

ORIGINAL ARTICLE

Patient Experience of Living With Cancer-Associated Thrombosis in Canada (PELICANADA)

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Abstract

Introduction: Previous research from the United Kingdom and Spain has identified several areas of unmet clinical and support need for cancer patients diagnosed with venous thromboembolism. It is not known whether such experiences are restricted to those countries health care systems and culture. We therefore evaluated patients' experience of cancer-associated thrombosis (CAT) within a Canadian setting.

Methods: Purposive sampling of patients with CAT attending a regional thrombosis clinic in Vancouver was undertaken. Semistructured interviews were audio recorded, transcribed, and coded using NVivo software. A deductive approach was taken by applying the framework matrix from the original study to these data on a case-by-case basis.

Results: Twenty patients (10 male, 10 female) aged 39 to 74 (mean, 63) representing a breadth of different cancers participated. Commonalities between the UK and Canadian patients included the traumatic nature of experiencing CAT, the need for information, and adaptive behaviors through ritualization. Two new themes were identified: (1) Patients with incidental pulmonary emboli (iPE) were usually telephoned about their thrombus with little support and suboptimal communication; and (2) cost implications of accessing low-molecular-weight heparin varied according to insurance cover. Patients were sometimes converted to warfarin for financial reasons.

Conclusion: The distress associated with CAT is a common experience across different populations but may be ameliorated by early access to specialist services, information, and support. The current process for managing iPE could be improved with better communication and a dedicated clinical pathway. Funding issues may influence choice of anticoagulant.

KEYWORDS

cancer-associated thrombosis, cultural, patient experience, qualitative, venous thromboembolism

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Essentials

- The impact of venous thromboembolism (VTE) on Canadian cancer patients is unknown.
- A qualitative study was undertaken to explore the impact of cancer-associated VTE on patients living in Vancouver.
- The diagnosis and management of incidental pulmonary emboli is associated with significant patient distress.
- Anticoagulant prescribing may be influenced by patients' financial or socioeconomic status.

1 | INTRODUCTION

Venous thromboembolism (VTE), comprising deep vein thrombosis (DVT) and pulmonary embolus (PE), is a major cause of morbidity and mortality among cancer patients.¹ The incidence of cancer-associated thrombosis (CAT), a thrombotic event occurring in someone known to have cancer, will vary according to primary cancer, stage, and treatments, but overall it affects approximately 20% of cancer patients during their lifetime.² The past decade has seen a growing understanding of the psychological impact of VTE in both the cancer and noncancer setting.³ Qualitative studies have suggested that some patients experience persistent anxiety following a VTE, which is independent of the severity or clot burden of the thrombotic event.^{3,4} Some may develop what has been termed *postthrombotic panic syndrome* with persistent symptoms meeting the diagnostic criteria for posttraumatic stress disorder.⁵

Studies initially undertaken to evaluate the experiences of CAT patients of self-injecting low-molecular-weight heparin (LMWH), identified a significant level of distress and anxiety associated with patients' experience and perceived meaning of CAT.^{6,7} The Patient Experience of Living With Cancer-Associated Thrombosis (PELICAN) study was a qualitative study, conducted in the United Kingdom to evaluate the impact of VTE on 20 cancer patients and their extended family.⁸ The study confirmed CAT to be a distressing experience, with limited support or information, in complete juxtaposition with the treatment they received for their cancer. Patients felt there was little health care professional ownership for the management of CAT, which further added to their distress. More recently, a similar study using identical methodology, Patient Experience of Living With Cancer-Associated Thrombosis in Spain (PELICANOS), was reported from Spain; a country with a similar model of central government-funded health care delivery to that seen in the United Kingdom.⁹ It followed a similar methodology to PELICAN, interviewing 20 patients and using framework analysis.⁸ Several commonalities between the UK and Spanish patients were identified, including the traumatic nature of being diagnosed with CAT, the need for information, and adaptive behaviors around injecting their LMWH through ritualization. However, the degree of anxiety observed in the Spanish cohort was greater than that observed in the UK cohort, and this level of distress extended to the immediate family, whose needs sometimes took primacy over the patient.

