

THE ROLE OF GPs IN SUPPORTING CAREGIVERS OF PERSONS WITH DEMENTIA IN SINGAPORE

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ABSTRACT

Caregiver interventions have been shown to reduce caregiver depression, the burden of care, and improve their health and quality of life. Caregiver support also benefits the person with dementia (PWD). It is important to recognise that caregivers need caring too. Caregivers of PWD are usually middle-aged daughters and sons followed by spouses. Foreign domestic helpers also play a pivotal role in Singapore. Stressors arising from caregiving change at different stages of the disease. As the disease progresses into the advanced stages, stress from dealing with behavioural problems can lessen as the burden from coping with physical and functional impairments increases. For this reason, caregiver interventions should be stage appropriate. There is a need to create a positive experience in the GP consultation with the important elements of early diagnosis, providing stage specific information and interventions, and up-to-date information on dementia resources available in the community. The role of the GP in supporting the caregiver is more important than ever amid the current COVID-19 pandemic.

Keywords: Caregiver intervention, proactive role, caregiver depression, burden of care, quality of life

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INTRODUCTION

The importance of caregivers and the crucial role they play in the well-being of persons with dementia (PWD) cannot be over-emphasised. Based on the findings of a study conducted by Alzheimer's Disease International in Asia Pacific¹, the prevalence of dementia in Singapore in 2050 will be approximately 187,000. By extension, this would mean an equivalent number or more of caregivers being required to take care of these PWDs.

Caregiver interventions have been shown to reduce caregiver depression, the burden of care and improve their health and quality of life. Such interventions also positively impact the quality of life, behavioural changes, medication compliance in the PWD, and reduced rates of institutionalisation.

In dementia care, it is paramount not to neglect the caregiver. He/she is often the silent patient or sufferer. Caregivers need support and care as well. Caring for caregivers includes: (1) continual assessment of their needs, (2) support in the form of education, empowerment and enablement, (3) helping them look after their own physical and emotional well-being.

Do GPs make a difference in dementia care? A study by Fortinsky² showed that when the symptoms of dementia emerge, patients and caregivers often turn first to their primary care physician for answers to questions about memory loss and obtain a diagnosis.

The current COVID-19 pandemic has illustrated that GPs are more essential than ever. Not only are GPs the vanguard of community screening for possible COVID-19 patients, but they also have a critical role as frontliners in screening for cognitive impairment among patients and caregiver burden during this time of unprecedented crisis.

CAREGIVERS

Local studies have shown that the majority of caregivers are Women.^{3,4,5,32} Caregivers are usually middle-aged and mostly children followed by spouses.^{4,5,32} Many caregivers rely on other family members for additional help. About half hold a full-time or part-time job.³ In the Chinese family, there is also a hierarchy of expectations that the relative will be a caregiver in the order of spouse, daughter, daughter-in-law, son and other kin.³ As a reflection of changing social norms and disintegration of the extended family, it is often the unmarried daughter or son who is left to care for the older patient.

Besides family members, the role of the Foreign Domestic Helper (FDH) must not be forgotten. Families of PWDs often engage a foreign domestic helper (usually from Philippines, Indonesia or Myanmar) to help take care of their loved ones. This is especially true in Singapore where a local study showed about 50 percent of families of PWD engage in foreign domestic help.³² This has led to a dichotomy of caregiving responsibilities. The foreign domestic helper does the physical caregiving while the children provide financial support and decide care decisions. In large families, it is not uncommon for the PWD and foreign domestic helper to rotate and stay in different children's homes for certain periods of time. The foreign domestic helper is sometimes the only person who resides with the PWD in a one or two-room Housing Development Board (HDB) flat for smaller families. It is thus important to look into the needs of FDHs as they often assume the role of the main caregiver and may be more aware of cognitive and behavioural changes in the PWD in the course of the illness. Local studies have shown that FDH face many challenges in caring for PWD, so they should be accorded the necessary support and assistance.³⁷

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Factors that affect caregiver performance

Demographic characteristics that influence caregiver performance include age, gender, healthcare status, kin relationship and racial/ethnic background (Table 1).⁶ Older spouses have more caregiver stress and burden as they are often beset with ill-health or even become cognitively impaired themselves. Women and wives tend to have more psychological stress in caregiving.^{7,8} The relationship to the PWD also matters. Daughters-in-law who have a difficult relationship with their mothers-in-law often have more caregiver stress.³ With regards to ethnicity and caregiving, not much is known locally; although Malay families appear more willing to take up caregiving roles for their relative with dementia.

