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Patient-centered care frameworks, models and approaches: An environmental scan

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Abstract

Although the definition of patient-centered care (PCC) remains unclear, researchers and healthcare professionals describe the concept as treating the patient as a unique human being with consideration for their physical and psychosocial needs and emphasize the importance of shared-decision making between patients and healthcare professionals. However, discussion around the connection and overlap between PCC and patient and family engagement (PE) has been limited. Some authors describe PE as an operationalization of PCC, while others consider PE a type of PCC. An enhanced understanding of PCC might allow for improvements in implementing PE across healthcare systems. Insight into the operationalization of PCC at a practical level may be attained through exploring models and programs introduced by various governments. We conducted an environmental scan examining models, approaches, and programs of PCC implemented by the governments of nine developed countries at regional and national levels, aiming to understand better how PCC is operationalized. We found seven major themes indicative of critical features of PE within PCC models: 1) recruitment and representation; 2) training and staff engagement; 3) rapport and relationships; 4) tools and support; 5) compensation and reimbursement; 6) knowledge translation; and 7) evaluation. Finally, we comment on how well the included PCC models promote diversity and cultural competence while highlighting the importance of cultural sensitivity and discussing potential strategies to integrate PCC and PE into healthcare activities.

Keywords

Patient-centered care, person-centered care, patient experience, patient engagement, models, frameworks, approaches, environmental scan, review).

Introduction

Patient-centered care (PCC), although widely used in many countries, remains a confusing concept with numerous meanings and definitions. Implementing PCC models has frequently been met with difficulties stemming from the absence of a clear and consistent definition.¹ However, there is some consensus on its core components which include a consideration for patient physical, emotional, and social needs; exchange of health-related information between patients and healthcare providers; respect for patients' beliefs; and shared decision-making.²⁻³ Recognizing, accepting, and respecting patients' perceptions and experiences regarding their health is critical for PCC.⁴ PCC advocates for viewing a patient as a whole and unique human being.⁵

PCC has been incorporated into healthcare through organizational models. For example, the Person Centered Medical Home Program⁶ approach coordinates and delivers accessible, culturally sensitive, and responsive patient care through primary care providers. There is also an overlap between PCC models and patient engagement

in research, organizational activities, and policymaking. For example, the Strategy for Patient-Oriented Research⁷ in Canada is a collaborative framework that fosters partnerships between patients, researchers, health practitioners, and policymakers by identifying patient priorities for health-related research, utilizing lessons derived from patient experiences and patient-oriented research to inform healthcare professionals in their practice, and incorporating research evidence into policies to shape a better healthcare system. Acknowledging patients' needs and desires in delivering health services is an essential component of care with many benefits, such as increasing patient autonomy, enhancing the continuity of care, and creating a collaborative environment where healthcare professionals act by individual patient preferences and concerns.^{4,8-10}

However, there is confusion regarding the connection between PCC and related concepts such as patient engagement (PE), patient collaboration, and patient involvement.¹ Concepts require clarity and accuracy for effective research communication.¹¹ An accurate and consistent understanding of PCC can aid in the practical

and meaningful operationalization of PCC models and an enhanced understanding of PE implementation. PCC models developed and implemented by governments offer great insight into how PCC is operationalized to improve health services at regional and national levels. We conducted an environmental scan of PCC models, approaches, and programs adopted by regional and national governments to examine the connection between PCC and PE.

Method

Approach

We conducted an environmental scan of grey literature to identify PCC models developed and published by governments at the national or regional level. An environmental scan captures a topic's scope using grey literature sources such as organizational documents, policy statements, and web pages.¹²⁻¹³ Environmental scans identify and categorize the descriptive characteristics of programs, policies, and interventions.