While the experience of CAT may vary according to culture, it is not known whether there are also variances according to health care systems. Health care provision in Canada differs from the social

security-funded national health care system in Spain and the United Kingdom. The Canadian system consists of 13 provincial and territorial health insurance plans that provide health care coverage on a provincial or territorial basis, within guidelines set by the federal government. Approximately 70% of health care expenditure comes through public funding, with the remainder covered by health insurance and individual payments.¹⁰ Approximately two-thirds of Canadians hold private health insurance to cover services excluded from public reimbursement such as prescription medicines, including anticoagulants.

We therefore undertook a study to explore the Patient Experience of Living With Cancer-Associated Thrombosis in Canada (PELICANADA), specifically of those living in the province of British Columbia. Within this province, the Medicare program is provided by the government-administered Medical Services Plan of British Columbia, for which residents are required to submit monthly premiums. Selected prescription drug costs, including LMWH, are partially subsidized based on annual family income.

Specifically, the study aims were to explore:

- The journey of CAT patients through lived patient experience
- The meaning of CAT to patients within the context of the cancer journey
- The impact of the treatment for CAT
- The emotional impact of CAT
- Information needs for patients

2 | METHODS

2.1 | Data collection

The methods have been described in detail previously.⁸ Purposive sampling of patients attending a thrombosis outpatient service at a university-affiliated teaching hospital, which serves a population of 2.3 million, were sequentially screened for inclusion in the study. Screening was undertaken by experienced thrombosis nurses (JS, AB, and KS), who also approached eligible patients face to face. Where patients attended with their partner or next of kin, they were also given an opportunity to be interviewed.

English-speaking participants were eligible if they had histologically confirmed cancer, had been receiving anticoagulation for proven new DVT or PE for at least 2 months and were able to consent to a 40-minute interview. They were ineligible if they had nonmelanoma skin cancer, the thrombosis predated their cancer diagnosis, or they were unable to participate in a 40-minute interview.

All participants provided informed written consent. Each interview was individually conducted by 1 of 3 researchers (JS, AB, or KS). In total, 20 qualitative interviews were undertaken between July 2015 and March 2016.

Participants were receiving treatment at the hospital where the interviewers worked; however, the interviewers did not have access to medical records beyond collecting demographic data.

While interviewers approached the interviews with knowledge of the UK PELICAN study, they had no fixed beliefs or bias with regard to cultural differences and no knowledge of the Spanish data. The patients received an information leaflet outlining the aims of the study but had no identified preinterview agenda. The interviewers were experienced in communication skills but were new to qualitative interviewing. They received interview training from the chief investigator (SN) and undertook pilot interviews with feedback. Interviews were audio recorded and transcribed verbatim. The chief investigator reviewed each interview, and feedback was given to further hone the interviewer's skills. Interviews were conducted at the preferred location of the patient: either the patient's home or a hospital outpatient clinic. Questions were guided by an interview schedule (see supplementary material) to ensure that the same issues were discussed at each interview.

Data were elicited on the following:

- Patients' and caregivers' experience of being diagnosed with CAT
- The physical and emotional impact of CAT and its treatment
- How patient care could be improved

To facilitate this, questions were open-ended, with the use of prompts to probe further into issues that arose as significant or meaningful to the participant. Interviews were recorded and transcribed verbatim. Field notes were also taken as required. Transcripts were available for participants to check and, where necessary, recommend amendments.

2.2 | Analysis

Transcripts were typed into a Word document, and data were managed using NVivo 10 computer software (QSR International, Melbourne, Australia).¹¹ Any identifying information was anonymized. Data analysis was undertaken using Framework Analysis as per the previous study using Richie and Spencer's 5 interconnected stages, namely: familiarization with data, identifying a thematic framework indexing the data, charting, mapping, and interpretation.¹² This method, known as coding, is the process of naming, labeling, and sorting data, which enables researchers to find emerging themes or patterns. However, a pragmatic approach was used, with an applied framework matrix and codes from the original study on a case-by-case basis using a deductive approach. If there was no evidence of a particular code, this field was left blank in order to take an overview of the commonalities and missing codes from the data set. For the next stage, all of the remaining uncoded data were analyzed with an inductive approach to establish a new set of themes.

