



Analyzing models of patient-centered care in Canada through a scoping review and environmental scan

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Abstract

Aim The objective of this study was to identify and synthesize models of patient-centered care in Canada and compare them with the normative models described in the literature.

Subject and methods Patient-centered care has gained momentum in the twenty-first century as a component of quality care. During the Covid-19 pandemic, the crisis often shifts the focus to the disease rather than the patient. The multiplicity of Canadian systems, including the federal, provincial, and territorial contexts, made a good case to search for a variety of models. This study was conducted using a scoping review method supported by an environmental scan to identify patient-centered care models in Canada.

Results The study identified 19 patient-centered interventions across Canada. The interventions included bedside interventions, patient-engagement projects at the organizational level, and citizen advisory panels at the system level. The organizational model was the most common. The goals of interventions ranged from enhancing the patient's experience of care to identifying ways to cut costs. In most organizational-level projects, there was a marked tendency to engage patients as members of quality improvement committees. Respecting patient dignity and autonomy in one-on-one clinical interactions was minimally addressed in the models.

Conclusion Health systems are not only technical, biomedical organizations but also socio-political institutions with goals of financial protection, the fair distribution of services and resources, and the meaningful inclusion of the citizens in the system, and thus patients need to be respected as individuals and as collectives within the healthcare system.

Keywords Patient-centered care · Canada · Patient engagement, models

Background

Patient-centered care (PCC) is an increasingly important component of quality healthcare systems. During the Covid-19 pandemic, it is more important to pay attention to the patient-centeredness of the care because the pandemic crisis often shifts the focus to the disease rather than the patient. The Institute of Medicine defines PCC as “care that is respectful of and responsive to individual patient preferences, needs, and values” (Bergeson and Dean 2006). The problem with this

concept is its elusiveness in the real world. During the Covid-19 pandemic, attention to patient-centeredness of the care becomes more important because the pandemic crisis often shifts the focus to the disease rather than the patient. This study aims to review and critique some real-world models presented as PCC in the Canadian context and to offer recommendations to refine the concept.

Researchers have proposed a number of normative models of PCC. Picker's eight principles, aligned with Gerteis et al.'s (1993) dimensions of PCC are access to care, continuity and transition, involvement of family and friends, emotional support, physical comfort, information and education, coordination and integration of care, and respect for patients' preferences (Shaller 2007). Although each of Picker's principles has its own significance, they are not theoretically or otherwise linked to one another to form a unified concept. A scoping review of patient-centered approaches identified 25 unique PCC models emphasizing communication, partnership, and health promotion (Constand et al. 2014). A narrative review of the literature on patient-centered models identified three

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themes around PCC: (a) patient involvement in decision-making, delivery of health services, and research and development; (b) enabling factors related to patients, providers, and organizations; and (c) anticipated outcomes in patient satisfaction, health outcomes, and the cost of services (Snyder and Engström 2016). Greene and colleagues have attempted to develop a comprehensive framework for PCC by charting interpersonal, clinical, and structural dimensions (Greene et al. 2012).

What becomes obvious from these studies is that PCC is not a unified construct (Stewart 2001; Epstein et al. 2005). It is known for what it is not or should not be: disease centered, doctor centered, hospital centered, and technology centered (Stewart 2001). When applied loosely, as is often the case, the concept overlaps with quality of care, quality improvement, and healthcare system reforms, among many other notions. Epstein et al. (Epstein et al. 2005) argue that patient-centeredness should be reserved to describe a moral philosophy with three core values: (1) considering patients' needs, wants, perspectives, and individual experiences; (2) offering patients opportunities to provide input into and participate in their care; and (3) enhancing partnership and understanding in the patient–physician relationship. We agree and explain this through this systematic search and analysis of Canadian PCC models.

Objectives

The objective of this study is to identify and synthesize models of PCC in the Canadian context and to assess the components of PCC in relation to the core principles of PCC described in the literature.

Methodology

The study followed Arksey and O'Malley's (Arksey and O'Malley 2005) scoping review methodology complemented with an environmental scan. The scoping review method entailed the following five steps:

(1) Identifying and formulating the research question:

The review method recommends that both a broad and a focused research question should be used to guide the initial identification and eventual selection of relevant studies. We started the review with the broad question: (1) What are the models of PCC in healthcare settings in Canada? This question supported the primary focus of this study on patient-centeredness within the Canadian health system. At the same time, a separate literature search was conducted to identify the normative models of PCC globally and to compare their differences and similarities. As

our understanding of the concept evolved, we refined the research question into (2) What are the elements of PCC models implemented in Canadian healthcare settings as compared with the normative models described in the literature?

(2) Searching and identifying the relevant studies (Table 1):

The primary search was conducted in the PUBMED (Medline), EMBASE, and CINAHL databases for peer-reviewed literature. The reason we did not include general databases such as Web of Science was due to focus on patient-centered models within healthcare settings, something that PubMed generally covers. The literature search was limited to sources published in English between 2010 and March 2019. As French is an official language in Canada, we acknowledge that not being able to include French in this study (due to small team and limited funding) is a limitation of this research. Preliminary search terms were “patient-centered” OR “patient-engagement” OR “patient involvement” OR “people-centered care” [MeSH] AND “Canada.”

