

# Impact of a Pivot Nurse in Oncology on Patients With Lung or Breast Cancer: Symptom Distress, Fatigue, Quality of Life, and Use of Healthcare Resources

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**Purpose/Objectives:** To examine the impact on continuity of nursing care delivered by a pivot nurse in oncology to improve symptom relief and outcomes for patients with lung or breast cancer.

**Design:** Randomized controlled trial in which participants were randomly assigned to an intervention group (n = 93) with care by a pivot nurse in oncology and usual care by clinic nurses or to a control group (n = 97) with usual care only.

**Setting:** Three outpatient ambulatory oncology clinics in a large university health center in Quebec, Canada.

**Sample:** 113 patients with lung cancer and 77 patients with breast cancer.

**Methods:** Participants in both groups completed the Symptom Distress Scale, Brief Fatigue Inventory, and Functional Assessment of Cancer Therapy Scale—General version 4 at eight intervals over six months. Healthcare usage was evaluated through a review of hospital records.

**Main Research Variables:** Symptom distress, fatigue level, quality of life, and healthcare usage.

**Findings:** Researchers found no significant differences in symptom distress, fatigue, quality of life, and healthcare usage between groups.

**Conclusions:** The new nursing role did not have an impact on the patient outcomes under study.

**Implications for Nursing:** Experienced nurses with specialized knowledge of oncology symptom assessment and management may reduce the symptom burden experienced by ambulatory patients with breast or lung cancer during active treatment.

Lung cancer is a leading cause of cancer mortality and morbidity for men and women (American Lung Association, 2005). About 1 of 16 women and 1 of 12 men in Canada will develop lung cancer during their lifetimes (Canadian Cancer Society, 2008). Breast cancer affects few men, but one of nine Canadian women will be diagnosed with the disease. Given that about one of three Canadians will develop some form of cancer in their lives (Canadian Cancer Society), robust nursing interventions must be developed and tested to help patients with cancer and their families manage the accompanying symptoms and distress.

The symptom experience of cancer varies greatly among patients and generally is a result of the disease or its treat-

## Key Points . . .

- ▶ Further study is needed to evaluate the strengths of different nursing care delivery models as the volume of cancer treatments and care in ambulatory clinic settings increases.
- ▶ Pivot nurses may help maintain lower symptom distress and improve continuity of care for patients with cancer.
- ▶ New models of care delivery are required to meet the growing needs of patients with lung cancer.

ments. Subjective symptoms often include fatigue, anxiety, constipation, depression, nausea, pain, problems with concentration, sleep disturbances, and dyspnea. Visible signs include vomiting, diarrhea, hair loss, and weight change (Cleeland, 2001; Dalal, Del Fabbro, & Bruera, 2006; Degner & Sloan, 1995; Given et al., 2004; Redeker, Lev, & Ruggiero, 2000).

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This article has been chosen as particularly suitable for reading and discussion in a Journal Club format. The following questions are posed to stimulate thoughtful critique and exchange of opinions, possibly leading to changes on your unit. Formulate your answers as you read the article. Photocopying of this article for group discussion purposes is permitted.

1. What experience do we have with “pivot” nurses (more commonly called patient or nurse navigators in the United States) in our facility?
2. How is the pivot nurse typically described in the literature? Who performs that role?
3. Are pivot nurses more useful for inpatient or ambulatory situations?
4. Does the lack of a significant difference demonstrated in the present study indicate that the pivot nurse role is not useful?
5. Besides the explanations given by the study’s authors, what other considerations might be important when evaluating the pivot nurse role?
6. In what ways would a pivot nurse enhance the care we are able to provide our patients?

At the end of the session, take time to recap the discussion and make plans to follow through with suggested strategies.

A nurse coordinator role has been advocated as an essential element of quality care to help patients and their families cope with symptoms across treatments and time (Gentry & Sein, 2007; Schroeder, Trehearne, & Ward, 2000). Such roles were created in Quebec, Canada, as part of the Quebec Program for the Fight Against Cancer. The pivot nurse in oncology (PNO) is a resource nurse who accompanies patients and families from diagnosis of cancer onward (De Serres & Beauchesne, 2000). The PNO’s four main functions in the care of patients and families are assessing and managing needs, teaching and providing information, providing support, and coordinating and ensuring continuity of patient care (De Serres & Beauchesne). Little research to date has examined the impact of care provided by a PNO; as a result, the present study was undertaken to assess the impact of PNO-provided care on levels of symptom distress, fatigue, quality of life, and use of healthcare resources for patients with lung or breast cancer.

