

Ontario Health Technology Assessment Series

Prostate Cancer Patient Perspectives on the Use of Information in Treatment Decision-Making: A Systematic Review and Qualitative Meta-synthesis

KEY MESSAGES

Prostate cancer is the most common cancer in men. For many men diagnosed with prostate cancer, the disease is considered low or intermediate risk. Their tumour is slow growing and unlikely to spread. These men have to decide whether to treat the cancer right away or take a wait-and-see approach, in which they get regular checkups to watch for changes in the tumour and then change to active treatment if needed. These decisions are challenging because active treatments, such as surgery and radiation, will remove or destroy the tumour but they can also have concerning side effects that affect men's quality of life.

This report looked at 29 studies of how men make decisions about their prostate cancer treatment. The studies show that men diagnosed with prostate cancer actively seek information to help them decide. They are interested in three key types of knowledge: medical information (to learn about their cancer and treatment options), lived-experience information (to learn from other patients who had faced a similar decision), and medical administrative information (to learn about the logistics of their care and the experience of their physicians). They consult a variety of sources such as health care providers, other patients, family members, friends, support groups, decision aids, patient education materials, and the Internet. Men with prostate cancer emphasize the importance of getting comfortable with their treatment choices. Having a chance to confirm their health care provider's recommendations helps them with this. So does having the freedom to be involved in the decision-making process according to their own personal preferences. Men also said they particularly want information that is relevant and personalized to their specific disease status and treatment options.

SYSTEMATIC REVIEW AND QUALITATIVE META-SYNTHESIS

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ABSTRACT

Background

Men with low- to intermediate-risk prostate cancer are typically asked to choose from a variety of treatment options, including active surveillance, radical prostatectomy, or brachytherapy. The Prolaris cell cycle progression test is intended to provide additional information on personal risk status to assist men with prostate cancer in their choice of treatment. To assist with assessing that new technology, this report synthesizes qualitative research on how men with prostate cancer use information to make decisions about treatment options.

Methods

We performed a systematic review and qualitative meta-synthesis to retrieve and synthesize findings across primary qualitative studies that report on patient perspectives during prostate cancer treatment decision-making.

Results

Of 8,610 titles and abstracts reviewed, 29 studies are included in this report. Most men diagnosed with prostate cancer express that their information-seeking pathway extends beyond the medical information received from their health care provider. They access other social resources to attain additional medical information, lived-experience information, and medical administrative information to help support their final treatment decision. Men value privacy, trust, honesty, control, power, organization, and open communication during interactions with their health care providers. They also emphasize the importance of gaining comfort with their treatment choice, having a chance to confirm their health care provider's recommendations (validation of treatment plan), and exercising their preferred level of independence in the treatment decision-making process.

Conclusions

Although each prostate cancer patient is unique, studies suggest that most patients seek extensive information to help inform their treatment decisions. This may happen before, during, and after the treatment choice is made. Given the amount of information patients may access, it is important that they also establish the trustworthiness of the various types and sources of information. When information conflicts, patients may be unsure about how to proceed. Open collaboration between patients and their health care providers can help patients manage and navigate their concerns so that their values and perspectives are captured in their treatment choices.

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BACKGROUND

This section offers a brief summary of the background and rationale for this report. A complete description of the clinical population and technology of interest can be found in the Health Quality Ontario report, “Prolaris Cycle Cell Progression Test for Localized Prostate Cancer: A Health Technology Assessment.”¹

Prostate cancer is the most commonly diagnosed cancer in Canadian men.² About 90% of newly diagnosed patients have cancer that is limited to the prostate (clinically localized), which is often asymptomatic.³ In current practice, the risk of prostate cancer metastasizing (spreading) is predicted through tumour biopsy and classified using the Gleason score.⁴ A higher Gleason score represents higher risk of the tumour growing outside the prostate gland and spreading to other tissue.⁵ Assessing this risk is important to determine which treatment options are appropriate for each patient. The goal is to avoid undertreating or overtreating the cancer, which can lead to poorer survival, on the one hand, and unnecessary treatment-related side effects, on the other.

For the 85% of men who receive an assessment of low- or intermediate-risk prostate cancer,^{6,7} choosing a treatment may be challenging. Despite the high odds of survival for this group, many low- and intermediate-risk patients are reluctant to decline active treatment due to residual uncertainty about the aggressiveness of the cancer.^{8,9} Definitive treatment of localized prostate cancer can consist of radiation therapy, hormone therapy, surgery, or combinations of treatments.³ All these treatments have associated potential complications and harms such as anxiety, pain, infection, bleeding, bowel dysfunction, urinary incontinence, and sexual dysfunction, all of which can considerably impact a man’s quality of life.¹⁰⁻¹³ To address concerns of potential overtreatment and side effects among more fit men with otherwise slow-growing cancers, an approach called active surveillance is promoted as a safe and appropriate management approach, and is generally the primary management strategy for low-risk patients.³ During active surveillance, the cancer is closely monitored via regularly scheduled tests and examinations, and curative treatment is given only if there is evidence that the cancer is progressing.⁵ Active surveillance for intermediate-risk patients is more controversial than for low-risk patients, due to notable differences between the two groups in terms of their risk of prostate-cancer specific mortality, overall mortality risk, and biochemical recurrence after treatment (the return of detectable levels of prostate-specific antigen, or PSA, in the blood, even if there are no other symptoms of cancer).¹⁴ Older patients, particularly those with more serious comorbidities, may opt for another approach known as watchful waiting: the patient and health care provider agree to wait for symptoms of metastatic disease to develop and to then start treatment to manage the symptoms or provide palliative care. The decision to pursue one management strategy or another is made collaboratively between patients and health care providers and an understanding of the patient’s risk level is fundamental to that decision.

Technology

The Prolaris cell cycle progression (CCP) test is a prognostic test designed to help assess risk of disease progression in patients with low- and intermediate-risk prostate cancer. It is a genomic test, meaning it measures the expression of certain genes in the tumour, and is intended to directly measure the growth characteristics of the prostate cancer tumour.¹⁵ The test yields a CCP signature, or score, that reflects changes in a panel of 46 genes, providing information about prostate tumour cell proliferation (how fast the cells are dividing).¹⁵ The score ranges from 0 to 10, and each unit increase represents a doubling of risk of disease progression.¹⁵

The CCP test is performed in a laboratory and analyzes the same biopsy tissue that is collected for routine diagnosis. Once the sample has been analyzed, a report is generated that includes the patient's clinicopathologic features (including age, pre-biopsy PSA level, tumour stage, percent of positive biopsy cores, Gleason score, and clinical risk group) and an assessment based on the CCP score. The assessment states whether the tumour is less aggressive, more aggressive, or consistent with the average risk of the relevant clinical risk group (based on the American Urological Association classification). The CCP report also provides an individualized estimate of a patient's 10-year prostate cancer-specific mortality risk (their risk of dying from prostate cancer within the next decade), reflecting the combined prediction of the clinicopathological variables and the CCP score.

