

# THE CANCER CARE NAVIGATOR

## Toward a conceptual framework for a new role in oncology

*Richard Doll, MSW, MSc; Maria Cristina Barroetavena, MD, PhD; Ann-Louise Ellwood, PhD; Lise Fillion, PhD; Martine E. Habra, PhD; Wolfgang Linden, PhD; Joanne Stephen, PhD*



### Top-line summary

The navigator role refers to a person who helps people with cancer coordinate complex and often confusing treatment processes and protocols. The navigator focuses on helping patients identify needs and locate appropriate health and community resources in a timely fashion. The literature suggests several role behaviours related to patient navigation but has largely failed to describe a supporting conceptual framework, particularly for the psychosocial functions related to this role. This absence compromises the effectiveness and uptake of programs. To address this concern, we propose placing the behavioural roles of the navigator in the context of existing psychologic concepts, namely social support, decision-making, active coping and self-efficacy. We suggest using these concepts to systematically assess patient needs and resources. Matching navigation approaches with these known theoretical constructs allows application of proven tools to measure outcomes.

Cancer patients are often overwhelmed by the many steps and lengthy processes of typical cancer care. The development of an integrated, coordinated system that ensures optimum access and continuity has been identified as a serious challenge for cancer control efforts.<sup>1,2</sup>

Continuity is especially important to cancer patients, as care is often intense yet distributed among a wide range of service providers. It usually spans a lengthy trajectory from initial diagnosis to treatment, then to cure or palliation.<sup>3</sup> Under-scoring the problems of discontinuity and lack of coordination faced by cancer patients, a recent study (not peer-reviewed) found that the number of physicians a patient encounters during his or her cancer experience ranges from a minimum of 13 to a staggering maximum of 97, with a median of 32.<sup>4</sup> Patients who have experienced the cancer system first-hand have referred to it as a “maze” or “no system at all.”<sup>2</sup>

Pressure to implement more integrative models of care and provide access to a seamless continuum of service arises from the desire to improve quality of care, avoid duplication of services and cut costs. As well, many patients and families are dissatisfied with poor communication and coordination between healthcare providers, and feel isolated as a result of fragmented care. Cancer patients and their care providers consider continuity of care and unrushed consultation to be very important. Discontinuity is perceived to lead to a lack of personal and case familiarity and to communication difficulties.<sup>5,6</sup>

Research-based evidence is lacking to support the use of any particular model to address these challenges.<sup>4</sup> A number of specific strategies have been recommended, such as concentrating care with as few providers as possible — including psychosocial care of patients and families — and adding case management or navigation as a formal program component.<sup>7-11</sup>

The absence of good evidence to support the effectiveness of the navigation approach can stymie needed program development in the area. This paper makes the case for the potential merits of a “patient navigator” while recognizing

**Richard Doll, MSW, MSc** is Provincial Program Leader, Cancer Rehabilitation and Director, Sociobehavioural Research at the British Columbia Cancer Agency (BCCA). **Maria Cristina Barroetavena, MD, PhD** is Clinical Assistant Professor at the Department of Health Care and Epidemiology, University of British Columbia (UBC), Vancouver, BC. **Ann-Louise Ellwood, PhD** is a Research Practitioner at the BCCA Centre for the Southern Interior. **Lise Fillion, PhD** is a Professor in the Faculty of Nursing, Université Laval, Québec, QC. **Martine E. Habra, PhD** is a Post-Doctoral Fellow at the Institut de Cardiologie de Montréal. **Wolfgang Linden, PhD** is a Professor in the Department of Psychology, UBC and a psychologist at the BCCA. **Joanne Stephen, PhD** is a Researcher and Clinical Practitioner at the BCCA and Adjunct Professor, Faculty of Health Sciences, Simon Fraser University, Burnaby, BC. Address for correspondence: Richard Doll, BC Cancer Agency, 600—750 West Broadway, Vancouver BC V5Z 1H5. Tel: (604) 877-6126; Fax: (604) 708-2091; Email: rdoll@bccancer.bc.ca



## CONTINUING CARE

navigator may correspond to a more comprehensive medical or social model of case management that values empowering patients and humanizing care.<sup>13</sup> This view emphasizes individuals taking responsibility for important decisions. Navigators oversee the treatment process, provide information and support to the patient, link with other professionals in the treatment process and act as a single, constant contact. In so doing they may provide psychosocial care to patients and relieve pressure on oncologists. The navigator can be someone who assists patients as an advocate, educator and support person throughout the illness, preparing them for procedures and linking them with networks of professional and volunteer helpers. Patients not only travel the healthcare maze in a more timely fashion, but their psychosocial well-being and quality of life may also be enhanced.

Although most patients with cancer report being extremely satisfied with the quality of medical care received for cancer treatment, several needs assessment surveys have identified that psychologic needs (e.g. managing emotions associated with coping with cancer and dealing with changes in social identity) and health information needs (e.g. managing symptoms and test results) are not being met.<sup>14-16</sup> These studies have also found that younger patients and women tend to report a higher level of unmet needs. A Canadian study encompassing all diagnoses found that over 90% of cancer patients reported that it was very important for them to have access to information about cancer treatment and side effect management — yet only half of those who sought out information about specific symptoms (e.g. fatigue and anxiety) reported being able to find it.<sup>17</sup>

Existing definitions of the navigator tend to focus on behaviours and tasks performed for or on the patient. These place the navigator somewhere on a continuum from “doing things for patients” at one extreme to “empowering patients to do things themselves” at the other end. Our approach attempts to ensure clarity and consensus about the degree of proactive behaviour that navigators engage in, and we propose a definition of psychosocial care more at the “empowering” end of the continuum.

