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## A qualitative analysis of the role of patient and physician advocacy in improving wait times for cancer care

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Study Type: Qualitative research

Author Statement: All authors contributed to the design, analysis and interpretation of results, have reviewed the manuscript and approved the final submission.

Sources of Support: This study was funded by the Canadian Institute of Health Research (PHE 91543), Newfoundland and Labrador Industry Research and Innovation Fund with in-kind contributions from the Eastern Regional Health Authority and the Canadian Cancer Society-Newfoundland and Labrador Division. We thank Nurun Chowdhury, Kathy Fowler, Sara Heath, Jennifer LeMessurier, Shelley May Neufeld, Matthew Piercey and Sharon Smith for their contributions to the study.

Statement of Competing Interests: We declare we have no competing financial interests.

Word Count: 2,499

Number of figures and tables: 1

## Abstract

### Background

There is growing interest in the role of physician as health advocate, however, few studies document advocacy from a patient's perspective. To address this gap, we examined the experiences of cancer patients from the onset of symptoms to the start of treatment in Newfoundland and Labrador and aimed to describe wait times and efforts to improve timeliness of care from the patients' perspective.

### Methods

We conducted qualitative interviews with 60 breast, prostate, lung, or colorectal patients who were recruited from a survey of cancer patients that was carried out as an earlier part of a larger study. All survey participants had received care at regional cancer clinics in the province and were selected using purposive sampling based on their type of cancer, level of satisfaction with care, and community of residence. Interviews were transcribed verbatim and coded using a thematic approach.

### Results

Patients, family members, and members of the patients' health care team engaged in a variety of efforts to reduce wait times. In all instances, study participants believed that these actions resulted in more timely care. Patients reported that "insider knowledge" of health professionals (whether friends, family members, or members of the care team) was particularly valuable to them in reducing delays.

### Interpretation

The use of advocacy was relatively commonplace, with more than half of the participants describing attempts to improve access to care. The role of advocacy, whether it originates from patient or care giver, is important to ensure access to timely and good quality cancer care.

**Keywords:** cancer care, satisfaction, wait times, patient perspectives, health advocate, self-advocacy

Confidential

## Introduction

Self-advocacy plays an important role for patients in the health care system [1-3]. Self-advocacy includes requesting up-to-date information about particular health conditions, obtaining multiple medical opinions, and fighting for specific rights related to privacy and employment [4]. Despite the recognition that self-advocacy is commonplace, there are few empirical studies that document how patients, their families, friends, or health care providers attempt to influence access to care, particularly in relation to wait times [5]. To date, much of the literature has been negatively framed (i.e. queue-jumping) [6, 7, 8]. Physicians are increasingly expected to advocate for patients [9-13]; in fact, physician as “health advocate” is a core competency of medical training in Canada [14]. While a small number of studies have examined the advocacy roles of physicians from a physician perspective, few studies have examined the patients’ perspectives, particularly in relation to improving wait times.

We used qualitative interviews with cancer patients to examine their experiences from the onset of symptoms to the start of treatment in Newfoundland and Labrador (NL). This study was part of a larger study examining patients’ wait times and wait-related satisfaction for cancer care. In the larger study, we found that wait-related satisfaction was not necessarily related to actual wait time (patients with short waits may be un-satisfied, whereas patients with long waits may be satisfied) and that the wait-time to diagnosis was particularly important to patients and predicted satisfaction with subsequent waits [15,16]. Through qualitative interviews, we found that whether or not the delay was avoidable or attributable to the patient, provider, or health system did not explain patient wait-related satisfaction [17]. Instead, we found that patients’ self-described satisfaction was related to three overlapping and interconnected dimensions: patient-perceived timeliness of care, physicians’ interpersonal skills, and coordination of care [18]. In

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3 this study, we describe patients' perspectives of their efforts to improve the timeliness of their  
4 care. Given that wait times are an important issue in the Canadian context [19, 20], studying  
5 cancer patients' waits provide a robust opportunity to understand how individuals attempt to  
6 expedite their care.  
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## 12 13 14 **Methods**

