

Profiling The Dementia Family Carer In Singapore

Alzheimer's Disease Association of Singapore

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1. EXECUTIVE SUMMARY

The key findings of the study can be summarized herein:

1. The carer of a person with dementia (PWD) is typically a middle-aged daughter with at least 10 years of education and holding a full-time or part-time job. Many carers have to cope with other responsibilities and pursuits, and about 50% of the carers are assisted by domestic maids. The “successful” carer is likely one who can balance these multiple roles well. The competence, coping and welfare of domestic maids need to be considered given their intimate involvement in dementia care.
2. The level of carer burden is significant, with 27.2% of carers expressing feelings of burden more often than sometimes. It is hence important to screen for carer burden in any dementia service. The highest stress statements pertain to the need to multi-task, with carers having to juggle between caregiving and work as well as other family commitments. Carers have to cope with the guilt of not doing enough and the burden of feeling personally responsible for the Person With Dementia (PWD). Helping carers juggle multiple responsibilities and supporting them through feelings of not being up to the task and guilt is key.
3. Most carers express a strong desire to look after the PWD themselves at home. However they realize the difficulties involved and seek assistance. Possible ways to help carers include making it less costly to employ domestic maids (e.g. waive

- levy), providing formal training and support in dementia care for domestic maids and giving an allowance to carers who wish to care for the PWD at home.
4. More outreach is needed for local dementia organizations while the media can help to increase awareness of the condition. Carers also expressed the desire for increased opportunities to speak to the attending doctor. There is a need to create more occasions for carers to interact and discuss with healthcare professionals about the care of the PWD. To this end, the provision of dementia counselling service for carers run by professionals may help.
 5. About half of the carers in the study had never utilized dementia services because of time constraints and because some of them had to provide care full-time to the PWD. Respite and elder-sit services should be in place to free carers to attend training programmes and empower themselves with more knowledge, skills and support in their role. Many carers also felt that they could “obtain their own information” on dementia. This is an important group to target as they are likely committed and interested carers who may not realize the importance obtaining proper information and skills from dementia care professionals. Information obtained on their own should always be discussed with a professional to ensure correct interpretation and proper usage.
 6. The commonest reasons cited for not using dementia services for the PWD (eg. day care) pertain to the availability of a maid, failure to see the need for the service and refusal on the part of the PWD. Financial considerations, although not expressly stated, is likely to feature as well. Providing proactive education for

carers on the physical and psychological benefits of a structured day activity programme for PWD is a possible solution to this issue. Carers need to see day programmes as a viable form of treatment and not merely for respite. Other measures include making the day care more accessible by extending opening hours and improving transport coverage, making it more affordable with increased subsidies and improving the quality of the day programmes by going beyond generic programmes and adapting to the varied needs of different clients.

7. The expressed needs of the carers call for more formal training for carers in managing difficult behaviour in dementia as well as end of life care, more opportunities for carers to discuss issues about care of the PWD with doctors and other healthcare professionals, provision of better quality care and increasing the capacity of current dementia daycares, improving the competence of healthcare professionals in dementia care across all health sectors from acute hospitals to nursing homes and day cares, and providing better home care support for the PWD and the carer eg. home medical care & nursing, elder-sit, end of life dementia care at home.

2. INTRODUCTION

The alarming statistics of dementia are now widely acknowledged. The most recent estimates indicate 24.3 million suffer from this condition worldwide, with a new case being diagnosed every 7 seconds. There are 22,000 persons estimated to suffer from dementia in Singapore today and this will increase to more than 50,000 by 2020.

Family carers remain the main persons providing care, having to face much emotional, practical and economic strain in the process. Caregiving typically stretches over a prolonged period and entails significant expenditure of time, energy, finances and tasks that may be unpleasant, emotionally stressful and physically exhausting. However, anecdotally and through some early research findings, caregiving can also bring about certain gains such as increased self awareness, personal growth and a new purpose in life. Little has been published on dementia carers in Singapore. It would thus be pertinent to try to understand them better, know their needs and find out how they are coping with the task of caregiving. This will enable better planning and provision of services to better support family carers of persons with dementia (PWD).