The central role of the navigator is to help the patient move through the system as smoothly as possible, and also to ensure that unmet needs are addressed. The navigator’s role is framed in a wider conceptual perspective that includes the interaction between navigator and patient: the navigator assesses the individual patient’s needs and tailors his/her activities to these identified needs. Four critical bodies of literature can help build such a framework and facilitate decisions on how best to achieve this tailoring: social support, decision-making, active coping and self-efficacy.

### Social support

Over the past 25 years, social support (or lack thereof) has emerged as one of the strongest psychosocial predictors of physical health. Numerous large-scale epidemiologic studies have indicated that a supportive environment is associated with decreased mortality from all causes.<sup>18-20</sup> The presence of supportive relationships has also been linked to improved cancer survival odds in both large population-based studies<sup>21,22</sup> and smaller clinical studies.<sup>23-26</sup> Social support has consistently

the need to develop conceptual models that can be understood and adapted for translation into practice. We also seek to clarify the differences between navigation and case management — a more widely used term — in addressing problems related to the integration, coordination and continuity of cancer care.

### ROLE OF THE PATIENT NAVIGATOR

Patient navigation denotes a system or professional role primarily intended to ease and expedite patients’ access to services and resources, improve continuity and coordination of care throughout the cancer care continuum, and serve as a patient advocate where needed. Various terms have been used to describe such a role, including Case Manager, Clinical Coordinator, and for those areas advocating nursing providers, Cancer Support Nurse, Follow-up Nurse or Advanced Practice Nurse. Many of the applications for navigators to date have been in breast cancer,<sup>7</sup> and a case manager is sometimes labeled as a patient navigator.<sup>9</sup>

A number of different models of case management are proposed in the literature. Minimal models involve outreach, client assessment and referral to service providers, whereas more comprehensive models add advocacy on behalf of patients, education, support, problem-solving and crisis intervention. Definitions often relate to a profession, organization or targeted client group.<sup>12</sup> Case managers come from many disciplines, and often have a background in nursing or social work. The role of case manager is evolving: for nurses, preparation for this role historically occurred within the organization that employed them, while more recently, academic preparation at the graduate level is often required.<sup>12</sup> Regardless of the profession and academic preparation, an effective patient navigator must possess clinical expertise, effective communication and problem-solving skills, and broad knowledge of the healthcare system.<sup>12</sup> All these roles fit in with the concept of a holistic approach that centres on the quality of life of the person with cancer.<sup>13</sup>

This navigator role goes beyond the initial minimal functions of the case manager, who typically helps the patient fill out forms and schedule appropriate appointments. The

# CONTINUING CARE

been associated with better psychosocial outcomes, including less depression,<sup>27</sup> better quality of life<sup>28</sup> and better psychologic adjustment.<sup>23,29,30</sup>

Social support has been conceptualized in many ways, highlighting features including the structural aspects of social networks (e.g. the size of a person's social circle or the number of resources provided), functional aspects of social support (e.g. emotional support or a sense of acceptance), and enacted support (e.g. provision of specific supportive behaviours in times of distress, such as reassurance or advice), as well as the subjective perception of support by the recipients.<sup>31-33</sup> Support has been defined in a more interpersonal light as an exchange between providers and recipients. Three main types of supportive social interaction have been described: emotional, informational and instrumental.<sup>34-36</sup> Emotional support involves verbal and nonverbal communication of caring and concern, and is believed to reduce distress by restoring self-esteem and permitting the expression of feelings. Informational support, which involves providing information used to guide or advise, is believed to enhance perceptions of control by reducing confusion and giving patients strategies to cope with their difficulties. Instrumental support involves providing material goods (e.g. transportation, money or physical assistance), and may also help decrease feelings of loss of control.

The nature and stability of social support is affected by the source of support, i.e. whether it emerges from natural or more formal support systems. Natural support systems include both family and friendship networks. More formal support is provided by professionals (such as mental health and medical professionals), through social-help of individuals with similar problems and through social or community ties (such as clubs or religious groups). Presumably, natural support networks are more enduring while other forms of support may be more transient. However, whether one is superior to the other as a source of support is not clear.<sup>37</sup> In light of this literature, the navigator is clearly a formal (transient) support provider who may directly offer or facilitate access to social support to patients in care.

## Decision-making process

Another function that a navigator can fulfill is facilitating and assisting in making decisions. There is a growing philosophy in healthcare that while responsibility is shared between patient, family and multiple healthcare providers, the patient exercises ultimate authority and must make critical decisions with respect to care.<sup>38</sup> Indeed, many patients do not wish to hand over decision-making control to their physician,<sup>39</sup> and being actively involved in the process can result in better psychosocial outcomes for patients.<sup>40</sup> Decisions to be made involve not only choices about treatment options (e.g. mastectomy vs lumpectomy in breast cancer), but also lifestyle changes (e.g. quitting smoking) and treatment adherence (e.g. completing a full course of chemotherapy). For choices about treatments, decision-making necessitates access to timely and relevant medical information. The patient navigator needs to develop clinical expertise to refer patients to key medical informants. As well, a useful approach for supporting lifestyle changes is to define the

gap between the current behaviour and the targeted one as a problem to solve.

