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Surgeon decision-making about referral for adjuvant therapy for persons with non-small-cell lung, breast, or colorectal cancer: a qualitative study

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Keywords: oncology, surgery, qualitative research, grounded theory, decision-making, referral

Word Count: 2472

No. of tables: 3

No. of figures: 1

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ABSTRACT

Background: The overall survival impact of recommended adjuvant therapies for patients with cancer will ultimately depend on their real world use in patients outside of clinical trial settings. Since surgeons are the main gatekeeper to cancer services, understanding how they make decisions related to referral for consideration of adjuvant therapies is important to optimize referral rates and oncology service utilization for patients with potentially curable disease. The primary objective of this study was to examine surgeon decision-making related to referral to oncology services for individuals having undergone curative-intent surgery for non-small-cell lung, breast, and colorectal cancer. The secondary objective was to identify potential strategies to promote referral.

Methods: A qualitative study was conducted, guided by the principles of grounded theory. Data were collected through semi-structured interviews with lung, breast, and/or colorectal cancer surgeons (n=29). Data were collected and analyzed concurrently. Analysis involved an inductive, grounded approach using constant comparative analysis. Data collection and analysis continued until theoretical saturation was reached.

Results: Seven factors influenced surgeon decision-making related to oncology referral: (1) indications/contraindications for adjuvant; (2) patient beliefs and preferences; (3) a belief that oncologists are the experts; (4) knowledge of local standards of care; (5) consultation with oncology colleagues; (6) system resources and capacity; and (7) a need to navigate patient logistics.

Interpretation: These findings represent a novel understanding of how surgeons make decisions about oncology referral. Thus, they provide important foundational knowledge

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3 to inform the design of strategies to promote referral to oncology services when adjuvant
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5 therapy is recommended.
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Confidential

INTRODUCTION

Lung cancer, breast cancer (BC), and colorectal cancer (CRC) account for 39% of all new cancer diagnoses in Canada.¹ These three cancers represent the leading causes of cancer mortality, accounting for 46% of all cancer deaths in 2014.¹ Patients diagnosed with early-stage non-small cell lung cancer (NSCLC), BC, or CRC represent potentially curable populations. For these individuals, surgical resection is the primary treatment, with adjuvant therapies (i.e., chemotherapy and/or radiotherapy) recommended according to the disease stage. Unlike some malignancies (e.g., prostate cancer²), treatment strategies for NSCLC, BC, and CRC are relatively standardized for most patients with localized disease receiving potentially curative surgery. Based on data from large randomized clinical trials demonstrating significant improvements in survival outcomes,³⁻¹⁰ clinical practice guidelines (CPGs) recommend specific adjuvant therapies for patients with stage II/IIIA NSCLC, stage I–III BC, stage II/III rectal cancer, and stage IIB/III colon cancer.¹¹⁻¹⁶

Despite clinical trials demonstrating clear efficacy, the impact of recommended adjuvant therapies will ultimately depend on their real world use in patients outside of those trials.¹⁷ In Nova Scotia (NS), it has been demonstrated that a substantial minority of patients with potentially curable NSCLC or CRC are not referred for an oncology consultation (20-33%, depending on cancer site and stage).^{17,18} Since surgeons are the main gatekeeper to the organized cancer system, understanding how they make decisions related to oncology is important to inform the development of appropriate interventions to optimize referral rates and utilization of oncology services for patients with potentially curable disease. Many researchers in Canada have observed variations in referral rates

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3 and receipt of oncology services and called for more detailed study of referral
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5 practices.¹⁸⁻²¹ While some patients are not referred to oncology services for reasons of
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7 age or comorbidity, there may be other factors that influence the decision not to refer.
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10 The *decision-making process* related to oncology referral amongst cancer surgeons is not
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12 well understood. Relying on traditional quantitative research approaches limits the ability
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14 to identify and describe the breadth of factors potentially influencing decision-making,
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16 and limits understanding of the complexity behind health care decision-making.^{22,23} The
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18 primary objective of this qualitative study was to examine surgeon decision-making
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20 related to referral to oncology services for individuals having undergone curative-intent
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22 surgery for NSCLC, BC, and CRC. The secondary objective was to identify potential
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24 strategies to promote referral to oncology services for patients for whom adjuvant therapy
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26 is recommended.
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34 **METHODS**