### 15 Sources of Data

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Memorial University Human Investigation Committee approved this study. All participants were recruited from a survey of cancer patients that was carried out as part of our larger study [15]. Qualitative interviews were conducted in addition to the surveys to allow us, as health services researchers, to explore in greater detail the differences in expectations care and the organization of services in relation to wait-related satisfaction, to disease or to residence in an urban or rural community. Not all survey respondents were invited to take part in an interview. Instead, using purposive sampling [21,22], we invited individuals to participate in an interview on the basis of their type of cancer (breast, lung, colorectal, or prostate), level of satisfaction with their wait for cancer care (satisfied or unsatisfied with any wait time interval), and community of residence (urban - population 100,000 or more, semi-urban - population 10, 000 to 99,999, or rural - population less than 10, 000). These data were gathered through the initial survey. For each type of community and cancer type we interviewed a minimum of three patients. We also ensured that both satisfied and unsatisfied patients were included within the sample. Interviews continued until data saturation was reached (i.e. until no new themes emerged among the participants' responses) [21, 22].

### Sample

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3 Eligible participants were 19 years of age or older, Newfoundland and Labrador  
4 residents, and diagnosed with either lung, prostate, colorectal, or breast cancer. Participants with  
5 previous or multiple cancer diagnoses were excluded.  
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### 10 Design

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12 We conducted interviews in English, in-person or by phone. All interviews were  
13 recorded and transcribed verbatim. During the interviews, participants were asked semi-  
14 structured questions related to the cause of wait times from the onset of their symptoms to  
15 accessing treatment, how they believed wait times could be improved, what barriers (personal,  
16 disease-related, or system-related) they experienced when trying to access care, and how  
17 satisfied they were with their wait times (Appendix A). These broad questions allowed  
18 participants the opportunity to talk about any activities they believed may have influenced wait  
19 times. In each interview, we conducted member checking to ensure that we understood  
20 participants' responses [21].  
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### 34 Analysis

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36 We conducted a thematic analysis [21,23]. All authors individually read a random  
37 sample of the transcripts in order to identify key terms and themes. Once agreement was reached  
38 amongst all members of the team on the key themes and definitions, a coding template was  
39 developed [21,23] and with NVivo software, was used to code all interviews [22]. Two authors  
40 (MM and DR) read all interview transcripts. We kept an audit trail to document all transcripts  
41 and coding templates. Disagreements in coding were resolved by consensus. To protect  
42 confidentiality, participants are described by number and quotations were edited to remove  
43 identifying features. Following each quotation, in square brackets we have identified the  
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3 participant, community of residence, general level of satisfaction with wait times, cancer type  
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5 and gender.  
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## 10 **Results**

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12 Research assistants identified 128 survey respondents who met the inclusion criteria. We  
13 invited 90 to participate in an interview; 60 completed an interview while 30 declined because  
14 they were not interested, could not schedule a time, or in too poor health to participate. Fifty-  
15 eight interviews were conducted by phone. The interviews lasted between eight and 82 minutes,  
16 with a mean duration of 27 minutes. Participants' demographic characteristics and satisfaction  
17 wait times for diagnosis are presented in Table 1; 36 (60%) satisfied and 24 (40%) unsatisfied  
18 patients were interviewed. Participants' ages ranged from 38-84. Slightly over half (33 of 60) of  
19 the participants described actions taken to reduce their wait for a cancer diagnosis and/or  
20 treatment during the interviews. Participants identified many ways that they, their families, or  
21 their healthcare team attempted to reduce wait times. There were no differences between patients  
22 who were satisfied and unsatisfied with wait times, or between the four cancer types.  
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### 41 *Efforts by the Patient to Reduce Waits*