Document Retrieval and Eligibility

We searched on Google.com for organizational documents and webpages on PCC models, approaches, and programs (strategic plans for implementing PCC in healthcare systems) supported by national or regional governments.¹⁴ We used the following search terms: patient-centered care, patient experience, patient-reported outcomes, patient engagement/involvement/participation, shared decision-making, and integrated care. We were most interested in the publications by the national or regional governments of ten developed countries with similar healthcare systems¹⁵: Australia, Canada, Denmark, New Zealand, Norway, South Africa, Sweden, the United Kingdom, and the United States. This decision allowed us to compare PCC models in countries with similar healthcare systems. Peer-reviewed and published academic literature, models for patient care delivery unrelated to PCC, and models that the governments of interest did not support at a national or regional level were excluded.

Data Analysis

We developed a data extraction form to retrieve the characteristics of PCC models, including the model's name, date of development, country, name of publishing government body or agency, level of government (national or regional), and the primary PCC concepts. We conducted a descriptive analysis of these characteristics to gauge the overall distribution of the included literature.

We performed pilot coding to understand the scope of PCC models and generate categories reflective of overarching themes and shared characteristics. We looked for data in included PCC models that discussed PE or related concepts. During the initial coding stage, information was extracted from the included PCC models

and frameworks into a table with the following themes:

- Concepts, definitions, and principles: core concepts and levels of engagement
- The rationale for PE: experiential knowledge, organizational and patient benefits, and ethical imperatives
- Characteristics of PE: recruitment and representation, training/staff engagement, rapport and relationships, tools and support, compensation and reimbursement, knowledge translation, and evaluation

In focused coding, the researchers reviewed the extracted information and developed narrative summaries for each theme and subtheme. One reviewer consolidated all summaries to develop a holistic findings section, which was reviewed critically by the research team.

Results

Search Results

A total of 25 PCC models, frameworks, and programs were examined in this analysis. We identified seven major themes that highlighted characteristics of PE in PCC: 1) recruitment and representation; 2) training and staff engagement; 3) rapport and relationships; 4) tools and support; 5) compensation and reimbursement; 6) knowledge translation; and 7) evaluation. A list of the included PCC models, frameworks, and approaches can be found in the supplementary file. A summary of the findings can be found in Table 1 (see Appendix).

Recruitment and Representation

Sixteen (64%) PCC models and frameworks described approaches to recruiting individuals for PE programs and strategies to increase representation.^{6-7,16-29} Models of PCC focused on engaging individuals that had utilized a particular healthcare system or service, including patients, family members, and care partners.^{6-7,18-20,22,25,27-29} Individuals were recruited into PCC programs through different mediums, such as health-related websites, social media platforms, health organizations, and directly from the community.²²⁻²³ Diversity constituted an essential aspect of the recruitment process. One way to ensure representation from diverse communities was to recruit individuals with different diseases or medical conditions who were accessing different health services.²¹⁻²² One study established diversity by engaging people with “favorable” and “unfavorable” experiences with the healthcare system.²² Moreover, PCC frameworks emphasized the importance of ensuring that participants were culturally, demographically, ethnically, geographically, linguistically, and socioeconomically diverse, focusing on recruiting underrepresented and marginalized groups.^{7,19,22,24,26}

Training and Staff Engagement

Seventeen (68%) PCC models discussed training and encouraging staff members to encourage patient involvement in healthcare indirectly.^{6-7,16,18-22,24,26,29-35} The training was provided to healthcare professionals on the effective use of digital technologies, focusing on improving data quality and clinical coding.³² Developing practical communication skills that cater to different patients' needs emerged as a major training goal and a means to improve staff engagement.^{7,19,22,24,34} Patients were provided orientation and educational sessions on their rights, their role as advisors, managing their health and utilizing tools for engagement.^{7,21-22,35} Patients and their family members also received effective training on sharing their perspectives, experiences, and preferences.^{7,22,34} They delivered staff training and took on the role of teachers and collaborators.²⁴ Furthermore, undergraduate, postgraduate, and nursing students; specialist nurses; medical assistants; midwives; managers; new staff members; patients; and their representatives were all identified as groups that required PCC training.^{7,20-21,24,30,34-35}

