

**EXPLORING PATIENT-CENTERED CARE IN THE EMERGENCY DEPARTMENT
THROUGH PATIENT ENGAGEMENT AND SYSTEMATIC REVIEW**

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Abstract

Patient-centered care (PCC) is an emerging priority in many healthcare settings but its methods lack clarity in the emergency department (ED). It is of interest to know what PCC practices are most important to patients to better their experience. The objective of this thesis is to explore PCC in the ED, its components, challenges, and benefits. We used patient engagement throughout the study, consulting with clinicians, subject-matter experts, patient partners and organizations to reflect patients' needs. We did a systematic review of articles in the ED context that had elements of PCC. Two independent reviewers screened 3136 articles and 13 were included. Meta-ethnographic analysis was conducted to determine common themes of PCC: emotional support, communication, education, involvement of patient/family in information sharing and decision making, comfort of environment, respect and trust, continuity and transition of care. Challenges in the ED reflected a lack of PCC. Moreover, implementation of PCC had many benefits including higher patient satisfaction with their care. Though there were commonalities of PCC components, there was no consistent definition for PCC in the ED. The findings of this review support the evidence that PCC is of high value to the ED setting and should be standardized in practice.

General Summary

Patient-centered care (PCC) is a method of providing care to patients that focuses on mutual respect, building relationships between patients and care providers, sharing in the decision-making process, and takes into account patients' spiritual and mental health needs. Understanding PCC from the point of view of patients is essential to ensuring that patients needs are being met. Through conversations with patients and community organizations, we developed a research question that examined PCC in the emergency department (ED). We conducted a systematic review of the literature and found the overarching aspects of PCC in the ED include communication, education, emotional support, respect and trust, comfort of environment, involvement of patient/family in information sharing and decision making, continuity and transition of care. The challenges in EDs represent a lack of PCC and the benefits increase patient satisfaction. By implementing better PCC, we can create a more patient-centric ED environment.

Acknowledgements

I acknowledge that Chapter 2 of this thesis has been registered as a systematic review protocol in the PROSPERO database, and Chapter 3 of this thesis has been submitted for publication in BMJ Emergency Medicine Journal.

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Abbreviations

PCC: patient-centered care

ED: emergency department

SUPPORT: Support for People and Patient-Oriented Research and Trials

SPOR: Strategy for Patient-Oriented Research

CIHR: Canadian Institutes of Health Research

JBI: Joanna Briggs Institute

CHAPTER 1. The Patient-Centered Emergency Department: Engaging Patients in a Systematic Review

1.1 Thesis Style and Structure

This thesis will follow the guidelines for the manuscript style of presentation. The current chapter describes the flow of this thesis and the objectives of the chapters. It also describes the methods of patient engagement that were used for this thesis. It intends to provide a primer for the following chapters to make clear to the reader how the objectives and research questions of Chapter 2 and Chapter 3 were shaped and developed through patient engagement. Chapter 2 is a systematic review protocol examining patient-centered care (PCC) in the emergency department (ED), the challenges and benefits of providing PCC, and the impacts of PCC. It has been registered in the PROSPERO database of systematic review protocols. Chapter 3 is the completed systematic review that was outlined in the Chapter 2 protocol, and describes the context, search strategies, data extraction, data analysis, results, and discussion. It has been submitted for publication in BMJ Emergency Medicine Journal. The Summary chapter at the end of this thesis concludes the study, provides a summary of the findings, and outlines possible clinical implications.

1.2 Study Objectives

The objective of this thesis is to explore PCC in the ED by using patient engagement to determine what factors of PCC are most important to patients who attend the ED, what methods of PCC are currently being used in ED settings, and if patient needs align with the commonly used components of PCC.

1.3 Co-Authorship Statement

All authors substantially contributed to the conception of this thesis. The thesis author (AW) developed the proposal, research question, study design, screened all literature for eligibility, extracted, analyzed, and interpreted the data, and provided an early draft of each chapter in this thesis. Dr. Shabnam Asghari (SA) is a methodology expert and made significant contributions to the development of the research question and design, methodology, study eligibility, data analysis and interpretation, and manuscript development. Dr. Chris Patey (CP), Dr. Holly Etchegary (HE), and Ms. Dorothy Senior (DS) made important contributions to the proposal, research question, study design, interpretation of results, and manuscript development. Ms. Elnaz Bodaghkani (EB) was essential to the development of the protocol, carrying out the eligibility screening process as a second reviewer for the systematic review, contributing to data extraction, analysis, interpretation, and manuscript development for Chapters 2 and 3. Ms. Lindsay Alcock (LA) also played a key role in refining and conducting the literature search, providing library support throughout the development of the study, and contributing to the manuscript development of Chapters 2 and 3.

1.4 Background of Patient Engagement in Research

Patient-oriented research is becoming a widely accepted norm for approaching issues within the healthcare system.¹⁻³ It is a method that “engages patients as partners, focuses on patient-identified priorities and improves patient outcomes” with the aim to “apply the knowledge generated to improve healthcare systems and practices”.⁴ In Canada, the Canadian Institutes of Health Research (CIHR) has made patient participation a priority by creating local Support for People and Patient-Oriented Research and Trials (SUPPORT) units that have

specialized knowledge in patient engagement initiatives and are equipped to help patients participate in research activities.⁵ Active participation of patients in research has many benefits, including direct applicability of the research and improvement in rates of study enrollment.⁶ It is further associated with positive changes in the attitudes of organizations and positive experiences from participating patients.^{7,8}

Although patient engagement has been seen largely in the beginning phases of research projects,⁶ patients can be involved in all levels of research from conceptual development to dissemination of results. Because patient engagement creates a collaborative opportunity for researchers, patients, clinicians, and other stakeholders, it allows the resulting research to have practical implications that have taken into consideration various perspectives. It is even better if there has been involvement of all collaborators at each stage of research decision-making.⁹ Thus, it is important for research teams to consider patients needs to stay involved and be flexible and accommodating to help make it feasible.

Some well-known strategies for conducting patient engagement in research are outlined by the CIHR's Strategy for Patient-Oriented Research (SPOR)¹⁰ in Canada and the Patient-Centered Outcomes Research Institute in the United States.¹¹ The SPOR patient engagement framework identifies successful patient engagement as that which includes a safe environment of mutual respect and honest conversations, patient involvement at all levels of research, shared leadership, capacity building, experiential knowledge valued as evidence, recognition of patients' needs, and a shared sense of purpose. There are also four essential pillars of patient engagement: patient initiation, building reciprocal relationships, co-learning, and reassessment and feedback.¹² Initiation allows patients to participate in the research process. Building reciprocal relationships treats all individuals as equal partners in research. Co-learning is a

process whereby researchers and patients learn from each other. Re-assessment and feedback involve routinely consulting with patients and making improvements in accordance with their input. These foundations are highly important because they represent a standard for patient engagement activities and can be used to guide the process of patient engagement so that it is meaningful and equitable for both patients and researchers.

Patient engagement can be implemented in many types of healthcare studies; however, one that is largely undocumented is the process of involving patients in conducting a systematic review. It has proven to be difficult to find reviews that include patient or public partners, stakeholders, and others as co-authors when there is no universal identifier for these studies.¹³ Furthermore, the methods used to involve patient partners and other contributors in the review process and what their contribution was are often unexplained.¹³ The results of a previous study called into question the impact that patients could make to a systematic review.¹⁴ Despite the limited evidence on standard practices for this type of research, there have been successful outcomes and lessons learned shared in the literature.¹⁵ Because patients partners are so important to provide relevant perspective, patient engagement should not be dismissed particularly for reviews of topics that are impactful to patients in the healthcare setting.

1.5 Patient Engagement and Patient-Centered Care

While patient engagement is driven through research, PCC is an activity that is a subject of research. PCC is widely defined as providing care that is responsive to patients' needs, building mutual respect between patients and healthcare providers, and involves the patient in the decision-making process surrounding their care and treatment.¹⁶ Patient engagement is sometimes used as an interchangeable term for PCC, but in reference to the engagement of a patient in their own treatment plan or care.¹⁷ It is important to note the difference between patient

engagement in research and patient engagement in treatment. Examples of patient engagement in treatment would include research where patients are the subject of study (e.g., examining patients' adherence to care plans) rather than partners on the research team. For the purposes of this thesis, patient engagement refers to patient-oriented research and involving patient partners as researchers. More detail on PCC can be found in Chapter 3.

1.6 Involving Patients in our Systematic Review

Our research team sought to investigate what aspects of the ED experience were important to patients. The goal was to conduct a systematic review around a topic that was determined by patient feedback and perspective on ED issues. To do this, we conducted patient engagement with patients, family members and advocates who have attended the ED to determine what could be changed about the ED environment to improve their care experience. We continued to engage with these patients as partners on our research team throughout the study to gain their experiential knowledge and check that our findings aligned with their perspectives on patient priorities. Patient engagement is a vital tool for determining the priorities that are most important to patients in the ED setting so that we can ensure the systematic review considers the aspects that are most relevant. The current chapter describes the process of engaging patients for the systematic review and the results of their participation.

