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Fighting Cancer in Québec and in Ontario: A Patient-Centred Approach

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FOREWORD

This publication is the result of an exceptional collaboration among the Institut de la statistique du Québec, Cancer Care Ontario, NRC Picker Canada and the Ministère de la Santé et des Services sociaux. By illustrating the productive contribution of data to reflecting on the quality of care and to building bridges, this overview of Québec and Ontario surveys has provided a means of comparing approaches in the fight against cancer and of informing best practices. Taking into account patients' opinions can only contribute to improving the services provided to them.

I would like to take this opportunity to thank the authors and their respective organizations for the work that has been accomplished. As Director General, I have greatly appreciated this model of collaboration, the results of which bode well for the future.

Director General,

Stéphane Mercier

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Frequently used in tables and figures

*	Coefficient of variation between 15% and 25%; interpret with caution.
**	Coefficient of variation higher than 25%; imprecise estimate provided for information purposes only.

Note to the reader

Because the data were rounded off, totals do not necessarily match the sum of all the parts.

Unless explicitly indicated otherwise, all differences presented in this publication are statistically significant with a confidence level of 95%.

To facilitate ease of reading, percentages higher than 5% are rounded off to the nearest whole number when indicated in the text and to one decimal place in the tables.

All the data from Québec in this publication were weighted.

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This joint study was born out of the desire to explore the data from Québec and Ontario surveys from a different perspective and provide a more in-depth means of understanding the various ways services are and can be organized to respond to the needs and expectations of people afflicted with cancer. We would first like to thank the patients who generously reported on a time period that was undoubtedly difficult in their lives. By giving us a brief overview of their experience of the care they received, the patients and their families provided significant input into a thought process wherein we can look beyond organizational logic to get to the heart of the matter, namely how to improve the experience of cancer patients.

We would also like to thank Cancer Care Ontario, the Institut de la statistique du Québec (ISQ), NRC Picker Canada and the Ministère de la Santé et des Services sociaux (MSSS) for having believed in this project and having given us all the latitude needed to exchange and share expertise.

Finally, our thanks go to Luc Côté (ISQ) for having worked on the overall methodological parameters of the Québec survey with the goal of accomplishing the joint study; to Melanie Jameson (NRC Picker Canada) for constructing the tables used to analyze the Ontario data; to Ariane Dubé-Linteau and Amélie Lavoie (ISQ) for background preparation and constructing the tables used to analyze the Québec data; and to Monique Bordeleau (ISQ), Louise Paquet (MSSS) and Viviane Cantin (MSSS) for being readers of the various versions of this document.

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INTRODUCTION

For more than a decade now, cancer has been the primary cause of mortality in Canada. The most recent statistics from the Canadian Cancer Society bear witness to its magnitude – in 2013, it is estimated that approximately 187,600 new cancer cases will be diagnosed and over 75,500 people will die as a result of the disease (CCS, 2013). It is estimated that between 41% and 46% of Canadians will be diagnosed with cancer during their lifetime, and that 25% will die from it. The burden placed on those afflicted with cancer and their families and on the health care system is such that various provincial governments have made fighting cancer a major priority.

In Québec, the *Programme québécois de lutte contre le cancer* (PQLC) (Québec Program to Fight Cancer) is presented 1998. Implementation of the PQLC and the first activities undertaken between 1998 and 2003 led to the creation in 2004 of the *Direction de lutte contre le cancer* (DLCC) (Department of the Fight Against Cancer), a Ministry[1] entity responsible for planning, managing, coordinating and evaluating programs and services in the fight against cancer. In 2012, the DLCC became the *Direction québécoise de cancérologie* (DQC) (Québec Cancer Department). In Ontario, organizing and coordinating the fight against cancer is the responsibility of Cancer Care Ontario (CCO), which was officially established in 1997.[2] The main recommendations of the Cancer Services Implementation Committee (2001) confirmed the need to reorganize services, and it was in this context that CCO was entrusted with the responsibility of integrating and coordinating various activities.

Indeed, the establishment of these organizations and their activities constitute a response to the various gaps observed in the provision of services to people with cancer. These include insufficient monitoring and follow-up, inadequate support, lack of communication among the various health care providers, problems in accessibility to services, lack of humanity in communication between care providers and the patient, etc.[3] To better respond to the needs of these people and improve the quality of care, both the Québec

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1. We are referring to the Ministère de la Santé et des Services sociaux du Québec (Ministry of Health and Social Services of Québec).

2. Cancer Care Ontario grew out of the Ontario Cancer Treatment and Research Foundation founded in 1943 shortly after the Cancer Act was enacted by the Government of Ontario.

3. For a detailed analysis of patients' needs, see A. Fraser (1995) and Ministère de la Santé et des Services sociaux (1998) for Quebec, and G. Turnbull et al. (2010 and 2012) for Ontario.

and Ontario strategies advocate a patient-centred approach. This means that the patient is not just viewed as a sick person to heal, but also as an ally who can take ownership of his/her health and participate in the decision-making process with health care providers at every step in the course of the disease (Boulé and Girard, 1999). This approach, based on respect for the patient as a person, his/her values and needs, involves providing a continuum of care and services to both patients and their families. They should be kept informed, supported, and surrounded by their loved ones. The continuum includes prevention, early detection and screening, diagnosis and treatment, palliative care for patients and their families, all the while ensuring continuity of services in various locations where they are provided (Hewitt and Simone, 1999).

This process, which places the patient at the heart of the health care system, also recognizes the importance of soliciting his/her point of view in order to measure the outcomes of a patient-centred approach. It is in this perspective that Québec and Ontario have conducted surveys on the patient experience of people afflicted with cancer. Indeed, their opinions on care and services have provided a means of comparing in this publication the organizational context of each province and the concrete experience of individuals in the clutches of the disease.

Therefore, the purpose of this publication is to shed light on what each of the two provinces can learn from the experience of the other in order to improve care and services provided to people with cancer. To accomplish this, first we will present a succinct overview of the specific context in which each province has adopted a patient-centred approach in the fight against cancer. In the second section, we will examine the main concepts and tools used to evaluate care and services from a patient perspective and the general methodological parameters of the Québec and Ontario surveys that measured the cancer patient experience. The third section will highlight results based on selected items common to both surveys in an attempt to address two issues: “How do we prepare a patient to receive the treatment prescribed?” and “How do we assist the patient to better manage the potential side effects of his/her treatment?” Based on the findings of the Québec and Ontario surveys, the fourth section will examine the ways in which a patient-centered approach can contribute to improving the care and services provided to cancer patients.

1

IMPROVING THE QUALITY OF CARE FOR CANCER PATIENTS IN QUÉBEC AND ONTARIO: A COMMON APPROACH, YET ORGANIZATIONS ADAPTED TO SPECIFIC CONTEXTS

During the 1990s, the transformation of the Québec and Ontario health care systems provided particular momentum to the reorganization of cancer care. The lack of coordination among services at various levels of intervention, combined with the burden cancer imposes on those afflicted with it and society at large, sounded the alarm during this period.

In parallel, various approaches designed to improve the quality of front-line services or those provided to people suffering from a chronic disease in industrialized countries had been evolving, such as patient centredness, to which the notion of empowerment is related.[1] As indicated in a 2001 consensus report entitled "*Crossing the Quality Chasm: A New Health System for the 21st Century*," the Institute of Medicine considered this approach to be an essential component of any initiative targeting improvement in the quality of services. The authors defined patient-centred care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."

This definition also provides a means of identifying a number of action paths: education and empowerment of patients; coordination and continuity of care; communication among health care providers, patients and their families to involve them in decisions that reflect their values; individual preferences and needs; and emotional support to confront patients' fears and anxiety. In summary, a patient-centred approach implies delivery of health care that moves from an institution-centred model to a patient-centred model.

In both Québec and Ontario, a number of committees and working groups dedicated to fighting cancer have focused on these issues to see how a more patient-centred approach could be translated into care and services. In the next two sub-sections, we will paint a succinct portrait of the context in which the fight against cancer is organized in Québec and Ontario, followed by patients' points of view in this regard.

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1. For a review of the literature, see P. Little et al. (2001), R. Boulé and G. Girard (1999), and A. E. Bauman et al. (2003).

1.1 THE QUÉBEC APPROACH IN THE FIGHT AGAINST CANCER

In 1998, Québec set up a program entitled *Pour lutter efficacement contre le cancer, formons équipe* (PQLC) (Ministère de la Santé et des Services sociaux, 1998) (To Fight Cancer Effectively, Let's Team Up). This program provided the first impulse to reorganize care and services to focus primarily on the patients themselves and their families. The main guidelines stated in the PQLC were the following:

- *Organize services* based on a comprehensive approach that integrates available tools in a *coordinated* and *complementary* fashion to intervene at both the individual and population levels.
- Implement a *patient-centred approach* that recognizes the place of the patient and his/her family in decisions regarding his/her treatment and that fosters the continuity of services across various service delivery locations.
- Develop *quality assurance criteria* that provide a means of determining the nature of care and services needed in the various stages of intervention.

To put into practice these major guidelines, the PQLC recommended "bringing services as close as possible to where people live while concentrating expertise in a health care network" (Ministère de la Santé et des Services sociaux, 1998: 47). To do so, the PQLC recommended implementing a hierarchical network of care and services, comprising *interdisciplinary teams at the local, regional and supra-regional levels*. The local teams are responsible for providing a range of general and specialized services to the person with or suspected of having cancer and his/her family. They provide services related to screening, examinations, tests, treatment, rehabilitation, support, palliative and end-of-life care. These teams bring together various health care providers to work with cancer patients, from general practitioners and surgeons, hematologists and oncologists, nurses, pharmacists, and homecare providers to volunteers. Local teams can count on a regional team for specialized services, training, support, supervision and evaluation. The regional team is in turn supported by supra-regional teams for ultra-specialized services proper to each cancer site or for specific complex problems (Ministère de la Santé et des Services sociaux, 2007).

The implementation of this hierarchical network was consolidated in 2005, when the first institutions were visited to evaluate their teams. Other activities were recommended by the PQLC in order to implement a patient-centred approach. For example, the PQLC suggested that each interdisciplinary team should have a pivot nurse responsible for assessing resources and patient needs, providing teaching and support, and coordinating care and services (Comité consultatif des infirmières en oncologie, 2008). Having a pivot nurse in interdisciplinary teams is one of the main criteria for designating such a team. Pivot nurses have been progressively assigned in oncology clinics since 2001.

The Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services) has the mandate to give direction to and support activities in the fight against cancer. Various authorities share this responsibility. The Direction québécoise de cancérologie (Québec Cancer Department) is responsible for the management, coordination and evaluation of efforts to combat cancer, and the Direction générale de la santé publique (Public Health Department) is responsible for monitoring, prevention and screening. At the regional level, 18 Agences de la santé et des services sociaux (ASSSs) (Health and Social Services Agencies) are responsible for the organization of services, management of resources, and allocation of funds to health care institutions. Clinical and administrative responsibilities are the purview of 95 Centres de santé et de services sociaux (CSSSs) (Health and Social Services Centres),[2] who are responsible for the health and well-being of the population in the territory they serve.

