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SUPPORTING CAREGIVERS OF PERSONS WITH DEMENTIA IN PRIMARY CARE

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ABSTRACT

Caregiver interventions have been shown to reduce caregiver depression and burden of care, while improving caregiver health and quality of life. Caregiver support also benefits persons 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. Migrant domestic workers play an important 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.

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 Pacific,[1] the prevalence of dementia in Singapore in 2050 will be approximately 187,000. By extension, this would mean an equivalent or a higher number of caregivers being required to take of these PWDs.

Caregiver interventions have been shown to reduce caregiver depression and burden of care, while improving health and quality of life. Such interventions also have a positive impact on the quality of life, neuropsychiatric symptoms, medication compliance, and rates of institutionalisation in the PWD.

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In dementia care, it is paramount to not neglect the caregiver(s). They are often the silent patients or sufferers and need support and care as well. Caring for caregivers include: (1) continual assessment of their needs; (2) support in the form of education, empowerment, and enablement; and (3) helping them look after their own physical and emotional well-being.

Do GPs make a difference in dementia care? A study by Fortinsky[2] 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 COVID-19 pandemic illustrated the critical role GPs play as frontliners in screening for possible COVID-19 patients as well as cognitive impairment among patients post COVID in the community.

CAREGIVERS

Local studies have shown that the majority of caregivers are women.[3-5,32] Caregivers are usually middle-aged and mostly children of the PWDs, 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 Migrant Domestic Worker (MDW) must not be forgotten. Families of PWDs often engage an MDW (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 that about 50 percent of families of PWD engage in foreign domestic help.[32] This has led to a dichotomy of caregiving responsibilities. The MDW does the physical caregiving while the children provide financial support and decide on care decisions. In large families, it is not uncommon for the PWD and MDW to rotate and stay in a different child's home for certain periods of time. The MDW 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 MDWs 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 MDWs face numerous challenges in caring for PWD, thus they should be accorded the necessary support and assistance.[37]

Factors That Affect Caregiver Performance

Demographic characteristics that influence caregiver performance include age, gender, healthcare status, kin relationship, and racial/ethnic background (refer to **Table 1**).[6] Older spouses have more caregiver stress and burdens 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 experience 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 relatives with dementia.

Table 1. Demographic characteristics that influence caregiver performance[6]

• Age
• Sex
• Healthcare status
• Kin relationship
• Racial/ethnic background

STRESSORS FROM CAREGIVING

As dementia progresses, caregivers can experience greater burden (refer to **Table 2**). A local study[4] 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 as 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 study[10] 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/her 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/her 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 she/he exhibits seemingly "difficult behaviour".

The impact of caregiving on the caregiver can also be felt in indirect ways (refer to **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 constantly looked out for and needs to be addressed early (refer to **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 burnout[6]

• 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 the Caregiver's Emotional Well-Being

In a previous study involving Chinese families of PWD in Singapore, behavioural symptoms were significantly related to caregiver stress. Overseas studies also paint a similar picture, with more than 40 percent of family and other unpaid caregivers of PWD rating the emotional stress of caregiving as high or very high. In general, up to a 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 experience a sense of grief or loss, 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 aware 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 study[3] 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,[12-15] reduced immune function,[12,16] slow wound healing,[17] new onset of hypertension,[18] 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 sex.[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 the Caregiver's 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, and home medical and nursing services, as well as ancillary services such as 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 from 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 depression[9] amongst caregivers, especially when they are persistently pessimistic and unable to see the positives 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, and 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, and 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 one- to eight-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 the 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."[26] 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.[26]

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 PWDs and thus caregivers need to be encouraged and supported to take an active part in assisting with administering medication.

OPTIMAL CARE AND THE HEALTHCARE TRIAD

In Singapore today, GPs have a wealth of resources to draw from to help in providing care to PWDs 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 Adler[27] 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; and (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 "healthcare 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:

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. Advance Care Planning (ACP)
7. Use of community resources

These key stages are elaborated below.

1. Diagnosis and 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

2a. Adaptation

Becoming a caregiver is often an unplanned, life-changing, and 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 and empathy are crucial at this stage.

2b. 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, PWDs who are still mentally competent and retain insight can make a Lasting Power of Attorney (LPA) and participate in Advance Care Planning (ACP)(see point 6 below).

2c. 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 study[3] 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 until a crisis or burnout occurs.