Research Question

For men with low- and intermediate-risk prostate cancer, it may be difficult to decide between definitive treatment, with its potential for significant side effects, and active surveillance. Information about the aggressiveness of their individual tumour, provided by the Prolaris CCP test, may help men make that decision more easily and confidently. Beyond the clinical, analytical, and economic implications of the CCP test, it is also important to know whether men with prostate cancer would value and use the information provided by the test.

We conducted a meta-synthesis of published qualitative studies to determine what types of information are valued by men with prostate cancer as they decide on a treatment modality. Since there is no qualitative research on the Prolaris CCP test, we broadened the question. Our research question was: How do patients diagnosed with prostate cancer use information in their treatment decision-making?

METHODS

Research questions are developed by Health Quality Ontario in consultation with experts, end users, and/or applicants in the topic area.

Sources

We performed a literature search on June 23, 2016, using Ovid MEDLINE, EBSCO Cumulative Index to Nursing & Allied Health Literature (CINAHL) and ISI Web of Science Social Sciences Citation Index (SSCI) for studies published from January 1, 2010, to June 23, 2016.

Search strategies were developed by medical librarians using medical subject headings (MeSH). To identify qualitative research, we developed a qualitative hybrid filter by combining existing published qualitative filters.¹⁶⁻¹⁸ The filters were compared, and redundant search terms were deleted. We added exclusionary terms to the search filter that would be likely to identify quantitative research and reduce the number of false-positives. The validation of this filter has been published.¹⁹ We applied the qualitative hybrid filter to the prostate cancer-specific search strategies supplied by the medical librarian at Health Quality Ontario.

See Appendix 1 for full details, including all search terms.

Literature Screening

At least two reviewers reviewed each title and abstract and, for those studies meeting the eligibility criteria, we obtained full-text articles.

Inclusion Criteria

- English-language full-text publications
- Studies published between January 1, 2010, and June 23, 2016
- Primary qualitative empirical research (using any descriptive or interpretive qualitative methodology, including the qualitative component of mixed-methods studies)
- Studies involving adult men (> 18 years of age) with experience with prostate cancer
- Research conducted in Canada, the United States, Australia, New Zealand, the United Kingdom (i.e., comparable to the Ontario context)
- Published research work (no theses)
- Studies addressing men's experiences of treatment decision-making

Exclusion Criteria

- Animal and in vitro studies
- Editorials, case reports, or commentaries
- Studies addressing topics other than prostate cancer
- Studies that did not include the perspective of men diagnosed with prostate cancer
- Studies labelled "qualitative" but that did not use a qualitative descriptive or interpretive methodology (e.g., case studies, experiments, or observational analyses using qualitative categorical variables)

Qualitative Analysis

We analyzed published qualitative research using techniques of integrative qualitative meta-synthesis,²⁰⁻²² also known as qualitative research integration. Qualitative meta-synthesis summarizes research over a number of studies with the intent of combining findings from multiple articles. The objective of qualitative meta-synthesis is twofold: first, the aggregate of a result reflects the range of findings while retaining the original meaning; second, by comparing and contrasting findings across studies, a new integrative interpretation is produced.

A predefined topic and research question about the experience of making prostate cancer treatment decisions guided the research collection, data extraction, and analysis. We defined topics in stages as relevant literature was identified, and the corresponding health technology assessment proceeded. First, all qualitative research relevant to the condition under analysis was retrieved. Next, a specific research question regarding the experience of using information to make prostate cancer treatment decisions was chosen, and a final search was performed to retrieve articles relevant to this question. The analysis in this report includes articles that addressed the issue of how men consider the use of information as they make treatment decisions after a diagnosis of prostate cancer.

Data extraction focused on, and was limited to, findings that were relevant to this research topic. Qualitative findings are the “data-driven and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation.”²¹ In addition to the researchers’ findings, we also extracted original data excerpts (participant quotes, stories, or incidents) to illustrate or communicate specific findings.

Using a staged coding process similar to that of grounded theory,^{23,24} findings were broken into their component parts (key themes, categories, concepts) and then regrouped across studies and related to each other thematically. This allowed us to organize and reflect on the full range of interpretative insights across the body of research.^{21,25} We used a constant comparative and iterative approach, in which preliminary categories were repeatedly compared with the research findings, raw data excerpts, and co-investigators’ interpretations of the studies.

Quality of Evidence

For valid epistemological reasons, the field of qualitative research lacks consensus on the importance of, and methods or standards for, critical appraisal of research quality.²⁶ Qualitative health researchers conventionally under-report procedural details, and the quality of findings tends to rest more on the conceptual prowess of the researchers than on methodological processes.^{22,26} Theoretically sophisticated findings are promoted as a marker of study quality because they make valuable theoretical contributions to social science academic disciplines.²⁷ However, theoretical sophistication is not necessary to contribute potentially valuable information to a synthesis of multiple studies, or to inform questions posed by the interdisciplinary and interprofessional field of health technology assessment. Qualitative meta-synthesis researchers typically do not exclude qualitative research on the basis of independently appraised “quality.” This approach is common to multiple types of interpretive qualitative synthesis.^{20,21,27-32}

For this review, we presumed the academic peer review and publication processes eliminated scientifically unsound studies, according to current standards. Beyond this, we included all topically relevant, accessible, and published research using any qualitative interpretive or descriptive methodology. We appraised the relevance of each study using the Critical Appraisal

Skills Programme (CASP) tool for qualitative research.³³ The CASP tool is composed of standardized methodological criteria. Two researchers reviewed each article and ranked it for relevance as low, medium, or high. These rankings were used as a discussion point to assess the relevance of each article and our confidence in it, but for the previously mentioned reasons regarding the controversy of quality appraisal in qualitative research, we did not exclude any articles based on the CASP assessment of relevance.

RESULTS

Literature Search

The bibliographic database search yielded 8,610 citations published between January 1, 2010, and June 23, 2016 (with duplicates removed). Articles were excluded based on information in the title and abstract; each abstract was screened by multiple reviewers according to the criteria listed above. Figure 1 presents the flow diagram for the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA).

Twenty-nine studies met the inclusion criteria. Studies were conducted in Australia (n = 6), the United Kingdom (n = 7), United States (n = 11), Canada (n = 3), and online forums that draw patients from these countries (n = 2) (Table 1). Methodologies varied, with a significant number of studies using thematic analysis (n = 9) and grounded theory and adapted approaches (n = 7) (Table 2). The 29 included studies incorporated data from 2,042 participants, including 1,848 patients, 170 family members, and 24 clinicians (Table 3).