1.6.1 Who to Involve

The people we sought to be involved in the systematic review were people who have lived experience attending the ED to seek care. It is also valuable to talk to caretakers, friends, or family members who have taken their loved one to the ED for treatment so that we can gain different, but equally important, perspectives.

It is ideal to attempt patient engagement through all of the four key areas previously identified by Vat, Ryan, and Etchegary¹⁸: social marketing; community outreach; health system; partnering with other organizations. The main method used for this initiative was partnering with other organizations. By connecting with Newfoundland and Labrador SUPPORT and the SurgeCon team interested in improving ED efficiency in the province,¹⁹ we were able to recruit a patient partner with previous ED experience to be a team member. In Newfoundland and Labrador, two prominent organizations that provide support to clients who would be likely to access ED services include the Canadian Mental Health Association Newfoundland and Labrador Chapter and the Consumers Health Awareness Network of Newfoundland and Labrador. By contacting these community organizations via email, we were able to speak with representatives of the organizations about the topic of research and ask for their involvement. Finally, for dissemination of results and feedback, we consulted with the SurgeCon¹⁹ patient engagement working group which is made up of researchers and patient partners exploring ED management and efficiency who can provide additional perspective on ED experiences.

1.6.2 When to Involve

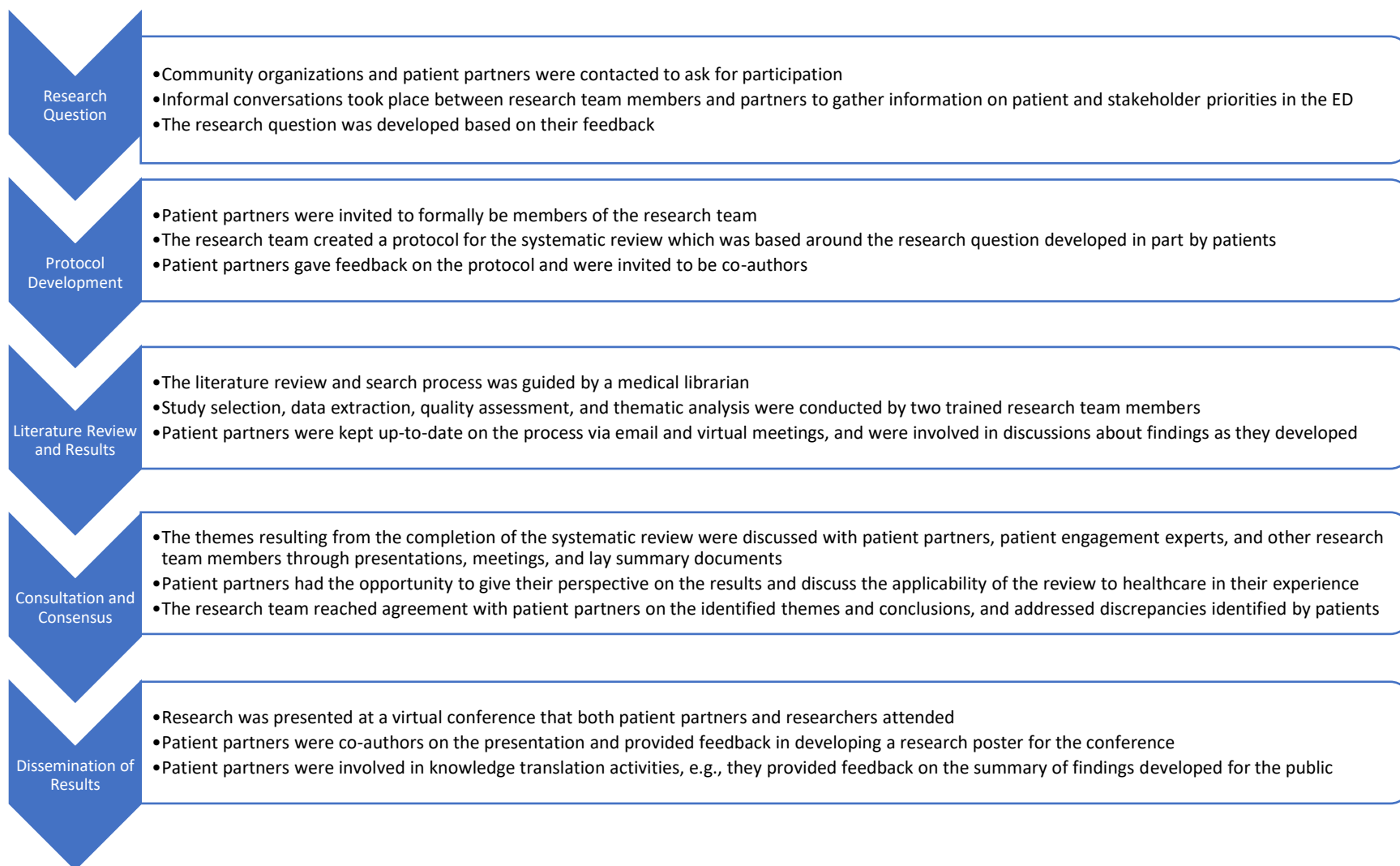
By recruiting patient partners at the beginning of the study, they can be involved throughout the entire study. They can decide what they are most comfortable being contributors to but are provided the opportunity to attend team meetings about project updates and contribute to any part of the research process including planning/proposal, data collection, writing, or dissemination. Since the question at hand is one of determining what matters most to patients so that we can apply that to a systematic review, patient partners were invited before the research began to help develop the research questions. Having patient involvement throughout the project will be equally as important. This way, we can ensure a project stemmed from their experiences

follows through to protect the integrity of that idea, while also being dynamic as the results develop.

1.6.3 Patient Engagement Activities

The activities ranged to reflect the level of involvement that the partners had (Figure 1). Since patients were not involved in the technical aspect of the review (e.g., screening studies and determining what PCC is in the literature), there were no training sessions provided. This also ensured that the experiential knowledge and feedback we received from patients was not primed by other research findings. The patient partner was consulted via email and through team meetings to provide perspective that helped to shape the research project throughout the course of the study. For the community organizations, we set up meetings to have open conversations with their representatives, separately, and let them lead the conversation to explore topics surrounding ED care that they felt were important to them and patients they work with. These meetings occurred during the research question development phase. Members of the research team took notes, but the meetings were not recorded or transcribed because patient partners are research team members rather than subjects of study. Their input was used in comparison with the feedback already provided by the patient partner and was compiled to create a concept that would be the focus of the systematic review. The patient engagement working group is comprised of research team members, patient partners, and committee members for this thesis and they were therefore involved throughout the entire process of study development, protocol development, results, and dissemination. Their feedback and discussion were received during working group meetings and via email responses on documents. Their comments were used to reflect real-world perspective and agreement or disagreement with the results of the study.

Figure 1. Pathway of patient and public involvement in the study.



The input from both the community organizations and our patient partner was used initially to inspire the research topic. Additionally, as a team member, the patient partner helped to shape the research question, selection of key words, provided input on context, gave feedback on the findings, and helped to develop key messages for knowledge translation and dissemination. The patient partner had significant involvement and was actively involved in conference abstract review, included as a co-author on all materials submitted to conferences, attended virtual conferences, and gave feedback on the development of a manuscript to be submitted for publication. The patient engagement working group members provided further perspective that helped contribute to valuable discussion points and differences between what is important to them in the ED and what was found in the literature.

1.7 Implications for Research Design

The patient engagement activities in this project served a strong purpose. First and foremost, the objective was to discover what aspects of the ED care experience were most important to patients. Many of the issues the patient partner and community organizations brought to light reflected a lack of PCC. This was a highly valuable realization because PCC ultimately became the focus of the systematic review. Furthermore, once it was collectively agreed upon that PCC would be the topic of research, we were able to consult with patient partners to derive appropriate research questions and objectives. This ensured that throughout our examination of PCC in the literature, we were looking for activities, themes, and outcomes that were most relevant and applicable to patients. They were able to share perspectives that reflected various health concerns, such as mental health emergencies, and indicate how treatment differs, thus inspiring a potential subset analysis of PCC for patients with mental health concerns. The value that patient engagement brought to the systematic review cannot be understated.

1.8 Limitations and Considerations

As noted in the literature,²⁰ the ED itself is a setting that presents challenges to patient engagement. Previous studies that have used patient engagement in an ED setting have emphasized that there are contextual differences with the ED as compared to other parts of the healthcare system that can make it difficult to do successfully.²⁰ However, that is not to say that patient engagement cannot be accomplished. In the case of this research project, a valuable lesson learned was to meet patients where they are and use their input at all stages of research. This resulted in successful feedback and engagement throughout the process of the study. Being understanding of patients' levels of interest in involvement and respecting their time is of utmost importance for a trusting partnership in research.

It is vital to have a representative group of patient partners from different backgrounds to get a full picture of their varying experiences. However, patients may not feel comfortable sharing their experiences for fear of sharing health information that is stigmatizing. This may make it difficult to know just how representative a group of patient partners is. It is also possible that being identified and tied to a study about health concerns, particularly regarding emergency care, is something patients do not want to be publicly known. Therefore, it is important to have flexibility and offer involvement in whatever capacity they choose.

