated with increased caregiver burden [10]. A previous study in Singapore found that caregivers reported behavioural problems as one of their main sources of stress, and caregiver stress levels were positively correlated with plans to institutionalise family members with dementia [11]. We hypothesised that increased stress on the caregiver could be due in part to an increase in the number of care hours required by an individual with behavioural features.

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## Methods

Because surveys of caregivers may overestimate care hours [12] and more objective measures are currently unavailable, this study utilised the Delphi technique [13–15] to develop subjective expert estimates of caregiver hours. While real-time data collection, such as having caregivers report in one-hour intervals how many minutes they spent providing care, may be useful in generating more accurate estimates, such studies are costly, difficult for participants, and time-consuming. Polling experts is one way to get a first approximation of caregiver hours while avoiding some of the issues accompanying more traditional data collection techniques.

A list of experts on dementia in Singapore was compiled for a previous study [16]. The experts were contacted via email and invited to attend one of two separate meetings to discuss dementia care in Singapore. Twenty experts agreed to attend, but four had schedule conflicts; thus, a total of 16 experts participated. The first group consisted of 10 people, and the second group consisted of six. In their current positions, 10 participants had an average of 15 years of experience involved in the planning of care for individuals with dementia either as administrators of community organisations or health policy advisors. Of the remaining six participants, four were physician providers (two geriatricians, one neurologist and one internist), and two were non-physician providers (one neuroscience nurse and another involved in geriatrics). Combined, the physician and non-physician providers also had an average of 15 years of experience in their respective fields. At least seven participants had obtained degrees in medicine, three had degrees in nursing, and others had master's degrees in relevant fields. Permission to conduct this study was granted by the Institutional Review Board of the National University of Singapore.

At the beginning of the session, participants were asked to fill out a table with their estimates of the number of hours of non-medical care required by individuals at different levels of dementia severity (mild, moderate and severe), with high or low behavioural features (see Appendix I). Although behavioural features are typically present only in more advanced stages of dementia [9], for consistency, all combinations of severity and behavioural feature levels (including the unlikely combination of mild dementia/high behavioural features) were included. Brief descriptions of each condition were provided (see Appendix I).

Respondents were asked to include in their estimates only non-medical care such as feeding, bathing, dressing or general supervising. They were told to exclude doctor or nurse visits and time spent in the hospital. For each case, respondents were asked to provide the average number of hours of care they thought a person would require and a range of hours that they thought would include the care needs of 95% of people with that condition. After the participants completed the exercise, the forms were collected and results were tabulated while participants listened to a presentation about dementia and

living arrangements. Next, each respondent was given a personalised paper (see Appendix II for an example) that included histograms of the group's responses for each question about the average number of care hours required. For questions about the range of hours that encompassed 95% of the population's care needs, the average minimums and maximums for each question were provided. The group then discussed the responses and any discrepancies that arose in their answers for 15 min. Afterwards, participants were asked to fill out the table again (see Appendix I) and were told that they were free to provide the same answers as before or to change their responses in light of their discussion.

To summarise the typical values and bounds, a beta distribution, re-scaled to the interval 0 to 24, was fit for each expert and category combination. In particular, for each expert and category combination, the beta distribution was found, which minimised the sum of deviations of greater than 1 hour of its mean, 0.025 quantile, and 0.975 quantile from the expert-provided quantities minus 0.0001 times its standard deviation. This had the effect of fitting a beta distribution which is slightly over-dispersed to the expert-provided quantities. With the aim of estimating a typical care distribution, two-way ANOVAs were performed on both the means and the standard deviations, which specify the corresponding beta distributions, on behavioural features and dementia severity.

## Results

There was no evidence of an interaction between behavioural features and dementia severity for either the mean or the standard deviation (respective *P*-values for interaction are 0.2 and 0.9). The means were found to be related directly to behavioural features (*P* < 0.001) and dementia severity (*P* < 0.001). The estimated relationship was:

$$\text{Mean} = 10.2 - 6.4(\text{Low Behaviour}) + 6.4(\text{Moderate Dementia}) + 8.1(\text{Severe Dementia}).$$

The standard deviations were found to be related to behavioural features (*P* = 0.008) but not dementia severity (*P* = 0.3). The estimated relationship was:

$$\text{Standard Deviation} = 2.05 - 0.8(\text{Low Behaviour}).$$

Figure 1 shows individual expert care distributions as well as typical distributions.

