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ORIGINAL CONTRIBUTION

Patient values and preferences in pulmonary embolism testing in the emergency department

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Abstract

Introduction: Patient-centered care is concordant with patient values and preferences. There is a lack of research on patient values and preferences for pulmonary embolism (PE) testing in the emergency department (ED), and a poor physician understanding of patient-specific goals. Our aim was to map patient-specific values, preferences, and expectations regarding PE testing in the ED.

Method: This qualitative study used constructivist grounded theory to identify patient values and expectations around PE testing in the ED. We conducted semi-structured interviews with ED patients who were being tested for PE in two EDs. Patients who were waiting for PE imaging or D-dimer results were approached and consented to take part in a 30-minute audio-recorded interview. Each interview was transcribed verbatim and analyzed using constant comparative coding. The interview script was modified to maximize information on emerging themes. Major themes and subthemes were derived, each representing an opportunity, barrier, or value to address with patient-centered PE testing.

Results: From 30 patient interviews, we mapped four major themes: patient satisfaction comes from addressing the patient's primary concern (for example, their pain); patients expect individualized care; patients prefer imaging over clinical examination for PE testing; and patients expect 100% confidence from their emergency physician when given a diagnosis. Subthemes included symptomatic relief, finding a diagnosis, receiving tests, rapid progression through their care, perception of highly accurate CT scans, willingness to seek a second opinion, direct physician communication, and expectation of case-specific testing with cognitive reassurance.

Conclusion: Addressing each of these four themes by realigning ED processes could provide patient-centered PE testing.

KEYWORDS
emergency medicine, Patient preferences, pulmonary embolism, testing

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INTRODUCTION

Patient-centered care in medical practice prioritizes patients' individual needs throughout the treatment process.[1] The goal of a patient-centered approach is to help physicians provide care that is concordant with patients' values and preferences.[1,2] Patient engagement during medical decision-making leads to better outcomes such as improved patient satisfaction and safety.[1] For example, in family medicine, patient engagement can help physicians individualize antibiotic treatment for urinary tract infections depending on which side effects are more bearable for the patient.[3]

There is little research on patient values and preferences in the emergency department (ED), and a limited physician understanding of patient-specific emergency treatment goals.[4] Existing conceptual models on the lived experience of ED patients have identified patient preferences and expectations that influence patient perceptions of care, and can inform physicians of knowledge gaps and improvements to communication skills.[4-6] In one US study, ED patients were asked about their risk tolerance when deciding to discharge low-risk chest pain patients. Forty-three percent of patients preferred to be discharged from the ED compared to 3% of emergency physicians who would discharge the patient,[7] demonstrating a gap between patient preference and physician decision making.

Sometimes, evidence-based guidelines on testing for pulmonary embolism (PE) are not followed by emergency physicians.[8-10] On one hand, a recent study found that patient expectation of undergoing diagnostic imaging was a barrier to using safe rule-out tests for PE, such as the Wells score and D-dimer.[11] However, on the other hand, there is evidence that some patients might decline CT scanning for PE when their physicians use standardized information sharing tools on the risks and benefits of CT.[12] A better understanding of patient priorities for PE testing is a first step to developing PE testing algorithms which incorporate both evidence and patient-centered values. The aim of this study was to identify patient expectations, values, and preferences regarding PE testing in the ED to inform future methods of achieving more patient-centered care.

METHODS

This was a prospective qualitative interview study. We followed the COREQ standards.[13] The study was approved by the Hamilton Integrated Research Ethics Board.

Population

The study was conducted in the EDs of two inner city hospitals in Hamilton, Ontario, Canada. Patients who were being tested for PE were eligible for enrollment (i.e. the ED physician had ordered a D-dimer blood test and/or a CT or ventilation-perfusion (VQ) scan for PE testing). To be included, patients had to be fluent in English, age 18 or over, and willing to spend 30 minutes in an interview while waiting for their tests. Patients who had cognitive impairment, were hemodynamically unstable, or too unwell to converse were excluded. ED patients were screened using the hospital's patient tracker system.

Interview

Patients were approached by their nurse to ask if they would speak with a researcher. The researcher (a female MSc student, VS), explained what the interview entailed, that it was part of a research study, and that details of the interview would be kept confidential within the research team. Written informed consent was obtained prior to participating in a 30-minute audio-recorded interview. The interview took place at the bedside while the patient waited for their test results. The semi-structured interview focused on the following topics: expectations of their ED experience, personal preferences and values associated with the ED environment and health care providers, understanding of PE and PE treatment, confidence in ED testing, and overall patient satisfaction (see Supplemental Appendix I for the interview transcript). Each interview was transcribed verbatim and the participant allocated a study number.

