



LESSONS IN LEARNING

The obstacles to learning about
caring for elders in Canada

July 12, 2007

Informal caregivers face obstacles in learning about elder care

More Canadians are celebrating an 85th birthday than ever before. Chances are, when they blow out all those birthday candles, it will be in their own homes, thanks to help from an informal caregiver. Usually spouses or middle-aged children, these unpaid caregivers are often ill-equipped for the physical, emotional, and financial toll of their responsibilities. But formidable barriers prevent them from acquiring the very information and services that would ease their burden.

Elder care in Canada

The proportion of the population that is over 65 has increased by 68% over the past two decades.¹ And the proportion of seniors who will live beyond 80 years has increased by 40%, a trend that is only expected to grow.²

Over one-fifth of Canadians aged 45 to 64 years care for 2.3 million seniors, usually their parents (67%), in-laws (24%), or friends and neighbours (24%). In addition to their caregiving responsibilities, almost three-quarters of informal caregivers work, most of them full-time; (in a majority of cases, their spouses work as well).³ One in five working caregivers belongs to the 'sandwich generation,' both looking after a parent and having children living at home.⁴

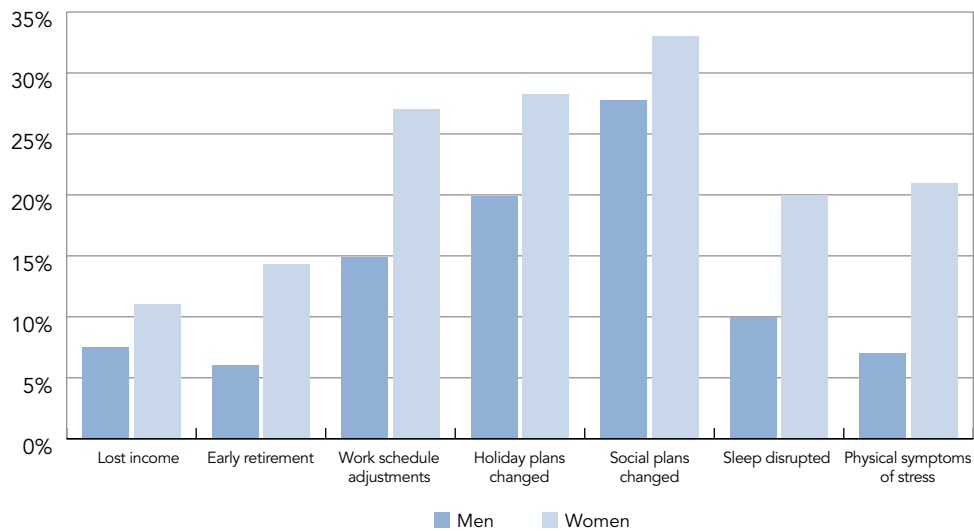
One in six informal caregivers is a senior citizen,⁵ with an average age of 72.⁶ Of these, 25% care for a spouse, while one-third help out friends, and almost one fifth, neighbours.⁷ This cohort of helpers spends almost 22% more time on their tasks compared to their younger counterparts,⁸ with elderly women logging over one-third more hours of caregiving than elderly men.⁹

Caregivers' work is partly determined by the nature and severity of the illnesses of the care recipient. Chronic conditions like arthritis, hyper-tension, diabetes, and dementia are common illnesses of the elderly, but vary in the demands they place on caregivers. As well, many seniors are vulnerable to acute, serious ailments like cancer (the most common cause of death in the elderly), which can require caregivers to perform tasks once delivered by health professionals.¹⁰

Wealth, health, and personal life

Informal caregivers can suffer adverse consequences from their labours: lost income, changes in work and social activities, as well as physical and psychological distress. Many studies have documented elevated rates of depression among informal caregivers, especially among the poor¹¹ and those caring for seniors with dementia.¹² Elderly caregivers pay a particularly steep price for looking after spouses: their mortality rate is 63% higher than their non-caregiving peers.¹³