1.2 THE ONTARIO APPROACH TO FIGHTING CANCER

In Ontario, work devoted to developing a new provincial framework for cancer care began in 1995. A committee bringing together the main actors in the fight against cancer was established, the Provincial Cancer Network, who developed a Cancer Action Plan, which was instrumental in creating Cancer Care Ontario (CCO) in 1997. This new organization picked up the torch from the Ontario Cancer Treatment and Research Foundation (OCTFR). The groundwork was laid for the changes that occurred in the first decade of the 2000s, including the development of a more regional and seamless system, with a greater focus on prevention and screening. Among the changes was a move to include more specialty areas, such as surgical oncology, with the realization that a multidisciplinary and multi-modality approach was essential for quality cancer treatment. These changes signalled the next phase of thinking on integrating and coordinating cancer treatment at the provincial level.

In the early 2000s, the Government asked for further changes to the cancer system in Ontario and formed the Cancer Services Implementation Committee (CSIC) with a mandate to review the focus of CCO with respect to service delivery and management of the cancer centres. As an outcome of the CSIC recommendations, regional cancer centres were integrated with and managed thereafter by their respective host hospitals in January 2004. CCO became the organization responsible for planning all cancer-related activities in the province and advising the Ministry of Health and Long-Term Care to ensure that the quality of care would be a priority, that standards would be set, and evaluation mechanisms would be implemented. Therefore the mandate of CCO was widened, and from then on it would ensure that every person afflicted with cancer or at risk of contracting it would have access to the services they require.

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2. CSSSs have the legal obligation to develop clinical plans in which they define and develop their services as a function of the health and social service needs of the population they serve, the resources in their territory, and local priorities. The clinical plans must include a “physical health – fight against cancer” component, which defines the services that should be provided by the CSSS to the population in all aspects of the continuum of care and services with regards to cancer, from prevention to palliative care. We should also indicate that the majority of CSSS are the result of a fusion of a local centre of community services and a hospital centre providing general and specialized care.

In 2005, CCO introduced the first formal plan for the cancer system. Various issues informed the Ontario Cancer Plan (2005-2008) such as an increase in incidence, the rising costs of cancer treatment and care delivery, the growing number of patient concerns with the lack of coordination, waiting times, variation in care, and the need for system transformation. The goals of the Ontario Cancer Plan (OCP) were to:

- Develop standards and guidelines
- Implement a regional cancer program model[3]
- Reduce demand while increasing capacity to meet the demand
- Implement rapid access strategies to reduce waiting time
- Invest in performance measurement and accountability
- Continue support for research.

There was an emerging focus on improving the care for patients across the system. Providing care closer to home and implementing consistent standards of care were particularly targeted.

The CCO's second action plan (2008-2011) focused on specific areas vital to the provision of patient-centred care delivery. The goals were the following:

- Reduce the impact of cancer through screening and earlier detection
- Improve access to diagnostic services and cancer care
- Improve the patient experience along every step of the cancer journey
- Improve system performance, and continue to build research capacity.

The priority of improving the patient experience and that of his/her family is also part of the third CCO action plan (2011-2015). It implies involving the patient in the treatment decision-making process, helping him/her navigate the various stages of care, and providing support to manage his/her symptoms. In addition, the necessity of creating and applying innovative models of care delivery to meet future needs reinforces the notion of establishing a team of health care providers to meet these needs across the system. Furthermore, evaluating the impact of care and treatment on symptoms and long-term health status is also key in providing care and follow-up to patients who recover and return to a life without cancer.

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3. The regional cancer programs located in each of 14 Local Health Integrated Networks (LHIN) are responsible for prevention, screening, early diagnosis, treatment and palliative care. These regional programs became the hub for satellite and affiliate systemic treatment sites in community hospitals at a distance from the regional centre in order to provide care closer to home. In addition, CCO set organizational standards for these programs and monitors compliance with the standards on a regular basis (Vandenberg, et al., 2007).

1.3 SIMILARITIES AND SPECIFICITIES OF THE FIGHT AGAINST CANCER IN QUÉBEC AND ONTARIO

For more than 10 years now, efforts devoted to organizing services for people with cancer in Québec and Ontario have been based on implementing a patient-centred approach. This has translated into a set of activities that have sometimes been similar, other times province-specific, which can be explained in part by the organizational configuration specific to each province. In Ontario, authority resides in a dedicated organization, Cancer Care Ontario, responsible for policies, programs and the management of the system in the fight against cancer in the province. However, funding decisions are under the authority of the Ministry of Health and Long-Term Care. In Québec, authority is based in the Ministère de la Santé et des Services sociaux, with certain powers delegated to a department devoted to the fight against cancer. Policies, programs and management of the entire system in the fight against cancer in the province are therefore under the authority of the Ministry, including funding decisions.[4]

Patient-centred care: similarities and specificities in Québec and Ontario

Cancer profoundly affects all aspects of people’s lives and the lives of their families. So to respond appropriately to patients’ needs, it takes more than one physician or clinic to treat the disease. It takes the care and support of an entire health care team that includes family doctors, oncologists, nurses, pharmacists, dieticians, psychologists, and other health and social service providers in a variety of institutions and care settings. The establishment and deployment of multidisciplinary teams in oncology in Québec and in Ontario has been identified as one means of responding to the multiple needs of cancer patients and their families.

The patient-centred approach also has characteristics specific to Québec and Ontario. In Québec, it involves the particular role of the pivot nurse in multidisciplinary cancer care teams. Responsible for assessing resources and the needs of patients, providing them with information and support, and coordinating care and services, the pivot nurse in oncology is the resource person who, as soon as the diagnosis has been made, facilitates communication between the patient and the health care team.

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[4] For more information on strategies in the fight against cancer in the various provinces of Canada, see AETMIS (2007).

In Ontario, improving communication between patients and health care providers became manifest by the implementation of the Edmonton Symptom Assessment System – ESAS, which provides a means for each patient to report the symptoms he or she is experiencing. First set up for lung cancer patients and people in palliative care, this system has covered all cancer patients since 2008.[5] The results are not only made public, but are also entered into the Cancer System Quality Index (CSQI) of Ontario.

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[5] To encourage the use of the ESAS, a computerized system was designed so that patients can enter scores directly on a touch-screen monitor. In addition, a system called ISAAC (Interactive Symptom Assessment and Collection), was implemented. This system is based on a database of demographic data and nine symptoms from the ESAS: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. Clinicians can therefore a) be notified by email when symptoms exceed certain parameters; and b) track symptoms over time and according to various criteria.

2

A PATIENT-CENTRED APPROACH: CONCEPTS, MEASUREMENT AND DATA

Each year, many people are diagnosed with cancer, and with the advice of medical personnel, must decide on a course of care. Cancer treatment often involves many options: surgery, chemotherapy, radiation treatment. It can be toxic, intense, protracted, and may involve long-term side effects and complications. Cancer takes patients and their families on a journey most have never taken before, the outcome of which is not always clear. This creates uncertainty, anxiety and fear. In addition, cancer means many health care providers are involved in treatment, and the primary-care doctors with whom patients have had long-term relationships are sometimes excluded from the process. How can the health care system respond to the needs of patients and their families to help them on their journey? Surveys conducted on the experience of cancer patients are one of the basic tools we can use to evaluate to what degree a patient-centred approach is contributing to the quality of care and services being provided.

2.1 CONCEPTS AND MEASUREMENT INSTRUMENTS

The trend towards evidence-based health care is reflected in the measurement of outcomes of programs and services. In the case of patient experience, the work of Harvey Picker[1] has been a prime source of inspiration in the development of measurement tools**.** Indeed, he defined the major principles upon which a patient-centred care approach should be based. Picker paved the way for other researchers in the development and validation of a survey instrument that measures patient experience in order to assess the quality of care.[2] Eight dimensions have therefore been identified: respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; continuity; and access.

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[1] H. Picker was the founder of the Picker Institute established in 1986 in the US. Research conducted by the Picker Institute led to a clinical approach designed to improve the patient experience throughout the care continuum. In the 1990s, other Picker institutes were established in Europe, namely in Sweden, Switzerland, Germany and the U.K. In 2000, Picker Institute Europe was founded and set up a survey program to measure the patient experience in England, in cooperation with National Health Services (NHS). It then became the main organization responsible for conducting surveys on the organization of health care services in England.

[2] See the groundbreaking *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*, edited by Margaret Gerteis, Susan Edgman-Levitan, Jennifer Daley and Thomas L. Delbanco, published in 1993.

We should indicate that surveying the patient experience is very different from assessing his/her level of satisfaction, although these two approaches can be used to assess the quality of health care services. For example, in assessing patient satisfaction, research has shown that given the same type of care, provided in the same location by the same personnel, patient satisfaction levels differ according to their prior expectations (Institut de la statistique du Québec, 2006). Therefore, the items used to evaluate satisfaction with the goal of improving the quality of services are a function of the personal expectations of patients (Institut de la statistique du Québec, 2007).

With regards to patient experience, items used to measure it are based on standard frameworks and "best practices." These can certainly vary from one reference set to another, but not from one patient to another (Institut de la statistique du Québec, 2007). In other words, while satisfaction surveys determine items for assessment based on patients' expectations, which vary from one individual to another, patient experience surveys are based on recognized standards and therefore respondent subjectivity is reduced. The data collected in patient experience surveys provide a means of targeting precise practices to improve the quality of specific care and services.

This was the case with regards to Ontario and Québec surveys conducted on cancer patients. In Ontario, patient experience and the perception of how care is being delivered during the course of treatment, has been measured since 2004. In collaboration with NRC-Picker (National Research Corporation-Picker), Cancer Care Ontario (CCO) developed and validated a measurement instrument[3] that was based on the Picker suite of surveys. It focuses on aforementioned dimensions of patient-centred care such as emotional support, physical comfort, respect for patient preferences, information, education and communication, coordination and continuity of care, and access to care.

The development of this instrument involved researchers, clinicians, quality improvement specialists from Ontario, Nova Scotia and British Columbia, and research staff at the National Research Corporation-Picker in the U.S. and Canada. Validation was conducted on approximately 5,000 cancer patients in the aforementioned three provinces during the winter of 2003. The instrument, called the Ambulatory Oncology Patient Satisfaction Survey (AOPSS), comprises 79 closed-ended items and one open-ended item. The aspects of care evaluated in this survey mainly cover two phases of the cancer care continuum – detection, and diagnosis / treatment; and relate to cancer diagnosis, treatment planning, tests, surgery, chemotherapy, radiotherapy, symptom management, health care providers and overall impressions.

To develop the *Enquête québécoise sur la qualité des services de lutte contre le cancer* (EQSLCC) (Québec Survey on the Quality of Services in the Fight Against Cancer), the Institut de la statistique and the Ministère de la Santé et des Services sociaux du Québec consulted a wide range of experts working in oncology and cancer patients themselves in

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[3] National Research Corporation. *Development and Validation of the Picker Ambulatory Oncology Survey Instrument in Canada*. Lincoln, NE, 35 p.