## Active coping

The literature on active coping can also be used to inform the role of the navigator.<sup>41-44</sup> Much research on the psychosocial aspects of cancer has focused on stress and coping. Many authors have sought to link specific approaches to coping (e.g. fighting spirit, emotional expression or nonexpression, denial) to cancer survival, and results have been inconsistent.<sup>45-47</sup> It seems that cancer patients as a group use a variety of coping strategies, with no clear demonstrable pattern.<sup>48,49</sup> This is not surprising given that factors such as longstanding coping habits, stage of illness, existing resources and distress level vary from patient to patient, and as such can have an important impact on coping.<sup>49</sup>

Our approach diverges from previous efforts: we attempt to frame the navigator role within the stress and coping literature, recognizing that cancer is a multifaceted, stressful experience that requires various coping strategies — matched to a variety of stressors according to preferences and past experiences. Coping strategies are often divided into active and passive coping, with active coping more problem-focused and solution-oriented and passive coping more oriented to avoiding stressors (cognitively or behaviourally). Problem solving and other problem-oriented active coping strategies are demonstrably more adaptive when problems are acute, controllable and have solutions available.<sup>50,51</sup> Chronic health problems, however, cannot be readily fixed with a single action and usually require emotional processing and acceptance. For example, when applying these concepts to a positive diagnosis of cancer, there is a major difference between an appropriate choice of coping strategy for early-stage basal cell carcinoma of the skin and one for metastasized, rapidly progressing cancer in the colon. Basal cell carcinoma has an excellent prognosis and quick action is of great benefit — and this can easily be made clear to patients. Metastasized colon cancer, of course, marks the other end of this continuum, and extensive active emotional coping, such as expressing and processing emotions, is very beneficial for most people and their families. There is no evidence to support passive coping behaviour patterns such as blaming others, complaining or suppressing emotion, although for many patients this is a natural and acceptable approach.

Recognizing and supporting a type of coping appropriate to a given problem is complicated by the fact that there are individual differences in preferred types of coping, irrespective of the type of problem faced. Some people tend to see all problems as requiring emotional coping, and others tend to see all problems as concrete and resolvable, and still others use both strategies. Coping preferences can be readily assessed and the resulting information can then be used to better understand patients and their unique approaches to coping. Two popular tools for assessing coping preferences are the Ways of Coping (WOC) Scale<sup>52</sup> and the COPE inventory.<sup>43</sup> Examples of active coping items on the WOC include “Get professional help and do what they recommend” and “Just concern yourself with what to do next”, while some passive coping items are “Try to forget the

whole thing” and “Accept sympathy and understanding from someone.” Thus, navigators need to:

- have a sense of the most suitable type of coping for a given situation (knowledge of cancer prognosis factors is critical)
- assess the coping strategy repertoire of a given patient
- learn about the intended choice of coping for individual patients in a given situation
- reinforce active coping strategies or help modify coping strategy

In the last step, if there appears to be a mismatch between patient coping preference and best strategy, the navigator needs to skillfully provide information on other coping options and help move the patient through stages of decision-making — striking a balance acceptable to the patient that recognizes individual needs and best medical approaches. This involves help with verbalizing emotional needs, and facilitating nonjudgmental, patient-centred processing of these needs.

## Self-efficacy

Self-efficacy is empirically recognized as one of the strongest predictors of health behaviour change<sup>53</sup> and is defined as an individual’s level of confidence in his/her ability to perform a particular behaviour (efficacy expectations). Self-efficacy theory states that the strength of belief in one’s capability is a good predictor of future behaviours. A strong perception of self-efficacy to perform a given healthy behaviour, such as exercising on a regular basis, is associated with a high probability of doing it. The patient navigator can assess self-efficacy perception in order to estimate the potential occurrence of relevant health behaviours. Self-efficacy can be measured using validated procedures following the Bandura