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43 To expedite their care, patients insisted on: 1) having tests for symptoms, 2) following  
44 up on test results, and 3) arranging appointments themselves. Participants believed that their  
45 actions ensured that they received information or care faster than if they had been more passive,  
46 and simply waited for information about test results or appointments to be provided to them.  
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48 Participants perceived that delays they had experienced stemmed from miscommunication  
49 between members of the health care team, or a lack of understanding of the patient's unique  
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3 circumstances. For example, one man, who had seen a physician for a persistent cough and had  
4 been prescribed antibiotics and sent home on two prior visits, insisted that his doctor order a  
5 chest x-ray (Table 2, Quotation 1). Not all efforts to insist on tests were met with success. For  
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8 example, a woman who had complained of stomach pains encountered resistance when she  
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10 wanted a colonoscopy (Table 2, Quotation 2): The woman initially had tests for celiac disease  
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12 but described having to hunt down her test results herself (Table 2, Quotation 3). The woman  
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14 believed that her doctor would not consider other investigations or conditions until celiac disease  
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16 had been ruled out. Given her subsequent diagnosis of cancer, the patient felt the physician was  
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18 uncaring and believed his unwillingness to help her increased the time it took to get a diagnosis.  
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20 A patient noted that advocating for oneself, especially for tests that a physician believed were not  
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22 needed, could sour the doctor-patient relationship (Table 2, Quotation 4).  
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30 Participants believed that by taking the initiative, they received care faster. One woman,  
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32 while waiting for a surgery date, recalled that when she contacted the surgeon's office, there was  
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34 no record of her referral (Table 2, Quotation 5). She was quickly scheduled for surgery  
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36 following her gastroenterologist's call. One participant who had advocated for an earlier  
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38 appointment felt her wait would have been longer if she has passively waited for the system to  
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40 work (Table 2, Quotation 6). The woman said the hospital called her back to set an appointment  
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42 time within 10 minutes of her call.  
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46 For rural patients, playing an active role in determining when and where appointments  
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48 took place could result in earlier appointments. Rural patients can see cancer specialists in St.  
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50 John's or during "travelling clinics" to the smaller regional centres. Rural patients were able to  
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52 get timelier appointments by contacting the staff and indicating a willingness to travel or attend a  
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3 particular clinic. A breast cancer patient noted she was willing to travel to get an earlier  
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5 appointment (Table 2, Quotation 7).  
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8 A participant who worked in the health care system believed her work experience gave  
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10 her an advantage in arranging her care. As a nurse, the participant was familiar with the testing  
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12 procedures and the general timelines that her care should have followed. She noted that she  
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14 knew who to ask and when information should be provided (Table 2, Quotation 8). The patient  
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16 believed that this “insider knowledge” helped her in advocating for herself and reduced time  
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18 waiting for care.  
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### 21 22 *Efforts by Family and Friends to Reduce a Patient’s Wait Time* 23

24 Family members and/or friends may assume the responsibility of advocating for the  
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26 patient or coordinating care. A prostate cancer patient said his wife called to see if there was an  
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28 earlier appointment available for him if he travelled to St. John’s rather than wait for a travel  
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30 clinic (Table 2, Quotation 9). In another example, the wife of a colorectal cancer patient was  
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32 displeased about the amount of time it was taking for her husband to start treatment. She called  
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34 the cancer clinic to advocate on his behalf, which resulted in a video conference with an  
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36 oncologist who then helped arrange her husband’s care (Table 2, Quotation 10).  
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40 Patients also relied on family members with connections in the health care system. For  
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42 example, one breast cancer patient’s daughter used her connection to arrange an appointment  
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44 with a specific doctor who was otherwise unavailable to see the mother (Table 2, Quotation 11).  
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46 Another patient was unhappy with the level of information her family doctor had provided. She  
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48 was unable to convince her doctor to provide her with a copy of her pathology report. However,  
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50 by calling her friends for help, she was able to talk to an oncologist about her report (Table 2,  
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52 Quotation 12).  
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### *Efforts by Members of the Health Care Team to Reduce a Patient's Wait Time*

Members of a patient's health care team, including family physicians, specialists, and nurses also worked on behalf of the patient to help them access information or health services in a timely manner. A patient who was told he had an initial wait of nine months for surgery described how one of referring surgeons wrote a letter on his behalf, advocating that he be prioritized for surgery in Halifax (Table 2, Quotation 13). Similarly, a surgeon advocated on behalf of a breast cancer patient so that the patient could get more information before agreeing to have a mastectomy (Table 2, Quotation 14). In another example, a family physician helped reduce a colorectal cancer patient's wait by proactively requesting follow-up tests (Table 2, Quotation 15).

