An Evaluation of Continuity of Cancer Care Through Regional Supportive Care Networks

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Timothy Whelan
Eva Grunfeld
Jonathan Sussman
Julia Abelson
Andrew Willan
Scott Sellick
Cathy Charles
Margaret Fitch
Carol Rand
Richard Tozer
Susan Schiff
Sara Tedford
Farhana Khondoker
Alan Edwardson
Sherrie Orr
Mary Ann O’Brien
Adrienne Hasler

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Principle Investigator:

Dr. Timothy Whelan
Director
Supportive Cancer Care Research Unit
Hamilton Regional Cancer Centre
699 Concession Street, Level 3-62
Hamilton, Ontario L8V 5C2

Telephone: (905) 387-9711 extension 64501
Fax: (905) 575-6308

E-mail: tim.whelan@hrcc.on.ca

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For more information on the Canadian Health Services Research Foundation, contact the foundation at:
1565 Carling Avenue, Suite 700
Ottawa, Ontario
K1Z 8R1
E-mail: communications@chrsf.ca
Telephone: (613) 728-2238
Fax: (613) 728-3527

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1565, avenue Carling, bureau 700
Ottawa (Ontario)
K1Z 8R1
Courriel : communications@fcrss.ca
Téléphone : (613) 728-2238
Télécopieur : (613) 728-3527
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Timothy Whelan\textsuperscript{1,2}  
Eva Grunfeld\textsuperscript{3}  
Jonathan Sussman\textsuperscript{2}  
Julia Abelson\textsuperscript{1}  
Andrew Willan\textsuperscript{1}  
Scott Sellick\textsuperscript{4}  
Cathy Charles\textsuperscript{1}  
Margaret Fitch\textsuperscript{5}  
Carol Rand\textsuperscript{2}  
Richard Tozer\textsuperscript{2}  
Susan Schiff\textsuperscript{2}  
Sara Tedford\textsuperscript{1}  
Farhana Khondoker\textsuperscript{3}  
Alan Edwardson\textsuperscript{4}  
Sherrie Orr\textsuperscript{2}  
Mary Ann O’Brien\textsuperscript{1,2}  
Adrianne Hasler\textsuperscript{2}

\textsuperscript{1} Université McMaster  
\textsuperscript{2} Juravinski Cancer Centre  
\textsuperscript{3} Centre de cancérologie régional d’Ottawa  
\textsuperscript{4} Northwestern CCOR  
\textsuperscript{5} Toronto Sunnybrook Regional Cancer Centre
Key Implications for Decision Makers

In 1997, Cancer Care Ontario (the provincial cancer control agency) decided to include supportive cancer care services in its mandate. These include homecare, nutritional support, and social, financial, and psychological counselling. The agency divided the province into eight regions, and asked each to develop a supportive care network. This study examined the effect of three of these networks on continuity of care for breast, colorectal, and prostate cancer patients.

• Cancer patients are not very aware of the supportive cancer care services available to them. Awareness did not improve as the networks moved from their start-up phase to maturity.

• Even fewer patients actually used supportive cancer care services. Use did not increase as the networks moved from their start-up phase to maturity.

• Healthcare practitioners are much more aware of the supportive cancer care services available to patients. However, most said they needed more information and that their awareness did not improve as the networks were being developed.

• Regions had difficulty developing their networks for two primary reasons. First, Cancer Care Ontario provided only broad definitions of “supportive care” and “networks,” making it difficult for the regions to put theory into practice. Second, most people interviewed identified a serious lack of resources, both financial and human.

• To provide patients with true continuity of care, supportive care services must be co-ordinated at the administrative and operational (patient-provider) levels.

• Supportive care networks require a formal administrative structure, with contractual agreements between community providers and organizations, and adequate, committed human and financial resources.
Executive Summary

This study looked at the effect of regional supportive care networks on continuity of care. It focused on supportive care for recently diagnosed cancer patients in three regions in Ontario — central-west, east, and northwest. Supportive care services include homecare, nutritional support, and social, financial, and psychological counselling. For newly diagnosed cancer patients, awareness and use of supportive cancer care services is a measure of continuity of care, since patients move across a number of healthcare jurisdictions. The study also evaluated the awareness of supportive cancer care services by healthcare practitioners.

Patients were surveyed five times, every six months from June 2001 to April 2003. Those studied were a population-based random sample of recently diagnosed breast, colorectal, and prostate cancer patients. A total of 3,316 patients was studied (between 552 and 755 at each survey) reflecting a response rate of 69 percent (between 65 percent and 72 percent at each survey).

Healthcare providers received one cross-sectional survey, conducted from May to September 2003. Those studied were all cancer specialists and nurses, along with a random sample of primary care physicians, in the three study regions. A total of 413 providers completed the survey, for a response rate of 45 percent.

Continuity of care was measured with a survey developed for this study. Continuity was measured as patient awareness and use of supportive cancer care services. There were 46
items on the survey, covering six areas of supportive cancer care: informational, psychological, social, physical, complementary therapy, and spiritual supports. A modified version was developed for practitioners, consisting of 27 items organized under four areas (excluding complementary therapy and spiritual supports).

Average patient awareness of services was 23.5 out of 46 and did not improve over time. Use of supportive cancer care services was considerably lower than awareness, with an average survey score of 8.7 out of 46. Use did not increase over time, either. The finding that patients’ awareness or use of supportive cancer care services did not increase over time suggests that networks were not effective in meeting their stated goal with respect to continuity of care.

Practitioners were more aware of supportive cancer care services, with an average score of 21.1 out of 27. However, only a minority indicated improvement in awareness of supportive cancer care services over the three-year period of the study. More than 70 percent of respondents reported they needed to know more about supportive cancer care.

The second part of the study was a case-study analysis of how the development of three regional supportive care networks contributed to the goal of improving continuity of care. This was done using interviews, document analysis, and observation of meetings.

Success was limited in all three regions studied (central-west, east, and northwest). Each region developed its supportive care network differently, with the structure, function, and
extent of maturity varying within and across regions. The reasons for lack of success varied by region but were attributed to i) different definitions of supportive care; ii) regional diversity; and iii) lack of resources.

The results demonstrate that healthcare networks are very complex in nature, and that many elements are necessary for success. To improve continuity for patients, service co-ordination that includes interventions both at the administrative and the operational (patient/provider) level are required. At the administrative level, the network requires a formal administrative structure with contractual agreements between service providers and mutual care management plans. Successful supportive care networks also require adequate infrastructure support, integrated information systems, and continuous quality management. Unfortunately the regional networks included in our study did not fully succeed due to a lack of administrative structure and resource support. Even if successful, without active interventions at the direct patient-care level, supportive care networks would have been unlikely to result in changes in continuity of care perceivable by patients.