

**FAMILY CAREGIVERS AND CAREGIVING IN DEMENTIA**

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**ABSTRACT**

Good care is important in the overall management of a person with dementia. Although good care has not been shown to alter the natural progression of the disease, it can improve well-being in the sufferer and certainly helps avert excess disability. Dementia caregiving is primarily provided by family caregivers who often feel overwhelmed in the task. An overburdened carer is unlikely to provide good care. Thus, assessing for caregiver burden must form an essential part in any dementia assessment. Where appropriate, caregiver intervention should be instituted to help provide well-meaning carers with the necessary skills and support. The ultimate goal in caregiver management is to indirectly help the patient by empowering the caregiver.

**THE IMPORTANCE OF CAREGIVING**

There is still no cure in the horizon for dementia, a disease that has been described as “a death that leaves the body behind.” For the afflicted person, it robs him of his identity and even his personhood. For the family members, bereavement begins from the early stages of the disease where a once treasured relationship is gradually eroded. Faced with a seemingly hopeless situation, the question that beckons is, what can we really do for a disease like dementia apart from the relentless pursuit for a comprehensive cure?

Family carers are constantly looking for answers to the daily problems they face in caregiving. If the key to the problems of dementia lies only in medical solutions, there is little difference caregivers can make to the lives of their loved ones. However, in recent years, a more hopeful scene is emerging. Testimonies by patients and caregivers, as well as a growing body of data supported by research in the psychosocial aspects of dementia<sup>1</sup>, suggest that good quality care can make a positive impact on the disease. As noted by Hall<sup>2</sup>, the goals of dementia care are to maximise the potential for safe function by controlling for excess disability and providing appropriate levels of assistance, encourage participation in activities as desired by the client, minimise discomfort caused from physical and emotional stressors, and maximise expression of comfort. The family carer is an indispensable part of the overall management of the dementia sufferer. He is instrumental to the quality of care and hence

quality of life for the patient. He needs to be empowered to provide good care but at the same time his needs need to be recognised and met. In dementia care, there are always two clients; the patient and his carer.

**UNDERSTANDING THE DEMENTIA CAREGIVER**

Who is the main family carer? Western literature points to the spouse as the most likely person, followed by daughters, daughters-in-law, sons and siblings<sup>3</sup>. Locally, similarly, women caregivers outnumber men. Carers are usually middle-aged and are more likely to be children rather than spouses. Other carers include daughters-in-law, granddaughters and sisters. Most receive help either from a domestic maid or another relative and more than half hold a full-time or part-time job<sup>4,5,6</sup>.

The responsibility of caring for a relative with dementia exerts much psychological, physical, social and financial toll on the carer. In the study on caregivers in the Singapore Chinese family by Kua EH et al<sup>4</sup>, slightly more than half of the caregivers scored above the threshold of 5 points on the GHQ (General Health Questionnaire). Certain groups of carers are more vulnerable to psychological distress and breakdown. Wives rather than husbands, women rather than men, and spouses more than children are more prone<sup>7</sup>. Spouses appear to have increased affliction apparently because of differences in perception rather than true differences in the health impact of providing care<sup>8</sup>. Other caregiver characteristics predictive of negative outcomes include those who are socially isolated, physically unwell or use immature coping mechanisms. On the other hand, patient factors are also important in predicting psychological distress in caregivers. Patients with more behavioural disturbances as well as urinary and faecal incontinence are more likely to be admitted to nursing homes<sup>9</sup>, suggesting increased coping problems in their carers.

**CAREGIVER BURDEN**

Studies show that caregiver burden is an important factor that determines when a patient with dementia becomes institutionalised<sup>10</sup>. Caregiver burden is an all-encompassing term to capture the impact of a variety of factors that cause strain, stress and distress to people providing care to patients with dementia<sup>11</sup>. It can be conceptualised as objective and subjective burden<sup>12</sup>. Objective burden can be defined as the time and effort required of one person to attend to the needs of another while subjective burden refers to the perceived beliefs and feelings of the caregiver about the performance of caregiver tasks and assumption of the caregiver role.