## Discussion

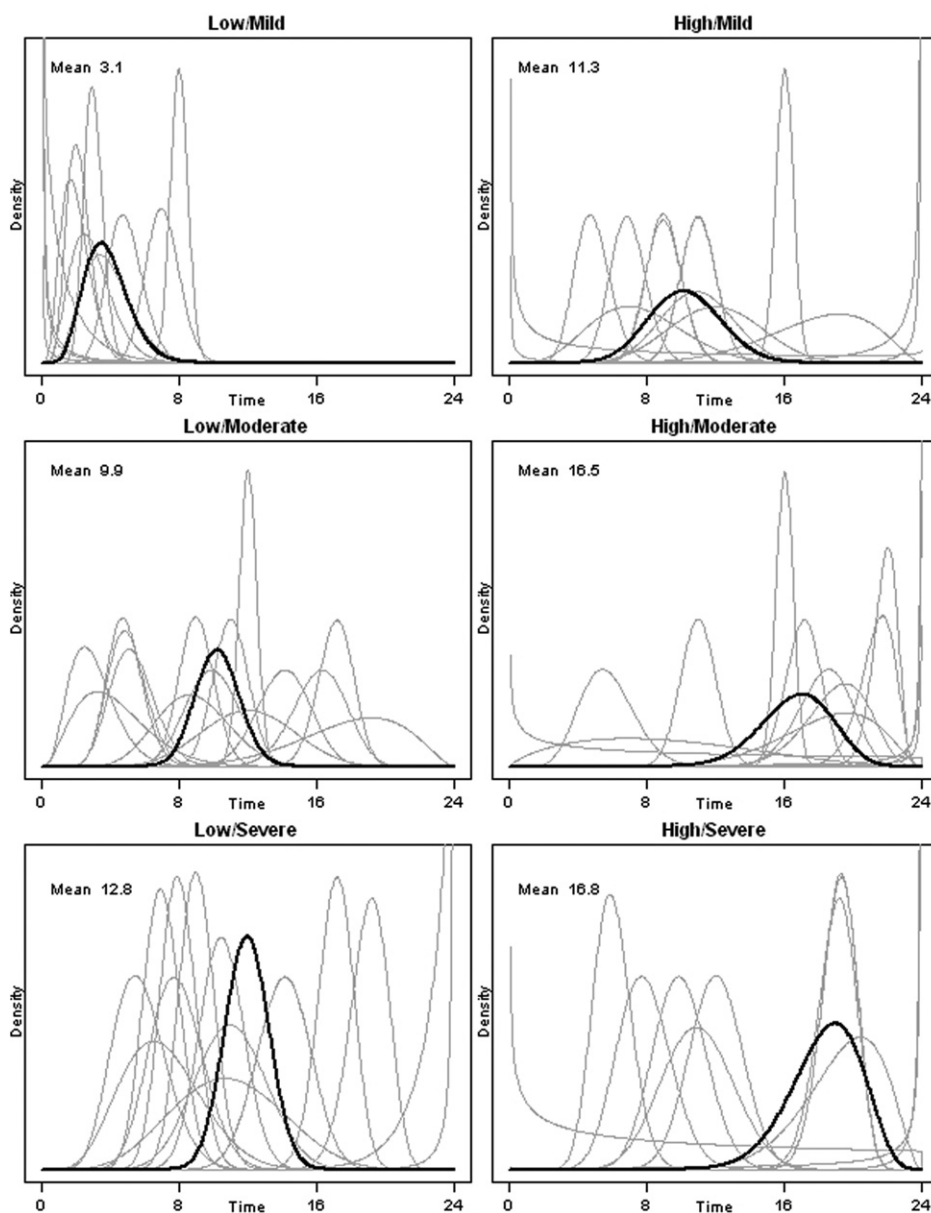
Results indicated that the mean number of care hours estimated by experts varies significantly by the degree of dementia severity and by the level of behavioural features. There was no interaction between dementia severity and behavioural features. Patterns were as expected, with the estimated mean number of care hours increasing as dementia severity increased from mild to moderate and moderate to severe. Similarly, the mean number of care hours was higher for those with high behavioural features than those with low behavioural features. Further, the experts' uncertainty in the required number of care hours tended to be greater for those

with high behavioural features, but did not change across levels of dementia severity. Although the pattern of the means was as expected, the distribution of each individual's mean and upper and lower bound often varied substantially from the average distribution (see Figure 1).