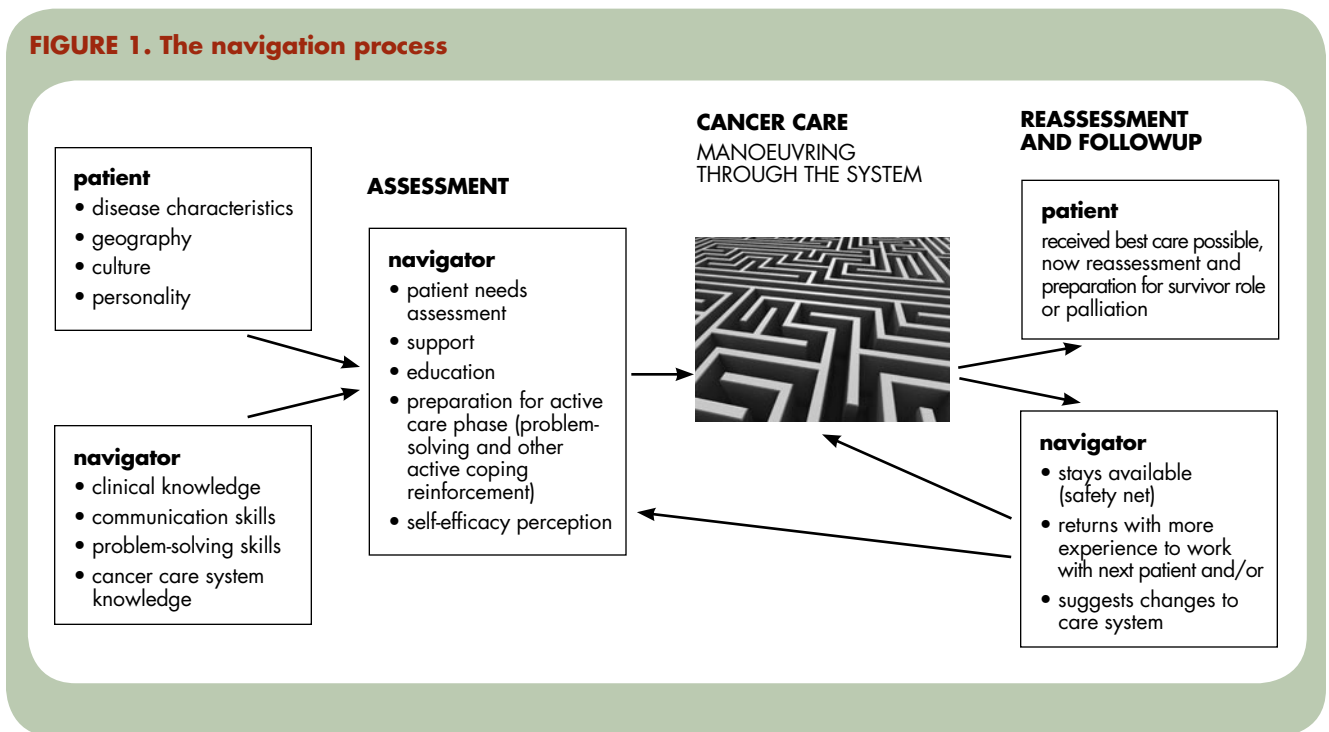
guidelines.<sup>53</sup> Low self-efficacy can be interpreted as an indicator of need for behavioural change support. Various interventions that incorporate specific efficacy-enhancing techniques — performance mastery, modeling, adjustment to stress or reinterpretation of physiologic symptoms, and verbal persuasion — have demonstrably resulted in fewer episodes of hospitalization and improved psychosocial adjustment to a new health status.<sup>54</sup>

## CONCEPTUAL FRAMEWORK AND PRACTICE RECOMMENDATIONS

To ensure precision in developing navigation we have proposed 4 concepts to serve as a foundation to conceptualize, apply and test navigational approaches (Figure 1). A first step typically absent in most approaches to supportive cancer care is the application of a comprehensive assessment tool to ensure a fit between patient need and decision-making preferences. Our work in developing screening tools to capture distress<sup>55</sup> could be applied to identifying patient needs in conjunction with tools that assess patient preferences in decision-making. Work conducted in assisting patients with breast cancer to solve problems using the COPE (Creativity, Optimism, Problem solving and use of Expert information) model could also be applied to navigation in all cancers.<sup>56</sup>

According to our framework, the first target in navigation work is to conduct a thorough assessment that includes the challenges facing the patient and the availability of social support resources. The literature suggests that individually tailored assessment could cover different types of support needs (emotional, instrumental and informational) and the possible sources for support provision (e.g. family, community, health professionals and navigator). Clearly, patients’ needs for different types of support will inevitably vary: for

**FIGURE 1. The navigation process**



# CONTINUING CARE

example, an elderly woman living in a rural environment may have pressing transportation problems, whereas a recent immigrant in an urban area may be impeded in attempting to access services by poor language skills and lack of awareness about the medical system. For the former, instrumental support is critical; the latter requires informational support. Given that the great majority of patients have already developed natural support systems before becoming ill, the navigator may first attempt to direct the patient to existing sources of support including available community resources, support groups and psychosocial services. Finally, the navigator will also be involved in identifying new resources to meet the needs of patients where gaps in service provision exist. It is expected that this stepped approach will help avoid expensive duplication of services, thus promoting system cost-efficiency.

We suggest that in conducting this needs assessment, the navigator should carefully consider the patient's characteristics and environment, learn what the disease prognosis is, be aware of the patient's disease knowledge, know what the patient's physical and social environment looks like, and know what services for informational, instrumental and

emotional support exist (formal and informal). Where gaps are found, the role of the navigator is to help fill them, preferably by activating lasting natural supports rather than making the patient dependent on the navigator (Table 1). To accomplish this, other role behaviours may be indicated, including facilitating decision-making with relevant and timely information (education role), assisting in problem-solving or conducting appropriate referrals to do so, enhancing active coping strategies and monitoring self-efficacy toward targeted health behaviours.

## THE FUTURE OF NAVIGATION PROGRAMS

About 5 years ago, the term patient navigator was relatively unknown in cancer care with a literature search yielding only a handful of references.<sup>7</sup> Today, navigation is viewed as a promising approach to address some of the fundamental problems that plague the system of care, specifically to improve access, continuity and coordination of care. These are lofty and perhaps unrealistic expectations. The Canadian Strategy for Cancer Control (CSCC) Rebalance Focus Action Group<sup>57</sup> has identified the development of patient navigation as a key national priority. Work groups have

**TABLE 1. Suggested tool for identifying the cancer patient's needs**

Please indicate needs and status of how they can be met by writing notes in the appropriate cells.