This was done in order to explicate potential cultural and operational differences that were not apparent in the UK and Spanish data sets. An independent researcher with no prior knowledge of CAT (PS) undertook primary coding, and this was verified by 2 senior researchers (SN and AN). A preagreed number of 20 interviews was planned, in keeping with the original PELICAN study, with an option to continue recruitment if theoretical saturation (ie, no new themes were emergent), as assessed by the researcher, had not been reached.

3 | RESULTS

Research ethics approval was obtained from the University of British Columbia BC Cancer Research Ethics Board (H14-01898) before study enrollment. Twenty patients agreed to participate, and their clinical characteristics are recorded in Table 1. Three patients who were approached declined to participate but gave no reason. No interviews needed repeating, and no participants requested transcripts to review. Theoretical saturation was reached at 14 interviews, when no new themes were apparent. The 3 major themes previously identified in the original PELICAN and PELICANOS studies were also observed in this data set, namely, the distressing experience of CAT, information requirements, and adaptive behaviors/ritualization^{8,9}. In addition, 2 new themes emerged: incidental pulmonary emboli and the cost implications of LMWH. These are summarized in Figure 1. Each theme is discussed below with its associated sub-themes. Themes are supported by patient quotes, which were chosen according to 2 criteria: They illustrate the theme being discussed, and they represent a breadth of data across as many participants as possible.

3.1 | Previously identified theme: Traumatic nature of CAT

Previous studies have highlighted the distress experienced by patients when diagnosed with CAT. The impact on Canadian patients appeared no different.

I cried. All the time I cried...I was an emotional wreck.
100-02

For some, the experience of CAT was more distressing than the cancer diagnosis itself. Previous research suggested this was due to either a distressing symptom burden or the rushed diagnostic process. In PELICANADA, patients found the delivery of the diagnosis of CAT to be rushed, and the fact that CAT was potentially life threatening exacerbated their distress.

Well, at first it made me feel that my health issues were even more terminal than the cancer originally.
100-03

TABLE 1 Characteristics of study participants

Code	Age	Sex M/F	Cancer diagnosis	Disease status	VTE details	Rx	Length of Rx (mo)	Admin
100-1	65	M	Myeloma	Palliative	DVT	WarfarinLMWH	12	Self
100-2	62	F	Lung	Post curative resection	PE	LMWH	9	Self
100-3	72	M	Metastatic Prostate	Palliative	iPE	LMWH	5	Self
100-4	74	M	Prostate	Curative	iPE	LMWH	12	Self
100-5	68	F	Metastatic Breast	Palliative	iPE	LMWH	7	Self
100-8	62	F	Metastatic Ovarian	Palliative	PE	LMWH	9	Self
100-9	55	F	Metastatic colorectal	Palliative	Stroke	LMWH	8	Self
100-10	71	F	Chronic Lymphocytic Leukemia	Post stem cell transplant	iPEiDVT	LMWH	5	Self
100-11	69	F	Renal cell carcinoma	Palliative	iDVT	Warfarin	11	Self
100-12	68	F	Metastatic breast	Palliative	PE	LMWH	6	Self
100-13	49	M	Metastatic colorectal	Palliative	PE	LMWH	14	Self
100-14	67	M	Gastric	Metastatic	PEDVT	LMWH	3	Self
100-15	65	F	Breast	Metastatic	PE	LMWH	4	Wife
100-16	68	F	Bladder	Curative	DVT	LMWH	9	Daughter
100-17	69	M	Myeloma	Post stem cell transplant	DVT	LMWH	5	Self
100-18	70	F	Acute myeloid leukemia	In remission	PE	LMWH	6	Husband
100-19	48	F	Metastatic ovarian	Palliative	iPE	LMWH	6	Self
100-20	63	F	Myeloma	In remission, on maintenance treatment	DVT	LMWH	8	Husband
100-21	39	M	Acute myeloid leukemia	Post stem cell transplant	DVT	LMWH	4	Self
100-22	58	F	Brain	Inoperable, palliative chemo	DVT	LMWH	6	Self

DVT, deep vein thrombosis; iDVT, incidental deep vein thrombosis; iPE, incidental pulmonary embolus; LMWH, low-molecular-weight heparin; PE, pulmonary embolus; VTE, venous thromboembolism.