1.9 Conclusion

True patient engagement is highly important so that patients receive solutions to issues that are relevant to their population. Too often, decisions are made by health authorities or clinicians who think they understand what patients would want and end up making decisions for them rather than with them. Patients can be involved in all types of research and should be

considered when designing research that centers around their needs. By including patients as partners in this project, it will be possible to make meaningful and clinically applicable change to better experiences for all.

CHAPTER 2. The Impact of Patient-Centered Care in the Emergency Department: A Systematic Review Protocol¹

Anna Walsh, Elnaz Bodaghkani, Holly Etchegary, Lindsay Alcock, Christopher Patey, Dorothy Senior, Shabnam Asghari.

2.1 Introduction and Rationale

This chapter introduces the protocol of the systematic review that has been registered in the PROSPERO database of systematic reviews, registration number CRD42020189752.²¹ It involves five stages and follows the Joanna Briggs Institute (JBI) format for mixed-methods systematic reviews.²² Since the review that was outlined in this protocol has been completed (Chapter 3), the grammatical tense used throughout this chapter has been altered slightly for the purpose of clarity.

The purpose of this protocol is to conduct a systematic review of PCC in the ED; from an initial search guided by the librarian on our research team, we were unable to find any existing reviews on this topic. Providing PCC is a method of engaging patients in their care and forming trusting relationships between patients and care providers. Although patients are often only in the ED for a brief period of time, it is a prime location to use PCC because emergency care requires quick relationship forming and strong communication.²³ Creating a positive and inclusive experience for patients should be a priority; thus, is of interest to know if and how EDs provide PCC and how that care impacts patients.

¹ This chapter has been registered in the PROSPERO Systematic Review Protocol Database.

2.2 Stage 1: Identifying the Research Question

The research question for this study was identified by a team of researchers and clinicians with consultation via patient engagement from stakeholder organizations that support community mental health (Canadian Mental Health Association Newfoundland and Labrador, Consumers Health Awareness Network Newfoundland and Labrador), as well as patient partners. Through discussion with these groups, we have been able to form meaningful research questions and identify factors that influence patient experience and satisfaction in the ED. Many of the values that were identified by patient engagement (e.g., respect from physicians, patient dignity) are consistent with providing patient-centered or person-centered care. Therefore, we are investigating PCC in the context of the ED.

Our research question is best summarized in two parts:

1. What are the components of patient-centered care in the ED?
2. What are the challenges and benefits, as perceived by ED staff and patients, of providing patient centered care in the ED?

2.2.1 Population

Our population of interest was any individual who attends or works at an ED. There was no exclusion based on sex, age, disease, or severity of illness as an ED is expected to serve individuals from all backgrounds.

2.2.2 Phenomena of Interest

The intervention, or phenomena of interest, included patient-centered care. We considered studies that involved patient-centered care, defined as “an approach to practice established through the formation and fostering of therapeutic relationships between all care providers, service users and others significant to them in their lives... underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding.”²⁴ In screening, any article that was related to PCC or included aspects of PCC as identified by this definition was eligible.

2.2.3 Outcomes

The outcomes of interest in individuals who attend an ED included any measures of patient satisfaction (e.g., perceived treatment by ED staff, patient concerns or perception) with regard to their overall ED experience. The outcomes of interest from ED staff included any measures that relay their experience with providing patient-centered care in the ED (e.g., challenges and benefits) with regard to providing patient-centered care.

2.2.4 Context

This review considered studies that took place in the context of an ED, as identified by the study team. We did not limit our search to a particular area of the ED or a specialized ED. There was no restriction on geographic location.

2.3 Stage 2: Search Strategy

Significant terms from the research question and possible synonyms/alternate terms were compiled for the search. Examples of related terms include "patient participation" OR "patient engagement" OR "patient centered care". Medical Subject Heading (MeSH) terms were utilized,

as well as any relevant terms from key words of existing references. Search terms were searched in combinations, guided by a librarian, to determine the best search strategy. A sample search strategy can be found in Appendix 1.

2.3.2 Search Databases

Search terms were identified and search strategies developed by a medical librarian. The primary strategy (PubMed MEDLINE) was peer reviewed using PRESS²⁵ and translated to search Embase (Elsevier), CINAHLPlus (EBSCO), PsycINFO (EBSCO), and Cochrane (Wiley) (Appendix 1). The reference sections of relevant studies were also examined for any additional references. The original searches were completed on June 6, 2020 and rerun on December 2, 2020.

2.3.4 Directory of Identified Studies

Memorial University's Library Services provided access to Covidence where all texts included or excluded are documented and tracked for future reference.

2.4 Stage 3: Study Selection

Study selection was an iterative process consisting of searching the literature, refining the search strategy, assessing articles for eligibility criteria, pre-screening the titles and abstracts, and reviewing the full text for inclusion. Selection of studies occurred in three stages as outlined below. Only articles that pertained to ED patient-centered care and/or patient engagement were retained.

2.4.1 Types of Studies

This review considered quantitative studies (e.g., observational studies, interventional studies), qualitative studies (e.g., ethnography, grounded theory, case studies, phenomenology) and mixed methods studies. Mixed methods studies were only considered if data from the quantitative or qualitative components can be clearly extracted. Studies included those published in any language, from any point in time until present.

2.4.2 Eligibility Criteria

Inclusion criteria is all literature from peer-reviewed journals and PhD theses. Exclusion criteria included audits or anecdotal information, research in the planning stage, book reviews, commentaries, editorials, conference abstracts, and policy analyses.

2.4.3 Study Selection Process

Pre-Screening. The titles and abstracts of all articles identified by the database searches were examined by two independent reviewers (AW and EB), after duplicates were removed. All articles deemed non-relevant, i.e. not related to the search subject, were removed. Texts that were relevant were recorded for full-text review.

Verification of Results. If there was a large number of articles that resulted from the search, we would randomly select 1% of the excluded articles to re-examine and ensure that all relevant articles are included. If it was found to be true that excluded articles were relevant, all excluded articles would be re-examined.

Full Text Review. All relevant texts were subject to a full text review. Any articles without full texts were noted. All full texts were reviewed by two independent reviewers. The two reviewers

(AW and EB) completed a calibration exercise with the first ten articles. If there had been little agreement between reviewers on relevant texts, the eligibility criteria would be modified. If there were any further disputes over relevance, a third reviewer would adjudicate (SA).

2.5 Stage 4: Data Extraction

Covidence was used to build an extraction tool to extract all necessary identifying information in an iterative process. Of interest is citation information (author names, year of publication, title, type of publication), study population, population subgroups (if applicable), sample size, geographical setting, country, study approach, study design, data collection method, duration of study, and characteristics of patient-centered care or patient engagement involved in the study. Further information related to satisfaction, experience measures, wait times, crowding, ED efficiency, or other outcome measures from each study were extracted if available. The first ten articles were used to validate the data collection tool, at which point any changes to formatting or additions required were made.

2.5.1 Quality Appraisal

The quality of each study was assessed using the scoring system for mixed studies reviews, as outlined by Pluye, Gagnon, Griffiths, and Johnson-Lafleur.²⁶ This allows reviewers to score the studies for their methodological quality. It can be applied to qualitative, quantitative, and mixed-methods studies. All relevant studies that meet the inclusion criteria were included, despite the quality score. This gives an overall picture of the quality of the literature that exists on the topic.

2.6 Stage 5: Data Synthesis and Integration

The JBI convergence segregated approach for mixed-methods studies⁸ was used for data synthesis and integration. This involves separate quantitative and qualitative synthesis followed by integration of the resultant evidence for a “configured analysis”. Quantitative study data should be pooled where possible for a meta-analysis (e.g. reported patient-centered care performance data, patient satisfaction ratings). Qualitative research findings should be pooled where possible using a meta-aggregation approach to generate a set of statements that represent and categorize findings with similar meanings (e.g. reported barriers of performing patient-centered care or patient engagement, patient experiences). Mixed-method studies should be synthesized both quantitatively and qualitatively. The process of combining quantitative and qualitative findings was refined based on the studies and available data. Since a configured analysis was not possible, the findings were presented in a narrative form using meta-ethnographic analysis. Further information on the analysis can be found in Chapter 3.

CHAPTER 3. Challenges and Benefits of Patient-Centered Care in the Emergency Department: A Systematic Review and Meta-Ethnographic Synthesis²

Anna Walsh, Elnaz Bodaghkani, Shabnam Asghari, Holly Etchegary, Lindsay Alcock,
Christopher Patey, Dorothy Senior.

3.1 Introduction

Quality improvement initiatives to help physicians manage an ED often focus on structures, processes, and outcomes – for example, how long a patient waits, the percentage of patients that leave without being seen by a physician, and the volume of patients during the intervention.^{27,28} Although these variables should be considered to create a more efficient ED that benefits the health system, the way in which patients perceive their experience is essential to acknowledge. Of importance are the services and interactions sought and experienced by patients in the ED and how to ensure patients leave with their expectations met.