The following demographic data were obtained: age, sex, highest level of education, past medical history (diabetes, hypertension, stroke, cancer, chronic obstructive pulmonary disorder, coronary artery disease, past PE diagnosis, and past deep vein thrombosis diagnosis), and previous or current administration of anticoagulants. The Pulmonary embolism rule out criteria (PERC) rule components, Wells score, D-dimer blood test, CT PE scan results, and final diagnosis were also recorded and entered into a secure database on a university server.

Thematic Analysis

The interviews were analyzed using constructivist grounded theory. Grounded theory is used to systematically analyze qualitative data to construct multiple themes,[14] when a pre-existing conceptual framework does not exist. Four researchers (VS, AS, KdW and SA) used constant comparative coding. Each researcher independently analyzed the interview transcript on Microsoft Word and then met to review and agree on common codes. Inductive coding was used to group codes into themes, and the interview script was modified to maximize information collection on developing and emerging themes. We derived major themes with associated subthemes – each representing an opportunity, barrier, or value which should be addressed in future PE testing. Interviews ceased when thematic saturation occurred. The investigators consisted of three postgraduate students who were knowledgeable about emergency medicine research, but had no prior experience of PE, and one emergency / thrombosis physician with extensive clinical and research experience of PE testing. At the outset, the investigators met to review

their own experiences and beliefs regarding PE testing to allow for reflexivity.

All 4 researchers (VS, AS, KdW and SA) met to review coding and discuss the data from the first 10 interviews. For the remaining 20 interviews, three researchers analyzed the data (VS, AS, and KdW). An average of three interviews were analyzed per meeting, and a total of 11 meetings were held. The interview script was modified after the 10th and 23rd interview to expand on emerging themes. After the 26th interview, no new themes were found (Table 1).

RESULTS

The first interview was conducted on October 24th, 2017 and the last interview was conducted on April 17th, 2019. In total, 30 interviews were conducted. The interviews lasted between 8 and 47 minutes in duration. One patient requested to stop the interview early as they were feeling tired. Six patients declined participation due to fatigue or they were uninterested in participating in a research study. Of the 30 patients who were interviewed, 16 patients were male and 14 were female. The median age was 60 years old (interquartile range 50–67). Twenty-six patients had a positive PERC score; 12 patients were categorized as Well's score likely (> 4), and 18 patients were categorized a Well's score unlikely (≤ 4); 17/27 patients had a D-dimer above 500 ng/mL (3 patients did not have a D-dimer ordered); 19 patients had a chest CT scan done during their ED visit, 7 of which were positive for PE. Of note, patients were interviewed before their PE diagnosis was made.

TABLE 1 Patient characteristics.

Characteristic	Number (N=30)
Median age	median 60 (IQR 50–67)
Female	14
Highest education level	
Elementary school	2
High school	12
University/College	13
Post-graduate studies	3
Diabetes	6
Hypertension	12
Stroke	5
Cancer	4
Chronic obstructive pulmonary disease	2
Coronary artery disease	4
Past DVT diagnosis	2
Past PE diagnosis	2
PERC positive	26
Wells' Score >4	12
D-dimer ≥500 ng/mL	17
Chest CT scan performed during initial ED visit	19
PE diagnosis in the ED	7

Note: IQR =interquartile range; DVT =deep vein thrombosis

We found four major themes which were subcategorized into subthemes (Table 2). A conceptual model was also created to illustrate the findings (Figure 1).

Theme 1: Patient satisfaction comes from addressing their primary concern

Patients presented with four main areas of concern: symptomatic relief, finding a diagnosis, receiving tests, and rapidly progressing through the emergency department. In general, if these concerns were not addressed by their physician, the patient expressed dissatisfaction with their ED visit. As patient satisfaction remains a poorly defined concept, for the purposes of this study we have defined it as satisfaction with respect to the overall lived experience in the ED and testing expectations mediated by personal values and preferences.[14]

Symptomatic relief.