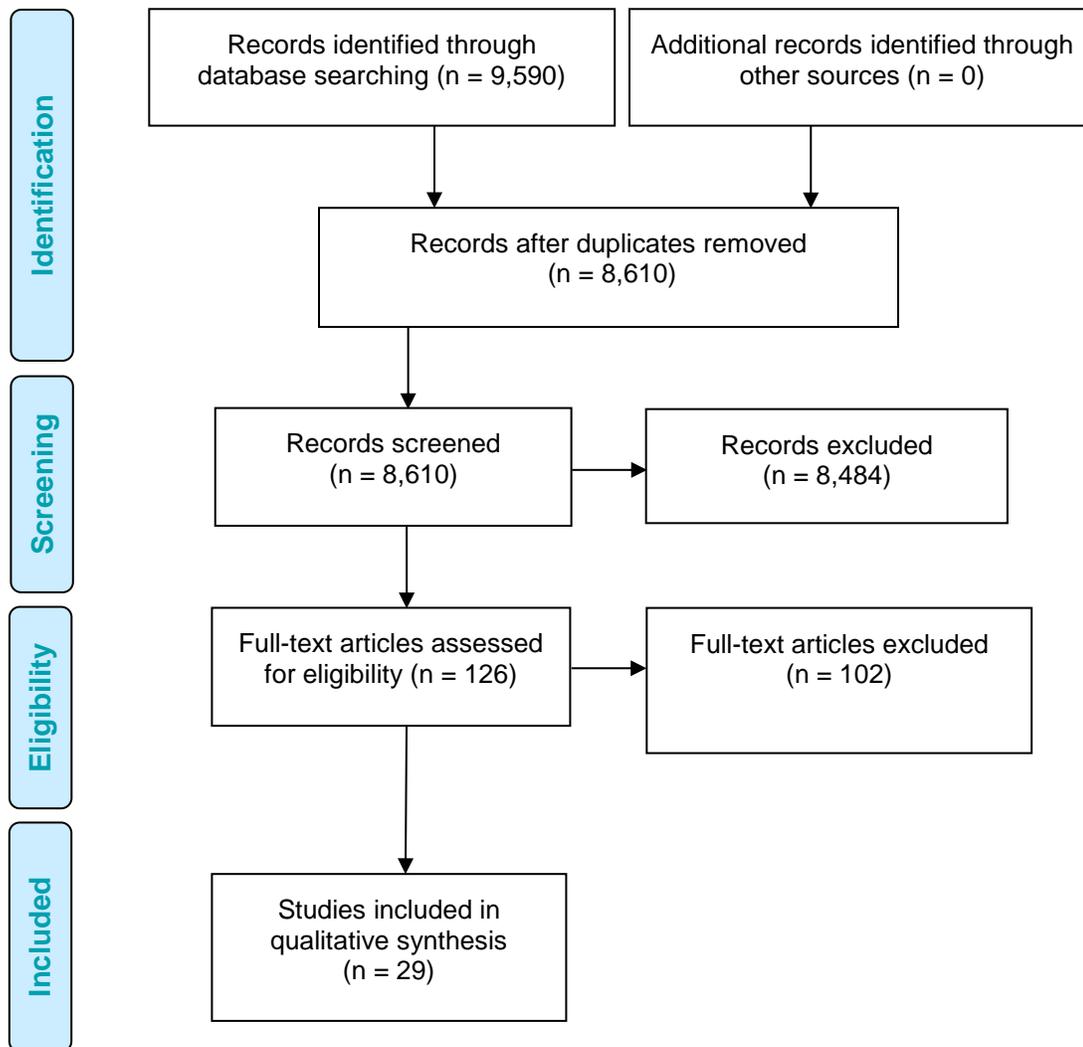


Figure 1: PRISMA Flow Diagram

Source: Adapted from Moher et al, 2010.³⁴

Table 1: Body of Evidence Examined According to Study Location

Study Location	Number of Eligible Studies
United States	11 (38%)
United Kingdom	7 (24%)
Australia	6 (21%)
Canada	3 (10%)
Web-based	2 (7%)
Total	29 (100%)

Table 2: Body of Evidence Examined According to Study Design

Study Design	Number of Eligible Studies
Thematic analysis	9 (31%)
Grounded theory and adapted approaches	7 (24%)
Phenomenological and adapted approaches	4 (14%)
Content analysis	2 (7%)
Framework analysis	2 (7%)
Qualitative but not otherwise specified	2 (7%)
Community-based participatory research	1 (3%)
Discourse analysis	1 (3%)
Interpretive descriptive	1 (3%)
Total	29 (100%)

Table 3: Body of Evidence Examined According to Type and Number of Participants

Type of Participant	Number of Participants
Patient	1,848
Caregiver or family member	170
Clinicians	24
Total	2,042

The Information-Seeking Pathway

The diagnosis of prostate cancer can be very difficult for men and their families, particularly around gathering information about the disease and deciding on treatment options. Many patients obtain initial medical information from their health care providers but then look for additional information to assist with treatment decision-making. Our analysis describes the three types of knowledge sought by patients and the sources from which they seek this knowledge. Generally, men’s information-seeking and decision-making journeys extend beyond their health care provider’s office, pulling from a variety of individual and social resources. The extent to which men engage in information-seeking varies, and our analysis reveals a spectrum of patient involvement in treatment decision-making. Some patients are very active in gathering additional information outside of their health care providers while others are satisfied to follow the knowledgeable and reliable advice of their physicians. These differences highlight the uniqueness of each prostate cancer patient and the need for health care providers to engage in open and collaborative communication to best support the needs of their patients.

Figure 2 depicts the “information-seeking pathway,” or the sources and types of information that prostate cancer patients gather for treatment decision-making. This figure demonstrates the types of information (orange, darker elements) that men may seek and the various sources they consult (blue, lighter elements).