## **Interpretation**

### Main Findings

Using qualitative interviews with cancer patients, we found that attempts to reduce waits and improve access to care were described by over half of the participants. Participants believed that these actions reduced their wait times and provided access to care (tests, professionals, etc.) that they would not otherwise have received. The data suggest that participants believed these actions were justified to ensure that needed tests were done, that results were communicated in a timely and correct manner, or that referrals to more appropriate or preferred practitioners were made. While timely care was an underlying concern, the patients' motivation appeared to be obtaining appropriate and high quality care, rather than queue jumping (i.e. personally

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3 convenient care at the expense of others). For these patients, passively waiting for the system  
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5 would mean waiting for poor quality care and increasing their personal stress and anxiety.  
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#### 8 Explanation and Comparison with Other Studies 9

10 Despite these limitations, the study describes patients' emic perceptions and experiences  
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12 of expediting cancer care. Our findings are consistent with studies that have described self-  
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14 advocacy in cancer care, and patients' attempts to improve wait times. In their study of women  
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16 with ovarian cancer, researchers described self-advocacy as way for patients to act in their own  
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18 best interest to deal with a cancer diagnosis and treatment, including by negotiating with care  
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20 providers [24]. In terms of actions taken, with the exception of paying for faster access,  
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22 participants confirm activities described in previous studies, including calling upon doctors and  
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24 other health professionals to expedite appointments and order further tests [6, 7].  
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30 The study highlights the role of health care professionals in facilitating access to care for  
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32 the cancer patient. Many patients may have had limited interaction with the health care system  
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34 (particularly at the secondary and tertiary level) prior to their cancer diagnosis, and may find the  
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36 system complex and difficult to navigate. Participants who either worked in the system or had a  
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38 family or friend with a health care background seemed to be better able to navigate the system  
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40 than people without this support. The willingness of health professionals to assume the advocate  
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42 role underscores the importance of "insider knowledge" of how the system works and its  
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44 potential pitfalls [8, 25, 26]. The actions of physicians described in the study are consistent with  
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46 descriptions of the "health advocate" competency [9, 11] and illustrate how this role influences  
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48 the quality and timeliness of patient care. Providing physicians with practical tips to help  
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50 patients navigate the system is one way to ensure physicians can fulfill the 'health advocate' role  
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52 [14].  
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### Limitations

The information collected from the interviews relied on patients' self-reported waits and wait-related experiences that are subject to recall. Moreover, given that our study included only individuals with confirmed cancer diagnoses, actions to reduce waits seem reasonable and well-justified. All but two interviews were done by phone; the mode of interview (in person or by phone) may have influenced participants' responses. Further research with individuals who were not ultimately diagnosed or treated for cancer is needed for a more complete portrayal of the use of advocacy in cancer care.

### Conclusions and Implications for Practice and Future Directions

Cancer patients, their family, and health care professionals often engage in advocacy behavior to expedite care and facilitate access to resources that would otherwise be unavailable (or difficult to obtain) to the patient. These interventions are relatively commonplace; more than half of study participants described attempts to improve access to various aspects of their care. Moreover, participants believed their actions ensured they received appropriate, high quality, and timely care. Patients also rely on individuals who work in the health care system, including physicians, to facilitate better access on their behalf. Advocacy, whether it consists of patients acting on their own behalf or health care professionals acting on the behalf of patients, plays an important role in ensuring access to timely and good quality cancer care.

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Table 1: Characteristics of interview participants by cancer type

Characteristics	Breast (n= 18)	Colorectal (n= 15)	Lung (n= 11)	Prostate (n= 16)	All Types (n= 60)
<b>Sex n (%)</b>					
Male	0 (0)	11 (73.3)	6 (54.5)	16 (100.0)	33 (55.0)
Female	18 (100)	4 (26.7)	5 (45.5)	0 (0)	27 (45.0)
<b>Age n (%)</b>					
Under 65	16 (88.9)	10 (66.7)	6 (54.5)	8 (50.0)	40 (66.7)
65 and over	2 (11.1)	5 (33.3)	5 (45.5)	8 (50.0)	20 (33.3)
<b>Community of Residence n (%)</b>					
Urban	6 (33.3)	5 (33.3)	1 (9.1)	3 (18.8)	15 (25.0)
Semi-urban	6 (33.3)	4 (26.7)	2 (18.2)	4 (25.0)	16 (26.7)
Rural	6 (33.3)	6 (40.0)	8 (72.7)	9 (56.3)	29 (48.3)
<b>Marital Status n (%)</b>					
Married or Equivalent	16 (88.9)	13 (86.7)	10 (90.9)	16 (100.0)	55 (91.7)
Single	2 (11.1)	2 (13.3)	1 (9.1)	0 (0)	5 (8.3)
<b>Overall Satisfaction with Wait Times n (%)</b>					
Dissatisfied	9 (50)	6 (40)	3 (27.3)	6 (37.5)	24 (40)
Satisfied	9 (50)	9 (60)	8 (72.7)	10 (62.5)	36 (60)
<b>Stage</b>					
Early	11 (61.1)	0 (0)	2 (18.2)	4 (25.0)	17 (28.3)
Late	6 (33.3)	9 (60.0)	7 (63.6)	12 (75.0)	34(56.7)
Unknown	1 (5.6)	6 (40.0)	2 (18.2)	0	9 (15.0)