3.2 | Previously identified theme: Information needs

Patients identified 2 main areas of information need. First, lack of forewarning regarding the risk of clots and possibility of death was a significant driver of distress. They also worried regarding the uncertainty of whether a clot may recur. Patients felt that adequate forewarning and information would help ameliorate this.

The blood clot was a scary thing because I didn't know if I should have been looking for something and from what questions I have been asked, there was nothing that would have alerted me. ... Because knowing nothing about clots, it just meant almost like a death sentence.

100-10

Second, information was needed regarding the administration of LMWH, which patients were often required to do themselves. Some patients acknowledged receiving information on how to inject but reported that this was often difficult to understand.

When I got the box of syringes, there was a very extensive description of what to do; however, ... the description of how to manipulate this little syringe was

not as clear as it could be and ... I almost had to figure it out on my own with the pharmacist on how to manipulate the needle and how to cover it back up and so on.

100-03

Some patients received no information on how to inject, which often led to poor technique and associated complications.

My stomach was so bruised that I didn't do the top part of my belly because nobody ever told me (to do) the top part. They didn't give me a program, like a sheet that says, you know, there is the top part and you go over to the side, 2 inches here, 2 inches there, 2 inches here, around the belly button.

100-02

3.3 | Previously identified theme: Acceptability of LMWH

The majority of patients received the anticoagulant LWMH, which required a daily subcutaneous injection. As with previous research, most patients found the injections an acceptable intervention within the context of their cancer journey.

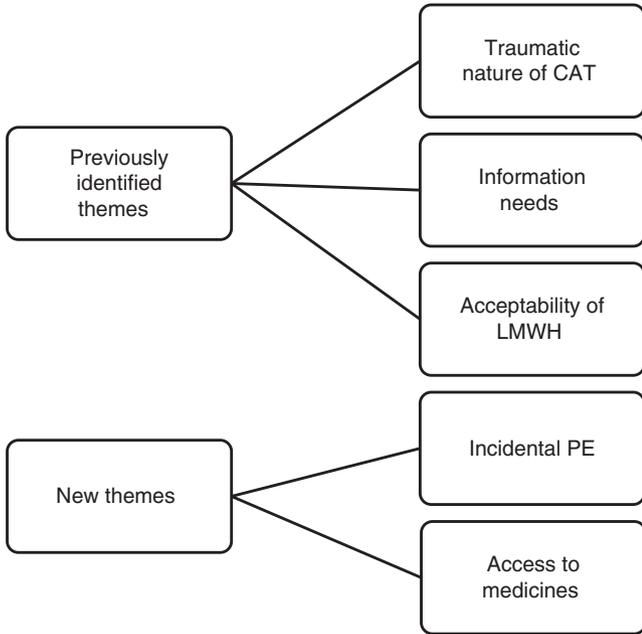


FIGURE 1 Previously identified themes and new themes

I have accepted it as a part of treatment. It is something I have no choice.

100-01

Patients and caregivers were willing to learn to self-inject, since it gave them more freedom and removed the need to attend the hospital for an injection or wait at home for a homecare nurse.

I knew that injecting myself was much easier for me than going to the hospital and have somebody else taking all the trouble of coming, so I tried to learn it. ... Administering this is so easy. I did myself because it wasn't worth going back and forth. Since then, I have been doing it myself.

100-01

In keeping with other studies, patients would normalize the process of self-injecting by developing habits and rituals. Some saw the process as heralding the beginning of the day.