Table 1. Demographic characteristics that influence caregiver performance⁶

- Age
- Gender
- Healthcare status
- Kin relationship
- Racial/ ethnic background

Stressors from caregiving

As dementia progresses, caregivers can experience greater burden (Table 2). A local study⁴ on the burden of caregiving in mild to moderate dementia revealed that even in the earlier stages of dementia, 48 percent of caregivers reported the caring process difficult. More importantly, these difficulties were pertinent enough to be significantly associated with the intention to institutionalise the PWD. Behavioural problems featured more prominently than functional disabilities in relation to the caregivers' experience of burden. The converse was seen in another local study¹⁰ done on patients with more advanced dementia. As dementia progresses and behavioural problems lessen in intensity, functional impairments become more pronounced. Caregivers therefore encounter changing issues and challenges in caregiving that emerge at different stages of the disease. Understanding the background, personality and life history of the PWD plays a crucial role in helping the caregiver understand the reasons behind his behaviour. Often, behavioural issues may seem bizarre but with the thoughtful reflection of the circumstances surrounding the emergence of the behaviour in the PWD in the light of his past, one can often find meaning and understanding behind the behaviour. This insight gained can direct the caregiver to offer comfort and solace to the PWD who may feel threatened, insecure, and vulnerable when he exhibits seemingly "difficult behaviour".

The impact of caregiving on the caregiver can also be felt in indirect ways (Table 3). Caregivers are often torn between the needs of the patient and that of their nuclear families. Primary caregivers may suffer restricted social lives and have less time for career pursuits, hobbies and other social activities. This can lead to feelings of disenchantment, disdain and even despair. A local

study showed that more than a quarter of Singapore caregivers of PWD reported feelings of burden more than 'sometimes'. Factors that increased burden included longer duration of caregiving and financial problems.³² Caregiver burnout thus has to be looked out for constantly and needs to be addressed early (Table 4).

Table 2. Stressors arising directly from caregiving (primary stressors)⁹

Pertaining to the PWD:

- Severity of cognitive problems
- Functional disability
- Behavioural problems
- Resistiveness to care

Table 3. Stressors arising indirectly from caregiving (secondary stressors)⁹

Pertaining to the caregiver:

- Restriction of social life/leisure time
- Role strain and role conflict
- Financial strain
- Family conflict

Table 4. Factors associated with caregiver burnout⁶

- Feeling overwhelmed, angry or frustrated by caregiving responsibilities
- Feeling frustrated or angry with the PWD
- Feeling that life or health has suffered since becoming a caregiver
- Feeling that one is not doing a good job
- Feeling that one's efforts do not matter or are futile

Impact of caregiving on Caregivers

The impact of caregiving on the caregivers can be divided into four categories:

(1) Impact on Emotional Well-Being

In a previous study on Chinese families of PWD in Singapore, behavioural symptoms were significantly related to caregiver stress. Overseas studies also paint a similar picture, more than 40 percent of family and other unpaid caregivers of PWD rate the emotional stress of caregiving as high or very high. In general, up to one-third of family caregivers experience symptoms of depression. However, in the local study, 47 percent of caregivers who had caregiving problems experienced significant depression. Caregivers also report feelings of bereft

and grief, which is more pronounced in caregivers of patients with more advanced dementia. It can also happen in caregivers of patients with mild to moderate dementia, especially if the disease threatens their relationship.³⁸ It is hence important to be vigilant of caregiver burden, depression and grief so that they can be addressed if present with the appropriate interventions.