Given the interest in Singapore-specific estimates, a small sample size was unavoidable. Thus, the number of respondents was not a key limitation of this study. One limitation may involve the ability of experts to accurately estimate caregiving hours versus other potential informants such as caregivers. However, the results presented in this paper are

relatively similar to those presented in other publications [3,5,17], which reported caregiver estimates based on dementia severity without regard for the presence of behavioural features. Another limitation may be that experts, as with caregivers [12], tend to overestimate care hours when compared with more objective measures such as real-time data collection. In addition, if more educational and informational support is provided to caregivers (e.g. learning to administer appropriate analgesics to care recipients when behaviour issues arise due to pain), then the number of required care hours may decline. This is an area for future research. Other potential areas of future study include the

**Figure 1: Older persons' care beta distributions by behavioural features and dementia severity categories.**



Individual expert distributions in grey and typical distributions in black. 'Low/High' for behavioural features; 'Mild/Moderate/Severe' for dementia.

degree to which caregivers agree with experts and with more objective measures of care hours, such as the real-time data collection mentioned above.

### Conclusion

Based on expert estimates, the number of hours needed for the care of individuals with dementia is independently influenced by severity of dementia and whether behavioural features are present. These estimates can serve as a useful first approximation for policy-makers in projecting the impact of caregiving for individuals with dementia.

#### Key Points

- Expert-estimated number of care hours increases as ageing-related dementia severity increases from mild to moderate and moderate to severe.
- Expert-estimated number of care hours is higher for those with high behavioural features than those with low behavioural features.
- Estimates can serve as a useful first approximation for policy-makers in projecting the impact of caregiving for individuals with dementia.

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### Appendix I

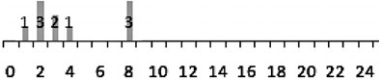

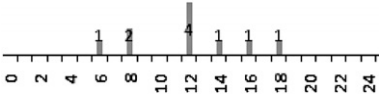

**Table A1: Participants filled out the table, were shown the responses of the group, and were allowed to discuss. After discussion, they filled out the table again**

Instructions: Please fill out the table provided. In the top half of the cell, please write the number of hours of non-medical care that you think that the average person in each condition would require per day. In the bottom half of each cell, please put the range of hours that you feel would encompass 95% of the population's care needs. Please do not discuss your answers with anyone else.

	<b>Low Behavioural Features</b> Either exhibits no behavioural features or only a few, minor ones such as agitation and/or pacing.	<b>High Behavioural Features</b> Exhibits several behavioural features, such as screaming, wandering, physical and/or verbal aggression, delusions, hallucination, and/or suspicion of others.
<b>Mild Dementia</b> Requires assistance only with more complex tasks, such as organising personal finances or making travel plans.	____ hours/day ____ hours/day to ____ hours/day	____ hours/day ____ hours/day to ____ hours/day
<b>Moderate Dementia</b> Requires assistance with everyday tasks such as dressing and bathing.	____ hours/day ____ hours/day to ____ hours/day	____ hours/day ____ hours/day to ____ hours/day
<b>Severe Dementia</b> Requires a high level of assistance and supervision, and is generally incontinent and unable to walk or stand without help.	____ hours/day ____ hours/day to ____ hours/day	____ hours/day ____ hours/day to ____ hours/day

## Appendix II

**Table A2: An example of the table that summarised the participants' responses. Each participant was given a personalised table after filling out Table A1. They were allowed to discuss their responses for about 15 minutes, and then were asked to fill out Table A1 again**

	<b>Low Behavioural Features</b> Either exhibits no behavioural features or only a few, minor ones such as agitation and/or pacing.	<b>High Behavioural Features</b> Exhibits several behavioural features, such as screaming, wandering, physical and/or verbal aggression, delusions, hallucination, and/or suspicion of others.
<p><b>Mild Dementia</b> Requires assistance only with more complex tasks, such as organising personal finances or making travel plans.</p>	 <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 2.5 hours/day to 5.5 hours/day</p>	 <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 10.1 hours/day to 14.9 hours/day</p>
<p><b>Moderate Dementia</b> Requires assistance with everyday tasks such as dressing and bathing.</p>	 <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 8.5 hours/day to 13.6 hours/day</p>	 <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 15.6 hours/day to 19.8 hours/day</p>
<p><b>Severe Dementia</b> Requires a high level of assistance and supervision, and is generally incontinent and unable to walk or stand without help.</p>	<p style="text-align: center;">┌</p> <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 12.2 hours/day to 16.3 hours/day</p>	<p style="text-align: center;">┌</p> <p>Your Answer: X hours/day to X hours/day</p> <p>Group Average: 19 hours/day to 21.4 hours/day</p>