Patient-centered care (PCC) is an emerging priority in many healthcare settings, yet it has not been incorporated into ED practice in a standard way. PCC is a method of forming trusting relationships between patients and care providers. It is widely defined as a holistic approach to providing care that includes patient involvement, communication, access to services, well-trained staff, and an environment that meets patients' psychosocial, physical, and cultural needs.²⁹ It has previously been explored in many fields of healthcare including, but not limited to nursing,²⁴ cancer care,³⁰ pediatrics,³¹ long-term care,³² mental health,³³ primary care,³⁴ and related areas such as social work.³⁵ PCC requires efforts on all levels including the patient, the provider, and

² This chapter has been submitted for publication to *Emergency Medicine Journal* and is under review at the time of this thesis submission.

the healthcare system³⁶ to ensure it is meaningfully practiced. Effective PCC should help patients and physicians to communicate in a respectful way that both parties understand within an environment that is conducive to appropriate care processes. Previous research demonstrates that when there is dissonance between patients' expectations and the services rendered, there are often components of patient-centeredness missing.³⁷⁻³⁹ PCC and its many components can make a huge impact on patients' experiences when performed properly.

Despite the growing literature on interventions that can be used to make the ED more efficient,⁴⁰⁻⁴³ there are currently no systematic reviews on how EDs include PCC. Thus, it is of interest to know what is most important to patients to better their experience, and how PCC can encompass those elements. The goal of this review is to examine PCC in the ED to better understand how EDs undertake this method and its impacts. The objectives are to determine (1) what the components of PCC are in the ED and (2) what the challenges and benefits of PCC in the ED are, as perceived by staff and patients.

3.2 Methodology

This study follows the strategy of review outlined in the protocol available on PROSPERO (registration number CRD42020189752).²¹ PRISMA 2020 guidelines were used to present the results.

3.2.1 Patient and Public Involvement

To better understand current and previous experiences of patients in the ED, we used patient engagement.⁴ By involving patient partners, the research in question becomes more patient-centered.⁴⁴ We discussed issues and needs with local advocacy groups to gain perspective from those with lived experience and included patient partners on the review team. Figure 1

depicts the process of patient involvement throughout the study from research question development to dissemination.

3.2.2 Search Strategy

Search terms were identified and search strategies developed by a medical librarian. The primary strategy (PubMed MEDLINE) was peer reviewed using PRESS²⁵ and translated to search Embase (Elsevier), CINAHLPlus (EBSCO), PsycINFO (EBSCO), and Cochrane (Wiley) (Appendix 1). Forward and backward citation searches were completed to identify any additional references. The original searches were completed on June 6, 2020 and rerun on December 2, 2020.

3.2.3 Study Selection

The titles and abstracts of all articles identified by the database searches were examined by two independent reviewers after duplicates were removed. Inclusion and exclusion criteria can be found in the protocol.²¹ Reviewers completed a calibration exercise with the first ten articles and reached agreement on inclusion criteria. All full texts were then reviewed. A third reviewer was invited to mitigate any dispute.

3.2.4 Quality Appraisal

The quality of each study was assessed using the scoring system for mixed studies reviews.²⁶ Studies 75% and above were good quality, 50-74% were fair, and below 50% were low. All studies that met the criteria were included, despite the quality score.

3.2.5 Synthesis of Results and Analysis

Two approaches were used for data synthesis and integration. The JBI convergence integrated approach for mixed-methods studies⁴⁵ was used to “qualitize” quantitative studies into textual descriptions to allow integration with qualitative data. “Qualitized” findings from quantitative studies are assembled into categories with qualitative findings based on similarity of meaning. To best determine the categories once all quantitative data was “qualitized”, we used a meta-ethnographic approach. Meta-ethnographic synthesis is suitable for understanding conceptual or theoretical underpinnings of a particular phenomenon.⁴⁶ This approach was selected to help understand what the various components of PCC were and what common components were used across all included studies. It was used to compile information regarding challenges and benefits of PCC and determine overarching categories across the literature. For the purposes of this study, “concepts” are defined as information extracted from the studies that include either direct quotes from study participants or authors’ interpretations of their own results. “Key concepts” are the groupings of similarities and differences across concepts from the included studies after the studies are translated into one another, and “themes” are the third-order constructs that are re-interpretations of the concepts and key concepts determined by the reviewers of this study.

There are multiple phases in meta-ethnographic analysis once relevant studies have been selected.⁴⁶ First, to determine how the studies were related, we extracted common themes, outcomes, and recurring concepts. Next, we translated the studies into one another using reciprocal translation by summarizing the concepts and findings from each of the studies and comparing them against one another. The concepts were separated based on the viewpoint, being

staff or patient/family. To address the research question of challenges and benefits from each perspective, two separate reciprocal translations were conducted, one for healthcare providers and the other for patients and families. To determine the common components of PCC, all concepts were compared to one another using a line of argument synthesis⁴⁶ to identify key concepts reflected in both patient/family and staff perspectives that described PCC activities. This was necessary to reach the next phase, of re-interpreting the relationships between the concepts and further emphasizing the themes. This approach involves “reading through the translations and noting down the similarities and differences”⁴⁶ to compile the concepts into themes and provide new interpretations of the evidence, also known as third order constructs.⁴⁷ Theme interpretation was completed by one reviewer (AW), based on the independent data extractions from both reviewers. All themes were discussed during weekly meetings between members of the research team, including a PCC expert and clinician, patient engagement expert, and methodologist, to reduce bias and ensure consensus was reached. Finally, the synthesis is expressed through tables and narrative format.⁴⁸

3.3 Results

3.3.1 Study Characteristics

The number of studies imported for screening was 3838. A total of 3136 articles were screened in the title and abstract phase, 69 were assessed for eligibility in the full-text phase, and 14 studies were included in the data extraction phase. Reasons for exclusion were no patient-centered care (n=48), setting of intervention outside of the ED (n=7), and full text article was not available (n=1). One study was removed during the extraction phase because the focus of the

article was social services rather than healthcare, despite being in the ED setting, leaving 13 articles for final data extraction and quality appraisal (Figure 2).

Figure 2. PRISMA diagram.