The notion that nursing home placement would bring relief of stress may not be the case in some families. One study found that family caregiver stress and depression were just as high after the placement as before placement. While caregiving's physical burden may be relieved with institutionalisation of the PWD, the emotional burden of guilt and feeling that one is not doing enough for the PWD often persists.

(2) Impact on the Caregiver's health

In a local study³ involving 50 family caregivers of Chinese PWD, 56 percent had poorer self-rated health based on the General Health Questionnaire (GHQ), which correlated significantly with incontinence, delusion, hallucination, agitation, sleep disturbance and depression in the PWD.

Caregivers of PWD are more likely than non-caregivers to report their health to be fair or poor.^{11,12}

Caregivers are also more likely than non-caregivers to have high levels of stress hormones^{12, 13, 14, 15}, reduced immune function^{12, 16}, slow wound healing¹⁷, new onset of hypertension¹⁸ and coronary heart disease.¹⁹ The impact on health can also be demonstrated at the chromosomal level: caregivers of Alzheimer's disease patients have significantly shorter telomeres on average than other people of the same age and gender.²⁰

(3) Impact on the Caregiver's employment

Many caregivers often have to reduce working hours, take time off or quit work because of caregiving responsibilities. One study found that 57 percent of caregivers were employed full-time or part-time. Of those employed, two-thirds had to go in late, leave early or take time off because of caregiving;¹⁸ percent had to take leave of absence; 13 percent had reduced hours; and 8 percent turned down promotions.²¹ Clearly, loss of income and employment adds to the caregiver burden as well.

(4) Impact on Caregivers' finances

Locally, many caregivers exhaust their finances, including their medisave accounts, in providing care for the PWD throughout the disease course. Besides food and basic necessities, other out-of-pocket expenses include medications, day care, foreign domestic helper employment, nursing home stay, home medical and nursing services as well as ancillary services such home help and meals delivery.

Positive aspects of caregiving

The positive aspects of caregiving are often overlooked. Physicians can help the caregivers identify and emphasise the positive aspects of caregiving.⁶ Cohen found that 73 percent of

her subjects could state at least one positive aspect of caregiving.²² A local study on caregiving gains identified three areas of gains: (1) Personal growth (2) Gains in relationship and (3) Higher level gains.²³ Caregivers can derive personal satisfaction and meaning in caregiving in knowing that their actions can promote positive situations and avoid negative ones.²⁴ They also gain new perspectives and a sense of purpose in life. The degree of meaningfulness in caregiving was also correlated with the presence of depression in a study by Noonan and Tennstedt.²⁵ Locally, factors associated with a higher likelihood of gains include having positive mental well-being, adopting more positive caregiving strategies, and attending caregiver training and support programmes.³⁴

GPs can certainly help the caregiver identify the positive aspects of caregiving and are well placed to encourage caregivers to seek help and support at various caregiver programmes in hospitals and community. This will boost caregivers' morale and provide opportunities for the GPs to detect low moods, burnout, and depression⁹ amongst caregivers, especially when they are persistently pessimistic and unable to see the positive in providing care for the PWD.

CAREGIVERS' EXPERIENCES WITH GPs

Caregivers report mixed experiences with GPs. A positive experience can bring about earlier detection and diagnosis of dementia, appropriate early intervention, reduction of caregiver stress and contribute to the overall holistic care of the PWD and caregiver alike. A negative experience often brings much frustration and stress on caregivers besides delay in diagnosis and treatment.

A small novel study done on GPs in Australia in 2008 focused on patients' and caregivers' experiences with GPs in settings where GPs provided a wide range of services in the absence of dementia specialist services.²⁶ The themes explored included diagnosis, cognitive testing, dementia knowledge, caregiver support, treatment, medication compliance. Below are some of the findings.