3. AIMS OF THE STUDY

The aim of this study is to profile the Singapore dementia carer in the following areas:

1. Carer characteristics and caregiving situation
2. Access and sources of information on dementia
3. Awareness and use of dementia support services
4. Views about current dementia services provided
5. Carers' expressed needs for themselves and for the PWD

4. METHODS & PROCEDURE

4.1 CONSENT

Ethics approval for this study was obtained from the Domain Specific Review Board of the National Healthcare Group (NHG) Singapore. A consecutive sample of study subjects was obtained from two sources, the ambulatory dementia clinic of a tertiary hospital (Alexandra Hospital) and the local Alzheimer's Association (Alzheimer's Association of Singapore). In the former, family carers visiting the clinic with their charges were invited to participate in the study whereas for the latter, the family carers were contacted through the clients' and carers' registry of the Association. The investigator explained the nature and aims of the study, the voluntary nature of participation, and the confidentiality of the responses. This information was also provided via an information sheet given to the subjects. Those who agreed to participate signed an informed consent form.

4.2 METHODOLOGY

Inclusion criteria comprised:

- a) Literacy in English or Mandarin and able to complete a survey questionnaire or be interviewed
- b) Any family member aged \geq 18 years providing care or assistance to a relative with dementia. Providing care could mean attending to the needs of the PWD, going to doctor's appointments with him, helping him take medication, helping with housework or cooking, helping him bathe or dress, providing emotional support, spending time talking to him, bringing him for outings and the like.

For Alzheimer's Disease Association, the subjects from the carers' registry were contacted through telephone to ask if they would like to participate in the research either through face to face interview or mailed questionnaire. Final year students from the Department of Psychology and Social Work, National University of Singapore were recruited as interviewers. Training on the administration of the questionnaire was conducted. Data collection started in Dec 2007 and ended in November 2008.

For Alexandra Hospital, although the survey questionnaire was designed to be self-administered, the subjects were first given an explanation and run-down on the questionnaire by the investigator before being left to answer on their own. Subjects could complete questionnaire on or off site and the latter would return the questionnaire by mail. Majority of the subjects returned the questionnaire within 10 days. Those who delayed returning the questionnaire after 2 weeks were reminded by telephone. Data collection started on 2 June 2008 and ended on 28 Feb 2009.

5. RESULTS, DISCUSSION & RECOMENDATIONS

The questionnaire was given out to 442 family carers and 340 (76.9%) were received at the end of the study. The carers who did not return the questionnaire cited problems such as poor eyesight, language difficulties, recent death of the relative with dementia, time constraints, and lack of interest. Differences between respondents and non-respondents could not be examined. A detailed description of the results, analysis of the findings and proposed directions to undertake are described in the table herein.

Domains assessed		Main findings		Analysis of findings	Implications / Recommendations
		Freq	(%)		
Language of survey	i) English	258	75.9	Majority of the carers are English or Mandarin literate in this study sample.	Literacy rate is high in this sample. The results should be interpreted with this understanding.
	ii) Mandarin	67	19.7		
	iii) English and Mandarin	9	2.6		
	iv) Dialects with or without Mandarin	6	1.8		
	Total	340	100.0		
<i>I. Carer characteristics and caregiving situation</i>					
Age (in years)	Mean: 51.59; S.D: 10.98		The predominance of children as carers accounts for the mean age of 50. This is relatively younger compared to Caucasian samples which feature more spousal and hence older carers.		
Gender	i) Male	97	28.5	The predominance of female carers is consistent with the caregiving situation worldwide.	
	ii) Female	242	71.2		
	iii) (No response)	1	0.3		
Ethnic Group	i) Chinese	321	94.4	As this study sample comprises majority Chinese carers, the results should be interpreted with this in mind.	More studies are needed to understand the needs of minority ethnic groups in Singapore.
	ii) Malay	3	0.9		
	iii) Indian	11	3.2		
	iv) Eurasian	3	0.9		
	v) Others	2	0.6		
Marital Status	i) Single	101	29.7	Majority of carers are married although single carers constitute a significant proportion as well.	The differing needs of both married and single carers need to be considered.
	ii) Married	216	63.5		
	iii) Widowed	8	2.4		
	iv) Divorced / Separated	13	3.8		
	v) (No response)	2	0.6		

