

Education about family caregiving

Advocating family physician involvement

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Family caregiving represents the first and predominant source of care for 75% to 80% of seniors in industrialized countries.^{1,2} Those suffering from stroke, Parkinson disease, and Alzheimer disease are most likely to require assistance, and a large part of published literature on interventions to help caregivers, in fact, focuses on dementia.³ This likely reflects the growing prevalence of this illness and the unique burden it places on caregivers.⁴

There is a risk that the term *caregiver* will become synonymous with *care of older adults*, when actually family caregiving is encountered throughout the lifespan and not restricted solely to the elderly. Medical advances, new drugs, improved technology, and possible preventive strategies might be decreasing mortality and extending life. The emphasis on short-term hospital admissions, less institutionally based care, and more ambulatory care since the 1970s has resulted in a progressive shift from “care in the community to care by the community.”⁵ A growing number of individuals with chronic diseases or disabilities require a family caregiver, or several, for physical, emotional, and financial support; for daily activities, such as housekeeping and transportation; and for medical interventions, such as urinary catheters, supplementary oxygen, feeding tubes, and intravenous administration of medication.

Examples of nongeriatric caregiving are increasingly observed in the neonatal population, as a by-product of improved survival of premature infants and newborns with complex congenital diseases. In adolescent and young adult groups, progress in emergency medical response has resulted in improved survival outcomes for trauma victims; however, some are left with residual disabilities that render them dependent on their families for aspects of daily living. Earlier detection of cancer and advances in medical and surgical oncology means that cancer is now perceived as a chronic illness. Similarly, developments in the management of ischemic heart disease, congestive heart failure, diabetes, chronic obstructive pulmonary disease, and stroke are all extending family caregiver activities. And for those with chronic psychiatric illness and behavioural problems, deinstitutionalization has created added strain, responsibility, and accountability for family members.

Inadequate physician knowledge

Throughout the lifespan the overall burden of caregiving has been identified as a risk factor for mortality.⁶ The cause of this is likely multifactorial, but lack of education and training almost certainly plays a role.

Physicians do not always appear to adequately respond to the needs of family caregivers; examples from a Cochrane review of information provision to caregivers of stroke victims,⁷ an American Alzheimer Association survey of caregivers of relatives with dementia,⁸ a Canadian study of caregivers of the frail elderly,⁹ and a self-report by 435 general practitioners working in France¹⁰ confirm this. The vast array of settings and illnesses in which caregiving occurs suggests that a range of knowledge, attitudes, and skills relating to caregiving are necessary for family doctors to effectively meet caregiver needs. Some of them are common to a number of illnesses; others might require special approaches or changes over the longitudinal trajectory or course of an illness. In response to temporal components of the caregiver's role, length of illness, duration and dynamic nature of the caregiving, and change in clinical status of the patient.^{11,12}

A structured approach to teaching caregiving issues in medical schools seems necessary and beneficial. However, results of a mail survey conducted by one of the authors (M.J.Y., unpublished), which was sent to associate undergraduate deans in Canada's 16 faculties of medicine, revealed that only 3 of 10 responding faculties had written teaching objectives on caregiving, and they had limited time (0.5 to 2 hours) allocated for achieving those objectives and little means to ensure that the teaching faculty actually role-modeled such comprehensive involvement with family caregivers. While these findings might have improved since the survey was conducted or might not reflect the situation in other countries, they do strongly suggest a need for improvement.

Position and influence

As family physicians care for their patients and patients' family members over the course of many years, they are well-situated to play a more active role in advocating for—and participating in—improved instruction of family caregiving. Members of family medicine departments are increasingly participating in faculty curriculum committees or as associate deans for undergraduate education, faculty development, and continuing medical education. In such contexts they would be well-placed

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to sensitize their colleagues to the relevance of teaching topics of caregiving and promote their inclusion in the curriculum, potentially alongside the teaching of lifespan issues, doctor-patient relationships, interviewing skills, ethics, or behavioural sciences. Caregiver topics could also be taught during classes, seminars, or ward rounds focusing on specific illnesses in which discussions might naturally include how the disease affects the patient as well as his or her family members. The family medicine clerkship in particular might offer opportunities and perspectives for caregiving education.