Rapport and Relationships

Fifteen (62.5%) models and frameworks covered rapport and relationships as characteristics of PCC.^{6-7,18-19,22,24,28,30-31,33-38} Communication between patients and staff was regarded as integral for implementing PCC. Patients were provided personalized information regarding their health, potential treatment strategies, and associated risks. This allowed them to participate actively in conversations and decisions surrounding their care, seek a second opinion, and accept or deny treatment options based on individual preferences.^{18,30} Empathy was recognized as a critical component of conversations between patients, family members, and healthcare professionals.^{30,38} These discussions were held using clear, culturally appropriate language and focused on understanding patients' perspectives.^{6,24} Support was received from a named coordinator (i.e., a designated professional responsible for overseeing a patient's care throughout their stay in the hospital whom a patient can identify by name), and conversations with patients started with healthcare professionals introducing themselves and describing their role.^{19,35,37-38} Empanelment is a technique that ensures each patient is assigned to a primary care provider and care team with consideration for individual needs and preferences. Patients were connected with primary care providers through empanelment, allowing a more efficient distribution of healthcare resources.⁶

Tools and Support

Eighteen (72%) PCC frameworks detailed supports and tools available for patients, consumers, and healthcare professionals.^{7,18-19,21,23-24,26-36,38} Patients were provided with informational materials and educational support, such as introduction letters, fact sheets, information books, color-coded prompt sheets, and written care plans.^{19,24,34-35}

Communication was tailored based on age and health literacy.^{19,21,36} Indigenous community workers facilitated discussions between patients and healthcare providers.²⁴ Linguistic support was provided through translators and interpreters, and patients were also given access to religious, cultural, and peer support.^{18,21,26-27,35} An emphasis was placed on extending telemedicine and home-based services, including video conferencing, telephone options, web-based treatment programs, mobile dental services, access to specialist care, and mobile sampling.^{19,21,24,26} Patients were provided with materials introducing them to telehealth and telemedicine, and appointments were preceded by guidance from healthcare professionals delivered through video, verbal, and written formats.¹⁹ Materials were also extended to healthcare professionals to familiarize them with virtual care and telehealth.¹⁹ Moreover, staff members were provided regular educational opportunities to learn and integrate PCC into clinical practice.²⁸

Compensation and Reimbursement

Four (16%) PCC frameworks and approaches examined in this study identified the importance of compensation and reimbursement.^{6-7,22-23} An emphasis was placed on recognizing patients' contributions and thanking them for their participation.^{7,23} Patients were also provided monetary compensation that reflected their contributions to the program in terms of personal experiences, effort, skills, and time.⁷ Their expenses were reimbursed for participation in engagement activities.²³ For example, honorariums were provided to recognize patients' time and reimburse any costs associated with participating in PE activities.^{7,22} There was some flexibility in the types of compensation provided, such as different payment options, including donations to an organization of choice, gift cards, the opportunity to attend a conference, and training and courses.⁷

Knowledge Translation

Twelve (48%) PCC programs and models contained information on knowledge translation methods for patients, caregivers, and community members.^{6,16-18,20-21,23,28-30,37-38} The knowledge disseminated as a part of these programs covered information on 1) the nature of the disease; 2) potential treatment options; 3) medication and their side effects; 4) health services; 5) the rights and responsibilities of patients; 6) the rights and responsibilities of care partners; 7) accessing appropriate health services; 8) insurance policies; 9) learned skills; and 10) increasing PE in health service design and delivery.^{6,16,18,21,29,38} PCC models emphasized the need to identify effective strategies for disseminating information from PE programs and improving knowledge dissemination at local, regional, and national levels.^{17,30}

Evaluation

Seventeen (68%) models included information on how various PCC approaches or programs were evaluated.^{6-7,16-18,21,23-24,26-27,29-32,34,37-38} Outcomes typically included patient experience, patient satisfaction, quality of life, duration of stay in the hospital, adverse events, frequency of negative feedback, staff satisfaction, recruitment and retention of staff, and conflict resolution.^{17,21,24,31,34} Surveys were administered to patients and staff members to obtain data on patient experiences of care and patient and staff satisfaction.^{16,24,34} Patients were allowed to provide feedback on engagement activities and health services and voice their concerns and complaints.^{6,18,23-24,27,38} Moreover, PCC programs were assessed through performance reviews for staff members, including accountability for ensuring a positive, person-centered experience for patients.^{24,26,34}