Diagnosis

Twenty-five percent (5/20) respondents reported prompt diagnosis by their GPs. The rest had delays of 1-8 year intervals between onset of symptoms and diagnosis. Three patients were aware something was wrong but only one was offered investigations. Two were frustrated when the diagnosis was initially refuted by their GPs.

Dementia Knowledge

Out of four respondents, two had positive comments on their GPs' ability to offer prompt diagnosis and access to support. Two had negative comments which were attributed to difficulties in accessing help and GPs' lack of knowledge about dementia.

Caregiver support

The interviews focused on caregiver support, discussing on issues ranging from the help they received to the frustration of being unable to access help. Many positive comments demonstrated that the most reliable, up-to-date source of information about dementia support services came from other caregivers who had first-hand knowledge of pitfalls and benefits, and not from the GP. A quarter (n=5) of the interviews produced negative comments about the services received, demonstrating the significant impact of negative experiences.

Medication compliance

Medication compliance was an issue in nearly half the cases (n=9). This was a major problem when the patient was self-caring.

This study showed that the diagnosis of dementia may often be missed in routine consultations. More importantly, it also showed that patients in the early stages may be aware of their condition and thus it was important to listen to them. With regards to dementia knowledge, “most PWD trusted their GPs to be informed about the disease and deficiencies in GP knowledge led to delayed diagnosis and consequently less optimal support and management.” ... “Negative comments were also received when GPs failed to identify the disease or arrange for support.” “Caregivers appreciated a diagnosis that explained what was happening, even when providing a prognosis was difficult.” For caregiver support, “PWD and caregivers expected their GPs to offer appropriate care and access to dementia services and wished for GPs to be better informed about support services.” It also showed that many older persons (and caregivers) valued a GP who could inform them.

Locally, some may have similar experiences with their GPs and this reinforces the view that GPs are well placed to initiate early support, diagnosis and treatment. In addition, medication compliance is a constant issue with PWD and thus caregivers need to be encouraged and supported to take an active part in assisting with administering medication.

OPTIMAL CARE AND THE HEALTH CARE TRIAD

In Singapore today, GPs have a wealth of resources to draw from to help in providing care and care to PWD and their families. Against a setting of limited consultation time in primary care, evolving symptoms with disease progression in the PWD, possible negative attitudes towards dementia diagnosis and treatment, inadequate reimbursement and lack of incentive for in-depth consultations, the quality of interaction between the GP, PWD and caregiver(s) is most critical for optimal dementia care. A review by Holmes and Adler²⁷ provided a few pointers that could enhance this interaction.

These include (1) being alert to the cognitive and behavioural changes in the PWD (e.g., missed appointments, poor compliance with medications, frequent telephone calls to the

clinic, missed payments and a family member accompanying the PWD to the clinic visit when there was none before), (2) involving persons with early dementia in their own care, (3) identification of a principal caregiver, (4) progressive involvement of the caregivers in the care plan as the disease progresses. The relationship of the GP with the PWD and caregiver thus forms a critical “health care triad”^{2,28}, which is essential for optimal dementia care and management.²⁹

MANAGEMENT AND SUPPORT OF CAREGIVER BY GPs

When and how?

The needs of the PWD change throughout the course of the illness, this means that support and intervention for the caregiver would also need to be different at various stages of dementia. These key stages are elaborated herein.

- (1) Diagnosis and disclosure
- (2) Early stage of the disease
- (3) Moderate stage of the disease
- (4) Severe stage of the disease
- (5) Bereavement
- (6) Referral and use of community resources

(1) Diagnosis & Disclosure

Patients and families want an accurate and clearly explained diagnosis and desire to better understand the course of the illness over time.³⁰ “Specifically, caregivers want their physicians to listen to their concerns, devote more time to discussing diagnosis and what it means, and include the PWD even if he or she may not fully understand”.³⁰ Research has documented that these factors are closely linked to with caregiver satisfaction.⁶

The disclosure process should be tailored to the patient and caregiver dyad. While most physicians and caregivers prefer to focus on discussions on memory problems and safety issues rather than the term Alzheimer’s disease; most families want more specific information regarding the diagnosis and prognosis as mentioned above.³⁰