2005 and 2006. The first cycle of the EQSLCC conducted in 2008 was the initial step in a process designed to assess the implementation of the Québec Program to Fight Cancer (PQLC) in terms of achieving its objectives over time. The PQLC began in 2001 with the gradual deployment of pivot nurses in oncology, followed in 2005 by the establishment of an evaluation process assessing the institutions and care provider teams in light of their appointment. Designed in such a way as to cover the continuum of the care path, the EQSLCC provides a means of collecting data on the services received at the time of screening, examination, tests, and diagnosis, through treatment to medical follow-up after treatment.

The development of the Québec survey drew inspiration from the aforementioned *Ambulatory Oncology Patient Satisfaction Survey* (AOPSS) conducted in various Canadian provinces by NRC-Picker Canada. Therefore many similar questions were asked of respondents in Québec and Ontario. So although the surveys differed in terms of the data collection methodology, many items in the dimensions of "information, education and communication" and "respect for patient preferences" were used in both surveys. As a result we can view the data from two perspectives. We can see how health care providers prepared patients to receive the treatment they were prescribed (patient as ally), and to what degree they were given the tools needed to manage the potential side effects of their treatment (patient as ally taking charge of his/her health). Each item was analyzed according to different cross-sectional variables such as sex, age and educational level, to see whether the provision of services varied with individual characteristics of the patients. Before examining the results presented in the next section, we will give a brief overview of the main methodological parameters of the two surveys and the scope and limitations of this study.

2.2 METHODOLOGICAL PARAMETERS OF THE QUÉBEC AND ONTARIO SURVEYS

The first cycle of the EQSLCC[4] was conducted in 2008 on people 18 years of age and over who were residents of Québec and had received at least one of three treatments targeted by the survey, namely surgery, radiation therapy (including curietherapy), or intravenous chemotherapy, between April 1, 2005 and March 31, 2006. Excluded from the target population were people who died before or during the survey, people residing in Cree and Inuit territories, and those in terminal phase at the time of the survey.

The sample frame was composed of data from the Med-Écho register of hospitalizations as well as those from the fee-for-service database of the RAMQ (Régie de l'assurance-maladie du Québec / Québec Health Insurance Board). Included were all people having been hospitalized during the target period and whose main diagnosis was cancer, and those who had had at least three medical services billed to the RAMQ on three different dates, one of which was recorded as a diagnosis of cancer.

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[4] For more information on the methodological aspects of the Québec survey, see G. Dubé et al., 2010.

A total of 14,790 people were selected and 8,753 filled out the questionnaire (1,929 ineligible), giving a weighted provincial response rate of 67%. The data were based on responses to a self-administered questionnaire sent in the mail. The ISQ, however, offered the possibility of completing the questionnaire by telephone, which comprised 16% of cases. Among the 8,753 respondents, 4,925 were retained for this joint study, namely all those who had undergone chemotherapy or radiation therapy. Those whose treatment comprised only surgery were excluded from the joint study so that the target population would be similar to that of the Ontario survey. The data were weighted, thereby allowing the results to be generalized to the target population.

Data for the AOPSS conducted in Ontario in 2006 were collected from patients who had visited one of 13 Integrated Cancer Program facilities for cancer treatment within six months of their service date. Inclusion criteria required that the patient had received at least one chemotherapy or radiation treatment. Service dates covered by the survey were between March 1 and August 31, 2005. Only patients 18 years and older at the time of their cancer centre visit and who had had a confirmed diagnosis of cancer were included in the sample.[5]

The general sampling strategy for participating facilities was designed to obtain approximately 360 completed questionnaires per cancer centre.[6] The goal was to achieve a margin of error of approximately 5%. Based on an assumed response rate of 60%, random samples of 600 were selected for most of the facilities. Smaller facilities that did not have a sufficient number of patients for the specified timeframe employed a census. One facility that had a continuous data collection methodology and was in field the entire calendar year sampled nearly twice as many patients as the facilities using the general sampling strategy. All samples were randomly generated. The targets for the distribution of the survey ranged from 140 to 1,108 per facility. However, most facilities were in the 500 to 600 range.

2.3 SCOPE AND LIMITS OF THIS JOINT STUDY

As stated earlier, the purpose of this study is to shed light on what each province can learn from the experience of the other in order to improve care and services provided to people afflicted with cancer. The data from the Québec and Ontario surveys are therefore used to attain this end. In spite of similarities in items, the estimates obtained for Québec cannot be statistically compared to those of Ontario.[7] Therefore, for the purposes of this joint study, we will be referring to trends within standard frameworks and "best practices" with regards to a patient-centred approach. This sub-section presents certain methodological limitations which will help gain a better understanding of the scope of this study.

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[5] For more information on the methodological aspects of the Ontario survey, see National Research Corporation, *Development and Validation of the Picker Ambulatory Oncology Survey Instrument in Canada*, Lincoln, NE, 35 p.

[6] In contrast to Québec, deceased patients in the timeframe of the Ontario survey were included in the sample because members of their family were offered the possibility of filling out the questionnaire on their behalf.

[7] This means that for a given variable, we cannot for example say that a proportion of 38% obtained for Québec is higher than a proportion of 24% obtained for Ontario.

First, in Ontario the time between treatment and data collection was approximately four to six months, while in Québec, it was two to three years, which could have engendered more memory biases among Québec respondents compared to Ontario ones. Furthermore, this longer time delay increased the possibility of obtaining a higher number of deceased people in the wake of their cancer in the Québec sample compared to the Ontario sample. If alive these people may have responded differently compared to the rest of the target population, given the outcome of their disease. In addition, the Québec survey defined deceased people as ineligible (n = 607), while the Ontario survey included family members who filled out questionnaires on behalf of the deceased (n = 179). However, although of great interest and value, we know that third-party responses could have differed from those that would have been provided by the cancer patients themselves if they were still alive.

Important differences also arise in terms of the sample frame and the sample itself in the two surveys. In Québec, the survey sample was derived from one sample frame made by matching administrative databases. Therefore, a person could only fill out one questionnaire. In Ontario, there were as many sample frames as there were participating hospitals, since a random sample of people was drawn from each one. Therefore, a person having been treated in more than one hospital could have been selected more than once. Furthermore, since these hospitals were not selected randomly at the outset, they could not be representative of all hospitals in Ontario. In short, although the Québec sample is representative of the target population[8] in the province, the Ontario one is only representative of participating hospitals.

Having said this, the sizes of the two samples, 4,925 in Québec and 2,942 in Ontario, upon which the data in this joint study are based, still provide estimates that present a good level of precision.[9] In spite of a few methodological differences in the surveys, this study is no less relevant, since it provides a means of ascertaining, for each province, gaps between what has been hoped for in implementing a patient-centred approach, and the concrete experience of patients. Since both Ontario and Québec have adopted the same philosophy of care in oncology, namely putting the patient at the heart of the process and applying a similar approach in terms of giving patients a voice, this joint study can also contribute to much-needed reflection on the role of data in any support-to-action model put into practice to ensure ongoing improvement in the quality of cancer care and services.

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8. As previously indicated, the target population of the Québec cancer survey (EQSLCC) comprised people 18 years of age and over, residing in Québec and having received at least one of three treatments, surgery, radiation therapy (including curietherapy), or chemotherapy (including intravenous) between April 1, 2005 and March 31, 2006.

9. Note that people who were treated only with surgery were excluded from the Québec sample used in this joint study.

3

THE PATIENT EXPERIENCE IN QUÉBEC AND IN ONTARIO: WHAT THE DATA TELL US

In this section, we examine the way in which cancer patients concretely bear witness to their role in the health care system based on the data collected in Québec and Ontario presenting certain similarities. Of particular interest is the information and support patients received in the period preceding treatment which could foster their involvement and that of their families in the decision-making process. Also presented is how the information needs of patients were addressed in terms of various aspects of their lives that could be affected by the treatments they were prescribed. The data are therefore analyzed from two perspectives – the way in which health care providers prepared their patients for receiving the treatment they were prescribed, and the information given to them so they could manage the potential side effects of such treatment.[1]

To gain a better understanding of the results presented in this report, first we will give a brief overview of the target population of this joint study by describing certain sociodemographic and health variables, such as sex, age, educational level, and cancer site.

3.1 DESCRIPTION OF THE TARGET POPULATION OF THE JOINT STUDY

Table 1 shows that in Québec, the proportion of women (60%) was significantly higher than that of men (40%) in the target population[2] of the study. Since cancer is particularly related to aging, it is not surprising that the study population in Québec was primarily composed of people 50 years of age and over (79% vs. 21% 18-49 years of age). In terms of the distribution of patients by educational level, the results reflect in part the distribution by age, since the proportion of people with no high school diploma (25%) was higher than that of those with a university degree (21%). In addition, upon examining the distribution of Québec patients by cancer site, we see that people with breast cancer (38%), prostate cancer (14%) or a haematopoietic cancer (13%) comprised nearly two-thirds of the target population of the joint study.

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[1] The questions retained for this joint study are presented in Appendix 1.

[2] It should be noted that the distribution of the target population in the joint study varied slightly from that of the Québec survey since, as previously indicated, people who were treated only with surgery were excluded from the analyses presented here. For a comparison of the two populations, see Appendix 2.

With regards to Ontario (Table 1), we see trends similar to those observed in Québec. Indeed, the proportion of women in the study (56%) was higher than that of men (44%), and the proportion of patients 50 years of age and over (86%) was also higher than that of patients under 50 (14%). In terms of the distribution by educational level, we see that the proportion of patients in Ontario with no high school diploma (30%) was higher than that of patients who had a university degree (25%). The distribution by cancer site in Ontario shows the predominance of breast cancer (30%), similar to that observed in Québec. We also see that prostate cancer accounted for 17% and colorectal cancer 11%.

To conclude this brief overview, we see that there were proportionally more women than men in the study populations of the two provinces and that breast cancer was predominant. We also see that Ontario patients in the study were older than Québec ones, which may explain the higher proportion of Ontario patients with no high school diploma.

Table 1

Distribution of the target population[1] in the joint study by sex, age, educational level and cancer site, Ontario (2006) and Quebec (2008)

	Ontario	Québec
	%	
Sex		
Men	43.6	39.5
Women	56.4	60.5
Age group		
18-49 years	13.7	21.5
50-59 years	23.0	26.3
60-69 years	27.4	29.0
70 years of age and over	35.9	23.2
Educational Level		
No high school diploma	30.0	25.3
High school diploma	21.7	25.5
Community college/Cégep/Trade/Technical school diploma	23.3	28.2
University degree	25.0	20.9
Type of cancer		
Colorectal, bowel	11.3	9.9
Cervical, uterine, ovarian	5.8	4.8
Prostate, testicular	17.2	14.4
Haematopoietic	9.3	13.3
Breast	30.4	37.9
Head, neck	3.9	5.3
Lung and bronchial tubes	6.7	5.8
Other	15.4	8.6

1. In Ontario, the target population of the AOPSS was composed of people 18 years of age and over who used the ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment between March 1 and August 31, 2005. In Quebec, patients who were treated only with surgery were excluded from the analyses so that the sub-sample derived from the EQLSCC 2008 could be a closer match with the sample of the *AOPSS*. Therefore the Québec results of the joint study can be inferred to people 18 years of age and over, who were residents of Québec, and had received at least one of two types of treatment, radiation therapy or chemotherapy, between April 1, 2005 and March 31, 2006.