Discussion

As a part of this environmental scan, we examined 25 PCC models, frameworks, and approaches implemented at a regional or national level by the governments in Australia, Canada, Denmark, New Zealand, Norway, South Africa, Sweden, the United Kingdom, and the United States. We found seven overarching themes that reflected how PCC is operationalized and its connection to PE: recruitment and representation; training and staff engagement; rapport and relationships; tools and support; compensation and reimbursement; knowledge translation; and evaluation.

Diversity

Previous research has found that minorities and marginalized communities receive lower quality care than Caucasian people, including poor patient-provider communication and rapport.³⁹ We identified diversity as a central concept in the frameworks included in this environmental scan. The PCC models analyzed in this study were focused on engaging individuals from diverse backgrounds with an emphasis on underrepresented, marginalized, and Indigenous communities.^{7,19,24,26} Participants were provided with cultural, linguistic, and religious support, for example, access to translators, interpreters, or peers. At the same time, staff members received training on indigenous communities' culture, needs, and communication preferences.^{18,21,26-27,35}

Cultural competence is a cornerstone of PCC. Providing care for minority populations in a culturally competent setting might lead to equitable access to high-quality care. Anderson et al.⁴⁰ have suggested that the following items contribute to the provision of culturally competent care: 1) diverse healthcare professionals that are reflective of the broader population; 2) availability of informational material in the patients' language, written in a culturally sensitive manner; 3) access to translators, interpreters, and healthcare staff that speak patients' language; and 4)

comprehensive training for staff to improve cultural awareness. Three of these four items were addressed in the models analyzed in this study. We found an emphasis on engaging ethnically diverse groups of individuals, using culturally appropriate language during patient-provider discussions and informational materials, and offering translators and other cultural or religious aids to health service users.^{6-7,18-19,21-22,24,26-27,35} We noticed that healthcare providers were extended training to enhance their cultural awareness where necessary based on the population they served. For example, in one model, healthcare professionals from Australia were given thorough training on the health-related needs and concerns of indigenous people and their culture and communicated with them in a culturally appropriate manner.²⁴

Although research suggests that most patients belonging to ethnic minority populations are treated by clinicians identifying as a part of the same ethnic community,⁴¹ we found no mention of measures to promote diversity among healthcare professionals in the included PCC models. This is likely because increasing diversity in healthcare staff requires systemic level changes, such as revising admission policies to improve the representativeness of medical students⁴² and other health-related education programs and promoting inclusive hiring practices to increase the representativeness of healthcare professionals, which are challenging to implement.

A more feasible approach is to promote cultural sensitivity among healthcare professionals as a part of these models. Integrating aspects of cultural sensitivity into clinical practice and health promotion leads to improved patient health outcomes.⁴³⁻⁴⁴ Although healthcare providers can only be familiar with some cultures, they should possess the skills to deal with diversity issues when providing care adequately. These skills should be fostered through workshops introducing healthcare professionals to ethnicity and culture, outlining the differences between Eastern and Western communities, and explaining the significance of cultural sensitivity and the multidimensional concept of cultural identity.⁴⁵⁻⁴⁶ Healthcare professionals should be encouraged to engage in activities that allow them to explore their cultural beliefs and practices, such as conversations surrounding naming practices in their family and community and the story behind their birth name.⁴⁵ Cultural sensitivity training should also help healthcare professionals become more aware of implicit biases during medical consultations.⁴⁶ This may be achieved through exercises where healthcare professionals recall some of their earliest memories of interacting with an individual belonging to a minority group and reflect on how such experiences have influenced their clinical practice.⁴⁵

