Dementia Caregiving: The Role of the Primary Care Physician

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ABSTRACT: Background: Family and friends play an important role in caring for individuals with dementia living in the community. In preparation for the Canadian Consensus Conference on Dementia held in Montreal, Canada in February 1998, the subject of dementia caregiving was reviewed in order to provide primary care physicians with some guidelines for their practice. The review was updated in June 2000 for preparation of this article. Method: Pertinent English-language publications and resources from the Alzheimer Society of Canada were reviewed from 1985 onwards. Findings related to the consequences of caregiving, services for caregivers and recommendations regarding the role of the primary care physician were reviewed. Findings: Dementia caregivers experience many positive and negative consequences of caregiving. Some comprehensive services for caregivers have been shown to delay institutionalization and reduce negative consequences of caregiving. The primary care physician has a role to play in working with families and should address the following issues: 1) education about dementia; 2) psychological support for caregivers; 3) assistance mobilizing caregiver social support networks. Conclusion: Primary care physicians have an important role to play in acknowledging and supporting the caregiving provided by family and friends to individuals with dementia.

This paper examines the responsibilities assumed by family caregivers in the care of their relatives who suffer from dementia, the effect of these responsibilities on the health and well-being of the caregivers and the role that family physicians can and should play in assisting them to manage these situations. A number of authors have described what they believe the family physicians’ role should be and these positions are summarised. The findings reviewed were retrieved via computerized searches from 1985 onwards of MEDLINE, Psychinfo and Ageline, and reference lists and guidelines issued by relevant professional and advocacy organizations. The recommendations were reviewed at the Canadian Consensus Conference on Dementia in 1998. This background paper was prepared for that conference and was updated in June 2000.


The Role of Caregivers in Dementia Care

Canada is fortunate in having recent and reliable epidemiologic data on the prevalence of people with dementia and on the characteristics of their informal caregivers. Approximately half of the individuals suffering from dementia in

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There may also be differences among subgroups of confirmed these findings. which may put them at increased stress that played by the caregivers be acknowledged and supported. Many caregivers find it particularly challenging that the patient often cannot thank them for their help and might resent some of the decisions the caregiver has to make. Up to 50% of caregivers experience significant psychiatric symptoms (anxiety and depression) during the course of their caregiving career and psychotropic drug use is high among this group. Dementia caregivers perceive their general health to be worse than others. Spousal caregivers exhibit impaired immune system functioning compared to noncaregivers which may put them at increased risk for health problems. Caregivers of dementia patients also use services billed by psychiatrists and internal medicine specialists more than a comparable group of family caregivers.

Low income, high perceived stress, low life satisfaction and poor self-esteem/mastery are all risk factors for negative health outcomes among caregivers. In addition, problem behaviours of the demented patient, severity of their cognitive impairment and limitations in their self-care all predict higher caregiver distress. Factors that seem to lessen caregiver burden include practical and emotional support from family and friends. Caregivers who view their role as satisfying and who use coping responses characterized by problem solving and seeking information report less distress.

There may also be differences among subgroups of caregivers, with spouses affected differently than children, and women and men caregivers reacting differently to the challenge. Those caring for young dementia patients (<55 years) may be at increased risk of negative consequences of caregiving.

CONSEQUENCES FOR FAMILY CAREGIVERS

The care provided by family and friends, although a major factor in the health and social system, is often hidden and poorly recognized. Increasingly, it is being suggested that the vital role played by the caregivers be acknowledged and supported.

Negative consequences

In recent years, a great deal has been learned about the stress and burden experienced by those caring for someone with dementia. Some caregivers adapt to the challenges of caregiving while others report increased stress as the disease progresses. Many caregivers find it particularly challenging that the patient often cannot thank them for their help and might resent some of the decisions the caregiver has to make. Up to 50% of caregivers experience significant psychiatric symptoms (anxiety and depression) during the course of their caregiving career and psychotropic drug use is high among this group. Dementia caregivers perceive their general health to be worse than others. Spousal caregivers exhibit impaired immune system functioning compared to noncaregivers which may put them at increased risk for health problems. Caregivers of dementia patients also use services billed by psychiatrists and internal medicine specialists more than a comparable group of family caregivers.

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Positive Consequences

Less has been written about the positive aspects of caregiving; however, caregivers do report a sense of satisfaction in a job well done, a sense of mastery in learning new skills and a feeling of accomplishment in keeping a loved one at home. Caregivers who report these experiences may be less likely to use formal support services or to desire nursing home placement for their dependants.

SERVICES AND INTERVENTIONS FOR CAREGIVERS

A variety of services and interventions have been developed to assist caregivers in dealing with their role and to alleviate the negative consequences of caregiving. While there has been a great deal of research examining the effectiveness of these interventions, methodological issues have plagued the research from the start and complicated the findings. Knight et al reviewed the interventions and concluded that “…respite interventions and individual psychosocial interventions are moderately effective compared with treatment as usual or uncontrolled use of community services. Group psychosocial interventions are less effective in the same comparison” (p.247). A recent review by Roberts et al confirmed these findings. Respite programs and day programs kept dementia patients in the community longer. Counselling for caregivers not only increased the time spent in the community by individuals with dementia but also increased psychosocial adjustment for caregivers with poor coping skills. Zarit et al stress that “studies in which … families received adequate amounts of help showed more consistently positive outcomes” (p.165).