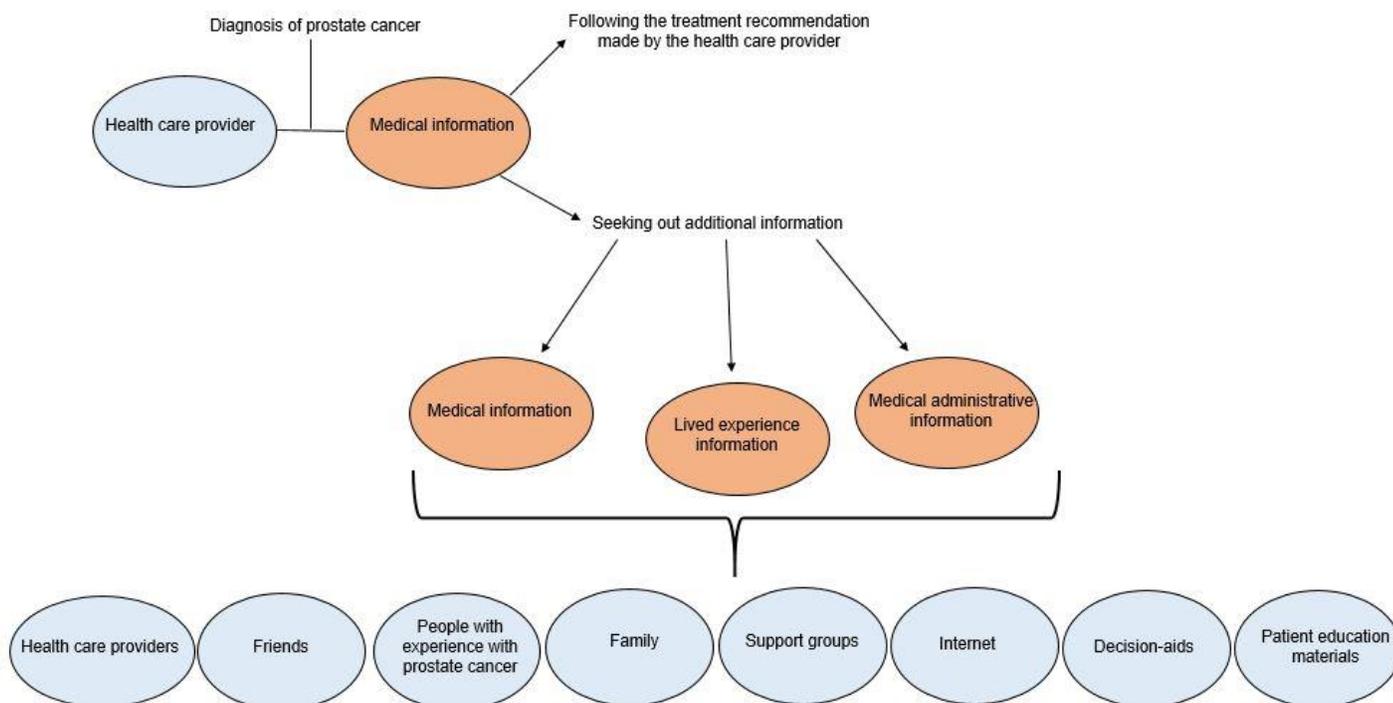


Figure 2: The Information-Seeking Pathway Used by Prostate Cancer Patients for Treatment Decision-Making

Most men enter this information-seeking pathway when they receive a diagnosis of prostate cancer. This diagnosis is typically accompanied by some basic information, including the notification that the patient will need to decide on a treatment decision in partnership with his health care provider. At this point, many patients choose to seek additional information, often from a variety of sources such as the Internet,³⁵⁻⁴⁰ other people who have experience with prostate cancer,^{36,40,41} family,⁴²⁻⁴⁴ friends,⁴⁵ support groups,^{35-37,43,46} decision aids,^{35,47} and patient education material.^{36,38,48} All these sources contribute various kinds of knowledge that inform men's treatment decisions.

While many patients choose to pursue additional information, some do not, preferring to rely on their health care provider to recommend a treatment option.⁴⁹ For those who do look beyond their provider's advice, the process is fueled by the desire to feel more comfortable with their treatment decision or to garner additional perspectives, for example by learning more about available treatment options and their consequences before confirming their choice. This point of comfort varies among individuals and is influenced by a variety of factors such as their ability to access information,³⁶ the time required to access different information sources,⁴⁹ their emotional wellbeing,⁵⁰ and the value they place on monitoring their own health.³⁵ Patients tend to highly value information as "currency to enhance their own sense of power and control during patient-provider interactions."³⁵

When searching for additional information, patients identified three main categories of information that was valued as important to their treatment decision.

- Medical information is technical information about diagnosis, treatment, and management from a source that does not have personal connection to the information^{35,36,38-42,44-49,51-59}
- Lived-experience information comprises "disease-prompted awareness"⁴⁵ or other information from people that have first-hand experience with the condition.^{35-40,42,44-46,49,51-53,58,59} For instance, other prostate cancer patients or survivors can contribute information about their own experiences with treatment side effects^{42,45,53}
- Medical administrative information^{35,38-40,46,48,54-56} includes information about the reputation and skill set of a physician^{35,39} and logistical information about health care services and systems^{40,48,54-56}

At all stages of their decision-making and treatment, patients reported a general lack of readily available information⁴⁶: diagnosis,^{38,56,59} prognosis,^{39,40,56} medical procedures,^{38,40,46,58} treatment options and side effects,^{36,38-40,42,47,48,51,58} and the logistics of care.^{35,40,48,54,55} Patients valued integrating information from different sources.^{40,46} However dissatisfaction with inadequate medical information is what initially propelled them to search other avenues, most notably their social resources, to learn from the lived experiences of family, friends, or prostate cancer support groups.^{37,39,45} In addition, the spouses of prostate cancer patients also felt a need to be involved in treatment and medical decision-making through the seeking of information.⁵⁰ In many cases, the type and variety of information obtained by spouses and partners were directly related to their level of emotional welling.⁵⁰ For example, couples who were not emotionally distressed gained access to a wide variety of sources, whereas those who were distressed had limited information and found it challenging to access more information.⁵⁰

In the following sections, we describe the types of information sought by men with prostate cancer, the sources of that information, and the points at which it is most valued in the decision-making process.

Medical Information

Active Surveillance and Watchful Waiting

Several studies considered patient perspectives on active surveillance or watchful waiting.^{38,41,44,56,58,59} A study suggested that men had done extensive independent research and consulted their health care provider before selecting active surveillance,⁵⁸ whereas another study found a general lack of information on these as trusted treatment options.⁵⁹ In cases where patients have limited information on treatment options in general, they may feel forced to choose active surveillance.⁵⁶ Furthermore, patients reported a need to understand the specifics, benefits, and disadvantages of all available treatment options.^{56,59} For example, one study reported a patient who opted for active treatment because his physician said active surveillance and watchful waiting were for older individuals who have a high risk of complications from surgical procedures.⁵⁹ In contrast, some patients may prefer having less information on treatment options if they have already established a preference for a particular treatment⁵⁶ or if information was redundant.⁴⁸