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36 This qualitative study employed grounded theory methodology²⁴ using semi-structured
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38 interviews of NSCLC, BC, and CRC surgeons. Grounded theory attempts to move
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40 beyond description and generate a general explanation, or theory, of a process or action
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42 that is shaped by the views of participants who have experienced the process or action.²⁴
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44 While the emphasis of this methodology is on the *inductive* nature of theory building, this
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46 process occurs in an ongoing dialogue between pre-existing theory and new
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48 observations/insights generated from empirical research.²⁵
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53 The study was informed by our ongoing research as well as the Penchansky and
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55 Thomas²⁶ model of access to health services. This model provides an approach to
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3 understanding access to healthcare that focuses on understanding the “fit” between a
4 patient’s needs and the system’s ability to meet those needs (see Table 1). The six
5 dimensions described in this model guided data collection and analyses. Ethical approval
6 to conduct this study was obtained from the ten health region research ethics boards in
7 NS. Written informed consent was obtained from each participant; this included
8 permission to audiotape the interviews and use anonymized quotes.
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20 Participants

21 Participants were surgeons in NS who performed NSCLC, BC, and/or CRC surgery.
22 These surgeons were purposively recruited, with investigators identifying participants to
23 ensure variation in career stage (junior, senior), level of training (general surgeon,
24 surgical oncologist), and practice location (community hospital, academic/tertiary care
25 center). Two investigators [RU, GAP] identified all potential participants. A research
26 coordinator initially approached each potential participant via email or telephone to
27 introduce the study and invite him/her to participate. If a potential participant failed to
28 respond to the initial contact within one week, the coordinator followed up via telephone.
29 If the participant responded in the affirmative, the research coordinator arranged for a
30 time to conduct the informed consent discussion and interview.
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48 Data collection

49 Semi-structured interviews were conducted with NSCLC, BC, and CRC surgeons.
50 Interviews were face-to-face in the surgeon’s office, or via telephone, depending upon
51 practical considerations. The questions and related probes were drafted based on the
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3 research objectives, team members' clinical experiences, and the Penchansky and
4 Thomas model.²⁶ The interview also included scenario-like questions to explore how
5 surgeons consider various factors (e.g., survival benefit, comorbidities) in the decision-
6 making process. These questions were customized for the cancer site since NSCLC, BC,
7 and CRC require different treatment approaches, each with varying degrees of relative
8 benefit. Two pilot interviews were conducted to assess and refine the interview script;
9 these were audiotaped, transcribed verbatim, and discussed amongst the entire research
10 team to ensure that all topics of interest were explored.
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22 One investigator [RU], with expertise in qualitative methods, conducted all
23 interviews. Only the investigator and interviewee were involved in the interview. The
24 investigator had prior understanding of the work of the participants; ensured participants
25 understood the study objectives, reasons for doing the study (i.e., prior population-based
26 research had demonstrated suboptimal referral practices), and interview procedure; and
27 encouraged participants to express their opinions by explaining that all responses were
28 valid/valuable and would be included in the analysis. Most participants practicing in
29 academic/tertiary care centers knew the investigator prior to the study, whereas most
30 practicing in community hospitals did not. All interviews were audiotaped, transcribed
31 verbatim by a research coordinator with experience in transcription, and verified by
32 listening to the audiotapes. The audiotapes and transcripts were supplemented with field
33 notes. Consistent with grounded theory, the interview guide was adapted during data
34 collection on the basis of previous interview findings to further explore important
35 concepts and emerging categories.^{27,28}
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Data analysis

Data were collected and analyzed concurrently, allowing emergent concepts and categories to be incorporated and explored in subsequent interviews. Analysis employed an inductive, grounded approach, using constant comparative analysis.²⁴ The pilot interviews were included in the analysis, with pilot participants' permission.

Data from the first 14 interviews (approximately half) were coded and analyzed independently by two investigators [RU, CK]. Through iterative discussion, they developed a codebook, which reflected unique ideas and concepts, to guide the coding scheme and subsequent categorization of data. Since consistency in coding was evident, the remaining data were coded and analyzed by one investigator [CK] with regular meetings between both to review the coded data and discuss any issues. Disagreements were resolved through discussion and, when needed, reexamining transcripts and coded data. Consistent with constant comparative analysis, open and axial coding of interview transcripts occurred simultaneously. These processes involved reading and rereading of transcripts, applying the coding scheme to the interview text, and grouping the coded text into more abstract categories. This was followed by selective coding, or the detailed development of categories, selection of a core theoretical category, and integration of categories.²⁴ Qualitative analysis was performed manually, with the assistance of qualitative software (NVivo; QSR International, Cambridge, MA, USA) for data management and to enable comparison and synthesis of codes. Research team meetings were held at three timepoints during the analysis to discuss emerging findings and question the data and interpretations. Data collection and analysis continued until

