

Putting the Patient First: A Scoping Review of Patient Desires in Canada

Donner la priorité au patient : examen de la portée des souhaits des patients au Canada



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Abstract

Patient-centred care is a key priority for governments, providers and stakeholders, yet little is known about the care preferences of patient groups. We completed a scoping review that yielded 193 articles for analysis. Five health states were used to account for the diversity of possible preferences based on health needs. Five broad themes were identified and expressed differently across the health states, including personalized care, navigation, choice, holistic care and care continuity. Patients' perspectives must be considered to meet the diverse needs of targeted patient groups, which can inform health system planning, quality improvement initiatives and targeting of investments.

Résumé

Les soins axés sur le patient sont une priorité clé pour les gouvernements, les fournisseurs et les intervenants, mais on en sait peu sur les préférences de soins des groupes de patients. Nous avons effectué un examen de la portée dans lequel 193 articles ont été analysés. Cinq états de santé ont été utilisés pour rendre compte de la diversité des préférences possibles en fonction des besoins en santé. Cinq grands thèmes ont été identifiés et exprimés différemment selon l'état de santé : les soins personnalisés, la navigation, le choix, les soins holistiques et la continuité des soins. Le point de vue du patient doit être pris en compte afin de répondre aux divers besoins des groupes ciblés, ce qui peut éclairer la planification du système de santé de même que les initiatives visant l'amélioration des soins ainsi que le ciblage des investissements.

Introduction

Increasingly, policy makers and health system managers are considering the perspectives and experiences of patients in reforming health systems (1–5). The emphasis on “patient-centred care” places patients (and caregivers) at the forefront of the planning, delivery and evaluation of healthcare services (2, 6, 7). The recently established Ontario Minister’s Patient and Family Advisory Council (PFAC) is the first of its kind in Canada and provides a formal mechanism for incorporating patient and family perspectives into decision making and system planning (7, 8). The idea of organizing healthcare around the patient seems, at first, uncomplicated, yet the concept itself is complex, and the application of the concept is multifaceted. The Institute of Medicine (IOM) informs much of the discourse and application on this topic (5). In this context, *patient-centred care* refers to “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (5: p. 3). As described by the IOM, the concept applies not only to care delivery but also to system planning and research (5). It also relates closely to patient experience and engagement (4, 9). Whereas *patient engagement* aims to solicit patient and family input based on their needs and preferences to co-design solutions (4), *patient experience* is defined as “how patients perceive and experience their care” (10).

The effective design and delivery of patient-centred care require a comprehensive understanding of the needs, desires and preferences of patients. Although high-performing health

systems identify patient-centred care as a critical health system priority, the healthcare system is often criticized because of its tendency to focus on the needs of healthcare providers, who often do not have a comprehensive understanding of patient needs. Alongside policy makers' increasing interest in patient-centred care is a growing body of scholarly research that aims to understand patient experiences with and their perspectives on the health system. Furthermore, when patient needs are explicitly recognized, the system is designed based on generalized assumptions of these needs, as if patients are a homogeneous group, yielding a "one size fits all" approach. Previous research has suggested that patients' needs vary significantly across different patient populations (6–10), but this research has not yet been systematically reviewed.

The purpose of this study was to gain a systematic understanding of the preferences of Canadian patients and, where possible, their caregivers. This information can be used to inform the design and tailored delivery of healthcare services for different patient and caregiver groups.

Methods

This scoping review follows the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (11), as well as Arksey and O'Malley's stepwise approach to conducting a scoping review (12).