Before Treatment

It is important to consider that the experience of illness is unique for each person and individuals react differently to their diagnosis. Some reported feeling extreme sadness, whereas others did not feel alarmed themselves but recounted the sadness experienced by their spouses.⁴⁶ After diagnosis and before treatment, patients reported using several information channels (e.g., health care professionals, the Internet, others who have experience with prostate cancer) to obtain and clarify information about their diagnosis,^{38,56,59} individual-specific cancer status,^{35,40,59} and the risk of disease progression.^{36,38,40,42,47,54,56,57,59} For patients who had access to them, tools or resources that were designed specifically to help patients make a treatment decision (decision aids) are perceived as central for decision-making^{46,47} because they provide a breadth of high-quality evidence that patients could understand and trust.⁵⁸ Patients reported using decision aids to gain a general understanding of their diagnosis^{35,40} and possible treatments,^{40,47,58} validate their treatment decisions,^{47,48} manage treatment side effects,⁵¹ understand lifestyle issues,^{40,47,58} anticipate progression of disease,⁴⁷ solidify their understanding of the origin and progression of prostate cancer,⁴⁰ and look up medical terminology.⁵⁸ Decision aids may also supplement decision-making about treatment by helping patients identify their values and beliefs.⁵⁸ In one study, patients reported a need for more personalized information in decision aids,⁴⁸ while other patients reported that the decision aids they used did effectively include personal information.⁵⁸

Patients valued having medical information about their diagnosis and the current state of their disease.⁵⁴ Diagnostic information, in the form of Gleason score, PSA level, and stage of cancer,³⁵ is often one of the first types of information delivered during physician-patient interactions.⁵⁴ Patients recognized the importance of understanding their diagnosis in the context of their specific cancer.^{35,40,59} However, many reported ambiguity and confusion surrounding the diagnostic information they received from their physicians, especially the way biopsy and PSA test results were conveyed.^{38,56,59} Furthermore, they reported a wish for more personalized diagnostic information, to understand the state of their specific tumour.⁴⁰ Unreliable or inadequate diagnostic information led patients to pursue other avenues, such as second and third opinions from health care professionals.³⁵ It also led them to associate the diagnosis with dying; patients who felt they had inadequate information equated the term “cancer” with death⁴⁹ and would ruminate on the ideas of metastases and death.²⁸

After diagnosis, patients valued information about the severity of their prostate cancer.^{39,40,56} Prognostic information about disease severity and progression is a key point of discussion during patient-physician interactions.⁵⁴ Patients said that information about survival rates specific to the severity of their prostate cancer and in relation to treatment options was important for their treatment decision-making.^{36,40,47,59} They reported understanding that their Gleason score, PSA level, and tumour size dictated the aggressiveness of their cancer.^{57,59} However, some experienced misunderstanding or uncertainty about disease progression,^{38,59} which caused anxiety about the future.^{38,42}

Patients also sought information to validate their treatment choices and information received from their physician.^{35,39,40,47,58} This manifested in finding resources online to confirm their decisions,³⁵ getting second opinions,^{35,36} and finding and understanding current research on treatment options.^{35,59} In weighing their treatment options, patients valued information on survival associated with each type of treatment^{35,39,40,59} and quality of life during and after treatment.^{41,47,49,59}

Patients emphasized the need for clear, trustworthy information from medical tests. For example, they wanted information about how medical procedures (e.g., PSA tests, tumour biopsies) are conducted and how they should be interpreted.^{38,40,46,58} Ambiguity and inconsistencies in test results provoked a sense of futility,^{38,46} frustration, and distress.³⁸ The distress caused by the lack of clarity from these tests is important because this information is crucial for determining whether curative treatment or active surveillance is appropriate.⁵⁸

During treatment decision-making, information about treatment options and associated side effects is important.^{35,38,40,41,49,56,57,59} Patients sought both general^{40,47} and personalized^{38,40,47,48,58} information about their treatment options. For example, one paper stated that patients reported using their Gleason score, PSA level, and stage of cancer as the three numbers that determined the best treatment choice³⁵; they valued the compilation of various information sources to guide them in their decision.^{40,46} Furthermore, a high Gleason score, PSA level, or tumour size suggested an unfavourable prognosis for which an immediate, aggressive treatment would be advantageous.⁵⁹ Patients also valued getting additional medical opinions^{35,36} because consulting with multiple clinicians allowed them to learn more about different treatment options.^{35,36,39} In addition, they reported a strong need for in-depth discussions of all treatment options,³⁶ with clarity and completeness.⁵¹

Quality of life after treatment was a particularly important factor for patients to consider when selecting a treatment option.^{35,40,41,49} To ascertain how different treatments would affect their quality of life, patients desired consistent, detailed information on treatment side effects.^{36,38,40,41} Patients had a special interest toward information that incorporated their personal circumstances and priorities⁵⁵ and saw a need for information to help them manage lifestyle changes during treatment,^{36,40,41,49,51} including strategies to mitigate physical and emotional side effects.⁴⁰

After Treatment

After treatment, patients reported a need for more information on post-treatment care⁴⁶ such as general advice about side effects,⁵¹ management strategies,⁴⁶ and resources to monitor their progress.³⁵ Making wise treatment decisions is closely linked to having sufficient information on post-treatment outcomes.⁴⁶ Some patients kept a detailed record of their treatments, medical

procedures, and PSA levels in order to be prepared for post-treatment complications.³⁵ However, the unexpectedness of some of the complications resulting from their treatment, such as the need for catheterization, shocked other patients.⁴⁶ Ultimately, learning about the possible effects and outcomes of their prostate cancer treatment is very important for treatment decision-making and aftercare, but the learning continues as men face emerging challenges that require new information.⁴⁰

Lived-Experience Information

Information from lived experience comes from sources with direct and personal connections to the information.^{40,42} Patients valued learning about other people's experience of prostate cancer as examples⁴⁵ or comparisons to their own situations.⁴² This type of information helped them prepare for post-treatment care⁴² and understand that others sympathize with their difficult situation.³⁷ The lived-experience information they sought included others' experiences with treatment options^{36,39,58} and, more importantly, treatment side effects.^{40,42,50-52,57}

Treatment Options

Patients reported a need to find other people who had personal experience with a variety of treatment options and speak with them in detail about their treatment choices.³⁶ Furthermore, hearing about others' experiences provided a chance to validate the treatment information they received from other sources.³⁹ For men with a relative who had died from prostate cancer, this lived experience within their own families influenced their preference for immediate curative treatment.⁵⁹

Treatment Side Effects

Patients described difficulties in obtaining information on the physical and psychological impacts of diagnosis and treatment, especially concerning chemotherapy.⁵¹ Lived experiences of treatment side effects may include living with a catheter,⁴² hot flushes after androgen-deprivation therapy,⁵² and erectile dysfunction.⁵³ These side effects led some patients to restrict their social life^{40,42} for fear of revealing their condition^{40,58} or displaying signs of prostate cancer.⁴⁰

Information on how to manage the impacts of treatment and other complications of their cancer was very important for patients.^{40,46} Obtaining this as lived-experience information was more convenient and practical than receiving it as medical information.⁴⁰ Some patients reported learning about peripheral strategies, such as meditation and yoga, to mitigate the physical and emotional consequences of the disease (e.g., anxiety from diagnosis, distress during treatment).⁴⁰ Men said they did not receive much information about these approaches from their health care providers and thus sought out the lived-experience knowledge of other people or visited cancer centres to develop these skills.⁴⁰