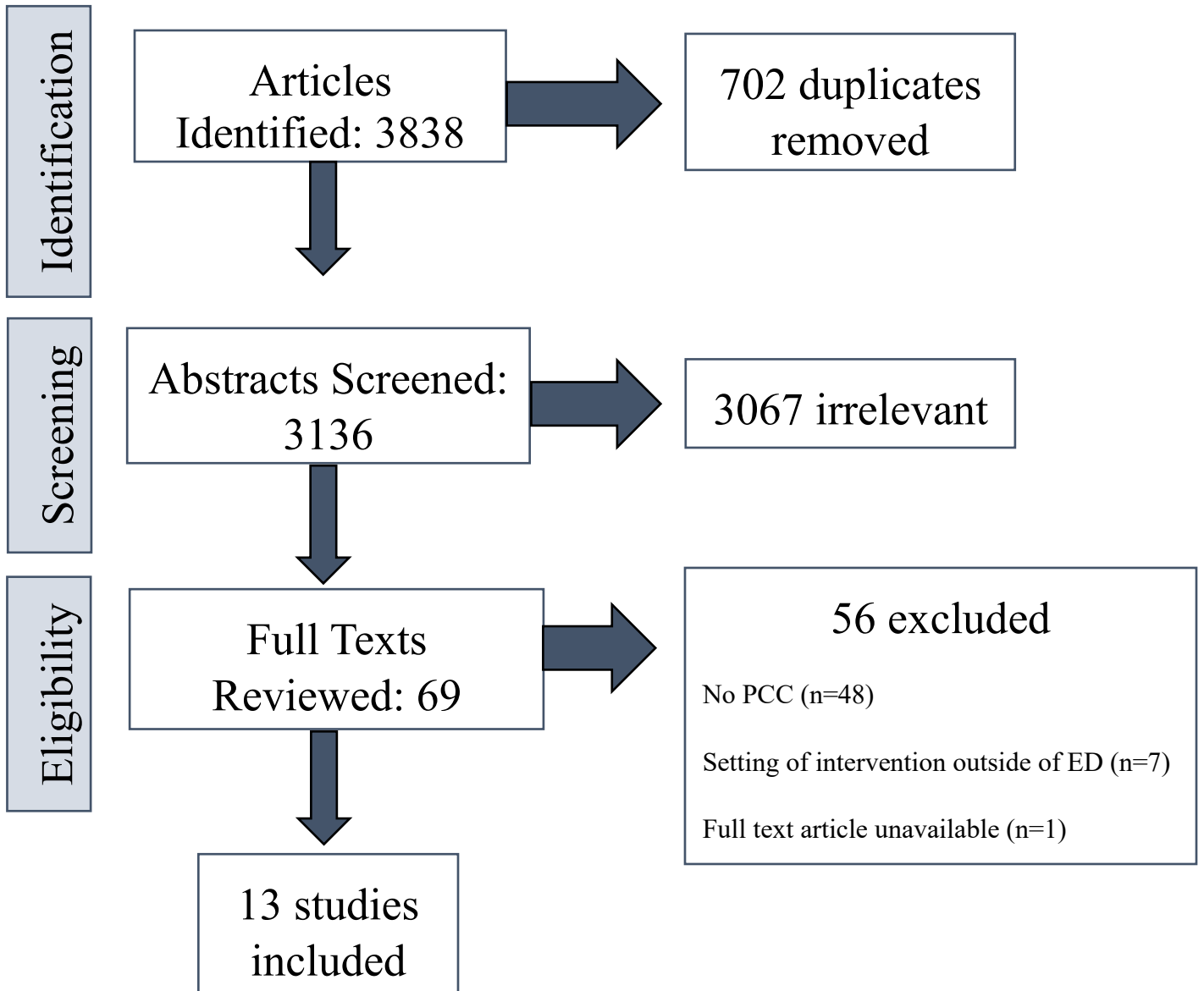


Table 1 demonstrates all study characteristics. Countries of study included the United States (n=4), Canada (n=2), United Kingdom (n=2), Sweden (n=2), Australia (n=2), and Taiwan (n=1). All studies included patient and/or healthcare professional populations that had experience in the ED. Eleven studies included populations related to adult ED care and two studies included populations related to pediatric ED care. While most studies were directly related to the ED setting (n=10), three studies investigated settings that were specialized units adjoined to or having direct impacts on EDs (n=3). The quality scores varied. Six studies (n=6) were considered good quality, six (n=6) were fair, and one (n=1) low.

Table 1. Characteristics of included studies.

Author (year)	Country	Study Objective	Study Design	Study Population	Sample Size	Quality Score ²⁶
Nicholas (2020)	Canada	To determine how patient and family-centered care is demonstrated in the ED for children with autism	Semi-structured interviews	Parents and family members of children with autism spectrum disorder, from two large Canadian EDs; ED-based health care providers	53 (10 physicians, 12 nurses, 31 parents of patients)	75%
Innes (2017)	Australia	To identify the activities and behaviours, including patient-centered care behaviours, of waiting room nurses (WRN) in the ED	Observational study	WRN from two EDs	8 WRN observed across 13 sessions	66.6%
Polveoi (2013)	United States	To compare a traditional resident consultation model with a co-management model, where the psychiatric consultation and liaison service	Prospective cohort study	Patients in a 29-bed urban academic ED between 2007 and 2009	1884 patient visits	66.6%

		assumes full responsibility for providing direct psychiatric care, to reduce length of stay for patients with psychiatric emergencies in the ED				
Frank (2009 B)	Sweden	Interviews to describe patients' perceptions of patient participation in their care in the ED	Phenomenographic study	Patients who attended one metropolitan ED in 2006	9 patients interviewed	66.6%
Frank (2009 A)	Sweden	Interviews to describe care giver's perceptions of patient participation in their care in the ED	Phenomenographic study	Health care providers in one metropolitan ED	11 health care providers (4 registered nurses, 4 auxiliary nurses, 3 physicians)	75%
Rogers (2015)	United States	To determine how the CARES unit, a crisis stabilization unit, influences length of stay and costs for psychiatric patients in the pediatric ED	Retrospective, chart review	All psychiatric patients presenting to the ED of a children's hospital between 2006-2008	1719 patients pre-CARES and 1863 patients post-CARES	66.6%

Wilhelm (2007)	Australia	To examine the effectiveness of the clinic (a novel brief intervention service for patients presenting to the emergency department following deliberate self harm – DSH – or with suicidal ideation) in terms of service utilization and patient and clinician feedback and to explore the correlates of repeated DSH	Retrospective, chart review	Patients with deliberate self harm or suicidal ideation who presented at an emergency department and got a “green card”, a referral to the clinic	456 patients were referred to the clinic	33.3%
Walker (2016)	United Kingdom	To explore nursing interventions for person-centred bereavement care in adult acute and critical care settings; Provide insight into nurses’ experiences of care for the suddenly bereaved; Examine the provision of person-centred bereavement care; Inform the	Descriptive exploratory study	Nurses who work in hospital areas where patient death is common and they participate in bereavement care, e.g. emergency/acute care, critical care, cardiac care	10 (4 emergency care nurses, 4 critical care nurses, 2 cardiac care nurses)	91.6%

		development of person-centredness in practice				
Tretheway (2019)	United Kingdom	To evaluate the activities of the psychiatric decisions unit (PDU) and its impact on the frequency of ED presentations and inpatient admissions, and patient satisfaction with the PDU services	Quasi-experimental study	Psychiatric patients referred to the PDU either by a street triage team or a rapid assessment interface and discharge team	385 patients referred to the PDU; 80 patients provided feedback on satisfaction with the PDU	50%
Zeller (2014)	United States	To assess the effects of a regional dedicated emergency psychiatric facility design – the Alameda Model – on boarding times and hospitalization rates for psychiatric patients in the ED	Cross-sectional	Patients who presented to the ED on an involuntary mental health hold	144 patients	83.3%
Wang (2016)	Taiwan	To explore the medical decision-making process of patients in the ED	Grounded theory, interviews	Patients of an ED between June-December 2011	30 patients interviewed	75%

Heifetz (2018)	Canada	To evaluate communication tools to be used by people with intellectual and developmental disabilities (IDD) in psychiatric and general EDs in three regions of Ontario, Canada	Descriptive study, evaluation	Stakeholders (e.g. hospital staff, community agency representatives, families) and individuals with IDD	18 stakeholders completed interviews 28 caregivers, parents, and individuals with IDD completed feedback questionnaires	58.3%
Owens (2006)	United States	To define exposure to intimate partner violence (IPV) among adult female patients in emergency psychiatric settings and the relationship between the dependent variable of disclosure of IPV in a psychiatric emergency setting to clinical staff and the independent variable of perception of the provider by respondents	Descriptive, exploratory	Adult women who present for emergency psychiatric evaluation who have experienced a form of IPV	216 patients	75%

3.3.2 Defining Components of Patient-Centered Care

Descriptions and definitions of PCC were extracted from all included articles (Table 2). Five articles had directly stated definitions or descriptions of patient-centered, person-centered, family-centered care. The other nine articles did not describe their activities using PCC-related terminology but were still included due to the presence of PCC components. The most cited components of PCC in the literature, and thus the themes of PCC, were comfort of environment (n=8), communication (n=7), education (n=7), involvement of patient/family in information sharing and decision making (n=7), respect and trust (n=7), continuity and transition of care (n=7), and emotional support (n=5) (Figure 3; Table 3).

Table 2. Definitions of PCC and key findings as identified by the included articles.

Author (year)	Description of PCC	Comparison Group	Key Finding
Nicholas (2020)	(1) dignity and respect (listening to families and incorporating their values, knowledge and beliefs in care), (2) participation (families are encouraged to participate in care and decision-making to the level they choose), (3) collaboration (families are involved in care delivery, institutional policy and program development, and (4) information sharing (timely, complete and accurate information shared with families).	No comparison	Patient and family-centered care in the ED for children with autism spectrum disorder is strongly recommended and beneficial for patients, family, and staff.
Innes (2017)	Patient centered care was given to patients by being respectful, empathetic and sincere when listening to patient histories; ensured that patients and families were involved in all discussions and decisions relating to their presentation and plan; clarify unclear points and use language/terminology appropriate for specific patients.	No comparison	Therapeutic engagement of emergency nurses with patients in the waiting room allowed them to deliver patient-centered, holistic, supportive and informative care.
Polveoi (2013)	Patient centered care was reflected in the coordination of services (continuity of care) provided to patients in the ED, and access to psychiatric services in the ED through staff collaboration.	Traditional resident consultation model compared to new co-management model	The co-management model marked a reduced length of stay for all psychiatric patients and a decrease in the number of

			patients who left without being seen.
Frank (2009 B)	Patient participation is a component of patient-centered care. Patient participation was defined by authors as having the right and duty to participate individually and collectively in the planning and implementation of their health care; it requires that formal health carers are willing to focus on the interpersonal relationship between patients and carer, as well as having an attitude that enables patients to relate to them as subjects taking part in care	No comparison	Patients go through different stages of participation in care and have different needs for participation. This has important implications for ED staff in practice.
Frank (2009 A)	Patient participation is a component of patient-centered care. Patient participation was defined by authors as having the right and duty to participate individually and collectively in the planning and implementation of their health care; it requires that formal health carers are willing to focus on the interpersonal relationship between patients and carer, as well as having an attitude that enables patients to relate to them as subjects taking part in care.	No comparison	Patient participation is conditional of the healthcare providers or caregivers. It is most often circumstantial, and difficult for caregivers when dealing with aggravated patients.
Rogers (2015)	The CARES unit reflects collaboration of ED and psychiatric staff, accommodating parents and guardians to remain with children moved to the unit, and rapid stabilization via access to resources in an appropriate environment.	Pre-intervention group compared to post-intervention group	The length of stay in the ED after the implementation of CARES was significantly reduced,

			as was the ED cost per patient.
Wilhelm (2007)	The intervention's patient-centered component involved providing patients with a choice of problem area, i.e. what they wanted to work on most for themselves, and that that change was empowering for them while also providing a 'taste' of what psychotherapeutic interventions have to offer. This reflects patient involvement in their own care and decision making.	Comparisons were made between repeat and first-time patient groups	The green card clinic provides a patient-centered, collaborative approach to intervention following self-harm and continuity of care through increased attendance in follow-up sessions.
Walker (2016)	Person-centred care places patients and families at the heart of care decisions. The person-centred nursing framework was used to code material based on five care processes: working with patient's beliefs and values, engagement, having sympathetic presence, sharing decision-making, and providing holistic care.	No comparison	Establishing a team philosophy of person-centered care can help promote consistency in the experiences of suddenly bereaved families.
Tretheway (2019)	Respect and understanding are components of patient-centered care that was measured using the patient satisfaction and feedback forms in this study. Patients felt they were treated with respect and understanding	Pre-PDU data was compared to post-PDU data	The PDU helps to relieve psychiatric pressure on busy EDs and creates a more optimum environment for psychiatric assessment.