Search strategy

We used the PICO (population, interest, context) framework for qualitative studies to operationalize the research purpose into searchable keywords (13). Four databases were searched in January 2019 (OVID Medline, CINAHL, EMBASE and PsycInfo). To maximize search results and derive search results that were manageable and focused, we conducted four separate searches within each database involving various combinations of Boolean operators (and/or) for life stage, health stage and population of interest. These searches are listed below:

- Search 1: Patients OR caregivers OR health stage, AND interest AND context
- Search 2: Patients OR caregivers OR social status OR health stage, AND interest AND context
- Search 3: Life stage OR health stage, AND interest AND context
- Search 4: Life stage OR health stage OR social status, AND interest AND context

Appendix 1 (available online at longwoods.com/content/26499) presents the application of Search 1 to OVID Medline. Search restrictions were imposed on language (English), setting (Canada, provinces/territories) and date of publication (January 2013 to December 2019). Pulling articles from 2013 onward was a practical and purposeful decision (12) as we wanted to obtain a manageable number of articles that was reflective of current Canadian

opinions of the health system, not a historical understanding of how needs have changed. To ensure a valid and reliable search, this search process was guided by a trained medical sciences librarian.

Study selection

Two reviewers performed a title/abstract screening of all articles following the removal of duplicate articles. The same reviewers then both performed the full-text review on all remaining articles. Articles were included if they met inclusion criteria concerning study setting (Canada and/or a Canadian province), study participants (patients of all ages and/or family/friend/caregiver) and study topic (healthcare experiences).

Data extraction and analysis

To account for the diversity of health needs across the Canadian population, we hypothesized five identifiable health states to organize patient groups, described in Table 1. Health states were initially identified within our interdisciplinary team and were adapted based on the presentation of populations within the literature (8–10, 14, 15). Although other health states could have been used for categorization, the five were generally quite effective and appropriate for describing the health needs found in studies. Studies were organized by health state based on the description of the population included in the study. It is possible that some populations may have fallen across multiple health states. In such cases, two reviewers independently allocated articles to the most appropriate health state, and disagreement was reconciled by the principal investigator. Appendix 2 (available online at longwoods.com/content/26499) provides a tally of how many articles spoke to each health state across a variety of life stages, which include age and other population subgroups (i.e., LGBTQ+ populations).

TABLE 1. Five health state categories and definitions

Health state	Definition
Walking well	Those who use primary preventive and alternative care to maintain health and well-being
Chronic conditions	Those who live with one or more chronic diseases and see more than one provider
Acute life-threatening	Those who seek care in emergency departments or have short intervals in hospitals
Mental/cognitive health and addictions	Those who seek care for mental health issues and/or addictions in any care setting
Palliative/end-of-life care	Those who receive end-of-life support and care in any setting

Two reviewers were responsible for independently extracting data from all articles following a pilot extraction of two articles. The extraction table included details on the study itself (i.e., year, purpose, location, population of interest, methods, key findings, etc.). All key findings were summarized within the extraction table, and representative quotations were pulled from the document. Following completion of the extraction, three researchers systematically reviewed the data, focusing mostly on the summarized key findings, and coded

details based on life stage (pediatric, youth and children, young adult, adult and older adult) while colour-coding experiences based on health state, as described above. Following this coding, an inductive thematic analysis was then conducted by three reviewers to summarize findings and themes (16), where the three researchers met to discuss consistent themes across life and health states. As themes and consistent experiences were identified, the researchers looked to identify both the similarities and the differences in desires across health stages.

Results

The PRISMA Flow Diagram (Appendix 3, available online at longwoods.com/content/26499) presents the article selection process. A total of 12,341 studies were pulled across all databases searched; 7,763 and 4,127 articles were excluded following deduplication and title/abstract screening, respectively. Full-text screening was then performed on the remaining 451 studies, and 193 were included for analysis (17–208). Appendix 4 (available online at longwoods.com/content/26499) presents a summary of all included articles, including author(s), year, location and aim. Recognizing that the populations studied may fall within different health states, we include a matrix tally that illustrates the overlap in health states across the studies included (Appendix 2, available online at longwoods.com/content/26499). Additionally, where data were available, the results highlight the perspectives of patients and caregivers. The majority of papers spoke to patient perspectives only, and in those instances we discuss the results and refer only to patients. If caregivers' perspectives were reported in the literature, we reference patients and caregivers together.