(3) Selecting studies based on inclusion and exclusion criteria (Table 2):

Articles were considered eligible for inclusion if they primarily focused on patient-centered models implemented in any setting in any province or territory of Canada. Only articles published after 1960 and before March 2019 that had the full text available and were written in English were included in this review. Articles that did not primarily focus on the patient-centered model in Canada, were not published in English, or were not published within the specified time frame were excluded. Articles that included the mere mention or small discussion of patient-centered models were excluded. Titles and abstracts of the retrieved articles were independently reviewed, primarily by AR. Articles that met the inclusion criteria were comprehensively reviewed by AR and MN. The two reviewers met regularly to share their initial coding and reach consensus in case of disagreement. During the study selection process, it was agreed to include studies of any quantitative design (such as cross-sectional, case series, reviews, cohort/observational studies) and qualitative design and exclude editorials, commentary news articles, conference abstracts, letters to the editor or book reviews. It was made sure that all included papers had focused research questions. Articles were not excluded based on quality criteria such as sample size or the rigor of the method. Articles on patient engagement in health research were excluded.

(4) Charting the data from the selected studies:

Table 1 Research strategy and keywords used to retrieve documents

Search method	Keywords used	Constrains
Title search	<i>Patient-centered OR patient-engagement OR patient involvement OR people-centered care [MeSH] AND Canada</i>	None
Title-abstract search	<i>Patient-centered OR patient-engagement OR patient involvement OR people-centered care AND Canada AND Human AND English</i>	None
Limit	Date: 2010 to 2019 (March)	

Data charting started with a review of the articles and the generation of a coding scheme. We then generated a data extraction template using NVivo 10 software, which was later exported to a Microsoft Excel spreadsheet. Further extraction of information based on the initial themes was carried out in Microsoft Excel. We extracted information on a variety of variables such as authorship, article type, year of publication, intervention location, and intervention setting. Thematic coding was initiated with identifying (1) models of PCC, (2) elements of the intervention, and (3) key insights. During the coding, other variables such as the type of patients, nature of patient engagement, type of providers, and nature of provider engagement were added to the extraction tool. Codes were compared and adjusted in regular meetings of the three researchers. The reviewers agreed on the final themes and sub-themes.

In addition to the academic literature, an exhaustive list of websites of Canadian healthcare organizations were hand-searched for gray literature (Appendix 1). Unfortunately, we were not able to include MSc/PhD theses in this study. The search found many reports, white papers, and working documents in the professional organization websites that were not published in the peer-reviewed journals. Data from these sources were charted separately from the academic literature. The academic and gray literature charts were merged toward the end of the analysis to remove any duplicates.

- (5) Collating, summarizing, and reporting results in a systematic manner:

The interpretation and classification of types of healthcare models, elements of interventions used in each model, and

focus areas and key insights into common themes were performed by AR and reviewed by MN. NVivo software was used to select, compile, and analyze data and highlight the reported elements related to each healthcare model. Thematic analysis was used to identify patterns from the documents and to describe the different healthcare models and facets of patient involvement.

The initial search yielded 12,028 references, which was reduced to 9275 after excluding articles not published in English. The research assistant, AR, conducted an initial scan of all titles and abstracts of the selected studies based on the inclusion criteria, and 319 articles were selected for full-text reviewing. Both reviewers then independently read the full articles to assess for eligibility. This led to the exclusion of 288 articles that did not meet all the inclusion criteria (details shown in the flowchart – Fig. 1). With no documents selected from the additional manual search, the final number of articles included in the analysis was 30. In terms of their quality, all the included papers had focused research questions and the typology of their research methods are summarized in Table 3.

Thematic analysis is an established process of identifying themes or patterns within qualitative data in order to make sense of data (Braun and Clarke 2006). The analysis process involved in this study was in line with the six phases of thematic analysis described by Braun and Clarke. At the beginning, familiarization with the content of the articles generated ideas for the creating of codes. Subsequently, those codes were grouped and linked with one another into themes. Then, each theme was reviewed to make sure it would reflect both its associated codes and the entire data set. Themes were generated from the content of the data to signify their specific

Table 2 Inclusion and exclusion criteria for literature review

Inclusion criteria	Exclusion criteria
(I) Articles that primarily focused on models of patient-centered care used in Canada’s healthcare settings	(III) Articles that do not primarily focus on the models of patient-centered care used in Canada’s healthcare settings
(I) Articles with specific objective and methodology mentioned in the methods section	(I)Articles do not follow the objective and methodology mentioned in the methods section
(II) Articles published from 2010 to 2019 (March)	(II) Articles not published within the time limit.
(IV) Articles published in English language	(IV) Articles published in other than English language
(V) Articles with their full texts that could be obtained online	(V) Articles with their full texts could not be obtained online

Table 3 Types of studies included in the review

Qualitative	Number
Descriptive case studies	15
Narrative review	6
Scoping review	2
Implementation research	1
Regulatory review	1
Quantitative	
Cross-sectional studies	3
Mixed methods	
Mixed methods	2

meaning. To analyze the articles, the activities within those were focused rather than the theoretical perspectives applied by the original authors or the labels used. Each theme was clearly defined and refined afterward. To minimize the risk of preconceptions and subjectivity, interpretations and definitions were discussed with the other researcher throughout the process. Finally, the focus area and key insights of each article were discussed. The purpose of this description was to present an overview of the findings identified in the studies.