Respite interventions include specialized dementia day care, in-home respite programs and out-of-home respite admissions, all of which are available to varying degrees across Canada. Despite their effectiveness, these respite services are consistently under-utilized by caregivers. The role of family physicians in recommending these services and facilitating their utilization is not well studied.

Individual psychosocial interventions might include a variety of individual psychotherapies provided by practitioners including family physicians. They might also include specific training programs such as those designed to teach caregivers problem-solving skills. Examples of group psychosocial interventions include support groups run by professionals and self-help groups, many of which are sponsored by local Alzheimer Society chapters.

Comprehensive support programs comprising several of these elements are often offered at specialized dementia centres. Brodaty et al developed a comprehensive program which focuses on three types of interventions: 1) education about dementia; 2) psychological support for the caregiver with a focus on stress management, communication, self care and grief work; 3) assistance to caregivers to develop their social support system – family, community and professional. Brodaty et al were able to demonstrate a delay in institutionalization of dementia patients when caregivers were enrolled in their program. From their research they conclude that these interventions are probably more effective in the early to middle stages of the dementing illness.

Mittelman et al developed an intervention that combined individual and family counselling sessions “with primary focus
Physicians will probably not be able to provide all the support and assistance caregivers need but will need to know where to refer caregivers so that they can get help as they need it. To this end, caregivers will need to be seen regularly by family physicians, not only to acknowledge their important role but also to assess their needs. This may be more complicated when the caregiver has a different physician than the dementia patient. Particular care must be taken in these situations for collaboration between family physicians.

There may be particular times in the dementia patient’s illness when caregivers need more frequent and intensive support: at the time of diagnosis; when the patient can no longer be left alone; when nursing home placement is being considered; and when the patient enters the last phase of the illness.

Many of the recommendations regarding the role of the family physician in supporting dementia caregivers can be subsumed under the three dimensions used by Brodaty et al.\textsuperscript{11} in designing their comprehensive program: (a) education, (b) psychological support and (c) assistance with social support.

\textbf{a) Education}

\textbf{i) The diagnosis and its meaning}

The family physician may be the clinician who conveys the diagnosis of dementia to the patient and his/her family. This requires sensitivity, clarity of language and sufficient time for the family members to hear what is being said. The information should include the fact that memory loss is not normal but is the result of disease processes; and that while it is not possible to be absolutely certain what the future will hold, dementias are progressive in nature.\textsuperscript{24} Caregivers need to understand that the dementia will affect the patient in many ways, i.e., changes in personality, increased risk for delirium and medical illness. Families also require information about the genetics of the disease and the risks to other family members,\textsuperscript{25} the implications of the disorder for activities such as driving,\textsuperscript{22} and that treatments and other strategies are available to assist with the changes in behaviour, cognition and ability to perform the activities of daily living that attend the disorder.\textsuperscript{22,24}

\textbf{ii) Management of behavioural changes related to the dementia}

The American Psychiatric Association\textsuperscript{22} suggests that the caregivers should be educated on how to alleviate behavioural symptoms and provided with a set of principles to guide them in dementia care. These include:

\begin{itemize}
  \item [a)] keeping requests and demands relatively simple and avoiding overly complex tasks that might lead to frustration;
  \item [b)] avoiding confrontation and deferring requests if the patient becomes angered;
  \item [c)] remaining calm, firm and supportive if the patient becomes upset;
  \item [d)] being consistent and avoiding unnecessary change;
  \item [e)] providing frequent reminders, explanations and orientation cues;
  \item [f)] recognizing declines in capacity and adjusting expectations appropriately;
\end{itemize}
ECOMMENDATIONS
This network might include family and friends as, prefer that their relatives receive what Vlicer Caregivers might need individual counselling or This will include at the Canadian ECOMMENDATIONS FOR PRIMARY CARE PHYSICIANS WORKING WITH DEMENTIA PATIENT CAREGIVERS

Acknowledgment the important role played by the caregiver in dementia care. Work with caregivers and their families on an ongoing basis, from the diagnosis of dementia until the death of the patient. Schedule regular appointments for patients and caregivers together and alone. (Level III evidence)

Educate patients and families about the disease and appropriate modifications that must be made day to day in the home environment and in communicating and interacting with the dementia patient. (Level III evidence)

Evaluate caregiver coping strategies and encourage caregivers to care for themselves, using health promotion strategies and stress reduction strategies. (Level III evidence)

Assess the caregiver’s social support system and help caregivers rally support for themselves from appropriate family members and friends. (Level III evidence)

Screen for caregiver burden, psychiatric problems and health problems by regularly meeting with caregivers and asking specific questions about their health and caregiver strain. Offer caregivers treatment for these problems (individual psychotherapy or medications as indicated) or refer to appropriate specialists or services. (Level III evidence)

Refer caregivers to appropriate community services for dementia care (i.e., day care, respite care, local Alzheimer Society, long-term care settings) realizing that it may take encouragement and time for these services to be used. If available, refer patients to specialized dementia programs that offer comprehensive treatment programs. (Level I evidence)

Discuss legal and financial issues and obtain appropriate help for caregivers and families if you are not comfortable with these issues. (Level III evidence)

Assess and treat the behavioural problems of dementia on an ongoing basis. If needed, refer caregivers to the Alzheimer Society for information on modifying behavioural problems. (Level III evidence)

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