We have our coffee and our muffin in the morning and it's time for my shot. We do it every day. ... Then I hold it there, hold the little pad over it and, for about 5 minutes, have my second cup of coffee and done for the day.

100-04

I do it in the morning, and then I am good for the whole day.

100-05

3.4 | New theme: Incidental PE

Incidental pulmonary emboli (iPE) are clots that are diagnosed on imaging ordered for indications other than PE. These usually occur when staging a newly diagnosed cancer or when evaluating response to treatment. Generally, these patients do not spontaneously volunteer symptoms suggestive of PE, although direct questioning may reveal a degree of symptom burden. Six patients (100-03, 100-04, 100-05, 100-10, 100-11, and 100-19) were diagnosed with iPE, which differs considerably from the PELICAN study (n = 2) and PELICANOS (n = 0). Their experiences offer a different insight into the experience of CAT than those presenting with symptoms.

Patients usually received the diagnosis of PE over the telephone, when they were asked to come in to the hospital as a matter of urgency.

Actually, we had finished an appointment at the hospital and we were on our way home, and we stopped for coffee at Starbucks for our daughter and then we got a phone call and said you better get back here quick sort of thing, said they discovered a clot.

100-10

Sometimes patients would have only recently attended the hospital and were reluctant to come back in. This would result in their being informed that they had a potentially life-threatening condition that could result in death if they did not return immediately.

It was a big deal when it was first discovered. Because remember she said you got to come in now.

100-05

And the doctor phones and says you better get in, it's life threatening.

100-04

Despite being informed that their condition was potentially life threatening and needed immediate hospital attendance, some patients found that the sense of urgency did not continue when they presented to the hospital. This was most apparent for those who attended the emergency unit: Patients reported that there was no sense of urgency when triaged and graded as low priority. This conflicting juxtaposition of urgency from those asking the patient to attend the hospital and the indifference from those receiving them created an additional cause for disquiet and confusion.

We went to emergency, and we sat there and waited and waited.

100-3

3.5 | New theme: Access to medicines

The cost of LMWH for the treatment of CAT was covered by the provincial health care plan (PharmaCare) for periods of 6 months,

renewable as long as the patient continued to have active cancer and needed anticoagulation.¹³ However, each patient is responsible for paying for their drug deductible each calendar year before the cost of drugs is covered by the government. This deductible is dependent on their personal and family income, so some patients are still paying out of pocket or are covered by private health insurance even with PharmaCare coverage. Where patients did not have appropriate health insurance, they would often incur additional financial costs to remain on LMWH.

I still don't have my PharmaCare in place, so yah, I am paying for [LMWH]. I am paying for a lot of things. So when I go to the pharmacy about once a month or every other month, I drop about a \$500 bill because I accumulate so I don't have to go back there all the time.

100-05

Some patients not covered by insurance would be converted from LMWH to a cheaper anticoagulant, warfarin, which was known to be less efficacious.

First, the doctor talked to me. Then, they came and talked to me about the warfarin, and they gave me some leaflets.

100-11

4 | DISCUSSION

The PELICANADA study sought to explore the experiences of cancer patients in Vancouver who had been diagnosed with VTE. Data from the United Kingdom and Spain have identified CAT to be a distressing experience and one for which patients receive limited information or support. These findings concurred with Canadian patients' experiences. This study also identified 2 important new areas of interest, namely, the impact of health care funding on prescribing practices and the challenge of managing iPE without increasing patient distress.