Among many possible areas on which to focus health system improvement, there were common preferences expressed across health states (summarized in Table 2) within the included articles. Table 2 demonstrates these reported preferences; if a preference was identified in the literature and associated with a particular health state, there is a check mark. These preferences were generally described to be of equal importance: 1) personalized care; 2) information on resources available and how to navigate the system; 3) choice in treatment, care setting and/or care provider; 4) holistic care and non-medical supports to overcome barriers to accessing care; and 5) care continuity (including care coordination).

TABLE 2. Overview of themes (preferences) across health states

Preference	Health states				
	Walking well	Mental and cognitive health	Acute life-threatening	Chronic conditions	Palliative care
Personalized care	✓	✓	✓	✓	✓
Information	✓	✓	✓	✓	✓
Choice	✓	✓		✓	✓
Holistic care and non-medical supports	✓	✓	✓	✓	
Coordinated care and continuity of care		✓		✓	✓

The following describes overarching preferences common to two or more health states as presented in the literature. We then explore the subtle nuances between health groups (unique preferences expressed by one health state), which are summarized in Table 3. These themes and the nuances within them have different implications for how the health system could be shaped or reshaped.

Personalized care

Within the literature, across all health states, personalized care was broadly characterized as representing respectful behaviour toward the patient, providing care in a preferred language, healthcare provider (HCP) awareness about the needs of vulnerable populations and delivery of care that considered both social and medical needs (25, 27, 31, 33, 39, 45, 50, 53–55, 57, 62, 68, 69, 74, 77, 79–81, 82, 85, 88, 90, 94, 99, 100, 102, 106–109, 111, 114, 116, 118, 119, 122, 124, 134, 135, 136, 141, 142, 147, 150, 154, 156, 158, 163, 165, 169, 172, 174, 176, 179, 184, 192, 193, 195–204, 208, 209). Consistent within the reviewed literature, patients and caregivers identified a preference for care that was holistic, individualized and culturally competent (19, 28, 53, 69, 74, 76, 80, 94, 99, 100, 102, 107, 108, 116, 121, 122, 124, 129, 132, 134, 135, 156, 162, 168, 176, 178, 180, 195, 197, 201, 208). Since care avoidance was often attributed to a fear of being stigmatized or judged, patients saw value in HCPs receiving diversity training.

Although holistic, individualized and culturally safe care was a common preference across all health states, respecting linguistic needs, such as a provider who speaks the patient's language or availability of interpretation services, was particularly important to the walking well group (53, 69, 74, 94, 99, 100, 102, 107, 108, 116, 122, 124, 134, 135, 156, 176, 195, 197, 201, 208).

Information

In the reviewed literature, all the health states expressed a preference for information from their HCP concerning resources available outside hospital walls (17, 21, 27, 31, 61, 64, 65, 70, 75, 87, 89, 92, 103, 110, 117, 121, 129, 139, 158, 163, 166, 167, 171, 173, 175, 178, 183).

Although the preference for information was evident across all the health states, the specific information needs differed between the groups. For example, the walking well group was interested in information on funding resources (117, 121, 129, 178). The acute life-threatening and chronic conditions groups were both interested in knowing the next steps after leaving the hospital (21, 22, 31, 50, 61, 64, 65, 70, 75, 87, 89, 92, 103, 110, 123, 130, 139, 154, 158, 163, 166, 167, 171, 175, 183, 196, 204). However, the chronic conditions group wanted to know about care plans and community resources given their prolonged trajectory of illness (21, 31, 50, 61, 64, 65, 70, 75, 87, 89, 92, 103, 106, 123, 139, 158, 163, 166, 167, 171, 175, 183). The walking well patient group and the mental health and addictions patient group noted the preference for online resources that would support improved self-management of health opportunities (23, 24, 28, 76, 96, 102, 124, 128, 168). The walking

well and palliative care groups wanted information regarding illness prognosis and treatment outcomes (e.g., drug side effects) in order to make informed decisions. Whether a decision was less sensitive (e.g., the decision to get screened for a medical condition or to receive a vaccination) or more sensitive (e.g., decision making around end-of-life care) did not obviate the need for comprehensive information (17, 23, 24, 27, 28, 76, 96, 102, 124, 128, 168, 173).