Patient and carer factors as well as circumstantial causes impact caregiver burden. It is not the cognitive state of the patient or his level of dependency in his daily activities that

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impacts burden but rather the psychotic, depressive and behavioural disturbances that matter<sup>11</sup>. Caregiver related factors that impact burden include being a spousal carer, low self-rated health and caregiving competence as well as carers with high expressed emotion<sup>13,14</sup>. Younger age of the carer and low marital cohesion in spousal carers are related to more depressive symptoms<sup>13,15</sup>. Circumstantial factors of importance are staying together with the patient and the degree of social support available<sup>16</sup>. Breaking points for carers include the amount of time spent caring for the patient, loss of own identity, patient misidentifications and clinical fluctuations, and nocturnal deterioration of the patient<sup>17</sup>.

There are several scales that help to assess caregiver burden in dementia. The Zarit Burden Interview<sup>18</sup>, Screen for Caregiver Burden<sup>19</sup> and Caregiver Strain Index<sup>20</sup> are examples of some commonly used measures. The carer distress segment of the Neuropsychiatric Inventory<sup>21</sup> is particularly helpful in relating carer stress to the behavioural and psychiatric manifestations of dementia. These scales provide an objective measure of the burden experienced by carers and are thus useful in identifying carers who need more urgent help. The scales can also be useful in a longitudinal fashion to monitor caregiver stress and assess the effects of intervention, pharmacologic or non-pharmacologic, on the carer. A recent local validation study of the shortened Burden Interview revealed three main factors that account for the burden experienced by family caregivers<sup>22</sup>. They are: (1) the effect of caregiving on the personal life of caregiver (2) negative emotions related to caregiving and (3) feeling the need to do more for the patient. Caregiving can certainly be disruptive to the life of the carer. Carers often feel that the patient is dependent on them, limiting their freedom and way of life. The personal needs of the carers often have to play second fiddle to the needs of those they care for and it is clear that with time, they grow to harbour negative emotions related to caregiving. Despite their tireless efforts, several caregivers expressed a lack of direction and purpose in what they do. They often wondered if they are doing it right or if they have missed something important. Feeling the need to do more represents a form of psychological burden for them.

Caregiving is not always associated with just negative outcomes. Positive outcomes have emerged and the notion of caregiving gain has been conceptualised as not merely the absence of negative outcomes but rather the ability to find meaning and fulfilment in the caregiver's life<sup>23</sup>. In the accounts of caregiving written by family caregivers, one cannot but sense that the caregiving journey has brought out the best in them<sup>24,25,26</sup>. Their lives have acquired a new purpose, relationships within the family have been enhanced and their own views about the world and about life have taken on a new meaning<sup>27</sup>. Farran, for example, has included an existential perspective with regard to understanding how some caregivers are able to find personal meaning through caregiving<sup>28</sup>. She wrote, "Difficult experiences provide caregivers the opportunity to find provisional and ultimate meaning; that the process of finding meaning or seeing the positive is a choice that caregivers can make."

Ultimately, several factors have been found to determine positive and negative outcomes in caregiving and they can be classified into patient and caregiver variables. Pertaining to patient variables, as aforementioned, behavioural problems have more impact on burden than cognitive or functional impairment. More importantly, it is the caregivers' perception of the behaviour and level of functional impairment that is key<sup>29</sup>. Caregiver variables are often more predictive of burden. Female carers often report higher levels of burden but this could actually reflect a gender difference in the expression of one's feelings<sup>14,30</sup>. Caregiver behaviour has been studied as a psychosocial variable that impacts caregiver and patient outcomes. More than one study has found that caregivers with high expressed emotions report more stress, more impairment in mental health, less social support, less effective coping strategies, greater suppressed anger, greater depression and greater caregiver burden<sup>14,31</sup>. The quality of past relationship between carer and patient has been examined and most studies have found that a more affectionate past relationship is associated with less burden and distress in carers<sup>16,32</sup>. Cultural and ethnic differences between carers can be relevant and it is interesting to note that our local validation of the short Burden interview found a higher cut-off for burden scores than that reported in the original paper validated in a Caucasian<sup>22,33</sup> population. This may reflect a true difference in beliefs and values whereby Orientals are more likely to see caregiving of a parent or spouse as an inevitable responsibility on their part and thereby articulate less burden. Finally, greater perceived support, as well as respite, can be protective and associated with reduced stress and burden<sup>34</sup>. The need for respite is commonly expressed by carers and thus having someone lend a helping hand ever so often gives them time away from the patient, to rest, rejuvenate and have some moments to themselves. However, controlled studies of the effects of respite care reveal that while they may delay nursing home placement, they have little long-term effect on caregiver burden or depression<sup>35</sup>.