Sources: Cancer Care Ontario, *Ambulatory Oncology Patient Satisfaction Survey*, 2006
Institut de la statistique du Québec, *Enquête québécoise sur la qualité des services de lutte contre le cancer*, 2008.

3.2 CANCER PATIENTS' PREPAREDNESS FOR TREATMENT

To assess how prepared Québec and Ontario patients felt they were for the treatment they received, we took eight questions from the EQLSCC 2008 and from the AOPSS 2006. For the purposes of this joint study, three questions from the Québec survey on the information received regarding possible side effects of the various treatments prescribed were also included.[3] The results are presented separately for Québec (Table 2) and Ontario (Table 3).[4] We also examined for each province whether the results for each item varied with certain sociodemographic characteristics such as sex, age and educational level. Only statistically significant differences are reported. A synthesis of the trends observed in the two provinces is presented at the end of the section.

3.2.1 What the Québec data tell us

The results presented in Table 2 show that a large majority (82%) of Quebec patients who had received radiation therapy or chemotherapy between April 1, 2005 and March 31, 2006 considered the explanations they were given regarding their tests and diagnostic examinations were "thoroughly"[5] understandable, while some reported they were "somewhat" understandable (12%) and a few said they were not (3.6%). Following the announcement of the diagnosis, nearly half of patients (48%) were put into contact with various resources to ease their anxiety and fears, while nearly a quarter of them (21%) said the opposite. It should be highlighted that 31% of patients reported they did not feel the need to be put into contact with such resources.

In terms of having been given sufficient information on the various stages of treatment, 84% of patients reported this was "thoroughly" the case while 13% qualified this as "somewhat," and 3.4% reported they had not. Information received on potential side effects of the various treatments varied with the therapeutic path of the patient. The data show that patients having received surgery or radiation therapy were less informed by health care providers of side effects than those who had received chemotherapy (66%, 76% and 86% respectively). For over one in ten patients (11%), information given on treatments or health status contained contradictions or was confusing.

Table 2 also presents patients' perceptions of their involvement as well as that of their family and friends in the treatment decision-making process, and whether their family and living situation were taken into account in planning treatment. Over 72% of patients reported having been "thoroughly" involved in the decisions regarding their treatment, 17% reported they were "somewhat" involved, and 11% not involved. Were family and friends encouraged to be involved in the decision-making process in planning treatment? Over half (51%) of patients indicated they were, while 4.6% would have liked this to have been

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[3] Questions from the questionnaires used in both surveys are presented in Appendix 1.

[4] The Institut de la statistique du Québec processed and verified the Québec data, while NRC-Picker Canada processed and verified the Ontario data.

[5] In the English version of the 2008 Québec survey, "Yes, thoroughly" was used as a response choice, whereas in the 2006 Ontario survey, "Yes, completely" was used.

Table 2
Québec cancer patients[1] preparedness for treatment, 2008

	%				
Health care providers explained diagnostic tests and procedures to the patient in a way that was easy to understand (B7)	Yes, thoroughly	Yes, somewhat	No	Did not have tests	**Total**
	81.9	11.9	3.6	2.5	**100**
Patient was put into contact with care providers or organizations to help cope with anxiety and fears (B13)	Yes	-	No	No, not needed	**Total**
	48.3		21.0	30.7	**100**
Patient was given information on the various stages of treatment (B16)	Yes, thoroughly	Yes, somewhat	No	-	**Total**
	83.9	12.7	3.4		**100**
Patient was involved in treatment decision-making as much as he/she wanted to be (B15)	Yes, thoroughly	Yes, somewhat	No	-	**Total**
	72.3	17.1	10.6		**100**
Patient was informed of the risks and possible side effects of surgery (C6)	Yes, thoroughly	Yes, somewhat	No	-	**Total**
	65.6	16.4	18.0		**100**
Patient was informed of the possible side effects of chemotherapy (C16)	Yes, thoroughly	Yes, somewhat	No	No, not needed	**Total**
	86.1	10.7	2.5	0.7**	**100**
Patient was informed of the possible side effects of radiation treatments (C22)	Yes, thoroughly	Yes, somewhat	No	No, not needed	**Total**
	75.8	15.0	7.4	1.8	**100**
Patient was given confusing or contradictory information about his/her health status or treatments (C38)	Never	Sometimes	Usually	Always	**Total**
	89.0	9.4	0.9*	0.8*	**100**
Health care providers involved family and friends in patient's treatment decision-making (B17)	Yes	No, but would have liked this	No, didn't want; or not needed	No family or friends who could be or wanted to be	**Total**
	50.7	4.6	41.7	3.1	**100**
Family and living situation[2] of patient was taken into account when planning treatment (B18)	Yes, thoroughly	Yes, somewhat	No	Didn't need to be	**Total**
	44.5	12.9	19.3	23.3	**100**
Patient felt comfortable talking about complementary, alternative, or non-traditional therapies with health care providers (B20)	Yes, thoroughly	Yes, somewhat	No, did not feel comfortable or feel the need	Did not use these therapies	**Total**
	24.1	6.0	23.8	46.1	**100**

* Coefficient of variation between 15% and 25%; interprets with caution.

** Coefficient of variation higher than 25%; imprecise estimate provided for information purposes only.

1. The target population was composed of people 18 years of age and over who were residents of Québec and had received at least one of two types of treatment, radiation therapy or chemotherapy, between April 1, 2005 and March 31, 2006.
2. In the English versions of the question in both the Ontario and Québec surveys, the term "living situation" was used, whereas in the French versions the term "mode de vie" was used, which generally means "lifestyle".

Source: Institut de la statistique du Québec, *Enquête québécoise sur la qualité des services de lutte contre le cancer*, 2008.

the case. In terms of their family or living situation at the time of planning treatment, 45% reported that these were "thoroughly" taken into account by health care providers, while 19% said they were not taken into account. To what degree did patients feel comfortable discussing non-traditional and alternative treatments with medical personnel? Among those who had used alternative treatments (54%), just as many felt "thoroughly" comfortable as those who did not or did not feel the need to discuss the topic.

Certain sociodemographic characteristics were associated with variables analyzed in this study, such as sex, age and educational level (data not shown).[6]

3.2.1.1 Quebec cancer patients' preparedness for treatment, by sex

- Proportionally more men than women did not feel the need to be put into contact with health care professionals or community organizations that could help ease their fears and anxiety after receiving their diagnosis (38% vs. 26%).
- Less women than men said they were "thoroughly" informed of the various stages their treatment would involve. However, they were more likely than men to say they had not been informed of the potential side effects of surgery (20% vs. 13%) or radiation therapy (9% vs. 5%).
- More women reported having been "somewhat" involved in the planning of their treatment compared to men (19% vs. 14%). Fewer women than men reported that their family or living situation was taken into account in the planning of the various stages of their treatment (43% vs. 48%).

3.2.1.2 Quebec cancer patients' preparedness for treatment, by age

- Patients 18-49 years of age were less likely to report that the explanations of their diagnostic examinations and tests were thoroughly understandable compared to those 60-69 years of age (77% vs. 85%). They were also less likely to report that the various stages of their treatment were "thoroughly" explained to them compared to people 70 years of age and over (10% vs. 15%).
- The 18-49 age group were also more likely to say that at one time or another, information on their health status or treatment was confusing or contradictory (15% vs. 10% for those 60-69 and 7% for those 70 and older).
- Fewer patients in the 18-49 age group reported not needing support to ease their anxiety and fears compared to those in the 60-69 and 70 and over age groups (22% vs. 34% and 40% respectively).
- Younger patients (18-49 years of age) were also less likely to feel as involved in treatment decision-making as they wanted to be compared to older patients (66% vs. 75% in the 60-69 and 70 and over age groups). They were more likely to report that their family or living situation was only "somewhat" taken into account when planning the various stages of treatment (17% vs. 11% in the 60-69 and 70 and over age group).

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[6] Only significant differences at the threshold of 0.05 are reported here.

3.2.1.3 Quebec patients' preparedness for treatment, by educational level

- Patients with no high school diploma were more likely to report not being involved as much as they would have liked in the decision-making process related to their treatment (15% vs. 9% with a high school diploma). However, they were more likely to report that their family and living situation was "thoroughly" taken into account when their treatment was being planned compared to those with a post-secondary diploma or degree (49% vs. 42%).
- In terms of potential side effects of the treatments, patients with no high school diploma were more likely to report they had not received information in this regard.

3.2.2 What the Ontario data tell us

The results in Table 3 show us how Ontario patients who used the ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment assessed the information given them when they underwent tests or diagnostic examinations, or at the time when their treatment was being planned. Did Ontario health care providers explain tests to cancer patients in an understandable way? The majority of patients reported that their health care provider explained the reason why they needed tests in a "completely" understandable manner (77%), 17% evaluated the explanations as "somewhat" understandable, while 1.8% did not receive any explanation. Were they put in touch with a health care provider to help with anxiety and fears? The data show that 36% of patients were not put in touch with other care providers for this purpose, 29% reported being referred, and 19% responded "somewhat." Even though it may appear surprising that people diagnosed with cancer would not have anxiety or fears related to the diagnosis, 17% of patients reported they had none.

Were patients informed about what the next step in their care path would be? More than half of patients (53%) said that they "always" knew, a third (34%) indicated that they "usually" knew, 10% knew "sometimes," and 3.6% "never knew." More than three-quarters of patients (76%) indicated that they were "never" given confusing or contradictory information about their health status or treatment, while slightly more than a fifth (22%) indicated that this "sometimes" happened.

Patient participation in the decision-making process regarding their treatment is considered as one of the key elements of a patient-centred approach. It is interesting to note that in 2006, 76% of cancer patients in the Ontario who used the ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment reported being involved as much as they wanted to be in decisions about their care, 20% said they were "somewhat" involved, and 3.6% reported "no" (Table 3). Were the patient's family or friends given the opportunity to be involved in care and treatment decisions made by the health care providers? The data indicate that 76% of patients reported their family or friends were given the "right amount" of opportunity to be involved, 5.3% said "not enough" opportunity, and 0.7% said "too much." It should be noted that 18% of patients indicated their "family or friends were not involved." The data presented in Table 3 also show that 58% of patients said that their family or living situation was "completely" taken into account when treatment was being planned, 24% said “somewhat,” and 17% said “no.” Among patients using complementary, alternative or non-traditional therapies (53%), 29% felt “completely” comfortable talking about them, 12% were “somewhat” comfortable and 11% did not feel comfortable talking about them.