Zeller (2014)	The Alameda model involves healthcare provider collaboration across EDs and EMS services to transfer patients to appropriate EDs equipped to handle psychiatric emergencies.	Earlier data collected in a 2012 California hospital survey	The Alameda model boarded psychiatric patients in the ED for 80% less time.
Wang (2016)	A component of patient-centered care is sharing in decision making processes with the patient. This study breaks the decision-making process down into three phases and identifies how the patient and provider can problem-solve and make healthcare decisions collaboratively.	No comparison	Decision making processes occur in different stages and ED staff should support patients faced with complex medical decision making through advocacy, patient-centered care, shared decision-making, and education.
Heifetz (2018)	Person-centered approach by easing communication between providers and patients with IDD	No comparison	The health passport tool allows patients to more easily communicate with healthcare providers but continued efforts are needed to educate staff on how to look for and use the tool effectively.
Owens (2006)	Patient-centered behaviors of providers include measures of trust, interpersonal interactions,	Group of women who disclosed their history with IPV to their physician was compared to a group that	Patient-centered behaviours play a role in assisting female abuse victims to

	communication, and knowledge of the patient as a person.	did not disclose their history with IPV in terms of patient-centered behaviors demonstrated by the physician	disclose their experience with IPV. The perception of a provider as knowledgeable about their patients was associated with increased disclosure.
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Figure 3. Components of PCC and corresponding number of articles.

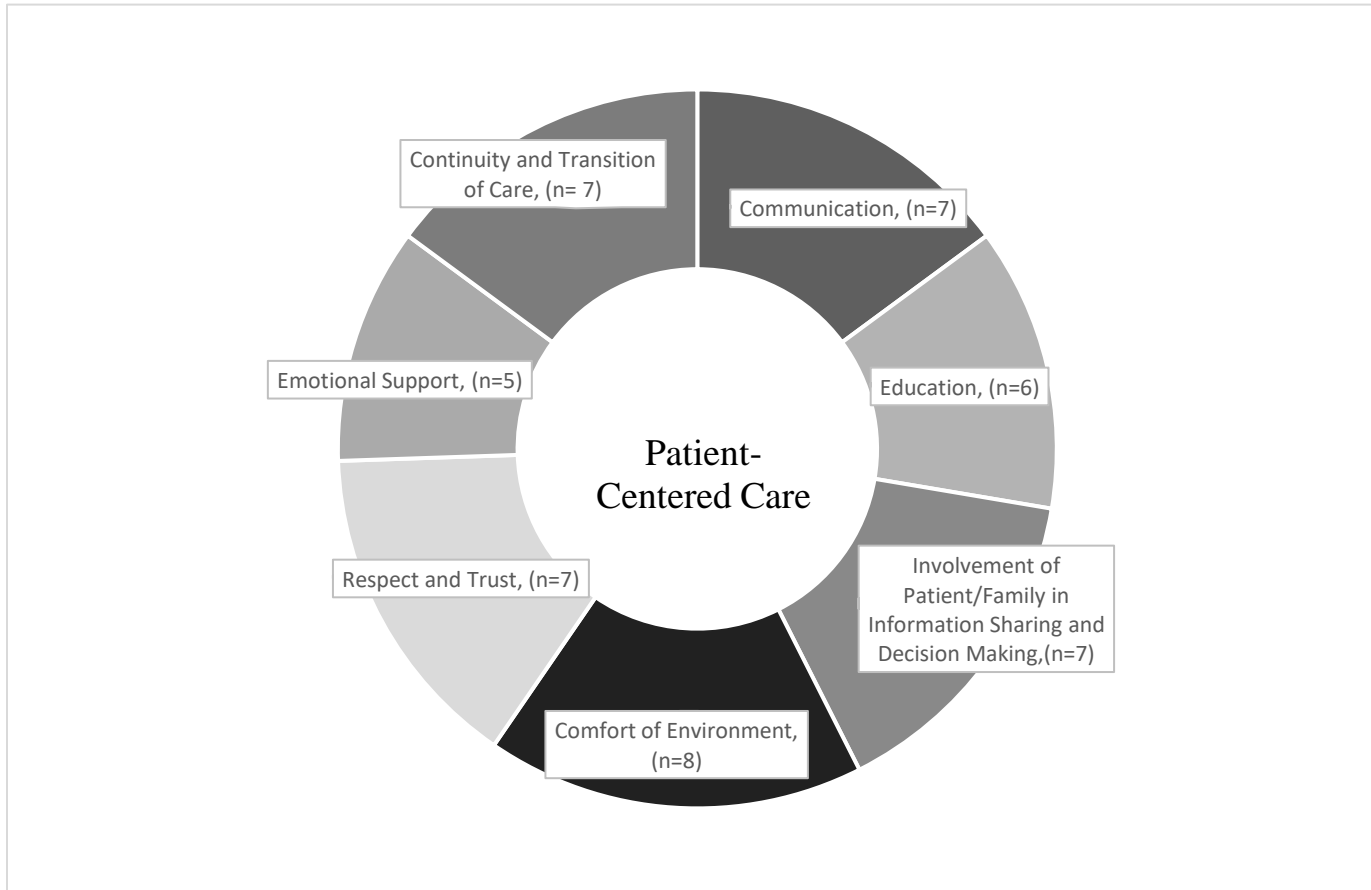


Table 3. Components of PCC as identified within the included articles.

	Communication	Education	Involvement of Patient/Family in Information Sharing and Decision Making	Comfort of Environment	Respect and Trust	Emotional Support	Continuity and Transition of Care
Nicholas (2020)	X	X	X	X	X	X	X
Innes (2017)	X	X	X	X	X	X	X
Polveoi (2013)				X			X
Frank (2009B)	X		X	X	X	X	
Frank (2009A)	X		X				
Wilhelm (2007)		X					X

Walker (2016)	X	X	X	X	X	X	
Tretheway (2019)				X	X		X
Zeller (2014)				X			X
Wang (2016)	X		X		X		
Heifetz (2018)	X	X	X	X			
Owens (2006)		X			X	X	
Rogers (2015)							X

3.3.3 Challenges and benefits of PCC as perceived by ED staff

Challenges and benefits of providing PCC were noted in four articles (n=4) (Table 4). Noted concepts of difficulties in providing components of PCC from the ED staff perspective were a lack of training or experience (n=2), communication barriers by having multiple care providers (n=1), complex patient needs (n=1), the design of the ED space being set up for efficiency rather than communication (n=2), patient frustration and negative attitudes (n=1), work demands impacting providers' ability to form relationships with patients and families (n=1), and professional conflicts impacting trust between patients and providers (n=1). However, components of PCC that were applied successfully saw beneficial results. ED staff reported that keeping patients informed helps to avoid emotional distress and uncertainty (n=2), patient placement in close proximity to ED staff with clear lines of sight allows staff to offer their presence (n=1), and encouraging patient participation (n=1) and treating patients and families as experts in their own care (n=1) brings about patient-provider collaboration.

Table 4. Number of articles noting challenges and benefits of providing (staff) or receiving (patient) components of PCC.