Patients were most concerned about chest pain and shortness of breath, with pain being the most common concern. When asked about the goal of their ED visit, symptomatic relief was stated as a priority. "Relieving the symptoms, of course, is right at the top of the list" (patient 23). Symptomatic relief was also mentioned when patients were asked about the most unsatisfactory part of their ED visit. One patient said: "normally waiting wouldn't bother me, except [I] can't breathe because it is too painful, so waiting is hard" (patient 20). Patients expressed frustration when they did not know when their symptoms would be addressed by a physician. One patient said: "I waited here for over an hour and a half in pain and agony with my IV empty. I know they are busy and understaffed, but I asked if I could get an answer and they keep saying 'Oh someone's coming, someone's coming'" (patient 9).

Finding a diagnosis.

Participants expressed that their physician's main role was to find a diagnosis. One patient said that their main goal was: "to get checked out and find out what's going on…what's the reason for the shortness of breath and the pain" (patient 11). "I find [that] my family doctor is there to get you in and get you out as quick as possible and doesn't care. At least [the ED doctor] is gonna get down to what's going on" (patient 13). These quotes emphasize the fact that patients seek care in the ED specifically to find a diagnosis. Many patients believed there must be a clinically important reason to explain their symptoms, and would not be satisfied receiving no diagnosis: "If I don't [have] pain from [a] blood clot, find another reason" (patient 8).

Receiving tests.

Patients felt they had been prioritized by the ED when they had a greater number of tests. Multiple tests made them feel their emergency physician was "doing something" about their case. One patient said that the most satisfactory part of their ED visit was: "that [their ED physician] acknowledged that there was something. No matter how big or how small, they still ran the tests. They made sure

TABLE 2 Themes and subthemes from patient Interviews.

Theme	Subthemes	Illustrative quotes
Patient satisfaction comes from addressing their primary concern	Providing symptomatic relief	"Relieving the symptoms, of course, is right at the top of the list" "Normally waiting wouldn't bother me, except [I] can't breathe because it is too painful, so waiting is hard" "I waited here for over an hour and a half in pain and agony with my IV empty. I know they are busy and understaffed, but I asked if I could get an answer and they keep saying 'Oh someone's coming, someone's coming'"
	Finding a diagnosis	"I want to know what happened" "If I don't [have] pain from [a] blood clot, find another reason [for the pain]"
	Getting tested	"[Satisfaction came from] the level of tests that the [doctor] put me through…It wasn't just one test he did, [he did] the scan, the ultrasound, chest X ray, blood work" "that [their ED physician] acknowledged that there was something. No matter how big or how small, they still ran the tests. They made sure that there was something and validated that I wasn't losing my mind"
	Getting rapid treatment	"[The ED visit was good. It was faster today. I don't know if that was because of what I was getting done, or if it was just circumstantial. Time is a good thing"
Patients prefer imaging over clinical examination when testing for PE	Patient-perception on high accuracy of CT scan	"[A] CT scan takes out all the guess work" "All I [can] tell you is 'I have pain here, and I have pain here', but [the ED physician doesn't] know exactly where I have pain because there is too much inside. There is a kidney and everything is inside. Only [a] CT scan can see what exactly is the problem"
	Clinical examination is insufficient when ruling out a clot	"I'd want the CT…[to avoid] human error" "I think [a clinical examination and a blood test] is effective…but go further so [the ED physician can] pinpoint where [the blood clot] is… and the CT scan can define where it is"
Patients expect 100% confidence when given a diagnosis	Expect absolute certainty when given diagnosis/no diagnosis	"Doctors aren't supposed to lie"
	Require ERP to conduct multiple tests in order to be 100% confident in the final diagnosis	"The doctor would need more tests [in addition to a CT] in order to be [100%] accurate, they cannot rely on just one" "[100% certainty comes from] the level of tests that the [doctor] put me through…It wasn't just one test he did, [he did] the scan, the ultrasound, chest X ray, blood work"
	Willing to seek a second opinion if expectations are not met	"I probably would try to reason with him, first of all. And if nothing came about it, then I would go to my family doctor and say that I want that test done, and I have a right to that test."
Patients expect individualized care	Direct communication with ERP about specific concerns	"I would need the doctor so I can ask my own questions…[visual aids are] good, but everybody learns differently, and for me, it doesn't help" "[I have] a recent history of a stroke, of PFO, and each time [I] come to the emergency it is like nobody knows anything about that, so there is a bit of a disconnect"
	Expect case-specific testing/treatment	"Different, because I'm different" "Well the thing is, if the doctor explained to me why [a test] wasn't needed, then I would be fine"