Need	Source of assistance	Family (spouse, children, friends)	Community (volunteers, church, local agencies)	Health professionals (RNs, GPs, specialists)	Navigator
<b>Financial support</b>					
• Budget for out-of-pocket expenses (lost income, home care, care services)					
• Obtaining medical care or home care assistance					
• Completing paperwork and understanding eligibility where appropriate					
<b>Medical information about</b>					
• Diagnosis					
• Tests & exams					
• Treatment					
• Future conditions					
• Side effects					
<b>Communication</b>					
• Understanding what medical staff say					
• Asking questions					
• Expressing concerns & wants					
• Comprehending written information provided					
<b>Decision making</b>					
• Understanding options and impacts					
• Understanding urgency of treatment					
• Talking about personal preferences					

been formed to help health authorities develop navigation programs and tools. A number of provinces have launched or are considering funding for navigation programs but have been hampered by the lack of clarity in the objectives of navigation programs, knowledge of the best methods for program development and limited data demonstrating program effectiveness.

Although the authors agree that the use of patient navigators is a positive step, we believe that the absence of conceptual frameworks to guide this work will limit the eventual effectiveness of program uptake. Conceptual frameworks can help organize our thinking, assumptions and values. Frameworks also assist in developing appropriate objectives, measures of achievement and program evaluation criteria. The inclusion of psychosocial theory will strengthen the understanding of patient behaviour, and these behaviours should be tied to target outcomes for navigation programs. The use of assessment tools ensures that patient needs for navigator support are understood, and acknowledges that some patients may not require a navigator. Efforts should be made to assess patient preferences particularly in terms of patient and family self-navigation. The role of the navigator in this instance becomes one of coach, supporter and teacher.

Existing services may be available but may not be accessible to patients because they are remote or poorly promoted. For example, family physicians are typically involved with patients in the early part of the trajectory but may be out of the loop during the treatment phase. Ideally the family physician could resume a navigation role to assist in the patient's reintegration during the post-treatment phase of care. We recommend due attention to all of these considerations in program planning for navigation.