Table 3
Ontario cancer patients[1] preparedness for treatment, 2006

	%				
Health care provider explained reasons for tests to the patient in an understandable way (Q17)	Yes, completely	Yes, somewhat	No	Did not have tests	**Total**
	77.1	16.8	1.8	4.4	**100**
Patient was put in touch with a care provider to help with anxiety and fears (Q5)	Yes, completely	Yes, somewhat	No	No anxieties or fears	**Total**
	28.6	18.8	35.7	16.8	**100**
Patient always knew the next step in his/her care path (Q56)	Always	Usually	Sometimes	Never	**Total**
	53.1	33.5	9.8	3.6	**100**
Patient was given confusing or contradictory information about his/her health or treatment (Q54)	Never	Sometimes	Usually	Always	**Total**
	75.5	22.1	0.9	1.4	**100**
Patient was involved in decisions about care as much as was wanted (Q9)	Yes, completely	Yes, somewhat	No	-	**Total**
	76.0	20.5	3.6		**100**
Opportunity given to family or friends to be involved in care and treatment decisions (Q11)	Right amount	Not enough	Too much	Family or friends not involved	**Total**
	76.0	5.3	0.7	18.0	**100**
Family or living situation of the patient was taken into account when planning treatment (Q10)	Yes, completely	Yes, somewhat	No	-	**Total**
	58.3	24.5	17.2		**100**
Patient felt comfortable talking about complementary, alternative, or non-traditional therapies with staff (Q48)	Yes, completely	Yes, somewhat	No	Did not use these therapies	**Total**
	28.9	12.3	11.5	47.3	**100**

1. The target population was composed of people 18 years of age and over who used the ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment between March 1 and August 31, 2005.

Source: Cancer Care Ontario, *Ambulatory Oncology Patient Satisfaction Survey*, 2006

Similar to what was observed in Québec, items analyzed in the Ontario data were associated with certain sociodemographic variables (data not shown).[7]

3.2.2.1 Ontario cancer patients' preparedness for treatment, by sex

- Men were more likely than women to report that their health care providers' explanations on why they needed tests were "completely" understandable (81% vs. 74%), that they did not have anxiety or fears (21% vs. 14%), they "always" knew the next step in their care path (56% vs. 50%) and that their family or living situation was "completely" taken into account by health care providers when planning treatment (63% vs. 55%).
- On the other hand, women were more likely to indicate that they were not comfortable talking about complementary, alternative or non-traditional therapies when compared to men (15% vs. 7%).

3.2.2.2 Ontario cancer patients' preparedness for treatment, by age

- Older patients felt that the explanations given by their health care providers about why tests needed to be done were understandable compared to other age groups (79% of patients 70 years of age and over vs. 73% of patients under 60).
- Patients 70 years of age and over were also more likely to report not having anxiety or fears regarding their cancer compared to other age groups (24% vs. 17% of 60-69 year-olds, 12% for 50-59 and 6% for 18-49).
- Compared to other age groups, elderly patients were more likely to report that that their family and friends were not involved in care and treatment decisions (22% of patients 70 years of age and over vs. 15% of 50-59 and 10% of 18-49 year-olds).
- Patients in the 70-and-over age group were less likely to report feeling uncomfortable in discussing alternative therapies when compared to other age groups (4.2% vs. 11% for those 60-69, 19% for those 50-59 and 17% for those 18-49 years of age).

3.2.2.3 Ontario cancer patients' preparedness for treatment, by educational level

- Patients who had not completed high school reported a higher degree of involvement in care decisions compared to patients with a post-secondary education (80% vs. 74% with a college/trade/technical diploma and 73% with a university degree).
- Patients with a university degree were more likely to want their family or friends to be involved in decision-making on their care (27%) compared to patients who were college graduates (18%), high school graduates (16%), and those without a high school diploma (12%).
- Patients with a university degree were less likely to indicate that their health care providers took their family or living situation into account when making treatment-related decisions (45% vs. 64% with no university degree).

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[7] Only differences significant at the threshold of 0.05 are reported here.

- ▷ Patients with a university degree were also more likely to indicate not feeling comfortable talking about non-traditional therapies when compared to those with a college diploma, high school diploma, or those who did not finish high school (18% vs. 12%, 9% and 6% respectively).

3.2.3 Summary and trends observed

Though implementing a patient-centred approach implies organizing services that put emphasis on the decision-making autonomy of patients (Perlin et al., 2005), it is still important that they be clearly informed of their disease and its treatment. Preparing the patient for required treatments not only implies respecting his/her needs, values and preferences (Institute of Medicine, 2001), but also involves taking into account psychosocial dimensions (Stewart et al., 2003).

The data collected in Québec and Ontario revealing differences observed by sex, age and educational level bear witness to the diversity of patient needs. Although the data cannot be statistically compared, it is interesting to observe similarities in certain trends. The fact that women were more likely than men to feel a need for other health care providers to ease their anxiety and fears, felt less involved in the treatment decision-making process, and felt that their family situation was only somewhat taken into account, undoubtedly translates into the need for information and support that cannot be fulfilled in the same way for all. The associations with age seem to reveal the same trend – the fact that patients in the youngest age group were less likely to feel completely informed or involved in decision-making can translate into their having needs that differ from those of older patients.

Certain trends based on the two provinces' data are worth highlighting. In Québec, when we specifically examined services in light of psychological and personal aspects, we see that the proportion of patients having reported not feeling the need to be put in touch with other health care providers or community resources to ease their anxiety and fears following their diagnosis was significantly higher than those who reported not being referred (31% vs. 21%), whereas the contrary was observed in Ontario (17% vs. 36%). A number of aspects may have contributed to these trends. For example, the fact that Ontario patients responded to the survey in the six months following their first treatment compared to up to two years for Québec patients could have led to relative differences in their experience with regards to anxiety or lack thereof following the announcement of their diagnosis. Furthermore, differences in the wording of the question could have played a role in the findings on anxiety and fears, since support groups and community organizations were among response choices in the Québec question. In addition, access to a pivot nurse in Québec could have contributed to reducing patient fears and anxiety, since one of her main functions is to support the patient at the time of diagnosis and coordinate the care and treatments to be received as a result.

Differences between the provinces were also observed in terms of whether the patient's family or living situation was taken into account when planning treatments. In Ontario, the proportion of patients having responded that this was the case was much higher than that of those who indicated it was not (83% vs. 17%) compared to what was observed in Québec (57% vs. 43%; “No,” all reasons combined). Though the different methodologies of the two surveys may once again explain these trends, it may be that certain Ontario initiatives designed to sensitize health care providers contributed to what was observed in the province. For example, in Ontario many Integrated Cancer Program facilities apply a philosophy of patient-centred care and have built awareness among health care providers to educate and engage patients and their families or friends in decision-making. Moreover, the fact that large teaching and community hospitals post their mission or values statements outlining patient-centred care for public reading, and report scorecards in this respect to their board meetings or in publications, has undoubtedly triggered a change in organizational culture. This may indeed result in the implementation of new strategies, processes and practices which will place the patient at the heart of the health care system.[8]

3.3 PREPAREDNESS OF CANCER PATIENTS TO MANAGE POTENTIAL SIDE EFFECTS OF THEIR TREATMENT

Side effects that can be engendered by various treatments patients receive to fight cancer can affect many dimensions of their lives. To assess to what degree patients were informed of these, six questions from both the Québec and Ontario surveys were analyzed for the purposes of this joint study. The results for Québec are shown in Table 4 and for Ontario in Table 5. The trends revealed in the two provinces are summarized at the end of the section.

3.3.1 What the Québec data tell us

A large majority of Québec patients who had received radiation therapy or chemotherapy between April 1, 2005 and March 31, 2006 felt a need for information on the changes that could arise in various aspects of their lives as a result of their treatment (physical appearance, 82%; sex life, 76%; emotions, 82%; nutritional needs, 84%; current activities, 75%; see Table 4). It is in the areas of physical appearance and nutritional needs where the largest proportion of patients reported they were “thoroughly” informed of what they might experience (58% and 52%), while the smallest proportions were seen in the aspects of couple / family life and sexual activity (33% and 39%). It was also in these two latter areas wherein the largest proportion of patients reported not having received any information (26% and 25% respectively).

Sex, age and educational level were associated with patients’ assessment of the information health professionals communicated to them so they could better manage the possible side effects of their treatment in various aspects of their lives (data not shown).

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[8] In 2010, this new approach was concretized into legislation – the Excellent Care for All Act.

Table 4

Québec cancer patients[1] being informed of the potential side effects of their treatment, 2008

	Yes, thoroughly	Yes, somewhat	No	Did not need information	**Total**
	%				
Information was given on possible changes in physical appearance (C43a)	58.5	12.7	11.3	17.5	**100**
Information was given on possible changes in sexual activity (C43b)	38.6	11.8	25.2	24.4	**100**
Information was given on possible changes in emotions (C43c)	41.2	18.4	22.5	17.9	**100**
Information was given on possible changes in relationship with spouse / partner and family life (C43d)	33.3	12.9	25.8	28.0	**100**
Information was given on possible changes in nutritional needs (C43e)	52.3	15.9	15.7	16.1	**100**
Information was given on possible changes affecting work or usual activity (C43f)	43.8	16.0	15.4	24.8	**100**

1. The target population was composed of people 18 years of age and over, who were residents of Québec, and had received at least one of two types of treatment, radiation therapy or chemotherapy, between April 1, 2005 and March 31, 2006.

Source: Institut de la statistique du Québec, *Enquête québécoise sur la qualité des services de lutte contre le cancer*, 2008

3.3.1.1 Québec cancer patients being informed of the potential side effects of their treatment, by sex

- Women were more likely than men to report being "thoroughly" informed of possible changes in their physical appearance following treatment (61% vs. 54%), while men were more likely to report not needing any information in this regard (22% vs. 14%).
- As far as information on potential side effects on sexual activity is concerned, significantly more women than men reported not needing any (30% vs. 16%). They were also more likely not to have been given such information compared to men (29% vs. 19%).
- Men were more likely than women to report they did not need any information on the possible side effects of treatment on their emotions (21% vs. 16%).
- Proportionally more women than men reported not needing information on potential effects on their couple and family life (30% vs. 23%). Yet women were less likely to report that they had been "thoroughly" informed (29% vs. 39%) and more likely not to have been given information on couple and family life (28% vs. 23%).
- Women reported being less informed about the possible side effects of treatment on their nutritional needs; 18% reported not being given such information compared to 13% of men, and 17% reported being "somewhat" informed about it compared to 14% of men.
- Women were also more likely to say they had been "somewhat" informed about the possible side effects on work or usual activity compared to men (18% vs. 13%).