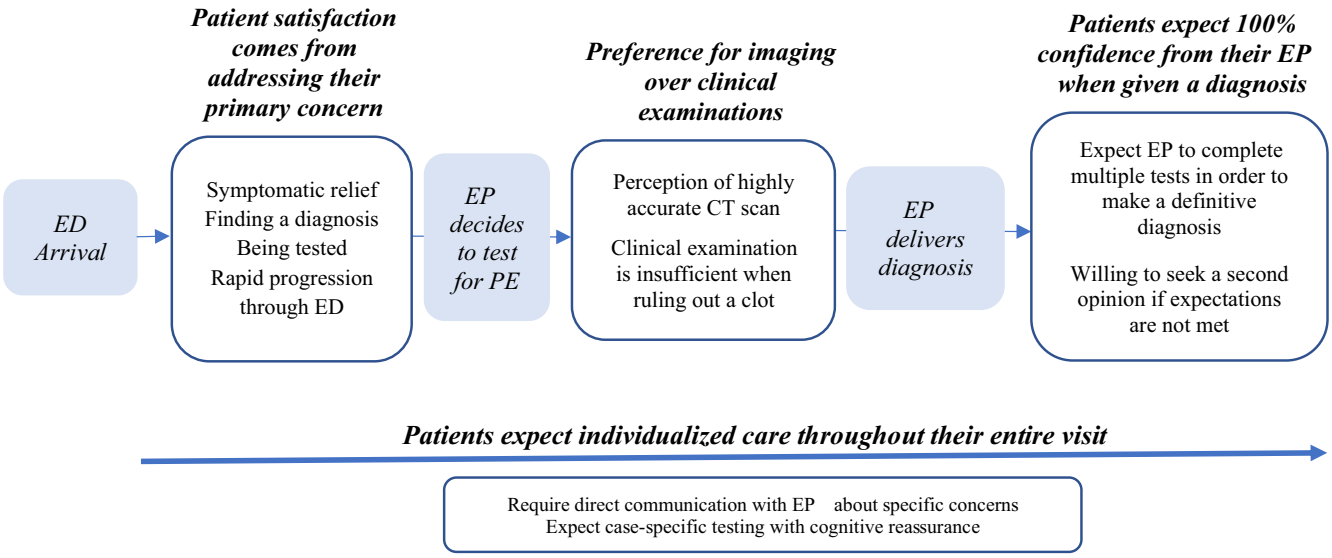

FIGURE 1 Conceptual model illustrating patient-specific values and expectations when tested for pulmonary embolism in the ED. Major themes are listed in bold, and their associated subthemes are listed in the boxes below. Abbreviations: ED, emergency department; ERP, emergency room physician; CT, computed tomography

that there was something and validated that I wasn't losing my mind" (patient 18). In these cases, patients felt that receiving multiple tests justified their ED visit because it meant that the symptoms the patient perceived to be serious, were legitimate. Some participants were focused on their heart and said they would only be satisfied with their visit if their heart was tested. When the researcher described PE to a patient with a previous heart condition, the patient said "I'm not too concerned about my lungs…as long as my heart is checked out, I'll be okay" (patient 14).

Rapid progression through the ED.

Rapid progression included: fast transfer from waiting room to hospital bed; short waiting time to see a physician or nurse; and short intervals between subsequent tests. Many patients mentioned that the rapidity of their ED assessment was the most satisfactory part of their ED visit: "They got at me right away. I didn't have to wait at all…Time is a good thing" (patient 7). Conversely, patients who were dissatisfied due to long wait times also expressed this as a primary concern. One patient said that her physician made her wait too long, which meant that her physician "[didn't] seem to take [her case] too seriously, they seem to take it too lightly" (patient 27).

Theme 2: Preference for imaging over clinical examinations

Perception of highly accurate CT scans.

Patients were asked if they would accept clinical examination and blood testing to rule out a PE diagnosis, or if they should receive a CT scan. Almost all patients said that they would prefer a CT scan over clinical examination and blood testing, even when the latter option could rule out PE with 99% certainty. This was largely because they felt that CT scans were 100% accurate in confirming a PE diagnosis. They felt that a CT scan are expensive machines that would be able to "show" a clot, whereas a clinical examination and a blood test would not. One patient said: "All I [can] tell you is 'I have pain here, and I have pain here', but [the ED physician doesn't] know exactly where I have pain because there is too much inside. There is a kidney and everything is inside. Only [a] CT scan can see what exactly is the problem" (patient 8).

Clinical examination is insufficient when ruling out a clot.