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3 theoretical saturation was reached – that is, the point whereby no new substantive
4 information was being collected to develop the explanation.²⁴
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8 Numerous steps were taken to optimize the rigor of this study. These included
9 field notes during interviews; detailed documentation of methodological and analytic
10 decisions; systematic data coding; use of direct quotations to ensure participant
11 perspectives are represented as clearly as possible; ongoing review and questioning of
12 data coding, analytic decisions, and resultant themes by two investigators [RU, CK];
13 three team meetings to discuss and question findings; and providing participants a
14 summary of the preliminary findings. Team members included three surgeons [GAP, PJ,
15 GB], a medical oncologist [DR], and an experienced grounded theorist [JS].
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29 **RESULTS**

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31 Of 33 surgeons contacted, 29 participated in this study. Two declined participation, while
32 two agreed to participate but their interviews had not been scheduled by the time
33 theoretical saturation was reached and data collection was discontinued. Interviews lasted
34 between 20-49 minutes. There were no repeat interviews. Of study participants, 59%
35 practiced in a community hospital and 83% were male, with 17%, 69%, and 76%
36 performing surgery for NSCLC, BC, and CRC, respectively. These percentages do not
37 equal 100% since many surgeons treated both BC and CRC.
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48 Figure 1 illustrates the key factors influencing decisions to refer patients with
49 NSCLC, BC, or CRC to medical or radiation oncology. Seven factors were found to
50 influence surgeon decision-making related to oncology referral, with the magnitude of
51 influence depending on their decisional proximity. At the core of surgeon decision-
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3 making is the *clinical encounter* wherein the decision is made. Within this encounter,
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5 surgeons consider and negotiate their understanding of (1) indications/contraindications
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7 for adjuvant therapy (e.g., tumor pathology, patient health status) alongside (2) patient
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9 beliefs and preferences (e.g., the desire or not for chemotherapy). Germane to this
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11 decision are a number of important *mediating factors*: (3) a belief that oncologists are the
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13 experts, (4) knowledge of local standards of care, and (5) consultation with oncology
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15 colleagues. The latter two factors reflect communication and integration mechanisms (or
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17 lack thereof) between surgeons and the formal oncology programs. When making
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19 decisions about oncology referral, surgeons are also acutely aware of the *outer context* in
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21 which these decisions occur, including (6) system resources and capacity (e.g., access to
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23 staging investigations, infrastructure to facilitate coordination of care) and (7) a need to
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25 navigate patient logistics (e.g., drug coverage, transportation/lodging). While factors
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27 within this outer context infrequently influence referral decisions in a direct way, they
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29 often make dealing with the referral more difficult. Table 2 briefly describes each of
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31 these factors and provides illustrative quotations. Table 3 presents surgeon-recommended
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33 strategies toward optimizing the decision-making process, with the majority targeted at
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35 the mediating factors and outer context.
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46 INTERPRETATION