Component of PCC	Challenges				Benefits			
	Staff		Patient		Staff		Patient	
	Frequency	Citation	Frequency	Citation	Frequency	Citation	Frequency	Citation
Communication	1	Nicholas (2020)	1	Frank (2009B)	0	NA	1	Frank (2009B)
Education	2	Nicholas (2020), Walker (2016)	2	Nicholas (2020), Heifetz (2018)	0	NA	0	NA
Involvement of Patient/Family in Information Sharing and Decision Making	0	NA	2	Nicholas (2020), Frank (2009B)	2	Innes (2017), Frank (2009A)	4	Nicholas (2020), Frank (2009B), Owens (2006), Wang (2016)
Comfort of Environment	2	Nicholas (2020),	1	Nicholas (2020)	1	Frank (2009A)	1	Nicholas (2020)

		Innes (2017)						
Respect and Trust	0	NA	2	Nicholas (2020), Frank (2009B)	1	Nicholas (2020)	0	NA
Emotional Support	2	Frank (2009A), Walker (2016)	0	NA	1	Frank (2009A)	0	NA
Continuity and Transition of Care	0	NA	0	NA	0	NA	1	Wilhelm (2007)

3.3.4 Challenges and benefits of PCC as perceived by patients

Patient experiences were described in six articles (n=6) demonstrating evidence of barriers to and benefits of receiving PCC (Table 4). Concepts and key concepts of patient concerns included overwhelming waiting rooms (n=1), difficulty of navigation (n=1), and untrained or inexperienced staff (n=2). Further barriers to a positive care experience were lack of frequent updates from staff (n=1), limited access to information on ED care processes (n=1), dismissive attitudes from ED staff towards patients' and families' input (n=2), difficulty establishing communication with ED staff (n=1), and the use of language by staff that patients cannot understand thus limiting their ability to participate in decision making (n=1). Patient satisfaction was often achieved when components of PCC were present. For example, having frequent contact with staff (n=1), when patients felt listened to and valued as experts in their own health (n=2), when interacting with trained staff (n=1), when respected by ED staff (n=2) and being treated courteously without scepticism (n=1). When they were able to establish relationships, patients were able to share more information with providers (n=1) and place their trust in care providers to make good medical decisions on their behalf (n=1). Furthermore, having a patient-focused environment with accessible features allows patients to be comfortable in the ED (n=1) and having continuity of care via follow-up clinics helped patients to make changes to their lifestyles and attitudes (n=1) that in turn better their health.

3.3.5 Impacts of PCC on outcomes

Four studies (n=4) assessed the impacts of PCC components on outcomes in the ED. Examples of quantitative impacts measured included patient length of stay (n=3), number of patients who left without being seen (n=1), and patient satisfaction (n=1). Results of these

studies demonstrated decreased length of stay (n=3), reduced number of patients who left without being seen (n=1), and greater patient satisfaction (n=1) with the implementation of PCC-related interventions. Further qualitative findings support the idea that the patient experience is bettered by the presence of PCC components both individually and altogether.

3.3.6 Contribution of Patient Engagement

The results of this study were shared with patient partners for feedback. There was agreement on the components of PCC in the ED that were identified, but it was noted that “building trust between patients and providers” might be another important component to consider. Inclusivity and ethnic representation among physicians were identified by patient partners as foundations to building better relationships as it helps patients feel like they can better relate to their care providers. Although these were not components identified in the literature, this may represent another gap in the knowledge of providing PCC in the ED when trying to meet patients’ cultural and psychosocial needs.

3.4 Discussion

PCC has an important place in the ED. PCC in the ED should include aspects of communication, education, involvement of the patient/family in information sharing and decision making, comfort of environment, respect and trust, emotional support, continuity and transition of care. However, there is not yet an operational definition for how PCC should be implemented in the ED. Though all the included studies shared common components, most of the studies did not include each component of PCC that was identified. This important finding demonstrates there is no agreed-upon framework for PCC in the ED setting. This is echoed throughout the literature and identifies a concern that there is currently a lack of consistency in PCC models

throughout the broader healthcare system. Where some studies lack multiple components of PCC, it is possible that they could have had better outcomes had they included the other aspects.

The PCC in the reviewed articles also varied greatly depending on what roles staff had, patients' illnesses, and the care process involved e.g., to move them quickly to a specialized unit for appropriate care or to make them more comfortable in the ED waiting room. The variations in perspective likely contributed to the resulting differences across the studies regarding what PCC was practiced and what patients or staff found to be beneficial or lacking. Additionally, there were many identified challenges echoed from both the staff and patient perspectives. For example, staff education was seen as a barrier and communication as an enabler to PCC by both the patients and the staff across multiple studies. This indicates that there is agreement and that the impact of PCC reverberates both positively and negatively throughout the healthcare system. This overlap may suggest a few key starting points to creating a unique definition for PCC in the ED.

Compared to models of PCC in different healthcare settings, there is an overlap of pillars that support patient-centered practices. In a review of over 900 studies on PCC across various healthcare settings,²⁹ a few of the most common principles included taking a holistic approach, seeing the patient as an expert in their own care, recognizing autonomy and sharing responsibility in decision making, ensuring services are accessible, and having supportive, well-trained staff who can communicate and engage with patients. Further frameworks^{49,50} outline that concepts related to the patient-centered environment include advocacy, values, and empowerment as well as staff being partners in care through collaboration, communication, and health promotion. Different healthcare settings may put emphasis on the components that are

more relevant to their context, but these broad ideas are aligned with the current findings and support the notion that PCC in the ED does not need major adaptations to be integrated. It should also be recognized that components of PCC were practiced before evolving into what is known as PCC today.⁵¹ Therefore, the conception of new PCC pillars throughout different healthcare settings is to be expected. Although the ED environment presents unique challenges, the way care providers approach and treat patients with patient-centeredness should be prioritized.

Until now, the components that should go into PCC in the ED have not all been recognized. Rather, they were accounted for piece by piece and not as a whole. Some PCC components are more represented across the literature than others seemingly because there are pillars across healthcare settings that are crucial to PCC, but there are also components specific to the ED setting that should be considered. One could argue that providing any one component of PCC is better than none; however, it is important to provide all components to have a well-rounded patient-centered practice. If any one piece of the PCC puzzle is missing in the ED, the holistic intention of the method will be unfulfilled.

This review can be useful as a foundation to understanding the components of PCC that will improve the ED experience. It can also be used to assist in the development of PCC training modules for ED staff, or implementation of better PCC practices in the ED. By using the outlined components of PCC and implementing some of the suggested methods and examples from the literature, it is possible to develop a comprehensive list of actionable PCC practices. Furthermore, this review can contribute to the formation of guidelines for including patients in a systematic review as research partners and exemplifies the importance of their continuous input throughout the research process. Without having engaged patient partners on this project, we

would not have been able to ensure the relevance of our findings within the patient population and would not have been able to identify any further components missing from the literature.

3.5 Limitations

The results of this review are limited by the evidence from the retrieved studies and by the quality of the information reported in those studies. In quantitative articles, neither the effect sizes nor significance levels were provided in some cases, so we were unable to report this information. Articles that are aligned with the current evidence are more likely to get published, therefore it is possible that evidence opposing the included studies was not available due to publication bias. We were unable to do meta-analysis due to the lack of quantitative results. Our search was limited to only English language, peer-reviewed articles; therefore, it is possible articles in other languages or non-peer-reviewed articles were missed. Finally, because some of the included studies had small sample sizes, it is possible that the evidence from those EDs would not be generalizable to another population. In future, should more quantitative evidence become available, it would be beneficial to do quantitative analysis to get a better understanding of the effect of PCC on patient outcomes. The strength of the evidence produced through this review should also be evaluated as new information becomes available surrounding PCC in the ED.

3.6 Conclusion

Despite the challenges faced by staff, patients, and families, PCC is beneficial to patients and providers. Some of the many downfalls of ED care identified by its users can be mitigated by implementing PCC. This study contributes to the literature on how we can address PCC in the ED and can be used to improve the ED environment. PCC is essential to improving the patient

experience and should be prioritized as an evidence-based method of providing care that meets the patients' needs.

CHAPTER 4. Summary

4.1 Summary of Systematic Review Findings

The main objective of this thesis was to determine what methods of PCC are currently being practiced based on the available literature identified through a systematic review. Undoubtedly, PCC in the ED is an influential method of providing care. It includes communication, emotional support, continuity and transition of care, education, respect and trust, comfort of environment, and involvement of patient and family in information sharing and decision making. It has been shown to encompass components that are not only valued by patients but make a better experience for healthcare providers and families and caregivers as well. There are many benefits to providing PCC, such as establishing better relationships with patients so that they can share more information with providers and making them feel comfortable, listened to, and respected. However, there are also struggles to providing PCC from the staff perspective, including complex patient needs, too much demand on staff, and the design of the ED not set up for optimal patient encounters. There are systemic problems that can make PCC difficult to do; however, it is possible to start small with changes to the way providers approach patients and adapt the physical environment over time.

The included articles only reflected PCC in developed countries. This is not surprising because, although PCC has a rich history, it is primarily practiced in developed countries.^{52,53} Interestingly, all the countries of study except for the United States currently have government-funded healthcare models. There is, however, speculation that the Affordable Care Act in the United States, which attempts to address fundamental healthcare problems and encourage patient-centered practice among other quality indicators, could be the solution to creating

healthier and more satisfactory care environments.^{54,55} It is possible that the shift toward universal healthcare can be a factor in the presence of PCC because both models put peoples' needs at the forefront.