When first asked if clinical exams and blood tests were effective in ruling out a clot, patients felt that these examinations would be inferior to an imaging test. One patient mentioned: "I'd want the CT…to avoid human error" (patient 3). Patients felt that additional testing was needed to make a more definitive diagnosis: "I think [a clinical examination and a blood test] is effective…but go further so [the ED physician can] pinpoint where [the blood clot] is… and the CT scan can define where it is" (patient 10). As the interview went on, patients were informed that examination findings and a blood test can exclude blood clots with 99% certainty. In response to this, many patients said that if this reasoning was provided by their doctor, they would be okay without the scan. This led to the emergence of themes relating to confidence in their physician (Theme 3) and perceptions of personalized care (Theme 4).

Theme 3: Patients expect 100% confidence from their emergency physician when given a diagnosis

When patients were asked how certain their physician should be when assigning, or not assigning, a PE diagnosis, most patients said they would accept only 100% certainty (6/30 patients responded that they didn't know how certain their physician should be when

giving a diagnosis). Further questioning on this topic lead to the following two subthemes:

Patients expect their ED physician to conduct multiple tests for a definitive diagnosis.

Receiving multiple tests in the ED was described as the most satisfying part of an ED visit because it meant their evaluation was thorough. When one of the patients was asked how the physician can be 100% certain, they said that it was because of "the level of tests that the [doctor] put me through…It wasn't just one test he did, [he did] the scan, the ultrasound, chest X ray, blood work" (patient 12). Multiple tests suggested the physician had checked everything. There were contradictory beliefs in that patients were aware CT scans were not 100% accurate for diagnosing PE, however continued to expect 100% accuracy from their physician when given a diagnosis. One patient explained this viewpoint by saying "the doctor would need more tests [in addition to a CT] in order to be [100%] accurate, they cannot rely on just one" (patient 17).

Willing to seek a second opinion if expectations are not met.

Some patients expressed that they would be unsatisfied with their diagnosis if their physician did not order enough tests, or if they felt that their physician could not be 100% confident in their diagnosis. In these cases, patients sought a second opinion. When one patient was asked what they would do if they received no diagnosis, they said: "I would get a second opinion to be sure" (patient 26).

Theme 4: Patients expect individualized care throughout their entire ED visit

Throughout all stages of the ED visit, patients unanimously expected care to be specifically tailored to their needs and circumstances.

Direct physician communication.

All patients emphasized the need to communicate with their physician throughout their ED visit. Specifically, many patients mentioned how a discussion with their doctor was the only way to guarantee that the physician had accurate information on their past medical history. For example, one patient had said "[I have] a recent history of a stroke, of PFO, and each time [I] come to the emergency it is like nobody knows anything about that, so there is a bit of a disconnect" (patient 10). A discussion with the physician verifies that their physician has all the required information.

Expectation of case-specific testing with cognitive reassurance.

Patients generally did not accept the idea of standardized testing – where other patients with similar signs and symptoms would receive the same tests and treatment. The majority felt that they were different, or an "exception to the rule" (patient 21) and standardized tests may not apply. For example, one patient said that: "[Testing should be] different, because I'm different" (patient 13). Cognitive reassurance or explanation and education from the physician was needed in order to verify that the testing had been case-specific. These explanations were heavily valued by all patients as it made them feel like their physician critically thought through their specific case. When asked what they would do if their doctor disagreed with their testing expectations, one patient said: "Well the thing is, if the doctor explained to me why [a test] wasn't needed, then I would be fine" The explanation assures the patient that the physician's decision to not order a test was specific to their case.

DISCUSSION

In this qualitative evaluation of patients' values and expectations around ED PE testing, we found four common themes: 1) patient satisfaction comes from addressing their primary concern; 2) patients prefer imaging over clinical evaluation; 3) patients expect 100% confidence from their physician when given a diagnosis; and 4) patients expect individualized care throughout their ED visit. Our conceptual model demonstrates these themes are intertwined throughout the course of a patient's ED visit.