GPs are well placed to offer assistance by being on the alert for caregiver distress, depression, and burnout (refer to **Table 4**). The ability of the caregiver to cope depends on his/her 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/her 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/she used to be. Depression is prevalent especially among caregivers who experience loss of companionship and a treasured relationship[6] 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 death[9] of the PWD. GPs can provide counsel and support for the caregiver trying to come to terms with the losses in dementia.

6. Advance Care Planning

Patients in the early stages of cognitive impairment, e.g., Mild Cognitive Impairment (MCI) and Mild/ Early Dementia, have the mental capacity and insight to do their own Advance Care Planning (ACP). A local study on 93 Early Cognitive Impairment (ECI) patients showed that only 38.7 percent chose to engage in ongoing ACP discussions. The three main reasons cited were: (1) Deferring of decision-making to families; (2)Perception of ACP as irrelevant or unnecessary; and (3) Displays of avoidance and denial during ACP discussions. [Ref: Cheong K, Fisher P, Goh J, Ng L, Koh HM, Yap P. Advance care planning in people with early cognitive impairment. BMJ Support Palliat Care. 2015 Mar;5(1):63-9. doi: 10.1136/ bmjspcare-2014-000648. Epub 2014 Oct 21. PMID: 25336042.] A qualitative study done among Australian GPs found that the GPs saw themselves playing an important role in facilitating ACP discussions, especially before the onset of dementia. It also highlighted that GPs' beliefs about the benefits of ACP could act as an enabler in successful ACP discussions. [Ref: Alam A, Barton C, Prathivadi P, Mazza D. Advance care planning in dementia: a qualitative study of Australian general practitioners. Aust J Prim Health. 2022 Feb;28(1):69-75. doi: 10.1071/PY20307. PMID: 34844662]. In light of this, initiation of ACP discussions among ECI patients at the GP clinics in the local setting could yield result in greater acceptance of ACP among these patients. [Ref: https://www.sma.org.sg/news/2023/ November/ACP-for-Persons-with-Cognitive-Impairment]

7. Use of Community Resources

Besides information from hospital-based memory clinics and Regional Health Clusters, Dementia Singapore (dementia.org.sg) and the Agency for Integrated Care (AIC) (www.aic.sg) rely on apps, community resources, and services (e.g., Dementia Day care centres) to support patients and

their caregivers. 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]

A recent home-based care programme to highlight would be the Home Support Team (HST). This support team assesses the needs of persons living with dementia and caregivers, with the aim for them to live well in the community by developing individualised interventions such as case management, counselling, psychoeducation, therapy, and training for holistic care. Working closely with community partners, hospitals, polyclinics, and General Practitioner partners, HST ensures the continuum of care for clients in the community. The team also promotes dementia awareness in the community to promote a dementia-friendly Singapore. HST is part of the Community Intervention Team (COMIT) and Community Resource, Engagement and Support Team (CREST) under the Community Mental Health Masterplan developed by the AIC, together with MOH. The objectives are to support persons with dementia and caregivers within the home by utilising behavioural management strategies, dementia psychoeducation, and supportive counselling. This programme is appropriate for caregivers facing high stress due to caregiving issues.

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/her 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/her 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 vent; 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 MDWs as they are caregivers as well. Enquire about her coping ability and caregiver stress as MDWs' 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 in providing respite for family or MDW caregivers. Caregiving agencies such as Homage, Jaga-Me, and Active Global Specialised Caregivers (to name a few) 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, a few of these agencies have care packages and subsidies to offset the costs.

CONCLUSION

Supporting caregivers of PWDs is paramount in good care of PWD. As Singapore hits "super-aged" status in 2026 (when the proportion of the population aged 65 and above reaches 21 percent), caregivers age as well. Primary care doctors, in working with the community and tertiary hospitals, are pivotal in ensuring healthier ageing of both patients and caregivers.

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LEARNING POINTS

- **Support for caregivers has been shown to reduce caregiver depression and the burden of care, improve their health and quality of life.**
- **Caregiver interventions also benefit PWDs.**
- **Caregivers of PWDs are usually middle-aged daughters and sons, followed by spouses. MDWs often provide direct care to the PWDs.**
- **Information given to caregivers should be tailored to their specific needs.**
- **Utilisation of community resources and services is essential in looking after the welfare of the caregivers.**