Table 2: Themes and Illustrative quotations.

Quotation Number	Theme and illustrative quotations
<i>Efforts by the Patient to Reduce Waits</i>	
1	“And the third time I went back I asked him if he would send me for a chest x-ray. ...because I was getting concerned that there might be something else. And he did, he sent me for a chest x-ray and the reports came back that there was a, a mass on my lung.” (ID 337, Rural, Satisfied, Lung Cancer, Male)
	I kept saying “my tummy doesn’t feel right, I feel like there’s something wrong. Maybe you could do an endoscopy test” and he’s [physician] like “you’re 39 and you don’t have any symptoms, there’s nothing wrong with you.” And they basically laughed in my face that I was complaining so much. (ID 219, Semi-urban, Colorectal Cancer, Dissatisfied, Female).
2	So I spent a few months being tested for celiac, that test got lost in the system. Four months later I tracked it down myself, and my family doctor refused to look for it ... Because he just assumed when it’s ready it would show up on his computer ... Eventually I phoned the blood labs in St. John’s and found my results and it came back negative.” (ID 219, Semi-urban, Colorectal Cancer, Dissatisfied, Female).
	And the problem with pressing is that the doctors, a lot of them will say, “The hell with you, get the hell out”, you know? So you're caught between a rock and a hard spot (ID 224, Urban, Dissatisfied, Male, Colorectal Cancer).
3	“I called [the referring gastroenterologist] back and said, ‘Look, [the surgeon] says I’m not on her list, or there’s no list, I’m not on her surgery list,’ and he said, ‘Well I definitely gave [your file] to her.’ So he said, ‘I’ll call her right away myself.’ (ID 231, Urban, Satisfied, Female, Colorectal Cancer).
4	“I think if I had sat home and just waited for the phone to ring, it would have been delayed a lot longer. But I called up to the appointments and insisted that an appointment be given ASAP.” (ID 231, Urban, Satisfied, Female, Colorectal Cancer).
5	“... in my case, I didn’t even ask [about travelling clinics], because I just said ‘whenever I can.’ Because if they came to Clarendville, you would have to wait for whenever they came to Clarendville. ...And for me I wanted to see them at the earliest appointment, so I was willing to travel...” (ID 117, Rural, Breast Cancer, Satisfied, Female).
6	I mean, I work in the health care system, and I think that gave me a little bit of an up on who to call. ... Anyone in the general public, who is waiting on this stuff ... doesn’t know how to insist, how to really self-advocate, unless you really know the system and know how to navigate it, you’re kind of a victim of it and you’re waiting and waiting ... (ID 107, Urban, Dissatisfied, Female, Breast Cancer).
<i>Efforts by Family and Friends to Reduce a Patient’s Wait Time</i>	
7	So I was waiting and waiting and waiting [to hear about the travel clinic to Corner Brook] and I waited two or three weeks and then the wife said, “I think it’s time for us to try to do something” and so she phoned St. John’s... and the [clerk] said, “Well, if you can be here,” for such a time or whatever it was, I think it was only a couple of days or something, “you can get in to see him.” I said, “Great,” I said,