Notwithstanding these suggestions, there is heavy competition for teaching time at the undergraduate level; therefore, family medicine residency programs should consider expanding their curricula to include lessons on caregiving. The College of Family Physicians of Canada, in recognition of the potential for caregiver activities across the lifespan, might add a statement to the third principle of family medicine ("The family physician is a resource to a defined practice population") affirming that family doctors must acquire the knowledge, attitudes, and skills to successfully assist caregivers. To accompany such a declaration, accreditation teams should be encouraged to specifically examine the quality of caregiver education provided to residents. The inclusion of a specific query (eg, "How does your program teach family caregiver issues across the lifespan?") on the pre-accreditation survey might serve as a stimulus for a program's internal review.

Within family medicine residency programs, preceptors in diverse settings could take note of their encounters with caregivers and extrapolate what is needed to adequately equip trainees for such complex interactions. This process would help justify a free-standing learning objective for caregiving issues (as opposed to the material being an adjunct to related topics, such as care of the elderly), which would be addressed by a combination of didactic and experiential learning. In addition, residency programs should be obliged to create comprehensive reading lists on caregiving for their trainees.

Taking action

Studies of the unmet needs of caregivers provide the content of a family medicine caregiver curriculum, which includes the following: medical and societal changes that promote the rise in family caregiving; the chronic disease model; issues of caregiving across the lifespan; the influence health belief models and family attitudes toward seeking or accepting help have on problem solving; family systems theory (including issues like enmeshment and communication patterns); patient and family experiences with illness; sex differences in caregiving; physical, emotional, financial, family, and vocational consequences of caregiving; the presence of somatic symptoms as a possible reflection of caregiver distress; techniques or inventories to evaluate caregiver burden;

and roles, interactions, and strengths and weaknesses of health care team members working with caregivers. Finally, in recognizing the complexity of the patient-caregiver-doctor triad, it might be beneficial to explore possible barriers to these encounters (eg, confidentiality). The use of "medi-drama" has been described as a successful means to specifically introduce and discuss many of these topics.¹³

Adopt rigorous learning objectives means residents will need to demonstrate competency. This can be assessed by direct supervision and by ensuring that written and practical examinations (such as simulated office orals) evaluate competency in assessing and managing caregiver concerns. With enhanced undergraduate and postgraduate education and training in caregiving issues comes the opportunity to conduct research. Further studies can explore whether or not better-trained physicians actually do improve caregiver satisfaction and coping, help to reduce caregiver burnout, and decrease caregiver mortality. There is a long way to go, but family medicine can and should lead the way. 

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Competing interests

None declared

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References

- Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national profile. *Gerontologist* 1987;27(5):616-26.
- Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan K. The experiences and challenges of informal caregivers: common themes and differences among whites, blacks, and hispanics. *Gerontologist* 2001;41(6):733-41.
- Mittelman M. Taking care of caregivers. *Curr Opin Psychiatry* 2005;18(6):633-9.
- Ory MG, Hoffman RR 3rd, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999;39(2):177-85.
- Heaton J. The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociol Health Illness* 1999;21(6):759-77.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999;282(23):2215-9.
- Forster A, Smith J, Young J, Knapp P, House A, Wright J. Information provision for stroke patients and their caregivers. *Cochrane Database Syst Rev* 2001; (3):CD001919.
- Roper Starch Worldwide Inc. *Alzheimer's disease study. Communication gaps between primary care physicians and caregivers*. Chicago, IL: Alzheimer's Association; 2001. Available from: www.alz.org/national/documents/report_communicationgap.pdf. Accessed 2008 Aug 27.
- Brotman SL, Yaffe MJ. Are physicians meeting the needs of family caregivers of the frail elderly? *Can Fam Physician* 1994;40:679-85. Available from: www.pubmedcentral.nih.gov/picrender.fcgi?artid=2380098&blobtype=pdf. Accessed 2008 Sep 4.
- Fantino B, Wainstein JP, Bungener M, Joubin H, Brun-Strang C. [Perspectives of general practitioners on the role of patients' caregivers in the process of consultation and treatment] [French]. *Santé publique* 2007;19(3):241-52.
- Kahana F, Kahana B, Johnson JR, Hammond RJ, Kercher K. Developmental challenges and family caregiving. In: Biegel DE, Wykle ML, Kahana E, editors. *Family caregiving across the lifespan*. Thousand Oaks, CA: Sage Publications; 1994. p. 3-41.
- Rolland JS. *Families, illness, and disability. An integrative treatment model*. New York, NY: Basic Books; 1994.
- Yaffe MJ. The medi-drama as an instrument to teach doctor-patient relationships. *Med Teach* 1989;11(3-4):321-9.