Moreover, healthcare professionals should be trained to include cultural history as a part of medical history taking, possibly through case vignettes and an introduction to a

series of questions that may encourage patients to reveal their cultural backgrounds.⁴⁶ Healthcare professionals should be educated on handling microaggressions in their practice appropriately and acceptably.⁴⁶ Where possible, international placements should be incorporated or offered as a part of education and professional training programs, allowing healthcare professionals to build their cultural sensitivity while adjusting and adapting to a different culture, an experience that may help them better understand patients who might be living in a country where the host culture is different from their ethnic background.⁴⁷⁻⁴⁸ Including cultural sensitivity training as an essential component of PCC models and frameworks may culminate in greater cultural awareness; a more open-minded attitude; and enhanced communication skills among healthcare professionals,⁴⁹ equipping healthcare professionals with the ability to respond effectively to the needs and concerns of patients from ethnic minority backgrounds, facilitating the provision of PCC for these individuals, potentially leading to increased patient satisfaction and in turn, greater adherence with their care plan and treatment.

Limitations

This study also has some limitations. Firstly, we did not review models and programs being implemented locally because this study would not have been feasible. Local PCC models and frameworks may have provided additional insight into PCC characteristics by providing other exciting or unique initiatives that could be taken up on a larger level. Moreover, it may have helped us understand the relationship between local PCC models and goals and regional and national PCC models and goals. Secondly, our search for PCC models was limited to ten developed countries. Examining PCC programs from other countries may broaden our understanding of how PCC varies across cultures. This additional insight may allow us to compare how PCC differs between developed and developing countries.

Conclusion

Recruitment and representation; training and staff engagement; rapport and relationships; tools and support; compensation and reimbursement; knowledge translation; and evaluation constitute key characteristics of PCC models in developed countries. Existing programs and models attempt to promote culturally competent care but must feasibly incorporate means to increase diversity among healthcare professionals. Governments should instead focus on fostering cultural sensitivity through PCC models and programs through proper training that will enable the healthcare team to handle diversity issues adequately.

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Appendix

Table 1. Summary of Findings

Characteristics of PE	Findings
Recruitment and representation	<ul style="list-style-type: none"> • Patient opinions on service planning, program development, and policymaking were reflective of the views and needs of the broader population^{7,27} • Recruitment was a proactive effort that emphasized active enrollment of patients instead of waiting for individuals to express interest²³ • The involvement of representatives from Indigenous communities was highlighted with the aim of reducing cultural barriers faced by these populations^{7,19,24,26} • Children, adolescents, and elderly individuals were identified as priority populations for engagement^{21,23-24,26} • Increasing representation for individuals with special needs and disabilities and encouraging the prioritization of engagement in the development and improvement of health services catered towards people experiencing mental health concerns^{21,23-24,26} • Programs involved the participation of the local community and public in policymaking, governance, and the design, development, and implementation of healthcare services^{18,21,23,26-27}
Training and staff engagement	<ul style="list-style-type: none"> • Digitalization of healthcare allowed staff to provide care and treatment online³⁰ • Several models delivered at least part of their training on PCC through online modules^{6,31-32} • There was a focus on enhancing communication abilities over telehealth and telemedicine¹⁹ • Healthcare professionals received access to DVDs with information regarding Aboriginal and Torres Strait Islander people, enabling them to gain a better understanding of their community, culture, needs, and concerns²⁴ • DVDs contained information on appropriate communication to help healthcare professionals develop skills that would allow them to hold health-related discussions with indigenous people in a sensitive manner²⁴ • Models identified the importance of incorporating PCC into educational programs for both undergraduate and postgraduate students²⁴ • Nursing students received education and training that covered patient experiences and highlighted the importance of PCC while specialist nurses were offered the opportunity to access continuing education²⁴ • Some models adopted a lifelong approach towards training which facilitated skill development, increased adaptability, and promoted PCC-related activities in hospital units^{21,30,33} • A culture of full-time employment was fostered with a focus on increasing recruitment and retention of healthcare professionals, encouraging them to establish lifelong career trajectories²¹
Rapport and relationships	<ul style="list-style-type: none"> • Patients' views were frequently requested through patient boards³⁶ • Communication between patients, families, and medical professionals facilitated the development of a mutually beneficial partnership in which all parties shared their experiences, skills, and abilities^{7,22,30} • Communicating updated information regarding waiting times, changes in condition, and care-related decisions to patients and families while checking for understanding was crucial^{24,28,35} • Frameworks of PCC stressed upon the importance of both active listening in health-related conversations and integrating values, cultural norms and beliefs to create personalized, sensitive care plans^{28,35} • Other means of establishing rapport included asking patients for preferred names, closing doors and curtains when talking to patients about their health, and providing bed boards for patients to keep track of their daily goals and helping them identify the healthcare professionals responsible for their care³⁵ • The camera was placed at eye level during virtual appointments such that both the patient and the healthcare professional were on the same level¹⁹ • Continuity of care was critical and medical professionals taking responsibility for a patient's care and treatment must not abandon them³⁸