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48 This study examined surgeon decision-making regarding referral to oncology for patients
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50 following curative-intent surgery for NSCLC, BC, or CRC. The findings demonstrate
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52 that, even when aware of and in agreement with the scientific evidence, many other
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54 factors influence surgeons' referral decisions. Pivotal to the decision-making process is
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3 the patient's health status and preferences with respect to adjuvant therapy. Other
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5 important factors include surgeons' trust in oncologists' knowledge and expertise,
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7 awareness of local standards of care, and relationships with oncology colleagues. These
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9 findings provide important and novel insights into the decision-making process related to
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11 oncology referral, and thus offer potential target areas for intervention. To the authors'
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13 knowledge, this study is the first to have qualitatively examined this issue.
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18 Though there is no defined "ideal" benchmark for referral or consultation rates,
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20 both referral to and consultation with an oncologist have been identified as measures of
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22 quality care for patients with resected (or resectable) disease.²⁹⁻³¹ This study found that
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24 surgeons' understandings of indications/contraindications for adjuvant therapy and
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26 patients' beliefs and preferences clearly influence whether a patient is referred to
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28 oncology services. Surgeons' beliefs that oncologists are the experts on these therapies
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30 also shape their discussions with patients when considering and offering referral,
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32 particularly when patients are reluctant to see an oncologist. Surgeons reported
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34 uncertainty about local standards of care and discussed informally consulting colleagues
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36 about referral decisions, in the absence of accessible communication mechanisms. These
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38 latter influences are important to consider in the context of implementing evidence-based
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40 care. First, prior research has demonstrated that surgeons and oncologists have
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42 conflicting views on CPG recommendations for adjuvant therapies for BC³² and CRC,³³
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44 while preferred approaches for the adjuvant management of NSCLC vary widely within
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46 and across medical and surgical specialties.³⁴ Thus, clinicians may have varied
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48 perspectives on the benefits/risks of cancer treatment and/or different interpretations of
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50 an increasingly complex evidence base. This implies that clarity on local management
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3 protocols/standards and opportunities to discuss management options are of great
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5 importance. Second, the influences represent potential areas for clear intervention. These
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7 include development and implementation of provincial standards, improvements in
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9 access to multidisciplinary tumour boards, and the development of systems that permit
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11 ‘just-in-time’ surgeon-oncologist consultation. Such interventions can increase
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13 collaborative decision-making¹⁸ and support co-management options for community-
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15 based surgeons who do not regularly interact with other cancer specialists.³⁵
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20 Many factors have been found to influence CPG awareness, agreement, adoption,
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22 and adherence, including patient needs and expectations, patient and provider
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24 characteristics, nature of the evidence, setting of care, and a myriad of organizational and
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26 system constraints or enablers.³⁶⁻⁴² Like all professionals in health care, surgeons operate
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28 within a complex care delivery system that is situated in an organizational, historical,
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30 social, economic, and political context. Taking this perspective, one might expect
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32 decisions related to adjuvant therapy to be influenced not only by disease and patient
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34 factors, but also by the broader health system in which surgeons operate. Indeed, several
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36 Canadian studies suggest that factors at multiple levels of the healthcare system
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38 influenced surgeons’ decisions to adopt sentinel lymph node biopsy for BC.^{43,44} In our
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40 study, surgeons highlighted the importance of logistical supports when referring patients
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42 to oncology services. In NS, like many jurisdictions in Canada, receipt of an oncology
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44 consultation requires patients to travel to a formal cancer centre. For some patients, this
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46 involves significant out-of-pocket costs, transportation challenges, and home/work
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48 disruption. While these factors typically do not directly affect the *decision* to refer,
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50 surgeons discussed how these factors changed the clinical encounter and posed
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3 considerable challenges for some patients (e.g., those with limited resources or with
4 dependents at home). Surgeons also discussed how they routinely seek out community
5 resources, where available, to help navigate these challenges (e.g., patient navigators,
6 voluntary sector). This suggests that optimizing oncology consultation might be
7 improved through policy interventions that provide logistic, supportive, and financial
8 supports to improve patients' access to oncology services.
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17 The main limitation of this study is that it occurred in one province only,
18 potentially limiting generalizability to other jurisdictions. The purpose of qualitative
19 research, however, is not to achieve generalizable results but to acquire detailed
20 knowledge about processes and context, and underlying causal mechanisms (i.e., the *why*
21 and *how*). Importantly, this study included many steps to maximize rigour, had a high
22 participation rate, attained theoretical saturation, and observed commonalities across
23 disease sites. As such, these findings should have applicability to other similar settings
24 (e.g., publicly-funded health care, centralized oncology services, or settings where
25 surgeons are the main gatekeeper to oncology services).
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39 These findings provide a novel understanding of how surgeons make decisions
40 about oncology referral and thus important foundational knowledge toward designing
41 contextually-appropriate strategies to promote referral to oncology services for persons
42 for whom adjuvant therapy is recommended. Future work should focus on designing and
43 testing such strategies, in collaboration with surgeons and their clinical colleagues, to
44 understand which ones work, in which settings, and why.
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ACKNOWLEDGEMENTS

We gratefully acknowledge study participants who took their valuable time to participate in this study as well as Margaret Jorgensen for her assistance with study coordination.

This study was funded by the Canadian Institutes of Health Research (Grant number: MOP-119493). The funder had no role in the design, collection, analysis, and interpretation of data; in the writing of the manuscript; and in the decision to submit this manuscript for publication.