Work Status	i) Working full time ii) Working part time iii) Homemaker / housewife iv) Not working v) Retired vi) (No response)	163 53 71 24 27 2	47.6 15.6 20.9 7.1 7.9 0.6	Most family carers either work full-time or part-time or need to attend to household needs as well.	Carer interventions need to factor this into account as family carers are likely to be multi-tasking, having to attend to the PWD, other family and work commitments. Being busy with multiple responsibilities would require them to prioritize their tasks well.
Highest Education Attained	i) No formal education ii) Primary iii) Secondary iv) College v) Diploma vi) University vii) (No response)	13 20 110 27 65 103 2	3.8 5.9 32.4 7.9 19.1 30.3 0.6	As noted above, this is a well-educated sample with about 90% having completed at least 10 years of education. The high proportion of child carers can explain this.	
Housing	i) 1-2 room HDB ii) 3-4 room HDB iii) HDB 5 room/ executive/ masionette iv) Condominium, including executive condominium and private apartment v) Terrace/ Semi-detached / Bungalow vi) (No response)	3 136 94 57 46 2	0.9 40.0 27.6 16.8 13.5 1.2	Consistent with the other findings, this study sample comprises subjects from at the least middle-income strata, with very low representation of the low-income segment.	More studies are needed to investigate the caregiving situation of the lower income families coping with dementia.

Relation-ship with PWD	<ul style="list-style-type: none"> i) Husband 23 6.8 ii) Wife 25 7.4 iii) Son 78 22.9 iv) Daughter 171 50.3 v) Son-in-law 2 0.6 vi) Daughter-in-law 25 7.4 vii) Grandson 2 0.6 viii) Grand-daughter 2 0.6 ix) Others 10 2.9 x) (No response) 2 0.6 	Spousal carers comprise about 14% whereas child carers make up 73%, with daughters forming the majority. The reasons for the lower representation of spousal carers include: i) spouse deceased ii) spouse ill and not well iii) in this study, primary carers are defined as the carer with the main responsibility of decision making for the PWD iv) Child carers are usually more literate and hence more likely to complete this survey form which is mainly self-administered.	As opposed to Western populations, children usually take on the responsibility of decision making and being primarily in-charge of the well-being of their parents in our Asian society. Aged spouses are more likely to be in the background. However, this may change as the new cohort of older persons are more educated and would like to be more in control of their affairs. Hence, carer interventions need to target spousal carers as well.
Living with PWD?	<ul style="list-style-type: none"> i) Yes 231 67.9 ii) No 105 30.9 iii) (No response) 4 1.2 	Living with the PWD can be a surrogate marker of the degree of involvement of the carer and one can surmise from the results that this sample is likely to comprise carers who are very much involved in caregiving.	
Main Carer	<ul style="list-style-type: none"> i) Yes 272 80.0 ii) No 66 19.4 iii) (No response) 2 0.6 	As explained above, this sample is made up of mostly main carers and close to 50% of them have been caring for the PWD for more than 3 years and >80% at least a year.	The data collected is thus valid and reliable with regards to understanding the caregiving situation and needs of main carers of PWD who have been providing care for a significant amount of time.
Length of Time Taking Care of PWD	<ul style="list-style-type: none"> i) < 6 months 15 4.4 ii) 6 months to 1 year 35 10.3 iii) > 1 year to 3 years 121 35.6 iv) > 3 years 166 48.8 v) (No response) 3 0.9 		