## Literature Review

### Symptom Experience

Symptom distress is a subjective interpretation of a lived, personal experience with a given set of symptoms (Boehmke & Dickerson, 2005; McCorkle & Young, 1978). The most salient symptoms do not necessarily cause the most distress, and patients often report multiple symptoms. Cheng, Thompson, Ling, and Chan (2005) found a mean of eight and a range of 0–22 symptoms in a study of Chinese patients with solid tumors. Despite differences in the diseases and treatments, patients with lung or breast cancer have reported similar symptoms, including lack of energy, fatigue, numbness, pain, nausea, and difficulty sleeping. In addition, patients with breast cancer reported bone pain, dry mouth, and worrying, and patients with lung cancer experienced dyspnea and cough (Boehmke & Dickerson; Cheng et al.). In lung cancer, two or more symptoms occur together in a cluster and may include fatigue, nausea, vomiting, appetite loss, altered taste, weight loss, and weakness (Gift, Jablonski, Stommel, & Given, 2004). Pain and fatigue were found to be the most distressing symptoms for patients with lung cancer (Cooley, Short, & Moriarty, 2003; Degner & Sloan, 1995; McCorkle & Benoliel, 1983).

Symptom incidence and distress levels vary over time and treatment, making continuity of management particularly important. For example, Cooley et al. (2003) looked at temporal patterns of symptom distress and found variations over the six-month period following lung cancer diagnosis. Symptom

distress was high at onset, then decreased at three months and increased again mildly at six months. The presence of several distressing symptoms, including dyspnea, drowsiness, and nausea, has been reported as a significant predictor of shorter survival in patients with lung cancer (Palmer & Fisch, 2005). Nursing interventions to decrease distress could improve patient outcomes.

Symptom distress is a complex experience with many factors that influence individual perceptions and evaluations. Contributing factors include depression and anxiety (Krishnasamy, Wilkie, & Haviland, 2001), locus of control (Segrestan, Cousson-Gelie, & Bussieres, 2005), and self-blame (Bennett, Compas, Beckjord, & Glinder, 2005). Laubmeier and Zakowski (2004) found that psychological distress and quality of life among patients with cancer were influenced more by perceived life threat than objective disease stage, further demonstrating the complexity of symptom distress and underscoring the need for individualized care. In addition, women undergoing treatment for breast cancer reported that unexpected symptoms caused greater distress than expected symptoms and that they were better able to cope with expected symptoms (Boehmke & Dickerson, 2005). The finding also suggests that symptom management interventions could reduce distress.

### Continuity of Care and the Nursing Role in an Ambulatory Setting

Continuity of care is essential in developing interventions to improve symptom management. Haggerty et al. (2003) defined continuity of care as the degree to which a series of discrete healthcare events is experienced as coherent, connected, and consistent with the patient’s medical needs and personal context. Many authors have recommended modifying nurses’ roles and interventions in ambulatory care to promote such continuity of care (American Academy of Ambulatory Care Nursing & American Nurses Association, 2000; *Gouvernement du Québec. Commission d’étude sur les services de santé et les services sociaux. Ministère de la santé et les services sociaux*, 2000; Swan, Conway-Phillips, & Griffin, 2006). For example, the case manager’s role is multidimensional (Cohen & Cesta, 2000; Haas, Hackbarth, Kavanaugh, & Vlasses, 1995; Simmons, 1992; Tahan, Downey, & Huber, 2006). The *Ordre des Infirmières et Infirmiers du Québec* (1996) labelled the role the “*infirmière de suivi de clientèle*” [nurse case manager]. Wagner, Austin, and Von Korff’s (1996) finding that such care improved outcomes for patients with chronic diseases was the impetus for the development of the PNO role in 2000.

