MEASURING THE QUALITY OF PERSONAL CARE IN PROSTATE CANCER RADIOTHERAPY

by

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Abstract

Background: Quality of care includes both technical and non-technical elements of care (personal care). We previously developed a questionnaire to assess the quality of personal care in prostate cancer radiotherapy. The objectives of this thesis were: 1) to determine which elements of personal care were most important to patients; 2) to develop a method of integrating ratings of importance and ratings of quality to identify elements of care that should become targets for quality improvement; 3) to describe the quality of personal care and identify the elements of care that should be targeted for quality improvement.

Methods: We surveyed 108 patients undergoing radiotherapy for localized prostate cancer. Patients completed a self-administered questionnaire and rated both the importance and the quality of their care for each of the 143 elements. The importance and the quality of each element was measured by the percentage of respondents who rated it “very important” and “very good”, respectively. Different methods for identifying elements to target for quality improvement were developed and compared.

Results: The percentage of elements rated “very important” and “very good” varied from patient to patient. Aspects of care deemed important to most patients were: the perceived competence of their caregivers, the empathy and respectfulness of their caregivers, and the adequacy of information sharing. Patients assigned their lowest quality ratings to elements relating to the treatment environment and comprehensiveness of services, but they also rated these elements as relatively unimportant. We developed three methods of identifying priorities for quality improvement and found that incorporating importance ratings with quality ratings identified different priorities than quality ratings alone. One method was theoretically superior since the ratings for importance and quality were linked for each individual. Elements of care relating to communication of information about the disease and its treatment were identified as the highest priorities for improvement.

Conclusions: We have developed indicators for measuring the quality of personal care in prostate cancer radiotherapy. We have shown that it is possible to measure the quality of personal care in routine practice and we developed a method for identifying priorities for quality improvement.

Co-Authorship

The manuscripts presented in this thesis were written by Kimberley A Foley in collaboration with her supervisors, William J Mackillop, Patti A Groome, and additional co-authors. Financial support for this work was provided by the Canadian Institutes for Health Research (ADC 83510), Prostate Cancer Fight Foundation – Ride for Dad, and the Queen’s University Terry Fox Training Program in Transdisciplinary Cancer Research in Partnership with CIHR.

Chapter 3 – Manuscript 1: *What Aspects of Personal Care are Most Important to Patients Undergoing Radiation Therapy for Prostate Cancer?* This manuscript is presented in the format published in the International Journal of Radiation Oncology*Biology*Physics in 2016. (Full citation: Foley KA, Feldman-Stewart D, Groome PA, Brundage MD, McArdle S, Wallace D, Yingwei P, Mackillop WJ. What Aspects of Personal Care Are Most Important to Patients Undergoing Radiation Therapy for Prostate Cancer? Int J Radiat Oncol • Biol • Phys 2016;94:280–8.) (Supplemental materials are included in Appendix B and additional results not included in the original manuscript are presented in Appendix C.) Data collection was conducted by Kimberley Foley with assistance from David Wallace. Data analysis, interpretation of the results and writing of the manuscript was done by Kimberley Foley with supervision from Deb Feldman-Stewart, Patti Groome and William Mackillop with additional input from Michael Brundage, Siobhan McArdle, David Wallace and Yingwei Peng.

Chapter 4 – Manuscript 2: *Development and Comparison of Methods to Identify Priorities for Improvement of the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer* This manuscript is formatted for submission to the International Journal for Quality in Healthcare. (Supplemental materials are included in Appendix D.) Data collection was conducted by Kimberley Foley. Data analysis, interpretation of the results and writing of the manuscript was done by Kimberley

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Chapter 5 – Manuscript 3: *Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer*. This manuscript is presented in the format published in Clinical Oncology in 2017. (Full citation: Foley KA, et al, Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer, Clinical Oncology (2017), <https://doi.org/10.1016/j.clon.2017.09.004>) (Supplemental materials are included in Appendix E and additional results not included in the original manuscript are presented in Appendix F.) Data collection was conducted by Kimberley Foley. Data analysis, interpretation of the results and writing of the manuscript was done by Kimberley Foley with supervision from Patti Groome and William Mackillop with additional input from Deb Feldman-Stewart, Michael Brundage, Jonathan Foley, and Siobhan McArdle.

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List of Abbreviations

3D-CRT 3-Dimensional Conformal Radiotherapy

CCSEO Cancer Centre of Southeastern Ontario

CIHI Canadian Institute for Health Information

CSQI Cancer System Quality Index

DRE Digital rectal examination

GEE Generalized Estimating Equations

Gy Gray

IGRT Image-guided Radiotherapy

IMRT Intensity-modulated Radiotherapy

IQR Interquartile range

MCAR Missing completely at random

OECD Organization for Economic Cooperation and Development

PREM Patient Reported Experience Measure

PSA Prostate-Specific Antigen

RAND Research and Development Corporation

WHO World Health Organization

Chapter 1

Introduction

1.1 Background and rationale

Delivering a high quality of care to patients is a priority for any health care system. Quality of care is defined by the Institute of Medicine as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (1). Before care delivered to patients can be improved, the current quality of care must be evaluated, and areas in need of improvement identified. Assessment of quality of care is complex as quality consists of both technical and non-technical elements of care (2), the latter referred to as “personal care”. Comprehensive assessments of quality must include an assessment of both technical and personal care.

Our research group previously conducted a study to assess the quality of technical care in prostate cancer radiotherapy (3,4). The current study assessed the quality of personal care to complement our previous work and ensure a comprehensive assessment of quality. Although health care providers are the best judges of the quality of technical care, they are not the best judges of the quality of personal care (5). To attain a high quality of personal care, it is not sufficient to simply deliver the care to patients. It must be delivered in a manner that is consistent with patients’ values and wishes and they must perceive the care provided as acceptable and adequate. Therefore, the best judge of the quality of personal care is the patient (5,6).

Our literature search found no appropriate, comprehensive tools to assess the quality of personal care in the context of prostate cancer radiotherapy. We addressed this gap by designing our own questionnaire, which formed the basis of my MSc Thesis (7). The questionnaire consisted of 143 elements of care organized within the 10 aspects of personal care: ‘patient centeredness’, ‘empathy and respectfulness of caregivers’, ‘competence of caregivers’, ‘adequacy

of information sharing', 'accessibility of caregivers', 'continuity of care', 'comprehensiveness of care', 'acceptability of the treatment environment', 'privacy' and 'convenience'. The questionnaire was organized into three modules corresponding to specific time points in the patient care continuum.

In order to accurately describe quality of care from the patient's perspective we need to make sure we are collecting data on the aspects of care that are important to patients (8,9). Furthermore, to ensure the data collected is useful in quality improvement, we need to synthesize and present it in a way that allows us to identify clear priorities for quality improvement (10,11).

1.2 Overview of study design

We conducted a cross-sectional study at the Cancer Centre of Southeastern Ontario in Kingston, Canada to collect information on the quality of personal care in patients starting curative radiotherapy for prostate cancer between May 2011 and August 2014. Patients were provided with each module of the questionnaire at appropriate time points during their care. For each element of care, patients were asked "*How important is this to you*" and "*How good was your care in this regard*"? Ratings of importance were provided on a 4-point scale (not important, somewhat important, important, very important) and ratings of quality were provided on a 5-point scale (very poor, poor, okay, good, very good). Beginning in May 2012, patients were invited to participate in a test-retest study. Additional details about the patients' cancer and treatment were obtained by medical chart review.

1.3 Objectives

This PhD thesis addressed three main objectives:

- 1) To determine which elements of personal care were most important to patients undergoing radiotherapy for prostate cancer
- 2) To develop a method of integrating ratings of importance and ratings of quality to identify elements of care that should become targets for quality improvement
- 3) To describe the quality of personal care delivered to patients undergoing radiotherapy for prostate cancer in routine practice and to identify the elements of personal care that should be targeted for quality improvement

1.4 Thesis organization

This thesis is written as a manuscript-based thesis consisting of six chapters and six appendices. Chapter 2 contains a literature review including a definition of quality of care, frameworks for quality assessment, an overview of prostate cancer management, and an overview of previous work done in the area of assessing the quality of personal care. Three manuscripts follow the literature review. The first manuscript describes the aspects of care most important to patients undergoing radiotherapy for prostate cancer. As it was published in an American journal, the terminology used throughout this chapter is “radiation therapy” instead of radiotherapy as written elsewhere in the thesis. This manuscript addresses the first objective of this PhD thesis but also includes relevant background information from my Master’s thesis as it addressed the following objective from my MSc: To define the scope of personal care and create a comprehensive list of the elements of personal care that are pertinent to patients who undergo radiation therapy for prostate cancer. The second manuscript describes and compares different methods for identifying targets for quality improvement, addressing objective 2 of this PhD

thesis. This manuscript is formatted for submission to the International Journal for Quality in Healthcare. The third manuscript describes the quality of personal care delivered to patients undergoing radiotherapy for prostate cancer and identifies the elements of personal care that should be targeted for quality improvement, addressing objective 3. The third manuscript identifies the priorities for improvement using one of the methods described in manuscript two, but it should be noted that the name of the method changed between manuscript 2 and 3 (this change was in name only, the method itself remains the same). In manuscript 2, the method is referred to as “individual priority-based method” to be in line with the names of the other two methods, but in manuscript 3, for simplicity we call it “importance/quality analysis”. This third manuscript was published in Clinical Oncology and therefore uses British spelling. Chapter 6 provides a general discussion of the overall strengths and limitations of this work and provides an overview of the next steps. The appendices include the ethics approval, the e-supplements for each manuscript, and additional results not published in the original manuscripts or e-supplements.

Chapter 2

Literature Review

2.1 Burden of Cancer

Cancer is the second leading cause of death worldwide with 8.7 million deaths in 2015 (12). The incidence of cancer is increasing; between 2005 and 2015 the incidence of cancer increased by 33% mainly due to an aging population and an increasing population size. In 2015 there were 17.5 million incident cancer cases, with large differences in the odds of being diagnosed with cancer depending on the country of origin (12).

In Canada, cancer is the leading cause of both death and premature mortality. In 2017, it is estimated that 206 200 people will be diagnosed with cancer and that 80 800 deaths will be attributed to a cancer diagnosis. The risk of developing cancer increases with age and in 2017 an estimated 89% of new cancers will be in people over the age of 50, and 45% in people over the age of 70. Individuals over the age of 65 are the fastest-growing age group in Canada, therefore the incidence and mortality due to cancer are expected to increase (13).

Cancer puts a strain on the health care system due to the resources required to diagnose, treat and manage this group of diseases. Cancer control strategies must be developed and implemented in order to prevent premature mortality and to ensure the health care system can meet the increasing needs of individuals in Canada and worldwide.

2.2 Strategies for Cancer Control

To reduce the burden of cancer, the World Health Organization (WHO) has recommended all countries adopt a national cancer control policy. Specifically, they recommend implementing a cancer control strategy that addresses prevention, early detection, screening, treatment and palliative care (14). In Canada, The Canadian Partnership Against Cancer has

developed such a strategy, which was recently updated for 2017-2022 and clearly describes an action plan for reducing the burden of cancer on Canadians (15). Ideally, we would control the burden of cancer solely through prevention. For some cancers, prevention or screening for precursors of the cancer is a feasible strategy for controlling disease. In other cases, this may not be possible, in which case treatment takes on a critical role in reducing the burden of cancer.

2.2.1 The Role of Treatment in Cancer Control

Treatment is an essential component of any cancer control strategy. Treatment has a variety of roles, including curing cancer, prolonging life, and alleviating symptoms (16). Various treatments for cancer are available, including surgery, radiotherapy, chemotherapy, immunotherapy and hormone therapy. The specific treatment choice depends on the type of cancer, its stage, and the ultimate goal of treatment. The WHO acknowledges that treatment involves more components than cancer management, in that it also encompasses non-technical elements such as psychosocial support for patients and families (16).

2.2.1.1 Radiotherapy

Radiotherapy is a key treatment modality as it is recommended in the treatment of approximately 42% of patients with cancer (17). Radiotherapy involves using radiation such as x-rays, gamma rays and charged particles to destroy cancer cells. Radiation works by damaging DNA, either directly, or indirectly by the creation of free radicals (18). Radiation damages normal cells in addition to cancer cells, but normal cells are better at repairing the damage caused by radiation treatment (19).

Techniques include external-beam radiotherapy, as well as brachytherapy. External beam radiotherapy is most often delivered by photon beams. Linear accelerators are the machines that provide the photon beams. Radiation doses are measured in gray (Gy), which is a unit representing the amount of radiation absorbed by 1 kg of tissue (18). External beam radiotherapy

can be delivered by 3-D conformal radiation (3D-CRT) or intensity-modulated radiation therapy (IMRT) with or without image-guidance. 3D-CRT delivers radiation using static treatment beams to precise targets generated by the radiation oncologist by contouring volumes on 3-D images captured in the planning phase, taking into account the size, shape and location of the tumour and the surrounding organs (18,20). IMRT is a technique that allows for modification of the intensity of radiation beams during a treatment session, meaning that the dose of radiation given to the tumour and to surrounding tissues can be further separated by conforming the dose more precisely to the target volumes. The way 3D-CRT and IMRT are planned differs slightly. In 3D-CRT, the radiation oncologist will often choose the number and angles of the radiation beams and the radiation dose will be calculated accordingly. In contrast, with IMRT, the radiation oncologist will specify the dose to the tumour and the maximum desired dose to surrounding tissues, and complex computer algorithms will determine the direction, intensity, and shielding of the treatment beams required to meet the prescription constraints (18). Image-guided radiation therapy (IGRT) means that additional imaging scans are obtained during the course of treatment, allowing comparison with the planning imaging. These comparisons ensure that the patient is positioned properly for treatment, and also allow changes in the treatment plan to be considered if patient anatomy changes over the course of therapy. Brachytherapy is “short-distance” radiotherapy, which involves placing radioactive sources internally in or near the tumour. Brachytherapy can be permanent or temporary. Permanent brachytherapy is a type of low-dose-rate treatment where continuous low-dose-rate radiation is provided over time and the radioactive seeds are not removed even after the radiation dose has been delivered. Temporary brachytherapy means that the radioactive source and the catheter used for its delivery are removed after treatment. Temporary brachytherapy can be delivered as either low-dose-rate or high-dose-rate in one or more sessions and involves the placement of radioactive sources in or close to the tumour, followed by their removal at the end of each session of treatment. In the case of permanently implanted seeds, the radioactive isotopes gradually decay over time and give off radiation to

nearby cells. Compared to external beam radiotherapy, brachytherapy may allow for higher doses of radiation to be delivered to the tumour with less damage to normal body tissues. Brachytherapy can also be given in addition to a course of external-beam radiotherapy to “boost” the radiation given to the tumour (18).

All of these radiotherapy techniques aim to deliver a targeted radiation dose to the tumour while minimizing damage to surrounding (healthy) tissues (21). In addition to factors such as the dose and a patient’s general health, the side effects experienced by patients will be related to the area(s) of the body irradiated. Therefore, many of the side effects from radiation are specific to the location/type of the cancer and some areas of the body are more susceptible to damage from radiation. Radiotherapy can cause both acute side effects (early, during the course of treatment) and chronic side effects (late, months or years after treatment) (18).

Radiotherapy may be given with the intention of curing the cancer (curative radiotherapy) or to decrease symptoms caused by the cancer and hopefully prolong life (palliative radiotherapy). Additionally, it may be given in addition to other treatments such as surgery (neoadjuvant if administered prior to surgery, or adjuvant if administered afterwards).

Radiotherapy is given as daily treatment over several weeks. The dose and number of treatments will vary depending on the treatment intent and type of tumour (18). A single dose of treatment is referred to as a fraction, and typically patients are given one fraction per day. By providing the total dose in fractions, this minimizes damage to normal body tissues and may increase the damage to cancer cells by exposing them to radiation at a point in the cell cycle when they are most susceptible to DNA damage (18).

Administration of any treatment must be done in an optimal manner in order to obtain optimal results. However, our capacity to improve the care delivered to patients will be limited based on the current technology available, the state of professional knowledge and other factors such as cost. We need to measure the current performance of this aspect of the health care system

and compare it to what is potentially achievable in order to identify and improve upon areas that are not functioning optimally (22).

2.3 Measuring Health System Performance

The performance of the health care system is measured in terms of accessibility, quality and efficiency. Accessibility means that patients receive the necessary care when it is needed. Quality means that the health care system provides the appropriate care, delivered in the correct way. Efficiency looks at whether the cost and resources used to deliver the care achieve an optimum balance with respect to the accessibility and quality of services (22). We can evaluate each of these components separately to identify areas requiring improvement and target interventions and policy to those specific areas. In this project, the focus is on the measurement of quality of care within a very specific disease and treatment context.

2.4 Quality of Care

2.4.1 Defining Quality of Care

Delivering a high quality of care to patients is a priority for any health care system. Quality of care is defined by the Institute of Medicine as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”(1). This is a very broad definition and useful in a general context, but a more specific definition is helpful for quality assessment.

2.4.2 Frameworks for quality assessment

Many frameworks exist to define quality of care and to identify specific quality indicators for use in quality assessment (23). All such frameworks build upon work initially done by Avedis Donabedian.

2.4.2.1 Donabedian Model

Avedis Donabedian was a groundbreaking researcher in the area of quality of care who developed a framework for assessing quality (2). This framework has been described as a “bulls-eye” with the health care practitioners in the center representing the fundamental pre-requisite to the provision of high quality patient care. Beginning with the center and moving outwards, there are several levels of care where quality can be assessed: the care provided by health care providers (subdivided into technical and interpersonal care), the care provided by health care institutions (including amenities such as privacy and comfort), the care implemented by the patient (patient compliance) and the care provided by the community (2). As one moves outward from the center the components build on each other. This framework is shown in Figure 2-1.

Figure 2-1: Levels of care where quality can be assessed (adapted from Donabedian (2))

Within each level of this framework, we can identify indicators of care representing one of three domains: structure, process or outcome. Structure refers to the types and number of staff resources or the physical layout of the institution in which care is provided. Process refers to the way that care is delivered, which includes both technical and non-technical elements of care. Outcomes are the result of care. The quality of technical care will affect outcomes such as

survival, whereas the quality of non-technical elements of care is likely to affect outcomes such as patient satisfaction or quality of life. By identifying and resolving any deficiencies in structures or processes of care, we can improve patient outcomes (24). Process measures are often the most useful in quality assessments as they are usually more sensitive measures and have the greatest potential to be targeted for future intervention (25).

Building upon the work done by Donabedian, several other frameworks have been developed for use in assessing quality of care. Three frameworks will be described here as examples: a global framework, a Canadian framework and one relevant to the Ontario Cancer system. All of these frameworks follow the same principles as the Donabedian framework; they define dimensions of quality that should be included in quality assessment and then identify indicators relevant to each dimension.

2.4.2.2 Organization for Economic Cooperation and Development Health Care Quality Indicators Project

This project was designed to develop a set of indicators for use in comparing the quality of health care across Organization for Economic Cooperation and Development (OECD) countries. The OECD framework distinguishes between health and health care, but it is the performance of the health care system that is of relevance here. It is a broad framework, but the relevant portion describes a matrix examining health care performance by health care needs. In assessing the quality of health care it focuses on effectiveness, safety and responsiveness/patient centeredness as the relevant dimensions of care. Health care needs include general elements which can be mapped onto the trajectory of patient cancer care: prevention, treatment or “getting better”, survivorship or “living with illness/disability” and palliative care or “coping with end-of-life” (see Table 2-1). Indicators can then be mapped to each position in the matrix (26). The section particularly relevant to this thesis would be the indicators within the “responsiveness/patient-centeredness” and “treatment” box.

Table 2-1: Selected elements from the conceptual framework for OECD Health Care Quality

Indicator Project (adapted from (26,27))

Healthcare needs	Quality of Health Care		
	Effectiveness	Safety	Responsiveness / Patient-Centeredness
Primary prevention (Screening)			
Getting Better (Treatment)			
Living with illness or disability (Survivorship)			
Coping with end-of-life (Palliative Care)			

2.4.2.3 Canadian Institute for Health Information Health Indicator Framework

The Canadian Institute for Health Information (CIHI) developed a performance measurement framework. Again, it is a broad framework, but indicators for measuring health system performance are related to acceptability, accessibility, appropriateness, competence, continuity, effectiveness, efficiency, and safety (28). The CIHI indicator relevant to this project falls under “acceptability: patient satisfaction (and quality rating of services received)” (29). This framework is useful on a national level for identifying indicators to use in quality assessment and for making comparisons between countries, but it is too broad to be useful in the specific context of this thesis work.

2.4.2.4 Cancer System Quality Index

The Cancer System Quality Index (CSQI) is a quality improvement tool used by the Cancer Quality Council of Ontario. This council is an “arms-length” advisory group associated with Cancer Care Ontario. The CSQI uses seven dimensions of quality: safe, effective, accessible, responsive (patient-centered), equitable, integrated and efficient. Indicators are mapped to these dimensions across the trajectory of patient cancer care including prevention, screening, diagnosis,

treatment, recovery and end of life (30). Indicators relevant to this thesis would fall within “responsive/patient centeredness” and “treatment”. In particular, there is a measure for patient experience with outpatient cancer care, using composite indicators based on data from the Ambulatory Oncology Patient Satisfaction Survey (31). Although this is useful on a programmatic level to monitor progress, and could be helpful as a screening tool to identify areas that should be examined further, it can be challenging to use composite indicators to identify specific areas to target for improvement (32).

Additional frameworks have been described in comprehensive reviews (33,34). Although all of these frameworks provide an overview of ways to assess health system performance and quality of care, they are too broad to be useful within the specific context of this thesis project. In order to accurately assess quality, a clear and specific definition is required, and specific quality indicators must be identified.

The Donabedian framework was used for this project as it clearly defines care within a health care institution to include amenities of care, as well as care provided by health care providers (which includes technical and interpersonal aspects of care). For our purposes, for the care provided by healthcare institutions, we have grouped together the two non-technical aspects of care (amenities of care and interpersonal aspects of care) and we refer to it as “personal care”. In order to have a comprehensive assessment of quality and to maximize patient outcomes, it is essential to assess both technical and personal care and to identify areas in need of improvement.

2.5 Evaluating Quality of Care within Healthcare Institutions

2.5.1 Evaluating the Quality of Technical Care

Providing high quality ‘technical care’ means that the patient receives the tests, procedures, and services that are needed and that they are provided appropriately (35). Health care professionals are the best judges of the quality of technical care provided to patients (36).

The quality of technical care has been studied extensively and many quality indicators have been identified (26,37,38). These indicators can be applied to data abstracted from patient medical records in order to assess the quality of care. Examples of this type of study are The American Patterns of Care studies in cancer radiotherapy (39).

2.5.2 Evaluating the Quality of Personal Care

In contrast to assessing the quality of technical care, health care providers are not the best judges of the quality of personal care (5). To attain a high quality of personal care, it is not sufficient to simply deliver the care to patients. It must be delivered in a manner that is consistent with patients' values and wishes and patients must perceive the care provided as acceptable and adequate (40). Therefore, the patient is the best judge of the quality of personal care (5,6,41,42).

Measuring and improving the quality of personal care has been made a priority in recent years (43,44) and there is increased interest in developing approaches to measure the cancer patient experience (45–47). It has been defined and evaluated in many different ways, including assessments of “patient-centred care”, “patient satisfaction” and through the use of “patient reported experience measures”. Each is briefly described below.

2.5.2.1 Patient-centred care

Patient-centred care means that the care provided is in accordance with patient's needs and wishes and that patients are actively involved in their care (48,49). A variety of tools and instruments are available to assess the quality of patient-centred care (50,51). Guidelines for the delivery of “person-centred care” now exist, emphasizing the importance of patient engagement in care (52). Indicators were recently developed to measure the quality of patient-centered care in oncology using a modified Delphi process (53), building upon previous work (48). These indicators cover domains of communication, physical support, psychosocial care, after-care and organization of care (53). It has been pointed out that these domains relate to aspects of provision

of information (54), which are essential components for the delivery of person-centered care, but this may not cover all aspects of “personal care” as we have defined it.

A comprehensive description of instruments available to assess the quality of patient-centered cancer care is available in a systematic review published in 2014 (41) with additional instruments reported in more recent reviews (45,55). Research in this field is in an early phase and it is not yet known how measuring the patient experience leads to improvements in the delivery of patient-centred care (45).

2.5.2.2 Patient satisfaction

Patient satisfaction questionnaires have traditionally been used to try to assess quality of care from the patient’s perspective (56–58). However, patient satisfaction has not been shown to be a valid indicator of quality (59). Patient satisfaction is affected by patients’ expectations prior to treatment, which can influence their perceptions of care (5). Satisfaction is also related to individual patient characteristics such as race/ethnicity, age, education level and marital status (5,60). Measures of patient satisfaction are often abstract in nature, and patient satisfaction questionnaires commonly report high, undifferentiated levels of satisfaction (59), making it difficult to identify targets for improvement. Although the relationship between quality of care and patient satisfaction is not clearly defined (61), satisfaction remains an important concept in quality measurement. High patient satisfaction has been shown to be related to patient compliance with treatment (62), which may affect treatment outcomes (63). Furthermore, patient satisfaction has traditionally been regarded as an essential component of quality assurance in the health care system and is an expected outcome of quality care (41,62).

Recent comprehensive reviews of specific patient satisfaction measures used to assess the cancer patient experience have been published (45,55). The conclusions of both of these reviews highlights the need for additional work in this area to further develop, validate and implement measures of patient experience (45) and to ensure the content of any patient questionnaire

designed for this purpose addresses all aspects of care that may be important to cancer patients receiving care in an outpatient setting (55).

2.5.2.3 Patient reported experience measures

More recently, in an attempt to combat the problems reported in the patient satisfaction literature, questionnaires have been developed that focus on asking patients to rate and/or report on their experiences with specific aspects of care instead of indicating their satisfaction (5,41,59). Patient reported experience measures (PREMs) gather information about patient perspectives on care, are increasingly being used in quality improvement activities (11,40,46,64) and their importance is increasingly being acknowledged (65). The Picker series of questionnaires are examples of these types (66). The Picker questionnaires ask patients to report whether certain events occurred during their experience with the health care system. It has been suggested that asking detailed questions about specific aspects of a patient's experience may be more useful for monitoring care than collecting information on satisfaction, and these results could be used to identify specific areas where care could be improved (67). The Picker Instruments were developed in consultation with patients and incorporate questions addressing eight dimensions of patient-centred care. Although the importance of selected elements of care was considered in the development of these instruments, the final questionnaire asks for patients to report their care experience only and does not collect information about the importance of each element of care to individual patients.

In the Netherlands, Booij *et al* have developed a Consumer Quality Index Cancer Care questionnaire. They wished to develop a generic questionnaire applicable for all cancer patients and made the assumption that patient experiences with cancer care were not specific to the tumour site. They aimed to identify the aspects of care important to cancer patients and describe the experience of patients with respect to the quality of care received. The authors noted that to keep the number of elements of care on their questionnaire to a reasonable size, they did not

include specific elements that would be applicable to only subgroups of patients, and acknowledged this as a potential limitation of their questionnaire (68).

Additional PREMs are described and reported in reviews conducted in 2015 (55), 2016 (45) and 2017 (46). The authors point out that data about the cancer patient experience are not collected in a routine and systematic way at this time (45), and further work is needed to determine the relationship between patient experiences and outcomes (55).

An alternate strategy was recently used where patient complaints about care were examined in order to identify priorities for quality improvement. Unsurprisingly, this approach identified personal aspects of care as the ones most in need of improvement from the patient perspective as opposed to technical elements of care (69).

This highlights that methods used to assess quality of care from the patient's perspective are diverse, and that no single method has been identified as best (60,70).

2.5.3 Evaluating quality of care in a specific context

Measuring quality of care is complex and quality indicators must be specific in order to effectively identify targets for quality improvement. Therefore, it may be beneficial to focus on assessing quality within a particular context. Our research group has focused on assessing quality of care in the context of prostate cancer radiotherapy.