Main text – findings

Canadian models of patient-centered care

The list of patient-centered interventions in a Canadian context is not exhaustive, but it can be representative. We have identified 19 interventions that were aimed at fostering PCC (Appendix 2). Most of the interventions were implemented in Ontario followed by Quebec, British Columbia, and Saskatchewan. Some provincial models followed a federal-level framework. There was one intervention at the federal level that included patients as advisors in regulatory committees on health matters (Klein et al. 2016). The majority of the interventions took place in hospital settings, and others occurred at the community level. The interventions engaged general patients, including those with acute or chronic illnesses. Families and communities were also engaged in health care as a component of PCC.

Generally, Canadian models of PCC can be divided into organizational and bedside interventions. Organizational interventions engage patients as advisors in committees to improve health care organization and delivery. Organizational changes are also aimed at improving patients' experience of care in which patients participate either as representatives of other patients in committees comprising providers or as a member of a group of patients to form an advisory panel. In organizational interventions, patients often participated in healthcare re-design, quality improvement interventions, the

evaluation of projects, and financial reforms. Patients also co-created educational material, co-designed solutions for process improvement, and identified cost-cutting methods. Patients were recruited to quality improvement committees through organized programs such as Quebec's Partnership in Care Program (Pomey and Lebel 2016). After recruitment, patients were often "activated" through orientation sessions, peer mentors, advisors and external facilitators, and leadership support and role modeling.

Patient-engagement has also been gaining momentum in Canada. Some bedside projects have included former patients with specific conditions (e.g., hand re-implantation) as part of the treatment team (Pomey and Lebel 2016). In these cases, former patients acted as an informational base and provided emotional support for the new patients. Current patients were also included in their own care plan. One intervention included patients in their care through having them fill out a form called "Your Story," with the intention of identifying the patient as a unique individual rather than another case number (Shiozaki et al. 2017).

Alongside bedside and organizational interventions, one traditional method used to include patients' perspectives in their care has been exit surveys, through which discharged patients shared their experience and suggested improvements in the care process.

All patient-centered interventions were led by providers who aimed to create organizational change or patient behavior change. Most of the providers included health care managers, followed by nurses and physicians. The role of the providers entailed leading the committees or building the capacity of other providers or patients. We identified one behavior change project for care providers in which the providers were required to state their names, their occupation, and say what they were going to do every time they interacted with a patient (Shiozaki et al. 2017). In the same project, providers were asked to encourage their colleagues whenever they were "Caught in the Act of Care" (CAC), or when they made a caring gesture toward a patient, by giving them a CAC sticker as a reward. The goal of this activity was to inspire caring behavior.

Conceptual challenges of terminologies and definitions

We have identified more than a dozen phrases related to PCC (Table 4). Every word in the phrase "patient-centered care" has multiple interchangeable terms. Person, client, stakeholder, and even family and community are used as substitutes for patient. Engagement, involvement, feedback, and experience are used as substitutes for "centeredness." Although health care and health systems are used as broader terms for care, specific terms used to refer to a certain component of care include decision-making (i.e., patient engagement in decision-making), therapeutic processes, quality improvement,