Medical Administrative Information

Access to medical administrative information is important for patients because it can contribute to reducing the fears associated with a prostate cancer diagnosis.³⁶ Information about administrative procedures at their care facility (e.g., hospital, clinic) and details around their physician's expertise and reputation are ongoing concerns for patients. For example, many patients reported a general lack of information about the health care system.⁴⁰ One study found that "most participants described entering illness with limited knowledge about cancer terminology, their disease or the health-care system."⁴⁰ In particular, patients wanted support

and direction to resources provided by the health care system⁴⁰ so they could manage their symptoms, anxieties,⁴⁰ and related complications. In another study, about men who have sex with men, patients found a lack of information and resources, such as support groups, specific to that aspect of their lives.⁵⁵ These findings show that prostate cancer patients need to seek out both general and specific information about the health care system and its various resources.^{40,54,55}

Many studies addressed patient's evaluation of the information provided by their physicians. Some patients doubted the objectivity of this information, fearing that physicians recommended particular treatment options based on their own specialty. They were concerned that by only consulting one specialist they were receiving biased information that should be validated by seeking other physician opinions.^{16,27,35} Patients were unhappy with physicians who provided information they deemed to be too focused, brief, and inadequate.³⁸ To improve their satisfaction with their health care provider, patients sought information about their physician's expertise, reputation, and specialties. For example, Dickerson et al³⁵ described a patient who wished online rankings were available on the success rates of physicians, to enable him to choose the specialist who would be most helpful to him. Another patient decided to proceed with a particular procedure because the physician had successfully performed it for many years.³⁹

In some cases, the structure and professionalism observed in the health care system provided patients with confidence⁵⁶ and information about their next steps.⁴⁸ Once patients understood that their health care team had their best interests in mind, clinical visits became more focused on treatment management than on the general acquisition of information.⁴⁸

Patient Values and Perspectives

In seeking information about treatment for their prostate cancer, patients valued privacy, trust, gaining increased awareness and knowledge about the disease, open and honest discussion, practical information, and comfort and support from their health care providers.^{35,43,45,49,53} Specifically, open and collaborative communication during physician-provider interactions was important to patients.³⁵ In fact, many used other information sources, such as the Internet, to acquire the necessary disease-specific knowledge so they could navigate discussions with their provider in an efficient way. For example, men in several studies described feeling confident about discussing treatment options with their provider and being prepared to ask relevant questions based on knowledge they had obtained online.^{35-40,46,48,50,59} Many men also realized they needed to respect their health care provider's time and did so by organizing their questions and avoiding discussions around irrelevant information.³⁵ Some stated that not having an open relationship with their health care provider led to mistrust and/or led them to find another physician with whom they could have a better rapport.³⁵ In addition, patients valued and benefitted from the emotional support and positive feelings (e.g., relief, less worry) they received when they shared their treatment decision with their social support network.⁶⁰

Overall, the process of gathering information was highly valued by prostate cancer patients as part of their treatment decision-making. Having that opportunity increased their comfort with their treatment plan, provided a chance to confirm their health care provider's recommendations (and validated their treatment choice), and encouraged freedom in treatment decision-making by providing a means to stay organized and focused, in control, and proactive during patient-provider interactions.^{35,36,47} Depending on the personal values they place on these factors at the time of interaction, patients fall on a spectrum in regards to how involved they wish to be in decision-making on treatment. Where some might be very active in gathering additional

information beyond their health care providers, others are satisfied with adhering to the knowledgeable and reliable advice of their physicians. In addition, the studies show that, as treatment options evolve, it is important to reassess patients' values so that their perspectives continue to be discussed during patient-provider interactions.⁶¹

An interesting pattern emerged in the literature, contrasting the influence of medical and lived-experience information. In some cases, patients were swayed to change their treatment decision solely based on lived-experience information,⁵⁹ whereas in other cases, medical information was the determining factor in treatment decisions.⁴⁴ While some cases demonstrate how the contrast between medical and lived-experience information illustrates the complexity that some patients may experience with treatment decision-making, other cases display the fine boundary between these types of information. For example, one patient said, "My three brothers have had it [prostate cancer] ... so I'm the last, you know, the last of the Mohicans (laughter) ... And that's why it was never a surprise, you know. I was watching PSA and when it went up I thought, 'oh, this is it.'"⁴² For this patient, a combination of lived experience (perceived susceptibility based on family history) and medical information (PSA levels) informed him about his personal cancer state.⁴²

DISCUSSION AND CONCLUSIONS

Summary of Main Findings

After a prostate cancer diagnosis, most men are highly motivated to seek information to inform their treatment decisions. Building on the information they receive from their health care providers, they seek and consider additional forms of medical information and lived-experience information, which they supplement with administrative information about the health care system. Treatment decisions are made through a negotiation among these various types of information.

Information about a patient's current disease state is important, but can often be highly confusing. A diagnosis of prostate cancer may be ambiguous, and low-risk patients struggle to balance their own emotional response to hearing the word "cancer" with other messages they receive from health care providers about the possibility of waiting to engage in curative treatment. In addition, understanding the efficacy of the various treatment choices is balanced with information from other patients' lived experiences about treatment side effects. When patients are aware of the significant side effects they might experience, the process of treatment decision-making becomes a negotiation about what quality of life they are willing to accept. In combination with the extensive amount of information that patients may access, they also need to establish the credibility of these different types and sources of information. When information conflicts, patients have trouble moving forward with a treatment choice. This is one of the reasons why a trusting, open relationship with their health care providers can help patients manage and work through their concerns without compromising their values and perspectives.

Comparison with Literature

While conducting the systematic search for primary qualitative research, we found several reviews of qualitative literature on related topics, such as factors for accepting or declining cancer treatment,⁶² experiences of and need for supportive care,⁶³ and the provision of information to support cancer care.⁶⁴ Congruent with our findings, Puts and colleagues⁶² describe the importance of patients' trust in their physicians in regards to treatment decision-

making. Physician recommendation was the most consistent factor in treatment decision-making in the studies they reviewed. Other factors that influenced treatment decision-making included fear of side effects, discomfort of treatments, and necessity of treatment.⁶²

In a systematic review and qualitative synthesis on the needs and experiences of supportive care in cancer treatment, patients identified one-on-one peer support, in person or online, as the most valued type of support.⁶³ This exemplifies the importance of lived-experience information, including information on treatment options and side effects, reported in our review. Furthermore, King and colleagues⁶³ report on the importance of partners in providing supportive care. Although our review only briefly touches on the relationship between partners and caregivers, they serve a unique role in the information-seeking pathway. In their critical literature review, Kazimierczak and colleagues⁶⁴ developed a framework for treatment-decision making by patients, similar to the prostate cancer information-seeking pathway that we report, but broadened to include all types of cancer. They describe the process as a “support for navigating the knowledge landscape,” while acknowledging the patient’s strong desire for timely and personally relevant information.⁶⁴ This idea recognizes the importance of navigating through the various sources of information in the treatment decision-making process, a process the study describes as one of “co-navigating” by patients and health care professionals.⁶⁴ Like our review, Kazimierczak et al⁶⁴ recognize that not all patients wish to participate as active decision-makers; they describe a passive strategy in decision-making as an “autonomous choice of dependency.” Consistent with our description of information-seeking as an ongoing process that patients navigate as their cancer journey unfolds, Kazimierczak and colleagues⁶⁴ understand information-seeking as a dynamic and progressive relationship between patients and the information that is relevant to them. Rather than being a single action or series of standardized steps, this process that patients go through when gathering information is an ongoing and iterative process.