Domestic Maid	i) Yes ii) No iii) (No response)	172 166 1	50.7 49.0 0.3	As expected, a large proportion of our carers (50%) are assisted by domestic maids.	Maids need to be the focus of carer training and intervention as well.
Contribution of Care to PWD	i) <10% ii) 10 - 20% iii) 21 - 40% iv) 41 - 60% v) 61 - 80% vi) 81 - 100% vii) (No response)	35 45 60 52 59 88 1	10.3 13.2 17.6 15.3 17.4 25.9 0.3	As the sample comprises majority (80%) main carers, more than 50% of the carers sampled contribute at to least 50% of the care rendered to the PWD. Likewise, about 75% of them get to see the PWD at least once a day.	As mentioned above, these statistics reinforce the validity of the data collected on family members who are the primary persons providing care for the PWD.
Frequency of Contact with PWD	i) Daily ii) Daily but only during certain hours of the day eg. at night iii) At least once a week iv) At least once a month v) Less than once a month v) (No response)	198 59 65 13 4 1	58.2 17.4 19.1 3.8 1.2 0.3		
Two main activities carer is occupied with other than providing care for	i) Full time or part time work or job/own business ii) Caring and meeting needs of other family members and or / domestic chores	210 189	61.76 55.58	As can be clearly seen, most carers have several other duties, concerns, needs and personal pursuits apart from caring for the PWD. The “successful” carer is likely one who can balance these multiple roles well.	This information has the following important implications: i. Prioritising multiple tasks is essential for the carer and help in this be an avenue of intervention for the perplexed carer

PWD	iii) Leisure activities or activities for pleasure	112	32.94		ii. The PWD may not always be foremost in a carer's list of priorities iv. Professionals in dementia care need to accept and respect carers' personal choice, especially carers who do not rank the needs of the PWD high.
	iv) Religious / Volunteer / Community work	60	17.64		
	v) Self enrichment / Learning	24	7.05		
	vi) Others	8	2.35		
Carer burden & 3 items with highest burden	Mean Zarit Burden score	35/88		The level of carer burden is significant, with 27.2% of carers expressing feelings of burden more than "sometimes" on the average. The 3 highest stress statements pertain to the need to multi-task, having to juggle between caregiving and work as well as other family commitments. Hence, carers have to cope with the guilt of not doing enough and feeling personally responsible for the PWD.	There is a need to assess carer burden routinely in dementia support facilities as it is a common phenomenon. Helping carers juggle multiple responsibilities and supporting them through feelings of guilt and not being up to the task is key.
	Subjects with burden score above median score of 44	91 (27.2%)			
	1) Feel stressed caring for PWD & meeting other responsibilities 2) Feel PWD is dependent on me (carer) 3) Feel need to do more for PWD				
<i>II. Awareness and use of dementia support services</i>					
Sources of information about dementia	i) PWD's doctor	183	53.82	The following is noteworthy: i. almost 50% of the carers did not attribute their source of information about dementia to the doctor attending to the PWD	These 3 areas require attention. While doctors are diagnosing the condition, some may not be spending enough time explaining about dementia.
	ii) Another doctor or healthcare provider	57	16.76		

	iii)Dementia Alzheimer's Disease organization	111	32.65		
	iv)The Internet	140	41.17	ii.	close to 70% did not obtain dementia related information from a local dementia service
	v) Books	79	23.23	iii.	only 13% learnt more about dementia over the TV or radio
	vi)Magazine and newspaper articles	129	37.94		
	vii)Medical journals	23	6.76		
	viii)TV and radio programmes	45	13.23		
	ix)Friends and family members	74	21.76		
	x)None/ don't look for info on dementia	4	1.17		
Awareness of local Dementia or Alzheimer's Disease organisations / services	i)Yes ii)No iii) (No response)	218 120 2	64.1 35.3 0.6	A significant proportion of carers (35%) had no awareness of local dementia organizations. This problem needs to be addressed	A possible solution is to have information about dementia services in Singapore routinely presented to the carer after diagnosis in the hospital memory clinics.
Attended any dementia	i)Yes, only once	106	31.2	While about 70% of the carers have attended carer educational or support	The relatively high proportion of 70% is likely