## CAREGIVER INTERVENTION

Given the immense burden of care incumbent on family carers, several efforts aimed at supporting carers and relieving their burden has emerged over the years. The goals are generally two-fold: to improve the quality of life for the patient and his carer, as well as to reduce premature and inappropriate institutionalisation. Caregiver variables have consistently emerged as stronger predictors of institutionalisation than patient factors<sup>36</sup>. The person centred model of care recognises the importance of factors apart from brain pathology, such as the patient's unique past and the present social environment, that influence the presentation and course of the disease<sup>37</sup>. Family caregivers can make a real difference because they know the patient and his past, and if empowered with the relevant knowledge and skills, can meaningfully contribute to the well-being of the patient with themselves benefiting in the process.

The forms of interventions include education, imparting of coping skills and problem solving methods, support groups,

respite care, family therapy and individual treatment, including counselling. These avenues of intervention can be delivered in structured activities and programmes in various forms. Educational training programmes focus on the provision of information in the medical, psychosocial and legal aspects of dementia, planning for future care with deterioration of functional abilities, imparting caregiving skills such as behaviour modification, communication and basic daily living skills. On the whole, increased knowledge has not been shown to improve the quality of life of caregivers or reduce their psychological burden. However, comprehensive programmes in addition to education offer psychological support to the carer as well as strategies to develop family, community and professional support systems have shown greater promise<sup>38</sup>.

One of the earliest intervention studies, the Prince Henry Hospital programme, comprising an intensive 10-day residential programme with continued support in the form of telephone conference calls over one year, showed significantly lower psychological distress in carers and lower rates of institutionalisation in the treatment group<sup>39</sup>. A comprehensive spouse-caregiver programme in the US comprising individual and family counselling, weekly support groups meetings and continuous availability of counsellors to provide ad hoc counselling to help with crises and the changing nature of the patient's symptoms over the disease's course, demonstrated decreased depression in the intervention group, reduced caregivers' reaction to behavioural problems and delayed nursing home placement by a median of 329 days<sup>40,41</sup>. The ongoing "3 Country Study"<sup>42</sup> is designed to examine if combining counselling and caregiver support with drug treatment is more effective than drug therapy alone. The results thus far suggest that psychosocial intervention improves caregivers' satisfaction with assistance from family and friends, and has an effect on whether the patient continues to take medication. Finally, a meta-analysis<sup>43</sup> found that psychosocial interventions for caregivers, such as counselling and training in how best to care, had moderate statistically significant benefits. The same study found that programmes that involve patients and their families, are more intensive and modified to caregiver needs, may be more successful.

Taken together, dementia caregiver intervention strategies appear to be beneficial if they are broad ranging and multi-dimensional. While knowledge and some caregiving skills can be imparted in a group setting, being able to tailor to the needs of individual carers in each of their unique circumstances is necessary. Most importantly, having a system of ongoing support that is responsive and continuous may prove most vital if carers are to feel supported and less burdened in their caregiving journey.

## CONCLUSIONS

Good dementia care must comprise three essential components: Disease-centred care for the patient, caring for the social, psychological and spiritual well being of the patient, and caring for the caregiver. The patient with dementia can no longer

help himself. It is the caregiver who will deliver care to the patient. He needs to be empowered and supported in this often lonely and arduous task. Ultimately, if care is primarily to the patient, the goal of carer intervention is to indirectly help the patient by helping the caregiver. Only when such an approach is adopted, can dementia care be complete.

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## LEARNING POINTS

- o Good dementia care is made up of three essential components: disease-centred care for the patient, caring for the social, psychological and spiritual well being of the patient, and caring for the caregiver.
  - o Dementia caregiving is primarily provided by family caregivers.
  - o Caregivers often feel overwhelmed in the task of caring for a family member with dementia.
  - o Assessing the caregiver burden forms an essential part in any dementia assessment.
  - o Caregiver intervention should be instituted to help provide well-meaning carers with the necessary skills and support.
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