Our search also identified two mixed-method studies discussing prostate cancer treatment and management.^{65,66} One study by Ihrig and colleagues⁶⁵ reported that most patients wanted to make their treatment decision with their physicians. They also found that most patients were generally satisfied with the information they received.⁶⁵ This contrasts with our findings that the information-seeking process continues irrespective of the information received. Another study looking at a psychosocial intervention in prostate cancer management described how important it was for patients to feel a sense of validation in their treatment decision.⁶⁶ Validation of choices, especially treatment decisions, was a recurring theme in our study as well.

Limitations

Qualitative research provides theoretical and contextual insights into the experiences of limited numbers of people in specific settings. Qualitative research findings are not intended to generalize directly to populations, although meta-synthesis across a number of qualitative studies builds an increasingly robust understanding that is more likely to be transferable. While qualitative insights are robust and often enlightening for understanding experiences and planning services in other settings, the findings of the studies reviewed here—and of this synthesis—do not strictly generalize to the Ontario (or any specific) population. The findings are limited to the conditions included in the body of literature synthesized (i.e., prostate cancer). This evidence must be interpreted and applied carefully, in light of expertise and the experiences of the relevant community.

Conclusions

Treatment decision-making about prostate cancer is a highly individualized process. Men who choose to engage actively in this process describe spending significant time and effort searching, interpreting, and negotiating different forms of information. Sometimes this needs to happen over a very short time, when treatment decisions must be made quickly. This may impair men's efforts to gain particular types of information, especially information about the lived experience of other prostate cancer patients. Not all men want to engage actively in treatment decision-making; some defer to the physician as the main decision-maker. Men's experiences with prostate cancer decision-making would benefit from an explicit invitation to participate in treatment decision-making, and from connections to trustworthy, comprehensive sources of information and the necessary time to absorb and consider that information. Types of information that patients find particularly important include information about their individual cancer, personalized information about the efficacy of various treatment options, and lived-experience information about the side effects of those treatment options. Informing patients about their current disease state in isolation from information about treatment options would not be as useful.

APPENDIX 1: LITERATURE SEARCH STRATEGIES

Conducted June 23, 2016 by DD
Limits: English, Human, 2010 – current

MEDLINE hits

8,339 references, 7,899 with duplicates removed (440 duplicates removed)

CINAHL hits

Add 108 references (excluding MEDLINE references). 7,982 total with duplicates removed (25 duplicates removed)

SSCI hits

Add 1,143 references. 8,610 total with duplicates removed (515 duplicates removed)

MEDLINE search

1	interview*.ti,ab.	236157	
2	qualitative.ti,ab.	127762	
3	themes.ti,ab.	33052	
4	Qualitative Research/	27475	
5	Nursing Methodology Research/		15894
6	Questionnaires/	348433	
7	Focus Groups/	20351	
8	discourse analysis.mp.	992	
9	content analysis.mp.	12998	
10	ethnographic research.mp.	560	
11	ethnological research.mp.	7	
12	ethnonursing research.mp.	29	
13	constant comparative method.mp.	968	
14	qualitative validity.mp.8		
15	purposive sample.mp.1899		
16	observational method\$.mp.	456	
17	field stud\$.mp.10298		
18	theoretical sampl\$.mp.	367	
20	phenomenological research.mp.	288	
21	life experience\$.mp.	3251	
22	cluster sampl\$.mp.	4266	
23	ethnonursing.af.	91	
24	ethnograph\$.mp.	6469	
25	phenomenol\$.af.	14873	
26	grounded theory.mp.	6559	
27	(grounded adj (theor\$ or study or studies or research or analys?s)).af.	6662	
28	(life stor\$ or women* stor\$).mp.	847	
29	(emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.	13802	
30	(social construct\$ or (postmodern\$ or post- structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.	382820	
31	(action research or cooperative inquir\$ or co operative inquir\$ or co- operative inquir\$).mp.	2581	

32 (humanistic or existential or experiential or paradigm\$.mp. 99142
 33 (field adj (study or studies or research)).tw. 11124
 34 human science.tw. 207
 35 biographical method.tw. 12
 36 qualitative validity.af. 8
 37 purposive sampl\$.af. 3355
 38 theoretical sampl\$.af. 367
 39 ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af. 35177
 40 (account or accounts or unstructured or open-ended or open ended or text\$ or
 narrative\$.mp. 402439
 41 (life world or life-world or conversation analys?s or personal experience\$ or theoretical
 saturation).mp. 11724
 42 lived experience\$.mp.2644
 43 cluster sampl\$.mp. 4266
 44 (theme\$ or thematic).mp. 52476
 45 observational method\$.af. 456
 46 field stud\$.mp.10298
 47 focus group\$.af. 28939
 48 questionnaire\$.mp. 498280
 49 content analysis.af. 12999
 50 thematic analysis.af. 5389
 51 constant comparative.af. 1773
 52 discourse analys?s.af. 1021
 53 ((discourse\$ or discurs\$) adj3 analys?s).tw. 1290
 54 (constant adj (comparative or comparison)).af. 2564
 55 narrative analys?s.af. 618
 56 heidegger\$.tw. 493
 57 colaizzi\$.tw. 393
 58 speigelberg\$.tw. 1
 59 (van adj manen\$.tw. 237
 60 (van adj kaam\$.tw. 25
 61 (merleau adj ponty\$.tw. 127
 62 husserl\$.tw. 158
 63 foucault\$.tw. 544
 64 (corbin\$ adj2 strauss\$.tw. 160
 65 (strauss\$ adj2 corbin\$.tw. 160
 66 (glaser\$ adj2 strauss\$.tw. 82
 67 glaser\$.tw. 663
 68 findings.af. 1393607
 69 qualitative.af. 138960
 70 qualitative research.sh. 27475
 71 Interview/ 26266
 72 exp Interview/ 26266
 73 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or
 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34
 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or
 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67
 or 68 or 69 or 70 or 71 2805684
 74 limit 73 to (english language and humans) 1979798
 75 limit 74 to (english language and humans) 1979798