The diagnosis of iPE usually occurs at a time of heightened anxiety for the patient because imaging was ordered either to stage a recently diagnosed new cancer or to assess response to recent treatment. As previous studies have illustrated, one of the drivers of distress around CAT is living with a potentially fatal condition that carries an ongoing risk of recurrence.⁷⁻⁹ Breaking the news to a cancer patient, already contemplating their mortality while waiting anxiously for their staging results, that they have developed another potential threat to life should be afforded the same sensitive approach of any other breaking bad news scenario. In practice, this rarely happens; instead, learning the findings from a stranger, by telephone, without the benefit of a supportive environment or customary approach to breaking bad news, is the norm. Patients reluctant to come to the hospital were often advised that the clots

could be life threatening, thereby adding to distress and also generating expectations for their arrival at the hospital. Having responded to the urgency of their condition, patients would be perplexed that their presentation was rarely greeted with a sense of urgency and in complete contrast to the advice and information given by telephone. These data make a strong case for the development and implementation of a clinical pathway for the diagnosis and management of iPE, which includes consideration of information delivery with respect to both diagnosis of the PE and its ongoing management. Such pathways do exist but arguably should be a minimum standard in CAT management.¹⁴ It is important to note that the issues around the diagnosis of iPE are probably not specific to Canada; it is more likely a reflection of the numbers of iPE patients in PELICAN and PELICANOS being too low for any meaningful signal to emerge in isolation. Furthermore, given that PE occurs in 3.6% of all staging computed tomography scans and accounts for 40% of all cancer-associated PE, management of this unexpected outcome is a common and important clinical scenario.^{15,16}

This is the first of the PELICAN studies to suggest that the type of health care funding may impact on which anticoagulant is used to treat CAT. Furthermore, it infers that patients of lower socioeconomic status (ie, those without health insurance or sufficient funds) are less likely to receive the current gold standard treatment. This is unsurprising; and American data from 2941 newly diagnosed CAT patients observed that the majority were anticoagulated with warfarin (47.7%), with the remainder receiving LMWH (25%) and rivaroxaban (24.1%).¹⁷ In an earlier observational study, only 19% of American patients with CAT received LMWH first line, and 81% warfarin. The most common reason given by patients receiving warfarin (49.4%) was that their medical insurance did not cover the cost of LMWH and they could not afford the out-of-pocket expenditure. This is the first data set from the PELICAN studies to highlight nonuniformity of care due to different health funding structure. It was beyond the remit of this study to follow up patients' long-term incidence of recurrent thrombosis and bleeding, but it is plausible that such inequalities in health provision could lead to different outcomes.

As with all studies, it is important to consider the data within the context of the study limitations. Interviews were conducted by 3 researchers (JS, AB, and KS), which could potentially lead to inconsistency in interview styles and questions asked. Every effort was undertaken to minimize this, including feedback where needed and independent review of data to ensure consistency. It is also important to acknowledge that Canada is a vast country with different health systems and even cultures across the different provinces and territories. As interviews were conducted in only one province, the degree to which these findings can be generalized is unclear. Finally, it is important to recognize that at the time interviews were conducted, the direct-acting oral anticoagulants were rarely used in the treatment of CAT, and as their use becomes more widespread, the experience of CAT for Canadian patients may change. Nevertheless, these data support findings from previous countries, including the distress of experiencing CAT, the need for information at the time of CAT diagnosis, and acceptability of LMWH. The emergence of

new themes, particularly those influenced by differing health care systems to those in previous studies, justifies further evaluation of patient experiences in other countries.

RELATIONSHIP DISCLOSURE

This study was funded by Leo Pharma as an Investigator Initiated Research Project. Leo Pharma had no input into any aspect of the study design, conduct, analysis or write up. Simon Noble has received honoraria for speaking from Bayer, Pfizer, Daiichi Sankyo and advisory board from Daiichi Sankyo. Agnes Lee has received received honoraria for speaking from Pfizer, Leo Pharma, advisory board from Bayer, Pfizer, Leo Pharma, and research funding from Bristol Myers Squibb. Annmarie Nelson, Jill Scott, Anne Berger, Karen Schmidt and Parinita Swarnkar have no relationships to declare.

AUTHOR CONTRIBUTIONS

SN devised the study, oversaw data quality, and is chief investigator of the PELICAN project. AN was responsible for secondary analysis of data. JS, KB, and KS were responsible for recruitment and data collection. PS undertook data analysis. AL was site principal investigator and oversaw recruitment and data collection. All contributed equally to authorship of the manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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