In their randomized, prospective trial, Jennings-Sanders and Anderson (2003) demonstrated that interventions provided by a case manager (e.g., coordinating care, lending emotional support, providing education) helped patients with breast cancer and their caregivers navigate the healthcare system and manage their symptoms and coexisting conditions. Nurse-led follow-up improved emotional functioning and quality of life, increased satisfaction with care, and decreased the number of physical symptoms among patients with lung or breast cancer (Given et al., 2002; Moore et al., 2002). Ambulatory nursing care interventions have been shown to improve outcomes with respect to symptom distress. In a randomized clinical trial studying the impact of home nursing care on patients with lung cancer, McCorkle et al. (1989) found significant differences in symptom distress levels, levels of enforced social dependency, and health perceptions. The groups receiving standard or specialized home nursing care had a six-week delay to time of elevated symptom distress scores, and the group receiving specialized home care had significantly fewer and slightly shorter hospitalizations. Other studies (McCorkle et al., 1989; McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998) have supported the importance of personalized oncology nursing provided in the home setting, and one study confirmed that such nursing interventions prolonged survival (McCorkle et al., 2000).

However, few researchers have studied the effect of PNO-delivered care in an ambulatory setting. Fillion et al. (2006) demonstrated the impact of PNOs on continuity of care and improved interdisciplinary collaboration in the healthcare setting. Although patient satisfaction generally is high with care delivery models (Corbeil, Hunter, Hutchison, & Edgar, 2004; Plante, 2004), no research to date has studied the effect of a PNO or any other navigator-type role on specific patient-outcome variables (e.g., symptom distress, quality of life, healthcare usage). In addition, little evidence of the roles' impact on nursing-related outcomes exists, despite considerable advocacy (Given & Sherwood, 2005; Kimball, Joynt, Cherner, & O'Neil, 2007). The present study will describe the care provided over time by a PNO to patients with lung or breast cancer and compare cancer types in relation to levels and patterns of symptom distress, fatigue, quality of life, and healthcare resource usage.

## A Model for Symptom Management

The present study used the Symptom Management Model (SMM) (Dodd, Janson, et al., 2001; Dodd, Miaskowski, & Paul, 2001; Larson et al., 1994) as the theoretical background for the development of the specialized nursing role to be examined. The model posits that effective management of any given symptom or group of symptoms must consider the three dimensions of symptom experience, symptom management strategies, and outcomes. The symptom experience dimension includes an individual's perception, evaluation, and response regarding a symptom. Symptom management requires a complementary patient-family-healthcare provider partnership that encourages patient and family management of symptoms. The outcomes dimension focuses on eight factors that can emerge from symptom management strategies and symptom experience (Dodd, Janson, et al.). Thanasilp and Kongsaktrakul (2005) concluded that the SMM is a

useful tool for predicting quality of life and promoting improved symptom management at the end of life in patients with cancer (Jablonski & Wyatt, 2005) and merits further application.

The present study investigated whether patients followed by a PNO would take longer to reach high scores of symptom distress and have fewer unscheduled clinic and emergency room visits and hospitalizations over a six-month period than a usual care group. In addition, the authors wondered what pattern of symptom experience and healthcare resource usage would be found for patients with different cancer types.

## Methods

### Design

In the present randomized controlled trial, patients were assigned to either a group that received care by a PNO in addition to usual care or the control group, which received usual care from oncology clinic nurses. Patients' patterns of symptom distress, fatigue, quality of life, and healthcare resource usage were assessed for both groups.

### Sample and Setting

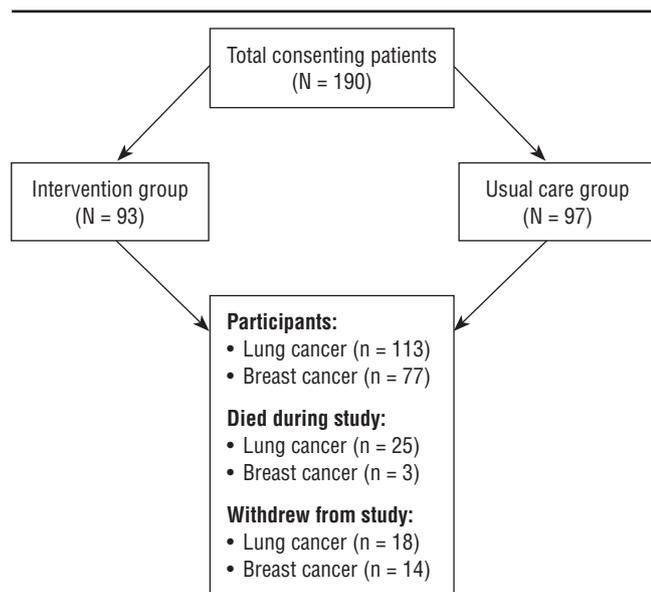
The target sample consisted of patients with breast or lung cancer receiving treatment (radiotherapy or chemotherapy) at one of three ambulatory oncology settings in a large university health center in Quebec, Canada. Participating patients were able to communicate in English or French, had no evidence of delirium, and received active treatment in the ambulatory settings.

An ideal sample size of 100 patients per group was calculated using nQuery based on a score of three or more on the Symptom Distress Scale, a 0.05 level of significance, and 80% power. Researchers attempted to recruit 400 patients because a high mortality rate was anticipated for patients with lung cancer.

The final sample consisted of 113 patients with lung cancer and 77 with breast cancer randomized into two groups (see Figure 1). The mean age of patients in the intervention group was 60.5 years (SD = 11.1), and the mean for the control was 59.3 (SD = 10.7) (see Table 1). Twenty-five of 28 patients who died during the study had lung cancer ( $\chi^2[1] = 12.11$ ,  $p = 0.001$ ). Another 32 patients (14 with breast cancer and 18 with lung cancer) withdrew. More patients in the usual care group ( $n = 23$ ) versus the intervention group ( $n = 9$ ) withdrew ( $\chi^2[1] = 6.68$ ,  $p = 0.01$ ).

### Procedure and Data Collection

Ethical approval was obtained from the research ethics committee of the health center. Patients were informed of the study by their physician or a clinic nurse and given an information brochure during ambulatory visits. Patients who expressed interest in participating met with a research assistant who described the study. When patients consented, the research assistant contacted one of the investigators for randomization and assigned the patients to groups. Randomization was done using a computer-generated list of numbers that only three of the investigators could access. Patients were divided into two groups that received either PNO-provided care as well as usual care by nurses in their cancer treatment setting or usual care only. At each regular



**Figure 1. Participant Profile**

visit (about every three weeks) over a six-month period, the patients completed questionnaires about symptoms and quality of life. The questionnaires took about 20 minutes to complete and usually were done while waiting before appointments. Some patients completed the survey at home. A maximum of eight measurements were obtained from each patient.

### Study Intervention

The PNO was a baccalaureate-prepared, experienced palliative care nurse who had received additional training in cancer symptom management and the SMM. Patients in the intervention group and their informal caregiver (if present) met the PNO in the ambulatory setting. The PNO reviewed understanding of the diagnosis, expected side effects of treatment, and available resources with the patients. The PNO identified potential sources of support for the patient by creating a genogram and ecomap. The genogram identified family members and the relationships between them, and the ecomap outlined significant people, agencies, or institutions and their relationships to the family (Wright & Leahey, 2000). The PNO assessed patients' needs and coping skills, taught specific ways to identify and cope with symptoms, and offered additional education and support as needed. The PNO also coordinated care across treatment modalities and the disease continuum. The PNO particularly advocated for patients during interdisciplinary rounds and developed care plans with referrals to specialized services when needed. The PNO initiated follow-up telephone calls as needed to provide support, information, coaching, or active listening to patients. Patients in the PNO intervention group also received usual care from nurses in the ambulatory setting during active treatment.

**Usual care:** The patients randomized to the control group received the usual nursing care provided to all patients receiving cancer treatment. Usual nursing care included symptom assessment and teaching management but was not organized in a formally coordinated model. Patients may not

have seen the same nurse at each appointment. Follow-up by telephone usually was limited to patient-initiated phone calls. Seventy-five percent of the nurses working in the oncology ambulatory care clinics had obtained certification in oncology nursing from the Canadian Nurses Association, which included content on symptom assessment and management during the different phases of the cancer trajectory.

### Instruments

All self-report instruments were available in English and French. The **Symptom Distress Scale** measures symptom distress, defined as the degree of distress or discomfort from 13 cancer-related symptoms (physical and psychosocial) using a five-point Likert scale (McCorkle & Beniel, 1983; McCorkle & Young, 1978). Items are added to yield a total score ranging from 13–65. A score of 25 is reflective of moderate distress levels (McCorkle & Young). The total scale internal consistency (Cronbach  $\alpha$ ) has ranged from 0.78–0.85 (Degner & Sloan, 1995; McCorkle & Beniel; McCorkle et al., 1989; McCorkle & Young).