76 exp Prostatic Neoplasms/ 105389
 77 Prostate/ 31253
 78 exp Neoplasms/ 2856174
 79 (prostat* adj3 (cancer* or carcinoma* or neoplas* or tumo?r* or adenoma* or adenocarcinoma* or malignan* or metasta*)).tw. 103698
 80 Prostatectomy/ 23993
 81 prostatectom*.tw. 21943
 82 77 and 78 14136
 83 76 or 79 or 80 or 81 or 82 134376
 84 75 and 83 20143
 85 limit 84 to (english language and humans and yr="2010 -Current") 8339

CINAHL search

S17S7 AND S15 Limiters - Published Date: 20100101-; English Language; Exclude MEDLINE records; Human

S7 AND S15 [108S16]

S15S8 OR S11 OR S12 OR S13 OR S14 [2,090]

S14 S9 AND S10 [14,218]

S13 TX prostatectom* [342]

S12 (MH "Prostatectomy") [2,055]

S11 TX (prostat* N3 (cancer* or carcinoma* or neoplas* or tumo?r* or adenoma* or adenocarcinoma* or malignan* or metasta*)) [1,662]

S10 (MH "Neoplasms+") [13,408]

S9 (MH "Prostate") [204,253]

S8 (MH "Prostatic Neoplasms+") [583]

S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6 [11,602]

S6 Heidegger* OR Colaizzi* OR Spiegelberg* OR van N1 manen* OR van N1 kaam* OR merleau N1 ponty* OR husserl* OR Foucault* OR Corbin* N2 strauss* OR strauss* N2 corbin* OR glaser* OR Qualitative

S5 lived experience* OR life experience* OR cluster sampl* OR (theme* or thematic) OR observational method* OR questionnaire* OR content analysis OR discourse* N3 analys?s OR discours* N3 analys?s OR constant N1 comparative OR constant N1 comparison OR narrative analys?s

S4 (social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret*) OR (action research or cooperative

inquir* or co operative inquir* or co-operative inquir*) OR (humanistic or existential or experiential or paradigm*) OR field N1 stud* OR field N1 research OR human science OR biographical method OR theoretical sampl* OR purpos* N4 sampl* OR focus N1 group* OR (account or accounts or unstructured or open-ended or open ended or text* or narrative*) OR (life world or life-world or conversation analys?s or personal experience* or theoretical saturation)

S3 ethnograph* OR phenomenol* OR grounded N1 theor* OR grounded N1 study OR grounded N1 studies OR grounded N1 research OR grounded N1 analys?s OR life stor* OR women's stor* OR (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$) OR data N1 saturat* OR participant observ*

S2 MH Ethnonursing Research OR MH Constant Comparative Method OR MH Qualitative Validity+ OR MH Purposive Sample OR MH Observational Methods+ OR MH Field Studies OR MH theoretical sample OR MH Phenomenology OR MH Phenomenological Research OR MH Life Experiences+ OR MH Cluster Sample+ OR Ethnonursing

S1 interview OR MH audiorecording OR Interviews+ OR MH Grounded theory OR MH Qualitative Studies OR MH Research, Nursing OR MH Questionnaires+ OR MH Focus Groups OR MH Discourse Analysis OR MH Content Analysis OR MH Ethnographic Research OR MH Ethnological Research

SSCI search

7 1,143 #6 AND #5
Indexes=SSCI Timespan=2010-2016

6 3,625 TOPIC: (prostat* NEAR/3 cancer*) OR TOPIC: (prostat* NEAR/3 carcinoma*) OR TOPIC: (prostat* NEAR/3 neoplas*) OR TOPIC: (prostat* NEAR/3 tumo\$r*) OR TOPIC: (prostat* NEAR/3 adenoma*) OR TOPIC: (prostat* NEAR/3 adenocarcinoma*) OR TOPIC: (prostat* NEAR/3 malignan*) OR TOPIC: (prostat* NEAR/3 metasta*)
Indexes=SSCI Timespan=2010-2016

5 340,168 #4 OR #3 OR #2 OR #1
Indexes=SSCI Timespan=2010-2016

4 24,439 (TS=(“theoretical saturation”) OR TS=(“lived experience”) OR TS=(“life experience”) OR TS=(“cluster sampl”) OR TS=(“observational method”) OR TS=(“content analysis”) OR TS=(“constant comparative”) OR TS=(“discourse analys?s”) OR TS=(“discurs* analys?s”) OR TS=(“narrative analys?s”) OR TS=(heidegger*) OR TS=(colaizzi*) OR TS=(spiegelberg*) OR TS=(“van manen”) OR TS=(“van kaam”) OR TS=(“merleau ponty”) OR TS=(husserl*) OR TS=(foucault*) OR TS=(corbin*) OR TS=(strauss*) OR TS=(glaser*)) AND LANGUAGE: (English)
Indexes=SSCI Timespan=2010-2016

3 52,379 (TS=(“field stud”) OR TS=(“field research”) OR TS=(“human science”) OR TS=(“biographical method”) OR TS=(“theoretical sampl”) OR TS=(“purposive sampl”) OR TS=(“open-ended account”) OR TS=(“unstructured account”) OR TS=(narrative*) OR TS=(text*) OR TS=(“life world”) OR TS=(“conversation analys?s”)) AND LANGUAGE: (English)

Indexes=SSCI Timespan=2010-2016

2 97,166 (TS=("life stor*") OR TS=("women's stor*") OR TS=(emic) OR TS=(etic) OR TS=(hermeneutic) OR TS=(heuristic) OR TS=(semiotic) OR TS=(data saturat*) OR TS=("participant observ*") OR TS=("social construct*") OR TS=(postmodern*) OR TS=("post structural*") OR TS=(feminis*) OR TS=(interpret*) OR TS=("action research") OR TS=("co-operative inquir*") OR TS=(humanistic) OR TS=(existential) OR TS=(experiential) OR TS=(paradigm*)) AND LANGUAGE: (English)
Indexes=SSCI Timespan=2010-2016

1 226,533 (TS=interview* OR TS=(theme*) OR TS=qualitative OR TS=("nursing research methodology") OR TS=questionnaire OR TS=(ethnograph*) OR TS=(ethnonursing) OR TS=("ethnological research") OR TS=(phenomenol*) OR TS=("grounded theor*") OR TS=("grounded stud*") OR TS=("grounded research") OR TS=("grounded analys?s")) AND LANGUAGE: (English)
Indexes=SSCI Timespan=2010-2016

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About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Who We Are.

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do.

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voice of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters.

We recognize that, as a system, we have much to be proud of, but also that it often falls short of being the best it can be. Plus certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

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