3.3.1.2 Québec cancer patients being informed of the potential side effects of their treatment, by age

- The younger the patient, the more likely he/she was to report having been "thoroughly" informed of possible changes in his/her physical appearance as a result of treatment (71% of patients 18-49 years of age vs. 44% of those 70 years of age and over). In contrast, the older the patient, the more likely he/she was to report not needing to be informed in this respect (31% of patients 70 years of age and over vs. 4.2% of those in the 18-49 age group).
- With regards to having been given information on the possible side effects on sexual activity, the older the patient the less he/she felt this was needed (10.5% of those 18-49 years of age; 19% of those 50-59 years of age; 26% of those 60-69 and 41% of those 70 and over). In contrast, the younger the patient, the more likely he/she was to report having been "thoroughly" informed in this regard (46% in the 18-49 age group vs. 37% in the 60-69 age group and 31% in the 70 and over age group).

- The same trends were observed for information pertaining to emotions – the older the patient, the more likely he/she was to say he/she didn't need any (35% in the 70 years of age and over group vs. 18% in the 60-69 age group, 12% in the 50-59 age group, and 6% in the 18-49 age group). Again in contrast, we observe that comparatively younger patients felt "thoroughly" informed about the possible impact on emotions compared to older patients (48% of those 18-49 years of age vs. 29% of those 70 and over).
- With regards to being given information on the effects on couple or family life, the same trends were observed. The older the patient, the more likely he/she was to report not needing this type of information (47% in the 70 years of age and over group vs. 30% in the 60-69, 22% in the 50-59 and 13% in the 18-49 age groups). However, older patients were less likely to report having been "thoroughly" informed in this regard compared to younger patients (24% of those 70 years of age and over vs. 39% of those 18-49 years of age).
- Older patients were also less likely to report needing information on possible changes in their nutritional needs (28% of those 70 years of age and over vs. 19% of those 60-69, 12% of those 50-59, and 5% of those 18-49 years of age) and less likely overall to report having been "thoroughly" informed in this regard (41% of those 70 years of age and over vs. 60% of those 18-49 years of age).
- Older patients were more likely to report not needing information on the impact of treatment on work or usual activity (44% of patients 70 years of age and over vs. 30% of those 60-69, 16% of those 50-59 and 8% of those 18-49 years of age). That being said, the youngest patients were more likely to report having been "somewhat" informed of the potential side effects of treatment on their work or usual activity (24% in the 16-49 age group vs. 17% in the 50-59, 13% in the 60-69, and 11% in the 70 and over age group).

3.3.1.3 Québec cancer patients being informed of the potential side effects of their treatment, by educational level

- The proportion of patients who reported not having been informed of changes that could arise in physical appearance was higher among those who did not have a high school diploma (15%) than those with a post-secondary diploma (10%) or a university degree (9%).
- Regarding information on the potential side effects of the treatment on sexual activity, a higher proportion of patients with no high school diploma said they did not need any compared to those with other educational backgrounds (30% vs. 23% of those with a high school diploma, 23% with a post-secondary diploma and 20% of those with a university degree). This result can be attributed in part to age, given that the educational level of older patients is often lower.
- The more education the patients had, the more likely they were to report having been "somewhat" informed of possible side effects on their emotions (20% of university graduates vs. 14% of those with no high school diploma).

- The same trends were observed for information on couple or family life (14% among those with a university degree vs. 9% of those with no high school diploma), nutritional needs (21% of university graduates vs. 13% of those with no high school diploma) and work and usual activity (18% among those with a university degree vs. 13% of those with no high school diploma).

3.3.2 What the Ontario data tell us

Similar to those in Québec, the majority of Ontario patients who used ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment indicated they needed information on possible changes in various aspects of their lives that could arise from the treatment they were prescribed (Table 5). In descending order, these were nutritional needs (85%), emotions (82%), physical appearance (78%), work and usual activities (70%), sex life (65%), and relationship with the spouse/partner (61%).

The findings shown in Table 5 also indicate that 50% of patients reported they were given information on possible changes in their physical appearance, 18% were "somewhat" provided with information, while 9% did not receive any information. As far as the possible impact on sexual activity was concerned, 28% of patients reported being "completely" informed, 15% "somewhat" informed, and 22% said they did not receive any information on the topic. Giving information on emotions seemed to be a difficult issue for health care providers. Though 29% of patients reported being "completely" informed, 28% reported being "somewhat" informed and 26% were not informed at all by health care providers. Rather similar results were observed with regards to the treatment's possible side effects on the patient's relationship with his/her spouse or partner: 17% said they were "completely" informed, 17% were "somewhat" informed, and 27% were not informed at all. Care providers seemed to have been better at informing patients about nutritional needs: 42% of patients reported that they were "completely" informed compared to 26% who reported being "somewhat" informed. With respect to the proportion of patients who received information on possible changes to their work or usual activities, 28% indicated that they were "completely" informed, 27% reported that they were "somewhat" informed on this possible side effect, while 15% reported that they were not given any information on this by their health care provider.

Similar to what was observed in Québec, the Ontario items analysed in this section were associated with sociodemographic variables (data not shown).

Table 5
Ontario cancer patients[1] being informed of the potential side effects of their treatment, 2006

	Yes, completely	Yes, somewhat	No	Does Not Apply	**Total**
	%				
Information was given on possible changes in physical appearance (Q40)	49.7	18.5	9.4	22.5	**100**
Information was given on possible changes in sexual activity (Q41)	27.5	15.4	21.7	35.4	**100**
Information was given on possible changes in emotions (Q42)	28.7	27.9	25.6	17.9	**100**
Information was given on possible changes in the relationship with the spouse or partner (Q44)	17.1	17.3	26.8	38.8	**100**
Information was given on possible changes in nutritional needs (Q43)	42.3	26.3	16.5	14.8	**100**
Information was given on possible changes in work or usual activities (Q45)	28.0	27.4	14.6	30.0	**100**

1. The target population was composed of people 18 years of age and over who used ambulatory oncology services (chemotherapy or radiation therapy) in one of 13 Integrated Cancer Program facilities for cancer treatment between March 1 and August 31, 2005.

Source: Cancer Care Ontario, *Ambulatory Oncology Patient Satisfaction Survey*, 2006

3.3.2.1 Ontario cancer patients being informed of the potential side effects of their treatment, by sex

- Compared to men, women were more likely to respond "Yes, somewhat" as to whether they had received enough information from health care providers on possible changes in their physical appearance as a result of their treatment (12% vs. 6%).
- Differences were also observed as far as being given information on the potential impact on sexual activity and emotions was concerned. Women were less likely to have been "completely" informed compared to men (20% vs. 37% and 25% vs. 33% respectively).
- With regards to health care providers giving enough information about possible changes in the relationship with a spouse or partner, it is interesting to note that proportionally more women than men reported that this type of information did not apply to them (46% vs. 30%), whereas fewer women reported they had been "completely" informed of this potential side effect (12% vs. 24%).
- Proportionally more women than men reported not having been provided enough information about possible changes in nutritional needs (19% vs. 13%).
- Women were less likely to say that they had been "completely" informed about the potential impact of treatment on work or usual activities (23% vs. 34%).

3.3.2.2 Ontario cancer patients being informed of the potential side effects of their treatment, by age

- Older patients were more likely to report that being given information on possible changes in physical appearance due to treatment did not apply to them (30% of the age group 70 years and over vs. 13% of the 50-59 and 11% of the 18-49 age groups), and were less likely to say that they had been "completely" informed on this topic (41% of those 70 and over vs. 50% of those 60-69, 61% of those 50-59 and 50% of those 18-49 years of age).
- Older patients were more likely to report not needing this type of information (53% of those 70 years of age and over vs. 33% of those 60-69, 23% of those 50-59 and 15% of those 18-49). Younger patients were more likely to say that they were somewhat informed on the effects of treatment on their sex life (26% of those 18-49 years of age vs. 13% of those 60-69 and 9% of those 70 and over).
- Being informed about the possible side effects on emotions followed the same trend: older patients seemed to feel that it did not apply to them compared to other age groups (30% of those 70 years of age and over vs. 17% of those 60-69, 8% of those 50-59 and 6% of those 18-49). Younger patients were more likely to report being "somewhat" informed of the possible effects on emotions (39% of those 18-49 vs. 34% of those 50-59, 24% of those 60-69 and 23% of those 70 and over).
- The same trend was observed regarding possible changes in the relationship with the spouse or partner: 27% of patients 18-49 years of age reported being "somewhat" informed compared to 13% of patients 70 years of age and over.

- Being informed about nutritional needs also varied according to the age group: patients 18-49 years of age were more likely to say that they were "somewhat" informed when compared to those 70 and over (35% vs. 22%) and also more likely to say that the information provided was not "enough" (26% vs. 16%).
- Information on the possible effect on work and usual activities seemed of concern to the youngest age group: 39% of patients 18-49 years of age reported being "somewhat" informed, while the proportion among patients 70 years of age and over was 20%.

3.3.2.3 Ontario cancer patients being informed of the potential side effects of their treatment, by educational level

- Patients who had not finished high school reported being "completely" informed about potential side effects of treatment on physical appearance in a larger proportion than those with a university degree (57% vs. 40%). In contrast, patients with a university degree were more likely to report being "somewhat" informed compared to the former group (23% vs. 15%).
- With regards to information provided on possible changes in a patient's sexual activity, emotions and his/her couple relationship, those with a university degree were more likely to report being "somewhat" informed compared to those without a high school diploma (20% vs. 10%; 34% vs. 18%; and 34% vs. 22%).
- Patients with a university degree were less likely to report being "completely" informed on possible changes in nutritional needs when compared to those without a high school diploma (31% vs. 55%) and more likely to say that they had not received enough information on this topic (28% vs. 10%).
- The same trend was observed as far as potential impact on work and usual activities was concerned. Patients with a university degree were less likely to report having received enough information when compared to those without a high school diploma (20% vs. 31%), and were more likely to say that they had not received enough information (23% vs. 9%) in this regard.

3.4 SUMMARY AND TRENDS OBSERVED

Side effects such as fatigue, pain and nausea engendered by various treatments cancer patients must undergo do not only have an impact on their physical and psychological well-being, but also on their daily lives, including their family life and everyday activities. It could be construed that informing patients of the changes that can arise in their lives during treatment will give them better tools to manage the possible side effects, thereby contributing to improving their quality of life during this period.

In both Ontario and Québec, the data show that the information health care providers gave to patients on the possible side effects of their treatment related to physical appearance, sexual activity, emotions, the couple's relationship, nutritional needs and current activities were responding to a need. However, though the majority of patients reported they had been informed about the aforementioned aspects of treatment, those related aspects of intimacy such as emotions, sex life, and couple and family relationships seemed to be less covered by health care providers. The proportion of patients who said they had been "completely" informed in this regard was indeed lower than that for physical appearance and nutritional needs.

The findings also showed that the information received varied with sex, age and educational level. In a number of aspects, women reported receiving less information, especially with regards to sexual activity and the couple's relationship. The youngest patients also felt they had not been informed of the possible side effects of treatment on these aspects. With regards to educational levels, in both Québec and Ontario, the most educated patients tended to say they had not received much information on the potential effects of their treatment on various aspects of their lives examined in this joint study. Variations based on sociodemographic characteristics undoubtedly reflect the diversity of needs that should be taken into account as suggested by the implementation of a patient-centred approach.