## References

- Canadian Strategy for Cancer Control. Health Canada. Supportive Care Workgroup Report, January 2002. Available at [www.cancercontrol.org](http://www.cancercontrol.org) > Publications / Reports > Supportive Care
- Trussler T. *The journey to supportive care. Uncovering the gaps: An inquiry of breast cancer care in British Columbia*. BC/Yukon Canadian Breast Cancer Foundation, 2002.
- Adeyuyi-Dalton R, Ziebland S, Grunfeld E, Hall A. Patients' views of routine hospital follow-up: a qualitative study of women with breast cancer in remission. *Psychooncology* 1998;7(5):436-39.
- Haggerty J, Reid R, McGrail K, McKendry. Here, There and All Over The Place: Defining and Measuring Continuity of Health Care. A discussion paper. 2001. Available at [www.chspr.ubc.ca](http://www.chspr.ubc.ca) > Publications > 2001.
- Bakker DA, DesRochers C, McChesney C et al. Community cancer clinics: patients' perspectives. *Support Care Cancer* 2001;9(4):234-40.
- Smith SD, Nicol KM, Devereux J, Combleet MA. Encounters with doctors: quantity and quality. *Palliat Med* 1999;13(3):217-23.
- Farber JM, Deschamps M, Cameron R. Investigation and assessment of the "navigator role" in meeting the informational, decisional and educational needs of women with breast cancer in Canada. Final Report prepared for The Education Strategy Committee of the Canadian Breast Cancer Research Initiative. 2002. Available at <http://www.phac-aspc.gc.ca> > Chronic Diseases > Cancer > Breast Cancer > Publications
- Holli K, Hakama M. Continuity of the doctor/patient relationship during the routine follow-up of a breast cancer patient. *Support Care Cancer* 1993;1(5):263-65.
- Lantz PM, Keeton K, Romano L, Degroff A. Case management in public health screening programs: the experience of the national breast and cervical cancer early detection program. *J Public Health Manag Pract* 2004;10(6):545-55.
- Lauria MM. Continuity of cancer care. *Cancer* 1991;67(6 Suppl):1759-66.
- O'Connell B, Kristjanson L, Orb A. Models of integrated cancer care: a critique of the literature. *Aust Health Rev* 2000;23(1):163-78.
- White P, Hall ME. Mapping the literature of case management nursing. *J Med Libr Assoc* 2006;94(2 Suppl):E99-106.
- Fillion L, de Serres M, Lapointe-Goupil R et al. Implementing the role of patient-navigator nurse at a university hospital centre. *Can Oncol Nurs J* 2006;16(1):11-7,5-10.
- Girgis A, Boyes A, Sanson-Fisher RW, Burrows S. Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Aust N Z J Public Health* 2000;24(2):166-73.
- Sanson-Fisher R, Girgis A, Boyes A et al. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000;88(1):226-37.
- Soothill K, Morris SM, Harman J et al. The significant unmet needs of cancer patients: probing psychosocial concerns. *Support Care Cancer* 2001;9(8):597-605.
- Ashbury FD, Findlay H, Reynolds B, McKerracher K. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;16(5):298-306.
- House JS, Robbins C, Metzner HL. The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. *Am J Epidemiol* 1982;116(1):123-40.
- Penninx BW, van Tilburg T, Kriegsman DM et al. Effects of social support and personal coping resources on mortality in older age: the Longitudinal Aging Study Amsterdam. *Am J Epidemiol* 1997;146(6):510-19.
- Yasuda N, Zimmerman SI, Hawkes W et al. Relation of social network characteristics to 5-year mortality among young-old versus old-old white women in an urban community. *Am J Epidemiol* 1997;145(6):516-23.
- Reynolds P, Kaplan GA. Social connections and risk for cancer: prospective evidence from the Alameda County Study. *Behav Med* 1990;16(3):101-10.
- Vogt TM, Mullooly JP, Ernst D et al. Social networks as predictors of ischemic heart disease, cancer, stroke and hypertension: incidence, survival and mortality. *J Clin Epidemiol* 1992;45(6):659-66.
- Eli K, Nishimoto R, Mediansky L et al. Social relations, social support and survival among patients with cancer. *J Psychosom Res* 1992;36(6):531-41.
- Marshall JR, Funch DP. Social environment and breast cancer. A cohort analysis of patient survival. *Cancer* 1983;52(8):1546-50.
- Waxler-Morrison N, Hislop TG, Mears B, Kan L. Effects of social relationships on survival for women with breast cancer: a prospective study. *Soc Sci Med* 1991;33(2):177-83.
- Hislop TG, Burhenne LJ, Basco VE, Ng VT. The Screening Mammography Program of British Columbia: pilot study. *Can J Public Health* 1991;82(3):168-73.
- Hann D, Baker F, Denniston M et al. The influence of social support on depressive symptoms in cancer patients: age and gender differences. *J Psychosom Res* 2002;52(5):279-83.
- Michael YL, Berkman LF, Colditz GA et al. Social networks and health-related quality of life in breast cancer survivors: a prospective study. *J Psychosom Res* 2002;52(5):285-93.
- Bloom JR. Social support, accommodation to stress and adjustment to breast cancer. *Soc Sci Med* 1982;16(14):1329-38.
- Funch DP, Mettlin C. The role of support in relation to recovery from breast surgery. *Soc Sci Med* 1982;16(1):91-98.
- Cohen S. Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychol* 1988;7(3):269-97.
- House JS, Landis KR, Umberson D. Social relationships and health. *Science* 1988;241(4865):540-45.
- Lakey B & Lutz CJ. Social support and preventive and therapeutic interventions. In *Handbook of social support and the family* (435-465). GR Pierce, BR Sarason, IG Sarason (Eds). New York, Plenum, 1996.
- Levitt MJ, Antonucci TC, Clark MC et al. Social support and well-being: preliminary indicators based on two samples of the elderly. *Int J Aging Hum Dev* 1985-1986;21(1):61-77.
- House JS, Kahn RL. Measures and concepts of social support. In *Social Support and Health* (pp. 83-108). S Cohen & SL Syme (Eds.). New York, Academic Press, 1985.
- Kahn RL, Antonucci TC. Convoys over the life course: Attachment, roles, and social support. In *Life-span Development and Behavior*, Vol. 3, (pp.253-286). PB Baltes & O Brim (Eds.) New York: Academic Press, 1980.
- Hogan BE, Linden W, Najarian B. Social support interventions: do they work? *Clin Psychol Rev* 2002;22(3):383-442.
- Bartholome WG. A revolution in understanding: how ethics has transformed health care decision making. *QRB Qual Rev Bull* 1992;18(1):6-11.
- Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? *Arch Intern Med* 1996;156(13):1414-20.
- Morris J, Royle GT. Offering patients a choice of surgery for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Soc Sci Med* 1988;26(6):583-85.
- Lazarus RS, Folkman S. Stress, appraisal, and coping. New York, Springer, 1984.
- Folkman S, Lazarus RS. *Manual for the ways of coping questionnaire* (Research Edition). Palo Alto, Consulting Psychologists, 1998.
- Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989;56(2):267-83.
- Stanton AL, Revenson TA, Tennen H. Health psychology: psychological adjustment to chronic disease. *Annu Rev Psychol* 2007;58:565-92.
- De Boer MF, Ryckman RM, Pruyn JF, Van den Borne HW. Psychosocial correlates of cancer relapse and survival: a literature review. *Patient Educ Couns* 1999;37(3):215-30.
- Glanz K, Lerman C. Psychosocial impact of breast cancer: A critical review. *Ann Behav Med* 1992;14(3):204-12.
- Spiegel D, Kato PM. Psychosocial influences on cancer incidence and progression. *Harv Rev Psychiatry* 1996;4(1):10-26.
- Buddeberg C, Sieber M, Wolf C et al. Are coping strategies related to disease outcome in early breast cancer? *J Psychosom Res* 1996;40(3):255-64.
- Dunkel-Schetter C, Feinstein LG, Taylor SE, Falke RL. Patterns of coping with cancer. *Health Psychol* 1992;11(2):79-87.
- Auerbach SM. Stress management and coping research in the health care setting: an overview and methodological commentary. *J Consult Clin Psychol* 1989;57(3):388-95.
- Wills TA. Stress and coping in early adolescence: relationships to substance use in urban school samples. *Health Psychol* 1986;5(6):503-29.
- Aldwin C, Folkman S, Schaefer C et al. The Ways of Coping: A process measure. Paper presented at APA 1980, Montreal/Canada, Sept 1-5, 1980.
- Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 1977;84(2):191-215.
- Lorig KR, Sobel DS, Stewart AL et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999;37(1):5-14.
- Linden W, Yi D, Barroetavena MC, MacKenzie R, Doll R. Development and validation of a psychosocial screening instrument for cancer. *Health Qual Life Outcomes* 2005 Sept 7;3:54.
- Houts PS, Nezu AM, Nezu CM, Bucher JA. The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Educ Couns* 1996;27(1):63-73.
- Information on the Rebalance Focus Action Group is available at [www.partnershipagainstcancer.ca](http://www.partnershipagainstcancer.ca)