Choice

Choice was preferred in four of the five health states in the reviewed papers. Groups who have a more prolonged course of illness (mental health and addiction, chronic disease and palliative care) wished to have choice in areas related to the involvement of their caregivers and in which setting to receive care (25, 27, 30, 31, 42, 82, 89, 92, 110, 112, 119, 150, 153, 160, 163, 166, 169–171, 181, 185, 186, 194, 198, 200).

Choice of HCP and choice of setting for the care services were particularly important for the walking well group (19, 24, 32, 41, 46, 59, 94, 104, 113, 115, 117, 125, 128, 132, 138, 140, 145, 149, 156, 161, 177, 195, 201, 206, 207). However, this was not the case in the acute life-threatening group, which likely relates to the short-term relationship that a patient often has with hospital-based providers. Patient groups with prolonged disease trajectories (i.e., chronic conditions and mental and cognitive health issues) wanted their caregivers to be partners in their care (39, 42, 43, 72, 119, 163, 170, 171, 185, 186, 189, 194, 202, 209).

Holistic care and non-medical supports

These supports were preferred to overcome barriers to accessing care among the walking well; those with chronic conditions; those with mental, cognitive and addiction-related issues; and those with acute life-threatening illnesses (19, 28, 39, 55, 72, 76, 90, 94, 99, 116, 121, 124, 129, 132, 134, 147, 150, 154, 168, 169, 172, 178, 195, 198, 200, 201, 208). The relationship between HCPs and patients was important across all of these health states. Interactions with HCPs were described positively in many cases, representing the trust that patients (particularly older patients) and caregivers placed within their HCPs. However, patients wanted HCPs to be more respectful of patient needs and treatment preferences; offer non-judgmental care; communicate in ways that patients and caregivers can understand; allow more time during patient interactions to listen to patients; treat and consider social needs; and help them navigate the healthcare system (discussing next steps, available resources and treatment options).

In terms of variations across patient groups, for the walking well group, holistic care meant being able to access non-Western approaches to healthcare free of financial barriers, including traditional Chinese medicine (28, 74, 76, 94, 99, 116, 121, 124, 129, 132, 162, 168, 178, 195, 201, 208). For the mental and cognitive health groups, holistic care specifically meant being able to access spiritual and culture-based services (39, 55, 72, 90, 147, 150, 169, 172, 189, 198, 200).

Coordinated, continuous care

Coordinated, continuous care represents an uninterrupted relationship with the same primary care provider. This is particularly significant given their critical role as gatekeepers and the first point of contact in the health system. This preference was expressed by all three health states, where patients live with multiple conditions or receive care from multiple providers (chronic conditions, palliative care and mental and cognitive health groups) (25, 27, 34, 43, 45, 65, 72, 75, 83, 123, 126, 152, 157, 163, 166, 169, 181, 185, 189, 198, 202). For the two groups who often receive care from more than one HCP – chronic conditions and mental health and addictions – coordinated transitions across various care settings were deemed vital (25, 34, 42, 43, 45, 65, 72, 141, 148, 157, 169, 189, 198, 202).

For the mental and cognitive health group, coordination of services while transitioning from youth to adult care services was important given the early onset and long-term nature of diseases affecting this group (126, 152). For the chronic conditions group, coordinated flow of information among providers and receiving care from interdisciplinary teams was crucial (21, 42, 148, 159, 169, 170, 181). For the palliative care group, there was a strong preference for both an ongoing relationship with their providers and having the same provider until the end of life (17, 26, 27).