2.6 Prostate Cancer

Prostate cancer is the fourth most common cancer worldwide with 1.6 million cases and 366 000 deaths in 2015 (12). Incidence greatly varies between countries and up to a 25-fold difference has been reported. Australia/New Zealand and North America have the highest age-standardized incidence rates, whereas Asia and Africa have the lowest. Much of the difference in incidence rates is likely attributable to widespread PSA testing in westernized countries (71). In Canada, prostate cancer is the most common cancer among men. There is a large variation in the

incidence of prostate cancer among provinces in Canada, which may reflect variation in screening rates (13). Although mortality from prostate cancer in Canada has been declining since 2001, it is still the third cause of cancer death in men and 4100 Canadian men are expected to die of prostate cancer in 2017 (13).

There are no known modifiable risk factors for prostate cancer at this time. The main risk factors for prostate cancer are age, race and family history (72,73). Other genetic, hormonal, behavioural and lifestyle risk factors have been explored (72–75), but further confirmatory studies are required to determine their role in the etiology of prostate cancer. Prostate cancer is rarely diagnosed prior to age 50 (73,74), and in Canada, it is most often diagnosed between ages 60 and 69 (13).

In the absence of known modifiable risk factors for this disease, we cannot reduce the burden of prostate cancer through primary prevention; therefore treatment has a critical role in reducing the burden of prostate cancer. Early detection of the cancer through screening is possible and may improve the outcomes of treatment by identifying cases at a time when cure is possible. Screening is done by Prostate-Specific Antigen (PSA) testing and digital rectal examinations (DRE). PSA is a protein naturally produced by the prostate gland to assist in nourishing sperm and it is normally found in low levels in the blood. Because prostate cancer cells secrete large amounts of PSA, high levels in blood may indicate the presence of prostate cancer. PSA levels may also be elevated as a result of benign prostatic hyperplasia or prostatitis however, so it is a non-specific test and additional tests, including a biopsy of the prostate, are required to diagnose prostate cancer. Although it is often done, routine screening using PSA testing is not currently recommended in Canada (76) and widespread PSA testing has led to concerns about over-diagnosis and overtreatment of this disease (77).

At diagnosis, patients are assessed to determine the stage of their cancer. Early-stage prostate cancer patients are grouped into one of three risk categories based on prognostic factors which include PSA level, clinical T stage and grade. Along with determining the prognosis of the

patient, the risk category helps to identify the possible treatment options open to the patient (78). Current standard treatment options for early-stage prostate cancer include surgery and radiotherapy. Active surveillance of the cancer is also an option for early stage disease, where treatment is delayed and patients are regularly monitored until progression of the cancer is detectable through either a change in prostate volume or change in grade (77,79). Currently there is no consensus on the best treatment option for men with early stage prostate cancer (80).

2.6.1 The Use of Radiotherapy as a Treatment for Early-Stage Prostate Cancer

Radiotherapy for prostate cancer consists of 3D-CRT, IMRT or brachytherapy (81). During the period of time we conducted our study, standard radiotherapy approaches were as follows: low-risk patients received single-phase IMRT photon therapy of 70 Gy / 35 fractions to the prostate and proximal seminal vesicles. A 0.8 cm margin was used for planning treatment volume. Intermediate-risk patients underwent the same technique, but received 76 Gy / 38 fractions. High-risk patients received treatment in two phases - 46 Gy / 23 fractions to the prostate and pelvic nodes followed by IMRT boost of 30 Gy / 15 fractions to the prostate and proximal seminal vesicles. High-risk patients also received 2 years of adjuvant hormonal therapy, which was usually initiated within 30 days of the start of hormone treatment. Standard approaches for radiotherapy delivery and adjuvant hormone treatment have changed since the initiation of our study. Active surveillance is now the recommended strategy for men with low-risk disease, and it may be an appropriate strategy for some intermediate-risk patients as well. Ongoing PSA tests, DREs and biopsies are recommended to monitor the progression of cancer and determine when to consider active treatment (79). Current clinical guidelines recommend delivery of dose-escalated IMRT and also now recommend brachytherapy and/or hormone therapy (either neoadjuvant or adjuvant), depending on the specific risk group of the patient (82,83).

As mentioned previously, there are possible side effects of radiation treatment. The likelihood of developing side effects depends on many factors including the patient's general health and the amount of radiation delivered to normal tissues. Acute side effects from radiotherapy for prostate cancer include urinary problems, bowel problems, fatigue, sexual problems, local skin reactions and local hair loss. Acute side effects typically improve shortly after treatment concludes. Long term side effects may develop months to years after the receipt of radiotherapy and include urinary problems, bowel problems, sexual difficulties, lymphedema, and hip and bone problems (20).

Approximately 53% of prostate cancer patients should receive radiotherapy in their lifetime (17). However, these utilization rates are based on both curative and palliative treatments. Approximately 36% of patients should receive radiotherapy within a year of diagnosis (17). Patients who receive radiotherapy instead of surgery as a treatment for their prostate cancer are typically older, with more co-morbidities than patients who receive surgery (84) however both of these treatments are considered to be effective (85).

Cancer treatments such as radiotherapy are processes that lend themselves to monitoring, evaluation and intervention. Additionally, aspects of the methods used to assess quality in this context could be applied to study quality of care in other cancer contexts.

2.6.1.1 Previous Research in the Quality of Technical Care in Radiotherapy

In the United States, the RAND (Research and Development) Corporation used a consensus method to develop a set of technical quality indicators for prostate cancer radiotherapy. They started with a comprehensive literature search to identify candidate indicators of quality of care, and then conducted focus groups and interviews with experts. They then used a modified Delphi process to develop a final list of indicators (86). These indicators were then applied to data abstracted from patient medical records to evaluate the quality of care delivered to patients (87–89).

In Canada, Health Services Researchers at Queen's University used a similar method to develop a set of Canadian quality indicators for prostate cancer radiotherapy. A literature search identified an initial list of 57 candidate indicators. A modified Delphi process undertaken with an expert panel reduced this list to 15 quality indicators (3). These indicators were subsequently used in a National Patterns of Care Study to assess the quality of technical care provided to patients undergoing radiotherapy for prostate cancer. They found that although compliance on many quality indicators was high, there were opportunities for improvement, and there was variation in quality of care delivered between centres (4).

2.6.1.2 Previous Research in the Quality of Personal Care in Radiotherapy

To complement the work done to assess the quality of technical care (3,4) and ensure a comprehensive assessment of quality, we must also assess the quality of personal care. As previously described, radiotherapy for prostate cancer involves daily attendance at a cancer centre for approximately seven weeks. During these seven weeks, patients visit the cancer centre for a designated appointment time, interacting with a team of radiation therapists who deliver the daily treatment. The intensity and frequency of contact between patients, the cancer centre, and their health care providers makes radiotherapy an excellent context for assessing the quality of personal care. Additionally, improvements in the quality of personal care delivered to patients may have a greater impact in this context due to the degree of contact patients have with both the health care system and their health care providers.

At the initiation of this project we did not find any published reports of an instrument specifically designed to comprehensively measure the quality of personal care of patients undergoing radiotherapy for prostate cancer (7). At that time, there were two questionnaires that we felt were relevant, but they were not deemed appropriate for assessing the quality of personal care in prostate cancer radiotherapy since they did not specifically address prostate cancer (90) and/or they had a narrow focus and only related to a particular point in time (91), thereby not

meeting our requirement that quality indicators need to be comprehensive and context-specific. We set out to define the scope of personal care and to create a comprehensive list of the elements of personal care that are pertinent to patients who undergo radiation therapy for prostate cancer. This developmental work formed the basis of my MSc thesis (7) and a description of that work forms part of the content of the published manuscript that is Chapter 3 of this thesis. As a brief summary of that work, we began by identifying the domains of the quality of personal care: ‘patient centeredness’, ‘empathy and respectfulness of caregivers’, ‘competence of caregivers’, ‘adequacy of information sharing’, ‘accessibility of caregivers’, ‘continuity of care’, ‘comprehensiveness of care’, ‘acceptability of the treatment environment’, ‘privacy’ and ‘convenience’ by adapting and refining domains referred to in the literature (90,92–95). We then searched the literature to identify items relevant to each domain by identifying items from surveys used to assess quality of care (96–98), patient satisfaction (93,99–106), patient needs assessments (107–113) as well as publications describing the development of quality indicators for cancer care (86,87,114–116). We supplemented the initial item list by seeking input from health care professionals and patients. The items were initially mapped to each step in the patient care continuum to identify gaps and redundancies. The items were then incorporated into a questionnaire consisting of 3 modules corresponding to appropriate time points in the patient care continuum.

Our questionnaire contains 143 items across 10 domains of personal care. For each item, patients are asked to rate the quality of that aspect of their care (using a 5-point scale from *very poor* to *very good*) and rate the item’s importance (using a 4-point scale from *not important* to *very important*) (see Figure 2-2). As part of the MSc thesis, the questionnaire was pilot tested on a small group of patients and the results indicated that patients were willing to complete it and did so without difficulty or distress (7).

Characteristic of good care	How important is this to you?	How good was <u>your</u> care in this regard?
	Not Important Somewhat Important Important Very Important	Very Poor Poor Okay Good Very Good Unable to answer
• Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
• The patient is given enough information about how the radiation treatment is planned	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
• The patient is given enough information to understand how the radiation treatment works	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐

Figure 2-2: Sample page of the self-administered questionnaire

Our questionnaire was developed in 2009 and there have been other questionnaires published since then. Some have been previously described in another section, but ones pertinent to prostate cancer radiotherapy are described here.

Researchers in England have developed a specific prostate cancer questionnaire to assess the patient experience (PCQ-P) (117). It addresses aspects of information and explanation, involvement in decision making, provision of advice and support, delays in care, choice, coordination of care, and practical issues (e.g. hospital facilities and travel). Using a similar approach to the questionnaire we developed, it separates the questionnaire into sections. However, the PCQ-P includes sections related to GP visits and referral, tests at the hospital, diagnosis and treatment decision, treatment and discharge, and monitoring. The authors allowed for different modes of administration of their questionnaire, and several sections were provided to patients at a time. Patient feedback recommended that the sections should be administered as separate questionnaires, or in smaller combinations containing just a few sections. Both patients and healthcare providers suggested administering it prospectively, as soon as possible after each stage of care was completed (117), which is the approach we have used with our questionnaire. The PCQ-P has not yet been used as part of quality improvement, but it has been suggested that

the PCQ-P could be used for benchmarking and comparisons between centres and that individual questions should be examined to identify areas of improvement. The PCQ-P asks patients to rate their experiences with elements of care covering all prostate cancer treatments. The treatment-specific segment of the PCQ-P is fairly brief and since it is generic, it does not include questions specifically about radiation therapists or about the weekly review appointments during treatment (118). Therefore specific elements that may be important to patients undergoing radiotherapy for prostate cancer may not be captured by this questionnaire.

Questionnaires for assessing aspects of the quality of personal care during radiotherapy are now available. A patient satisfaction survey was used in British Columbia, Canada to assess satisfaction with radiotherapy delivery (119). The results from this survey were shared among staff members in order to identify areas in need of improvement. Despite the general nature of some of the satisfaction questions, they were able to identify areas in need of improvement and make changes that led to increased satisfaction scores (119). A modified version of this tool was used in Ontario, Canada, and although the researchers obtained similar results, they did not identify any specific areas to target for improvement. The researchers noted that it may be beneficial to time the delivery of the questions more closely to when the patient experienced that element of their care. They also acknowledged that it might be helpful to pair each question with a question about importance to identify priorities to patients (120), which is what we have done.

A questionnaire specific to radiotherapy has recently been developed in Sweden that includes 23 items focusing on the specific radiotherapy experience. Questions focus on domains related to psychological stress, physical discomfort and coping during treatment (121). These are very important issues, but this questionnaire does not address the full patient care continuum and does not cover all aspects of personal care.

Researchers in the Netherlands conducted focus groups and a concept-mapping exercise as a first step towards developing an instrument for use in assessing the quality of radiotherapy (122). This work is related to the generic Consumer Quality Index Cancer Care described earlier.

Although the elements identified were specific to quality of care in radiotherapy, they included patients receiving treatment for all cancers. The elements of care identified as important may not then pertain to prostate cancer radiotherapy, as specific aspects of care important to patients may be unique to their situation (57). This work is still under development and the instrument is not yet available as this study focused on identifying elements of care, and their next steps involve designing a questionnaire to assess the quality of care from the patient's perspective (122).

Similarly, another survey was conducted in Australia by Mackenzie *et al* to gather patients' views about their care during radiotherapy. They used a unique approach of asking patients whether their well-being would have been improved if better care was provided across different domains of patient-centredness. They included eight questions, each related to a different domain. They identified domains that require improvement, but it is not yet clear how to develop targeted interventions to improve care for patients (54), which may be related to the general nature of the questions they asked.

The elements of care pertinent to patients undergoing radiotherapy for prostate cancer may be specific to their particular experience. We wanted to comprehensively assess the quality of personal care of patients undergoing radiotherapy for prostate cancer to complement previous work (4). We did a comprehensive search for a suitable instrument in 2009 and did not find one available (7). Although work has been done since, there is still no instrument available that is specifically designed to assess the quality of personal care in prostate cancer radiotherapy.

2.7 Validity and Reliability

Measurements of the quality of personal care need to be valid. Validity in this context relates to two different components: the validity of the indicators selected for quality assessment and the validity of the measurement tool (questionnaire) used to assess quality of care. As described in detail in chapter 3 of this thesis, when we identified the indicators of personal care

applicable to prostate cancer radiotherapy, we focused on ensuring both face and content validity (7).

As for the validity of the information gleaned from a patient questionnaire, the quality of care delivered by a single institution cannot be accurately measured by an individual patient, but instead must be assessed across all patients receiving care. As mentioned previously, measurements of quality from the individual patient's perspective are affected by their expectations and perceptions of care (62), which are influenced by their own norms and values. Furthermore, the indicators within our questionnaire are definitive or causal indicators, which means each can influence the patient's well-being independent of the relationship to other elements of care (123,124). Standard psychometric techniques often used for assessing construct validity and/or internal consistency of questionnaire items are not appropriate to use in this context (123,125–128). We can, however, assess the stability of individual patient responses over time (129).

2.8 Using Patient Feedback in Quality Assessment

It is essential that patient views are incorporated when evaluating the quality of personal care (130). In 2016, the Canadian Partnership for Quality Radiotherapy produced a document with a specific guideline addressing patient involvement: “the radiation treatment program has a process to define, monitor and evaluate patient and family perspectives on service quality and to respond to feedback within a specified time frame...” (131,132) We previously identified indicators of the quality of personal care and incorporated those into a patient questionnaire. This is an important part of the first step(s) of the health services research process to assess health system performance. This framework is shown in Figure 2-3, and indicates this process starts with “choosing and defining indicators” of health system performance, which are measurable aspects of care received (133). Once the measurement instrument is developed, the next step in the framework is “describe performance”, but in describing the quality of care from the

perspective of patients we must first make sure we are assessing elements of care important to patients (8,9).

Figure 2-3 Framework for Health Services Research (adapted from 22)

Ultimately, to move this work forward and ensure data gathered is useful in a quality improvement setting, it needs to be summarized and presented in a way that allows health care managers and health care professionals to identify actionable targets for quality improvement (10,11). Much of the published literature focuses on the development of questionnaires designed to assess the quality of care from the patient's perspective, but there is little research on how to effectively use patient data for quality improvement (8,134–142). A recent systematic review highlights the lack of research in this area and proposes a framework for using patient data in

quality improvement that involves “making sense of data” (benchmarking and comparing results), “communicating and explaining data” (interpret and disseminate results) and “planning for improvement” (discuss results with stakeholders to identify and select priorities for improvement). However, they point out that in order to effectively use patient experience data it is essential that an organization’s leaders can understand the data collected (140). Barriers to using patient-reported data have been identified and tend to fall into three categories: characteristics of the organization, characteristics of the data, or characteristics of the individuals using the data (8,10,136). Although many organizations have started collecting data in order to describe quality of care from the patient’s perspective, few have adequate systems to use the data effectively and efficiently (70,143). It has previously been recognized that a structured, organized system for collecting and processing patient data in a timely manner, combined with an organizational environment that is open to using patient feedback, may enhance the use of data in quality improvement (10,136,139–141,144). Additionally, data that are specific to the local context may increase uptake and use since it may make it easier to identify specific targets for quality improvement (8,143,145).

2.9 Summary and Rationale

Measuring quality of care from the perspective of patients is essential as they are the best judges of the quality of non-technical (personal) aspects of care (5). In order to integrate quality assessments into a quality assurance program, we must begin by choosing and defining specific indicators of performance. Once we have appropriate indicators, we can then assess quality of care and seek to describe the current performance of the health care system (Figure 2-3) (22). In describing the current quality of care delivered to patients, we must focus on the aspects of care that are important (8,9). In using quality data to evaluate and potentially improve care, we need to ensure we have appropriate methods for identifying the elements of care in need of improvement to patients.

We have already asserted that measuring quality of care is complex and that quality indicators must be specific in order to effectively identify targets for quality improvement. Building upon this, we have also highlighted the challenges in summarizing and reporting on patient experiences and the lack of information about how to use these data effectively as part of a quality improvement program. It may be useful to conduct an assessment within a focused population as a model for conducting this type of work, and then, if successful, the applicability to more general contexts can be considered.

Previously, we developed a questionnaire for assessing the quality of personal care in prostate cancer radiotherapy (7). The objectives of this PhD thesis were: 1) to determine which elements of personal care were most important to patients undergoing radiotherapy for prostate cancer; 2) to develop a method of integrating ratings of importance and ratings of quality to identify elements of care that should become targets for quality improvement, and; 3) to describe the quality of personal care delivered to patients undergoing radiotherapy for prostate cancer in routine practice and to identify the elements of personal care that should be targeted for quality improvement.

Chapter 3

What Aspects of Personal Care Are Most Important to Patients Undergoing Radiation Therapy for Prostate Cancer?

3.1 Abstract

Purpose/Objective(s): The overall quality of patient care is a function of the quality of both its technical and non-technical components. The purpose of this study was to identify the elements of non-technical (“personal”) care that are most important to patients undergoing radiotherapy for prostate cancer.

Materials and Methods: We reviewed the literature and interviewed patients and health professionals to identify elements of personal care pertinent to patients undergoing radiotherapy for prostate cancer. We identified 143 individual elements relating to 10 aspects of personal care. Patients undergoing radical radiation therapy for prostate cancer completed a self-administered questionnaire in which they rated the importance of each element. The overall importance of each element was measured by the percentage of respondents who rated it as “very important”. The importance of each aspect of personal care was measured by the mean importance of its elements.

Results: One hundred eight patients completed the questionnaire. The percentage of patients who rated each element “very important” ranged from 7% to 95% (mean 61%). The mean importance rating of the elements of each aspect of care varied significantly: “perceived competence of caregivers”, 80%; “empathy and respectfulness of caregivers”, 67%; “adequacy of information sharing”, 67%; “patient centeredness”, 59%; “accessibility of caregivers”, 57%; “continuity of care”, 51%; “privacy”, 51%; “convenience”, 45%; “comprehensiveness of services”, 44%; and “treatment environment”, 30% ($p < 0.0001$). Neither age nor education was associated with importance ratings, but the patient’s health status was associated with the rating of some elements of care.

Conclusions: Many different elements of personal care are important to patients undergoing radiotherapy for prostate cancer, but the 3 aspects of care that most believe are most important are: the perceived competence of their caregivers, the empathy and respectfulness of their caregivers, and the adequacy of information sharing.

3.2 Introduction

Quality of care has been defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (1). Health care has technical and non-technical components, and the quality of each influences the likelihood of achieving optimal outcomes (2). In the context of radiation therapy, the technical quality of treatment influences the probability of cure and complications, and the quality of nontechnical aspects of care may influence quality of life both during and after treatment.

Optimizing cancer outcomes therefore requires the optimization of quality of care (146). The importance of technical quality assurance in radiation therapy is already universally accepted. Standards for the technical quality of many components of radiation therapy practice are available, and quality indicators for the overall operations of radiotherapy programs have been published (147). In addition, technical quality indicators for specific types of radiotherapy have been developed and used to audit the quality of care of specific groups of patients. The American College of Radiology’s Patterns of Care Study, today known as Quality Research in Radiation Oncology, was the pioneer in this field (39). Following their example, we recently developed a suite of Canadian indicators of the technical quality of radiotherapy for prostate cancer, based on evidence in the literature supplemented by expert opinion (3). These indicators were used in a nationwide, criterion-based audit of the technical quality of radiation therapy that identified

opportunities for technical quality improvement at every center surveyed (3,4). This study, however, did not evaluate the quality of nontechnical aspects of patient care. We therefore plan now to develop a suite of indicators of the quality of nontechnical aspects of care of patients undergoing radiotherapy for prostate cancer, to complement the technical quality indicators reported previously (3).

Donabedian referred to nontechnical aspects of care as interpersonal care (24), and for convenience we refer to it here as personal care. We searched the literature for a method of evaluating the quality of nontechnical aspects of the care of patients who undergo radiation therapy for prostate cancer, but did not succeed in identifying an appropriate instrument. Satisfaction questionnaires have been used in the past to assess quality of care from the patient's perspective (56–58,148), but satisfaction is not a direct measure of quality because it is highly dependent on the patient's expectations (5). Furthermore, such studies often report uniformly high levels of satisfaction (59), making it difficult to identify targets for improvement.

The first step toward developing indicators of the quality of personal care was to define the scope of personal care and create a comprehensive list of the elements of personal care that are pertinent to patients who undergo radiation therapy for prostate cancer. We approached this by reviewing the literature and interviewing not only health professionals but also patients, who are recognized as the best judges of the quality of personal care (5) and therefore should be involved in the selection of appropriate indicators of care (130,149,150). The second step was to survey patients undergoing radiation therapy for prostate cancer to determine which elements of personal care were most important to them.

3.3 Methods

This study was approved by the Health Sciences Research Ethics Board at Queen's University (#6003838).

3.3.1 Defining the Scope of Personal Care

We used a bottom-up inductive approach (149). We reviewed the literature and analyzed the content of existing instruments for measuring patients' satisfaction and patients' needs to identify a pool of items relating to individual elements of personal care pertinent to patients undergoing radiation therapy for prostate cancer. See appendix B2 for a complete list of sources that provided the 500 elements of care initially included in the study (see Figure 3-1). We classified these individual elements into 10 categories, each relating to a particular aspect of the quality of personal care. A preliminary classification, based on concepts and terms used in the literature pertaining to quality of care, patient satisfaction, and patients' rights, was expanded to accommodate all the elements of personal care (95) (Table 3-1). Each element of care was mapped to the corresponding step in the continuum of care, as shown in Figure 3-1 and described in detail in Appendix B1.

Figure 3-1: Identifying elements of the quality of personal care relevant to radiotherapy for prostate cancer (for details, see methods).

Table 3-1: Aspects and sample elements of the quality of personal care

Aspect of care	Sample elements
Patient centeredness	The patient is involved as much as he wants in making the final decision about which treatment to have
	The patient is encouraged by the cancer center to bring a relative or friend along to the first appointment with the radiation oncologist
	If the patient wants, the radiation oncologist is willing to answer all the questions the patient's family and friends have
Empathy and Respectfulness of Caregivers	The nurses shows sensitivity to the patient's feelings and emotional needs
	The radiation therapists treat the patient with respect
	The radiation oncologist makes the patient feel like he can ask any questions he wants to
	The nurses are polite to the patient
Perceived competence of caregivers	The radiation oncologist reads the patient's previous medical records before seeing the patient for the first time
	The patient has confidence in his treatment team that he is treated correctly every day
	The radiation therapists are knowledgeable and experienced in dealing with prostate cancer
	The radiation oncologist is aware of the test results and has the results available when seeing the patient for the first time
	The radiation oncologist carefully assesses the patient's suitability for radiation treatment
Adequacy of Information Sharing	The radiation oncologist explains the different forms of treatment that are available for prostate cancer
	Someone on the health care team offers written information about prostate cancer to the patient that he can take home with him
	The radiation oncologist makes sure the patient understands the treatment options before making up his mind about which treatment to have
	The radiation oncologist listens carefully to all the patient's concerns
Accessibility of caregivers	Someone at the cancer centre is available to answer the patient's questions in between appointments
	The radiation oncologist takes the time to answer all of the patient's questions
	The patient has a short wait to get an appointment to see the radiation oncologist for the first time
	The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time

Continuity of care	The patient sees the same radiation therapists each time he goes for radiation treatment
	The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer
	The patient is aware of who to contact with questions about his prostate cancer and treatment
Comprehensiveness of Services	Someone on the healthcare team is available if needed to help explain the diagnosis to family members
	Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members
	Someone at the cancer centre arranges for the patient to receive any help he needs in dealing with his anxiety about the diagnosis
	A social worker is available to provide advice on financial and social issues arising from the diagnosis
Treatment Environment	The furniture in the waiting room is comfortable
	The cancer centre appears to be clean and well looked after
	The waiting area and treatment rooms are quiet
Privacy	There is enough space in the waiting room that the patient can have a private conversation with his companion
	The patient is aware that no one else other than him and the healthcare professionals looking after him are able to see his medical records without his permission
Convenience	Appointments are scheduled for a time that is convenient
	Transportation to/from the cancer centre is available for the patient if needed
	Directions and signs inside and outside the cancer centre are easy to understand
	There is somewhere convenient to park

3.3.2 Questionnaire Development

We then constructed a self-administered questionnaire in which each element of quality was presented as a positive statement (Figure 3-2). Patients were asked to rate the importance of each element, on an ordinal scale, as shown in Figure 3-2.

Characteristic of good care	How important is this to you?				How good was <u>your</u> care in this regard?					
	Not Important	Somewhat Important	Important	Very Important	Very Poor	Poor	Okay	Good	Very Good	Unable to answer
• The patient has a short wait to get an appointment to see the radiation oncologist for the first time	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
• The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
• The patient is encouraged by the cancer centre to bring a relative or friend along to the first appointment with the radiation oncologist	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Figure 3-2: Sample page of the self-administered questionnaire

The questionnaire was revised on the basis of feedback about its clarity and comprehensiveness, obtained through cognitive interviews conducted by K.A.F. with a convenience sample of 8 patients who had undergone radiation therapy for prostate cancer and 4 health professionals from the Cancer Centre of Southeastern Ontario (CCSEO) involved in the care of patients with prostate cancer. The final questionnaire was divided into 3 modules, designed to be administered sequentially. Module 1, including elements pertinent to pre-treatment assessment and the treatment decision, was administered in the first week of treatment; module 2, including elements pertinent to treatment delivery and plans for follow-up, was administered at the end of treatment;

and module 3, including elements relating to general aspects of care, was administered at first follow-up visit (7) (Figure 3-1). Each module also asked the patient to identify any other elements of care that he thought should be included. Preliminary testing on 28 patients showed that it was feasible for them to complete the questionnaire without difficulty or distress. Patients did not suggest any new elements of care to add to the questionnaire (7). Additional details of how the questionnaire was developed are available in the expanded methods section in appendix B1.

3.3.3 Survey Population

Patients starting radical external beam radiation therapy for localized prostate cancer at CCSEO between May 2011 and August 2014 were eligible to participate. Patients with clinically positive nodes were excluded. Patients who were incarcerated were excluded. Patients were excluded if the attending oncologist did not approve their recruitment (see Figure B1, Appendix B). Patients who had undergone prostatectomy or would receive brachytherapy were excluded. Patients who received adjuvant hormone treatment were included. Radiation therapy treatment protocols used at CCSEO for low-risk, intermediate-risk, and high-risk cases are described in appendix B1.

3.3.4 Administration of the Questionnaire

Patients were invited to participate in the study during their first week of radiation therapy. Participants were assured that their responses were confidential and that they would remain anonymous. Consenting patients were given each module of the questionnaire by hand at the appropriate point in time (Figure 3-1) along with a stamped addressed envelope in which to return it. Patients were asked to complete the questionnaire at home to give them as much time as they wished to complete this task and the opportunity to do so in the privacy and security of their own home.

To assess test-retest reliability, patients recruited after May 2012 were mailed a second copy of module 3 within 10 days of the return of the first copy and were asked to complete it on receipt. The rationale for this approach is described in the expanded methods section in appendix B1.

3.3.5 Data Management

Questionnaires were stored in a locked cabinet in a secure facility. Patients were identified by study number only. Data were entered into a password-protected Microsoft Access database with the use of double entry. Analyses were conducted with SAS 9.3 (151).

3.3.6 Analyses

3.3.6.1 Ranking by Importance

Two different methods were used to rank the importance of the elements of care. We first dichotomized the ratings of importance provided on the 4-point scale shown in Figure 3-2 as “very important” *versus* “less important”. The elements of care were then ranked based on the proportion of patients rating each as “very important”, with ties being resolved based on the proportion rating each as “important” and, if necessary, by the proportion rating each as “somewhat important” (Method A). We also calculated the rank assigned to each element, by each individual patient, using fractional ranking to deal with ties. We then calculated the mean rank assigned to each element by the group of patients. Finally, each element was ranked based on the mean rank assigned to it by the group (Method B). For the overall group of patients, the 2 methods yielded almost identical results (Spearman $r = 0.99$). We therefore used the simpler method A in our primary analysis. The importance of the 10 aspects of personal care was

calculated by the mean importance of its constituent elements. The importance of different aspects of care was compared using generalized estimating equations.

3.3.6.2 Sample size

A target sample size of 96 patients was set to ensure maximum confidence intervals of +/- 10 % on proportions of patients (152) (see also appendix B1 and appendix C1).

3.3.6.3 Agreement

We calculated the percentage of patients agreeing with the majority opinion on whether each element of care was or was not “very important” using the following formula: $50 + |50 - \% \text{ “very important”}|$ (153). This is scaled from 50 to 100, where 50 is complete disagreement and 100 is complete agreement. A threshold of agreement was set at 60% because at 60% agreement, with 108 respondents, the 95% confidence interval just excludes 50 and therefore represents the majority opinion.

3.3.6.4 Test-retest Reliability

Test-retest reliability was described by concordance on ratings of “very important”, referred to as percentage of positive agreement (154). The kappa statistic was not used to describe test-retest reliability because the distribution of responses was skewed toward “very important” (155).

3.3.6.5 Patient characteristics and importance rankings

Spearman correlation was used to compare the importance rankings of different subgroups of patients defined by age, education and health status. Method B was used here to rank the elements of care because it is not influenced by the way in which different groups of individuals use the scale. (For additional explanation, see the expanded methods section in appendix B1). The Wilcoxon rank sum test was used to compare differences in the importance of individual elements of care from the perspective of different subgroups of patients. This exploratory analysis involved

multiple comparisons, and we therefore applied the procedure suggested by Benjamini and Hochburg in assessing statistical significance (156), with the acceptable false discovery rate set at 0.25.

3.4 Results

3.4.1 Study Population

Overall, 188 potentially eligible patients were seen at CCSEO between May 2011 and August 2014, of whom 147 consented to participate in the study, 139 received all 3 modules of the questionnaire, and 108 completed all 3 modules. Reasons for nonparticipation or noncompletion are shown in Figure B1 (Appendix B). Response rates for individual modules are provided in appendix B3.

Table B3-1 (Appendix B) shows the characteristics of the 108 patients who completed the entire questionnaire. Fifty-six percent were over the age of 70. Forty-five percent had received some postsecondary education. Eighty-one percent rated their health as “good” or “excellent”. The age distribution of patients who did not complete the questionnaire was similar to that of patients who did complete it (Appendix C2).

The median time for completion of the complete questionnaire (all 3 modules) was 46 minutes (range, 17-105 minutes). Completion times for individual modules are provided in appendix B3.

3.4.2 Ratings of Importance

There were few missing responses. Ratings of importance were provided by >90% of patients for every element. For additional details, see appendix B3.

The respondents did not identify any additional elements of care that were important to them.

The percentage of patients rating each element of care as “very important” ranged from 7% for “*the patient is treated in the same treatment room each day*” to 95% for “*the radiation oncologist is knowledgeable and experienced in dealing with prostate cancer*”. Table 3-2 shows the 10 highest ranked and 10 lowest ranked elements of care. Table B3-2 (Appendix B) shows the ranking of importance of all elements of care. The elements are ordered based on the percentage of patients rating each element of care as “very important” (method A), but rankings based on the mean rank assigned by the group are also shown for comparison (method B).

Table 3-2: Highest and lowest ranked elements of care by percentage of patients rating each one “very important”

Elements of Care <i>Top 10 Elements</i>	Importance	
	<i>% Very Important (95% CI)</i>	<i>Rank</i>
The radiation oncologist is knowledgeable and experienced in dealing with prostate cancer	95.3 (89.4, 98.5)	1
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body	93.5 (87.0, 97.3)	2
The patient trusts the radiation oncologist to look after him properly	91.6 (84.6, 96.1)	3
The cancer centre seems to have all the equipment and facilities needed to completely care for the patient’s prostate cancer	88.0 (80.3, 93.4)	4
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer	87.8 (80.1, 93.3)	5
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer	87.0 (79.2, 92.7)	6
The radiation oncologist takes the time to answer all of the patient’s questions	86.9 (79.0, 92.7)	7
The radiation oncologist is honest with the patient	86.0 (77.9, 91.9)	8
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means	85.0 (76.9, 91.2)	9
The radiation oncologist gives the patient enough information about the side effects of each treatment option	84.8 (76.4, 91.0)	10

<i>Bottom 10 Elements</i>	<i>% Very Important (95% CI)</i>	<i>Rank</i>
The waiting area and treatment rooms are quiet	30.6 (22.0, 40.2)	134
The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time	26.4 (18.3, 35.9)	135
A social worker is available to provide advice on financial and social issues arising from the diagnosis	24.7 (16.5, 34.4)	136
Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members	23.8 (15.9, 33.3)	137
The furniture in the waiting room is comfortable	23.2 (15.6, 32.2)	138
The patient sees the same radiation therapists each time he goes for radiation treatment	22.2 (14.8, 31.2)	139
There is enough space in the waiting room that the patient can have a private conversation with his companion	19.6 (12.6, 28.4)	140
Food and drink facilities are available in or near the waiting room	11.3 (6.0, 18.9)	141
Waiting areas are decorated nicely	10.4 (5.3, 17.8)	142
The patient is treated in the same treatment room each day	6.6 (2.7, 13.1)	143

Figure 3-3 shows the ratings of importance of each aspect of care. The mean percentage of patients rating elements of care as “very important” within each category varied as follows ($p < 0.0001$): “perceived competence of caregivers”, 80%; “empathy and respectfulness of caregivers”, 67%; “adequacy of information sharing”, 67%; “patient centeredness”, 59%; “accessibility of caregivers”, 57%; “continuity of care”, 51%; “privacy”, 51%; “convenience”, 45%; “comprehensiveness”, 44%; and “the treatment environment”, 30% (for additional details please see appendix C3). Importance ratings also varied among the elements of individual aspects. For example, the percentage of patients rating elements of care within “adequacy of information sharing” as “very important” ranged from 38% for “*The patient is made aware that he has the right to get a second opinion from another radiation oncologist*” to 93% for “*The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and*

there is no sign that it has spread to any other part of the body”.

Figure 3-3: Comparison of the importance of aspects of personal care. Elements of care (o), mean importance of elements within each aspect (+).

3.4.3 Agreement on Ratings of Importance

The majority of patients agreed that 80 elements of care were “very important” and that 22 elements of care were not “very important”. Patients were divided in their opinion about the importance of the 41 other elements of care.

3.4.4 Test-Retest Reliability

Ninety-five patients were enrolled in the test-retest component of the study, and 63 completed and returned both copies of module 3. The median time between return of the first and second

copies was 20 days (range, 8-74 days; interquartile range, 16-26 days). Variations in the interval between completion dates for the 2 copies of module 3 were primarily due to variations in the times the patients took to return the second copy of the questionnaire. Median positive agreement for the 64 elements included in module 3 was 82% (range, 58%-97%). Positive agreement was < 70% for 5 elements. (These 5 elements, which all ranked low in importance, are shown in table B3-3, Appendix B). Median agreement on ratings of not “very important” (negative agreement) was 73% (range, 40%-95%).

3.4.5 Relationship between patient characteristics and ratings of importance

Figure 3-4 compares the ranks of importance assigned by different subgroups of patients. The high rank correlation coefficients indicate that patients ranked most elements of care similarly, regardless of age (Figure 3-4a), educational level (Figure 3-4b), and health status (Figure 3-4c). After the Benjamini-Hochburg procedure was applied, there were no significant differences among subgroups of patients defined by age and education level, but there were 3 elements where the importance differed on the basis of health status (Figure 3-4c).

Figure 3-4: Relationship between patient characteristics and ratings of importance. Comparison of the ranks of each element of care between patients of different age (A), education level (B) and health status (C). Elements of care (o), elements of care rated significantly differently by subgroups of patients (●). Three elements were more important to patients in poorer health: 1) The cancer centre appears to be clean and well looked after; 2) The patient feels that his rights for privacy are fully protected at the cancer centre; 3) The patient's family physician is kept informed about the cancer care.

3.5 Discussion

We found that many different elements of personal care are pertinent to patients who undergo radiation therapy for prostate cancer, but the aspects of care that are most important to most patients relate to the perceived competence of their caregivers, the empathy and respectfulness of caregivers, and the adequacy of information sharing. Individual patients expressed different priorities, but these were not predictable on the basis of their age, education or health status.

We used an inductive approach to identify the elements of personal care and determine the scope of personal care. We began by searching the literature for elements pertinent to patients undergoing radiation therapy for prostate cancer, and supplemented that list through cognitive interviews with prostate cancer patients and health care professionals and through successive rounds of pilot testing. The present survey failed to identify any additional elements, attesting to the content validity of the final questionnaire. These elements of care are what others have referred to as definitive, or causal, indicators (123,124); that is, each element could influence a patient's well-being regardless of its relationship to other elements (123,124). In this context, the results of validity or reliability investigations using correlation methods are difficult to interpret (125) and may encourage the elimination of important items, with a negative impact on content

validity (123,126–128). We therefore did not use factor analysis to assess construct validity, or Cronbach's alpha to assess internal consistency.

Our questionnaire was long, but surprisingly we achieved a response rate at least comparable with that observed in similar studies (68,111,153). The setting in which the patients completed the questionnaire might have affected their responses. Our patients completed the questionnaire in their own homes because we believed they would be most likely to communicate their true feelings in this secure environment. However, they were not specifically instructed to do this independently, and some may have had help from others. We acknowledge also that patients' rating of the importance might well change over time. Our questionnaire was delivered as 3 modules at specific points in time, with the goal of asking about the importance of each element at the point in time when it would be most relevant to that patient. However, the timing of delivery of the questions was not perfectly matched to the individual patient's trajectory, and differences between patients' scores may reflect differences in the timing of the questions in relation to key events in their trajectory. For example, the timing of delivery of module 1 in relation to the date of diagnosis varied depending on whether the patient started adjuvant hormone therapy before receiving radiation therapy (see Appendix C4). Finally, this study elicited the opinions of patients treated at just one center, and the generalizability of our findings is unknown.

Most previous studies that have sought to identify the aspects of care that are important to cancer patients have evaluated heterogeneous groups undergoing diverse treatments (68,90,122,157). However, the specific aspects of care that are important to patients may be unique to their situation (57). The present study is unusual in focusing on the elements of care that are most important to a specific group of patients undergoing a specific type of treatment. Nonetheless our findings are largely consistent with those of other broader studies (68,90,122,157).

Efforts to improve the quality of personal care should focus on the elements of care that matter to patients (9). Previous work on the quality of nontechnical aspects of care has largely focused on assessing patient satisfaction (158,159), evaluating the quality of specific aspects of care (91,100,111), and identifying patients' needs (113). The questionnaire we used here was designed only to meet the limited objectives of the present study, but the inventory of elements of the quality of personal care that we assembled and prioritized based on the views of our respondents may be useful in developing better instruments for assessing the quality of personal care in future.

Chapter 4

Development and Comparison of Methods to Identify Priorities for Improvement of the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer

4.1 Abstract

Background: We previously developed a questionnaire to assess the quality of personal care in prostate cancer radiotherapy. Patients are asked to rate the importance of 143 elements of their care and to rate the quality of their care for each element. In order to improve the quality of care delivered to patients, the elements of care most in need of improvement must be identified.

Objective: To develop a method of integrating ratings of importance and ratings of quality to identify elements of care that should become targets for quality improvement.

Methods: We surveyed 108 patients undergoing radiotherapy for prostate cancer. We developed three methods to identify elements of care to target for quality improvement that were both important to the patient(s), and sub-optimal in quality. Spearman correlation was used to compare ranking of priorities across all three methods. Generalized estimating equations was used to assess the statistical ability of each method to discriminate between priorities for quality improvement.

Results: Integrating importance and quality ratings identified different priorities than using quality ratings alone. Two of the integrated methods identified priorities for quality improvement and their ranks similarly ($r=0.91$, $p<0.0001$). Two methods were able to discriminate at the top 3 priorities, whereas the other method was only able to discriminate at the top 5. All methods identified elements related to communication of information about the disease and its treatment as priorities.

Conclusions: Two methods produced similar results although one is easier to understand and theoretically superior since the ratings for importance and quality are linked for each individual and therefore not vulnerable to ecological fallacy. Further consultation with stakeholders is needed to determine how to best use these results as part of a quality improvement program.

Keywords: prostate cancer, quality, radiotherapy, quality improvement

4.2 Introduction

Quality of care is defined by the Institute of Medicine as “the degree to which health services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge” (1). Medical care consists of two components, technical care and non-technical care, the latter referred to as interpersonal care (24) or “personal care” (160). The quality of care delivered to patients affects outcomes (2).

Quality of care must be assessed in order to identify areas in need of improvement. Since a high quality of personal care is care that is consistent with patients’ values and wishes, it is the patients who must assess its quality (5,6).

We recently developed a suite of indicators for the assessment of personal care in the context of prostate cancer radiotherapy and surveyed patients about the quality of their care (160) [please note: reference 160 is included in this thesis as Chapter 3]. However, for data gathered to be useful in a quality improvement setting, it needs to be synthesized so that health care managers and health care professionals can identify actionable targets for quality improvement (10).

Methods for identifying targets for quality improvement need to be valid, accurate, complete, actionable in terms of their ability of influence change, and easy to understand and interpret for relevant stakeholders (23,133,161–163). Furthermore, when summarizing and describing patient data for quality improvement it is essential to target things that matter to patients (8,9).

The objective of this study was to develop a method of integrating ratings of importance and ratings of quality to identify elements of care that should become targets for quality improvement.

4.3 Methods

4.3.1 Data Collection

We developed a questionnaire as previously described (160). Briefly, we identified elements of personal care relevant to patients undergoing radiotherapy for prostate cancer after a comprehensive literature review and interviews with patients and health care providers. We then grouped the elements of care into 10 categories corresponding to 10 aspects of personal care: ‘empathy and respectfulness’, ‘perceived competence of caregivers’, ‘accessibility of caregivers’, ‘patient centeredness’, ‘privacy’, ‘continuity of care’, ‘communication’, ‘convenience’, ‘treatment environment’, and ‘comprehensiveness of services’. We constructed a self-administered questionnaire that asked patients to rate the importance and quality of the care they received with respect to each element. Patients were asked: *How important is this to you?* and *How good was your care in this regard?*, and provided responses on an ordinal scale, as shown in Figure 4-1. Patients were also asked to provide information about their age, education level,

marital status and general health. Details of the patient's cancer and treatment were obtained by medical chart review.

Characteristic of good care	How important is this to you?	How good was <u>your</u> care in this regard?
	Not Important Somewhat Important Important Very Important	Very Poor Poor Okay Good Very Good Unable to answer
• Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
• The patient is given enough information about how the radiation treatment is planned	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐
• The patient is given enough information to understand how the radiation treatment works	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐

Figure 4-1: Sample Page of the self-administered questionnaire

4.3.2 Patient Selection and Recruitment

Patients were eligible for this study if they started curative radiotherapy for prostate cancer at the Cancer Centre of Southeastern Ontario between May 2011 and August 2014. Patients were excluded if they had received brachytherapy. Patients were given the questionnaire by hand and asked to complete it at home and return by mail.

4.3.3 Data Management

Completed questionnaires were stored in a locked filing cabinet in a secure facility. Patients were identified by a study number only. Data were entered into a password protected Microsoft Access database using double entry.

4.3.4 Identifying Priorities for Quality Improvement

Our goal was to synthesize the patient group's perception of quality of care to target elements of care for quality improvement that were both important to the patient(s), and sub-optimal in quality. We developed and compared three methods for identifying these targets, as described below.

The "*individual priority-based method*" begins by identifying the elements of care that each individual scored as both "very important" *and* less than "very good". These elements were deemed to be the individual's personal priorities for improvement. The priorities of the group were established by ranking the elements, based on the percentage of patients that identified them as a personal priority.

In the "*group priority-based method*" priorities for quality improvement were identified by ranking each element based on the product of the percentage of the group that rated it less than "very good", and the percentage of the group that rated it "very important": $(100\% - \% \text{ "very good"}) * (\% \text{ "very important"})$.

The "*group ranking-based method*" is based on the principles of importance performance analysis by Martilla and James (1964). The elements of personal care were first ranked independently, by quality and by importance. Importance was ranked based on the percentage of patients rating each element "very important". Quality was ranked from best to worst, based on the percentage of patients rating each element "very good". Each element was characterized by

two values: importance rank, and the inverse quality rank (quality ranked from worst to best). The elements were then ranked using the lower of the two ranks.

We used the Spearman correlation to compare the complete ranking of priorities across all three methods. We also used the Spearman correlation to compare the ranking of priorities from each method to the overall rank order generated using quality ratings or importance ratings alone. The statistical ability of each method to discriminate between priorities for quality improvement was assessed using generalized estimating equations (GEE). We did GEE with repeated measures to account for potential correlation of responses within patients, and we used the results of the type 3 analysis. Analyses were conducted with SAS 9.3 (151).

4.3.5 Ethics

This study was approved by the Health Sciences Research Ethics Board at Queen's University (#6003838).

4.4 Results

4.4.1 Recruitment and Compliance

There were 188 patients who started radiotherapy for localized prostate cancer at CCSEO between May 2011 and August 2014. Of these, 108 patients completed the full questionnaire. For a more detailed description, please refer to our previous publication (160).

4.4.2 Study Population

Fifty-six percent (56%) of patients were aged 70 or older, and 45% had postsecondary education. Fifty-one percent (51%) reported their health as “good” and 30% reported their health as “excellent”. Eighty-four percent (84%) were married/living common law. Ten percent (10%) had low-risk disease, 50% had intermediate-risk disease, and 40% had high-risk disease.

4.4.3 Missing Responses

There were few missing responses. For each patient, the median number of elements missing an importance rating was 0 (range 0 to 32, IQR 0 to 2), and the median number of elements missing a quality rating was 9 (range 0 to 49, IQR 5 to 16). However, for the individual priority-based method, ratings of importance and quality are linked, therefore patients must provide both ratings. The median number of elements missing either a quality, or importance rating was 9 (range 0 to 49, IQR 5 to 16) (for additional details please see Appendix D1).

4.4.4 Identifying Priorities for Quality Improvement

The correlation between each of the three methods and the overall rank order based on quality alone was: individual priority-based method versus quality, $r=0.64$ ($p<0.001$); group priority-based method versus quality, $r=0.80$ ($p<0.0001$); and group ranking-based method versus quality, $r=0.26$ ($p=0.001$). Therefore, the ranking of priorities for quality improvement generated by each method differs from the order of priorities generated using quality ratings alone.

Figure 4-2 compares the overall ranking of priorities for quality improvement between methods. There was a strong correlation between the overall ranking of elements of care provided by the group priority-based method and the individual priority-based method ($r = 0.91$). The correlation

between the group ranking-based method and the other two methods was weaker: group ranking-based method versus the individual priority-based method $r=0.68$, and the group ranking-based method versus the group priority-based method $r=0.69$.

Figure 4-2: Rank correlation between results of the three methods

For each method, the GEE analyses showed that the top 10 elements of care were identified as significantly different from the bottom 10 elements of care (in all cases, $p < 0.0001$). We then compared the top 10 elements to the next set of 10 elements, and again, found that the top elements of care were significantly different than the next set of 10 (individual priority-based method, $p = 0.0001$; group priority-based method, $p = 0.0003$; group ranking-based method, $p = 0.0003$). We then modified the cut-off point to assess whether one method was better at discriminating between priorities for improvement (Table 4-1). The individual priority-based method and the group priority-based method were both able to discriminate at the top 3 priorities, whereas the group ranking-based method was only able to discriminate at the top 5 (for additional details, please see Appendix D2).

Table 4-1: Comparison of the three methods based on their ability to discriminate between top priorities for quality improvement*

Method	Comparison by GEE (generalized score statistic, p-value)			
	Top 3 to next 3 elements	Top 5 to next 5 elements	Top 10 to next 10 elements	Top 15 to next 15 elements
Individual priority-based method	9.1, $p = 0.0026$	15.9, $p < 0.0001$	14.5, $p = 0.0001$	28.2, $p < 0.0001$
Group priority-based method	14.6, $p = 0.0001$	9.1, $p = 0.0025$	12.9, $p = 0.0003$	28.9, $p < 0.0001$
Group ranking-based method	0.85, $p = 0.36$	16.8, $p < 0.0001$	13.0, $p = 0.0003$	19.2, $p < 0.0001$

*The priorities for quality improvement identified by each method are shown in Table 4-2 and Table D3-1 (Appendix D3).

Figure 4-3 shows the relationship between the quality and the importance of each element, using the format introduced by Martilla and James (164). The quality of each element is ranked from

worst to best, based on the percentage of patients rating each element less than “very good”. The top ranked elements of care identified using each of the three methods of integrating importance and quality ratings are highlighted in this figure and listed in Table 4-2. The full ranking of priorities for quality improvement is presented in Appendix D3. The individual priority-based method and the group priority-based method identified very similar elements in their top 10, with 8 elements of care in common. The top priorities identified by these two methods include elements with intermediate importance but very poor quality, and others that have intermediate quality but very high importance. The group ranking-based method has four elements in common with the group priority-based method and these same elements in common with the individual priority-based method with the addition of one other. These common elements are all related to communication of information about the disease or treatment and are elements that are of high importance and poor quality. The group ranking-based method prioritized elements of care with higher ratings of importance, but did not prioritize any elements of care with very low quality ratings that were still very important to a minority of patients.

Figure 4-3: The Relationship between quality and importance: Each circle represents an element of care, ranked by importance on the x-axis, and by quality on the y-axis. Importance is ranked from most to least important. Quality is ranked from worst to best. The top priorities for quality improvement identified by each method are as follows: the individual priority-based method (⊕), the group priority-based method (⊖), the group ranking-based method (●). Elements of care identified by more than one method are shown by combining the appropriate symbols. The vertical and horizontal lines show the median ranking of importance and quality, for reference.

Table 4-2: The top elements of care identified by each method for identifying targets for quality improvement

	Summary Ratings				Methods*					
	Quality		Importance		Individual priority-based		Group priority-based		Group ranking-based	
Element of Care	Inverse rank	% “Very Good” (95% CI)	Rank	% “Very Important” (95% CI)	Rank	% “very good” AND “very important”	Rank	(100% - % “very good”)*(% “very important”)	Rank	Lower rank of inverse quality or importance
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time	4	39.8 (29.8, 50.5)	49	69.9 (60.1, 78.6)	1	40.9 (30.8, 51.6)	1	4209.4	5	49
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful	5	41.9 (31.8, 52.6)	71	63.4 (53.2, 72.7)	2	34.8 (25.2, 45.4)	2	3679.3	22	71
There is somewhere convenient to park	2	35.2 (26.2, 45.2)	113	45.8 (36.1, 55.7)	3	29.5 (21.0, 39.2)	3	2965.4	82	113
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function	33	65.0 (55.0, 74.2)	40	73.3 (63.8, 81.5)	4	23.5 (15.7, 33.0)	9	2562.9	2	40
Someone on the healthcare team explains what prostate cancer is and how it can affect the patient’s health	12	50.0 (39.6, 60.4)	86	58.6 (48.6, 68.2)	5	22.9 (15.0, 32.6)	4	2932.5	38	86
Someone on the healthcare	30	63.1	42	72.4	6	22.6	6	2670.1	3	42

team explains that radiation treatment may permanently affect bladder function	(53.0, 72.4)	(62.8, 80.7)	(14.9, 31.9)		
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body	66 77.7 (68.4, 85.3)	2 93.5 (87.0, 97.3)	7 20.4 (13.1, 29.5)	20 2087.0	16 66
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment	16 55.1 (44.1, 65.6)	100 54.2 (44.3, 63.9)	8 20.2 (12.4, 30.1)	12 2436.2	58 100
The patient is given enough information to understand how the radiation treatment works	15 54.7 (44.8, 64.4)	73 62.3 (52.3, 71.5)	9 20.0 (12.8, 28.9)	5 2819.1	23 73
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option	38 66.3 (56.2, 75.4)	26 78.1 (69.0, 85.6)	10 19.8 (12.5, 28.9)	7 2628.8	1 38
The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means	52 73.3 (64.5, 81.6)	12 83.2 (74.7, 89.7)	10 19.8 (12.5, 28.9)	15 2223.4	8 52
The patient is made aware of who to contact if he is concerned about the cancer coming back	42 67.4 (56.5, 77.2)	34 75.9 (66.8, 83.6)	12 19.8 (12.0, 29.8)	11 2472.3	3 42
Someone at the cancer centre arranges for the patient to receive any help he needs in dealing with his anxiety about	21 59.1 (36.4, 79.3)	77 60.9 (38.5, 80.3)	14 18.2 (5.2, 40.3)	10 2490.2	29 77

the diagnosis					
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means	58 75.5 (66.0, 83.5)	9 85.0 (76.9, 91.2)	18 16.7 (10.0, 25.3)	21 2084.6	10 58
Someone on the healthcare team explains that the PSA level is all that is needed to tell if the cancer is under control or not	50 72.4 (61.8, 81.5)	51 69.5 (59.8, 78.1)	19 16.1 (9.1, 25.5)	27 1918.1	6 51
Someone on the healthcare team answers any questions the patient has about the possible causes of prostate cancer	13 53.8 (37.2, 69.9)	96 56.1 (39.8, 71.5)	23 15.4 (5.9, 30.5)	8 2589.0	52 96
The patient is given enough information about the chance of curing his cancer with radiation treatment	51 73.1 (63.5, 81.3)	28 77.4 (68.2, 84.9)	26 14.6 (8.4, 22.9)	22 2082.5	6 51
The radiation oncologist explains what each treatment option involves	53 73.3 (64.5, 81.6)	56 68.3 (58.4, 77.0)	54 8.9 (4.2, 16.2)	31 1824.9	9 56

*Grey shaded boxes highlight the top elements of care identified for each method

Figure 4-3 illustrates that the integration of importance and quality ratings identifies different quality improvement targets than quality ratings alone since there is a cluster of elements in the top left of Figure 4-3 that are not identified for quality improvement.

As a sensitivity analysis, we explored the impact of flagging elements of care as needing improvement if they were rated less than “good”, rather than less than “very good” as in our main results. We used the Spearman correlation coefficient to compare the rank order using this modified approach and the original approach for each of the three methods. The Spearman correlation coefficients were: individual priority-based method $r = 0.88$ ($p < 0.0001$), group priority-based method $r = 0.91$ ($p < 0.0001$), group ranking-based method $r = 0.90$ ($p < 0.0001$). Very few elements identified as top priorities for quality improvement differed between the two approaches.

The number of elements of care we identified as a priority for each patient varied (median 7, range 0 to 126, IQR 1 to 15). Despite this variability, the percentage of elements of care identified as priorities for quality improvement for each patient was similar among subgroups of patients defined by age, educational level, and health status, and there were no statistically significant differences (Appendix D4).

4.5 Discussion

We developed three methods for identifying priorities for quality improvement by integrating patients’ importance and quality ratings. All three methods identified different priorities

compared to quality rankings alone. The individual priority-based method and group priority-based method generated a similar overall rank order ($r = 0.91$). These methods were also both able to discriminate between top quality improvement priorities and the rest. The specific elements they prioritized were similar: elements of intermediate importance but very poor quality, and others of intermediate quality but very high importance. The group ranking-based method chose elements of care with higher importance and gave less priority to very low quality ratings.

Identifying priorities for quality improvement using patient survey data has often focused on identifying the elements of care with the lowest quality ratings (141), but as shown here, this approach differs from what is found when ratings of importance are incorporated into ranking methods. In our study, all three methods identified elements of communication as ones in greatest need of improvement, which is consistent with the results of a recent systematic review that identified communication as the aspect of care most frequently reported as important by patients for the delivery of high quality of care (165). However, aspects of communication are not commonly targeted for quality improvement based on the results of surveys of patients experience (141).

For each method, we dichotomized both of our rating scales to consider only the highest cut-point. Other researchers who have collected data on importance as well as on quality have converted rating scales to numeric scales and calculated means and/or medians for each question (68,166), but we felt this was not an appropriate approach to take with our dataset especially since there were no numbers associated with the words in the original questionnaire to which patients could refer (167). We conducted a sensitivity analysis by modifying our cut-point for ranking

elements of care based on quality ratings and found the ranking of priorities for quality improvement were similar across all three methods, regardless of how we defined our cut-point for quality.

The two group-based methods use aggregate data. The elements of care that are rated less than “very good” may not be the same elements of care rated “very important” to individual patients and therefore these methods are subject to an ecological fallacy. Since the individual priority-based method links the ratings of importance and quality for each patient, it is not subject to the concerns of using aggregate data.

For each method, the denominator used for all calculations includes the percentage of patients providing a rating of importance and/or quality, not the total number of patients. Therefore, for all three methods, theoretically, elements of care applicable to only a minority of the population could be identified as priorities for quality improvement (assuming that missing responses indicate the element of care is not applicable to that patient). In using any of these methods in future, the number of individuals rating each element of care could be considered alongside the ranking and further discussions with health care managers and health care providers may be warranted to determine appropriate thresholds regarding the applicability of that element of care to the patient population (48).

We considered how easy it was to understand the quantities that underlay the final list of ranked elements of care. The quantities generated using the group priority-based method have limited meaning and are difficult to interpret (168), which is a disadvantage of this method in comparison

to the other two (see Table 4-2). It is also worth noting that it is possible to generate confidence intervals for the individual priority-based method but we were unable to generate confidence intervals for the group priority-based and group ranking-based methods. We sought expert statistical advice and were informed that methods for calculating confidence intervals for these two methods are not straightforward, and that even if we did calculate them, they may not be useful.

The individual priority-based method offers an advantage over the other two methods since the quality and importance ratings are linked for individual patients. However, this advantage can also be a disadvantage as it doubles the amount of data required to collect. We previously found that ratings of importance were not associated with patient characteristics (160), and although we would certainly expect to observe differences in quality of care delivered between centres, it may be that importance ratings from patients do not differ from centre to centre. If this is true, then it adds an unnecessary burden on patients by asking them to rate the importance of each element, doubling the length of the questionnaire. If the group priority-based or group ranking-based methods were used to identify priorities for quality improvement, the aggregate importance ratings could be used and in future only quality ratings would be collected from patients.

In this paper, we presented the top elements of care identified as priorities for quality improvement using three integrated methods. For the individual priority-based method, these top priorities are ones where 19.8% or more of patients rated the element as “very important” and less than “very good”. This threshold could be varied. For example, if a minimum threshold of 25% was used, this would have identified only 3 elements of care. Alternatively, a threshold of 15%

would identify 25 elements of care as priorities for improvement. Consultation with healthcare providers and managers could identify appropriate thresholds to use for quality improvement, as others have done using similar approaches (166).

Although many organizations are collecting feedback from patients in order to improve quality of care, it is not yet known how to best use these data to improve care (139,141,169). Three methods for integrating information about importance and quality of personal care have been presented here, but one is easier to understand and theoretically superior since the ratings for importance and quality are linked for each individual. Further involvement of stakeholders is needed to make sure these integrated methods address their needs (70,170,171). Our future work will involve gathering feedback from clinicians and managers about the methods used here (116,172). We believe that monitoring and reporting on the quality of personal care should be part of regular cancer centre quality assurance programs, and that the integrated methods presented here may be useful in identifying quality improvement targets.

Chapter 5

Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer

5.1 Abstract

Purpose: To describe the quality of the non-technical component of the care (personal care) of patients receiving radical radiotherapy for prostate cancer and identify elements of personal care that should be priorities for quality improvement.

Methods: One hundred and eight patients undergoing radiotherapy for localised prostate cancer completed a self-administered questionnaire that asked them to rate the importance of 143 non-technical elements of care and to rate the quality of their own care with respect to each element. The elements that a patient rated as both “very important” *and* less than “very good” were deemed to be his priorities for improvement. The priorities of the population were established by ranking the elements based on the percentage of patients who identified them as a priority (importance/quality analysis).

Results: The response rate was 65%. The percentage of elements rated “very good” varied from patient to patient: median 79% (interquartile range 69%-92%). The percentage of elements rated either “very good” or “good”, was higher: median 96% (interquartile range 86%-98%). Nonetheless, almost every patient rated at least some elements of his care as less than optimal, regardless of the cut-off point used to define optimal quality. Patients assigned their lowest quality ratings to elements relating to the quality of the treatment environment and comprehensiveness of additional services available to them. However, patients rated most of these elements as relatively unimportant, and importance/quality analysis identified elements of care relating to communication of information about the disease and its treatment as the highest priorities for quality improvement.

Conclusions: Most patients rated most elements of their personal care as very good, but almost all were able to identify some elements that were less than optimal. When ratings of quality were integrated with ratings of importance, elements relating to communication emerged as the patients' highest priorities for quality improvement.

Keywords: prostate cancer; quality; quality improvement; radiotherapy

5.2 Introduction

The quality of medical care is defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (1). Medical care has technical and non-technical components (24), the latter sometimes referred to as “interpersonal care” or “personal care” (24,160). The quality of care affects outcomes (2). In oncology, the quality of technical care may affect survival, whereas the quality of personal care may affect a patient's quality of life and their satisfaction with their care. Both technical and personal care must be optimised to achieve the best possible overall outcomes (146).

Quality improvement requires the definition of quality indicators and the development of methods for measuring quality in practice (22). Technical quality assurance has long been an integral part of the practice of radiotherapy, and indicators for the technical quality of the overall operations of radiation therapy programmes are already widely available (173). Indicators of the technical

quality of radiation therapy for certain types of cancer have also been developed (39). Our group recently developed a suite of indicators of the technical quality of radiotherapy for prostate cancer (3). These indicators were used in a nationwide audit of the quality of radiotherapy for prostate cancer across Canada and opportunities for technical quality improvement were identified at every participating center (4). The quality of personal care was not evaluated in that audit.

We have since developed a self-administered questionnaire to elicit patients' views about the quality of the personal care that they receive while undergoing radiotherapy for prostate cancer (160) [please note: reference 160 is included in this thesis as Chapter 3]. The objectives of the present study were to describe the quality of personal care delivered to patients undergoing radiotherapy for prostate cancer in routine practice and to identify the elements of personal care that should be targeted for quality improvement.

5.3 Materials and Methods

5.3.1 Questionnaire Development

Elements of personal care relevant to patients undergoing radiotherapy for prostate cancer were identified based on a literature review and interviews with patients and health care providers and then organized into 10 categories relating to different aspects of personal care (160). We constructed a self-administered questionnaire to allow patients to rate the importance and quality of each of these elements based on their own experience. Each element of quality was presented as a positive statement and the patient was then asked: *How important is this to you?* and *How good was your care in this regard?* Patients provided their responses on ordinal scales as shown

in Figure 5-1. The questionnaire was divided into three modules (160). Module 1, containing 60 questions pertinent to the treatment decision, was delivered in the first week of radiotherapy. Module 2, containing 19 questions pertinent to the treatment period, was delivered in the last week of radiotherapy. Module 3, containing 64 questions pertinent to the overall treatment experience, was delivered at the first post-treatment visit, approximately 3 months after treatment was completed.

Characteristic of good care	How important is this to you?				How good was <u>your</u> care in this regard?					
	Not Important	Somewhat Important	Important	Very Important	Very Poor	Poor	Okay	Good	Very Good	Unable to answer
• The patient has a short wait to get an appointment to see the radiation oncologist for the first time	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
• The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
• The patient is encouraged by the cancer centre to bring a relative or friend along to the first appointment with the radiation oncologist	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Figure 5-1: Sample page of the self-administered questionnaire

5.3.2 Patient Selection and Recruitment

The Cancer Centre of Southeastern Ontario (CCSEO) is a regional cancer centre integrated within a large general hospital. During the study period, the centre had 8.4 full-time equivalent radiation oncologists and treated a total of about 1100 new cases each year with radiotherapy. Patients starting external beam radiotherapy for localised prostate cancer at CCSEO between May 2011

and August 2014 were eligible. Patients who had brachytherapy were excluded. We wanted to study a group of patients whose treatment experience was as uniform as possible and therefore we also excluded patients who had previously had a prostatectomy. If the radiation oncologist agreed, the patient was invited to participate during his first week of radiotherapy. Patients were assured that their responses were confidential.

5.3.3 Administration of the Questionnaire

Radiation therapists personally delivered each module of the questionnaire to the patient at the appropriate time points previously described, with instructions to complete it at home and return it by mail. To assess test-retest reliability, patients recruited after May 2012 were mailed a second copy of module 3 within 10 days of the return of the first copy and asked to complete it upon receipt.

5.3.4 Patient Characteristics

The questionnaire given at the start of treatment asked about the patient's age, education, marital status and general health. Details of the cancer and its treatment were obtained by chart review.

5.3.5 Data Management

Questionnaires were stored in a locked cabinet in a secure facility. Patients were identified by study number only. Data were entered into a password-protected Microsoft Access database using double entry.

5.3.6 Analytic Approach and Statistics

5.3.6.1 Test-retest Reliability

Test-retest reliability was described by the percent positive agreement of ratings of “very good” for each element (155). Kappa was not used because the distribution of responses was skewed towards “very good” (154).

5.3.6.2 Describing the Overall Quality of Personal Care

The overall quality of the personal care of each patient was described by the percentage of the elements of care that he rated as “very good”. The overall quality of personal care of groups of patients was described by the median percentage of elements rated as “very good” by the group. The Wilcoxon rank sum test was used to compare the ratings of overall quality provided by different groups of patients.

The quality of each element of personal care was described by the percentage of patients who rated it as “very good”.

5.3.6.3 Identifying Priorities for Quality Improvement

The elements were ranked by quality based on the percentage of patients rating each element as “very good” and ties were resolved based on the percentage of patients rating each element as “good”. Similarly, the elements were ranked by their importance based on the percentage of patients rating each as “very important”. The elements of care that a patient rated as both “very important” *and* less than “very good” were deemed to be his personal priorities for improvement. The priorities of the population were established by ranking the elements based on the percentage

of patients who identified them as a personal priority. This process is referred to below as importance/quality analysis. All analyses were conducted using SAS 9.3 (151).

5.3.7 Ethics

This study was approved by the Health Sciences Research Ethics Board at Queen's University (#6003838).

5.4 Results

5.4.1 Recruitment, Consent and Completion Rates

Between May 2011 and August 2014, 188 patients started radiotherapy for localised prostate cancer at CCSEO. Of these, 108 completed the full questionnaire (57%). Seventeen were excluded by the attending radiation oncologist, 147 agreed to participate, 20 declined and four were missed by the research team (Figure e1, Appendix E). Thirty-eight of the 147 participants dropped out before completing all three modules and one was excluded when his RT was discontinued (response rate, 65%). Ninety-five per cent of the 108 patients who completed the entire questionnaire answered at least 99% of the questions. There was no deadline for the return of each module of the questionnaire, but 90% of questionnaires were returned within 6 weeks.

5.4.2 Test-retest reliability

Fifty-eight of the 78 patients included in the test-retest substudy repeated module 3. The median positive agreement for quality ratings of the 64 elements in module 3 was 92% (range 68%-100%) (for details, see Appendix F1).

5.4.3 The Study Population

Table e1 (Appendix E) describes the characteristics of the study population. Fifty-six per cent were over the age of 70 years, and 49% had no postsecondary education. Eighty-one per cent described their general health as good or excellent. Ten per cent had low-risk disease, 50% had intermediate-risk disease, and 40% had high-risk disease. Table e2 (Appendix E) describes their treatment. Most low- and intermediate-risk patients received 76 Gy/38 to the prostate by intensity-modulated radiotherapy. Most high-risk patients received with 46 Gy/23 to the pelvis followed by 30 Gy/15 to the prostate, plus hormonal therapy.

5.4.4 Assessment of the Quality of Personal Care

Panel A of Figure 5-2 shows that the percentage of the elements of care that each individual patient rated as “very good” varied with a median of 79% and interquartile range (IQR) of 69%-92%. The median percentage of elements that each patient rated as less than “very good” was 21% (IQR 8%-31%). Panel A of Figure 5-2 also shows that the percentage of elements that each patient rated as either “very good” or “good” was higher, with a median of 96% (IQR 86%-98%) and the percentage rated less than “good” was lower, with a median of 4% (IQR 2%-14%).

Some elements of care are more important than others to the individual patient (160). Panel B of Figure 5-2 shows the results of a separate analysis that included only elements of care identified as “very important” by the individual patient. Patients rated a higher percentage of these elements as “very good” (median 92%, IQR 81%-99%), or at least “good” (median 98%, IQR 93%-100%) and a lower percentage as less than “very good” (median 8%, IQR 1%-18%) or less than “good” (median 2%, IQR 0%-7%).

Figure 5-2: Patients’ assessment of the quality of their care. Panel A shows frequency distributions of the percentage of all elements rated “very good” (black bars) and the percentage

of elements rated either “very good” or “good” (grey bars). Panel B shows similar frequency distributions, but for the subset of elements that each patient rated as “very important”.

Subgroups of patients defined by age, educational level, health status and details of their treatment all rated a very similar percentage of the elements of care as “very good” and there were no statistically significant differences between the quality ratings of any of these subgroups (for details see Table e3, Appendix E. Appendix F2 includes the results of an additional analysis comparing the percentage of elements of care rated “very good” over the course of the study period).

In Module 3, patients were asked to comment on the overall quality of their personal care during treatment; 93% rated this as “very good” and 5% rated this as “good”. However, patients who rated their overall care as “very good” rated many of the individual elements of their care as less than “very good” (median 19%; IQR 8-26%) and some as less than “good”(median 4%; IQR 1-12%).

5.4.5 Identifying Opportunities for Quality Improvement

We reasoned that the potential for quality improvement is greatest where quality is worst. We therefore ranked the elements of personal care based on the patients’ collective ratings of their quality. The elements of care were ranked based on the percentage of patients who rated each element as “very good”, which ranged from 33 to 96%. Table 5-1 shows the top-ranked 10 and bottom-ranked 10 elements. The top 10, with least scope for improvement, included elements relating to the empathy and respectfulness of the healthcare providers, their communication skills, and the patient’s perception of their competence. The bottom 10, with the greatest scope for

improvement, included elements relating to the treatment environment, the comprehensiveness of services provided, the adequacy of the information provided about options available if radiotherapy fails and the right to a second opinion. A complete ranking of the quality of all the elements of care is provided in Table e4, Appendix E. A secondary analysis in which the elements were ranked based on the percentage rating each element as either “good” or “very good” gave very similar results (Appendix F3).

Table 5-1: Quality ranking of the elements of care based on the percentage of patients rating each element as “very good”. The 10 highest ranked and 10 lowest ranked elements are given*.

10 Highest Ranked Elements of Care	Quality	
	<i>% Very Good (95% CI)</i>	<i>Rank</i>
The radiation oncologist is polite to the patient	96.3 (90.7, 99.0)	1
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer	96.2 (90.6, 99.0)	2
The radiation oncologist treats the patient with respect	96.2 (90.6, 99.0)	3
The radiation therapists are honest with the patient	96.1 (90.3, 98.9)	4
The radiation therapists care about the patient’s well-being	95.2 (89.0, 98.4)	5
The radiation therapists treat the patient with respect	94.3 (88.0, 97.9)	6
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer	94.3 (88.0, 97.9)	7
The radiation therapists take the time to answer all of the patient’s questions	94.3 (88.0, 97.9)	7
The radiation therapists explain things to the patient in a way that he can understand	94.3 (88.0, 97.9)	7
The radiation therapists are polite to the patient	94.2 (87.9, 97.8)	10

10 Lowest Ranked Elements of Care	Quality	
	% Very Good (95% CI)	Rank
There is enough space in the waiting room that the patient can have a private conversation with his companion	48.5 (38.6, 58.6)	134
The patient is made aware that he has the right to get a second opinion from another radiation oncologist	47.3 (36.9, 57.9)	135
The cancer centre provides resources to assist the patient in understanding and dealing with prostate cancer (e.g. staffed information services, library of books and DVDs about cancer)	44.8 (34.2, 55.9)	136
Food and drink facilities are available in or near the waiting room	43.8 (33.6, 54.2)	137
Waiting areas are decorated nicely	42.4 (32.9, 52.4)	138
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful	41.9 (31.8, 52.6)	139
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time	39.8 (29.8, 50.5)	140
A social worker is available to provide advice on financial and social issues arising from the diagnosis	39.7 (27.0, 53.4)	141
There is somewhere convenient to park	35.2 (26.2, 45.2)	142
Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members	33.3 (23.1, 44.9)	143

* The quality ranking of all elements is provided in Table e4, Appendix E

Figure e2, Appendix E shows that patients ranked the quality of the elements of care very similarly, regardless of their age, educational level, health status or treatment regimen.

Figure e3, Appendix E displays the patients' ratings of the quality of groups of elements relating to different aspects of personal care. The quality of a group of related elements of care was described by the mean percentage of patients who rated those elements as "very good". We used generalised estimating equations to determine the significance of differences in the quality ratings

of different groups of elements (174). (For additional details of this analysis please see Appendix F4). The mean percentage of patients rating elements of care “very good” within each group varied as follows: ‘empathy and respectfulness’, 92%; ‘perceived competence of caregivers’, 88%; ‘accessibility of caregivers’, 81%; ‘patient centeredness’, 80%; ‘privacy’, 79%; ‘continuity of care’, 73%; ‘communication’, 72%; ‘convenience’, 70%; ‘treatment environment’, 60%; ‘comprehensiveness of services’, 56% ($p < 0.0001$). Figure e3, Appendix E also shows that there were large differences between the quality ratings of individual elements within groups.

5.4.6 Identifying Priorities for Quality Improvement

Figure 5-3 displays the relationship between the quality and the importance of each element of care in a format introduced by Martilla and James (164). Quality is ranked from worst to best, based the percentage of patients rating each element *less than* “very good”. Based on these aggregate results, the elements in quadrant B, which rank above the median by importance and below the median by quality, would clearly be a higher priority for improvement than those in quadrant C, which rank below the median by importance and above the median by quality.

Figure 5-3: The relationship between quality and importance: Each circle represents an element of care, ranked by importance on the x-axis, and quality on the y-axis. Importance is ranked from the most to least important. Quality is ranked from worst to best. The division of each axis at the median creates four quadrants: (A) lower importance/lower quality, (B) higher importance/lower quality, (C) lower importance/higher quality and (D) higher importance/higher quality. The black circles represent the top priorities for quality improvement identified by the importance/quality analysis.

We prioritised individual elements for quality improvement based on the percentage of patients who rated the element as both “very important” *and* less than “very good”, using the process of importance/quality analysis described above. The top priorities are listed in Table 5-2 and flagged in Figure 5-3. Table 5-2 shows that the top priorities for quality improvement identified by importance/quality analysis differ from those identified by analysis of quality or importance alone. This is explained by the fact that many of the elements that ranked lowest in quality also ranked low in importance, and many of those that ranked highest in importance also ranked high in quality (see Figure 5-3). The top 10 priorities identified by importance/quality analysis therefore include some elements that have intermediate importance but very poor quality, and others that have intermediate quality but very high importance. Table 5-2 shows that most of the elements identified as highest priorities for improvement by importance/quality analysis relate to the communication of information about the disease itself and about the risks and benefits of treatment. A complete ranking of all elements is provided in Table e5, Appendix E.

Table 5-2: Top priorities for quality improvement. The priority ranking of all elements of care is provided in Table e5, Appendix E.

Element of Care*	<i>Rank by Importance/ quality</i>	<i>Rank by Quality (inverse)</i>	<i>Rank by Importance</i>
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time (2)	1	4	49
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful (2)	2	5	71
There is somewhere convenient to park (5)	3	2	113
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function (2)	4	33	40

Someone on the healthcare team explains what prostate cancer is and how it can affect the patient's health (1)	5	12	86
Someone on the healthcare team explains that radiation treatment may permanently affect bladder function (2)	6	30	42
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body (1)	7	66	2
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment (4)	8	16	100
The patient is given enough information to understand how the radiation treatment works (3)	9	15	73
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option (2)	10	38	26
The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means (1)	10	52	12

*The number in parentheses indicates the step in the treatment pathway the element refers to: (1) Pretreatment assessment, (2) Treatment decision-making, (3) Treatment planning, (4) Treatment and follow-up, (5) General aspects of care

5.5 Discussion

This survey showed that most patients undergoing radiotherapy for prostate cancer at this centre rated most of the elements of their personal care as “very good”, the highest response category provided in the questionnaire. Patients assigned very high quality ratings to many of the elements of care that they rated as most important. This suggests that caregivers and managers share the patients' values and endeavor to optimise the quality of the elements of care that matter most to everyone. More importantly, however, most patients were able to identify many elements of their care that were suboptimal. This was true regardless of the cut-off point used to define suboptimal quality and regardless of whether the analysis was restricted to elements that the patient rated as

important. Moreover, even patients who rated the overall quality of their personal care as “very good” rated many individual elements of their care as less than optimal. Thus, there seems to be substantial scope for improving the quality of the personal care of this group of patients. Most of the top priorities for quality improvement that emerge from the importance/quality analysis relate to problems in sharing information about the disease itself, and about the risks and benefits of treatment.

The survey was completed by only 57% of the potentially eligible patients treated during the study period (Figure e1, Appendix E). Patients who were excluded from participation at the request of their doctor and those who declined to participate might have rated the quality of their care differently from those who participated. However, those who completed the questionnaire rated the quality of their care very similarly, regardless of their age, educational level or general health status. This makes it unlikely that our findings were greatly influenced by the mix of patients included. However, it is possible that patients’ reports of quality of care may have been influenced by how they felt during treatment (175). Our results are based on observations at a single centre and there is no basis for assuming that the quality of personal care is similar elsewhere. Furthermore, we do not know what level of quality is, in fact, achievable in this context. It would be unrealistic to expect that every patient would assign the highest possible rating to every element of his care, even under optimal conditions. It is not possible to set *a priori* performance targets for this type of quality indicator. Similar evaluations at multiple centers could, however, be used to determine the best achievable ratings, an approach we have used to set benchmarks for some indicators of the technical quality of radiotherapy for prostate cancer (4). It

might then be possible to create specific guidelines for the delivery of the quality of personal care that could then be used for ongoing monitoring and quality assessment.

Previous studies of the non-technical component of health care have mainly been based on measurements of “patient satisfaction” (56–58,148). This approach differs from ours in that the patients’ satisfaction depends on their expectations, as well on as the quality of care delivered (59). Moreover, patient satisfaction surveys may not be the best way of identifying opportunities for quality improvement, because the broad questions that they usually ask often elicit uniformly high levels of satisfaction (61,176). Likewise, in the present study, we found that most patients rated their overall care as “very good”, while rating many individual elements of their personal care as less than optimal. Thus, allowing patients to report on individual elements of their care seems to be a more useful way of identifying specific and potentially actionable opportunities for quality improvement (59).

Our finding that elements of personal care related to patients’ information needs were high priorities for quality improvement is consistent with the results of previous related work (54,177). Optimising communication between healthcare providers and patients is challenging (178,179), but interventions to meet the information needs of patients with early prostate cancer have been designed and evaluated (180,181). One of these is an information booklet that has been shown to enhance patient knowledge and comprehension of facts about their disease, and that directly targets most of the communication-related elements of care that were identified as priorities for improvement in the present study (180).

In collaboration with the genitourinary radiotherapy team at our centre, we plan to use the results of this survey to design an intervention to enhance the quality of personal care in this group of patients and to repeat this survey once this has been implemented. Although some elements of this questionnaire are necessarily specific to patients undergoing radiotherapy for localised prostate cancer, it could readily be adapted for use in other patient groups and we hope to extend its use to other sites. In the long term, we believe that monitoring the quality of personal care should become an integral part of ongoing programmes of quality assurance and quality improvement in the routine practice of radiotherapy.

Chapter 6

General Discussion

6.1 Summary of Main Findings

In the first manuscript, “*What Aspects of Personal Care Are Important to Patients Undergoing Radiation Therapy for Prostate Cancer?*” we surveyed patients undergoing radiotherapy for prostate cancer to determine which elements of personal care were most important to them. Aspects of care most important to most patients were the perceived competence of their caregivers, the empathy and respectfulness of caregivers, and the adequacy of information sharing. The aspects of care of lesser importance to patients included convenience, comprehensiveness of services and the treatment environment. Importance ratings were not associated with the patient’s age, education, or health status.

In the second manuscript, “*Development and Comparison of Methods to Identify Priorities for Improvement of the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer*” we developed and compared three methods for identifying priorities for quality improvement by integrating importance and quality ratings from patients. All three methods identified different priorities from what would be identified using quality rankings alone. Two methods produced similar results and prioritized elements of intermediate importance but very poor quality, and others of intermediate quality but very high importance. One method was easier to understand and theoretically superior since the ratings for importance and quality are linked for each individual and therefore not vulnerable to ecological fallacy.

In our third manuscript, “*Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer*” we described the quality of personal care of patients undergoing radiotherapy for prostate cancer and identified the elements of personal care that should be targeted for quality improvement, incorporating some of what we learned from the first two manuscripts. We found that although most patients rated most elements of their care as “very good”, they were also able to identify elements of care that were suboptimal. This was true regardless of the cut-off point we used to define quality, and whether or not the analysis was restricted to just the elements of care that were most important to individual patients. The top priorities for quality improvement related to communication of information about the disease, and the risks and benefits of treatment.

This thesis identified aspects of personal care important to men undergoing radiotherapy for prostate cancer and determined the relative importance of each element of care, developed and compared methods for integrating importance and quality ratings, and then used one of those methods to identify priorities for quality improvement. Throughout this work we explored some aspects related to implementation of this questionnaire; assessing the feasibility and acceptability of this questionnaire to patients, and the usability of the data gathered in terms of identifying priorities for quality improvement.

6.2 Strengths and Limitations

The individual manuscripts include a description of strengths and limitations relevant to each objective. In this section, the focus will be on the strengths and limitations of the overall thesis.

We provided a detailed and comprehensive description of the quality of personal care patients receive while undergoing radiotherapy for prostate cancer. We had a very clearly defined study population undergoing a specific treatment and we determined it was feasible to conduct a survey to comprehensively assess the quality of their care during radiotherapy. The response rates for each module (conditional on completing earlier modules) was >85% (Appendix B3) and missing data for our questionnaire was low. These observations support our earlier assertion in my MSc thesis that, based on pilot testing, the questionnaire does not appear to pose an undue burden on patients and that incomplete or missing data are likely related to the relevance of the content of the element of care to that individual patient (7).

We developed a method that integrated importance and quality ratings from patients and this allowed us to identify elements to target for quality improvement. The method that we developed is easy to understand and identifies a ranked list of priorities. The elements of care are very specific, and therefore actionable (67). The specificity and relevance of our results to a particular group of patients undergoing a particular treatment may make it easier to use these results for quality improvement (182).

Furthermore, by collecting ratings of importance in addition to quality we were able to determine the impact of the importance ratings on various methods for identifying priorities for quality improvement. It has been shown that the importance of each element of care, in addition to the quality of care received, will affect the patient experience (183). However, it is possible that importance ratings may already be partially incorporated into the patients' quality ratings, a topic that has been discussed in the quality of life literature with respect to importance and satisfaction ratings (168). Our results suggest that it is still beneficial to collect importance ratings in addition to quality, since in all cases, we found that by using importance ratings in addition to

quality ratings we identified different priorities than if we had used quality ratings alone. Our method uses the importance ratings as a filter for selecting the elements of care applicable to each patient instead of multiplying ratings, which may address some of the concerns raised in the literature about weighting quality by importance using multiplicative methods (168).

There are several factors to consider when developing quality indicators and applying them to the assessment of quality of care (133), not all of which were evaluated in this study. We were able to assess the content validity and test-retest reliability of our questionnaire. Patients did not suggest any unique elements of care to add to our questionnaire, and our results suggest our questionnaire has acceptable test-retest reliability as the median percent positive agreement was 82% for the importance ratings and 92% for the quality ratings. Although we identified specific elements of care that can be targeted for quality improvement, further consultation with healthcare managers and healthcare providers is needed to determine how to best apply these indicators to the evaluation of quality of care. Additionally, our questionnaire is intended to be evaluative; therefore it should possess a high level of agreement to measure important changes in the quality of care. It should also be responsive to changes over time (184), but these are not properties we were able to assess in this study and further research is needed.

One consequence of our decision to study a well-defined population undergoing a specific treatment is that data collection took place over a 4-year time period. Therefore it is possible that the quality of care delivered to patients during the study period may have changed over time. One might be concerned that the elements of care identified as priorities for improvement and the description of quality of care may not be an accurate representation of the care experienced by patients over the full study period. The cancer centre did undergo several changes during the time period of the study: physical construction, change in managers of the

radiotherapy department, changes in the radiation therapist team, and an overall increased interest in improving the patient experience (185). However, it is important to note that treatment protocols did not change during the study period and as shown in Appendix F2 the percentage of elements rated “very good” by each patient enrolled in the first half of the study compared to the second half were not statistically significantly different. Although there were no changes in treatment during the study period, there has since been a change in prostate cancer treatment guidelines with brachytherapy recommended for many of the patients who took part in our study (83). Future uses of this questionnaire will require review of the elements of care with this changing patient population in mind.

There may be barriers to the implementation of this questionnaire. In order to ensure the elements identified for quality improvement were actionable, we needed to have a comprehensive, specific set of elements. Therefore, our questionnaire is long and patients are asked to complete it over three time points. This appears to be quite a daunting task. However, we have shown that it is possible to conduct this type of assessment in this specific patient population, and by asking radiation therapists to hand out our questionnaires, we conducted our study alongside routine clinical practice. We believe it would not be difficult to do this type of quality assessment again in other centres.

Finally, the generalizability of our findings is unknown. In addition to the change in clinical practice guidelines, we don’t know if our results are applicable to other institutional contexts. It would not be reasonable to assume the specific quality ratings would be generalizable as they should be reflective of the quality at our particular centre. However, the importance ratings may be generalizable, and the methods proposed to identify priorities for quality improvement may be generalizable as well. In our study, we found that quality and importance

ratings were not associated with measured patient characteristics, but it is important to note that we were unable to measure all characteristics that may be associated with ratings (e.g. race/ethnicity). Since we focused on a specific population, although this work may provide a model for quality assessment, at the moment the questionnaire and our results are only applicable to this specific group of patients receiving external beam radiotherapy.

6.3 Contributions of this research

Previous research has identified indicators for the cancer patient experience (47) and indicators for patient-centered care (48,53), but our work is unique in that we identified a comprehensive set of actionable indicators specific to a particular disease and treatment context, thus allowing for targeted quality improvement. This work also complements the work done by Brundage *et al* to assess the quality of technical care in prostate cancer radiotherapy (3,4). As such, these two sets of indicators can be used to comprehensively assess the quality of care delivered to this patient population.

We identified a method for identifying priorities for quality improvement that involves combining importance and quality ratings. This particular approach of combining ratings is not unique, but the specific method we chose is novel as our method uses the importance ratings as a way to filter the elements of care used to describe quality, ignoring any elements of care that were less than “very important” to the patient.

This PhD thesis (together with work initiated in my MSc) developed indicators of the quality of personal care in prostate cancer radiotherapy, and explored some of issues around applying these quality indicators to the assessment of the quality of personal care in prostate cancer radiotherapy. This provides a foundation for conducting a national survey similar to the

national patterns of care study done for assessing the quality of technical care in prostate cancer radiotherapy (4).

6.4 Conclusions and Future Directions

Returning to the Health Services Research Framework presented in Figure 2-3, this PhD project has built upon work completed during my Master's degree in which I identified indicators relevant to the quality of personal care of patients undergoing radiotherapy for prostate cancer and developed a measurement instrument. This PhD thesis has focused on the next step in the framework, "describing performance" by identifying the aspects of care important to patients, describing the quality of care received by patients and identifying potential areas to target for quality improvement. However, measurement alone is not sufficient for quality improvement and the process of using survey data to improve care is complex (133,136–138,186). Further research will work on determining how to use these results as part of a quality assurance program to improve care. Similar assessments of the quality of personal care could be conducted at other centres following a process that our group has used previously for assessing the quality of technical care (4). Cross-centre assessments could help identify the highest achievable ratings of quality of personal care, which could be used to assign benchmarks and in setting standards.

It may be important to consider issues related to case-mix when making comparisons between centres. Although our data suggest case-mix adjustment may not be necessary, some previous research has indicated there is a need for case mix-adjustment with patient experience data (187–189). Such adjustment could also increase the acceptability of the findings by health care providers (142). However, case-mix adjustment should be done cautiously as observed differences may reflect true differences in the quality of care and therefore may result in over-adjustment (163,190).

There is a need for further research to assess how changes in processes of care may lead to quality improvement and improve patient outcomes (47). The validity of measures can also be assessed by examining their relationship with outcomes we believe are likely affected by the quality of personal care, such as patient satisfaction, decision regret, and quality of life.

Alternate approaches to data collection could be considered in future when using this questionnaire. We defined “responders” for this study as individuals who completed all three modules of the questionnaire, but this obviously meant it took longer to recruit patients to achieve our desired sample size. A faster approach would be to conduct cross-sectional surveys. Such surveys would target individuals all along the radiotherapy care continuum at one point in calendar time. For this study, we decided not to use this approach as we wanted patients to respond to all 143 elements of care on our questionnaire. However, faster, more timely results could enhance their use in quality improvement activities (9,182).

Incorporating assessments of the quality of personal care into clinical practice requires engagement of healthcare providers and managers (8,135). Future considerations and consultation with stakeholders should involve further assessment of the feasibility and acceptability of data collection, and refining appropriate methods for reporting on quality of care. As previously mentioned, we have recommended a method for identifying priorities for improvement but it simply produces a ranked list of priorities. Input from healthcare providers and managers is needed to determine the appropriate thresholds to use for quality improvement activities in order to “set standards” and “evaluate performance” (Figure 2-3) (191). We have already highlighted a few areas that should be considered when choosing appropriate thresholds for identifying priorities for improvement such as determining the applicability of that indicator to the specific patient population (48), but practical issues such as feasibility and cost of undertaking quality

improvement activities are additional considerations that healthcare managers may need to make. For example, “there is somewhere convenient to park” emerged as the 3rd priority for quality improvement in our results. Although this was deemed to be a priority for improvement by 29% of patients (and applicable to almost all patients; quality and importance ratings were provided by 97% of patients), it may not be practical to focus quality improvement efforts on this area. Ultimately, to see changes in the quality of care provided to patients, quality improvement activities need to be comprehensive and aim to engage all levels (healthcare providers, department, hospital) (192).

Comprehensive assessments of quality of care must include assessments of the quality of personal care. Although we designed our questionnaire with a focus on the quality of personal care in prostate cancer radiotherapy, many of its elements could be easily made generic to radiotherapy for all cancers. A more generic questionnaire could be more useful than one targeted at a specific patient group, allowing department-wide assessment of quality of care that would still ensure actionable results (9,182). This would of course make our instrument more comparable to other published work (54,91,119,121,122), but our suite of indicators is a complete list covering the full patient care continuum, and our modular approach gathers data at relevant time points. In future, we hope to see regular monitoring of the quality of personal care as part of quality assurance and quality improvement programs in radiotherapy.

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Appendix A

Ethics Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD

March 5, 2010

This Ethics Application was subject to:

- ☐ Full Board Review
Meeting Date:
☒ Expedited Review

Dr. William Mackillop
Department of Community Health and Epidemiology
Queen's University

Dear Dr. Mackillop,

Study Title: Defining and evaluating quality indicators of personal care in prostate cancer external beam radiotherapy
Co-Investigators: Dr. D. Feldman-Stewart, Dr. M. Brundage, Ms. K. Foley and Mr. D. Wallace

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

- **Reporting of Amendments:** If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see <http://www.queensu.ca/vpr/reb.htm>).
- **Reporting of Serious Adverse Events:** Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.
- **Reporting of Complaints:** Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.
- **Annual Renewal:** Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert Clark
Chair, Research Ethics Board

March 10, 2010
Date

ORIGINAL TO INVESTIGATOR - COPY TO DEPARTMENT HEAD - COPY TO HOSPITAL(S) /P&T (If appropriate) - FILE COPY

Study Code: EPID-304-10

- **Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete**

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD

The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards as defined by the Tri-Council Policy Statement; Part C Division 5 of the Food and Drug Regulations, OHRP, and U.S DHHS Code of Federal Regulations Title 45, Part 46 and carries out its functions in a manner consistent with Good Clinical Practices.

Federalwide Assurance Number : #FWA00004184
#IRB00001173

Current 2009 membership of the Queen's University Health Sciences
& Affiliated Teaching Hospitals Research Ethics Board

Dr. A.F. Clark	Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)
Dr. H. Abdollah	Professor, Department of Medicine, Queen's University
Rev. T. Deline	Community Member
Dr. M. Evans	Community Member
Dr. S. Irving	Psychologist, Providence Care, St. Mary's of the Lake Hospital Site
Prof. L. Keeping-Burke	Assistant Professor, School of Nursing, Queen's University
Mrs. J. Kotecha	Research & Programs Manager, Centre for Studies in Primary Care, Department of Family Medicine, Queen's University
Dr. J. Low	Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital
Dr. W. Racz	Emeritus Professor, Department of Pharmacology & Toxicology, Queen's
Dr. B. Simchison	Assistant Professor, Department of Anesthesiology, Queen's University
Dr. A.N. Singh	WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital
Dr. E. Tsai	Associate Professor, Department of Paediatrics and Office of Bioethics, Queen's University
Rev. J. Warren	Community Member
Ms. K. Weisbaum	LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)
Dr. S. Wood	Director, Office of Research Services (Ex-Officio)

Appendix B

E-Supplement for the manuscript titled, “What Aspects of Personal Care Are Most Important to Patients Undergoing Radiation Therapy for Prostate Cancer?”

Appendix B1: Expanded Methods

Defining the Scope of Personal Care

Personal care was defined here as including all the nontechnical elements of care provided to patients within a health care institution. We used a “bottom-up” inductive approach to identify elements of personal care pertinent to patients undergoing radiation therapy for prostate cancer. We reviewed the literature and analyzed the content of existing instruments for measuring patients’ satisfaction and patients’ needs to identify a pool of questions relating to individual elements of personal care pertinent to patients undergoing radiation therapy for prostate cancer. Literature searches were conducted in MEDLINE. A comprehensive search strategy was used to target previous work on the assessment of personal care. Specific search terms included: “patient satisfaction”, “questionnaire”, “process assessment”, “patient care”, “quality of health care”, “quality indicators, health care”, “health care surveys”, “needs assessment”, “patient centered care”, and “health care quality, access and evaluation”. This search was conducted in December 2009 and since we wanted to identify recent work on this topic, only papers published between 1996 and 2009 were considered. The references from relevant papers were also searched and papers outside of the targeted year range were included. The ‘grey’ literature was also searched

using Google with the above key words. See appendix B2 for a complete list of sources that provided the 500 elements of care initially included in the study (see Figure 3-1).

Classifying the Elements of Care

We then classified these individual elements into 10 categories, each relating to a particular aspect of the quality of personal care. A preliminary classification, based on concepts and terms used in the literature pertaining to quality of care, patient satisfaction, and patients' rights, was expanded to accommodate all the elements of personal care (95) (Table 3-1). Two reviewers (KAF an epidemiologist, and WJM a radiation oncologist) classified each element independently and consensus was reached on elements where reviewers disagreed.

Mapping the Elements of Care to the Continuum of Care

Each element of care was mapped to the corresponding step in the continuum of care as shown in Figure 3-1. KAF and DW organized the elements into sub groups within each step of the care continuum and within each aspect of care based on similarity. Areas of disagreement were discussed with WJM and consensus was reached. Redundant and closely overlapping elements were identified and replaced by a single element which was constructed by KAF and WJM to capture the focus of the similar items.

Questionnaire Development

We then constructed a self-administered questionnaire in which each element of care was presented as a positive statement (Figure 3-2). All the elements of quality of personal care were presented as positive statements to minimize the risk of patients becoming confused as they worked their way through this long questionnaire. Elements of care were organized by topic and

we also ensured that their order followed the temporal sequence of events during care delivery. Patients were asked to rate the importance of each element, on an ordinal scale, as shown in Figure 3-2. Patients were also asked to rate the quality of each element of their personal care. Only the ratings of importance were analyzed here. Patients' assessment of quality will be described in a future manuscript.

Cognitive Interviews

The questionnaire was revised based on the basis of feedback about its clarity and comprehensiveness, obtained through cognitive interviews conducted by KAF with a convenience sample of 8 patients who had undergone radiation therapy for prostate cancer and 4 health professionals from the Cancer Centre of Southeastern Ontario (CCSEO) involved in the care of patients with prostate cancer.

Because the questionnaire was long, the interview was split into a series of interviews, arranged so that each one took approximately one hour. Five of the eight patients completed the full questionnaire in a series of interviews; three patients only completed part of the questionnaire. Pre-scripted verbal probes were primarily used to gather information about the cognitive processes used to rate each indicator (7). Spontaneous verbal probes were also used during the interviews, as the need arose. We made many changes to the questionnaire in response to feedback provided by the interviewees, including: changes to the response categories; changes to the order in which the elements were presented; addition of new elements; elimination of redundant elements; and clarification of the wording of confusing elements (Figure 3-1).

Configuring the Questionnaire

The final questionnaire was divided into 3 modules, designed to be administered sequentially. Module 1, including elements pertinent to pretreatment assessment and the treatment decision, was administered in the first week of treatment; module 2, including elements pertinent to treatment delivery and plans for follow-up was administered at the end of treatment; and module 3, elements relating to general aspects of care, was administered at first follow-up visit (7) (Figure 3-1).

Each module also asked the patient to identify any other elements of care that he thought should be included. Preliminary testing on 28 patients showed that it was feasible for them to complete the questionnaire without difficulty or distress. Patients did not suggest any new elements of care to add to the questionnaire (7).

Survey Population

Patients starting radical external beam radiation therapy for localized prostate cancer at CCSEO between May 2011 and August 2014 were eligible to participate. Patients with clinically positive nodes were excluded. Patients who were incarcerated were excluded. Patients were excluded if the attending oncologist did not approve their recruitment (see Figure B1). Patients who had undergone prostatectomy or would receive brachytherapy were excluded. Patients who received adjuvant hormonal treatment were included. Patients with low-risk localized disease received single-phase IMRT photon therapy, 70 Gy/ 35 fractions to the prostate and proximal seminal vesicles with a 0.8 cm margin for planning treatment volume. Patients with intermediate-risk disease received 76 Gy/38 fractions to the same volume with the same technique. Patients with high-risk localized disease (PSA >20ng/ml or Gleason Score 8 or higher, clinically node

negative) received two phase treatment, with 46 Gy/23 fractions to prostate and pelvic nodes, followed by IMRT boost of 30 Gy/15 fractions to the prostate and proximal seminal vesicles, and 2 years of adjuvant hormonal therapy. Radiation therapy was usually started within 30 days of start of hormonal therapy; long courses of neoadjuvant therapy were not utilized during the study period.

Administration of the Questionnaire

Patients were invited to participate in the study during their first week of radiation therapy. Participants were assured that their responses were confidential and that they would remain anonymous. Consenting patients were given each module of the questionnaire by hand at the appropriate point in time (Figure 3-1) along with a stamped addressed envelope in which to return it. Patients were asked to complete the questionnaire at home to give them as much time as they wished to complete this task and the opportunity to do so in the privacy and security of their own home.

To assess test-retest reliability, patients recruited after May 2012 were mailed a second copy of module 3 within 10 days of the return of the first copy, and were asked to complete it upon receipt. Test-retest reliability was assessed on module 3 only, because it was not deemed feasible to assess reliability at the points in time when modules 1 and 2 were administered because the patient's health and treatment status was rapidly evolving. Our intention was to have patients complete the second copy of module 3, 10-14 days after they had completed the first. We selected this period for assessing the reliability of importance ratings, on the assumption that it would probably be long enough to prevent them from recalling their previous scores, but probably not long enough for a change in their true beliefs about the importance the elements of care included

in module 3. Although we planned for a test-retest interval of 10-14 days, this was not strictly controlled and patients who returned their second copy of module 3 later than we had intended were not excluded from the analysis.

Data Management

Questionnaires were stored in a locked cabinet in a secure facility. Patients were identified by study number only. Data were entered into a password-protected Microsoft Access database with the use of double entry. Analyses were conducted with SAS 9.3 (151).

Analyses

Ranking by Importance

Two different methods were used to rank the importance of the elements of care. We first dichotomized the ratings of importance provided on the 4-point scale shown in Figure 3-2, as “very important” *versus* less important. The elements of care were then ranked based on the proportion of patients rating each as “very important”, with ties being resolved based on the proportion rating each as “important”, and, if necessary, by the proportion rating each as “somewhat important” (Method A). We also calculated the rank assigned to each element, by each individual patient, using fractional ranking to deal with ties. We then calculated the mean rank assigned to each element by the group of patients. Finally, each element was ranked based on the mean rank assigned to it by the group (Method B). For the overall group of patients, the two methods yielded almost identical results (Spearman $r = .99$). We therefore used the simpler method A in our primary analysis. The importance of the 10 aspects of personal care was

calculated by the mean importance of its constituent elements. The importance of different aspects of care was compared using generalized estimating equations.

Sample size

Since we planned to describe importance by the proportion of patients rating each element “very important”, a target sample size of 96 patients was set to ensure maximum confidence intervals of $\pm 10\%$ on proportions of patients (152).

Agreement

We calculated the percentage of patients agreeing with the majority opinion on whether each element of care was or was not “very important” using the following formula: $50 + |50 - \% \text{ “very important”}|$ (153). This is scaled from 50 to 100, where 50 is complete disagreement and 100 is complete agreement. A threshold of agreement was set at 60% because at 60% agreement with 108 respondents, the 95% confidence interval just excludes 50 and therefore represents the majority opinion.

Test-retest Reliability

Test-retest reliability was described by concordance on ratings of “very important”, referred to as percentage of positive agreement (154). The K statistic was not used to describe test-retest reliability because the distribution of responses was skewed toward “very important” (155).

Patient characteristics and importance rankings

Spearman correlation was used to compare the importance rankings of different subgroups of patients defined by age, education and health status. Initially we used Method A to compare the percentage of patients rating each element of care “very important” between subgroups, but we realized this method was influenced by the way in which different groups of individuals use the scale. For example, younger patients tended to rate more things “very important” than older patients, and as a result, many elements of care were identified as significantly different between these two groups simply because older and younger patients used the scale differently. Therefore, Method B was used here to rank the elements of care because it is not influenced by the way in which different groups of individuals use the scale. The Wilcoxon rank sum test was used to compare differences in the importance of individual elements of care from the perspective of different subgroups of patients. This exploratory analysis involved multiple comparisons, and we therefore applied the procedure suggested by Benjamini and Hochburg (156) in assessing statistical significance, with the acceptable false discovery rate set at 0.25.

Appendix B2: Source references used to identify elements and aspects of the quality of personal care relevant to patients undergoing radiation therapy for prostate cancer

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Figure B1: Recruitment and retention of patient study subjects. The attending radiation oncologist excluded 17 patients for the following reasons: anxiety (5), depression (2), schizophrenia (2), cognitive difficulties (2), language barrier (1), other co-morbidities (3). Reasons for exclusion for 2 patients are unknown.

Appendix B3: Time to completion, Response Rate by Module and Completeness of Responses

The median time of completion was: module 1, 23 minutes (range 7-70); module 2, 10 minutes (range 2-35); and module 3, 13 minutes (range 5-40). The median time for completion of the complete questionnaire (all three modules) was 46 minutes (range 17 to 105).

The response rate for module 1 (for the 139 patients provided with all 3 modules of the questionnaire) was 86%. The response rate for module 2 (conditional on completing module 1) was 95% and the response rate for module 3 (conditional on completing modules 1 and 2) was 93%.

There were few missing responses. Ratings of importance were provided by >90% of patients for every element; the mean completeness of responses for all elements was 98.4%. Mean completeness of responses rates was: higher for younger patients *cf* older patients (98.8% vs 98.1%); higher in those with more education *cf* less education (99.2% vs 97.6%); and higher in those in excellent health *cf* those in poorer health (98.7% vs 98.2%). These differences were statistically significant ($p<.05$), but too small to have any meaningful impact on our results.

We conducted a sensitivity analysis to assess the impact of missing data on our rank order. Missing responses were coded as “very important” and the elements of care were re-ranked based on the percentage of patients rating each one as “very important”. The Spearman correlation

coefficient comparing the new rank order to the original order was 1.0 and there were no changes in the 10 highest and 10 lowest ranked elements of care.

Table B3-1: Patient characteristics

Characteristic	# of Patients (%)
Age	
<50	0 (0)
50-59	7 (7)
60-69	40 (37)
≥70	61 (56)
Education Level	
Less than high school	17 (16)
High school	36 (33)
College diploma	24 (22)
University degree	16 (15)
Post-graduate degree	9 (8)
Unknown	6 (6)
Marital Status	
Single	0 (0)
Separated/Widowed/Divorced	12 (11)
Married/Living common-law	91 (84)
Unknown	5 (5)
Health Status	
Poor	1 (1)
Fair	14 (13)
Good	55 (51)
Excellent	32 (30)
Unknown	6 (6)

*Percentages may not add up to 100 due to rounding.

Table B3-2: Importance ratings for all elements of the quality of personal care

Element of Care	Importance (Method A: % “Very Important”)		Importance (Method B: mean ranks)
	% (95% CI)	Rank	Rank
The radiation oncologist is knowledgeable and experienced in dealing with prostate cancer	95.3 (89.4, 98.5)	1	1
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body	93.5 (87.0, 97.3)	2	2
The patient trusts the radiation oncologist to look after him properly	91.6 (84.6, 96.1)	3	3
The cancer centre seems to have all the equipment and facilities needed to completely care for the patient’s prostate cancer	88.0 (80.3, 93.4)	4	4
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer	87.8 (80.1, 93.3)	5	6
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer	87.0 (79.2, 92.7)	6	5
The radiation oncologist takes the time to answer all of the patient’s questions	86.9 (79.0, 92.7)	7	7
The radiation oncologist is honest with the patient	86.0 (77.9, 91.9)	8	8
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means	85.0 (76.9, 91.2)	9	9
The radiation oncologist gives the patient enough information about the side effects of each treatment option	84.8 (76.4, 91.0)	10	11
The radiation oncologist makes the patient feel like he can ask any questions he wants to	84.1 (75.8, 90.5)	11	10
The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means	83.2 (74.7, 89.7)	12	12
The nurses are knowledgeable and experienced in dealing with prostate cancer	83.0 (74.5, 89.6)	13	13
The radiation oncologist is aware of the test results and has the results available when seeing the patient for the first time	82.7 (74.0, 89.4)	14	15
The radiation oncologist explains the different forms of treatment that are available for prostate cancer	82.1 (73.4, 88.8)	15	17

The radiation oncologist makes sure the patient understands the benefits of radiation treatment and its side effects before asking for consent to have radiation treatment	81.3 (72.6, 88.2)	16	16
The patient is aware of who to contact with questions about his prostate cancer and treatment	81.3 (72.6, 88.2)	16	19
The radiation oncologist listens carefully to all the patient's concerns	81.3 (72.6, 88.2)	16	18
The radiation oncologist explains things to the patient in a way that he can understand	81.1 (72.4, 88.1)	19	20
The radiation therapists are honest with the patient	81.0 (72.1, 88.0)	20	14
The patient is given enough information about the possible side effects of radiation treatment	80.2 (71.3, 87.3)	21	22
The patient gets all the help he needs from the radiation oncologist to make up his mind about which treatment to have	80.2 (71.3, 87.3)	22	25
The patient has confidence in his treatment team that he is treated correctly every day	79.2 (70.3, 86.5)	23	21
The radiation oncologist carefully assesses the patient's suitability for radiation treatment	78.8 (69.7, 86.2)	24	24
The information about treatment options is provided to the patient before any decision is made about the way he will be treated	78.1 (69.0, 85.6)	25	28
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option	78.1 (69.0, 85.6)	26	27
The patient trusts the radiation therapists to look after him properly	77.8 (68.8, 85.2)	27	23
The patient is given enough information about the chance of curing his cancer with radiation treatment	77.4 (68.2, 84.9)	28	29
The radiation oncologist makes sure the patient understands the treatment options before making up his mind about which treatment to have	77.4 (68.2, 84.9)	29	34
The radiation oncologist cares about the patient's well-being	76.6 (67.5, 84.3)	30	26
The radiation oncologist treats the patient with respect	76.6 (67.5, 84.3)	31	30
The patient has enough time with the radiation oncologist to get all of the information he needs about treatment options	76.4 (67.2, 84.1)	32	35
The patient gets enough information from the radiation oncologist to be able to participate in the decision about treatment	76.2 (66.9, 84.0)	33	36

The patient is made aware of who to contact if he is concerned about the cancer coming back	75.9 (66.8, 83.6)	34	33
The radiation oncologist makes sure the patient understands the results of the biopsy of the prostate, the blood tests, and any x-rays and scans he may have had	75.7 (66.5, 83.5)	35	31
The nurses explain things to the patient in a way that he can understand	74.8 (65.4, 82.7)	36	31
The radiation therapists explain things to the patient in a way that he can understand	73.6 (64.2, 81.7)	37	37
During treatment, the radiation oncologist, nurses and radiation therapists do everything they can to help the patient get through treatment with as few problems as possible	73.6 (64.2, 81.7)	38	38
The patient is involved as much as he wants in making the final decision about which treatment to have	73.6 (64.2, 81.7)	39	46
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function	73.3 (63.8, 81.5)	40	39
Someone on the healthcare team explains that doctors will be monitoring PSA levels at regular intervals during follow-up from radiation treatment	73.2 (63.8, 81.2)	41	40
Someone on the healthcare team explains that radiation treatment may permanently affect bladder function	72.4 (62.8, 80.7)	42	42
The nurses take the time to answer all of the patient's questions	72.0 (62.4, 80.2)	43	41
The nurses listen carefully to all the patient's concerns	72.0 (62.4, 80.2)	44	45
The nurses make the patient feel like he can ask any questions he wants to	72.0 (62.4, 80.2)	44	43
The patient trusts the nurses to look after him properly	72.0 (62.4, 80.2)	46	44
The nurses are honest with the patient	71.4 (61.8, 79.8)	47	47
The cancer centre appears to be clean and well looked after	70.0 (60.5, 78.6)	48	48
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time	69.9 (60.1, 78.6)	49	51
The patient has enough time to consider the treatment options before it is decided how he will be treated	70.0 (60.1, 78.6)	50	59

Someone on the healthcare team explains that the PSA level is all that is needed to tell if the cancer is under control or not	69.5 (59.8, 78.1)	51	53
The radiation oncologist reads the patient's previous medical records before seeing the patient for the first time	69.2 (59.4, 77.9)	52	56
Someone on the healthcare team explains the arrangements for follow-up care after the radiation treatment is over	68.9 (59.1, 77.5)	53	50
The radiation therapists make the patient feel like he can ask any questions he wants to	68.6 (58.8, 77.3)	54	49
The radiation oncologist is polite to the patient	68.5 (58.9, 77.1)	55	55
The radiation oncologist describes and explains all of the treatment options that are available to the patient other than radiation treatment	68.3 (58.4, 77.0)	56	60
The radiation oncologist explains what each treatment option involves	68.3 (58.4, 77.0)	56	57
The radiation therapists take the time to answer all of the patient's questions	67.9 (58.2, 76.7)	58	52
Someone on the healthcare team explains that radiation treatment often causes urinary symptoms during treatment	67.3 (57.6, 76.0)	59	61
The radiation therapists listen carefully to all the patient's concerns	66.7 (56.8, 75.6)	60	54
The nurses treat the patient with respect	66.7 (56.8, 75.6)	61	58
The radiation oncologist tells the patient about his PSA level and explains what that means	66.4 (56.6, 75.2)	62	63
The radiation oncologist shows sensitivity to the patient's feelings and emotional needs	65.7 (56.0, 74.6)	63	64
Someone on the healthcare team explains who to contact if additional care is needed in recovery after radiation treatment	65.7 (55.8, 74.7)	64	62
Someone on the healthcare team explains that radiation treatment often causes bowel symptoms during treatment	65.4 (55.6, 74.4)	65	65
Someone on the healthcare team gives the patient written information about the side effects of each treatment option	65.1 (55.2, 74.1)	66	66
Someone on the healthcare team is always available to answer the patient's questions and advise on the management of side effects during the course of radiation treatment	64.8 (55.0, 73.8)	67	67
The nurses care about the patient's well-being	64.8	68	68

	(54.8, 73.8)		
The radiation oncologist asks the patient about any other medical problems he may have	63.8 (53.8, 73.0)	69	70
Someone on the health care team offers written information about prostate cancer to the patient that he can take home with him	63.8 (53.8, 73.0)	70	71
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful	63.4 (53.2, 72.7)	71	74
The radiation therapists care about the patient's well-being	62.9 (52.9, 72.1)	72	69
The patient is given enough information to understand how the radiation treatment works	62.3 (52.3, 71.5)	73	76
Someone on the healthcare team explains that radiation treatment involves the use of high energy rays directed at the prostate from outside the body	61.7 (51.8, 70.9)	74	72
The patient feels that he can trust the radiation oncologist with confidential information	61.7 (51.8, 70.9)	75	73
Someone at the cancer centre is available to answer the patient's questions in between appointments	61.3 (51.4, 70.6)	76	75
Someone at the cancer centre arranges for the patient to receive any help he needs in dealing with his anxiety about the diagnosis	60.9 (38.5, 80.3)	77	109
The radiation therapists treat the patient with respect	60.4 (50.4, 69.8)	78	78
The patient feels that his rights for privacy are fully protected at the cancer centre	60.2 (50.3, 69.5)	79	82
Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment	60.2 (50.3, 69.5)	80	84
The nurses are polite to the patient	59.8 (49.9, 69.2)	81	77
Someone on the healthcare team explains that radiation treatment may permanently affect sexual functioning	59.8 (49.9, 69.2)	82	92
The patient understands that there is no immediate rush to make a decision about treatment although it's best to make a decision within a week or two	59.4 (49.5, 68.9)	83	85
The patient feels that he can trust the radiation therapists with confidential information	59.3 (49.4, 68.6)	84	79
The radiation therapists are polite to the patient	59.0	85	80

	(49.0, 68.6)		
Someone on the healthcare team explains what prostate cancer is and how it can affect the patient's health	58.6 (48.6, 68.2)	86	81
The radiation therapists show sensitivity to the patient's feelings and emotional needs	58.5 (48.5, 68.0)	87	83
The patient is aware that no one else other than him and the healthcare professionals looking after him are able to see his medical records without his permission	58.3 (48.4, 67.8)	88	99
The nurses show sensitivity to the patient's feelings and emotional needs	58.1 (48.1, 67.7)	89	89
The radiation oncologist shows interest in the patient as a person, not just as a patient	58.1 (48.1, 67.7)	90	93
The patient's family physician is kept informed about the cancer care	57.4 (47.5, 66.9)	91	95
Someone on the healthcare team explains that the course of treatment needs to be completed without taking a break (of longer than a few days)	57.0 (47.1, 66.5)	92	87
Someone on the healthcare team explains that radiation treatment often causes temporary fatigue	56.6 (46.6, 66.2)	93	94
The patient feels that he can trust the nurses with confidential information	56.5 (46.6, 66.0)	94	86
The radiation oncologist explains to the patient that he can change his mind about which treatment to have as long as he does so before the treatment starts	56.2 (46.2, 65.9)	95	97
Someone on the healthcare team answers any questions the patient has about the possible causes of prostate cancer	56.1 (39.8, 71.5)	96	110
The patient is given enough information about how the radiation treatment is planned	56.1 (46.2, 65.7)	97	88
The patient has enough time with a member of the healthcare team to discuss the treatment plan	56.1 (46.2, 65.7)	97	90
The radiation therapists show interest in the patient as a person, not just as a patient	54.3 (44.3, 64.0)	99	103
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment	54.2 (44.3, 63.9)	100	98
The patient is aware that he has a right to see all the information in his medical record	54.2 (44.3, 63.9)	101	96
Someone on the healthcare team gives enough information and direction to the patient about how to care for himself after radiation treatment	53.8 (43.8, 63.5)	102	91

The nurses show interest in the patient as a person, not just as a patient	53.8 (43.8, 63.5)	103	104
Someone on the healthcare team explains how the patient should modify his diet to avoid bowel upset during the course of radiation treatment	53.7 (43.8, 63.4)	104	100
The patient has a short wait to start treatment after the decision was made to have radiation treatment	53.3 (43.4, 63.0)	105	102
The cancer centre has a place to stay overnight if the patient lives far away	53.0 (42.8, 63.1)	106	111
The patient has a short wait to get an appointment to see the radiation oncologist for the first time	51.9 (42.0, 61.7)	107	106
Before radiation treatment starts, the patient is given enough information about what will happen each day when he comes for treatment	51.8 (42.0, 61.6)	108	101
The patient is given enough information about how the treatment is scheduled and flexibility in the daily appointment times	51.4 (41.5, 61.2)	109	108
If the patient wants, the radiation oncologist is willing to answer all the questions the patient's family and friends have	50.6 (39.3, 61.9)	110	105
Once an appointment is made for the patient it is not cancelled or postponed	49.1 (39.3, 58.9)	111	107
Transportation to/from the cancer centre is available for the patient if needed	49.0 (38.7, 59.3)	112	119
There is somewhere convenient to park	45.8 (36.1, 55.7)	113	112
If the patient wants, someone on the healthcare team is willing to answer questions about treatment from family or friends	45.6 (30.9, 61.0)	114	121
Once the treatment starts, someone on the healthcare team reminds the patient of the potential side effects to expect during the course of radiation treatment	43.5 (34.0, 53.4)	115	113
The patient is encouraged by the cancer centre to bring a relative or friend along to the first appointment with the radiation oncologist	43.4 (33.8, 53.4)	116	118
Someone on the healthcare team is available if needed to help explain the diagnosis to family members	43.0 (33.1, 53.3)	117	127
The patient is welcome to bring a friend or relative with him to his appointments	42.9 (33.2, 52.9)	118	115
Someone on the healthcare team explains that prostate cancer is not infectious and that it cannot be transmitted to anyone else	42.6 (32.8, 52.8)	119	123

Someone on the healthcare team explains that radiation treatment is delivered by the radiation therapists, not a radiation oncologist	42.1 (32.6, 52.0)	120	125
The radiation oncologist or the nurse see the patient at least once a week during the course of radiation treatment	41.5 (32.0, 51.5)	121	114
Appointments are scheduled for a time that is convenient	39.8 (30.5, 49.7)	122	116
Directions and signs inside and outside the cancer centre are easy to understand	39.6 (30.2, 49.6)	123	120
The patient has enough privacy during his care	38.9 (29.7, 48.8)	124	117
Someone on the healthcare team explains that radiation treatment can only be delivered at a few specialized treatment centres	38.2 (28.8, 48.4)	125	131
The patient is made aware that he has the right to get a second opinion from another radiation oncologist	38.1 (28.8, 48.1)	126	130
The patient can find his way around the cancer centre easily	38.0 (28.8, 47.8)	127	122
The atmosphere in the waiting room is relaxing	37.0 (27.9, 46.9)	128	124
The patient has a short wait in the waiting room for daily radiation treatment	36.1 (27.1, 45.9)	129	128
The radiation oncologist sees the patient at least once a week during the course of radiation treatment	35.9 (26.7, 46.0)	130	129
During treatment, the radiation therapists make enough time for the patient	34.9 (25.9, 44.8)	131	126
Someone on the healthcare team other than the radiation oncologist is available to provide support to the patient in making the decision about treatment	34.6 (25.6, 44.6)	132	132
The cancer centre provides resources to assist the patient in understanding and dealing with prostate cancer (e.g. staffed information services, library of books and DVDs about cancer)	32.7 (23.7, 42.7)	133	133
The waiting area and treatment rooms are quiet	30.6 (22.0, 40.2)	134	134
The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time	26.4 (18.3, 35.9)	135	135
A social worker is available to provide advice on financial and social issues arising from the diagnosis	24.7 (16.5, 34.4)	136	140

Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members	23.8 (15.9, 33.3)	137	137
The furniture in the waiting room is comfortable	23.2 (15.6, 32.2)	138	136
The patient sees the same radiation therapists each time he goes for radiation treatment	22.2 (14.8, 31.2)	139	139
There is enough space in the waiting room that the patient can have a private conversation with his companion	19.6 (12.6, 28.4)	140	138
Food and drink facilities are available in or near the waiting room	11.3 (6.0, 18.9)	141	142
Waiting areas are decorated nicely	10.4 (5.3, 17.8)	142	141
The patient is treated in the same treatment room each day	6.6 (2.7, 13.1)	143	143

Table B3-3: Elements of care with <70% positive agreement

Element of Care	Positive Agreement (%)	Rank (% “Very Important”)
Waiting areas are decorated nicely	67	142
If the patient wants, the radiation oncologist is willing to answer all the questions the patient’s family and friends have	65	110
The furniture in the waiting room is comfortable	62	138
Food and drink facilities are available in or near the waiting room	60	141
There is enough space in the waiting room that the patient can have a private conversation with his companion	58	140

Appendix C

Additional results for the manuscript titled, “What Aspects of Personal Care Are Most Important to Patients Undergoing Radiation Therapy for Prostate Cancer?”

Appendix C1: Additional rationale for our sample size calculation

Since we planned to describe importance by the proportion of patients rating each element “very important”, a target sample size of 96 patients was set to ensure maximum confidence intervals of $\pm 10\%$ on proportions of patients. In discussion amongst our study team we agreed that a maximum of $\pm 10\%$ would provide a reasonable degree of precision on our proportions. We agreed that it was not practical or feasible to significantly extend the study period to recruit additional study participants in order to obtain narrower confidence limits.

Appendix C2: Comparing ages between responders and non-responders

Table C2-1 shows the age distribution of responders and non-responders, $p=0.90$.

	Age <70 N (%)	Age ≥ 70 N (%)	Total
Non responder	17 (45)	21 (55)	38
Responder	47 (44)	61 (56)	108
Total	64	82	146*

*Although there were 147 patients who consented to participate in this study, one patient’s treatment was discontinued and therefore became ineligible (Figure B1, Appendix B).

Appendix C3: Assumptions of Generalized Estimating Equations

Generalized Estimating Equations (GEE) assumes that data is missing completely at random (MCAR). This assumption is not likely met in our dataset, but we decided not to use imputation to address this. Previous research has shown imputation is not necessarily needed when using GEE as results on incomplete datasets are comparable to results when imputation is used (193). Additionally, the amount of missing data in our study was low. For each patient, the median percentage of elements missing an importance rating was 0% (range 0% to 22%, IQR 0% to 1%).

The working correlation structure must be specified when using GEE to ensure parameters are estimated appropriately. We compared various correlation structures using the QIC for comparison, and although the “independent” structure resulted in the smallest QIC, we decided to use the “exchangeable” correlation structure instead. The exchangeable correlation structure assumes that correlations within a subject are equally correlated, which we felt was more appropriate than an independent correlation structure. When QIC values are similar, selecting a correlation matrix that makes more sense theoretically has been identified as an appropriate approach (194). However, fortunately GEE is robust to the choice of correlation structure even if we have misspecified the correlation matrix (195).

Table C3-1: QIC values for different GEE correlation structures

Correlation structure	QIC value
Exchangeable	19279.6
Autoregressive	22755.0

Independent	19278.9
Unstructured	19685.2

Appendix C4: Timing of module 1 in relation to the diagnosis

After this study was published we completed a chart review. The median length of time from diagnosis to the beginning of treatment in this study population was about 12 weeks (median 12.1 weeks, IQR 9.3-19.6).

Appendix D

E-Supplement for the Manuscript titled, “Development and Comparison of Methods to Identify Priorities for Improvement of the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer”

Appendix D1: Missing Responses and Sensitivity Analyses

We conducted a sensitivity analysis to assess the impact of missing data on our ranking of priorities for quality improvement by the individual priority-based method. For each patient, missing responses were coded for importance and quality as “very important” and less than “very good”, respectively. The elements of care were re-ranked based on the percentage of patients rating each one as a priority for quality improvement. The Spearman correlation coefficient comparing the new rank order to the original order was 1.0 and there were no changes in either the specific elements of care or in the rank order of the elements identified as the 10 highest priorities for quality improvement.

Appendix D2: Assumptions of Generalized Estimating Equations

Assumptions of GEE were outlined in Appendix C3 with respect to the analysis of the results of the importance ratings. However the same approach was used here; we did not use imputation to deal with missing data as it is not necessarily needed with GEE (193) and again, the amount of missing data was relatively low as described in the results. As a reminder, for each patient, the

median number of elements missing an importance rating was 0 (range 0 to 32, IQR 0 to 2), and the median number of elements missing a quality rating was 9 (range 0 to 49, IQR 5 to 16). Again, we compared various correlation structures using the QIC. For simplicity, I have only shown the QIC for the models using the individual priority-based method. However again, we chose the “exchangeable” structure as we felt it was most appropriate for these data (194).

Table D2-1: QIC values for different correlation structures (comparing the top 10 to the bottom 10 using the individual priority-based method)

Correlation structure	QIC value
Exchangeable	1368.4
Autoregressive	1368.5
Independent	1369.3
Unstructured	Not calculated (error)

Table D2-2: QIC values for different correlation structures (comparing the top 3 to the next 3 using the individual priority-based method)

Correlation structure	QIC value
Exchangeable	705.3
Autoregressive	705.7
Independent	705.2
Unstructured	705.6

Table D2-3: QIC values for different correlation structures (comparing the top 5 to the next 5 using the individual priority-based method)

Correlation structure	QIC value
Exchangeable	1215.0
Autoregressive	1215.2
Independent	1215.2
Unstructured	QIC calculated, but procedure terminated due to errors

Table D2-4: QIC values for different correlation structures (comparing the top 10 to the next 10 using the individual priority-based method)

Correlation structure	QIC value
Exchangeable	2061.7
Autoregressive	2062.5
Independent	2062.9
Unstructured	Not calculated (error)

Table D2-5: QIC values for different correlation structures (comparing the top 15 to the next 15 using the individual priority-based method)

Correlation structure	QIC value
Exchangeable	2760.1
Autoregressive	2061.0
Independent	2761.3
Unstructured	Not calculated (error)

Appendix D3: The full ranking of priorities for quality improvement identified by each method

Table D3-1: The elements of care identified by each method for identifying targets for quality improvement

	Summary Ratings				Methods*					
	Quality		Importance		Individual priority-based		Group priority-based		Group ranking-based	
Element of Care	Inverse rank	% “Very Good” (95% CI)	Rank	% “Very Important” (95% CI)	Rank	% “very good” AND “very important”	Rank	(100% - % “very good”)*(% “very important”)	Rank	Lower rank of inverse quality or importance
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time	4	39.8 (29.8, 50.5)	49	69.9 (60.1, 78.6)	1	40.9 (30.8, 51.6)	1	4209.4	5	49
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful	5	41.9 (31.8, 52.6)	71	63.4 (53.2, 72.7)	2	34.8 (25.2, 45.4)	2	3679.3	22	71
There is somewhere convenient to park	2	35.2 (26.2, 45.2)	113	45.8 (36.1, 55.7)	3	29.5 (21.0, 39.2)	3	2965.4	82	113
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function	33	65.0 (55.0, 74.2)	40	73.3 (63.8, 81.5)	4	23.5 (15.7, 33.0)	9	2562.9	2	40
Someone on the healthcare team explains what prostate cancer is and how it can affect the patient’s health	12	50.0 (39.6, 60.4)	86	58.6 (48.6, 68.2)	5	22.9 (15.0, 32.6)	4	2932.5	38	86
Someone on the healthcare team	30	63.1	42	72.4	6	22.6	6	2670.1	3	42

explains that radiation treatment may permanently affect bladder function	(53.0, 72.4)	(62.8, 80.7)	(14.9, 31.9)		
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body	66 77.7 (68.4, 85.3)	2 93.5 (87.0, 97.3)	7 20.4 (13.1, 29.5)	20 2087.0	16 66
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment	16 55.1 (44.1, 65.6)	100 54.2 (44.3, 63.9)	8 20.2 (12.4, 30.1)	12 2436.2	58 100
The patient is given enough information to understand how the radiation treatment works	15 54.7 (44.8, 64.4)	73 62.3 (52.3, 71.5)	9 20.0 (12.8, 28.9)	5 2819.1	23 73
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option	38 66.3 (56.2, 75.4)	26 78.1 (69.0, 85.6)	10 19.8 (12.5, 28.9)	7 2628.8	1 38
The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means	52 73.3 (64.5, 81.6)	12 83.2 (74.7, 89.7)	10 19.8 (12.5, 28.9)	15 2223.4	8 52
The patient is made aware of who to contact if he is concerned about the cancer coming back	42 67.4 (56.5, 77.2)	34 75.9 (66.8, 83.6)	12 19.8 (12.0, 29.8)	11 2472.3	3 42
Someone on the healthcare team gives enough information and direction to the patient about how to care for himself after radiation treatment	20 57.6 (46.9, 67.8)	102 53.8 (43.8, 63.5)	13 19.6 (12.0, 29.2)	14 2279.3	62 102
Someone at the cancer centre arranges for the patient to receive any help he needs in dealing with his anxiety about the diagnosis	21 59.1 (36.4, 79.3)	77 60.9 (38.5, 80.3)	14 18.2 (5.2, 40.3)	10 2490.2	29 77
Someone on the healthcare team	29 63.0	64 65.7	15 17.4	13 2428.6	14 64

explains who to contact if additional care is needed in recovery after radiation treatment	(52.3, 72.9)	(55.8, 74.7)	(10.3, 26.7)		
The radiation oncologist gives the patient enough information about the side effects of each treatment option	60 76.0 (66.6, 83.8)	10 84.8 (76.4, 91.0)	16 17.3 (10.6, 26.0)	25 2037.6	11 60
The radiation oncologist tells the patient about his PSA level and explains what that means	41 67.3 (57.3, 76.3)	62 66.4 (56.6, 75.2)	17 16.8 (10.1, 25.6)	17 2168.0	13 62
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means	58 75.5 (66.0, 83.5)	9 85.0 (76.9, 91.2)	18 16.7 (10.0, 25.3)	21 2084.6	10 58
Someone on the healthcare team explains that the PSA level is all that is needed to tell if the cancer is under control or not	50 72.4 (61.8, 81.5)	51 69.5 (59.8, 78.1)	19 16.1 (9.1, 25.5)	27 1918.1	6 51
Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment	31 64.5 (54.6, 73.5)	80 60.2 (50.3, 69.5)	20 15.9 (9.5, 24.2)	18 2137.3	32 80
Someone on the healthcare team explains how the patient should modify his diet to avoid bowel upset during the course of radiation treatment	25 61.7 (51.8, 70.9)	104 53.7 (43.8, 63.4)	20 15.9 (9.5, 24.2)	24 2057.8	66 104
Someone on the healthcare team explains that the course of treatment needs to be completed without taking a break (of longer than a few days)	40 67.0 (57.0, 75.9)	92 57.0 (47.1, 66.5)	22 15.5 (9.2, 24.0)	29 1881.9	46 92
The radiation oncologist makes sure the patient understands the results of the biopsy of the prostate, the blood tests, and any x-rays and scans he	61 76.0 (66.6, 83.8)	35 75.7 (66.5, 83.5)	23 15.4 (9.1, 23.8)	32 1819.8	12 61

may have had					
Someone on the healthcare team answers any questions the patient has about the possible causes of prostate cancer	13 53.8 (37.2, 69.9)	96 56.1 (39.8, 71.5)	23 15.4 (5.9, 30.5)	8 2589.0	52 96
The patient is made aware that he has the right to get a second opinion from another radiation oncologist	9 47.3 (36.9, 57.9)	126 38.1 (28.8, 48.1)	25 15.2 (8.6, 24.2)	26 2007.5	108 126
The patient is given enough information about the chance of curing his cancer with radiation treatment	51 73.1 (63.5, 81.3)	28 77.4 (68.2, 84.9)	26 14.6 (8.4, 22.9)	22 2082.5	6 51
Someone on the healthcare team explains that doctors will be monitoring PSA levels at regular intervals during follow-up from radiation treatment	73 79.4 (70.0, 86.9)	41 73.2 (63.8, 81.2)	27 14.4 (8.1, 23.0)	50 1508.4	23 73
The radiation oncologist makes sure the patient understands the benefits of radiation treatment and its side effects before asking for consent to have radiation treatment	64 77.4 (68.2, 84.9)	16 81.3 (72.6, 88.2)	28 14.3 (8.2, 22.5)	30 1840.9	14 64
The patient is given enough information about how the radiation treatment is planned	27 62.9 (52.9, 72.1)	97 56.1 (46.2, 65.7)	29 13.6 (7.6, 21.8)	23 2082.4	54 97
Someone on the healthcare team explains that prostate cancer is not infectious and that it cannot be transmitted to anyone else	11 50.0 (39.0, 61.0)	119 42.6 (32.8, 52.8)	30 12.8 (6.6, 21.7)	19 2128.5	94 119
Someone on the healthcare team explains that radiation treatment may permanently affect sexual functioning	57 74.8 (65.4, 82.7)	82 59.8 (49.9, 69.2)	31 12.3 (6.7, 20.1)	49 1509.0	33 82
The cancer centre appears to be clean and well looked after	96 85.8 (77.7, 91.9)	48 70.0 (60.5, 78.6)	31 12.3 (6.7, 20.1)	83 991.8	52 96

The patient has a short wait to get an appointment to see the radiation oncologist for the first time	54 73.6 (64.1, 81.7)	107 51.9 (42.0, 61.7)	31 12.3 (6.7, 20.1)	61 1370.9	70 107
The patient is given enough information about how the treatment is scheduled and flexibility in the daily appointment times	19 57.0 (47.1, 66.5)	109 51.4 (41.5, 61.2)	31 12.3 (6.7, 20.1)	16 2209.7	74 109
The patient's family physician is kept informed about the cancer care	46 69.2 (57.8, 79.2)	91 57.4 (47.5, 66.9)	35 11.5 (5.4, 20.8)	35 1766.5	44 91
The patient is given enough information about the possible side effects of radiation treatment	77 80.4 (71.6, 87.4)	21 80.2 (71.3, 87.3)	36 11.3 (6.0, 18.9)	42 1574.1	29 77
The patient has a short wait in the waiting room for daily radiation treatment	49 72.2 (62.8, 80.4)	129 36.1 (27.1, 45.9)	37 11.1 (5.9, 18.6)	82 1003.1	114 129
The patient is aware that no one else other than him and the healthcare professionals looking after him are able to see his medical records without his permission	59 75.6 (64.9, 84.4)	88 58.3 (48.4, 67.8)	38 11.0 (5.1, 19.8)	57 1422.7	40 88
The information about treatment options is provided to the patient before any decision is made about the way he will be treated	74 79.4 (70.3, 86.8)	25 78.1 (69.0, 85.6)	39 10.8 (5.5, 18.5)	39 1608.1	25 74
Someone on the healthcare team explains the arrangements for follow-up care after the radiation treatment is over	68 77.9 (68.2, 85.8)	53 68.9 (59.1, 77.5)	40 10.6 (5.2, 18.7)	46 1522.7	18 68
Before radiation treatment starts, the patient is given enough information about what will happen each day when he comes for treatment	34 65.1 (55.2, 74.1)	108 51.8 (42.0, 61.6)	41 10.4 (5.3, 17.8)	33 1810.1	72 108
The patient has a short wait in the waiting room when he comes to the	44 67.9 (58.2, 76.7)	135 26.4 (18.3, 35.9)	41 10.4 (5.3, 17.8)	97 847.6	126 135

cancer centre to see the radiation oncologist for the first time						
A social worker is available to provide advice on financial and social issues arising from the diagnosis	3 39.7 (27.0, 53.4)	136 24.7 (16.5, 34.4)	43 10.3 (3.9, 21.2)	52 1492.8	127 136	
Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members	1 33.3 (23.1, 44.9)	137 23.8 (15.9, 33.3)	44 10.3 (4.5, 19.2)	41 1584.1	128 137	
Someone on the healthcare team other than the radiation oncologist is available to provide support to the patient in making the decision about treatment	14 53.9 (43.0, 64.6)	132 34.6 (25.6, 44.6)	45 10.2 (4.8, 18.5)	40 1594.9	120 132	
The radiation oncologist reads the patient's previous medical records before seeing the patient for the first time	69 78.3 (68.4, 86.2)	52 69.2 (59.4, 77.9)	46 9.8 (4.6, 17.8)	51 1505.1	19 69	
The patient gets all the help he needs from the radiation oncologist to make up his mind about which treatment to have	93 84.6 (76.2, 90.9)	22 80.2 (71.3, 87.3)	47 9.7 (4.8, 17.1)	71 1233.3	48 93	
The patient is aware that he has a right to see all the information in his medical record	47 69.9 (59.5, 79.0)	101 54.2 (44.3, 63.9)	48 9.7 (4.5, 17.6)	38 1632.3	60 101	
The patient gets enough information from the radiation oncologist to be able to participate in the decision about treatment	82 82.9 (74.3, 89.5)	33 76.2 (66.9, 84.0)	49 9.6 (4.7, 17.0)	66 1305.9	33 82	
The radiation oncologist explains to the patient that he can change his mind about which treatment to have as long as he does so before the treatment starts	35 66.0 (55.7, 75.3)	95 56.2 (46.2, 65.9)	50 9.4 (4.4, 17.0)	28 1911.6	51 95	

The radiation oncologist asks the patient about any other medical problems he may have	62	76.0 (66.4, 84.0)	69	63.8 (53.8, 73.0)	51	9.0 (4.2, 16.4)	45	1531.4	19	69
The radiation oncologist is aware of the test results and has the results available when seeing the patient for the first time	85	83.2 (74.4, 89.9)	14	82.7 (74.0, 89.4)	51	9.0 (4.2, 16.4)	60	1391.7	37	85
The patient is encouraged by the cancer center to bring a relative or friend along to the first appointment with the radiation oncologist	32	65.0 (54.8, 74.3)	116	43.4 (33.8, 53.4)	51	9.0 (4.2, 16.4)	48	1519.0	86	116
The radiation oncologist explains what each treatment option involves	53	73.3 (64.5, 81.6)	56	68.3 (58.4, 77.0)	54	8.9 (4.2, 16.2)	31	1824.9	9	56
The radiation oncologist makes sure the patient understands the treatment options before making up his mind about which treatment to have	94	85.3 (76.9, 91.5)	29	77.4 (68.2, 84.9)	54	8.9 (4.2, 16.2)	73	1138.0	49	94
The radiation oncologist explains the different forms of treatment that are available for prostate cancer	92	84.3 (75.8, 90.8)	15	82.1 (73.4, 88.8)	56	8.8 (4.1, 16.1)	68	1287.8	46	92
The radiation oncologist sees the patient at least once a week during the course of radiation treatment	18	56.7 (46.6, 66.4)	130	35.9 (26.7, 46.0)	56	8.8 (4.1, 16.1)	43	1554.3	116	130
Someone on the healthcare team gives the patient written information about the side effects of each treatment option	55	74.3 (64.8, 82.3)	66	65.1 (55.2, 74.1)	58	8.6 (4.0, 15.8)	37	1673.5	16	66
Someone on the healthcare team is always available to answer the patient's questions and advise on the management of side effects during the course of radiation treatment	76	80.0 (71.1, 87.2)	67	64.8 (55.0, 73.8)	59	8.6 (4.0, 15.6)	67	1296.2	27	76
Directions and signs inside and outside the cancer centre are easy to understand	23	61.3 (51.4, 70.6)	123	39.6 (30.2, 49.6)	59	8.6 (4.0, 15.6)	44	1532.5	101	123

Someone on the healthcare team explains that radiation treatment involves the use of high energy rays directed at the prostate from outside the body	63	76.6 (67.5, 84.3)	74	61.7 (51.8, 70.9)	61	8.5 (4.0, 15.5)	56	1440.8	25	74
The patient trusts the radiation oncologist to look after him properly	109	88.7 (81.1, 94.0)	3	91.6 (84.6, 96.1)	61	8.5 (4.0, 15.5)	79	1036.8	74	109
The radiation oncologist is knowledgeable and experienced in dealing with prostate cancer	120	91.5 (84.5, 96.0)	1	95.3 (89.4, 98.5)	61	8.5 (4.0, 15.5)	101	809.4	96	120
Once the treatment starts, someone on the healthcare team reminds the patient of the potential side effects to expect during the course of radiation treatment	43	67.6 (57.9, 76.3)	115	43.5 (34.0, 53.4)	64	8.3 (3.9, 15.2)	58	1410.5	86	115
The patient can find his way around the cancer centre easily	28	63.0 (53.1, 72.1)	127	38.0 (28.8, 47.8)	64	8.3 (3.9, 15.2)	59	1406.0	110	127
The cancer centre provides resources to assist the patient in understanding and dealing with prostate cancer (e.g. staffed information services, library of books and DVDs about cancer)	8	44.8 (34.2, 55.9)	133	32.7 (23.7, 42.7)	66	8.0 (3.3, 15.9)	34	1802.4	122	133
The patient understands that there is no immediate rush to make a decision about treatment although it's best to make a decision within a week or two	81	82.5 (73.8, 89.3)	83	59.4 (49.5, 68.9)	67	7.8 (3.4, 14.9)	78	1038.8	35	83
The patient has enough time with the radiation oncologist to get all of the information he needs about treatment options	83	82.9 (74.3, 89.5)	32	76.4 (67.2, 84.1)	68	7.6 (3.4, 14.5)	65	1309.8	35	83
The patient has enough time to consider the treatment options before it is decided how he will be treated	90	84.2 (75.6, 90.7)	50	70.0 (60.1, 78.6)	69	6.9 (2.8, 13.8)	75	1107.2	42	90
Someone on the healthcare team	22	60.2	125	38.2	70	6.9	47	1520.8	106	125

explains that radiation treatment can only be delivered at a few specialized treatment centers	(49.2, 70.5)	(28.8, 48.4)	(2.6, 14.4)		
The radiation oncologist describes and explains all of the treatment options that are available to the patient other than radiation treatment	70 78.4 (69.2, 86.0)	56 68.3 (58.4, 77.0)	71 6.9 (2.8, 13.6)	53 1472.6	21 70
Someone on the healthcare team explains that radiation treatment is delivered by the radiation therapists, not a radiation oncologist	48 70.6 (60.8, 79.2)	120 42.1 (32.6, 52.0)	71 6.9 (2.8, 13.6)	69 1237.0	96 120
The patient is aware of who to contact with questions about his prostate cancer and treatment	88 83.8 (75.4, 90.3)	16 81.3 (72.6, 88.2)	73 6.7 (2.7, 13.2)	64 1316.4	40 88
The nurses explain things to the patient in a way that he can understand	105 87.8 (80.1, 93.4)	36 74.8 (65.4, 82.7)	74 6.5 (2.7, 13.0)	88 908.4	67 105
Someone on the healthcare team is available if needed to help explain the diagnosis to family members	37 66.2 (54.6, 76.6)	117 43.0 (33.1, 53.3)	75 6.5 (2.1, 14.5)	54 1452.1	90 117
The atmosphere in the waiting room is relaxing	39 66.7 (57.0, 75.4)	128 37.0 (27.9, 46.9)	76 6.5 (2.6, 12.9)	70 1234.5	112 128
The cancer centre has a place to stay overnight if the patient lives far away	112 89.8 (77.8, 96.6)	106 53.0 (42.8, 63.1)	77 6.1 (1.3, 16.9)	125 540.6	80 112
The radiation oncologist carefully assesses the patient's suitability for radiation treatment	97 85.9 (77.4, 92.0)	24 78.8 (69.7, 86.2)	78 6.1 (2.3, 12.7)	74 1114.9	54 97
The radiation oncologist shows interest in the patient as a person, not just as a patient	76 80.0 (70.8, 87.3)	90 58.1 (48.1, 67.7)	79 6.0 (2.2, 12.6)	72 1162.0	42 90
The nurses show sensitivity to the patient's feelings and emotional needs	91 84.2 (75.6, 90.7)	89 58.1 (48.1, 67.7)	80 5.9 (2.2, 12.5)	87 920.3	44 91
The patient is involved as much as he	107 88.4	39 73.6	81 5.9	93 857.2	70 107

wants in making the final decision about which treatment to have	(80.5, 93.8)	(64.2, 81.7)	(2.2, 12.4)		
The nurses care about the patient's well-being	103 87.4 (79.4, 93.1)	68 64.8 (54.8, 73.8)	82 5.8 (2.2, 12.2)	100 817.3	64 103
The radiation oncologist is honest with the patient	129 93.2 (86.5, 97.2)	8 86.0 (77.9, 91.9)	82 5.8 (2.2, 12.2)	121 584.7	114 129
The patient has enough time with a member of the healthcare team to discuss the treatment plan	56 74.3 (64.8, 82.3)	97 56.1 (46.2, 65.7)	84 5.7 (2.1, 12.0)	55 1441.6	54 97
The radiation oncologist shows sensitivity to the patient's feelings and emotional needs	100 86.7 (78.6, 92.5)	63 65.7 (56.0, 74.6)	84 5.7 (2.1, 12.0)	90 876.3	58 100
Someone on the healthcare team explains that radiation treatment often causes urinary symptoms during treatment	101 86.8 (78.9, 92.6)	59 67.3 (57.6, 76.0)	84 5.7 (2.1, 12.0)	89 888.9	60 101
The radiation oncologist cares about the patient's well-being	113 90.5 (83.2, 95.3)	30 76.6 (67.5, 84.3)	84 5.7 (2.1, 12.0)	110 729.6	82 113
The radiation oncologist explains things to the patient in a way that he can understand	118 91.4 (84.4, 96.0)	19 81.1 (72.4, 88.1)	84 5.7 (2.1, 12.0)	111 695.3	92 118
The patient feels that his rights for privacy are fully protected at the cancer centre	65 77.5 (67.4, 85.7)	79 60.2 (50.3, 69.5)	89 5.6 (1.8, 12.6)	63 1352.5	31 79
The nurses take the time to answer all of the patient's questions	106 87.8 (80.1, 93.4)	43 72.0 (62.4, 80.2)	90 5.6 (2.1, 11.8)	91 874.3	69 106
Once an appointment is made for the patient it is not cancelled or postponed	71 78.5 (69.5, 85.9)	111 49.1 (39.3, 58.9)	90 5.6 (2.1, 11.8)	76 1055.0	78 111
The cancer centre seems to have all the equipment and facilities needed to completely care for the patient's prostate cancer	121 91.6 (84.6, 96.1)	4 88.0 (80.3, 93.4)	90 5.6 (2.1, 11.8)	105 739.7	98 121

If the patient wants, someone on the healthcare team is willing to answer questions about treatment from family or friends	26	62.5 (45.8, 77.3)	114	45.6 (30.9, 61.0)	93	5.1 (0.6, 17.3)	36	1711.9	84	114
The nurses are honest with the patient	110	88.9 (81.0, 94.3)	47	71.4 (61.8, 79.8)	94	5.0 (1.7, 11.4)	102	793.6	76	110
The patient feels that he can trust the nurses with confidential information	84	83.0 (74.2, 89.8)	94	56.5 (46.6, 66.0)	95	5.0 (1.6, 11.3)	85	960.2	49	94
Transportation to/from the cancer centre is available for the patient if needed	80	82.5 (67.2, 92.7)	112	49.0 (38.7, 59.3)	95	5.0 (0.6, 16.9)	94	857.2	80	112
Someone on the health care team offers written information about prostate cancer to the patient that he can take home with him	87	83.5 (74.9, 90.1)	70	63.8 (53.8, 73.0)	97	4.8 (1.6, 11.0)	77	1052.9	39	87
Someone on the healthcare team explains that radiation treatment often causes bowel symptoms during treatment	102	86.9 (79.0, 92.7)	65	65.4 (55.6, 74.4)	98	4.7 (1.6, 10.7)	96	855.7	62	102
The nurses listen carefully to all the patient's concerns	111	89.6 (82.2, 94.7)	44	72.0 (62.4, 80.2)	98	4.7 (1.6, 10.7)	104	746.9	78	111
The radiation oncologist takes the time to answer all of the patient's questions	119	91.5 (84.5, 96.0)	7	86.9 (79.0, 92.7)	98	4.7 (1.6, 10.7)	107	738.0	94	119
The radiation oncologist listens carefully to all the patient's concerns	126	92.4 (85.7, 96.7)	16	81.3 (71.6, 88.2)	98	4.7 (1.6, 10.7)	117	613.9	108	126
The radiation oncologist makes the patient feel like he can ask any questions he wants to	132	93.4 (86.9, 97.3)	11	84.1 (75.8, 90.5)	98	4.7 (1.6, 10.7)	124	555.1	120	132
The patient has a short wait to start treatment after the decision was made to have radiation treatment	79	82.2 (73.7, 89.0)	105	53.3 (43.4, 63.0)	103	4.7 (1.5, 10.6)	86	946.1	67	105
Appointments are scheduled for a time that is convenient	72	78.5 (69.5, 85.9)	122	39.8 (30.5, 49.7)	103	4.7 (1.5, 10.6)	95	855.9	100	122

The nurses make the patient feel like he can ask any questions he wants to	123 91.6 (84.6, 96.1)	44 72.0 (62.4, 80.2)	103 4.7 (1.5, 10.6)	118 605.2	101 123
The furniture in the waiting room is comfortable	17 55.6 (45.7, 65.1)	138 23.2 (15.6, 32.2)	106 4.6 (1.5, 10.5)	80 1028.8	132 138
Someone at the cancer centre is available to answer the patient's questions in between appointments	67 77.8 (67.8, 85.9)	76 61.3 (51.4, 70.6)	107 4.4 (1.2, 11.0)	62 1362.5	27 76
The nurses show interest in the patient as a person, not just as a patient	99 86.3 (78.0, 92.3)	103 53.8 (43.8, 63.5)	108 3.9 (1.1, 9.7)	106 738.3	64 103
The nurses are knowledgeable and experienced in dealing with prostate cancer	115 91.2 (83.9, 95.9)	13 83.0 (74.5, 89.6)	108 3.9 (1.1, 9.7)	109 732.2	86 115
During treatment, the radiation oncologist, nurses and radiation therapists do everything they can to help the patient get through treatment with as few problems as possible	123 91.6 (84.6, 96.1)	38 73.6 (64.2, 81.7)	110 3.8 (1.0, 9.4)	116 618.8	101 123
During treatment, the radiation therapists make enough time for the patient	105 87.8 (80.1, 93.4)	131 34.9 (25.9, 44.8)	110 3.8 (1.0, 9.4)	131 424.2	118 131
The waiting area and treatment rooms are quiet	45 68.5 (58.9, 77.1)	134 30.6 (22.0, 40.2)	112 3.7 (1.0, 9.2)	84 962.0	124 134
The patient is welcome to bring a friend or relative with him to his appointments	78 80.8 (71.7, 88.0)	118 42.9 (33.2, 52.9)	113 3.0 (0.6, 8.6)	99 822.5	92 118
There is enough space in the waiting room that the patient can have a private conversation with his companion	10 48.5 (38.6, 58.6)	140 19.6 (12.6, 28.4)	114 2.9 (0.6, 8.4)	81 1010.2	136 140
The radiation therapists care about the patient's well-being	139 95.2 (89.0, 98.4)	72 62.9 (52.9, 72.1)	115 2.9 (0.6, 8.3)	140 304.9	134 139

The radiation therapists are polite to the patient	134 94.2 (87.9, 97.8)	85 59.0 (49.0, 68.6)	116 2.9 (0.6, 8.2)	137 340.7	124 134
The patient trusts the nurses to look after him properly	108 88.6 (80.9, 94.0)	46 72.0 (62.4, 80.2)	117 2.9 (0.6, 8.1)	98 822.5	72 108
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer	137 94.3 (88.0, 97.9)	5 87.8 (80.1, 93.3)	117 2.9 (0.6, 8.1)	126 501.6	128 137
The radiation therapists explain things to the patient in a way that he can understand	137 94.3 (88.0, 97.9)	37 73.6 (64.2, 81.7)	117 2.9 (0.6, 8.1)	132 420.1	128 137
Someone on the healthcare team explains that radiation treatment often causes temporary fatigue	98 86.1 (78.1, 92.0)	93 56.6 (46.6, 66.2)	120 2.8 (0.6, 8.0)	103 786.2	57 98
The nurses are polite to the patient	114 90.6 (83.3, 95.4)	81 59.8 (49.9, 69.2)	120 2.8 (0.6, 8.0)	123 564.0	84 114
The patient has confidence in his treatment team that he is treated correctly every day	127 92.5 (85.8, 96.7)	23 79.2 (70.3, 86.5)	120 2.8 (0.6, 8.0)	120 592.8	110 127
The radiation oncologist treats the patient with respect	141 96.2 (90.6, 99.0)	31 76.6 (67.5, 84.3)	120 2.8 (0.6, 8.0)	141 288.9	138 141
Waiting areas are decorated nicely	6 42.4 (32.9, 52.4)	142 10.4 (5.3, 17.8)	120 2.8 (0.6, 8.0)	119 597.4	140 142
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer	142 96.2 (90.6, 99.0)	6 87.0 (79.2, 92.7)	120 2.8 (0.6, 8.0)	138 328.1	140 142
The patient trusts the radiation therapists to look after him properly	124 91.7 (84.8, 96.1)	27 77.8 (68.8, 85.2)	126 2.8 (0.6, 7.9)	114 647.9	104 124
If the patient wants, the radiation	95 85.5	110 50.6	127 2.6	108 732.5	76 110

oncologist is willing to answer all the questions the patient's family and friends have		(75.6, 92.6)		(39.3, 61.9)		(0.3, 9.2)			
The patient feels that he can trust the radiation therapists with confidential information	128	93.1 (86.4, 97.2)	84	59.3 (49.4, 68.6)	128	2.0 (0.2, 6.9)	133	406.5	112 128
The patient feels that he can trust the radiation oncologist with confidential information	125	92.2 (85.3, 96.6)	75	61.7 (51.8, 70.9)	129	1.9 (0.2, 6.8)	127	479.2	106 125
The radiation therapists listen carefully to all the patient's concerns	117	91.4 (84.2, 96.0)	60	66.7 (56.8, 75.6)	130	1.9 (0.2, 6.8)	122	576.7	90 117
The radiation therapists take the time to answer all of the patient's questions	137	94.3 (88.0, 97.9)	58	67.9 (58.2, 76.7)	131	1.9 (0.2, 6.7)	135	387.8	128 137
The patient sees the same radiation therapists each time he goes for radiation treatment	24	61.3 (51.4, 70.6)	139	22.2 (14.8, 31.2)	132	1.9 (0.2, 6.6)	92	859.5	134 139
The nurses treat the patient with respect	133	93.5 (87.0, 97.3)	61	66.7 (56.8, 75.6)	133	1.9 (0.2, 6.6)	130	436.0	122 133
The radiation oncologist is polite to the patient	143	96.3 (90.7, 99.0)	55	68.5 (58.9, 77.1)	133	1.9 (0.2, 6.6)	142	256.3	142 143
The radiation therapists show interest in the patient as a person, not just as a patient	116	91.2 (83.9, 95.9)	99	54.3 (44.3, 64.0)	135	1.0 (0.0, 5.3)	128	478.8	88 116
The radiation therapists are honest with the patient	140	96.1 (90.3, 98.9)	20	81.0 (72.1, 88.0)	135	1.0 (0.0, 5.3)	139	317.3	136 140
The radiation therapists show sensitivity to the patient's feelings and emotional needs	130	93.2 (86.5, 97.2)	87	58.5 (48.5, 68.0)	137	1.0 (0.0, 5.3)	134	397.7	116 130
The radiation therapists make the patient feel like he can ask any questions he wants to	131	93.2 (86.5, 97.2)	54	68.6 (58.8, 77.3)	137	1.0 (0.0, 5.3)	129	466.3	118 131

The radiation therapists treat the patient with respect	138	94.3 (88.0, 97.9)	78	60.4 (50.4, 69.8)	139	1.0 (0.0, 5.2)	136	344.8	132	138
The patient is treated in the same treatment room each day	36	66.0 (56.2, 75.0)	143	6.6 (2.7, 13.1)	139	1.0 (0.0, 5.2)	143	224.1	142	143
The radiation oncologist or the nurse see the patient at least once a week during the course of radiation treatment	89	84.1 (75.8, 90.5)	121	41.5 (32.0, 51.5)	141	0.9 (0.0, 5.1)	112	659.6	98	121
The patient has enough privacy during his care	86	83.3 (74.9, 89.8)	124	38.9 (29.7, 48.8)	142	0.9 (0.0, 5.0)	113	648.3	104	124
Food and drink facilities are available in or near the waiting room	7	43.8 (33.6, 54.2)	141	11.3 (6.0, 18.9)	143	0.0 (0.0, 3.8)	115	636.8	138	141

*Grey shaded boxes highlight the top elements of care identified for each method

Appendix D4: Comparing the percentage of elements of care identified as priorities for improvement among subgroups of patients

Table D4-1: Comparison of the percentage of elements of care identified as priorities for quality improvement (QI) by different subgroups of patients

Characteristic	Median % of elements identified as priorities for QI	p-value
Age		
<70	5.9	0.25
≥70	3.9	
Educational status		
No postsecondary education	5.1	0.51
Postsecondary education	5.9	
Self-rated health status		
Poor, fair or good	5.4	0.29
Excellent	4.1	

Appendix E

E-supplement for the manuscript titled, “Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer”

Figure e1: Recruitment and retention of patient study subjects.

Table e1: Patient characteristics

Characteristic		Number of Patients (%)
Age	<50 50-59 60-69 ≥70	0 (0%) 7 (6%) 40 (37%) 61 (56%)
Self-reported Health Status	Poor Fair Good Excellent Unknown	1 (1%) 14 (13%) 55 (51%) 32 (30%) 6 (6%)
Education Level	Less than high school High School College diploma University degree Post-graduate degree Unknown	17 (16%) 36 (33%) 24 (22%) 16 (15%) 9 (8%) 6 (6%)
Marital Status	Single Separated/Widowed/Divorced Married/Living common-law Unknown	0 (0%) 12 (11%) 91 (84%) 5 (5%)
T-category	T1c T2 T2a T2b T2c T3	57 (53%) 3 (3%) 25 (23%) 14 (13%) 7 (6%) 2 (2%)
Pre-Treatment PSA	<10 10-19 ≥20	68 (63%) 26 (24%) 14 (13%)
Gleason score	6 7 8 9	12 (11%) 65 (60%) 14 (13%) 17 (16%)
Risk Group	Low Intermediate High	11 (10%) 54 (50%) 43 (40%)

*Percentages may not add up to 100 due to rounding.

Table e2: Treatment

	Total number of cases	Low risk	Intermediate risk	High risk
Hormone therapy				
Yes	46	0	5	41
No	62	11	49	2
RT to Prostate only:	62			
70 Gy, 35 fractions		6	0	0
76 Gy, 38 fractions		5	49	2
RT to Pelvis* + prostate:	46			
**76 Gy, 38 fractions		0	5	36
**74 Gy, 37 fractions		0	0	2
**72 Gy, 36 fractions		0	0	1
**70 Gy, 35 fractions		0	0	1
66 Gy, 33 fractions		0	0	1*
Total	108	11	54	43

*All pelvic radiation was given as 46 Gy in 23 fractions

**Total dose to prostate

***After the study had been completed, this patient was discovered to have had a previous radical prostatectomy. We elected not to exclude this case. No other patients included in the study had either radical surgery or brachytherapy.

Table e3: Comparison of the overall quality of care provided by different subgroups of patients

Characteristic	Median % of elements rated “very good”	p-value
Age		
<70	79	0.69
≥70	80	
Educational status		
No postsecondary education	78	0.91
Postsecondary education	80	
Self-rated health status		
Poor, fair or good	80	0.80
Excellent	77	
Hormone treatment		
Yes	78	0.44
No	80	
Region irradiated		
Prostate only	80	0.33
Whole pelvis	77	

Table e4: Elements of care ranked by the percentage of patents rating each one “very good”

Elements of Care	Quality	
	% <i>Very Good</i> (95% CI)	Rank
The radiation oncologist is polite to the patient	96.3 (90.7, 99.0)	1
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer	96.2 (90.6, 99.0)	2
The radiation oncologist treats the patient with respect	96.2 (90.6, 99.0)	3
The radiation therapists are honest with the patient	96.1 (90.3, 98.9)	4
The radiation therapists care about the patient’s well-being	95.2 (89.0, 98.4)	5
The radiation therapists treat the patient with respect	94.3 (88.0, 97.9)	6
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer	94.3 (88.0, 97.9)	7
The radiation therapists take the time to answer all of the patient’s questions	94.3 (88.0, 97.9)	7
The radiation therapists explain things to the patient in a way that he can understand	94.3 (88.0, 97.9)	7
The radiation therapists are polite to the patient	94.2 (87.9, 97.8)	10
The nurses treat the patient with respect	93.5 (87.0, 97.3)	11
The radiation oncologist makes the patient feel like he can ask any questions he wants to	93.4 (86.9, 97.3)	12
The radiation therapists make the patient feel like he can ask any questions he wants to	93.2 (86.5, 97.2)	13
The radiation therapists show sensitivity to the patient’s feelings and emotional needs	93.2 (86.5, 97.2)	14
The radiation oncologist is honest with the patient	93.2 (86.5, 97.2)	15
The patient feels that he can trust the radiation therapists with confidential information	93.1 (86.4, 97.2)	16
The patient has confidence in his treatment team that he is treated correctly every day	92.5 (85.8, 96.7)	17
The radiation oncologist listens carefully to all the patient’s concerns	92.4 (85.7, 96.7)	18
The patient feels that he can trust the radiation oncologist with confidential information	92.2 (85.3, 96.6)	19
The patient trusts the radiation therapists to look after him	91.7	20

properly	(84.8, 96.1)	
During treatment, the radiation oncologist, nurses and radiation therapists do everything they can to help the patient get through treatment with as few problems as possible	91.6 (84.6, 96.1)	21
The nurses make the patient feel like he can ask any questions he wants to	91.6 (84.6, 96.1)	21
The cancer centre seems to have all the equipment and facilities needed to completely care for the patient's prostate cancer	91.6 (84.6, 96.1)	23
The radiation oncologist is knowledgeable and experienced in dealing with prostate cancer	91.5 (84.5, 96.0)	24
The radiation oncologist takes the time to answer all of the patient's questions	91.5 (84.5, 96.0)	25
The radiation oncologist explains things to the patient in a way that he can understand	91.4 (84.4, 96.0)	26
The radiation therapists listen carefully to all the patient's concerns	91.4 (84.2, 96.0)	27
The radiation therapists show interest in the patient as a person, not just as a patient	91.2 (83.9, 95.9)	28
The nurses are knowledgeable and experienced in dealing with prostate cancer	91.2 (83.9, 95.9)	29
The nurses are polite to the patient	90.6 (83.3, 95.4)	30
The radiation oncologist cares about the patient's well-being	90.5 (83.2, 95.3)	31
The cancer centre has a place to stay overnight if the patient lives far away	89.8 (77.8, 96.6)	32
The nurses listen carefully to all the patient's concerns	89.6 (82.2, 94.7)	33
The nurses are honest with the patient	88.9 (81.0, 94.3)	34
The patient trusts the radiation oncologist to look after him properly	88.7 (81.1, 94.0)	35
The patient trusts the nurses to look after him properly	88.6 (80.9, 94.0)	36
The patient is involved as much as he wants in making the final decision about which treatment to have	88.4 (80.5, 93.8)	37
The nurses take the time to answer all of the patient's questions	87.8 (80.1, 93.4)	38
During treatment, the radiation therapists make enough time for the patient	87.8 (80.1, 93.4)	39
The nurses explain things to the patient in a way that he can understand	87.8 (80.1, 93.4)	39
The nurses care about the patient's well-being	87.4 (79.4, 93.1)	41
Someone on the healthcare team explains that radiation treatment	86.9	42

often causes bowel symptoms during treatment	(79.0, 92.7)	
Someone on the healthcare team explains that radiation treatment often causes urinary symptoms during treatment	86.8 (78.8, 92.6)	43
The radiation oncologist shows sensitivity to the patient's feelings and emotional needs	86.7 (78.6, 92.5)	44
The nurses show interest in the patient as a person, not just as a patient	86.3 (78.0, 92.3)	45
Someone on the healthcare team explains that radiation treatment often causes temporary fatigue	86.1 (78.1, 92.0)	46
The radiation oncologist carefully assesses the patient's suitability for radiation treatment	85.9 (77.4, 92.0)	47
The cancer centre appears to be clean and well looked after	85.8 (77.7, 91.9)	48
If the patient wants, the radiation oncologist is willing to answer all the questions the patient's family and friends have	85.5 (75.6, 92.6)	49
The radiation oncologist makes sure the patient understands the treatment options before making up his mind about which treatment to have	85.3 (76.9, 91.5)	50
The patient gets all the help he needs from the radiation oncologist to make up his mind about which treatment to have	84.6 (76.2, 90.9)	51
The radiation oncologist explains the different forms of treatment that are available for prostate cancer	84.3 (75.8, 90.8)	52
The nurses show sensitivity to the patient's feelings and emotional needs	84.2 (75.6, 90.7)	53
The patient has enough time to consider the treatment options before it is decided how he will be treated	84.2 (75.6, 90.7)	54
The radiation oncologist or the nurse see the patient at least once a week during the course of radiation treatment	84.1 (75.8, 90.5)	55
The patient is aware of who to contact with questions about his prostate cancer and treatment	83.8 (75.4, 90.3)	56
Someone on the health care team offers written information about prostate cancer to the patient that he can take home with him	83.5 (74.9, 90.1)	57
The patient has enough privacy during his care	83.3 (74.9, 89.8)	58
The radiation oncologist is aware of the test results and has the results available when seeing the patient for the first time	83.2 (74.4, 89.9)	59
The patient feels that he can trust the nurses with confidential information	83.0 (74.2, 89.8)	60
The patient has enough time with the radiation oncologist to get all of the information he needs about treatment options	82.9 (74.3, 89.5)	61
The patient gets enough information from the radiation oncologist to be able to participate in the decision about treatment	82.9 (74.3, 89.5)	62
The patient understands that there is no immediate rush to make a decision about treatment although it's best to make a decision within a week or two	82.5 (73.8, 89.3)	63

Transportation to/from the cancer centre is available for the patient if needed	82.5 (67.2, 92.7)	64
The patient has a short wait to start treatment after the decision was made to have radiation treatment	82.2 (73.7, 89.0)	65
The patient is welcome to bring a friend or relative with him to his appointments	80.8 (71.7, 88.0)	66
The patient is given enough information about the possible side effects of radiation treatment	80.4 (71.6, 87.4)	67
The radiation oncologist shows interest in the patient as a person, not just as a patient	80.0 (70.8, 87.3)	68
Someone on the healthcare team is always available to answer the patient's questions and advise on the management of side effects during the course of radiation treatment	80.0 (71.1, 87.2)	68
The information about treatment options is provided to the patient before any decision is made about the way he will be treated	79.4 (70.3, 86.8)	70
Someone on the healthcare team explains that doctors will be monitoring PSA levels at regular intervals during follow-up from radiation treatment	79.4 (70.0, 86.9)	71
Appointments are scheduled for a time that is convenient	78.5 (69.5, 85.9)	72
Once an appointment is made for the patient it is not cancelled or postponed	78.5 (69.5, 85.9)	73
The radiation oncologist describes and explains all of the treatment options that are available to the patient other than radiation treatment	78.4 (69.2, 86.0)	74
The radiation oncologist reads the patient's previous medical records before seeing the patient for the first time	78.3 (68.4, 86.2)	75
Someone on the healthcare team explains the arrangements for follow-up care after the radiation treatment is over	77.9 (68.2, 85.8)	76
Someone at the cancer centre is available to answer the patient's questions in between appointments	77.8 (67.8, 85.9)	77
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body	77.7 (68.4, 85.3)	78
The patient feels that his rights for privacy are fully protected at the cancer centre	77.5 (67.4, 85.7)	79
The radiation oncologist makes sure the patient understands the benefits of radiation treatment and its side effects before asking for consent to have radiation treatment	77.4 (68.2, 84.9)	80
Someone on the healthcare team explains that radiation treatment involves the use of high energy rays directed at the prostate from outside the body	76.6 (67.5, 84.3)	81
The radiation oncologist asks the patient about any other medical problems he may have	76.0 (66.4, 84.0)	82
The radiation oncologist makes sure the patient understands the	76.0	83

results of the biopsy of the prostate, the blood tests, and any x-rays and scans he may have had	(66.6, 83.8)	
The radiation oncologist gives the patient enough information about the side effects of each treatment option	76.0 (66.6, 83.8)	84
The patient is aware that no one else other than him and the healthcare professionals looking after him are able to see his medical records without his permission	75.6 (64.9, 84.4)	85
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means	75.5 (66.0, 83.5)	86
Someone on the healthcare team explains that radiation treatment may permanently affect sexual functioning	74.8 (65.4, 82.7)	87
The patient has enough time with a member of the healthcare team to discuss the treatment plan	74.3 (64.8, 82.3)	88
Someone on the healthcare team gives the patient written information about the side effects of each treatment option	74.3 (64.8, 82.3)	89
The patient has a short wait to get an appointment to see the radiation oncologist for the first time	73.6 (64.1, 81.7)	90
The radiation oncologist explains what each treatment option involves	73.3 (64.5, 81.6)	91
The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means	73.3 (64.5, 81.6)	92
The patient is given enough information about the chance of curing his cancer with radiation treatment	73.1 (63.5, 81.3)	93
Someone on the healthcare team explains that the PSA level is all that is needed to tell if the cancer is under control or not	72.4 (61.8, 81.5)	94
The patient has a short wait in the waiting room for daily radiation treatment	72.2 (62.8, 80.4)	95
Someone on the healthcare team explains that radiation treatment is delivered by the radiation therapists, not a radiation oncologist	70.6 (60.8, 79.2)	96
The patient is aware that he has a right to see all the information in his medical record	69.9 (59.5, 79.0)	97
The patient's family physician is kept informed about the cancer care	69.2 (57.8, 79.2)	98
The waiting area and treatment rooms are quiet	68.5 (58.9, 77.1)	99
The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time	67.9 (58.2, 76.7)	100
Once the treatment starts, someone on the healthcare team reminds the patient of the potential side effects to expect during the course of radiation treatment	67.6 (57.9, 76.3)	101
The patient is made aware of who to contact if he is concerned about the cancer coming back	67.4 (56.5, 77.2)	102
The radiation oncologist tells the patient about his PSA level and explains what that means	67.3 (57.3, 76.3)	103

Someone on the healthcare team explains that the course of treatment needs to be completed without taking a break (of longer than a few days)	67.0 (57.0, 75.9)	104
The atmosphere in the waiting room is relaxing	66.7 (57.0, 75.4)	105
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option	66.3 (56.2, 75.4)	106
Someone on the healthcare team is available if needed to help explain the diagnosis to family members	66.2 (54.6, 76.6)	107
The patient is treated in the same treatment room each day	66.0 (56.2, 75.0)	108
The radiation oncologist explains to the patient that he can change his mind about which treatment to have as long as he does so before the treatment starts	66.0 (55.7, 75.3)	109
Before radiation treatment starts, the patient is given enough information about what will happen each day when he comes for treatment	65.1 (55.2, 74.1)	110
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function	65.0 (55.0, 74.2)	111
The patient is encouraged by the cancer center to bring a relative or friend along to the first appointment with the radiation oncologist	65.0 (54.8, 74.3)	112
Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment	64.5 (54.6, 73.5)	113
Someone on the healthcare team explains that radiation treatment may permanently affect bladder function	63.1 (53.0, 72.4)	114
Someone on the healthcare team explains who to contact if additional care is needed in recovery after radiation treatment	63.0 (52.3, 72.9)	115
The patient can find his way around the cancer centre easily	63.0 (53.1, 72.1)	116
The patient is given enough information about how the radiation treatment is planned	62.9 (52.9, 72.1)	117
If the patient wants, someone on the healthcare team is willing to answer questions about treatment from family or friends	62.5 (45.8, 77.3)	118
Someone on the healthcare team explains how the patient should modify his diet to avoid bowel upset during the course of radiation treatment	61.7 (51.8, 70.9)	119
The patient sees the same radiation therapists each time he goes for radiation treatment	61.3 (51.4, 70.6)	120
Directions and signs inside and outside the cancer centre are easy to understand	61.3 (51.4, 70.6)	121
Someone on the healthcare team explains that radiation treatment can only be delivered at a few specialized treatment centers	60.2 (49.2, 70.5)	122
Someone at the cancer centre arranges for the patient to receive	59.1	123

any help he needs in dealing with his anxiety about the diagnosis	(36.4, 79.3)	
Someone on the healthcare team gives enough information and direction to the patient about how to care for himself after radiation treatment	57.6 (46.9, 67.8)	124
The patient is given enough information about how the treatment is scheduled and flexibility in the daily appointment times	57.0 (47.1, 66.5)	125
The radiation oncologist sees the patient at least once a week during the course of radiation treatment	56.7 (46.6, 66.4)	126
The furniture in the waiting room is comfortable	55.6 (45.7, 65.1)	127
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment	55.1 (44.1, 65.6)	128
The patient is given enough information to understand how the radiation treatment works	54.7 (44.8, 64.4)	129
Someone on the healthcare team other than the radiation oncologist is available to provide support to the patient in making the decision about treatment	53.9 (43.0, 64.6)	130
Someone on the healthcare team answers any questions the patient has about the possible causes of prostate cancer	53.8 (37.2, 69.9)	131
Someone on the healthcare team explains what prostate cancer is and how it can affect the patient's health	50.0 (39.6, 60.4)	132
Someone on the healthcare team explains that prostate cancer is not infectious and that it cannot be transmitted to anyone else	50.0 (39.0, 61.0)	133
There is enough space in the waiting room that the patient can have a private conversation with his companion	48.5 (38.6, 58.6)	134
The patient is made aware that he has the right to get a second opinion from another radiation oncologist	47.3 (36.9, 57.9)	135
The cancer centre provides resources to assist the patient in understanding and dealing with prostate cancer (e.g. staffed information services, library of books and DVDs about cancer)	44.8 (34.2, 55.9)	136
Food and drink facilities are available in or near the waiting room	43.8 (33.6, 54.2)	137
Waiting areas are decorated nicely	42.4 (32.9, 52.4)	138
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful	41.9 (31.8, 52.6)	139
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time	39.8 (29.8, 50.5)	140
A social worker is available to provide advice on financial and social issues arising from the diagnosis	39.7 (27.0, 53.4)	141
There is somewhere convenient to park	35.2 (26.2, 45.2)	142
Someone at the cancer centre gives the patient information about	33.3	143

support groups in his area for patients and/or family members	(23.1, 44.9)	
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Figure e2: Relationship between patient characteristics and ratings of quality. Comparison of the ranks of each element of care between patients of different ages (<70 vs ≥ 70) (A), education level (college diploma or higher vs high school or less) (B), health status (excellent health vs poor, fair or good) (C), receipt of hormone treatment (yes vs no) (D), and region irradiated (prostate only vs whole pelvis) (E).

Figure e3: Patients' assessment of the quality of ten different aspects of their care. The individual elements of care (o) were assigned to ten categories corresponding to different aspects of care. The mean percentage of "very good" ratings in each category is shown by a cross (+).

Table e5: Ranking of the priorities for quality improvement identified by the importance/quality analysis and ranking by quality and importance alone

Element of Care*	Aspect of Care	<i>Rank by Importance /quality</i>	<i>Rank by Quality (inverse)</i>	<i>Rank by Importance</i>
Someone on the healthcare team explains that radiation treatment cannot usually be given to the prostate again if it is not successful the first time (2)	Adequacy of Information Sharing	1	4	49
Someone on the healthcare team explains the other treatments that are available if radiation treatment is not successful (2)	Adequacy of Information Sharing	2	5	71
There is somewhere convenient to park (5)	Convenience	3	2	113
Someone on the healthcare team explains that radiation treatment may permanently affect bowel function (2)	Adequacy of Information Sharing	4	33	40
Someone on the healthcare team explains what prostate cancer is and how it can affect the patient's health (1)	Adequacy of Information Sharing	5	12	86
Someone on the healthcare team explains that radiation treatment may permanently affect bladder function (2)	Adequacy of Information Sharing	6	30	42
The radiation oncologist makes sure the patient knows that the cancer is confined to the prostate, and there is no sign that it has spread to any other part of the body (1)	Adequacy of Information Sharing	7	66	2
Someone on the healthcare team explains when the patient can resume all of his previous activities after radiation treatment (4)	Adequacy of Information Sharing	8	16	100
The patient is given enough information to understand how the radiation treatment works (3)	Adequacy of Information Sharing	9	15	73
The radiation oncologist gives the patient enough information about the chance of curing his cancer with each treatment option (2)	Adequacy of Information Sharing	10	38	25

The radiation oncologist makes sure the patient knows the stage of his cancer and understands what that means (1)	Adequacy of Information Sharing	10	52	12
The patient is made aware of who to contact if he is concerned about the cancer coming back (4)	Continuity of care	12	42	34
Someone on the healthcare team gives enough information and direction to the patient about how to care for himself after radiation treatment (4)	Adequacy of Information Sharing	13	20	102
Someone at the cancer centre arranges for the patient to receive any help he needs in dealing with his anxiety about the diagnosis (1)	Comprehensive ness	14	21	77
Someone on the healthcare team explains who to contact if additional care is needed in recovery after radiation treatment (4)	Adequacy of Information Sharing	15	29	64
The radiation oncologist gives the patient enough information about the side effects of each treatment option (2)	Adequacy of Information Sharing	16	60	10
The radiation oncologist tells the patient about his PSA level and explains what that means (1)	Adequacy of Information Sharing	17	41	62
The radiation oncologist makes sure the patient knows the grade of his cancer and understands what that means (1)	Adequacy of Information Sharing	18	58	9
Someone on the healthcare team explains that the PSA level is all that is needed to tell if the cancer is under control or not (4)	Adequacy of Information Sharing	19	50	51
Once the decision to have radiation treatment has been made, the patient is given enough information about how long he will have to wait to start treatment (3)	Adequacy of Information Sharing	20	31	80
Someone on the healthcare team explains how the patient should modify his diet to avoid bowel upset during the course of radiation treatment (4)	Adequacy of Information Sharing	20	25	104
Someone on the healthcare team	Adequacy of	22	40	92

explains that the course of treatment needs to be completed without taking a break (of longer than a few days) (3)	Information Sharing			
The radiation oncologist makes sure the patient understands the results of the biopsy of the prostate, the blood tests, and any x-rays and scans he may have had (1)	Adequacy of Information Sharing	23	61	35
Someone on the healthcare team answers any questions the patient has about the possible causes of prostate cancer (1)	Adequacy of Information Sharing	23	13	96
The patient is made aware that he has the right to get a second opinion from another radiation oncologist (2)	Adequacy of Information Sharing	25	9	126
The patient is given enough information about the chance of curing his cancer with radiation treatment (2)	Adequacy of Information Sharing	26	51	28
Someone on the healthcare team explains that doctors will be monitoring PSA levels at regular intervals during follow-up from radiation treatment (4)	Adequacy of Information Sharing	27	73	41
The radiation oncologist makes sure the patient understands the benefits of radiation treatment and its side effects before asking for consent to have radiation treatment (2)	Adequacy of Information Sharing	28	64	16
The patient is given enough information about how the radiation treatment is planned (3)	Adequacy of Information Sharing	29	27	97
Someone on the healthcare team explains that prostate cancer is not infectious and that it cannot be transmitted to anyone else (1)	Adequacy of Information Sharing	30	11	119
Someone on the healthcare team explains that radiation treatment may permanently affect sexual functioning (2)	Adequacy of Information Sharing	31	57	82
The cancer centre appears to be clean and well looked after (5)	Acceptability of Treatment Environment	31	96	48
The patient has a short wait to get an appointment to see the radiation	Accessibility	31	54	107

oncologist for the first time (1)				
The patient is given enough information about how the treatment is scheduled and flexibility in the daily appointment times (3)	Adequacy of Information Sharing	31	19	109
The patient's family physician is kept informed about the cancer care (5)	Continuity of Care	35	46	91
The patient is given enough information about the possible side effects of radiation treatment (2)	Adequacy of Information Sharing	36	77	21
The patient has a short wait in the waiting room for daily radiation treatment (4)	Accessibility	37	49	129
The patient is aware that no one else other than him and the healthcare professionals looking after him are able to see his medical records without his permission (5)	Privacy	38	59	88
The information about treatment options is provided to the patient before any decision is made about the way he will be treated (2)	Adequacy of Information Sharing	39	74	25
Someone on the healthcare team explains the arrangements for follow-up care after the radiation treatment is over (4)	Adequacy of Information Sharing	40	68	53
Before radiation treatment starts, the patient is given enough information about what will happen each day when he comes for treatment (3)	Adequacy of Information Sharing	41	34	108
The patient has a short wait in the waiting room when he comes to the cancer centre to see the radiation oncologist for the first time (1)	Accessibility	41	44	135
A social worker is available to provide advice on financial and social issues arising from the diagnosis (1)	Comprehensiveness	43	3	136
Someone at the cancer centre gives the patient information about support groups in his area for patients and/or family members (1)	Comprehensiveness	44	1	137
Someone on the healthcare team other than the radiation oncologist is available to provide support to the	Comprehensiveness	45	14	132

patient in making the decision about treatment (2)				
The radiation oncologist reads the patient's previous medical records before seeing the patient for the first time (1)	Competence	46	69	52
The patient gets all the help he needs from the radiation oncologist to make up his mind about which treatment to have (2)	Patient Centeredness	47	93	22
The patient is aware that he has a right to see all the information in his medical record (5)	Patient Centeredness	48	47	101
The patient gets enough information from the radiation oncologist to be able to participate in the decision about treatment (2)	Patient Centeredness	49	82	33
The radiation oncologist explains to the patient that he can change his mind about which treatment to have as long as he does so before the treatment starts (2)	Adequacy of Information Sharing	50	35	95
The radiation oncologist asks the patient about any other medical problems he may have (1)	Competence	51	62	69
The radiation oncologist is aware of the test results and has the results available when seeing the patient for the first time (1)	Competence	51	85	14
The patient is encouraged by the cancer center to bring a relative or friend along to the first appointment with the radiation oncologist (1)	Patient Centeredness	51	32	116
The radiation oncologist explains what each treatment option involves (2)	Adequacy of Information Sharing	54	53	56
The radiation oncologist makes sure the patient understands the treatment options before making up his mind about which treatment to have (2)	Adequacy of Information Sharing	54	94	29
The radiation oncologist explains the different forms of treatment that are available for prostate cancer (1)	Adequacy of Information Sharing	56	92	15
The radiation oncologist sees the patient at least once a week during the course of radiation treatment (4)	Continuity of care	56	18	130

Someone on the healthcare team gives the patient written information about the side effects of each treatment option (2)	Adequacy of Information Sharing	58	55	66
Someone on the healthcare team is always available to answer the patient's questions and advise on the management of side effects during the course of radiation treatment (4)	Accessibility	59	76	67
Directions and signs inside and outside the cancer centre are easy to understand (5)	Convenience	59	23	123
Someone on the healthcare team explains that radiation treatment involves the use of high energy rays directed at the prostate from outside the body (2)	Adequacy of Information Sharing	61	63	74
The patient trusts the radiation oncologist to look after him properly (5)	Competence	61	109	3
The radiation oncologist is knowledgeable and experienced in dealing with prostate cancer (5)	Competence	61	120	1
Once the treatment starts, someone on the healthcare team reminds the patient of the potential side effects to expect during the course of radiation treatment (4)	Adequacy of Information Sharing	64	43	115
The patient can find his way around the cancer centre easily (5)	Convenience	64	28	127
The cancer centre provides resources to assist the patient in understanding and dealing with prostate cancer (e.g. staffed information services, library of books and DVDs about cancer) (1)	Comprehensiveness	66	8	133
The patient understands that there is no immediate rush to make a decision about treatment although it's best to make a decision within a week or two (2)	Adequacy of Information Sharing	67	81	83
The patient has enough time with the radiation oncologist to get all of the information he needs about treatment options (2)	Accessibility	68	83	32
The patient has enough time to	Patient	69	90	50

consider the treatment options before it is decided how he will be treated (2)	Centeredness			
Someone on the healthcare team explains that radiation treatment can only be delivered at a few specialized treatment centers (2)	Adequacy of Information Sharing	70	22	125
The radiation oncologist describes and explains all of the treatment options that are available to the patient other than radiation treatment (2)	Adequacy of Information Sharing	71	70	56
Someone on the healthcare team explains that radiation treatment is delivered by the radiation therapists, not a radiation oncologist (3)	Adequacy of Information Sharing	71	48	120
The patient is aware of who to contact with questions about his prostate cancer and treatment (5)	Continuity of care	73	88	16
The nurses explain things to the patient in a way that he can understand (5)	Adequacy of Information Sharing	74	105	36
Someone on the healthcare team is available if needed to help explain the diagnosis to family members (1)	Comprehensiveness	75	37	117
The atmosphere in the waiting room is relaxing (5)	Acceptability of Treatment Environment	76	39	128
The cancer centre has a place to stay overnight if the patient lives far away (5)	Convenience	77	112	106
The radiation oncologist carefully assesses the patient's suitability for radiation treatment (1)	Competence	78	97	24
The radiation oncologist shows interest in the patient as a person, not just as a patient (5)	Patient Centeredness	79	76	90
The nurses show sensitivity to the patient's feelings and emotional needs (5)	Empathy and Respectfulness of Caregivers	80	91	89
The patient is involved as much as he wants in making the final decision about which treatment to have (2)	Patient Centeredness	81	107	39
The nurses care about the patient's well-being (5)	Empathy and Respectfulness of Caregivers	82	103	68

The radiation oncologist is honest with the patient (5)	Adequacy of Information Sharing	82	129	8
The patient has enough time with a member of the healthcare team to discuss the treatment plan (3)	Accessibility	84	56	97
The radiation oncologist shows sensitivity to the patient's feelings and emotional needs (5)	Empathy and Respectfulness of Caregivers	84	100	63
Someone on the healthcare team explains that radiation treatment often causes urinary symptoms during treatment (2)	Adequacy of Information Sharing	84	101	59
The radiation oncologist cares about the patient's well-being (5)	Empathy and Respectfulness of Caregivers	84	113	30
The radiation oncologist explains things to the patient in a way that he can understand (5)	Adequacy of Information Sharing	84	118	19
The patient feels that his rights for privacy are fully protected at the cancer centre (5)	Privacy	89	65	79
The nurses take the time to answer all of the patient's questions (5)	Accessibility	90	106	43
Once an appointment is made for the patient it is not cancelled or postponed (5)	Convenience	90	71	111
The cancer centre seems to have all the equipment and facilities needed to completely care for the patient's prostate cancer (5)	Comprehensiveness	90	121	4
If the patient wants, someone on the healthcare team is willing to answer questions about treatment from family or friends (2)	Patient Centeredness	93	26	114
The nurses are honest with the patient (5)	Adequacy of Information Sharing	94	110	47
The patient feels that he can trust the nurses with confidential information (5)	Privacy	95	84	94
Transportation to/from the cancer centre is available for the patient if needed (5)	Convenience	95	80	112
Someone on the health care team offers written information about	Adequacy of Information	97	87	70

prostate cancer to the patient that he can take home with him (1)	Sharing			
Someone on the healthcare team explains that radiation treatment often causes bowel symptoms during treatment (2)	Adequacy of Information Sharing	98	102	65
The nurses listen carefully to all the patient's concerns (5)	Adequacy of Information Sharing	98	111	44
The radiation oncologist takes the time to answer all of the patient's questions (5)	Accessibility	98	119	7
The radiation oncologist listens carefully to all the patient's concerns (5)	Adequacy of Information Sharing	98	126	16
The radiation oncologist makes the patient feel like he can ask any questions he wants to (5)	Empathy and Respectfulness of Caregivers	98	132	11
The patient has a short wait to start treatment after the decision was made to have radiation treatment (4)	Accessibility	103	79	105
Appointments are scheduled for a time that is convenient (5)	Convenience	103	72	122
The nurses make the patient feel like he can ask any questions he wants to (5)	Empathy and Respectfulness of Caregivers	103	123	44
The furniture in the waiting room is comfortable (5)	Acceptability of Treatment Environment	106	17	138
Someone at the cancer centre is available to answer the patient's questions in between appointments (5)	Accessibility	107	67	76
The nurses show interest in the patient as a person, not just as a patient (5)	Patient Centeredness	108	99	103
The nurses are knowledgeable and experienced in dealing with prostate cancer (5)	Competence	108	115	13
During treatment, the radiation oncologist, nurses and radiation therapists do everything they can to help the patient get through treatment with as few problems as possible (4)	Competence	110	123	38
During treatment, the radiation	Accessibility	110	105	131

therapists make enough time for the patient (4)				
The waiting area and treatment rooms are quiet (5)	Acceptability of Treatment Environment	112	45	134
The patient is welcome to bring a friend or relative with him to his appointments (5)	Patient Centeredness	113	78	118
There is enough space in the waiting room that the patient can have a private conversation with his companion (5)	Privacy	114	10	140
The radiation therapists care about the patient's well-being (5)	Empathy and Respectfulness of Caregivers	115	139	72
The radiation therapists are polite to the patient (5)	Empathy and Respectfulness of Caregivers	116	134	85
The patient trusts the nurses to look after him properly (5)	Competence	117	108	46
The radiation therapists are knowledgeable and experienced in dealing with prostate cancer (5)	Competence	117	137	5
The radiation therapists explain things to the patient in a way that he can understand (5)	Adequacy of Information Sharing	117	137	37
Someone on the healthcare team explains that radiation treatment often causes temporary fatigue (2)	Adequacy of Information Sharing	120	98	93
The nurses are polite to the patient (5)	Empathy and Respectfulness of Caregivers	120	114	81
The patient has confidence in his treatment team that he is treated correctly every day (4)	Competence	120	127	23
Waiting areas are decorated nicely (5)	Acceptability of Treatment Environment	120	6	142
The radiation oncologist, nurses and radiation therapists work well together when treating the patient for prostate cancer (5)	Continuity of care	120	142	6
The radiation oncologist treats the patient with respect (5)	Empathy and Respectfulness of Caregivers	120	141	31
The patient trusts the radiation	Competence	126	124	27

therapists to look after him properly (5)				
If the patient wants, the radiation oncologist is willing to answer all the questions the patient's family and friends have (5)	Patient Centeredness	127	95	110
The patient feels that he can trust the radiation therapists with confidential information (5)	Privacy	128	128	84
The patient feels that he can trust the radiation oncologist with confidential information (5)	Privacy	129	125	74
The radiation therapists listen carefully to all the patient's concerns (5)	Adequacy of Information Sharing	130	117	60
The radiation therapists take the time to answer all of the patient's questions (5)	Accessibility	131	137	58
The patient sees the same radiation therapists each time he goes for radiation treatment (4)	Continuity of care	132	24	139
The nurses treat the patient with respect (5)	Empathy and Respectfulness of Caregivers	133	133	61
The radiation oncologist is polite to the patient (5)	Empathy and Respectfulness of Caregivers	133	143	55
The radiation therapists show interest in the patient as a person, not just as a patient (5)	Patient Centeredness	135	116	99
The radiation therapists are honest with the patient (5)	Adequacy of Information Sharing	135	140	20
The radiation therapists make the patient feel like he can ask any questions he wants to (5)	Empathy and Respectfulness of Caregivers	137	131	54
The radiation therapists show sensitivity to the patient's feelings and emotional needs (5)	Empathy and Respectfulness of Caregivers	137	130	87
The radiation therapists treat the patient with respect (5)	Empathy and Respectfulness of Caregivers	139	138	78
The patient is treated in the same treatment room each day (4)	Continuity of care	139	36	143
The radiation oncologist or the nurse see the patient at least once a week	Continuity of care	141	89	121

during the course of radiation treatment (4)				
The patient has enough privacy during his care (5)	Privacy	142	86	124
Food and drink facilities are available in or near the waiting room (5)	Acceptability of Treatment Environment	143	7	141

*The number in parentheses indicates the step in the treatment pathway the element refers to: (1) Pretreatment assessment, (2) Treatment decision-making, (3) Treatment planning, (4) Treatment and follow-up, (5) General aspects of care

Appendix F

Additional Results for the Manuscript Titled, “Measuring the Quality of Personal Care in Patients Undergoing Radiotherapy for Prostate Cancer”

Appendix F1: Test-retest Reliability

Median positive agreement for quality ratings of the 64 elements in module 3 was 92% (range 68% to 100%). There was only one element of care with <70% positive agreement: “There is somewhere convenient to park”.

Appendix F2: Percentage of elements rated “very good” over time

We compared the percentage of elements rated “very good” by each patient recruited in the first half of the study to the second half of the study and the differences were not significant (median percentage of elements rated “very good” in the first half of the study to the second half was 78.9% vs 79.9%, $p=0.7$).

Appendix F3: Sensitivity analyses for ranking methods and missing data

A secondary analysis in which the elements were ranked based on the percentage rating each element as either “good” or “very good” gave very similar results to the original ranking based on “very good”. The Spearman correlation coefficient comparing the overall ranking of elements was 0.92 ($p<0.0001$). The ranking of elements based on the percentage of patients rating each one

“very good” or “good” identified 7 out of the same 10 elements of care in the bottom 10 as the analysis by “very good” only.

We conducted a sensitivity analysis to assess the impact of missing data on the ranking of elements of care based on ratings of “very good”. For each patient, missing responses were coded as less than “very good” and the elements of care were re-ranked based on the percentage of patients rating each one as “very good”. The Spearman correlation coefficient comparing the new rank order to the original order was 1.0. Although there were some changes in the elements ranked in the top 10, there was only only 1 element in the bottom 10 ranked elements of care that differed.

Appendix F4: Assumptions of Generalized Estimating Equations

This topic was described in Appendix C3 with respect to the analysis of the results of the importance ratings. The same rationale applies to this analysis; we did not use imputation to deal with missing data as it is not necessarily needed with GEE (193) and again, the amount of missing data was relatively low; for each patient, the median percentage of elements missing a quality rating was 6% (range 0% to 34%, IQR 3% to 11%). Again, we compared various correlation structures using the QIC for comparison, and again, chose the “exchangeable” structure as we felt it was most appropriate for these data (194).

Table F3-1: QIC values for different GEE correlation structures

Correlation structure	QIC value
Exchangeable	14787.3

Autoregressive	16506.6
Independent	14787.0
Unstructured	15279.0