Our findings are congruent with Vaillancourt et al., who interviewed 46 people assessed in the ED for a diverse array of presenting symptoms.[15] Our studies shared three similar themes: the search for a diagnosis, the need for symptomatic relief, and expectation of testing. Both studies found patients attend the ED to obtain a diagnosis and are discontented if no diagnosis is found or diagnostic uncertainty is communicated. Care expectations included being able to understand why they had symptoms. If this need was not fulfilled, patients said they would visit another ED. Bhise et al. demonstrated that patients perceive their physician to have lower technical competence and trust their physician less when told their physician did not know the cause for their symtpoms.[16] Vaillancourt et al. found patients valued other aspects of the ED visit, including symptomatic relief, especially relief from pain, making the point that persistent pain after discharge caused patients to worry more about their condition. They also noted patients expected to have multiple diagnostic tests, which patients viewed as a diagnostic aid for their physician. We found that patients equated more testing to reduced diagnostic uncertainty. Several existing conceptual frameworks that describe ED patient experiences and determinants that influence their perceptions of care emphasize our themes/subthemes, including: symptomatic relief, wait times, and direct communication with physicians.[4-6]

These findings are at odds to the emergency physician's perception of their role. Emergency physicians define themselves as experts who quickly spot dangerous conditions,[11,17] rather than physicians who counsel patients why they do not need a chest scan or who explain potential causes of chest pain when no physical diagnosis can be made. Most evidence-based diagnostic advances have focused on reducing imaging use in the ED, with movements such as Choosing Wisely encouraging physicians to limit advanced testing to a subset of patients who will benefit from it (for example restricting CT pulmonary angiography to those with a high Wells score or positive D-dimer).[18] Limiting access to imaging is contrary to patient expectation and requires the physician to provide cognitive reassurance which takes time. A study conducted by Dainty et al. suggested that integration of solutions that may increase time spent

counseling patients may require a shift in emergency physician culture.[17] Evidence-based medicine introduces further discord by quantifying the false negative rate associated with excluding PE without imaging. Research papers frequently state that a post-test probability of PE of less than 2% is acceptable for exclusion of PE,[19] however our study highlighted that patients expect complete confidence from their physician when they are told they do not have PE. We found multiple such gaps exist between patient expectations and contemporary emergency medicine, which ran contrary to physician training, existing guidelines, and diagnostic tools. Paradoxically, as reported in a study by Rising et al., poor expectation fulfillment can lead patients to present several times to the ED.[20] So, if CT scanning is not offered and patients are not provided with cognitive reassurance that imaging is not clinically indicated, cost savings could be offset by the cost of subsequent visits.

How should emergency physicians address this gap? Lin et al. compared patient-ratings for 11 physician opening phrases among patients who were considered likely to have a negative CT scan.[21] They found the most popular patient-rated ED physician phrase was "I have carefully considered what you told me and what brought you here today" over phrases mentioning examination findings, research findings, side effects, or cost of CT scanning. We found that patients looked for reassurance during long wait times when there were limited interactions with their physician because they often felt their case was not being taken seriously. Blackburn et al. found patients valued being kept regularly informed of their ED progress, thorough treatment explanations, and written communication of information,[22] which suggests that some of this work could be shared by nurses and other ED professionals. Examples of advances in information sharing include shared decision-making tools or apps. Such tools increased parent knowledge and reduced health care utilization for minor head injury in children,[23] and increased patient involvement without additional encounter time in atrial fibrillation'.[24]

LIMITATIONS

Our study has inherent limitations. The exploratory nature of qualitative research allows us to identify patient expectations and values to generate hypotheses and inform future studies focused on PE testing in the ED. However, qualitative research does not allow us to test these hypotheses. In this study, we included 30 patients of different ages, genders, time of day, and experiences with PE testing. Patients who were not interested in participating in the research study may have had different preferences and values to those included. Patients were not followed past their ED visit to gauge whether their expectations shifted post-discharge and/or if they visited another ED.

Although we reached thematic sufficiency, the sample is small and the study was conducted in two Canadian emergency departments. Furthermore, this study describes patient satisfaction with respect to expectation fulfillment. In current literature, satisfaction in the context of a patient's perception on the overall quality of service in healthcare remains poorly defined. Thus, broader conclusions on patient satisfaction cannot be made.[25]

CONCLUSION

We identified patient-specific values, preferences, and expectations for PE testing in these qualitative interviews highlighting communication and expectation gaps in the physician-patient relationship that present as barriers to patient-centered care for PE testing in the ED. The broader implications of our findings are two-fold. Firstly, future research should focus on which emergency staff behaviours and information adjuncts bring greater satisfaction for ED patients. Secondly, researchers could ensure successive advances in research evidence are congruent with ED patient values by adequately engaging ED patients at the hypothesis development stage of future research.

CONFLICT OF INTEREST

VS reports no conflict of interest to disclose.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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