4

IMPROVING THE QUALITY OF CANCER CARE: THE CONTRIBUTION OF A PATIENT-CENTRED APPROACH

Cancer has become the leading cause of mortality and remains the most important risk factor in terms of potential years of life lost. Therefore the importance ascribed to its prevention and treatment is not surprising. Many indicators on the quality of services in the health care system refer to aspects related to the results of screening for and treatment of cancer. Among the main indicators are the survival rates of breast cancer, cervical cancer and colorectal cancer. References are also made to the screening methods used.[1] However, though major indicators can provide international comparisons, they do not bear witness to certain aspects of patients' needs, which are often more complex to ascertain and measure. Furthermore, the advance of knowledge in health care has highlighted the importance of psychosocial factors that should be taken into account with regards to the ability of patients to cope with the devastating effects of cancer on all aspects of their lives and often those of their family and friends.

The progress in terms of standards of practice and the organization of health care services Ontario, Québec and in industrialized countries in general, reflect increasing awareness of the importance of various dimensions associated with appropriate care – information, respect for patient preferences, consideration for family and friends, and coordination of various services during all stages of treatment. As much as the essential nature of these dimensions has become increasingly clear, the quality of the health care system's response to these needs is difficult to measure using clinical and administrative data. The limits of information systems and the similarity of new concerns related to responding to all the needs of cancer patients no doubt explains the kind of data sought after by the surveys conducted in Ontario and Québec and other provinces in Canada.

Therefore, even though the surveys conducted in Québec and Ontario were not done from a statistically comparative perspective, their goals were similar, and there were enough questions covering common dimensions of the cancer care process that a joint study could reveal certain trends. Indeed, this joint study has provided a means of examining certain organizational options that could better respond to patient needs, thereby resulting in improvements in the quality of care and services provided.

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[1] See S. Mattke (2006).

In Québec, the decision to conduct this type of survey was directly related to assessing the impact of implementing the *Programme de lutte contre le cancer* (Program to Fight Cancer). The aim was to improve the health care system's response to the needs of patients and their families and provide effective support for the desired changes. The survey was repeated in 2013 in order to see whether over time the Québec program has contributed to patients' quality of life throughout their treatment path. In Ontario, evaluation and improvement of the patient experience is an important strategic priority, and annual surveys are one of the tools that have been used since 2004 to determine if the changes brought about the way cancer care is delivered have been beneficial for patients.

4.1 A COMPARATIVE OVERVIEW OF THE QUÉBEC AND ONTARIO DATA

The data collected in the Ontario and Québec surveys have provided a means of assessing cancer patients' concrete experience of a patient-centred approach to care. Do we clearly inform patients about their disease, their treatment and the potential side effects that can seriously impact various aspects of their lives? Do we involve them and their families and friends in the cancer care decision-making process? Do we support them psychologically in order to ease the anxiety and fears that can arise at the time of diagnosis? These are some of the questions which this joint study has attempted to answer. Although caution is required in interpreting the trends observed in the data based on the Ontario and Québec surveys, certain differences merit in-depth discussion.

The data from both Québec and Ontario in this joint study illustrate the importance of adapting clinical practices to the personal characteristics of patients such as sex, age and educational level. For example, the fact that compared to men, more women indicated the need for support in assuaging their anxiety and fears, felt less involved in the decision-making process regarding their treatment or that their family situation was only "somewhat" taken into account, undoubtedly reflect specific needs in terms of information, support and involvement. Analyses of the data by age revealed that younger patients were less likely to feel "completely" informed or involved means they may have needs that differ from those of older patients. Can the gap observed between practices suggested by a patient-centred approach and those experienced by patients be reduced if the aforementioned dimensions are taken into account by health care providers? This is a question worth asking.

Analyses of the data on informing cancer patients of the potential side effects of treatment on various aspects of their lives also seemed to indicate a gap between clinical practices suggested by a patient-centred approach and the concrete patient experience. The greatest gaps were observed for aspects related to intimacy (emotions, sexual activity and the relationship with the spouse/partner). Again there were differences observed according to sociodemographic characteristics entered in the analyses. For example, in general, women reported they received less information when compared to men in a number of aspects, such as sexual activity and the couple's relationship. Younger patients also considered they did not receive enough information regarding potential side effects on these aspects of their lives. In both Québec and Ontario, patients with a higher level of education were more likely to say they had not received much information on the potential side effects of their treatment on a number of aspects of their lives covered in the joint survey.

Data analyses also revealed trends specific to Québec and to Ontario. Though a number of methodological reasons can be cited to explain these, it still remains that the divergent trends observed provide a means of comparing the organizational context of each province and the experience of cancer patients in each. For example, the comparison of the proportions of patients who reported not needing to be put in contact with various resources to ease their anxiety and fears with those who had not been put into contact may be attributed to the way services are provided. To what degree has establishing pivot nurses in oncology in Québec contributed to better fulfilling the psychosocial needs of cancer patients? This issue should be examined in more depth.

Data on consideration given to the patient's family or living situation during the treatment-planning process revealed other differences between the two provinces that should be highlighted. In comparing results on these two items, we must ask ourselves how services are provided in the two provinces with regards to implementing a patient-centred approach. To what degree has the support given to health care providers working in Integrated Cancer Program facilities contributed to improving the patient experience? This again merits more in-depth analysis.

4.2 RESPONDING TO THE NEEDS OF CANCER PATIENTS AND IMPROVING THE QUALITY OF CARE AND SERVICES – THE CONTRIBUTION OF DATA FROM THE JOINT STUDY

Ensuring service quality for cancer patients is a major issue in Québec as it is in Ontario. Though developing and implementing a patient-centred approach is seen as a means of substantially improving the quality of health care, it is important to document the specificity of the patient experience to truly understand the path they have traveled and the one still facing them. Without accurate data, our ability to fully understand the patient experience and move in the right direction is severely limited and is based on anecdotal rather than scientific investigation.

Giving a voice to patients in the Ontario and Québec surveys has shed light on ways of assessing actions, adjusting clinical practices and providing care and services that reflect these. Through precise descriptions of the patient experience, the survey data in this joint study have cast a critical eye on the gaps observed between the quality of care expected or desired, and the quality received. Interpreting these gaps provides an opportunity for reflection, discussion and innovation in terms of the ways in which care and services provided to patients can be improved.

In Québec, the provincial survey conducted in 2008[2] on patients having received treatment in 2005-2006 was re-conducted in early 2013 on patients who were treated in 2010. To facilitate trend analyses with those of other provinces, the questionnaire administered to Québec patients has been revised notably to allow for analyses based on the Picker dimensions (access, physical comfort, respect for preferences, information, education and communication, coordination and continuity, and support). Other than additional analyses that can be conducted following changes made to the questionnaire, comparing the findings of the first and second cycles of the survey will provide a means of seeing whether assigning pivot nurses to the multidisciplinary health care team has improved the coordination of care in oncology, rendered it more patient-centred, and whether patients are being asked to be and indeed are more involved in their care path, or better informed of the potential side effects of their treatment.

In Ontario, "patient experience" surveys have been conducted annually since 2004, providing feedback for patients, health care providers, and administrators. They are being used to evaluate the attainment of certain action plan objectives, and to redefine the expectations of various people involved in the fight against cancer.

The data collected in the Québec and Ontario surveys merit further in-depth analyses. Multivariate analyses would help us gain a better understanding of the main factors associated with effective patient management (informing, involving, supporting). Matched with clinical and administrative data, data from these surveys can provide great opportunities for research on possible associations between patient experience and health status (tests and diagnostic results, co-morbidity, drugs, use of services, etc.) and the performance of the health care system (access, waiting periods, etc.). The findings generated by such value-added research would no doubt ensure better monitoring and follow-up of the care being provided, thereby improving the quality of life of cancer patients and their families.

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[2] The goal of the first cycle of the Québec survey was to evaluate the quality of cancer services at time point 0, namely at the time interdisciplinary teams, essentially comprising pivot nurses, were implemented and assigned as prescribed by the PQLC.

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APPENDIX 1

Items taken from *Enquête québécoise sur la qualité des services de lutte contre le cancer* (2008) used to make Table 2, French version

(B7)
Est-ce que les professionnels de la santé vous ont expliqué d'une manière facile à comprendre pourquoi vous deviez passer des tests ou des examens diagnostiques?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'ai pas passé d'examen ou de test diagnostique

(B13)
Après l'annonce de votre diagnostic de cancer, avez-vous été mis en contact avec des professionnels de la santé ou avec des organismes pouvant vous aider à apaiser vos craintes, vos peurs et votre anxiété?

- Oui, avec un groupe d'entraide ou un organisme communautaire
- Oui, avec une infirmière pivot en oncologie
- Oui, avec un psychologue
- Oui, avec un travailleur social
- Oui, autre, précisez:
- Non, je n'ai pas été mis en contact avec un professionnel de la santé ou un organisme
- Non, je n'en avais pas besoin

(B16)
Vous a-t-on expliqué les différentes étapes que comporterait votre traitement?

- Oui, tout à fait
- Oui, en partie
- Non

(B15)
Avez-vous été impliqué dans les décisions à prendre concernant vos traitements autant que vous l'auriez souhaité?

- Oui, tout à fait
- Oui, en partie
- Non

(C6)
Est-ce que les professionnels de la santé vous ont parlé des risques et des effets secondaires possibles liés à votre première chirurgie (ou opération)?

- Oui, tout à fait
- Oui, en partie
- Non

(C16)
Est-ce que les professionnels de la santé vous ont parlé des effets secondaires possibles de vos traitements de chimiothérapie?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'explication

(C22)
Est-ce que les professionnels de la santé vous ont parlé des effets secondaires possibles de vos traitements de radiothérapie (ou de curiethérapie)?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'explication

(C38)
Vous a-t-on donné des renseignements qui portaient à confusion ou qui étaient contradictoires concernant votre état de santé ou vos traitements?

- Jamais
- Quelques fois
- La plupart du temps
- Toujours

(B17)
Est-ce que les professionnels de la santé ont impliqué vos proches (conjoint, enfants, amis, etc.) dans les décisions concernant vos traitements?

- Oui
- Non, je ne voulais pas
- Non, mais j'aurais aimé que les professionnels de la santé impliquent mes proches
- Non, ce n'était pas nécessaire
- Je n'avais pas de proches qui pouvaient ou voulaient s'impliquer

(B18)
Est-ce que les professionnels de la santé ont tenu compte de votre situation familiale ou de votre mode de vie lorsqu'ils ont planifié les différentes étapes de vos traitements?

- Oui, tout à fait
- Oui, en partie
- Non
- Non, on n'avait pas à tenir compte de ma situation familiale ou de mon mode de vie

(B20)
Vous êtes-vous senti à l'aise de discuter des approches complémentaires, parallèles et alternatives (par exemple massage, acupuncture, homéopathie) avec les professionnels de la santé?