Flow chart

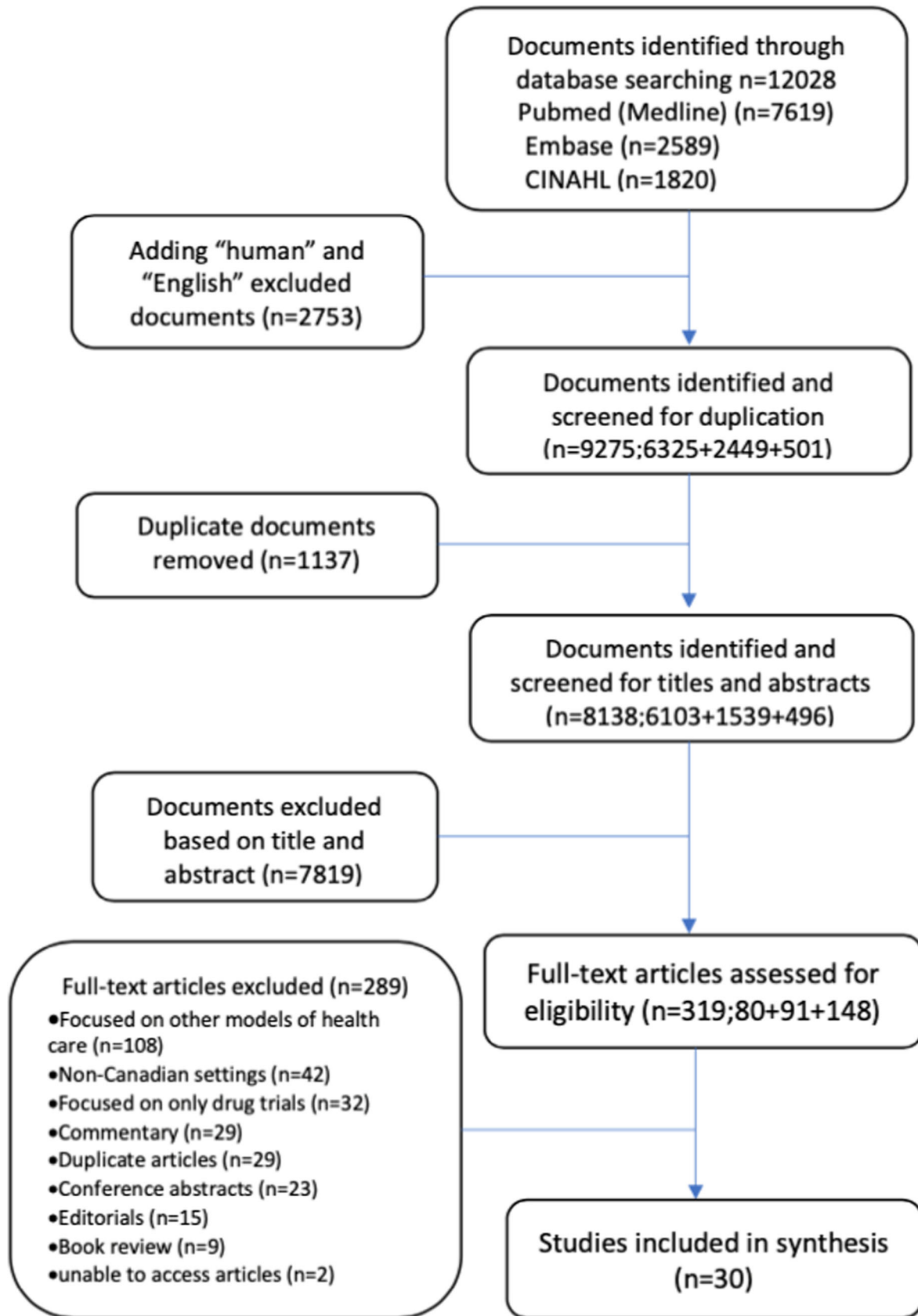


Fig. 1 The flowchart

Table 4 List of various terminologies used alternatively with patient-centered care

Phrases with the term “patient”	Alternative phrases to “patient”
“patient engagement”	“person centered care”
“patient feedback”	“client-centered care”
“patients as partners in care”	“community engagement”
“patient centered care”	“community involvement”
“patient experience”	“family centered care”
“patient involvement in healthcare”	“stakeholder engagement”
“patient-engaged care”	“shared decision-making”
“patient and professional partnership”	

program evaluation, system design and re-design, drug development, and research (despite our efforts to exclude articles that focused on patient engagement in research).

Similar to the multiplicity of terminologies, definitions also vary. A list of definitions is provided in Table 5. The definitions are provided by a variety of organizations, including research institutes, networks of health care providers, and professional organizations.

The definitions have a number of themes in common:

1. Respect for patient dignity and autonomy
2. Integrating patients’ perspectives of illness into health care services
3. Engaging patients in the process of care

The multiplicity of dimensions: model of care, principles, levels, and continuum of patient engagement

We found that PCC interventions focused on multiple dimensions of PCC, including models of care, principles of PCC, PCC at different levels of the healthcare system, and the continuum of patient engagement. Models of care services are divided into paternalistic, patient-centered, and collaborative models (Pomey and Lebel 2016). The paternalistic model views patients as passive recipients of care services. The patient-centered model identifies patients as the focal point of care for each individual provider. The collaborative model focuses not only on the agency of the patient but also on interprofessional partnership with providers to improve patients’ experience of care.

Box I: Patient care models (Pomey and Lebel 2016):

- Paternalism
- Patient-centered care
- Partnership of care (interprofessional collaboration)

Table 5 Various terms referring to patient-centered care and their definitions

Patient-centered care:

1. The most widely used definition of **patient-centered care** is provided by the Institute of Medicine (IoM), which defines PCC as “care that is respectful of and responsive to individual patient preferences, needs, and values” (Bergeson and Dean, 2006).
 2. **Patient-engaged care** is a practice orientation that seeks the best possible participation of the patient, and, when appropriate, the family, through exchanges that enhance patient- and family-centered goals and values (Casimiro et al. 2014).
 3. **Patient-centered care** has been described as a merging of patient education, self-care, and evidence-based models of practice. Patient-centered care consists of four broad domains: communication, partnership, health promotion, and physical care (Fredericks et al. 2012).
 4. The Department of Family Medicine at the University of Western Ontario defines **patient-centered care** as encompassing six interacting components: exploring the disease and the illness experience, understanding the whole person, finding common ground, incorporating prevention and health promotion, enhancing the patient–doctor relationship, and being realistic (Kuluski et al. 2016).
 5. The Ontario Medical Association (OMA) defines a patient-centered care system as one in which **patients can move freely along a care pathway** without regard to which physicians, other healthcare providers, institutions or community resources they need at that moment in time. The system is one that considers **the individual needs of patients and treats them with respect and dignity**.
 6. Coulter (2002a) defines patient-centered care as “Health care that meets and responds to patients’ wants, needs and preferences and where **patients are autonomous** and able to decide for themselves.” (Coulter, 2002a)
- Patient engagement/patient-engaged care**
7. **Patient engagement** is a process whereby those people who have a legitimate and meaningful relationship with the healthcare organization and its providers should be involved in a meaningful discourse and set of transactions with the organization and the providers (Rogers et al. 2014).
 8. At the University Health Network (UHN), “**patient engagement**” is synonymous with the notions of “interested involvement,” “personal investment” or “motivated contribution,” which can occur in a number of ways and in a number of places along the engagement continuum (Rogers et al. 2014).
 9. **Patient and family engagement** is defined as the “involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g., planning, evaluation, care, research, training, and recruitment) ... which involves collaboration and partnership with professionals” (Baket et al. 2016; Abelson et al. 2018).
 10. The Canadian Foundation for Healthcare Improvement (CFHI) defines “**Patient engagement** is the involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g., planning, evaluation, care, research, training, and recruitment). Starting from the premise of expertise by experience, patient engagement involves collaboration and partnership with professionals” (Fancott et al. 2018).
- Person-centered care
11. The Health Innovation Network in London, England (London HINS 2015) defined **person-centered care** as: “not just about giving people whatever they want or providing information. It is about considering people’s desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual, and working together to develop appropriate solutions” (Kuluski et al. 2016).
 12. **Person-centered care** can mean different things; it typically entails paying attention to the needs and background of health system users, involving them in decisions that affect their health, assessing their care goals, and implementing a coordinated plan of care that aligns with their unique circumstances (Kuluski et al. 2016).

Client-centered care

13. The Canadian Association of Occupational Therapists (CAOT) defines **client-centered care** as: Core concepts of client-centered practice include providing clients with informed choices about their health care, facilitating

Table 5 (continued)

<p>client decision-making, developing partnerships between those receiving and providing service, and ensuring that services are accessible and appropriate for the client (Restall et al. 2018).</p> <p>Other terms</p> <p>14. Shared Decision-Making (SDM): SDM is consistent with client-centered care, as defined by the Institute of Medicine and Registered Nurses' Association of Ontario. Client-centered care involves the provision of care that is responsive to individual patient preferences and includes empowering clients, respecting their autonomy, and involving clients in decision-making such that patients' values guide clinical decisions (Legare et al. 2007).</p> <p>15. Patient and Professional Partnership (PPP): The PPP perspective proposes that the patient should be considered as a healthcare provider, an equally valued member and partner of the healthcare team (Pomey and Lebel 2016).</p>

Two sets of principles for PCC are identified in the Canadian models. The Quebec model of patient partnership in healthcare includes three main principles: (1) the recognition that patients and their family members have experiential knowledge of health situations and the use of services, (2) the acknowledgement of the status of patients/family members as full members of the (care) team, and (3) the recognition of their ability to make free and clear decisions based on their life goals [11]. Ontario's Patient-centered Primary Care Collaborative has seven principles: (1) continuous relationship with a personal physician, (2) a team approach to care, (3) whole-person orientation, (4) care coordination across the complex health care system, (5) quality and safety, (6) enhanced access to care, and (7) appropriate payment (Rosser et al. 2010, 2011).

Pomey and Lebel have identified PCC at three levels of health care services: the clinical, organizational, and political levels. Clinical-level PCC is focused on the patient-provider relationship. The organizational level focuses on structural and administrative arrangements that enhance the patient experience of care. The political level of engagement focuses on patient advocacy and engagement at higher governmental and legislative decision-making.

Box II: Levels of PCC:

- Clinical Level
- Organizational Level
- Political Level

Another aspect of PCC is the continuum of patient engagement that ranges from information sharing to consultation to partnership (Pomey and Lebel 2016). Whereas information sharing could still be viewed as a paternalistic approach, the partnership of patients in the care process is considered as more inclusive and patient centered.

Box III: Continuum (level) of patient engagement (Pomey and Lebel 2016):

- Information sharing
- Consultation
- Implication
- Partnership co-construction

Discussion

Similar to the elusiveness of the concept of PCC, the 19 patient-centered interventions identified in the Canadian context are diverse. Terminologies vary, definitions differ, and multiple dimensions of PCC, including principles, levels, and the continuum of patient engagement, fluctuate in the interventions. In this discussion, we have explored a conceptual gap in the concept and some empirical advantages of and challenges to PCC interventions.

The variety of terminology used to connote one or another aspect of "patient-centered care" can be both confusing and illuminating. It is confusing because the combination of a variety of terms with different meanings muddles the field of study. It is illuminating because each term has ideological baggage. "Patient" is considered a paternalistic term for people with illnesses, who are passive recipients of technically competent care. "Client" is a business term that refers to a transactional relationship between a purchaser and a seller. "Client" can refer to individuals, groups of people, organizations, or any entity with the capability to purchase goods. The term "client" also implies that health care services are commodities and healthcare is a business industry. In business, profit maximization is the ultimate goal, and it can have far-reaching, dehumanizing implications, the discussion of which is beyond the scope of this study. "Person" is more of a neutral term that can offset the historical discourse on the patient-centeredness of health care. While the term "patient" carries the historical paternalism of medicine, "person" assumes a fresh start between physicians and patients. All three terms focus on individuals rather than communities. That is probably the reason for the introduction of alternative phrases such as "family-centered" and "community-centered."