The **Functional Assessment of Cancer Therapy Scale—General (FACT-G) version 4** (Cella, 1994; Cella et al., 1993), a measure of quality of life, is composed of 27 items divided into the four subscales of physical, social/family, emotional, and functional well-being. The subscales are scored by reverse coding designated items, calculating the mean for the subscale items answered (provided that more than 50% of the items were answered), and multiplying by the number of subscale items. Higher scores are indicative of perceptions of better QOL (Cella, 2006). The Cronbach  $\alpha$  is 0.89, and individual subscale reliabilities range from 0.65–0.82. Test-retest reliability is 0.92 for the total scale and ranges from 0.82–0.88 for the subscales (Cella et al.).

The **Brief Fatigue Inventory** is a nine-item self-report measure with nine questions (Mendoza et al., 1999) that

**Table 1. Sample Demographics**

Characteristic	Control (N = 97)		Intervention (N = 93)	
	$\bar{X}$	SD	$\bar{X}$	SD
Age (years)	60.5	11.1	59.3	10.7
<b>Characteristic</b>	<b>%</b>		<b>%</b>	
Language				
• English	54		61	
• French	46		39	
Female	71		67	
Married	67		72	
Secondary school education	51		42	
Has adequate financial resources	83		75	
Has adequate help at home	76		73	
Cancer type				
• Breast	40		41	
• Lung	60		59	
Cancer stage III or IV	36		51	
Has presence of recurrence	12		14	
Has presence of metastases	19		23	
Treated with combination chemotherapy and radiation	44		39	

has good internal consistency and reliability. Concurrent validity has been supported through correlations with the fatigue subscale of the FACT-G. Cronbach alpha was 0.95 for activity and work subscales and 0.96 for the remaining items (Mendoza et al.).

Patients' healthcare usage was obtained from hospital records and included all clinic appointments (scheduled and unscheduled), emergency department visits, and hospitalizations. Demographic data were collected from patients and information about disease characteristics was obtained from the same records.

## Data Analysis

Descriptive statistics were used to characterize the samples randomized to each group. Simple parametric and nonparametric techniques were used to provide a sample description. All analyses were by intention-to-treat, meaning all participants' data were included, whether or not they provided survey data at each assessment period or died before completing the study. Repeated measures analyses of variance using linear mixed models were conducted to determine whether the scores in the intervention and usual care groups varied over time and across groups. All analyses were done using Proc Mixed procedure from SAS version 8 (SAS Institute Inc., 1999).

## Results

### Symptom Distress Scale

Over the eight measurement periods, the mean Symptom Distress Scale scores for both groups ranged from 21.8–25.9, with a standard deviation of 5.3–7.5. No statistically significant difference was found between the groups over time ( $t[182] = -0.42, p = 0.675$ ). However, the results showed a statistically significant difference in distress over time based on cancer type, with patients in the lung cancer group exhibiting more distress than those in the breast cancer group ( $t[178] = -2.297, p = 0.023$ ).

### Brief Fatigue Inventory

Little difference was found between the intervention and usual care groups for the Brief Fatigue Inventory. The mean scores ranged from 23.8–38.2, with a standard deviation of 16.5–24.5. No statistically significant differences were observed over time between groups ( $t[200] = -0.883, p = 0.378$ ), but scores based on cancer type were significantly different, with patients with lung cancer in both groups reporting more fatigue ( $t[202] = 3.215, p = 0.002$ ).

### Functional Assessment of Cancer Therapy Scale—General

The total scale score on the FACT-G was not different between the two groups ( $t[160] = 1.38, p = 0.169$ ). Means ranged from 70.9–77.5, with a standard deviation from 14.7–19.3. The scores on the individual subscales did not differ significantly over time. A statistically significant lower quality-of-life score was reported for patients with lung cancer ( $t[160] = 9.54, p = 0.0024$ ).

### Healthcare Usage

The number of unscheduled visits to the clinic, admissions, and visits to the emergency room were not significantly different between groups. Overall, patients with breast cancer

were less likely to have hospitalizations shorter than 72 hours compared to patients with lung cancer ( $\chi^2[1] = 12.71, p = 0.001$ ).

## Discussion and Implications

The findings revealed no difference in symptom distress, fatigue level, quality of life, and healthcare usage for patients in the intervention and usual care groups over the entire six-month interval. In addition, no differences were reported in unscheduled clinic visits, emergency department visits, and hospitalizations. The results negated researcher expectations that the care provided by a PNO would cause the intervention group to take longer to reach high levels of symptom distress compared to the usual care group. In the present study, both groups of patients only experienced moderate levels of symptom distress on the Symptom Distress Scale. Both groups also reported only low-to-moderate levels of fatigue. Other studies have reported higher levels on some measures; Mendoza et al. (1999) reported higher average Brief Fatigue Inventory scores in patients with cancer. McCorkle et al. (1989) reported somewhat higher Symptom Distress Scale scores than the present study.