	<p>“I’ll drive to St. John’s.”... [If] I would have had to wait for him to come into Corner Brook ... I think it [would have been] another month longer.... (ID 445, Semi-urban, Prostate Cancer, Dissatisfied, Male).</p>
	<p>“And we met with [oncologist] through the video conference and he ran upstairs and he got one of his colleagues to see when they could do radiation and he came back and he had the appointment dates and everything to go into St. John’s.” (ID 223, Rural, Dissatisfied, Colorectal Cancer, Male)</p>
8	<p>... My daughter who’s a nurse in Nova Scotia, she had contacts with a doctor there and he had contacts with Newfoundland. ... Someone in St. John’s knew this [doctor’s name] in Clarendville. And she [the doctor] was full but she agreed to take me [as a patient]. (ID 103, Rural, Dissatisfied, Female, Breast Cancer).</p>
9	<p>So I ended up on the phone with my friend who is a resident radiologist, she told me to go on down to the cancer center. So, I called the cancer center first and friend of mine, a friend of another friend ... She answered the phone. I didn’t even know she worked at the cancer center ... and we started talking and she said, “Come on down and [oncologist’s name] will see you.” So my husband and I walked down that afternoon and walked into [oncologist’s] office, like without an appointment or anything... (ID 104, Semi-urban, Breast Cancer, Dissatisfied, Female).</p>
<p><i>Efforts by Members of the Health Care Team to Reduce a Patient’s Wait Time</i></p>	
10	<p>“And in our opinion,” the doctor wrote, “[patient name] should not have to wait that long. And it would be advisable to seek other options for him.” (ID 449, Rural, Dissatisfied, Male, Prostrate Cancer).</p>
11	<p>So, I asked him [the surgeon], I said, “Do you, do you confer with an oncologist, or is it not done that way?” He said, “No, it’s not normally done that way,” but he said, “If you want to speak to one,” he said, “I’ll set up an appointment.” Which he did, I must say, the very next Wednesday I had an appointment with [the oncologist] at the cancer clinic ... And I didn’t know how long that was going to wait, but [the surgeon] ... contacted that unit and you know, explained to them that [I] needed to have this done, you know, pretty much ASAP. And I was scheduled in as quick as they could get me in.” (ID 118, Urban, Satisfied, Breast Cancer, Female)</p>
12	<p>“when he [family doctor] made an appointment for the CAT scan he said, ‘I’m going to set you up for a colonoscopy just in case, down the road, I’ll make an appointment now, so the lead time would have gone, you won’t have so much lead time if you do need one.’” (ID 226, Semi-urban, Satisfied, Colorectal Cancer, Male).</p>

## Appendix A: Interview Guide

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1. We are interested in finding a little more about the waiting times you experienced for your cancer. When did you first start feeling ill?

Probes:

When did you first notice symptoms?

What were your symptoms?

When did you see a physician?

What screening tests did you have?

2. Can you talk about your first visit to the physician?

Probes:

What happened?

What did you discuss?

How did you feel when the visit was over?

Did the have an opportunity to talk with the physician about how long it would take to get a definitive diagnosis?)

3. If you did not go to see a physician, when you first noticed the symptoms, can you talk about what caused you to delay seeking treatment?

Probes:

Competing demands on time?

Fear, anxiety, or denial?)

Availability or reputation of physicians?

Seeking alternative therapy?

Care giving responsibilities (Child or elder care?)

4. What happened once you found out you had cancer?

Probes:

Tests

Referral to specialist

Surgery

5. What do you think about the amount of time it took to diagnose your cancer? Was it acceptable/satisfactory? Why or why not?

Probes:

What could be done to improve the amount of time it takes to diagnose cancer?

Was there anything anyone could have done to help you while waiting for your diagnosis?

6. What did you think of the amount of time it took to see the oncologist? Was it acceptable/satisfactory? Why or why not?

Probes:

What could be done to improve access to oncologists?

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3 What could be done to improve access to cancer treatments?  
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6 7. In your community, what are the barriers to having timely cancer care?  
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8 Probes:

9 To diagnosis? Transportation/financial issues

10 Once you have been diagnosed? Availability of treatments  
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12 8. In your community, what helps to provide timely cancer care?  
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14 Probes: Local clinics

15 Visiting specialists

16 Telemedicine  
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19 9. Other comments? Is there anything you would like to tell me about your experience that I  
20 have not asked you?  
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Confidential

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**