The multiplicity of the terms can also be informative of the many aspects of care that need a transformation to become more "patient-centered." A disregard for human autonomy and self-determination at times of sickness has often been observed at various levels of healthcare systems, and the need for PCC has evolved from this negligence, leading to the emergence of the multiplicity of terminologies.

Conceptually, PCC needs to be differentiated from other health care concepts that are closely linked with improved patient experiences and health outcomes.

Quality of care, quality improvement, health system reforms, and health system strengthening are a few examples. These concepts might have instrumental value, but at the core of PCC is respect for the dignity and autonomy of patients in the continuum of care, irrespective of the outcome. Improved working conditions for health care providers, for instance, may improve the experience of patients and health outcomes but can fall on the opposite side of PCC, i.e., behavior change aimed at providers. Undignified health care services may prolong life but can hurt patients psychologically. At the heart of PCC remains respect for patient dignity, autonomy, and self-determination, all of which have intrinsic value.

Empirically, PCC has a number of advantages and a few challenges. Baker et al. (2016) state that patients are “experts by experience.” The “lived experiences” of patients, particularly those with chronic conditions, provide a rich source of knowledge for better health care services (Born and Laupacis 2012; Pomey and Lebel 2016). Patient engagement facilitates the inclusion of patients’ perspectives, preferences, and values in the care process (Born and Laupacis 2012). Many researchers agree that patient engagement increases patients’ satisfaction with and experience of care (Poochikian-Sarkissian et al. 2010; Bedos and Loignon 2011; Pomey and Lebel 2016; Abelson et al. 2018). Patient engagement, particularly through adherence and better communication, also improves the technical quality of care and safety (Bedos and Loignon 2011; Pomey and Lebel 2016; Fancott et al. 2018; Abelson et al. 2018). Studies identified increased job satisfaction for professionals when patients were engaged in the care process (Poochikian-Sarkissian et al. 2010; Sidani et al. 2018). Negative experiences with health care often create distance between the public and the system (Abelson et al. 2018). Patient engagement has the potential to bridge that distance between the public and the healthcare system (Abelson et al. 2018) and improve accountability, public trust, and confidence in the system (Poochikian-Sarkissian et al. 2010; Born and Laupacis 2012).

Barriers to PCC are related to providers, organizations, and patients. One of the questions often raised by providers and also by some researchers is whether patients were capable to engage. Not only in regard to children and patients with mental health disorders but also general patients; Butler and Fox (2019) argue that the acuity of patients’ conditions may make them emotionally and cognitively vulnerable and hence interfere with their ability to fully understand the nature, benefits, and the risks of alternative treatments. Frederics et al. (2012) state that self-management requires a certain level of cognitive functioning in order for patients to engage in

collaboration decisions. Proponents of PCC, on the other hand, suggest “activating patients”—a concept that refers to educational initiatives for the patients to enable them to better engage in their care (Snow et al. 2018). Other major barriers are time and resources, both of which are in short supply in the healthcare system. Providers fear that engaging patients in decision-making requires additional time and resources in an already overburdened care environment (Baker et al. 2016). Additionally, providers are under pressure to move patients through the system (Fox & Butler, 2016). Bedos & Loignon et al. (2011) state that providers will also need to hone their communication skills if they are to provide effective PCC. Finally, there is the cost of engagement for patients. Direct costs may include transportation and childcare, and indirect costs can include missed social or work opportunities (Snow et al. 2018).

This paper has a number of limitations. First, similar to all reviews, this study does not review the quality of evidence and synthesize various types of information from a wide range of study designs and methods. This study was limited to the English language, missing information from French, the second official language of Canada. This study focused particularly on healthcare settings and the databases were selected accordingly. While some patient-centered care might fall beyond the healthcare system, and may have been missed to be included in this research. Whereas there are some limitations, scoping reviews can become very large if some boundaries are not set around inclusion criteria.

Conclusion

In theory, patient-centered care has been primarily about respecting the human dignity of patients. In practice, though, patient engagement at varying levels and dimensions of care has replaced a true PCC approach. It is not that patient engagement is unimportant. On the contrary, the participation of patients in organizational change can make a valuable contribution toward patient-centeredness, but respecting the human dignity of patients in the patient–provider relationship has intrinsic value irrespective of saving lives. The ultimate measure of patient-centeredness must be respect for patient dignity and autonomy. The instrumentality of PCC can redirect attention to other dimensions of care (i.e., the longevity of human lives and representation of patients in organizational aspects of care). PCC interventions at any level (the clinical, organizational, or system level) must be measured by whether the care has been respectful of the dignity and autonomy of patients.

Appendix 1

Table 6 List of websites hand searched for patient-centered care models

List of websites hand-searched between July 22 – July 26, 2019

Public Health Agency of Canada (PHAC) <http://www.phac-aspc.gc.ca/>
 CanadaInfoway <https://infoway-inforoute.ca/en/>
 Canadian Institute for Health Information <https://www.cihi.ca/en>
 Health Canada <https://www.canada.ca/en/health-canada.html>
 New Brunswick Ministry of Health <https://www2.gnb.ca/content/gnb/en/departments/health.html>
 Newfoundland Ministry of health <https://www.health.gov.nl.ca/>
 Nova Scotia Ministry of Health <http://www.nshealth.ca/>
 PEI Ministry of Health: Minister of Health and Wellness - Government of Prince Edward Island <https://www.princeedwardisland.ca/en/topic/health-and-wellness>
 Ministry of Health Ontario: <www.health.gov.on.ca>
 Manitoba Ministry of Health: <https://www.gov.mb.ca/health/>
 Saskatchewan Ministry of Health: <https://www.saskatchewan.ca/government/government-structure/ministries/health>
 Alberta Ministry of Health: <https://www.alberta.ca/health.aspx>
 British Columbia Ministry of Health: <https://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/health>
 Yukon Ministry of Health <http://www.hss.gov.yk.ca/>
 Northwest Territories Ministry of Health: <www.hss.gov.nt.ca>
 Nunavut Ministry of Health: <https://www.gov.nu.ca/health>
 The Gathering Place <www.Kindnesswanted.ca>
 North End Community Health Centre <www.nechc.com>
 NB-Fredericton Downtown Community Health Centre <https://en.horizonnb.ca/home/facilities-and-services/facilities/fredericton-downtown-community-health-centre.aspx>
 Access Alliance Multicultural Health & Community Services <www.accessAlliance.ca>
 Vibrant Healthcare <www.vibranthealthcare.ca>
 Manitoba- Nine Circles Community Health Centre <www.ninecircles.ca>
 The Alex Community Health Centre and Community Food Centre <www.thealex.ca>
 Reach Community Health Centre <www.reachcenter.bc.ca>

Appendix 2

Table 7 Models of patient-centered care in Canada

No	Name of intervention	Setting	Province	Contents (goals, activities, outcomes)	Patient type	Role of patients	Provider type	Role of provider	Measurement	Source	Year
1	Best-practice guidelines for Clinical Nurse Specialist	Hospital	ON	Training and skills development - Decision-making in scientific/expert advisory committees of Health Canada - Information sharing - Regulatory activities - Engaging patients in quality improvement processes (organizational change) Decision-making as a part of committees Co-designed tests of change, delivered, and evaluated unit-level quality improvement initiatives with frontline staff.	Acute and chronic	Advisory	Clinical Nurse Specialist	Proximity to a patient: physical, narrative, moral proximity	Picker 8 dimension (Know/do/be approach) Professional Proximity with patients	Ford et al. 2011	2011
2	Regulatory decision-making in Canada	National Ministry	Pan	- Decision-making in scientific/expert advisory committees of Health Canada - Information sharing - Regulatory activities - Engaging patients in quality improvement processes (organizational change) Decision-making as a part of committees Co-designed tests of change, delivered, and evaluated unit-level quality improvement initiatives with frontline staff.	General Patients	Advisory	Regulatory committee	Policy decision-making	Professional Proximity with patients	Klein et al. 2016	2016
3	Transforming Care at the Bedside (TCAB) program Rapid cycle improvements to physical environment (Lean) Organizational change	Hospital (Academic Health Sciences Centre), QC	QC SK BC	Engaging patients in quality improvement processes (organizational change) Decision-making as a part of committees Co-designed tests of change, delivered, and evaluated unit-level quality improvement initiatives with frontline staff.	Patients	Partner Redesigning the care process, implementation	Nurses	Lead Patient safety, quality of care, and quality of work life	Transforming Care at the Bedside (TCAB) Program Aiming to address waste, inefficiency, and patient experience through an organizational change.	Baker et al. 2016	2016
4	Client and family-centred (CFCC) care Lean management system Development and design of the new Children's Hospital of Saskatchewan	Health Region, SK	SK	Engaging patients in quality improvement processes Redesign of the care process Advisors work together with staff to design and test rapid changes.	Patients and families	Advisory	Health care managers and providers	Leading quality improvement	Client and Family-Centered Care Measurement by Rapid Process Improvement Workshops (RPWs) per month	Baker et al. 2016	2016
5	Development of an evidence-based toolkit, the FReSH START Toolkit: Fracture Recovery for Seniors at Home: A Hip Fracture Guide for Patients and Families	Vancouver Coastal and Fraser Health Authorities, BC	BC	Engaging patients in quality improvement process Redesigning the care process (organizational change) Patients provided input and patient advisors	Hip fracture patients and families	Advisory	All health care providers	Development of toolkit in partnerships with patients and caregivers	Fresh START Toolkit	Baker et al. 2016	2016

Table 7 (continued)