(2) Early stage of the disease

Accepting and adapting to the role of a caregiver is the primary goal for most caregivers at this stage.⁶ Caregivers can be in denial during this stage and fearful of grappling with the unknown. Time taken to educate and empower the caregiver certainly helps the caregiver to cope better. Simple explanations with written materials, brochures and books, and information from caregiving websites are useful. Repetition of important information over several visits is also helpful. Referrals to caregiver support programmes are a good way for caregivers to seek peer support and advice.

Other care initiatives that can be established with the caregiver at this stage include:

- Adaptation
- Financial, legal planning and advance directives
- Establishment of a support system for the caregiver

Adaptation

Becoming a caregiver is often unplanned, life-changing and a long-term event. Spouses or children have to discard old roles and take on new ones, for example, a son becoming the caregiver and decision-maker for the father. Emotional support & empathy are crucial at this stage.

Financial, legal planning and advance directives

Advice should also be given to the PWD and caregiver on sorting out financial issues such as bills, CPF/ bank accounts, and insurance. With the enactment of the Mental Capacity Act, PWD who are still mentally competent and retain insight can make a Lasting Power of Attorney (LPA) and participate in Advance Care Planning (ACP).

Establishment of a support system for the caregiver

Helping the caregiver look after him/herself is also important. GPs can play a role in involving extended family members and friends in caregiving so as to relieve the burden on the primary caregiver(s). Besides caregiver support groups, caregivers can be encouraged to seek support through religious or voluntary groups and even close neighbours.

(3) Moderate stage of the disease

This stage is characterised by the emergence of more behavioural/ personality changes in addition to progressive cognitive and functional decline. Most caregivers face significant burdens and need more help at this stage. However, some caregivers may not see that they need more help and accepting help from others also presents an issue. The local caregiver study³ revealed that Chinese caregivers relied more on family support and less on psychogeriatric services for fear of 'losing face'. Hence, caregivers may delay seeking help till a crisis or burnout occurs.

GPs are well placed to offer assistance. GPs need to be on the alert for caregiver distress, depression and burnout (Table 4). The ability of the caregiver to cope depends on his personal coping resources as well as the amount and quality of formal and informal support.³ Early referral to the appropriate caregiver resources is recommended and the GP can help the caregiver select the service appropriate for his needs. These resources can be specific to the PWD or primarily targeted at caregivers. Regular contact with the GP or attending specialist can help the caregiver tide over difficult periods.

(4) Severe stage of the disease

At this stage, patients are often debilitated and require round-the-clock care for their activities of daily living. Caregivers are faced with decision-making and preparation for various end-of-life issues and trust their physician to guide them in making difficult choices. These issues include do-not-resuscitate orders, tube feeding, rational use of medications and specialist palliative care.

(5) Bereavement

Bereavement on the part of the family caregiver often begins in

the earlier stages of dementia when the PWD progressively ceases to be the person he used to be. Depression is prevalent especially among caregivers who experience loss of companionship and a treasured relationship⁶ as the PWD becomes increasingly foreign and distant. Studies show that even after death, caregivers can still have grief reactions up to three years after death⁹ of the PWD. GPs can provide counsel and support for the caregiver trying to come to terms with the losses in dementia.

(6) Referral and use of community resources

Besides information from hospital-based memory clinics, the Alzheimer's Disease Association of Singapore (www.alzheimers.org.sg) and the Agency for Integrated Care (www.aic.sg) provide much information on community resources and services. ADA also runs a helpline for caregivers and the general public. A local study found that knowledge and awareness of dementia services was the single significant predictor of the use of these services. There is hence a need to provide timely and relevant information on services and resources for dementia in the community to enhance their uptake.³⁵