Figure 1:
Financial, Social and Health Impacts of Caregiving



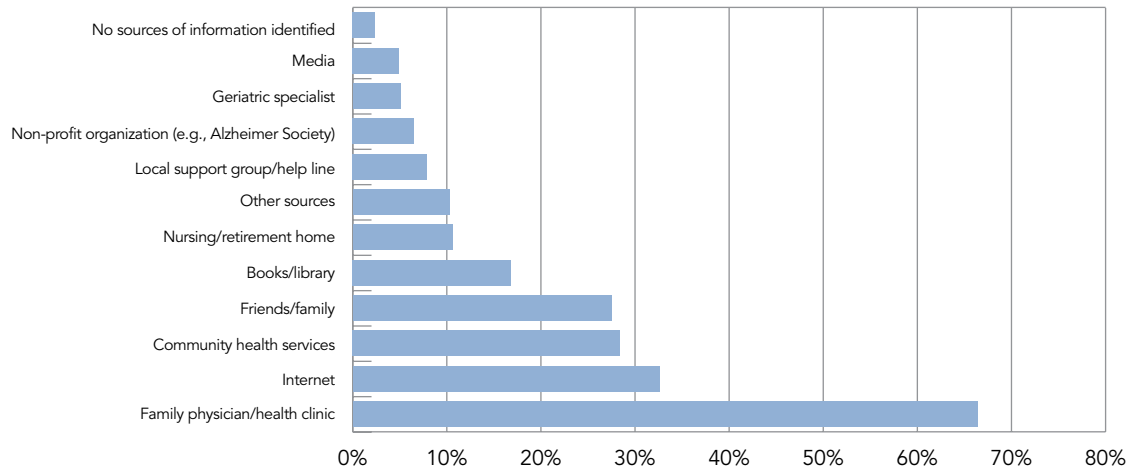
Adapted from Habtu & Popovic (2006)

Unmet needs among caregivers

Despite the challenges, most caregivers report the experience enriches their lives, deepening their relationship with the care receiver, and giving back something of the benefits they have enjoyed in life.¹⁴ Nevertheless, caregivers report they need more resources to help them effectively look after family members.

The 2006 Survey of Canadian Attitudes toward Learning (SCAL) asked Canadians where they would go for information if they were responsible for looking after an elderly relative; respondents were not necessarily providing elder care at that point. Respondents identified a number of avenues of help, suggesting a relatively high degree of confidence in their ability to learn about informal caregiving.

Figure 2:
Survey of Canadian Attitudes towards Learning: Respondents identify potential sources of information on elder care

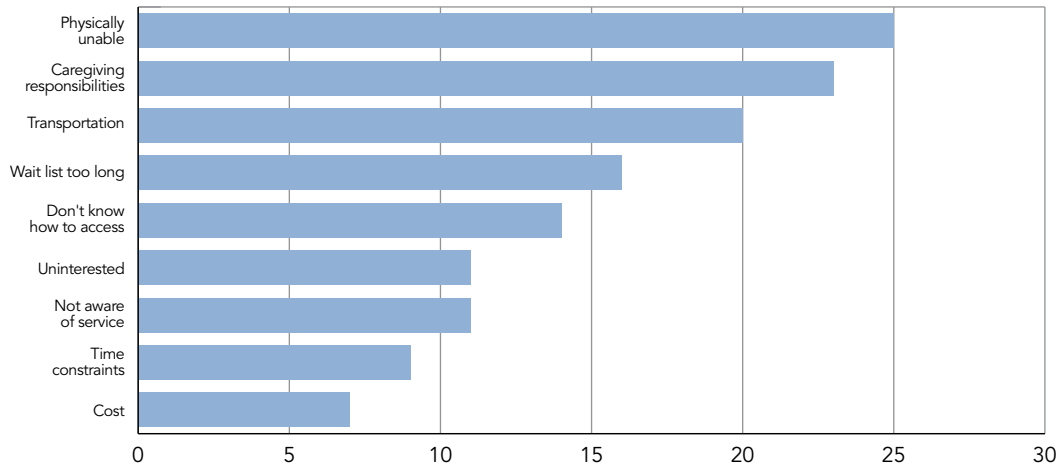


Other research that focuses on people actually providing care tells a slightly different story. The available evidence suggests that informal caregivers have a number of unmet needs, including: access to counselling;¹⁵ respite care; flexible work schedules;¹⁶ help with practical tasks, such as housework and personal care; as well as support via telephone, newsletter, support groups, or the internet.¹⁷

In addition, many of these Canadians express an important unmet learning need: about half of the caregivers surveyed in a Statistics Canada study wanted more information about how best to do the tasks required of them and on the specific ailments afflicting their elderly relatives.