educational or support sessions for carers	ii)Yes, more than once iii)No iv) (No response)	132 101 1	38.8 29.7 0.3	sessions, 30% have only attended once. The reasons for this are detailed below.	because a sizable portion of the sample comprises carers from ADA’s carer registry.
Have services utilized/attended be of help	i) Yes ii) No iii)N/A iv) (No response)	217 16 105 2	63.8 4.7 30.9 0.6	Only a small percentage of those who have attended carer services found it not to be helpful. N/A refers to carers who have never attended carer services.	The sizable number of “yes” speaks for the quality of the carer programmes and services.
Reasons for not using/attending carer service programme regularly	i) Don’t see need or relevance ii)No time/ too busy iii)Don’t have topics or things interested in iv)Generally not worth time/ money spent v)Too much commitment vi)Don’t want to think or talk too much about dementia	15 90 6 10 9 6	4.41 26.47 1.76 2.94 2.64 1.76	The 3 most important reasons are: i. no time ii. can obtain own information iii. full-time carer Although only 5%(17 subjects) said they were not aware of carer services, this is still an area that needs to be attended to.	“No time” can be understood in the light of the finding that many carers have several other commitments and responsibilities. It can however also be construed that for some carers may not rank caregiving foremost on their priorities. The carers who chose “can obtain own information” is an important group to target as they are likely committed and interested but may not realize the importance of obtaining proper information from dementia care professionals. Information obtained on their own should always be discussed with a

	<p>vii)Too far / inconvenient 15 4.41</p> <p>viii)Obtain info from own reading and research 56 16.47</p> <p>ix)Unable to attend because full- time carer 20 5.88</p> <p>x)Not aware 17 5.00</p> <p>xi)N/A: use service regularly 134 39.41</p>		<p>professional to ensure correct interpretation and proper usage.</p> <p>Elder-sit or respite services need to be in place for full-time carers who are unable to attend programmes because of the need to constantly provide care for the PWD.</p>
Preferred Option of Care for PWD	<p>i) Have nursing home care for him 46 13.52</p> <p>ii)Take care of him at home by myself and help from domestic maid 183 53.82</p>	<p>Majority of the carers chose to care for the PWD themselves at home but clearly expressed their need for help in the form of :</p> <ul style="list-style-type: none"> - domestic maid (53.8%) - day care (39.1%) - other family members (38.5%) <p>Only 13.5% of the carers chose nursing home care.</p>	<p>One can surmise that most carers have a strong desire to look after the PWD themselves at home.</p> <p>However they realize the difficulties involved and seek assistance. Possible ways to meet help meet this desire of carers include:</p>

	iii)Take care of him at home by myself and help from day care centre	133	39.11		
	iv)Take care of him at home by myself and help from home help service	28	8.23		
	v)Take care of him at home by myself and help from other family members	131	38.52		
	vi) Take care of him at home by myself	22	6.47		
	vii)Others	7	2.05		
	viii(No response)	8	2.35		
					<ul style="list-style-type: none"> - formal training in dementia care for maids - making it less costly to employ maids (eg. waive levy) - providing an allowance for carers who wish to care for the PWD at home

III. Carers' views on dementia services for the PWD				
Age of PWD	Mean age: 79.15; S.D: 8.56			
Gender	i) Male	122	35.9	The sample comprised mostly female PWDs with moderate stage dementia.
	ii)Female	216	63.5	
	iii)(No response)	2	0.6	Understanding the profile of the PWD is important when analyzing the findings on utilization of services for the PWD.
	Total	340	100.0	
Dementia stage of PWD	i) Mild	86	25.3	
	ii) Moderate	156	45.9	
	iii) Advanced	96	28.2	
	iv)(No response)	2	0.6	
Use of dementia services by PWD (includes prior use and may have now stopped)	i)Day care / Rehabilitation / Dementia activity programme	148	43.5	N/A implies PWD never utilized any dementia service to date. Expectedly, day care programmes for both rehabilitation and social activities are most utilized. A sizable proportion (41.8%) have never utilized any services and this is evaluated in the section below. Utilization of services is dependent on both availability and demand. This should
	ii) Early dementia programme	19	5.6	
	iii)Meal services for patient staying alone	2	0.6	
				Ground experience often reveals the need for befriender and eldersit services. The low utilization of these services could thus be explained by lack of availability. PWD who are in the moderate stage are most likely to use day care services. Those with advanced

	iv)Home-help and housekeeping services	3	0.9	be considered in analyzing the results.	<p>dementia may no longer be able to interact and benefit from day programmes. Persons with advanced dementia would require more nursing care at home. This calls for:</p> <ul style="list-style-type: none"> i. for more trained personnel to be able to provide home-based nursing care ii. More formalized training for family carers and domestic maids in care for the person with advanced dementia. <p>Persons with early dementia may still be independent and have a daily agenda of their own. They may thus not be willing to be confined to the routines and structure of day centres. Conversely, this also calls into question the suitability of current day centre programmes to meet their needs. There is a need to evaluate the needs of those with early dementia to better design services to meet their needs.</p>
	v)Befriender services	2	0.6		
	vi)Home nursing	8	2.4		
	vii)Others (e.g. elder-sit)	12	3.5		
	viii)N/A	142	41.8		
	ix)No response)	4	1.2		

Reason for no longer utilizing or not utilizing dementia service	i) Don't see need or relevance	60	17.64	<p>N/A implies PWD is using dementia services regularly.</p> <p>The commonest reasons cited for not using dementia services are:</p> <ul style="list-style-type: none"> i. Maid available (20%) ii. PWD refuses (18.8%) iii. Don't see need (17.6%) <p>Issues with timing, convenience, transport and lack of time make up 12.6%.</p> <p>A possible way to interpret the findings is to categorise the reasons into:</p> <ul style="list-style-type: none"> a) PWD factors <ul style="list-style-type: none"> - advanced disease, lack of insight, less sociable personality, worry about finances, interests cannot match programme (eg. early dementia, higher social economic status) b) Carer factors <ul style="list-style-type: none"> - issues with time, other priorities, finances, awareness of importance of regular activities and engagement for the PWD. 	<p>The high proportion (40%) of those utilizing dementia services can be explained by the sample being comprised partly of carers from the ADA carers' registry. The actual usage of dementia services for the PWD is likely to be lower.</p> <p>Financial considerations, although not expressly stated, is likely to feature in (i), (ii) and (iii).</p> <p>The following recommendations can help to increase uptake of dementia day programmes:</p> <ul style="list-style-type: none"> i. proactive education for carers on the benefits of a structured day activity programme for PWD. This can be provided as standard for carers of persons with newly diagnosed dementia in hospital memory clinics. ii. Making the day care more accessible by extending opening hours and improving transport coverage iii. Making day care more affordable with increased
	ii) PWD refuses	64	18.82		
	iii) Domestic maid can care, okay for now	68	20.00		
	iv) No time, busy, other commitments	18	5.29		
	v) Don't have services / benefits needed	4	1.17		
	vi) Generally not worth time / money spent	9	2.64		
	vii) Timing not ideal, hard to schedule	9	2.64		
	viii) Inconvenient / Difficult with transport accessibility	16	4.70		

	ix)Not aware of services	10	2.94		subsidies
	x)N/A	137	40.29		iv. Improving the quality of the programmes by going beyond generic programmes and adapting to the varied needs of different clients

IV. Carers' expressed needs for themselves and for the PWD

Carers expressed needs for themselves	Mean scores	Implications & Recommendations
a) Access to detailed information about dementia	4.38	<p>For this part of the survey, the family carers were asked to rate the importance of 26 needs statements using a 5-point Likert scale (1= not important, 2=not so important, 3=not sure, 4=somewhat important and 5=important). The mean scores for each statement are shown here and it can be seen that apart from items (i), (l) and (n) which pertain to the emotional needs of the carers, and item (s) which refers to prolonging the life of the PWD, the rest of the items had a mean score >4, suggesting that they were issues that were at least somewhat important to the carers. The items that scored >4.5 are shaded in grey and they represent issues that are most important to the carers. From the findings, it appears that the carers are looking for practical help in caregiving as the issues of importance to them mostly pertain to practical support, learning skills and better care for the PWD (medical treatment, more trained staff, daycare, safe environment).</p>
b) Opportunities to discuss the PWD's condition and treatment options in detail with the doctor	4.65	
c) Acquire new communication skills to be able to engage with the PWD meaningfully	4.34	
d) Learn to cope with difficult behaviour in PWD	4.77	
e) Learn skills to care for advanced dementia and cope with end of life issues	4.43	
f) Better financial support for you as caregiver	4.33	
g) Support from family, relatives & friends to aid in your caregiving role	4.58	
h) Support from community services & professionals to aid in your caregiving role	4.36	
i) Chance to share and voice needs & concerns & learn with other carers eg. in a support group	3.98	
j) Free time for yourself, away from caregiving to rest or pursue what you like	4.36	
k) A domestic maid to help care for the patient	4.01	
l) PWD can show gratitude & love to you	3.45	
m) Leisurely outings with patient	4.05	
n) Being able to enjoy caregiving & life as caregiver	3.99	
o) Better public awareness and media coverage on the economic and social realities of dementia	4.28	