CONTRIBUTORS' STATEMENT

Robin Urquhart led the conception, design, conduct, analysis, and interpretation of this study. She drafted the article, made all revisions based on co-author feedback, gained co-authors' final approval, and agrees to act as guarantor of the work. Cynthia Kendell contributed to study design, acquisition of data, and analysis and interpretation of data. She revised the article critically for intellectual content, gave final approval of the version to be published, and agrees to act as guarantor of the work. The remaining authors, Gordon Buduhan, Daniel Rayson, Joan Sargeant, Paul Johnson, Eva Grunfeld, and Geoffrey A Porter, all contributed to study design and analysis and interpretation of data; revised the article critically for intellectual content; gave final approval of the version to be published; and agrees to act as guarantor of the work.

Table 1. Six dimensions related to the Penchansky and Thomas²⁶ model of access to health services.

	Dimension	Examples
<i>Original Penchansky and Thomas model</i>	<i>Availability</i> of healthcare resources	Resources (personnel, equipment, technology), prevailing wait times
	<i>Accessibility</i> as it relates to geographic considerations	Centralized services, “close to home” care, transportation
	<i>Accommodation</i> in terms of how health care is organized and delivered	Coordination and integration of services, satellite cancer clinics, telemedicine
	<i>Affordability</i> as it relates to direct and indirect costs of receiving care	Funding of cancer services, insurance/drug coverage, indirect patient costs (lodging, transportation)
	<i>Acceptability</i> as it relates to the attitudes and characteristics of patients and providers	Patient and provider attitudes toward one another, patient characteristics (e.g., age, sex, comorbid conditions, life expectancy), patient preferences, provider characteristics (sex, years of practice, level of specialization, surgery volume)
<i>Added*</i>	<i>Awareness</i> of services and indications for their use	Patient and provider awareness of evidence for therapy, clinical practice guidelines, structures that support multidisciplinary dialogue/consultation

*More recently, MacKillop⁴⁵ identified and described this additional important dimension of access.

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Table 2. Factors influencing surgeon decision-making and illustrative quotations.

	Factor	Illustrative quotations
Clinical Encounter	Indications/contraindications for therapy: Surgeons consider indications and contraindications based on tumor characteristics (e.g., lymph node status, stage, high risk features), length of time post-surgery, and a patient’s age and health status (e.g., frailty, co-morbidities).	<i>“You know, you can be 60 and too frail, you know? 60 and really have the frailty of most of my 90 year olds. ... you are on 100 medications with a bum heart and kidneys ... in my opinion these are patients that, you know, the oncologist doesn’t necessarily need to see.” [Surgeon 01]</i>
	Patient beliefs and preferences: Surgeons’ decisions are influenced by patient beliefs and preferences. If a patient desires a consultation, he/she is normally referred. If a patient is reluctant to see a medical or radiation oncologist or expresses fear with regard to adjuvant therapy but the surgeon feels a consultation is warranted, the surgeon will attempt to convince him/her to have the consultation, but recognizes it is the patient’s choice.	<i>“When you break it down, some will digest that and say ‘thanks, but no thanks’, but others, they want to be more aggressive and will opt for it. I say, ‘they are not going to stick a needle in you and start the chemo, they are going to talk to you and weigh the pros and cons and they may feel that you are not a candidate for chemotherapy.’ But I try to give them the benefit of the doubt ... unless they have real contraindications, things like bad renal function or ... they just don’t want it and are not interested, then I won't [refer].” [Surgeon 08]</i>
Mediating Factors	Knowledge of local standards of care: Surgeons’ decisions are impacted by their knowledge (or lack thereof) of local standards of care. Surgeons reported mixed messages from oncologists and confusion about whether or not to refer certain patients. This was particularly true for community surgeons.	<i>“... the biggest problem is the oncologists in [Cancer Centre A] do not communicate with those of us outside of [Cancer Centre A] very well in what their feelings are on management and that sort of thing. When new studies are published and they change their practice, they don’t tell the rest of us ... I ask them ‘well, what is the group’s approach to this?’ and they don’t communicate.” [Surgeon 20]</i>
	Consultation with colleagues: Surgeons perceive formal processes to consult with colleagues as largely unavailable or inaccessible. They rely on relationships with colleagues, and believe their informal consultation with these colleagues benefit their decisions and improve patient care.	<i>“The benefit of having people you can call is for the people that don’t fit the mold and you can't plug everybody into the same protocol and you can't plug everybody into the same algorithm and when you have got those people, it is wonderful to call [a colleague] and say, ‘this is not the run of the mill.’” [Surgeon 26]</i>
	Oncologists are the experts: Surgeons’ decisions are influenced by their beliefs that medical and radiation oncologists are experts in adjuvant therapy and thus better able to address patients’ fears/concerns and informational needs, and advise on contraindications for therapy and treatment toxicities/side effects.	<i>“I don’t like to make the ‘no’ decision for chemo, or radiation for that matter. What I tell patients is that ‘I am not the expert on this, see what they have to say.’ So I don’t want to prevent them from getting a therapy because [I am] a gatekeeper. If you don’t refer them, they don’t get it. I prefer not to be a gatekeeper.” [Surgeon 09]</i>