- Oui, tout à fait
- Oui, en partie
- Non, je n'étais pas à l'aise d'en discuter
- Non, je n'ai pas senti le besoin d'en discuter
- Non, je n'ai pas utilisé ce type d'approches

Items taken from *Enquête québécoise sur la qualité des services de lutte contre le cancer* (2008) used to make Table 2, English version

(B7)
Did the health care providers explain to you, in a way that was easy to understand, why you needed to have diagnostic tests and procedures?

- Yes, thoroughly
- Yes, somewhat
- No
- I did not have any diagnostic tests or procedures

(B13)
After you received your cancer diagnosis, did someone put you in touch with any health care providers or organizations to help you cope with your fears and anxieties?

- Yes, with a support group or community-based organization
- Yes, with a pivot nurse in oncology
- Yes, with a psychologist
- Yes, with a social worker
- Yes, other, please specify:
- No, I was not put in touch with any health care providers or organizations
- No, I did not need any

(B16)
Were the various stages of your treatments explained to you?

- Yes, thoroughly
- Yes, somewhat
- No

(B15)
Were you involved in the treatment decision-making as much as you would have wanted?

- Yes, thoroughly
- Yes, somewhat
- No

(C6)
Did your health care providers talk to you about the risks and possible side effects of your first surgical operation?

- Yes, thoroughly
- Yes, somewhat
- No

(C16)
Did your health care providers talk to you about the possible side effects of your chemotherapy treatments?

- Yes, thoroughly
- Yes, somewhat
- No
- I did not need any explanations

(C22)
Did you health care providers talk to you about the possible side effects of your radiation therapy treatments (or internal radiation therapy)?

- Yes, thoroughly
- Yes, somewhat
- No
- I did not need any explanations

(C38)
How often were you given confusing or contradictory information about the state of your health or your treatments?

- Never
- Sometimes
- Usually
- Always

(B17)
Did the health care providers involve your family or friends in decisions about your treatment?

- Yes
- No, I did not want my family or friends to be involved
- No, but I would have liked that the health care providers involved my family and friends (sic)
- No, there was no need to involve them
- I had no family or friends who were able or willing to be involved

(B18)
Did the health care providers take your family or living situation into account in planning for your treatments?

- Yes, thoroughly
- Yes, somewhat
- No
- No, they do (sic) not have to take into account my family or living situation

(B20)
Did you feel comfortable talking about complementary, non-traditional or alternative therapies (for example, massage, acupuncture, homeopathy) with your health care providers?

- Yes, thoroughly (sic)
- Yes, somewhat
- No, I did not feel comfortable to talk (sic) about it (sic)
- No, I did not feel the need to talk about it
- No, I did not use complementary, non-traditional or alternative therapies

Items taken from the *Ambulatory Oncology Patient Satisfaction Survey, (Ontario, 2006)* used to make Table 3, French version

(Q17)
Est-ce que la personne qui vous soignait vous a expliqué d'une manière facile à comprendre pourquoi vous deviez passer des examens?

- Oui, absolument
- Oui, plutôt
- Non
- N'a pas passé d'examen

(Q5)
Lorsque vous avez appris que vous étiez atteint (e) du cancer, est-ce que quelqu'un vous a aidée (e) à prendre contact avec d'autres personnes soignantes capables de vous aider avec vos inquiétudes ou vos craintes?

- Oui, absolument
- Oui, plutôt
- Non
- Je n'ai pas eu d'inquiétudes ni de craintes

(Q56)
Étiez-vous au courant quelle serait l'étape suivante concernant votre thérapie?

- Jamais
- Quelquefois
- La plupart du temps
- Toujours

(Q54)
Vous a-t-on donné (e) des renseignements qui portaient à confusion ou qui étaient contradictoires concernant votre état de santé ou vos traitements?

- Jamais
- Quelquefois
- La plupart du temps
- Toujours

(Q9)
Avez-vous été impliqué (e) dans les décisions à prendre concernant vos soins autant que vous l'auriez souhaité?

- Oui, absolument
- Oui, plutôt
- Non

(Q11)
Jusqu'à quel point les personnes qui vous ont soigné ont donné l'occasion à votre famille et amis de s'impliquer dans vos soins et traitements?

- Pas assez
- Juste assez
- Trop
- Ma famille ou mes amis n'ont pas participé

(Q10)
Lors de la planification de vos traitements, est-ce que les personnes qui vous ont soigné ont tenu compte de votre situation familiale ou de votre mode de vie?

- Oui, absolument
- Oui, plutôt
- Non

(Q48)
Vous êtes-vous senti (e) à l'aise de discuter des traitements complémentaires, alternatifs ou non traditionnels avec le personnel médical?

- Oui, absolument
- Oui, plutôt
- Non
- Je n'ai pas utilisé de traitements complémentaires

Items taken from the *Ambulatory Oncology Patient Satisfaction Survey, (Ontario, 2006)* used to make Table 3, English version

(Q17)
Did your care provider explain why you needed tests in a way you could understand?

- Yes, completely
- Yes, somewhat
- No
- Didn't have tests

(Q5)
When you were first told of your illness, did someone put you in touch with other care providers who could help you with anxieties and fears?

- Yes, completely
- Yes, somewhat
- No
- I had no anxieties or fears

(Q56)
How often did you know what the next step in your care would be?

- Never
- Sometimes
- Usually
- Always

(Q54)
How often were you given confusing or contradictory information about your health or treatment?

- Never
- Sometimes
- Usually
- Always

(Q9)
Were you involved in decisions about your care as much as you wanted?

- Yes, completely
- Yes, somewhat
- No

(Q11)
How much opportunity did your care providers give your family or friends to be involved in your care and treatment?

- Not enough
- Right amount
- Too much
- Family or friends were not involved

(Q10)
Did your care providers take your family or living situation into account in planning for your treatment?

- Yes, completely
- Yes, somewhat
- No

(Q48)
Did you feel comfortable talking with the staff about complementary, alternative, or non-traditional therapies?

- Yes, completely
- Yes, somewhat
- No
- I don't use complementary therapies

Items taken from *Enquête québécoise sur la qualité des services de lutte contre le cancer* (2008) used to make Table 4, French version

(C43a)
Durant la période de vos traitements, vous a-t-on fourni de l'information utile à propos des changements possibles concernant...

a) votre apparence physique?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

(C43b)
a) votre sexualité?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

(C43c)
a) vos émotions?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

(C43d)
a) votre relation de couple et votre vie de famille?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

(C43e)
a) vos besoins alimentaires?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

(C43f)
a) votre travail ou vos activités courantes?

- Oui, tout à fait
- Oui, en partie
- Non
- Je n'avais pas besoin d'information

Items taken from *Enquête québécoise sur la qualité des services de lutte contre le cancer* (2008) used to make Table 4, English version

(C43a)
During the course of your treatments, were you given helpful information about changes that might occur in...

a) your physical appearance?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

(C43b)
a) your sexual activity?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

(C43c)
a) your emotions?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

(C43d)
a) your relationship with your spouse or partner and your family life?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

(C43e)
a) your nutritional needs?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

(C43f)
a) your work or usual activity?

- Yes thoroughly
- Yes, somewhat
- No
- I did not need any information

Items taken from the *Ambulatory Oncology Patient Satisfaction Survey, (Ontario, 2006)* used to make Table 5, French version

(Q40)
Avez-vous reçu suffisamment d'information au sujet des changements possibles qui pourraient survenir au niveau de votre apparence physique?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

(Q41)
Avez-vous reçu suffisamment d'information au sujet des changements possibles au niveau de votre sexualité?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

(Q42)
Avez-vous reçu suffisamment d'information au sujet des changements possibles au niveau de votre émotivité?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

(Q44)
Avez-vous reçu suffisamment d'information concernant les changements possibles au niveau de votre relation de couple?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

(Q43)
Avez-vous reçu suffisamment d'information au sujet de vos besoins alimentaires?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

(Q45)
Avez-vous reçu suffisamment d'information au sujet des changements possibles qui pourraient survenir au niveau de votre travail ou de vos activités courantes?

- Oui, absolument
- Oui, plutôt
- Non
- Sans objet

Items taken from the *Ambulatory Oncology Patient Satisfaction Survey, (Ontario, 2006)* used to make Table 5, English version

(Q40)
Did you get enough information about possible changes in your physical appearance?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

(Q41)
Did you get enough information about possible changes in your sexual activity?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

(Q42)
Did you get enough information about possible changes in your emotions?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

(Q44)
Did you get enough information about possible changes in your relationship with your spouse or partner?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

(Q43)
Did you get enough information about your nutritional needs?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

(Q45)
Did you get enough information about possible changes in your work or usual activities?

- Yes, completely
- Yes, somewhat
- No
- Doesn't apply

APPENDIX 2

Table A2

Comparison between the target population of the *Enquête québécoise sur la qualité des services de lutte contre le cancer* (EQSLCC, 2008) and that of the joint study[1] according to sex, age group, educational level and cancer site, Québec, 2008

	EQSLCC Target population	Joint study Target population[1]
	%	
Sex		
Men	46.1	39.5
Women	53.9	60.5
Age group		
18-49 yrs.	18.9	21.5
50-59 yrs.	24.9	26.3
60-69 yrs.	29.8	29.0
70 yrs. of age and over	26.5	23.2
Educational Level		
No high school diploma	27.1	25.3
High school diploma	24.7	25.5
College/Cégep/Trade or Technical School diploma	27.6	28.2
University degree	20.6	20.9

Table A2 *(continued)*
Comparison between the target population of the *Enquête québécoise sur la qualité des services de lutte contre le cancer* (EQSLCC, 2008) and that of the joint study[1] according to sex, age group, educational level and cancer site, Québec, 2008

	EQSLCC Target population	Joint study Target population[1]
	%	
Cancer site (type of cancer)		
Colorectal, bowel	11.8	9.9
Cervical, uterine, ovarian	5.5	4.8
Prostate, testicular	15.9	14.4
Haematopoietic	8.0	13.3
Breast	26.5	37.9
Head, neck	6.3	5.3
Lung, bronchial tubes	5.7	5.8
Other	20.3	8.6
Population (n)	8,753	4,925

1. It should be noted that for the joint study, the Quebec patients who were treated only with surgery were excluded from the analyses so that the sub-sample derived from the *Enquête québécoise sur la qualité des services de lutte contre le cancer (2008)* could be brought closer to the sample of the Ambulatory *Oncology Patient Satisfaction Survey (Ontario, 2006)*. Therefore, the Québec results of the joint study can be inferred to people 18 years of age and over, who were residents of Québec, and had received at least one of two treatments targeted by the survey, namely radiation therapy or intravenous chemotherapy, between April 1, 2005 and March 31, 2006.

Source: Institut de la statistique du Québec, *Enquête québécoise sur la qualité des services de lutte contre le cancer*, 2008

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