Table 1. Summary of Findings (cont'd.)

Characteristics of PE	Findings
Tools and support	<ul style="list-style-type: none"> • Patients were extended information on self-management strategies to help deal with their health concerns³⁵ • A great deal of emphasis was placed on the use of simple and plain language and the avoidance of jargon in both informational materials and conversations with patients^{21,23-24,27,34,38} • Other forms of support included the provision of quiet rooms and lounge areas, accessible call bells, appropriate lighting, and same-gender accommodation³⁵ • Where only mixed-gender accommodation was available, it was ensured that patients' safety and support needs were being adequately addressed³⁵ • Navigators, consumer advocates, and volunteers were used to relay information to patients, connect them to the appropriate services, resolve complaints, and provide assistance when needed²⁶ • A program for advanced care was implemented at the national level in Australia which enabled individuals to record their healthcare preferences and choices, planning for a time when they would not be able to make these decisions themselves²⁴ • A component of delivering PCC involved the digitalization of health services and the introduction of new technology to improve the distribution of healthcare resources and provide better treatment²¹ • Healthcare professionals working as a part of the National Health Service in Scotland were given packages with guidance on providing individualized health-related advice to patients and their families²⁹ • Tools were utilized to support healthcare organizations and practices in understanding and interpreting collected data with suggestions that such tools be specifically tailored to each of the various parts of care³⁰⁻³¹
Compensation and reimbursement	<ul style="list-style-type: none"> • The rate at which participants were paid was determined using a Financial Administration Manual in a manner that aligned with government guidelines on how patients and families serving in an advisory role should be compensated²² • Honoraria covered expenses related to childcare, eldercare, transportation, and parking²² • Individuals attending out-of-town events were reimbursed for costs associated with meals, accommodation, and transportation²² • Consistency in the rates of compensation was vital in implementing PCC⁷ • Compensation for indigenous elders and knowledge keepers was governed by a separate protocol whereby they were given a flat rate for each day of contribution independent of the hours worked and reimbursement for costs associated with participation in engagement activities along with a gift such as a scarf, tea, or blanket⁷
Knowledge translation	<ul style="list-style-type: none"> • Annual general meetings and board meetings were opened to the general public²³ • Meetings were streamed live and the recordings were uploaded to the organization's website post-meeting²³ • Agendas and schedules were published prior to meetings while the meeting minutes were made available after the meetings had ended¹⁷ • Information was communicated through the distribution of complimentary newsletters and annual reports^{16,23}
Evaluation	<ul style="list-style-type: none"> • Questionnaires were generally distributed on an annual basis or prior to and after the completion of the PCC program^{24,27,31,34} • Feedback was incorporated into the model while complaints were thoroughly investigated and addressed^{27,38} • Other means of evaluation comprised of benchmark reports, weekly quality improvement meetings, and self-assessments for managers^{6,30-31} • A Quality Alliance was established for regularly monitoring the quality of one PCC initiative in Scotland while in another Scottish model, experts, local authorities, and decision conferences assessed several proposals for PCC initiatives^{16,29}