Some caregivers report that practical issues, such as cost and time, prevent them from learning about elder care. But a significant number are also hobbled by difficulties in getting information about what services are available or how to access them. These obstacles are outlined in the following chart:

Figure 3:
Barriers to Services for Caregivers



Adapted from Williams, Forbes, Mitchell, Essar & Corbett (2003)

Literacy: The invisible barrier

Low literacy is one of the most prevalent barriers to accessing health information and resources. General literacy (i.e., the ability to read and write), and its cousin, health literacy, are significant problems for the elderly and their caregivers, yet are often overlooked.¹⁸ Four in ten Canadians have such weak literacy skills that meeting the demands of everyday life is a challenge.¹⁹ Health literacy, which largely depends on general literacy, refers to individuals' ability to understand information relevant to their health, effectively navigate the healthcare system, and acquire the necessary services for their well-being. Health literacy requires sufficient cognitive, social, and communication skills—as well as the personal motivation—to ask the right questions and to assert one's needs.²⁰

Some populations tend to have lower general and health literacy.²¹ One in six caregivers is a senior citizen, a group that is disproportionately represented at the bottom end of the literacy spectrum.²² Moreover, general literacy declines with advancing years,²³ as does health literacy.²⁴

The population of informal caregivers reflects the country's demographics.²⁵ One in six Canadians, including Aboriginal people, is an Allophone, for whom neither French nor English is their mother tongue.²⁶ Their language status puts them at risk of having low health-literacy skills.²⁷ Cultural insensitivity in health care may exacerbate the problems created by Allophones' poor fluency and literacy²⁸ in English or French.²⁹

The number of caregivers who potentially face challenges getting the information they need to care for the elderly and for themselves effectively is clearly considerable. Health information is ubiquitous: it is found in every hospital and physician's office, in the print and electronic media, on the internet, and in books. But much of this material is inaccessible to the very population requiring it. For instance, one study found that the reading level of 75% of the pamphlets in a Montreal primary-care clinic, were written for an audience with a Grade level of 11.5,³⁰ well beyond the grasp of those with low literacy levels.

Lessons in learning: Overcoming obstacles

One approach to improving the accessibility of written information is to keep the language simple,³¹ ideally to the Grade 5-7 level.³² However, plain language is a necessary but not sufficient condition to engage readers. The quality and clarity of the graphic design and the inclusion of pictures (especially if they are culturally relevant) increase the odds that written materials are read, understood and remembered.³³

Even the best-designed and most clearly worded pamphlets often do not provide the information being sought. Some health professionals believe consumers need one type of information, yet consumers sometimes want something altogether different.³⁴ In one study, pamphlets intended for diabetics—a common disease of the elderly—failed to address cost issues, even though these were the primary concerns of the pamphlet's intended audience.³⁵ Consulting and collaborating with end-users of health-information is one way to successfully align user needs with what professionals believe they should know.³⁶

Locally-produced materials also appear to be the most useful to consumers. Cancer patients in an Australian study evaluated five versions of a booklet on chemotherapy. They gave the highest marks to the booklet that was locally produced, even though it was not written according to plain language principles and had no pictures.³⁷

Some minorities have developed health education materials for their communities. The Ningwakwe Learning Press publishes health information for Aboriginal audiences, integrating evidence-based western medicine with Aboriginal traditional practices and perspectives on health. These publications use everyday words, real-life examples, illustrations, and a narrative style consistent with the cultural beliefs of the community.³⁸

Health professionals play an important role in helping caregivers and care recipients receive timely, accurate, and understandable information. Many patients with low literacy are ashamed of their level of comprehension; they resist asking questions about resources and disease management, in order to mask their difficulties.³⁹ Universities and professional organizations now offer training for health workers to acquire the cultural competencies and communication strategies that will allow them to work effectively with the diverse populations they encounter—including those with language and literacy challenges.⁴⁰ University of Ottawa nursing students, for example, learn about working with cultural minorities, and complete a practicum teaching new Canadians enrolled in English as Second Language (ESL) classes not only about various health topics, but also about how to access health services.⁴¹

Health professionals already in the workforce are also being sensitized to the issue of low literacy, and are offered training in best practices to help this group. The American Medical Association, for instance, teaches its members to focus on creating office environments that will encourage patients to ask questions, and to answer those queries in a style that will be understood by all clients, no matter their degree of literacy. These include speaking slowly, using non-technical jargon, presenting only two or three concepts at a time, while regularly checking for understanding by asking patients to teach back what they have learned.⁴² Similar techniques are being taught in workshops and using materials developed by Canadian literacy and health organizations and hospitals.⁴³

Health online and on the telephone

The internet is a significant source of health information for Canadians, and is used by about half of the people who do the most informal elder care.⁴⁴ The abundance of health information on the internet can be a problem for users, however, as many lack the critical-thinking skills to appraise the quality of the information they find.⁴⁵

Much of the health content on the Internet is inaccessible to non-English speakers: over 65% of the web's content is in English only.⁴⁶ Internet health information is often written to senior grade levels: one study found that information about the most common cancers (breast, prostate, colorectal) is written to a Grade 12.9 level.⁴⁷ Discussions within the medical information community have recently focused on rewriting web content to conform to plain-language principles.⁴⁸

Even if the text is clear and engaging, computers pose other challenges for low-literacy users. Many have difficulty generating search terms that are specific enough to yield useful results. They also fail to use links that would answer specific questions and have difficulty distinguishing a sponsored site.⁴⁹

Some initiatives have been undertaken to help under-served populations profitably use the internet. The Colonias project in southern Texas trained community-based workers on accessing information via MedlinePlus, a repository of reliable health information in Spanish and English maintained by the American National Library of Medicine.⁵⁰ These paraprofessionals, or promotoras, succeeded in helping clients make health decisions regarding medications and treatment, to understand health conditions, relieve anxiety, and perhaps most importantly, improve the quality of their interactions with health-care providers.⁵¹

Web-based learning modules have been developed around specific health issues for targeted communities, such as seniors and their caregivers. In one study, such an approach proved to be a useful intervention to educate the elderly and their caregivers about preventing hip fractures, a common problem among the elderly.⁵²

Supporting and educating informal caregivers via telephone contact with a professional has been piloted in a number of jurisdictions. Caregivers—especially in rural and remote areas—find telephone support convenient, time-saving, and economical, as such virtual visits with professionals do not require travel.

This approach has been demonstrated to promote better communication between caregivers and health professionals as well as improved access to other services; it is most effective when the tele-homecare is integrated with other health services in order to provide clients with a continuity of care.⁵³

Low-tech solutions

Informal caregivers often receive health instructions from the care recipient's physician or another health professional. In addition to such ad hoc instruction, some caregivers receive comprehensive individual or group instruction.

Recognizing that elderly cancer patients often suffer significant discomfort once they go home after surgery, one hospital created an individualized bedside training program for informal caregivers. Caregivers learn how to manage post-operative symptoms and monitor patients' recovery, receiving both information (e.g., how to manage nausea) as well as "hands-on" instruction (e.g., how to use a gastronomy tube). Training sessions continue until caregivers feel confident about their ability to deliver care, and are able to demonstrate proficiency in it. Caregivers favourably assess this interactive, non-threatening training, as well as the plain-language manual of care that they receive to use at home.⁵⁴

A program that has been widely used in the United States, *Caring for You/Caring for Me*, aims to develop a broad range of caregiver strengths and abilities that can be adapted to any situation. Offered through non-profit groups, hospitals, and local government agencies,⁵⁵ it consists of five, 2½ -hour workshops, and brings together both professional and informal caregivers. The first session teaches participants how to take care of themselves, and then moves on to identify the knowledge and skills they need to look after the person in their care. One module is entirely devoted to teaching caregivers how to access information, obtain resources, and surmount barriers in their way. The ultimate goal is for caregivers to become empowered to take actions that will enhance the quality of their lives—and the person in their care.

Putting it all together

Caregivers are as demographically diverse as Canada itself, and if all of their information and learning needs are to be met, similarly varied strategies need to be developed and implemented by multiple players, including caregivers themselves.

Caregivers assume a burden that can be costly to their personal health and their financial well-being. Helping informal caregivers learn as much as they need about the role they have taken on may well require a significant investment. But it is unlikely to approach the value of informal caregivers' contributions to society, a number which Statistics Canada pegs at \$15.3 to \$25 billion annually.⁵⁶

References

- ¹ Turcotte, M. & Schellenberg, G. (2007). A portrait of seniors in Canada, 2006. Statistics Canada Catalogue no. 89-519-XIE
- ² Cranswick, K. (2003) General Social Survey Cycle 16: Caring for an aging society, 2002. Statistics Canada, Catalogue no. 89-582-XIE. [Accessed April 15, 2007]
- ³ Habtu, R. & Popovic, A. (2006, April) Informal caregivers: Balancing work and life responsibilities. *Work and Life Balance* 8:3, pp. 1-14. Statistics Canada Catalogue No. 11-008 [accessed 17 April 2007]
- ⁴ Habtu & Popovic (2006)
- ⁵ Stobert, S. & Cranswick, K. (2004) Looking after seniors: Who does what for whom? *Canadian Social Trends* (Autumn 2004) pp. 2-6. Statistics Canada Catalogue No. 11-008. Calculation based on the table on p. 4
- ⁶ Stobert & Cranswick (2004) p. 3
- ⁷ Stobert & Cranswick,(2004) p. 4-5
- ⁸ Stobert & Cranswick (2004) p. 3
- ⁹ Stobert & Cranswick (2004) p. 3. Actual numbers are Men 20.9 and women 32.9 hours/month.
- ¹⁰ Haigler, D.H., Bauer, L. J., & Travis, S. S. Finding the common ground of family and professional caregiving: The education agenda at the Rosalynn Carter Institute. *Educational Gerontology*, 30, 2004, p. 98
- ¹¹ In the middle: A report on multicultural boomers coping with family and aging issues (2001) Washington DC: AARP [accessed 18 April 2007]
- ¹² Haigler, Bauer, Travis, & Shirley (2004) p. 98
- ¹³ Schultz, R. and S.R. Beach. (1999) Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study, *Journal of the American Medical Association* 282 pp. 2215-2219.
- ¹⁴ Cranswick (2003)
- ¹⁵ Habtu & Popovic (2006) p. 8
- ¹⁶ Stobert & Cranswick (2004) p. 4
- ¹⁷ Colantonio, A., Kositsky, A. J., Cohen, C., Vernich, L. (Sep/Oct 2001) What Support do Caregivers of the Elderly Want? Results from the Canadian Study of Health and Aging. *Canadian Journal of Public Health* 92 pp. 376-379
- ¹⁸ Rootman, I. (2006) Health literacy: Where are the Canadian doctors?" *Canadian Medical Association Journal*. 175: 6, pp. 606-607. "It is unfortunate that the Canadian medical community has not played a more active role in health literacy, since it is clearly an important issue in the practice of medicine." (p. 606). Rootman, I. & Ronson, B. (Mar/Apr 2005) Literacy and health research in Canada. *Canadian Journal of Public Health* 96:Sup, 2, pp. 262-277.
- ¹⁹ Adult Literacy and Life Skills Survey, Statistics Canada, 2003

- ²⁰ Mika, V.S., Kelly, P.J., Price, M.A., Franquiz, M., & Villarreal, R. The ABCs of health literacy. *Community Health* 28:4, p. 352
- ²¹ Shohet, L & Renaud, L. (May/June 2006) Critical analysis on best practices in health literacy. *Canadian Journal of Public Health* 97: Sup. 2, p S10.
- ²² Shohet, Linda. (2004) Seniors and literacy: Revisiting the issue. *LACMF* 17:2, p. 3. [Accessed 17 April 2007]
- ²³ Rootman, I. and Ronson, B. (Mar/Apr 2005) Literacy and health research in Canada: Where have we been and where should we go? *Canadian Journal of Public Health* 96: Sup.2, p. S67, S68.
- ²⁴ Erlen, J.A. (Mar/Apr 2004) Functional health illiteracy: Ethical concerns. *Orthopaedic Nursing*, 25:2, pp 150-153
- ²⁵ Decima Research (Sep 2002) National profile of family caregivers in Canada: Final report. Health Canada
- ²⁶ Profile of languages in Canada: English, French, and many others. 2001 Census: Analysis Series Statistics Canada, 2002. [accessed 17 April 2007]
- ²⁷ Shohet, L. & Renaud, L. (2006)
- ²⁸ International Adult Literacy Skills Survey, 2003. (Nov 9, 2005) The Daily accessed 15 April 2007]. Half the Aboriginal population of Yukon, 69% of the Aboriginal population in the Northwest Territories, and 885 of Inuit in Nunavut scored below Level 3 on the prose literacy scale, while 60% of the urban Aboriginal population in Saskatchewan and Manitoba scored below level 3. About 60% of immigrants scored below level 3 in literacy.
- ²⁹ Zanchetta, M.S. & Poureslami, I.M. Health literacy Within the reality of immigrants' culture and language. *Canadian Journal of Public Health* 97: sup. 2, S26-S30; Smylie, J, Williams, L, Cooper, N. Culture-based literacy and aboriginal health. (May/June 2006) *Canadian Journal of Public Health*, 97. S21-S25
- ³⁰ Smith, J.L., Haggerty, J. (2003) Literacy in primary care populations: Is it a problem? *Canadian Journal of Public Health* 94(6): 408-412
- ³¹ Plain language and patient education: A summary of current research. (2003) Research Briefs on Health Communications, Montreal, QC, The Centre for Literacy
- ³² Plain language and Patient Education (2003) p. 2
- ³³ Plain language and Patient Education (2003) p. 2
- ³⁴ Plain language and Patient Education (2003) p. 2
- ³⁵ Plain language and patient education (2003)
- ³⁶ Plain language and patient education (2003)
- ³⁷ Plain language and patient education (2003)
- ³⁸ Morrison, M. (2005) Aboriginal literacy and health publications. *Canadian Public Health Association* accessed 16 April 2007]

- ³⁹ King, J. (2005) Patient education: The Literacy connection. Canadian Public Health Association accessed 16 April 2007]
- ⁴⁰ Shohet, L. & Renaud, L. (May/June 2006) Critical analysis on best practices in health literacy. Canadian Journal of Public Health 97 Sup. 2, p. S11
- ⁴¹ Chiarelli, L & Edwards, P. (May/June 2006) Building Healthy Public Policy. Canadian Journal of Public Health 97 Sup. 2, p. S40
- ⁴² Schwartzberg, J. (2005) Improving communication with patients with low literacy. American Medical Association Foundation and American Medical Association. Canadian Public Health Association [accessed 18 April 2007]
- ⁴³ For example, the National Literacy and Health Program, a project of the Canadian Public Health Association, is a consortium of 28 national health associations educating health professionals about best practices in serving their clients with low literacy. See also: Ros, M. & Moody C. (2005) One Day Wonders Best Practices in Literacy and Health Conference, Canadian Public Health Association, 2005. [accessed 18 April 2007] and
Wizowski, L. & Hutchings, T. (2005) Health literacy workshops for professionals and students: Building on 10 years of experience. Best Practices in Literacy and Health Conference, Canadian Public Health Association [accessed 18 April 2007]
- ⁴⁴ The internet experience of younger and older Canadians (2007) Innovation Analysis Bulletin Statistics Canada Catalogue No. 88-003-XIE
- ⁴⁵ Gray, N.J., Klein, J.D., Noyce, P. R., Sesselberg, T.S., & Cantrill, J.A. (2005) The internet: A window on adolescent health literacy. Journal of Adolescent Health, 37
- ⁴⁶ Norman, C.D. & Skinner, H.A. (Apr-June 2006) eHealth literacy: Essential skills for consumer health in a networked world. Journal of Medical Internet Research 8, p. 3. [accessed 16 April 2007]
- ⁴⁷ Friedman, D.B., Hoffman-Goetz, L. & Arocha, J.F. (Mar 2006) Health literacy and the world Wide Web: Comparing the readability of leading incident cancers on the Internet. Medical Informatics and the Internet in Medicine 31(1): 67-87.
- ⁴⁸ Norman, & Skinner (2006)
- ⁴⁹ Birru, M.S., Monaco, V.M., Charles, L., Drew, H., Njie, V., Bierria, T., Detlefsen, E., & Steinman, R.A. (Jul-Sep 2004) Internet usage by low-literacy adults seeking health information: An observational analysis. Journal of Medical Internet Research. pp. 1-16 [accessed 18 April 2007]
- ⁵⁰ www.medlineplus.gov
- ⁵¹ Olney, C.A., Warner, D. G., Reyna, G., Wood, F.B., & Siegel, E.R. (Jan 2007) MedlinePlus and the challenge of low health literacy: findings from the Colonias Project. Journal of the Medical Librarians Association, 95(1) pp. 31-36.

- ⁵² Nahm, E.S., Resnick, B., & Covington, B. (Sep-Oct 2006) Development of theory-based, online health learning models for older adults: Lessons learned. *Computer Information in Nursing*, 24:5, 261-68.
- ⁵³ Hogenbirk, J.C., Liboiron-Grenier, L., Pong, R. W., & Young, N.L. (2005) How can telehomecare support informal care? Examining what is known and exploring the potential. Home and continuing Care Policy Unit, Health Canada.
- ⁵⁴ Hendrix, Cristina C. (Nov 2006) Informal caregiver training on home care and cancer symptom management prior to hospital discharge: A feasibility study. *Oncology Nursing Forum*. 33:4.
- ⁵⁵ Haigler, Bauer, & Travis (2004).
- ⁵⁶ Zukewich, N. (Autumn 2003) Unpaid informal caregiving. *Canadian Social Trends Statistics Canada Catalogue No. 11-008*, p. 18.