Table 2. Continued.

	Factor	Illustrative quotations
Outer Context	Navigating patient logistics: Surgeons discussed many logistical factors (e.g., lodging, caregiving responsibilities, insurance coverage) that influence a patient's willingness and/or ability to consult an oncologist. Typically, if a surgeon deems a referral appropriate and is aware that logistical factors are an issue, the surgeon refers the patient, but simultaneously attempts to access supports on the patient's behalf. Surgeons vary greatly with regard to their awareness of available resources for patients.	<i>"We try to use our social service people as much as possible and we try and engage other family members, community organizations ... in our rural areas we have some really good volunteer groups that look after cancer patients, other patients and they will often volunteer to help out. You know, we have all sorts of people who are willing to do all sorts of things, bend over backwards to help others here. ... you have to deal with the situation that you have and try to give every patient the best opportunity to get the best treatment available and sometimes that requires jumping through extra hoops and, you know, making some unusual arrangements." [Surgeon 07]</i>
	System Resources/Capacity: Surgeons are aware of the limitations of the system in which they practice: e.g., suboptimal access to investigations, shortage of human resources, wait times, and inadequate technology systems. These limitations tend not to directly affect decision-making <i>per se</i> but can complicate referral processes and affect patients' timely access to formal oncology services.	<i>"It is quite a slog to get a patient navigated through the system quickly and truthfully it is hit and miss and a lot of patients don't get through quickly ... and throughout all of this I have got a patient who, by standard of care and guidelines, I can't operate on [because he/she has not received a staging MRI], and who has symptoms and needs treatment but also need the emotional reassurance that things are underway and they are getting something..." [Surgeon 01]</i>

Table 3. Surgeon-recommended strategies to optimize referral decisions and processes.

Level of influence	Recommended strategies
Clinical Encounter	<ul style="list-style-type: none"> • <i>Patient education materials</i> to inform patients of purpose and nature of an oncology consultation, and of local resources to help with logistical issues related to visiting a cancer centre
Mediating factors	<ul style="list-style-type: none"> • Improve access to <i>multidisciplinary case conferencing</i>* • Develop and actively disseminate[†] provincially-endorsed <i>guidelines and standards</i> • Improve <i>on-call oncology services</i> to enable surgeons to reach oncologists with expertise in the particular cancer site for which he/she requires consultation
Outer context	<ul style="list-style-type: none"> • <i>Patient navigation</i> in health regions lacking this service • Invest in <i>community-based supportive care resources</i> • Enhance policies/programs to facilitate access to <i>transportation services</i> • <i>Streamline referral processes</i> to facilitate the delivery of quality care (e.g., ‘true’ urgent cases should be triaged and seen in a timely manner)

*Nearly every surgeon reported difficulty attending multidisciplinary case conferencing; the issues included the time of case conferencing (e.g., in the middle of the day when many surgeons are in the operating room), a lack of personnel at community hospitals to schedule and set up Telehealth services, no direction or guidance on exactly how to join these conferences, etc.

[†]While some surgeons were aware of efforts to develop provincial guidelines and/or standards, most did not perceive guidelines and/or standards were actively communicated to them or implemented in their hospitals/care settings.

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3 **Figure Captions**
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5 Figure 1. Surgeon decision-making related to oncology referral for non-small-cell lung,
6 breast, and colorectal cancer patients.
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“Outer context”

System resources
& capacity

Navigating
patient logistics

Mediating factors

Oncologists are
the experts

Consultation
with colleagues

Clinical Encounter

Indications for
therapy

Patient beliefs and
preferences

Knowledge of local
standard of care

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