## Invited commentaries on the cancer patient navigator role

**Sally Thorne, RN, PhD, Director, School of Nursing, University of British Columbia**

The topic of cancer care navigators is an urgent priority in cancer care planning, engendering considerable debate and dissension. Urquhart and Grunfeld (*Oncology Exchange* Vol. 6, No. 3, pages 39–42) reported on a recent invitational meeting of experts and opinion leaders in implementing care navigator roles. Their article outlined the elements that seem to have made various projects successful, and summarized barriers to implementation and knowledge development in relation to the navigator role. The present paper by Doll and colleagues is a call for conceptual clarity before we leap onto a bandwagon of implementing care navigator roles. It challenges us to ensure that we can measure and evaluate role effectiveness and to resolve the care system fragmentation problems that navigation strategies aim to address.

### SYSTEM CONCERNS

The concept of care navigators within the cancer care system is fraught with complexities. It introduces a new designated role within an already tangled web of care team relationships. In delegating that function to a specific health team member, it may seem to absolve others of responsibility for care coordination. While there is little debate that too many patients currently suffer the effects of disjunctures and fragmentation within our cancer care delivery systems, what to do about it depends upon one's perspective. In the Canadian context, what seems contentious at the moment is whether we ought to be articulating and striving toward standardization of care navigation roles and processes, or whether we ought to be working toward a diversity of approaches to address the apparent need.

At issue here are very practical and important questions of how we invest our precious resources, and how we will know if we have made the right decisions. Cancer care planners are charged with very difficult resource allocation decisions, and any significant investment in a widespread mechanism to provide better care will have implications for other vitally important elements of the cancer control system. Thus, the debate is not about whether something should be done, but rather about whose model or approach ought to become the gold standard. For this reason, it seems important to critically examine the assumptions and beliefs upon which the current initiatives and imperatives are founded so we can understand the perspectives that will determine the path forward toward problem resolution.

### SYSTEM AND PATIENT DIVERSITY

The cancer care planning world has quite naturally become one in which evidence-based decision-making is the dominant ideologic orientation. Where cancer treatment planning on behalf of the Canadian population is concerned, the value of standardized evidence is incontestable. However, in the context of a system culture in which we've become accustomed to thinking about planning on the basis of very large samples, tightly controlled investigations, and globally accepted quality

criteria, the issue of human experience has remained, for the most part, resistant to standardization and quantification. Attempting to resolve "patient journey" issues on the basis of population-level data could lead to trying to determine which kind of navigation support is going to best serve the "average" cancer care consumer. But we live in a country of marvelously distinct regions, cancer control systems and population subgroups. Patients affected by cancer encounter quite different versions of care discontinuities and frustrations associated with a diversity of treatment modalities, disease variables and healthcare relationship contexts. To the extent that we only think about typical scenarios, we inherently disserve the many non-dominant groups we regularly encounter and, paradoxically, may exacerbate the fragmentation of the cancer journey for those who don't fit our prototypes.

Thus, comparing the effectiveness of social work navigators in Ottawa against community-based nurse navigators in Nova Scotia, without fully understanding the base of system effectiveness into which they were introduced, the populations they are serving and the specific mechanisms with which they implement their roles, will almost always create misleading conclusions. While there is a tremendous appeal to the idea of creating Canada-wide standards of excellence toward which each provincial system aspires, articulating them in the form of standard care models may be ultimately shortsighted and ineffective. Rather, our goal in system redesign must be to identify the principles and values upon which we can build strategically positioned resources and supports so that they are as accessible as possible to those who require them. Some patients navigate our systems brilliantly and feel fully supported in their cancer journey by the existing clinical and support resources; others find cancer care an indescribable labyrinth of confusion and misrepresentation; and most fall somewhere in between. In that middle position, some require confirmation that they won't offend us if they assert their care preferences, assurance that they have the right to access certain services, or even handholding as they take initial steps toward negotiating for what they need. There will be a general set of resources, supports, information and coaching to which all patients might deserve access, but patients will exhibit quite different patterns of need for each form of navigational support, and will require different levels of active prompting to fully engage the supports they need. We must work toward a system that is amenable to the individual variations that the population of cancer patients inherently represents.

