



UBC CENTRE FOR
HEALTH SERVICES AND
POLICY RESEARCH

Patient Experiences with **Ambulatory Cancer Care** in British Columbia, 2005/06

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About CHSPR

The Centre for Health Services and Policy Research (CHSPR) is an independent research centre based at the University of British Columbia. CHSPR's mission is to advance scientific enquiry into issues of health in population groups, and ways in which health services can best be organized, funded and delivered. Our researchers carry out a diverse program of applied health services and population health research under this agenda. The Centre's work is:

- Independent
- Population based
- Policy relevant
- Interdisciplinary
- Privacy sensitive

CHSPR aims to contribute to the improvement of population health by ensuring our research is relevant to contemporary health policy concerns and by working closely with decision makers to actively translate research findings into policy options. Our researchers are active participants in many policy-making forums and provide advice and assistance to both government and non-government organizations in British Columbia (BC), Canada and abroad.

Funding and Support

CHSPR receives core funding from the BC Ministry of Health, and ongoing support from the University of British Columbia and the UBC College of Health Disciplines. This enables the Centre to focus on research that has a direct role in informing policy and health reform, and facilitates CHSPR's continuing development of the BC Linked Health Database.

Our researchers are also funded by competitive external grants from provincial, national and international funding agencies. They include the Canadian Health Services Research Foundation, the Canadian Institutes of Health Research, the Commonwealth Fund, Health Canada, the Michael Smith Foundation for Health Research, and WorkSafeBC.



Acknowledgements

Under the direction of the Deputy Minister of Health and Chief Executive Officers of the health authorities of British Columbia (BC), a Patient Satisfaction Steering Committee has undertaken to learn and share information about the experiences that BC residents have with health care they receive in the province. In late 2006, that Steering Committee engaged our team to: (a) assist them in portraying the results of their work in the area of ambulatory cancer care, and (b) conduct work in 2007 to glean additional insights from survey data collected under a contract with NRC+Picker (www.nrcpicker.com).

Between November 2005 and May 2006, more than 12,200 adults with cancer received health care services on an ambulatory or outpatient basis in BC.

Over 6,900 of these patients completed a survey in order to share information about their first-hand experiences with ambulatory cancer care. Their contributions made this report possible.

This project has benefited from the contributions of many other individuals. In particular, we would like to acknowledge the expert advice provided by Lena Cuthbertson, Co-Chair, BC Patient Satisfaction Steering Committee, and Sandra Broughton, Regional Administrator of the BC Cancer Agency, Centre for the Southern Interior. Each of our external reviewers also provided valuable insights and comments. Heidi Matkovich assisted with copy-editing and Chris Balma assisted with layout and design.



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This report relies solely on documents that contained the results of analyses conducted by researchers and analysts at NRC+Picker. Errors or omissions in this report may therefore reflect errors in the original analyses of data.

Executive Summary

British Columbians are increasingly learning more about the accessibility and quality of health care in their province. In 2003, a council comprised of the Deputy Minister of Health, other Ministry executives, and the Chief Executive Officers of the health authorities struck a steering committee to commission and oversee surveys of patients to obtain information for quality improvement initiatives. In 2006, the spotlight was directed toward understanding and reporting on the accessibility and quality of cancer care through the eyes of patients. Between November 2005 and May 2006, more than 12,200 adults received ambulatory cancer care for intravenous chemotherapy and/or radiation services in British Columbia (BC). Over 6,900 of these patients completed a survey—the Ambulatory Oncology Patient Satisfaction Survey, which was developed and validated in Canada—in order to share information about their first-hand experiences with ambulatory cancer care.

A cancer diagnosis marks the beginning of a complex partnership between health care providers, patients and their families. Patients require ongoing assessment, treatment, care and support. Thus, they often begin a regime of intensive health services and may have a lot to say about the accessibility and quality of cancer care. When asked about the overall quality of the ambulatory cancer care they received in the preceding six months, 97% of patients rated the quality of services as excellent, very good or good. When responses to more detailed questions regarding specific aspects of quality are tallied, patients see more room for improvement. At this level, they give relatively higher ratings to access to care, physical comfort and

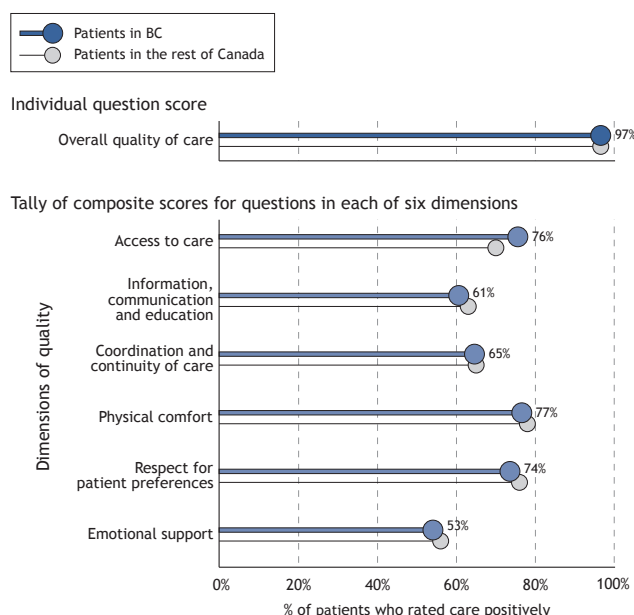
respect for patient preferences. Access to care is the one dimension of quality in which BC outperformed the Canadian average of other jurisdictions that have implemented the same survey.

After patients knew what their treatment was going to be, 78% feel that they did not wait too long to get their first appointment for treatment. After arriving at scheduled appointments, 69% of patients waited less than 30 minutes for chemotherapy and 74% of patients waited less than 15 minutes for radiation therapy treatments. When asked how often this wait time exceeded expectations, approximately 60% reported “never” and an additional 35% reported “sometimes”. The majority of patients who had to wait for treatment indicate that staff did everything they could to make them feel comfortable (80%). Most also report that they received all of the services they thought they needed (81%).

Patients report that care providers had respect for their preferences, treated them with dignity and respect, and offered opportunities for family and friends to be involved in their care and treatment. The majority of patients feel they could trust their care provider with confidential information (88%). Care providers also offered support to address their physical comfort needs. Many patients report that care providers did everything they could to address the side effects of cancer treatment but could do more to control their pain or comfort. Five per cent of patients report that they believe that they or their families suffered personal injury or harm resulting from a medical error or mistake.



Patients in BC rate overall quality of care highly, but give mixed ratings when asked about more specific dimensions of quality



Patients in BC and elsewhere in Canada also give relatively lower quality ratings to coordination and continuity of care, to information, communication and education, and to emotional support. Most patients in BC report that they knew who was in charge of their therapies (83%) and that care providers knew enough about therapies to treat cancer (79%). But just over half report that they always knew what the next steps in their care would be (53%) or who to ask when they had questions about health problems (57%). Half of patients report that their care providers were not always familiar with their medical history.

Many patients report they were given enough information about cancer therapies (66%), felt comfortable talking with providers about new cancer treatments (73%), and understood why tests were needed (79%), and their results (69%). But half report that they didn't receive enough information about what to expect regarding possible changes in their energy levels, nutritional needs and work or usual activities. Only half report that someone fully discussed different treatments with them.

Patients see the area of emotional support as having the most room for improvement. Sixty-nine per cent report being told of their diagnosis in a sensitive matter, but few were put in touch with other care providers who could help with anxieties and fears when they were first told of their illness (35%) or thereafter (24%). Few patients report that they were given enough information about possible changes in their emotions (34%) or their relationship with a spouse or partner (28%).

The experiences of patients who receive cancer care matter—to themselves, their families and friends, and to those who work in health care. They also matter to other British Columbians, who look to first-hand accounts to learn and pass judgement about the performance of their health care system. This report provides a snapshot of what patients with cancer have to say about the accessibility and quality of ambulatory cancer care. We hope that this work will inform and stimulate improvements to patient-centred care in BC.

Introduction

Canadians care passionately about their health care system—two-thirds of adults identify health care as the sector they want their leaders to give the greatest attention to.¹ Over time, Canadians have become increasingly concerned about lack of timely access to needed services and the quality of health care.² Many people want greater transparency and information regarding the performance of their health system and the results of initiatives to improve the situation.³ These views have not gone unnoticed—health care policy makers, managers and providers have made commitments to health care system renewal and are taking action to improve access, quality and accountability.

British Columbians are increasingly learning more about the accessibility and quality of health care in their province from first-hand accounts. In 2003, a council comprised of the Deputy Minister of Health, other Ministry executives and the Chief Executive Officers of the health authorities struck a steering committee to commission and oversee surveys of patients who receive health care in all emergency rooms, acute care hospitals and long-term care facilities. In 2006, the spotlight was directed toward understanding and reporting on access to and quality of ambulatory cancer care through the eyes of patients. Ambulatory care includes services provided to people who do not stay overnight in a health care facility.

Quality of health care is a multi-faceted concept and measurement of it requires assessment from many different perspectives. Patient-centred care has been identified as one of six^{*} domains of quality and it focuses on “the patient’s experiences of illness and health care and on the systems that work or fail to work to meet individual patients’ needs.”⁴ Upon

receiving a cancer diagnosis, patients often begin a regime of intensive health services and may have a lot to say about the accessibility and quality of care. Patient experiences, therefore, provide an essential perspective from which we can assess information that is critical to further stimulate, inform and target initiatives to improve cancer care in BC.

The purpose of this report is to compile a snapshot of what patients with cancer have to say about the accessibility and quality of ambulatory cancer care in BC.

Between November 15, 2005 and May 15, 2006, over 12,200 adults received intravenous chemotherapy and/or radiation services at 50 cancer care facilities across the province ([Appendix 1](#) lists these facilities). All of these patients were mailed the Ambulatory Oncology Patient Satisfaction Survey (AOPSS)—a standard patient survey that has been used internationally and elsewhere in Canada⁵—which 6,974 individuals (60%) elected to complete ([Appendix 2](#) describes this survey in more detail). The results presented in this report summarize the experiences of these patients. In some instances, experiences of British Columbians are compared to patients in other Canadian jurisdictions who completed the same survey.^{**}

* The other five domains of quality include: safe, effective, timely, efficient and equitable.

** The AOPSS has been used to assess ambulatory cancer care in Alberta, Manitoba, Nova Scotia, Ontario, and Saskatchewan (n=26,616).



We focus on features of health care deemed important to patients—respect for their values, preferences and expressed needs; coordination and continuity of care; information, communication and education; physical comfort; emotional support, including relief of fear and anxiety; and involvement of family and friends.⁶ We report on composite scores for six survey categories (or dimensions), and results for individual questions within each category. We also pay attention to other facets of quality that have been identified as a priority by those that work in health care in BC—access to care and safety (i.e., medical error or mistake).

The former features are included in the AOPSS, while the latter facets of quality were included in the survey as additional questions asked of residents in BC.

This report does not rely on analyses of survey data conducted by the UBC Centre for Health Services and Policy Research. We relied solely on documents that contained the results of data analyses undertaken by researchers and analysts at NRC+Picker (www.nrcpicker.com), who conducted the survey.



What did we learn?

Cancer Diagnoses and Health Status

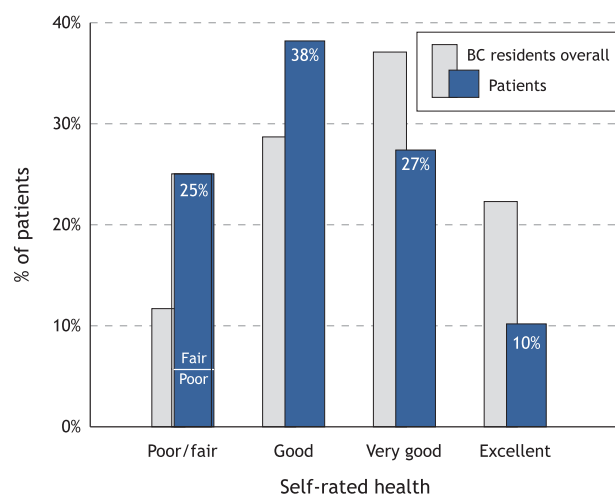
Patients report being first told of their cancer diagnosis by a family physician (39%), surgeon (33%), cancer specialist (20%) or someone else. Sixty-nine per cent report being told about their diagnosis in a sensitive manner, but of those who had anxieties or fears, 65% report that their health care provider “did not put them in touch” or “only somewhat put them in touch” with other care providers who could help with any anxieties or fears.

Forty-two per cent of patients were first told about their diagnosis between six and 12 months prior to completing the survey. Others were told within the past six months (12%) or one or more years ago. Many report that their treatment was for a first-time cancer diagnosis (70%). The most common diagnoses were breast (33%), prostate/testicular (15%), colorectal/bowel (11%) and lung (8%).

When asked to rate their general health, patients report it to be excellent (10%), very good (27%), good (38%), fair (19%) or poor (6%). The general health reported by patients is lower than that reported by the adult population in BC. Patients are less likely to rate their health as excellent or very good and more likely to rate it as good, fair or poor relative to other BC residents (Figure 1).

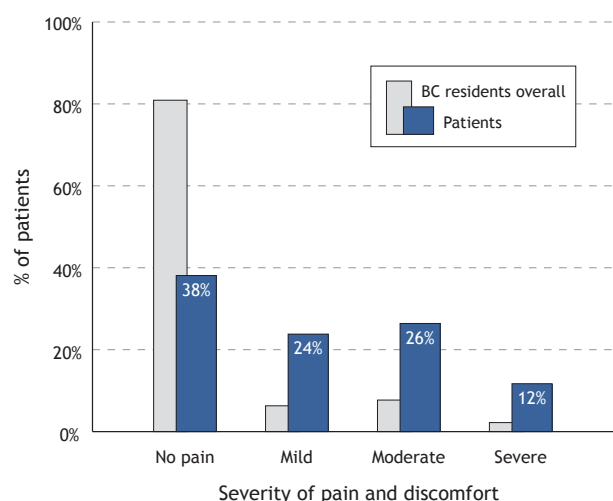
Over the six-month period prior to completing the survey, 62% of patients experienced pain and rated it to be severe (12%), moderate (26%) or mild (24%). Thirty-eight per cent report that they did not have pain in the past six months. These levels of pain are markedly higher than those reported by the general population of adults in BC (Figure 2).

Figure 1» Patients in BC report poorer health than BC residents overall



AOPSS respondents were asked “In general, how would you rate your health?” Comparison data is for population aged 12+. Sources: Statistics Canada. Canadian Community Health Survey (Cycle 3.1), 2005. CANSIM table 105-0422. Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Figure 2» Patients in BC report more pain than BC residents overall



AOPSS respondents were asked “In the past 6 months, if you had pain, was it usually severe, moderate, or mild?” Comparison data is for the population aged 12+ who answered “yes” or “no” when asked if they were usually free of pain or discomfort. Severity of pain is measured as severe, moderate or mild. Sources: Statistics Canada. Canadian Community Health Survey (Cycle 3.1), 2005. CANSIM table 105-0422. Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.



Use of Health Services

When asked which health care provider was “involved most” in their treatment planning, patients were most likely to report cancer specialists (81%), surgeons (11%) and family doctors (6%). When asked about the number of different doctors they visited for cancer treatment in the past six months, patients report having seen one (27%), two (32%), three (22%) or four or more (19%). These patterns of use of physician and specialist services are similar to Canadians in other provinces who receive ambulatory cancer care.

Sixty-one per cent of patients received chemotherapy at a hospital setting within BC’s Community Oncology Network. Forty-nine per cent of patients received radiation therapy. Sixty per cent had surgery after their cancer diagnosis. Eighty-seven per cent of patients report being given information before they were first seen in a cancer program, such as an orientation to the program, who to see or what to bring. Approximately one-third had stayed at a hospital overnight—one night (19%), two nights (6%) or more than two nights (9%).



Overall Impressions and Experiences

Patients give high ratings to overall quality

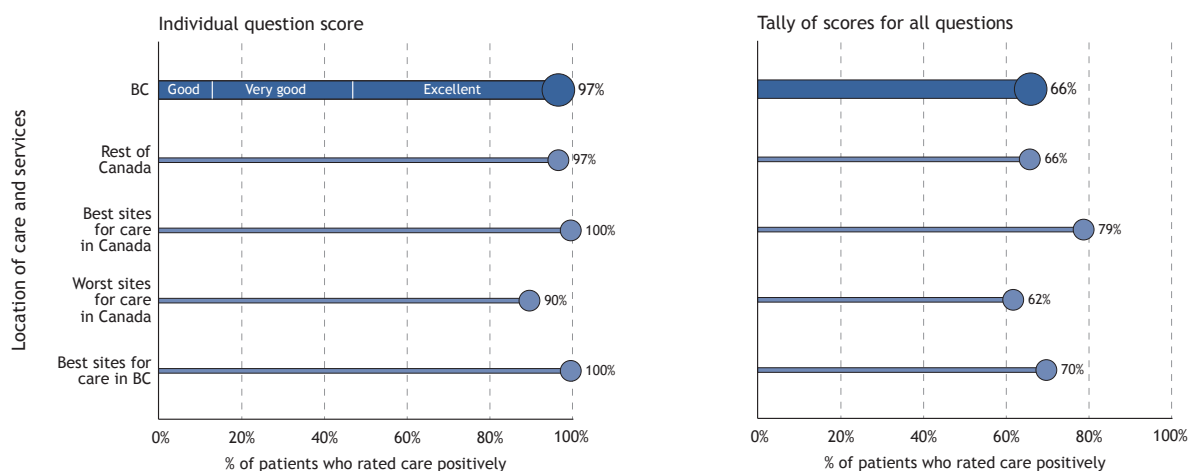
When asked to think about the ambulatory cancer care they received in the preceding six months in BC, 97% of patients rate the quality of their care and services as excellent (50%), very good (34%) or good (13%). This level of overall satisfaction with quality of care and services is similar to Canadians who received ambulatory cancer care in other provinces. Patients give ratings ranging from 90% to 100% to different sites across BC and Canada (Figure 3).

If patients give high ratings to overall quality, would patients recommend their health care providers to family and friends? Eighty-five per cent answered “yes, completely” when asked this question and an additional 13% answered “yes, somewhat”. This provides confirmation of high ratings of overall impressions.

When responses to separate, more detailed sets of questions regarding the quality of ambulatory cancer care in BC are tallied, 66% of responses were positive. Performance on this metric of overall impressions among patients in BC is similar to that reported by Canadians who received ambulatory cancer care in other provinces (Figure 3).

Aspects of ambulatory cancer care in which providers are doing well relate to wait times for scheduled appointments, treating patients with dignity and respect, giving family and friends opportunities to be involved in care and treatment, and making patients feel comfortable sharing confidential information. Table 1 lists the top five areas in which close to 90% or more of patients offer positive ratings. Respondents offer positive ratings of approximately 80% to the next five areas when survey questions are rank ordered on the basis of positive ratings.

Figure 3» Patients in BC generally rate the quality of care and services very highly...



... but a tally of ratings on individual questions shows patients rate quality less highly when asked more specific questions.

AOPSS respondents were asked “Overall, how would you rate the quality of all of your care in the past 6 months?” as well as many more questions. The tally of ratings on individual questions is the percentage of total responses in the survey that were positive. Sites could be a geographic region, group of similar facilities or a single facility. Best and worst sites are those with the highest or lowest ratings. Comparisons should be made with caution as results are not adjusted for other factors (age and gender) that might account for differences between groups. Sources: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.


Table 1» Top five areas where health care providers are doing well, rank ordered

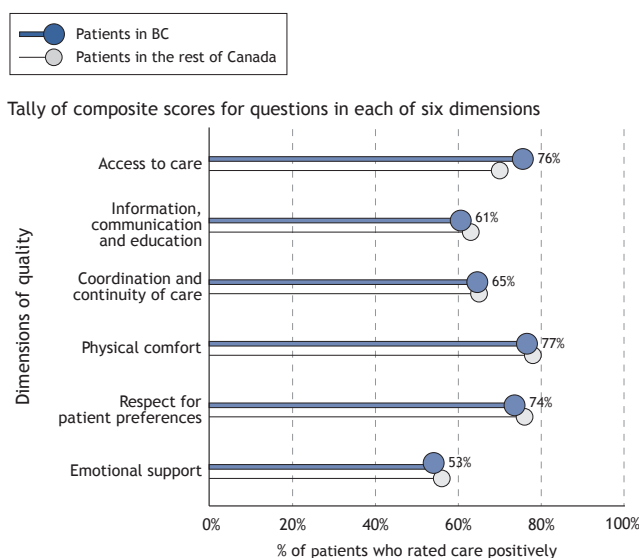
Ambulatory Oncology Patient Satisfaction Survey question		Patients who offer positive ratings
How long did you usually have to wait from your scheduled appointment until your radiation treatment?*	Access	95%
Did your care providers treat you with dignity and respect?**	Respect for patient preferences	92%
How much opportunity did your care provider give your family or friends to be involved in your care and treatment?†	Respect for patient preferences	92%
How long did you usually have to wait from your scheduled appointment until your chemotherapy treatment?‡	Access	90%
Did you feel you could trust your care providers with confidential information?***	Emotional support	88%

Notes: *Rating is the percentage who answered '15 minutes or less' or 'between 15 and 30 minutes'. Other possible answers were 'between 30 and 45 minutes', 'between 45 and 60 minutes', or 'more than 60 minutes'. **Rating is the percentage who answered 'yes, completely'. Other possible answers were 'yes, somewhat' or 'no'. †Rating is the percentage who answered 'right amount'. Other possible answers were 'not enough' or 'too much'. Individuals who answered 'family or friends were not involved' were not included in the calculation. ‡Rating is the percentage who answered 'less than 30 minutes' or 'between 30 minutes and 60 minutes'. Other possible answers were 'between 1 and 3 hours' and 'more than 3 hours'.

Patients give high ratings to some, but not all, dimensions of quality

Patients give different ratings to different dimensions of quality. They give the highest quality ratings to access to care, physical comfort and respect for patient preferences. But patients also see room for improvement—they give the lowest quality ratings to information, communication and education, coordination and continuity of care, and emotional support.

Patients see the area of emotional support as having the most room for improvement. These responses are similar to those reported by Canadians in other jurisdictions (Figure 4).

Figure 4» Patients in BC give mixed ratings to different dimensions of quality


Ratings reflect composite index scores for each dimension of quality. Sources: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Patients give high ratings to access to care

The accessibility of ambulatory cancer care includes issues related to the availability of services and wait time experiences, as well as the degree to which patients report that they received all the services they need. Patients in BC give relatively high ratings to access (composite score = 76% positive ratings)—higher ratings than reported by Canadians who received ambulatory cancer care in other provinces (Figures 4 and 5). Indeed, this is the one area in which BC outperforms the Canadian average of other jurisdictions that have implemented the same survey.

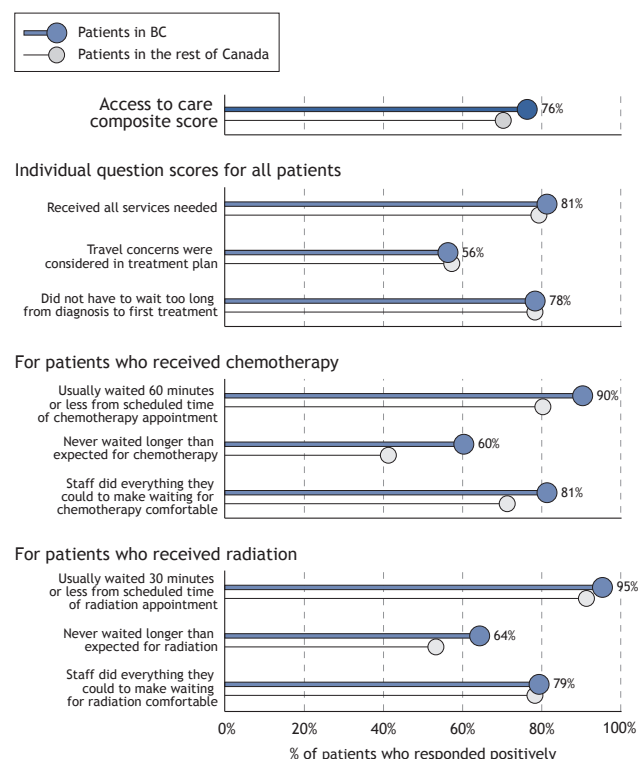
In the last six months, for adults who received ambulatory cancer care and “needed medical advice or help right away”, the following approaches to access were deemed by patients to be “most helpful”:

- Call to the cancer centre/hospital (22%)
- Visit with family doctor (20%)
- Emergency department (14%)
- Call to family doctor (10%) or other

An additional 26% of patients report not needing medical advice or help right away. Patients from BC were slightly less likely to call a cancer centre/hospital and slightly more likely to visit/call family doctors than Canadians who received ambulatory cancer care in other provinces. Importantly, the majority of patients report that they received all of the services they thought they needed over the past six months (81%).

After patients knew what their treatment was going to be, many feel that they did not wait too long to get their first appointment for treatment (78%). If a wait was experienced, half of patients were given a complete explanation (51%) and an additional 23% were given “somewhat” of an explanation (Figure 7). Many of those who underwent surgery report being given enough information about how long they would have to wait until the day of surgery (76%). Lastly, over half of all patients report that health care providers took their travel concerns into consideration when planning their treatment (56%) (Figure 5).

Figure 5» Patients in BC give high ratings to access to care



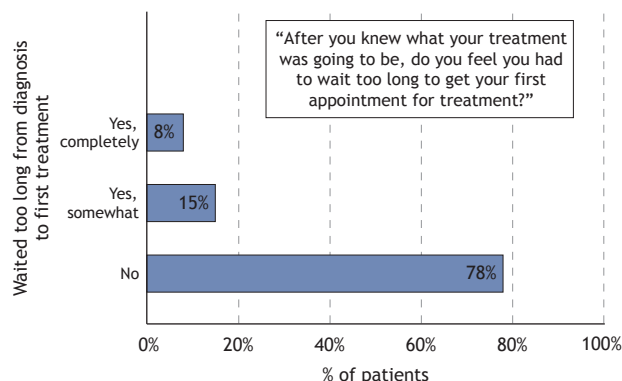
Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Patients who received chemotherapy or radiation therapy were asked how long they usually had to wait for scheduled appointments. Many patients waited less than 30 minutes for chemotherapy (69%) or less than 15 minutes for radiation (74%) (Figure 7). When patients were asked how often their wait time exceeded expectations, approximately 60% reported “never” and an additional 35% reported “sometimes” (Figure 8). The vast majority of patients who had to wait report that “staff did everything they could to make [them] feel comfortable” during their wait (Figure 9).

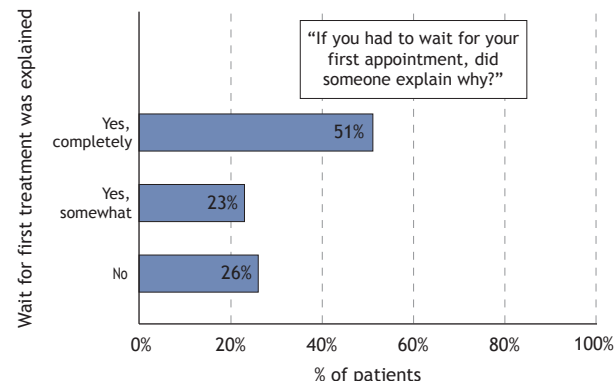


Figure 6» Most patients in BC did not wait too long from diagnosis to first treatment, and when they did wait, an explanation was usually offered

Individual question score for all patients



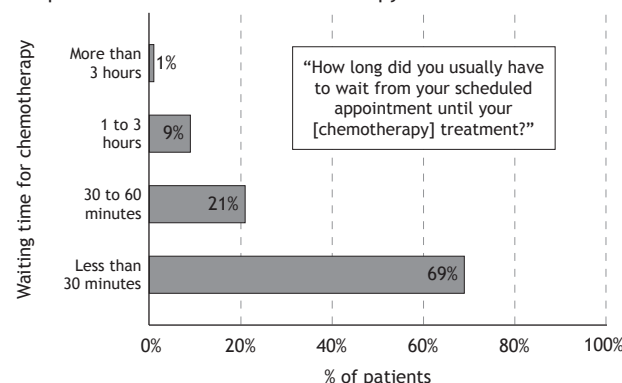
Individual question score for all patients



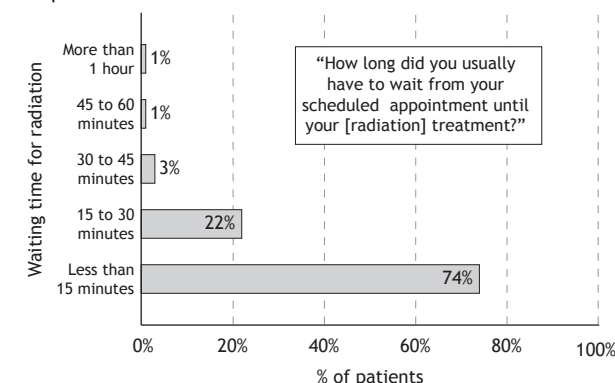
Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Figure 7» Most patients in BC did not wait long from the time of their scheduled appointment until their treatment

For patients who received chemotherapy



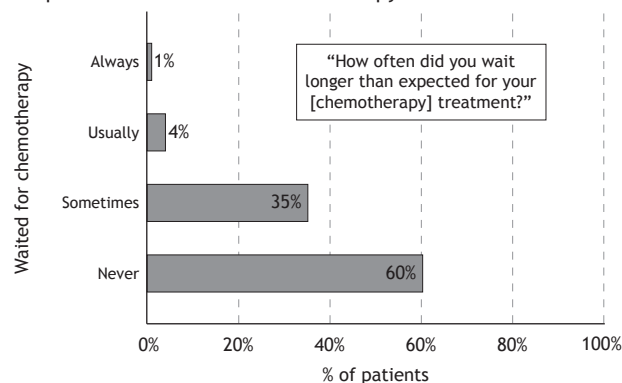
For patients who received radiation



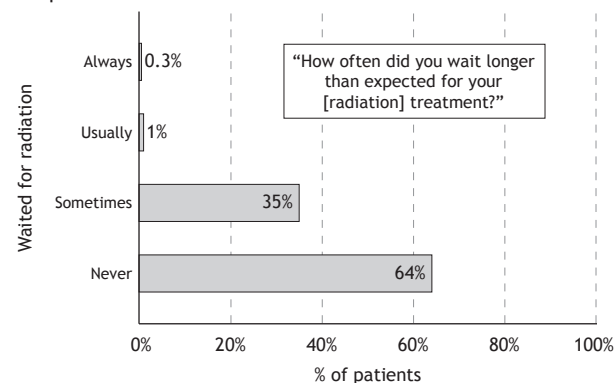
Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Figure 8» Most patients in BC did not usually wait much longer than expected from the time of their scheduled appointment until their treatment

For patients who received chemotherapy

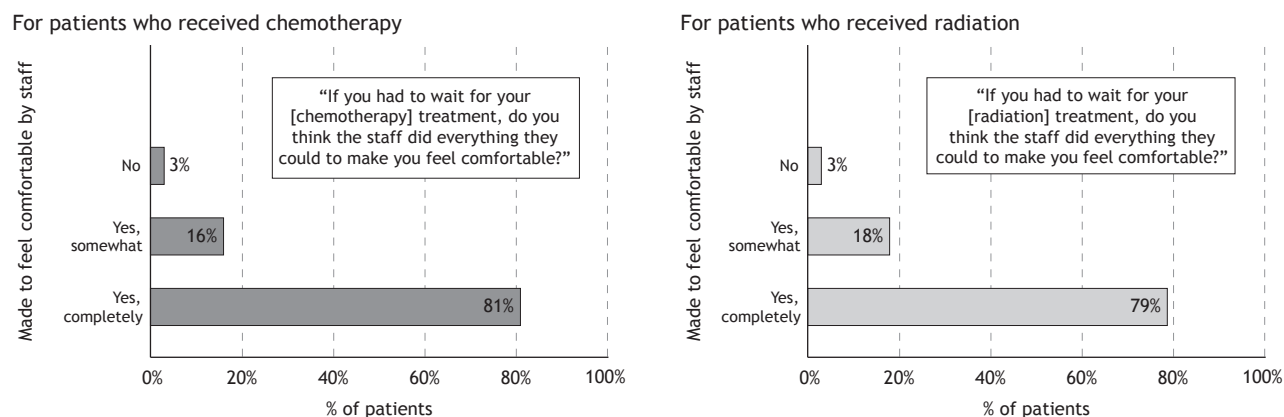


For patients who received radiation



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Figure 9» Most patients in BC report staff made them comfortable during their wait



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

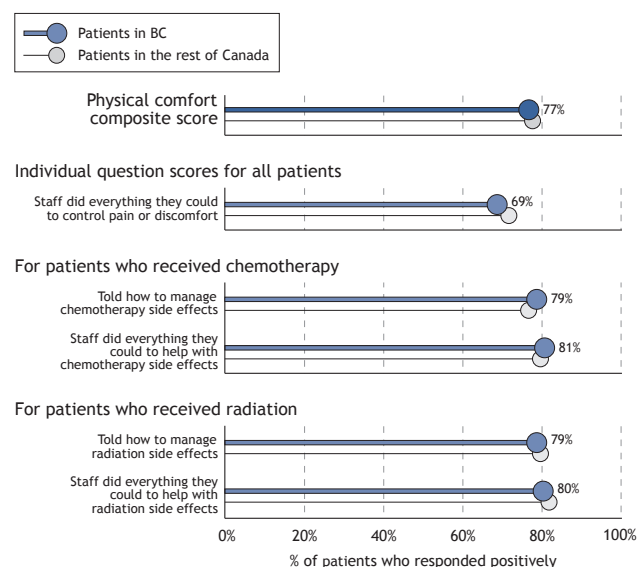
Patients report that health care providers offer physical support but that more could be done to control their pain or discomfort

Another dimension of quality relates to the degree to which health care providers offer support to address patient needs relative to physical comfort. Patients in BC give relatively high ratings to this dimension (composite score = 77% positive ratings)—ratings similar to those reported by Canadians who received ambulatory cancer care in other provinces (Figure 10).

The majority of patients report that health care providers did everything they could to help them with the side effects of chemotherapy (81%) or radiation therapy (80%) and told them how to manage any side effects of chemotherapy (79%) or radiation therapy (79%).

Of the 62% of patients who report they experienced severe (12%), moderate (26%) or mild (24%) pain in the preceding six months, 69% report that staff did everything they could to control their pain or discomfort. However, it is important to note that three in 10 patients who experienced pain do not have this view.

Figure 10» Patients report that care providers offer support relative to physical comfort



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.



Patients report that health care providers have respect for their preferences

Another dimension of quality relates to the degree to which patients report that health care providers have respect for their preferences. Patients in BC give relatively high ratings to these issues (composite score = 74% positive ratings)—ratings similar to those reported by Canadians who received ambulatory cancer care in other provinces (Figure 11).

Most patients report that health care providers treated them with dignity and respect (92%) and involved their family and friends appropriately in their care and treatment (92%). Many were involved in decisions about their care as much as they wanted (73%).

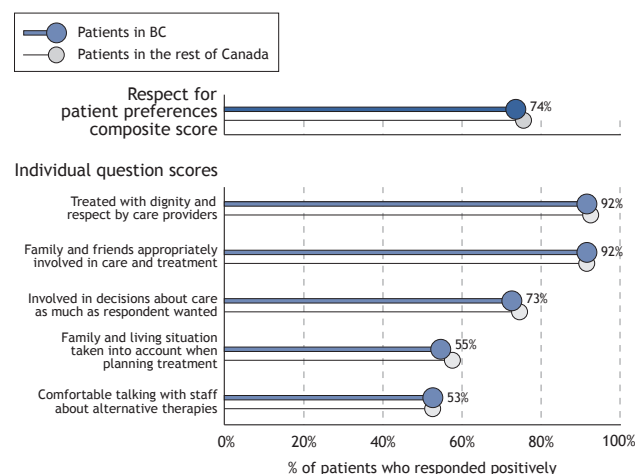
Approximately half of patients report that health care providers took their family and living situation into account in planning treatment (55%), or that they felt comfortable talking with health care providers about complementary, alternative or non-traditional treatment (53%).

Patients understand explanations offered by care providers but report that they don't receive enough information about what to expect

Another dimension of quality relates to the degree to which patients and providers communicate and share information. Patients in BC give relatively modest ratings to these issues (composite score = 61% positive ratings)—ratings similar to those reported by Canadians who received ambulatory cancer care in other provinces (Figure 12).

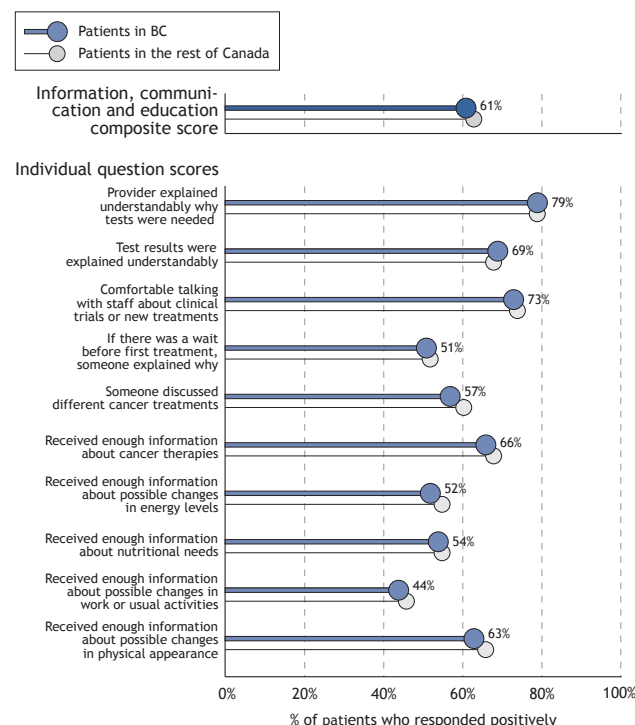
Many patients report that health care providers explained why tests were needed (79%) or explained test results in an understandable manner (69%). Among those who had surgery, many report that the results of this intervention were explained in an understandable manner (78%). Many were comfortable talking with their health care provider about new or experimental cancer treatments (73%).

Figure 11» Patients report that health care providers respect their preferences



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Figure 12» Patients offer relatively modest ratings to communication and report they don't receive enough information



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

Over half of patients report that someone fully discussed different treatments for cancer with them (57%) and more felt they were given enough information about different treatments for cancer (66%). Only half report that they got enough information about possible changes in their energy levels (52%) or about their nutritional needs (54%). A minority report that they got enough information about possible changes in their work or usual activities (44%).

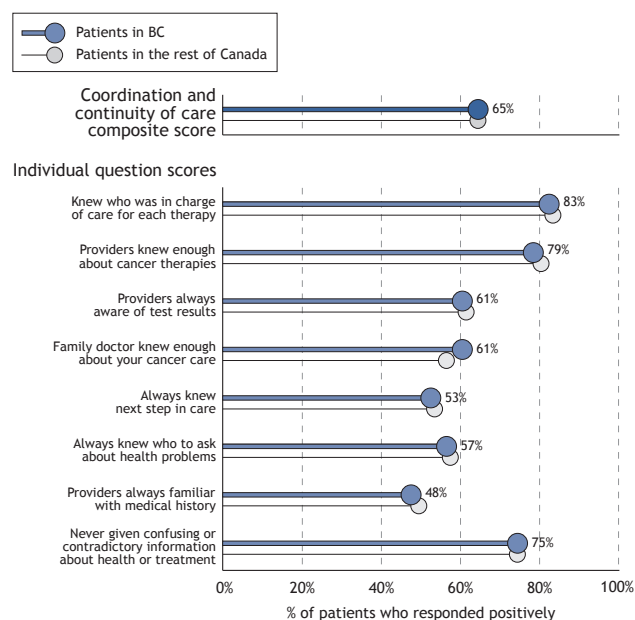
Patients know who is in charge of their therapies but report that their care could be better coordinated

Another dimension of quality relates to the degree to which health care is coordinated and patients experience continuity in their care. Patients in BC give relatively modest ratings to these aspects of their care (composite score = 65% positive ratings)—ratings similar to those reported by Canadians who received ambulatory cancer care in other provinces (Figure 13).

The majority of patients knew who was in charge of care for each of their therapies (83%) and report that care providers knew enough about therapies for treating cancer (79%). Sixty-one per cent report that health care providers were always aware of their test results. Among those who had a visit with their family doctor in the preceding six months, 61% thought that this doctor knew enough about their cancer care.

Patients see the area of coordination of their care as having room for improvement. Approximately half of patients always knew what the next steps in their care would be (53%), or who to ask when they had questions about their health problems (57%). Less than half report that their care providers were always aware of their medical history (48%). One-quarter were given conflicting or contradictory information about their health or treatment (Figure 13: 75% were never given conflicting or contradictory information).

Figure 13» Patients give modest ratings to coordination and continuity



Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

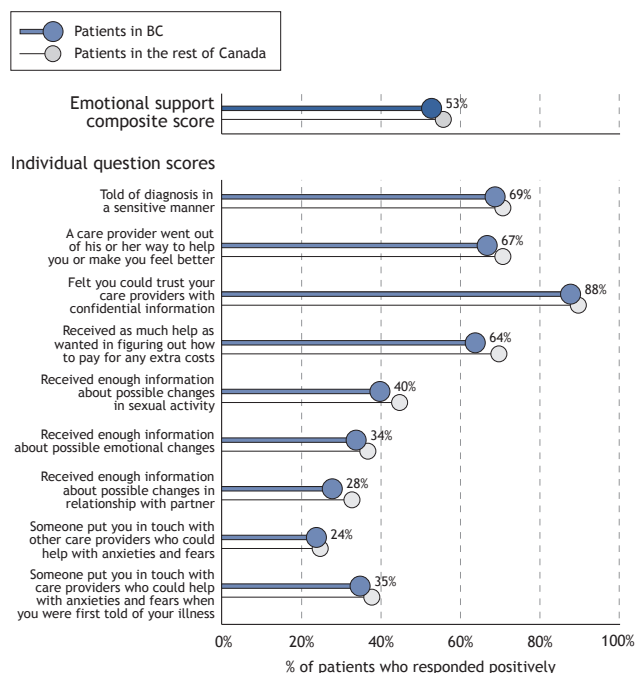
Patients see the area of emotional support as having the most room for improvement

An important dimension of quality, particularly from the patient perspective, relates to how well health care providers offer support to address patient needs relative to emotional well-being. Patients in BC give relatively low ratings to this dimension (composite score = 53% positive ratings); ratings similar to those reported by Canadians who received ambulatory cancer care in other provinces (Figure 14).

Many patients report being told of their diagnosis in a sensitive manner (69%), and that a care provider went out of their way to help them feel better (67%). Furthermore, patients report that they usually or always got as much help as they wanted in figuring out how to pay the extra costs for cancer care (64%).



Figure 14» Patients give relatively low ratings to emotional support

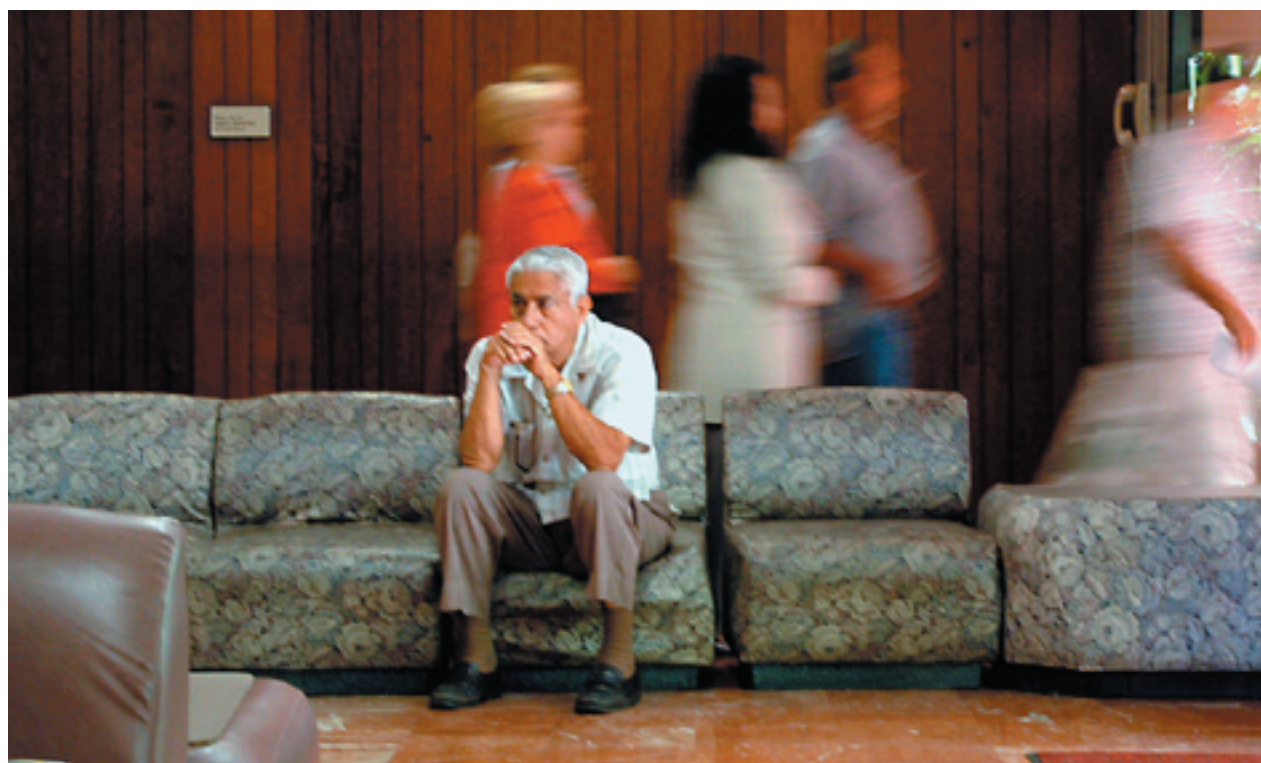


Source: Ambulatory Oncology Patient Satisfaction Survey data collection and statistical analyses by NRC+Picker, 2006.

A minority of patients report being given enough information about possible changes in sexual activity (40%) or their emotions (34%). Few were given enough information about possible changes in their relationship with a spouse or partner (28% were given enough information). Importantly, few were put in touch with other care providers who could help with anxieties and fears (24% were put in touch) and few were put in touch for these reasons when first told of their illness (35% were put in touch).

Patients in BC report few medical errors or mistakes

During the course of their cancer care, 5% of patients report that they believe that they or their family suffered personal injury or harm resulting from a medical error or mistake. A preliminary analysis by NRC+Picker indicates that these safety issues are not concentrated in a single health authority, facility type or facility. A further 86% of patients indicated they had not suffered personal injury or harm, and 9% indicated they did not know if they had suffered personal injury or harm.



What do patient experiences tell us about quality improvement priorities?

Patients offer insights into areas for improvement when asked specific questions about their experiences. When a tally is done to identify specific issues related to accessibility and quality of ambulatory cancer care, patient experiences can highlight priorities for quality improvement.

Patients give the lowest ratings to emotional support, information, communication and education, and coordination and continuity of care. [Table 2](#) lists the top ten areas in which the lowest proportion of patients offered high ratings.

Table 2» Top ten areas for quality improvement, rank ordered

Ambulatory Oncology Patient Satisfaction Survey question		Patients who offer positive ratings
In the past six months, has someone at [name of health care facility] put you in touch with other care providers who could help you with anxieties and fears?	Emotional support	24%
Did you get enough information about possible changes in your relationship with your spouse or partner?	Emotional support	28%
Did you get enough information about possible changes in your emotions?	Emotional support	34%
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?	Emotional support	35%
Did you get enough information about possible changes in your sexual activity?	Emotional support	40%
Did you get enough information about possible changes in your work or usual activities?	Information, communication and education	44%
How often were your care providers familiar with your medical history?*	Coordination and continuity	48%
If you had to wait for your first appointment, did someone explain why?†	Information, communication and education	51%
Did you get enough information about possible changes in your energy levels?	Information, communication and education	52%
How often did you know what the next step in your care would be?*	Coordination and continuity	53%

Notes: *Except where noted, rating is the percentage who answered 'yes, completely'. Other possible answers were 'yes, somewhat' or 'no'. Individuals who answered 'doesn't apply' were not included in the calculation. **Rating is the percentage who answered 'always'. Other possible answers were 'usually', 'sometimes' and 'never'. †Rating is the percentage who answered 'yes, completely'. Other possible answers were 'yes, somewhat' or 'no'.



Conclusion

British Columbians and those responsible for delivering their health care are increasingly learning more about the accessibility and quality of care from first-hand accounts. In 2006, the spotlight was directed toward understanding and reporting on access and quality of ambulatory cancer care through the eyes of patients.

Research consistently demonstrates that when Canadians rate their experiences with health care they are overwhelmingly positive, but have suggestions for improvements. The same is true for ambulatory cancer care. When asked about the overall quality of the ambulatory cancer care they received in the preceding six months, 97% of patients rated the quality of services as excellent, very good or good.

But when probed, patients have a lot to say about both the areas where health care and treatment are strong, and the areas requiring improvement.

Respondents in this survey gave relatively higher quality ratings to access to care, physical comfort and respect for patient preferences. They gave relatively lower quality ratings to information, communication and education, coordination and continuity of care and emotional support. Patients see the area of emotional support as having the most room for improvement.

This purpose of this report is to compile a snapshot of what patients with cancer have to say about the accessibility and quality of ambulatory cancer care in BC. This work will provide more information to further stimulate, inform and target initiatives to improve cancer care in BC.



Appendix 1: Participating Cancer Care Facilities

Provincial Health Services Authority

British Columbia Cancer Agency Fraser
Valley Cancer Centre
British Columbia Cancer Agency Centre
for the Southern Interior
British Columbia Cancer Agency Vancouver Centre
British Columbia Cancer Agency
Vancouver Island Centre

Interior Health Authority

East Kootenay Regional Hospital
Arrow Lakes Hospital
Castlegar and District Community Health Centre
Kootenay Boundary Regional Hospital
Boundary Hospital
Slocan Community Health Centre
Victorian Community Health Centre
Nicola Valley General Hospital
Queen Victoria Hospital
Kootenay Lake Regional Hospital
Penticton Regional Hospital
Royal Inland Hospital
Shuswap Lake General Hospital
Vernon Hospital
100 Mile House District General Hospital
Cariboo Memorial Hospital

Fraser Health Authority

Burnaby Hospital
Chilliwack General Hospital
Ridge Meadows Hospital
Royal Columbian Hospital
Delta Hospital
Langley Memorial Hospital
Mission Memorial Hospital
Matsqui-Sumas-Abbotsford General Hospital

Vancouver Coastal Health Authority

Lions Gate Hospital
Powell River General Hospital
The Richmond Hospital
Squamish General Hospital
St Mary's Hospital
St Paul's Hospital
Vancouver General Hospital

Vancouver Island Health Authority

Campbell River and District Hospital
Cowichan District Hospital
Nanaimo Regional General Hospital
St Joseph's General Hospital
West Coast General Hospital
Royal Jubilee Hospital

Northern Health Authority

Prince George Regional Hospital
Fort Nelson General Hospital
Bulkley Valley District Hospital
Dawson Creek and District Hospital
Fort St John Hospital and Health Centre
Mills Memorial Hospital
Prince Rupert Regional Hospital
GR Baker Memorial Hospital
Kitimat Hospital



Appendix 2: How Was the Survey Done?

In 2005, a council comprised of British Columbia's Deputy Minister of Health, other Ministry executives and the Chief Executive Officers of the health authorities struck a Patient Satisfaction Steering Committee to commission and oversee surveys of patients who received ambulatory cancer care. The Committee engaged NRC+Picker to conduct the survey using a standardized instrument, the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). This survey—based on the Picker suite of surveys—was developed and validated in Canada.⁵ It has also been used in Alberta, Manitoba, Nova Scotia, Ontario and Saskatchewan (n=26,616).

The AOPSS was mailed to patients in BC who were 18 years or older, had a confirmed diagnosis of cancer, and who received chemotherapy or radiation treatment or follow-up on an ambulatory care basis at one of 50 designated health care facilities or centres between November 15, 2005 to May 15, 2006. Patients were excluded from the survey if they had no fixed address, had not received active treatment on an out-patient basis in the past six months, had received only inpatient services or oral chemotherapy treatment or were deceased.

BC Cancer Agency data were used to establish each patient's eligibility status and create a census of those who were mailed a survey (N=12,215). The survey contained items to verify each patient's eligibility status. Individuals who received care from more than

one facility were sent a survey for each facility. These individuals were asked to complete each survey, since cancer care facilities were given results for patients they served. The survey asked patients to answer questions in six dimensions of quality. Results represent the percentage of positive responses that patients gave to questions. Percentages were calculated by excluding non-respondents.

Surveys with accompanying cover letters and return envelopes were mailed to patients' home addresses between June and August 2006. The mailed survey was in English but Chinese, Punjabi and French versions were available by calling a 1-866 number. A reminder letter and survey were sent 24 days later to those who had not yet responded. Privacy officers for all health regions approved of this project and the Office of the Information and Privacy Commissioner was notified of this initiative.

The overall response rate to the survey was 60%; this varied from 56% to 67% across health authorities in the province (Table 3). The age and gender structure of respondents did not differ significantly from the population of adults who received ambulatory cancer care (Table 4). Among completed surveys, 83% were done by the patient, 11% by the patient with someone else's help and 6% by someone else.

Appendix 2: How Was the Survey Done? (Continued)

Table 3» Respondents and response rates by health authority, and overall

Health Authorities	People Surveyed	Completed Surveys	Survey Not Able to be Delivered	Response Rate
Fraser	931	482	75	56%
Interior	1,579	954	135	66%
Northern	563	303	47	59%
Provincial	6,855	3,937	193	59%
Vancouver Coastal	1,236	640	88	56%
Vancouver Island	1,051	658	70	67%
British Columbia	12,215	6,974	608	60%

Table 4» Age and gender structure of population of adults that received ambulatory cancer care and survey respondents

		Received a questionnaire						Responded					
		Health Authority						Health Authority					
		FHA	IHA	NHA	PHSA	VCHA	VIHA	FHA	IHA	NHA	PHSA	VCHA	VIHA
Age group (years)	18 - 51	15%	14%	18%	19%	17%	14%	12%	11%	16%	17%	16%	11%
	52 - 58	14%	13%	20%	16%	17%	14%	15%	14%	20%	15%	15%	14%
	59 - 63	13%	12%	13%	13%	13%	12%	11%	13%	14%	13%	13%	12%
	64 - 68	11%	14%	13%	12%	13%	12%	13%	14%	15%	13%	13%	13%
	69 - 73	14%	15%	13%	12%	12%	13%	14%	16%	16%	14%	14%	15%
	74 - 78	15%	14%	8%	13%	13%	16%	18%	15%	9%	14%	13%	19%
	79 +	18%	19%	14%	14%	15%	18%	18%	17%	11%	13%	16%	17%
		100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
Gender	Female	60%	60%	57%	56%	60%	58%	59%	62%	61%	57%	62%	59%
	Male	40%	40%	43%	44%	40%		41%	38%	39%	43%	38%	41%



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