Carers expressed needs for the PWD	Mean scores	Implications & Recommendations
p)Medical treatment for the PWD to control the symptoms of dementia even though there is no cure	4.66	<p>Carer support groups do not feature high in the needs of carers and this may explain why some support groups suffer from poor turnout.</p> <p>Having more financial support was deemed at least important with mean score of 4.33 but was not amongst the highest needs expressed. Again, this being a more literate and economically viable sample may account for this finding.</p> <p>Moving forward, based on the needs expressed, the following can be done: i.more formal training for carers in managing difficult behaviour in</p>
q)Less behavioural problems in the PWD	4.41	
r)Better trained staff caring for PWD in care centres, hospitals and nursing homes	4.65	
s)Prolonging the PWDs life	3.48	
t)A safe & supportive home environment for the PWD	4.75	
u)PWD able to maintain or return to his usual daily activities and lifestyle	4.41	
v)PWD maintains social life with family, relatives and friends	4.49	
w)A nursing home to care for the PWD full time	4.04	
x)A daycare programme with activities for the PWD to attend regularly	4.56	
y)PWD learning memories strategies & brain stimulation techniques to maintain brain function	4.48	

<p>z)More opportunities for PWD to go out with you or with family and friends</p>	<p>4.31</p>	<p>dementia as well as end of life care. ii. more opportunities for carers to discuss issues about care of the PWD with doctors and other healthcare professionals iii. Providing better quality care and increasing the capacity of current dementia day cares iv. Improving the competence of healthcare professionals in dementia care across all health sectors from acute hospitals to nursing homes and day cares. v. Providing better home care support for the PWD and the carer eg. home medical care & nursing, elder-sit, end of life dementia care at home.</p>
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6. CONCLUSION

This project was undertaken to provide a cross-sectional view of family carers of PWD in Singapore with respect to understanding the demographic profile of the carers and their caregiving situation, knowing how they obtain information on dementia, assessing their awareness, utilisation and views about current dementia services and understanding their needs in this role for themselves and for the PWD. The number of subjects recruited is the largest to date on this subject and the project has achieved its basic purpose in obtaining a descriptive overview of the caregiving situation for dementia in Singapore. It is hoped that the findings of the study will serve as useful information for the planning and development of services for PWD and their family carers in Singapore.

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8. REFERENCES

1. Asia Pacific Members of Alzheimer's Disease International. Dementia in the Asia Pacific Region: The Epidemic is Here. Alzheimer's Disease International 2006.
Available at:
<http://www.accesseconomics.com.au/publicationsreports/search.php?searchby=year&searchfor=2006>
2. D Yeo, T Lee, Ng LL, Seng BK, Luo N, J Lim, Lee SM, Chionh HL, J Goh, P Yap. Alzheimer's Disease International's global survey of dementia carers – Singapore's perspective. Presented at 24th Alzheimer's International Conference, Singapore 2009.
3. Fong NP, Luo N, Seng BK, Ng WY, J Lim, Chionh HL, J Goh, T Lee, P Yap. Needs of family caregivers of persons with dementia in Singapore. Presented at 24th Alzheimer's International Conference, Singapore 2009.
4. Seng BK, Luo N, J Lim, Ng WY, P Yap, Lee SM, T Lee, Ng LL, D Yeo. Validation of the Zarit Burden Interview for caregivers of persons with dementia in Singapore. Presented at 24th Alzheimer's International Conference, Singapore 2009.