While population-based cancer control systems capable of delivering treatment according to best evidence are the ideal for dealing with diseases, my view is that standardized approaches are not the optimal mechanism for supporting individual human experiences. Cancer is a major life event characterized by raw emotion, vulnerability and danger. Our task in wrestling with the problem of disjointed cancer care systems is to develop mechanisms that will ensure that complex and diverse individuals not only obtain the standard of treatment that will best deal with their malignancies, but also feel confident that the system can meet their illness-related human needs.

Because professionals who live within the formal systems are most comfortable working with population norms and standardized systems when setting priority agendas, I fear that even the best of the formalized care navigation systems we adopt may obscure the tailored, individualized human requirements that we have conceptualized as this “navigation” problem. If we don’t address it in all of its complexity as an integrated system priority, with all of the features of blending standards and variations we can manage, we place ourselves at considerable risk of creating a for-profit “cottage industry” of external patient navigators.

While I congratulate these authors on taking up the challenge of resolving the problems that so many patients have in navigating our cancer care systems, I caution us all to remember the inherent limits of conventional science and theory as tools for solving these problems.

**Andrew Padmos, MD, FRCPC, Chief Executive Officer, Royal College of Physicians and Surgeons of Canada; Chair, Human Resources Advisory Group, Canadian Partnership Against Cancer.**

## THE NOVA SCOTIA MODEL

Cancer Care Nova Scotia, the provincial program of the Department of Health, was an early adopter and facilitator of the cancer patient navigator role, formally introduced in 2002. The fundamental design of the role in Nova Scotia places these health professionals in communities and district health authorities outside the major metropolitan centre, far from the tertiary care cancer treatment facility located in the academic health centre. The Cancer Patient Navigator in the Nova Scotia model is an indispensable element of each district health authority’s cancer program, which seeks to support and link local health, medical and surgical resources to the tertiary care and subspecialized facilities and personnel located in the cancer treatment centre in Halifax. Since the most important player in this model is the family physician, the Cancer Patient Navigator is positioned, oriented and trained to support the family physician in providing ongoing and comprehensive care to cancer patients. Such districts and communities usually have few dedicated cancer resources or personnel and the addition of the Cancer Patient Navigator provides a focal point around which comprehensive cancer services can be organized, facilitated and evaluated.

The Cancer Patient Navigators receive coordinated training and familiarization visits organized and supervised by Cancer Care Nova Scotia. Their success is due to their knowledge of both the local setting, including the particular circumstances of the patient and family, and the extensive resources available in the tertiary care centre. This enables them to untie procedural knots with a single telephone call, expedite needed testing and investigations through local referrals and keep patients, families, their family doctors and referring physicians and surgeons abreast of developments pertaining to a particular patient and treatment protocols for particular cancer types. In fulfilling their role, Cancer Patient Navigators call upon a wide range of skills and knowledge sources. Interventions that make a real difference in the lives of cancer

patients are commonplace. For example, babysitters and pet sitters are arranged on short notice to allow patients to travel or commute to the tertiary care centre in Halifax, social services are lined up for those who need them, counselling is arranged for those in distress, and signs and symptoms are identified and relayed to local and distant medical practitioners. Followup visits are coordinated and symptom management is supported through provision of specific information to patients and practitioners. Patients are better prepared for consultation and treatment visits at the referral centre and local district cancer programs. In our experience, most patients had significant issues concerning transportation, psychosocial support and access to medications and rehabilitation services. Without the intervention provided by local Cancer Patient Navigators, many patients would refuse care or be lost to followup.

## FURTHER DEVELOPMENT OF THE ROLE

In the preceding issue of *Oncology Exchange* (Vol. 6, No. 3) Urquhart and Grunfeld identified important areas of research to solidify the role of cancer patient navigators in the health-care system. Evaluation of their role will require collection of specific data elements and information on outcomes that go beyond satisfaction. As identified by Doll et al here, creating a conceptual framework will assist this process by delineating data requirements. Electronic data systems, particularly those that integrate data from multiple sites and programs, will be required for comprehensive and indepth analysis of these roles. In the meantime, cancer patient navigation has attracted great interest from cancer programs and centres across Canada where several models are now in place and under development. A common feature of all models is attention to the patient as the centre of care with focused coordination of service provision and a strong background of patient education and information support.

Satisfaction and convenience may not be enough to support the widespread application of navigation services to already complicated and expensive service delivery models in cancer centres and programs. Longitudinal research studies will be needed to determine and evaluate benefits measured in terms of survival, costs and deployment of scarce health human resources. There will be difficulties in measuring inputs and clinical outcomes in cancer services.

Many cancer patients cannot follow best-practice protocols and guidelines, due to wide variation in both what is actually prescribed to cancer patients with similar diseases and stages, and in what individuals can tolerate. Cancer patient navigators are particularly well suited to assist and advise patients and their health professionals (especially important when both are located far from tertiary cancer centres) on adherence to treatment regimens, clinical trial protocols and guidelines. Since Navigators are also alert to clinical signs and symptoms, they play important roles in ensuring that patients receive optimal diagnostic and supportive care.

We all hope and expect that the exponential growth of medical and scientific knowledge will produce miraculous cures. However, in most communities, the welcome interventions of a trained, committed and considerate cancer patient navigator will provide more comfort and help than any number of claims of future miracles. 