4.1.1 Practical Implications of the Review

This review provides insight to the foundations of PCC that should be included in ED care. Furthermore, this review has taken patient input into consideration through patient engagement to ensure that these principals align with real patient perspectives. This information can be used in practice by creating PCC training for care providers around the key components identified. In Newfoundland and Labrador, the SurgeCon project¹⁹ sets an example for ED management and better patient flow by implementing a series of interventions including external review of the department, Lean training, fast tracking and streaming patients, door-to-doctor approach, performance reporting, an action-based surge capacity protocol, and a patient-centeredness approach. In the context of the first SurgeCon implementation study, PCC included “(1) providing quality ED care to all patients regardless of urgency; (2) treating all patients with respect; and (3) always considering the patient’s visit to an ED to be necessary as they may have no other option”, as well as (4) environmental changes to the waiting room.¹⁹ The values outlined reflect some of the components identified in the review such as comfort of environment and respect, however there are additional considerations as made evident through our systematic review. This review will be used in conjunction with their previous findings to build a new training model for staff surrounding patient-centeredness as SurgeCon is implemented into various EDs across the province. By implementing this model of PCC and refining what it means to practice each of the identified components, it is possible to set an example that can help streamline the way that PCC is introduced to different EDs in future.

4.2 Summary of Patient Engagement

Another primary objective of this thesis was to use patient engagement to determine what factors of PCC are most important to patients who attend the ED. This was accomplished by including patient partners and stakeholders throughout the development of the study. Having a patient partner as a member of the team provided key information regarding patient perspective and applicability of the study. Along with community organizations, they assisted in shaping the research question toward PCC. This inspired the objective to explore factors of PCC in the ED and resulted in the development of a protocol for a systematic review (Chapter 2).

The final objective of this thesis was to determine if patients' needs align with the commonly used components of PCC. On completion of the review (Chapter 3), by collecting their feedback on thematic interpretations, we were able to make a connection between the findings from the literature and real patient perspective. There was agreement from the patient partner and the rest of the team, including clinicians and subject-matter experts, on the results of the review including the components of PCC identified and their importance. Further, the results were presented to the patient engagement working group as part of the SurgeCon¹⁹ project to provide additional feedback on the components of PCC in the ED. This group agreed with the identified components from the review but added valuable commentary that factors such as ethnic diversity and representation among ED staff and physicians can play a role in the formation of trust between a provider and patient.

Upon reflection, very few included studies offered demographic characteristics of the patients and providers involved. Although racial disparity was not found to be a barrier to PCC in this review, this could represent another gap in the knowledge of providing PCC in the ED

when trying to meet patients' cultural and psychosocial needs and deserves further exploration. As identified by the patient partners, having healthcare providers of different races and ethnicities is of value to them so that they can better relate to the person providing their care. Previous research has demonstrated that racial disparities contribute to difficulty with relationship-building between patients and physicians due in part to a lack of cultural sensitivity.⁵⁶ This can certainly play a role in affecting mutual respect, trust, and information sharing amongst patients and providers. Interestingly, there is indeed a shift towards increasing cultural sensitivity and competency in healthcare.⁵⁷⁻⁶⁰ Furthermore, the evidence on how it is practiced in the ED is sparse. This presents another opportunity to engage patients and involve them in future studies that address possible cultural barriers to meaningful PCC in the ED.

4.2.1 Future Considerations for Patient Involvement

A limitation to this study is a lack of evaluation of patient engagement. Because this is a subproject of SurgeCon, we did not evaluate patient engagement for this systematic review. However, patient engagement will be evaluated using the Public and Patient Engagement Evaluation Tool⁶¹ throughout the course of the SurgeCon project as it is implemented into additional hospitals in the province overtime. This evaluation tool contains questionnaires for the organization, the patients, and the overall project. It allows researchers and clinicians to work together to evaluate how the patient engagement is working, how it is contributing to the research, and how it continues to be an active part of the project. Although results of patient engagement for the SurgeCon project are in progress and will have some generalizability to this study given the cross-over of research team members (e.g., SurgeCon shares the same patient partner as the current study), conducting a formal evaluation for this particular study would have been helpful for assessing the outputs and impacts of engagement in a systematic review.

4.3 Conclusion

Identifying the needs of the patient that receives PCC is crucial to understanding how PCC should be practiced. In addition to the research evidence gathered through a systematic review, gaining patient perspective on the results of the study in the context of our own healthcare system in Newfoundland and Labrador is essential to move forward. Including patients as partners allows them not only to be heard, but to contribute in impactful ways. When patients are given the opportunity to articulate their experiences and be involved in a study, it gives realistic context to the research and increases its applicability. Reaching consensus on key components of PCC with patient partners who have had first-hand encounters in emergency care demonstrates the importance of connecting research with reality. Any model of PCC is only as effective as it is beneficial for patients who experience it. This thesis contributes not only to the evidence on PCC in the ED, but to the evidence on involving patients as research team members in a systematic review. It has been invaluable to this study and should be considered a priority when investigating any healthcare matter involving patients, especially PCC.

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Appendix 1: Sample search strategy

MEDLINE (PubMed) & Cochrane	
#1	"Patient Participation"[Mesh] OR "Patient-Centered Care"[Mesh]
#2	"patient participation" OR "patient engagement" OR "patient centered care" OR "patient centred care" OR "person centered care" OR "person centred care" OR "patient involvement" OR "patient empowerment" OR "patient activation" OR "patient centered" OR "patient centred" OR "patient focused"
#3	#1 OR #2
#4	((("Emergency Medical Services"[Mesh] OR "Emergency Treatment"[Mesh]) OR ("Emergency Nursing"[Mesh] OR "Emergency Service, Hospital"[Mesh] OR "Emergency Medicine"[Mesh] OR "Emergency Services, Psychiatric"[Mesh] OR "Pediatric Emergency Medicine"[Mesh])) OR "Crisis Intervention"[Mesh]
#5	"emergency department" OR "emergency departments" OR "emergency medicine" OR "emergency services" OR "emergency unit" OR "emergency units" OR "emergency ward" or "emergency room" OR "emergency rooms" OR ((psychiatric or mental) AND (emergency or emergencies or crisis))
#6	#4 OR #5
#7	"Mental Disorders"[Mesh]
#8	"mental illness" OR "mental health" OR "mental disorder" OR "mental disorders"
#9	#7 OR #8
#10	#3 AND #6 AND #9

CINAHL	
#1	MH "Patient Centered Care" OR MH "Consumer Participation"
#2	"patient participation" OR "patient engagement" OR "patient centered care" OR "patient centred care" OR "person centered care" OR "person centred care" OR "patient involvement" OR "patient empowerment" OR "patient activation" OR "patient centered" OR "patient centred" OR "patient focused"
#3	#1 OR #2
#4	(MH "Emergency Service") OR (MH "Psychiatric Emergencies") OR (MH "Emergency Services, Psychiatric") OR (MH "Emergency Patients") OR (MH "Emergency Treatment")
#5	"emergency department" OR "emergency departments" OR "emergency medicine" OR "emergency services" OR "emergency unit" OR "emergency units" OR "emergency ward" OR "emergency room" OR "emergency rooms" OR ((psychiatric or mental) AND (emergency or emergencies or crisis))
#6	#4 OR #5
#7	(MH "Mental Disorders+") OR (MH "Mental Health")
#8	"mental illness" OR "mental health" OR "mental disorder" OR "mental disorders"
#9	#7 OR #8
#10	#3 AND #6 AND #9
PsycInfo	
#1	DE "Client Participation"

#2	"patient participation" OR "patient engagement" OR "patient centered care" OR "patient centred care" OR "person centered care" OR "person centred care" OR "patient involvement" OR "patient empowerment" OR "patient activation" OR "patient centered" OR "patient centred" OR "patient focused"
#3	#1 OR #2
#4	(DE "Emergency Medicine" OR DE "Emergency Services" OR DE "Crisis Intervention") OR (DE "Crisis Intervention Services")
#5	"emergency department" OR "emergency departments" OR "emergency medicine" OR "emergency services" OR "emergency unit" OR "emergency units" OR "emergency ward" or "emergency room" OR "emergency rooms" OR ((psychiatric or mental) AND (emergency or emergencies or crisis))
#6	#4 OR #5
#7	DE "Chronic Mental Illness" OR DE "Mental Health and Illness Assessment" OR DE "Mental Disorders"
#8	"mental illness" OR "mental health" OR "mental disorder" OR "mental disorders"
#9	#7 OR #8
#10	#3 AND #6 AND #9

EMBASE	
#1	'patient care'/exp OR 'patient participation'/exp
#2	"patient participation" OR "patient engagement" OR "patient centered care" OR "patient centred care" OR "person centered care" OR "person centred care" OR "patient involvement" OR "patient empowerment" OR "patient activation" OR "patient centered" OR "patient centred" OR "patient focused"
#3	#1 OR #2
#4	'emergency health service'/exp OR 'emergency care'/exp OR 'psychiatric emergency service'/exp OR 'emergency treatment'/exp OR 'pediatric emergency medicine'/exp OR 'crisis intervention'/exp OR 'hospital emergency service'/exp
#5	"emergency department" OR "emergency departments" OR "emergency medicine" OR "emergency services" OR "emergency unit" OR "emergency units" OR "emergency ward" or "emergency room" OR "emergency rooms" OR ((psychiatric or mental) AND (emergency or emergencies or crisis))
#6	#4 OR #5
#7	'mental health'/exp OR 'mental disease'/exp
#8	"mental illness" OR "mental health" OR "mental disorder" OR "mental disorders"
#9	#7 OR #8
#10	#3 AND #6 AND #9