Additional tips for GPs in meeting the needs of the caregiver

- Establish contact and liaise with the specialist to gain a greater understanding of the needs of the PWD and his caregiver.
- Understand the life history and personality of the patient. This is cardinal to providing person-centred care.³¹ Oftentimes, one can understand the reason behind certain behavioural issues in the PWD in light of his past. This can help the caregiver achieve a greater understanding of the PWD, cope better, and reduce caregiver stress.
- Provide information to caregivers appropriate to their situation and relevant to the problems consistent with the patient's stage of dementia. Divide important information into "bite-sized" portions over several visits.
- Offer a listening ear to the caregiver and allow time for him/her to ventilate; this can be therapeutic for the caregiver.
- Enquire about the caregiver's health and coping regularly as some caregivers may not volunteer information about their own well-being.
- Engage the foreign domestic helpers (FDH) as they are caregivers as well. Enquire about her coping ability and caregiver stress as FDH's needs are often overlooked and they can be silently suffering while caring for the PWD. Oftentimes, they give a better history regarding the cognitive and behavioural function of the PWD.
- Home-based respite for caregivers can be a useful alternative to provide respite for family or FDH caregivers. Caregiving agencies such as Homage, Jaga-Me and Active Global Specialised Caregivers provide time flexible caregiving services for the patient at home that can reduce caregiver burden and improve the quality of life of caregivers. For those patients who qualify, Homage and Active Global Specialised Caregivers have care packages and subsidies to offset the costs.

CAREGIVER SUPPORT DURING THE CURRENT COVID-19 PANDEMIC

We are currently living in a time like no other. The COVID-19 pandemic continues to ravage the world leaving behind a trail of human devastation, healthcare crises and unprecedented challenges in ageing societies. During lockdowns around the world and our own Circuit Breaker in 2020, many community-dwelling PWD and their caregivers suffered adversely. From the sudden curtailment of dementia day care attendances to being confined at home with a lack of cognitive engagement and exercise, many PWD had sudden changes in behaviour and functional decline (both cognitive and physical). Caregivers had to grapple with the care of the PWD and at the same time juggle the demands of work, care of other family members and provision of daily needs. Not a few had a loss of income or became unemployed. This severely increased caregiver burden and lowered quality of life. By necessity, home-based care strategies have evolved rapidly to meet the changing needs amidst the social distancing measures imposed by a rampant virus. A landmark review article published last year on tackling the challenges in the care of Alzheimer's Disease and other dementias amid the COVID-19 pandemic highlighted the need for strategic directions and changes in protecting and caring for older people with dementia at home during the current pandemic.³⁶ A recent local publication also addressed issues about dementia in light of the COVID-19 pandemic in Singapore.³⁹ Suggested measures to alleviate the concerns and stress of the caregivers at home include³⁶:

- Regular screening for anxiety, stress and depression among the caregivers and prompt intervention.
- Through video conferencing, encourage caregivers to have regular home-based exercise, recreational activities, and other ways to relieve stress (e.g., listening to music).
- Health care providers can organise guided online self-help caregiver support groups for updating infection control measures and at the same time, open a platform for stress reduction programs.
- Show appreciation for/gives praise to/cheer up informal caregivers.
- Making contingency plans for caring the patients in case the caregivers become sick.

Besides hospital and community-based dementia care services, the GP is well placed to provide all of the above.

CONCLUSION

Caregiver interventions have been proven to improve caregiver coping and reduce caregiver depression and burden. The GP's role in supporting the caregivers of PWDs in the community has long been an important one. This role is even more crucial now as we continue to find new ways to deliver holistic care to PWDs and their caregivers amid an uncertain pandemic world.

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LEARNING POINTS

- Support for caregivers has been shown to reduce caregiver depression, the burden of care, and improve their health and quality of life.
- Caregiver interventions also benefit PWD.
- Caregivers of PWD are usually middle-aged daughters and sons, followed by spouses. Foreign domestic helpers often provide direct care to the PWD.
- Information given to caregivers should be tailored to their specific needs.
- GPs have a crucial role in supporting the caregivers during the current COVID-19 pandemic.