No	Name of intervention	Setting	Province	Contents (goals, activities, outcomes) - Be as short and concise as possible	Patient type	Role of patients	Provider type	Role of provider	Measurement	Source	Year
6	Patient and professional partnership model (Partnership of Care program)- Integrated Health and Social Services University Centres- (CIUSSS) and centres without university affiliation (CISSS) were created	Hospitals, family medicine groups, long-term residences	QC	worked on the core team to codesign strategies for improvement. At the micro, meso or macro level; PPP had the following components: sharing information with patients, consulting with patients or focus groups on treatment, involving patients in decision-making and policy-making	Patients throughout the healthcare system	Decision-making, providing recommendations on health care priorities, participating in quality improvement projects	All providers	Providing patients' information on diagnosis and treatment options, involving patients in decision-making on treatment		Pomey and Lebel 2016	2016
7	Partnership for Care Program	Hospital	QC	Setting up continuous improvement committees: Joint decision-making to improve the quality of care	Patients	Advisor Quality improvement Committee members	All providers	Quality improvement committee members	Advisory role for patients – Organizational level	Pomey and Lebel 2016	2016
8	Patient advisor at the bedside	Hospital	QC	Centre for Hand Replantation and Revascularization	Patients	Advisor			Clinical level	Pomey and Lebel 2016	2016
9	Patients First Policy		ON	Involve people and their families in care planning	Patients with multimorbidity	Involved in decision-making on treatment	All providers	Involving patients in care plan and treatment goals	Patient survey	Kuluski et al. 2016	2016
10	Seniors Managing Independent Living Easily (SMILE) program		ON	Improves access to formal and non-traditional providers such as neighbors	Patients with multimorbidity	Improved access to providers	All providers	Involving patients in care plan and treatment goals	Patient survey	Kuluski et al. 2016	2016
11	Toronto Central CCAC's Integrated Client Care Program		ON	Patients and families are involved in co-designing a care plan. Each patient is assigned to a single pharmacy, emergency department and hospital, thereby fostering a more integrated experience	Patients with complex needs	Involved in co-designing care plan	All providers	Involving patients in care plan and treatment goals	Patient survey	Kuluski et al. 2016	2016
12	The Patient-Driven Care project	Community Hospital	Lakeridge, ON	1-Colleague consultation 2-Patient's "My story" 3-"Caught in the Act of Care" 4-"Caught in the Act of Care" Story	Post-Acute Patients	Share your story	All providers	Provide care and support one another.	Picker's questions showed improvement: 1-Respect and Dignity 2-Access to staff 3-Engagement in decisions	Shiozaki et al. 2017	2017

Table 7 (continued)

No	Name of intervention	Setting	Province	Contents (goals, activities, outcomes) - Be as short and concise as possible	Patient type	Role of patients	Provider type	Role of provider	Measurement	Source	Year
13	Patient Engagement Projects (PEPs) I & II		Pan	5- th NOD, name, occupation, DO?" Engagement of patients in the design, delivery and evaluation of health services	All types of patients and families	Design and evaluation of health services	All providers	Co-design health services with patients	Qualitative research (interviews, document review)	Fancott et al. 2018	2018
14	Partnering with Patients and Families for QI (PFEC)		Pan	Partnering with patients and families to improve quality across the healthcare continuum	All types of patients and families	Participating in quality improvement of healthcare organizations	All providers	Co-design health services with patients	Team surveys, social network analysis, document review, collaborative assessment scale, interviews	Fancott et al. 2018	2018
15	Better Together (part of larger campaign)		Pan	Building organizational capacity to assess, plan, implement, evaluate and sustain family presence and support patient- and family-centered care in hospitals	All types of patients and families	Participation in improving care services and evaluation	All providers	Co-design health services with patients	Surveys, document review, collaborative assessment scale, interviews	Fancott et al. 2018	2018
16	Health Canada's public involvement continuum Northumberland Hills Hospital's Citizen Advisory Panel (CAP) [Yolande et al. 2013]	Hospital	ON	Communication, listening, consulting, engaging and partnering with patients	All patients in hospitals	Involvement in decision-making, developing programs and services, evaluation	All providers	Providing inputs in decision-making	Patient survey	Born and Laupacis 2012	2012
17	Health Canada's public involvement continuum Kingston General Hospital Patient and Family Advisory Council	Hospital	ON	Including community members on the hospital board for decision-making on care services	All patients in hospitals	Decision-making on the care process	All providers	Providing inputs in decision-making	Patient survey	Born and Laupacis 2012	2012
18	Health Canada's public involvement continuum St. Michael's Hospital's Community Advisory Panels (CAPs)	Hospital	ON	Involving patients, family members, and hospital staff in the improvement of quality of care and patient experiences, development of patient-responsive facilities	All patients in hospitals	Involvement in decision-making, developing programs and services, evaluation	All providers	Providing inputs in decision-making	Patient survey	Born and Laupacis 2012	2012
19	Ontario's Family Health Team (FHT)		ON	Coordinated, integrated, and personalized care to patients, enhanced healthcare access	All patients in the family health center	Healthcare access, shared responsibility of own health care	Physicians at FHC	Provide integrated and personalized care to patients	The Ontario Health Quality Council uses billing data to assess quality of FHT	Rosser et al. 2010, 2011	2011

Abbreviations PCC, Patient-centered care

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Declarations

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