The current study's findings may differ because the groups had frequent contact with nurses while attending ambulatory visits. The intervention group also had easy access to the PNO in the care settings or by phone. Because both groups reported similar levels of distress, fatigue, and quality of life, the symptom management care provided by the PNO who was not certified in oncology nursing and ambulatory care nurses may be comparable. Although data on the nurses' practice patterns are not available, the nurses in the oncology settings had more than 10 years of experience on average and 75% had oncology nursing certification. Therefore, the patients in the oncology settings likely benefited from frequent expert oncology nursing. Limited published evidence currently supports the contention that oncology certification improves patient outcomes, but nurses who hold certification generally are older and more experienced than their peers (Cary, 2001; Frank-Stromborg et al., 2002; Sechrist, Valentine, & Berlin, 2006). Nurses reported that the certification process has enabled them to detect early signs of complications and initiate interventions sooner (Cary). The results might be significantly different if the study was replicated in a region distant from large cities given the higher prevalence of certified nurses in urban health centers compared to rural ones (Cary).

The results of the patient surveys also were analyzed by cancer type. The authors found a clinically significant difference in symptom distress, fatigue, and quality of life between disease types, which can be explained by the dissimilar disease trajectories for breast and lung cancer. The differences are well documented in the literature (Graves et al., 2007; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) with regard to disease severity and symptom experience for patients with lung cancer, demonstrating the need to develop effective care-delivery models.

The present study's findings demonstrate a need for a more rigorous and systematic approach for PNOs to use in practice related to the management of cancer symptoms. More structured and focused interventions have been effective in other populations. For example, Kurtz, Kurtz, Given, and Given

(2006) tested the impact of a systematic cognitive-behavioral intervention to promote symptom self-management in an ambulatory oncology population and found a significant reduction in the number of emergency room visits for patients in the intervention group. However, the study was limited by the use of nonvalidated instruments. Bourbeau et al. (2003) conducted a structured comprehensive patient education intervention to promote self-care in patients living with chronic obstructive pulmonary disorder. The results showed that hospital admissions, emergency room visits, and unscheduled physician visits decreased by 40%, 41%, and 58%, respectively, suggesting that the intervention by the PNO in the present study needs more structure to provide greater impact.

### Limitations

The present study was limited by the inability to recruit the target sample size of 400 patients because of time frame and budget. However, the sample size did not make a difference in the main outcomes because the scores and confidence intervals were very close and had considerable overlap. Therefore, the risk of type II error was low. Other researchers have documented similar recruitment challenges when conducting randomized clinical trials (Berger, Neumark, & Chamberlain, 2007).

In addition, more information about the oncology nurses' practice patterns would have been helpful, given the lack of significant differences between groups with respect to symptom assessment and intervention. The authors cannot explain the lack of differences in the outcomes between the intervention and usual care groups because data on the nurses' usual care were not collected (e.g., obtained through a chart review).

Further research is needed on the impact of PNOs on patient outcomes. A study should be developed to assess the impact of structured, formal interventions and multiple outcomes, including patient satisfaction. The relationship between PNOs' interventions and outcomes should be examined when patients are followed longitudinally from diagnosis to remission or palliation. Further information is needed about the role of PNOs after patients have finished treatment and are monitored long-term. As the role of the PNO becomes more fully established across Quebec, further studies can be completed to determine whether PNOs' nursing experience and tenure in the role influence patient outcomes.

The patients in the present study attended oncology clinics in a tertiary care center in a major urban city. They had access to specialized and experienced nursing care and an interdisciplinary team; in that context, the groups were the same in terms of outcomes of interest. Therefore, the present study should be replicated in more diverse settings.

The impact of the PNO's four role components have not been studied fully to date. Given that the five-year survival of Canadian patients with cancer is increasing (Canadian Cancer Society, 2008), more patients will require long-term follow-up. Nurses need to understand the best model of care delivery and the dose of care required for patients. PNOs may be the appropriate professionals to ensure that care, but further research is needed to examine outcomes in relation to all role components.

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