TABLE 3. Differences in patient group stated preferences, by health state

Health state	Preferences				
	Personalized care	Information	Choice	Holistic care and non-medical supports	Coordinated, continuous care
Walking well	Availability of interpretation and translation service	Clear presentation of funding and insurance options	Choice in the type of provider Choice in healthcare setting	Access to non-Western medicine approaches	
Mental and cognitive health		Access to HCPs who are aware of mental health resources, offer early dissemination of counselling information and understanding of disease trajectory	Include caregivers as partners in care	Exposure to spiritual care	Support transitions from youth to adult services
Acute life-threatening		Information on discharge procedures, care plans and disease trajectory			
Chronic conditions		Support with filling out complicated forms Understanding of discharge procedures and care plans Improved channels to access personal health information	Include caregivers as partners in care		Continuity in information and understanding between providers Access to interdisciplinary teams
Palliative care		Information around possible complications Support with filling out complicated forms			Continuous and ongoing relationships with HCPs, particularly when transitioning from acute to palliative and end-of-life care

As presented in Table 3, there were some nuances in how patient groups perceived the five common preferences across the different health states in the reviewed papers. Although holistic, individualized and culturally safe care was a common preference across all health states, respecting language preferences and needs was of particular importance for the walking well group (53, 69, 74, 94, 99, 100, 102, 107, 108, 116, 122, 124, 134, 135, 156, 176, 195, 197, 201, 208). Access to information was expressed differently across health states. For example, the walking well group was interested in understanding the availability of funding (28, 76, 121, 132, 168, 195, 201) whereas the chronic conditions group was more interested in having access to their health information and community resources (21, 31, 61, 64, 65, 70, 75, 87, 89, 92, 103, 110, 123, 139, 158, 163, 166, 167, 171, 175, 183). The ability to choose their provider and healthcare settings was notable for the walking well group (24, 46, 113, 149, 207). Those with a chronic condition or mental health illness noted that they preferred the choice to engage their caregivers as partners in care. For the walking well and mental and cognitive health groups, holistic care was about accessing care that goes beyond traditional medical services to spiritual and culture-based services (28, 74, 76, 94, 99, 116, 121, 124, 129, 132, 162, 168, 178, 195, 201, 208). For the mental and cognitive health groups, coordination of services meant smooth transitions from youth to adult services (126, 152). For the chronic conditions group, coordinated flow of information among providers and receiving care from interdisciplinary teams were important (21, 42, 148, 159, 169, 170, 181). For the palliative care group, this meant having ongoing relationships with the same provider until the end (27).

Interpretation

Recognizing the diversity of experiences, values and expectations that reflect the broader health and socio-demographic profile of Canadians, a comprehensive understanding of the current needs of patients and their caregivers is needed to better inform tailored, patient-oriented and equitable approaches to health system design and health service delivery. Although patient-centred care is ultimately an individual concern, this review reveals five broad preferences across a wide range of patient groups, which we have further subcategorized as five distinct health states. Even with similarities across health states, the way these preferences and needs were expressed and the examples of changes to healthcare systems that were suggested differed across these groups. These differences have implications for provincial and territorial as well as more local (based on geography or defined population) health systems in Canada in terms of how they should be shaped or reshaped.

Past research eliciting the views of healthcare users has largely focused on the needs and experiences of disease-specific groups – for example, those with diabetes (105, 106, 153). Much of the healthcare system, however, is not organized around disease-specific groups, as clearly illustrated in the case of primary care. This review has shown that needs can be organized around health states and that disease state does have an impact on care preferences.

Provincial governments in Canada are initiating a number of changes to achieve more integrated and coordinated care. With the consolidation of all the province's health regions into a single province-wide health authority (Alberta Health Services) in 2008 and, more recently, the introduction of Primary Care Networks, the Government of Alberta has tried to better coordinate care through aligning governance structures. British Columbia is working toward patient medical home and primary care network models to improve the needs of patients by linking integrated systems of care between health professionals, networks and coordinated specialty services within the community. Similarly, