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UNIT NO. 6

THE ROLE OF GENERAL PRACTITIONERS IN HELPING CAREGIVERS OF PERSONS WITH DEMENTIA

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ABSTRACT

Caregiver interventions have been shown to reduce caregiver depression, 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 too, need care. Caregivers of PWD are usually middle-aged daughters and sons followed by spouses. Foreign domestic workers 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 having to deal with behavioural problems can lessen as the burden from coping with functional impairments increases. For this reason, caregiver interventions should be stage appropriate. There is a need to work towards creating 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 depression, caregiver intervention, proactive role, caregiver depression, burden of care, quality of life

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INTRODUCTION

Caregivers are an integral part of the support and care of the person with dementia (PWD). Caregiver interventions have been shown to reduce caregiver depression, burden of care and improve their health and quality of life.

More importantly, intervening through the caregiver also impacts quality of life, behavioural changes, medication compliance and rates of institutionalisation in PWD as has been shown in several studies. In dementia care, two tenets are espoused: (1) Treatment through both pharmacological and non-pharmacological means, (2) Treating the PWD as well as the caregiver.

The importance of caregivers cannot be over-emphasised. In Singapore, based on the findings of a study conducted by Alzheimer's Disease International in Asia Pacific[1], the prevalence of dementia in 2020 and 2050 will be approximately 53,000 and 187,000 respectively. By including caregivers in the tally, this means the same number of caregivers and/ or families will be affected as well.

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

In ageing Singapore, General Practitioners (GPs) will play an increasing role in meeting the healthcare needs of the silver generation. In addition, care of PWD by GPs will gain increasing importance because there will be too many patients and insufficient specialists to meet the need.

Can GPs make a difference to 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 to obtain a diagnosis. As GPs are in regular contact with their patients, they are in a position to recognise early signs of cognitive decline in them. They also have the benefit of having a long-standing relationship with their patients. Therefore, a GP is well poised to provide holistic care for the PWD and his caregiver. GPs will have an increasingly important role in contributing to the care of PWD and their caregivers in the years to come.

CAREGIVERS

Local studies have shown that the majority of caregivers are women[3-6] Caregivers are usually middle-aged and mostly children followed by spouses[4-6]. 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 expectation 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, quite often it is usually the unmarried daughter or son who is left to care for the older patient.

Besides family members, most families engage the help of a foreign domestic worker (usually from Philippines, Indonesia or Myanmar). This is especially true in Singapore where a local study showed about 50 percent of families of PWD engage foreign domestic help[6]. This has led to a dichotomy of caregiving responsibilities. The foreign domestic worker does the physical caregiving while the children provide financial support and make the decisions regarding care. In large families, it is not uncommon for the PWD and foreign domestic worker to rotate

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and stay in the homes of different children for certain periods of time. For smaller families, the foreign domestic worker is sometimes the only person who resides with the PWD in a one or two room Housing Development Board (HDB) flat. It is thus important to look into the needs of domestic workers 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.

Factors that affect caregiver performance

Demographic characteristics that influence caregiver performance include: age, gender, healthcare status, kin relationship and racial/ethnic background (Table 1)[7]. Older spouses have more caregiver stress and burden as they themselves are often beset with ill-health or even become cognitively impaired. Women and wives tend to have more psychological stress in caregiving[8-9]. The relationship to the PWD also matters. Daughters-in-law who have a difficult relationship with the PWD 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 Performance[7]

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

Stressors from caregiving

As dementia progresses, caregivers can experience greater burden (Table 2). A local study[4] done in 1999 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 to be a difficult one. 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 behaviour. Often, behavioural issues may seem bizarre but with 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. This insight gained can direct the caregiver to find means to offer comfort and solace to the PWD who may be feeling 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 recent local study showed that more than a quarter of Singapore caregivers of PWD reported feelings of burden more than 'sometimes' and the factors that increased burden included a longer duration of caregiving and financial problems[6]. Caregiver burnout must be constantly looked out for and needs to be addressed early (Table 4).

TABLE 2. Stressors Arising Directly from Caregiving (Primary Stressors)[11]

Pertaining to the PWD:

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

TABLE 3. Stressors Arising Indirectly from Caregiving (Secondary Stressors)[11]

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[7]

- 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.

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 compared to before placement. While the physical burden of caregiving 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) and that 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[12,13].

Caregivers are also more likely than non-caregivers to have high levels of stress hormones[13-16], reduced immune function[13,17], slow wound healing[18], new onset of hypertension[19] and coronary heart disease[20]. 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[21].

(3) Impact on the Caregivers' employment

Many caregivers often must 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 responsibilities; 18 percent had to take leave of absence; 13 percent had reduced hours; and 8 percent turned down promotions[22]. 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[23]. A local study on caregiving gains identified three areas of gains: (1) Personal growth (2) Gains in relationship and (3) Higher level gains[24]. Caregivers can derive personal satisfaction and meaning in caregiving in knowing that their actions can promote positive situations and avoid negative ones[25]. 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[26]. Locally, factors associated with a higher likelihood of gains include having positive mental well-being, adopting more positive caregiving strategies and attendance at caregiver training and support programmes[27].

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 programme in hospitals and community. This will boost morale of caregivers and also provide opportunities for the GPs to detect low moods, burnout and depression[11] 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[28]. 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 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 patients 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 firsthand 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.

"Not a damned thing happened for us. That was the hard part because she had no help. You didn't know what help there was."

(A daughter)

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 the 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 Adler[29] 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, 30] which is essential for optimal dementia care and management[31].

MANAGEMENT AND SUPPORT OF CAREGIVER

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 disease.
(3) Middle stage disease.
(4) Final stage 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[32]. "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"[32]. Research has documented that these factors are closely linked to with caregiver satisfaction[7].

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[32].

(2) Early stage disease
Accepting and adapting to the role of a caregiver is the primary goal for most caregivers at this stage[7]. 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 support system for the caregiver.

<u>Adaptation</u>
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.

<u>Financial, legal planning and advance directives</u>
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 can assign health care decision making designees (known as donees). Other considerations include advance medical directives, will and estate planning.

<u>Establishment of support system for the caregiver</u>
Helping the caregiver look after him/herself is also important. GPs can play a role in involving extended family members and friends in caregiving 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) Middle stage 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 burden 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 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/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) Late stage 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 from 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 relationship[7] 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[11] 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 websites of Alzheimer's Disease Association of Singapore (https://alz.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 recent study found that knowledge and awareness of dementia services was the single significant predictor of 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[33].

Additional tips for GPs in meeting the needs of the caregiver

- Establish contact and liaise with the specialist to gain 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[34]. Oftentimes, one can understand the reason behind certain behavioural issues in the PWD in the light of his past. This can help the caregiver achieve greater understanding of the PWD, cope better and in turn 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. As such, assessment with a caregiver burden scale such as the Zarit Burden Interview can be appropriate[35].
- Engage the foreign domestic workers (FDW) as they are caregivers as well. Enquire about her coping ability and caregiver stress as FDW'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.

CONCLUSION

Caregiver interventions have been proven to improve caregiver coping and reduce caregiver depression and burden. Caregiver support also benefits the PWD. It is important to recognise that caregivers too need care. The GP has an indispensable role in holistic dementia care. As GPs in Singapore take up more proactive roles in dementia care in Singapore, the importance of this role cannot be over-emphasised.

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LEARNING POINTS

- **Support for caregivers has been shown to reduce caregiver depression, 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 can work towards a more proactive role in dementia care in Singapore.**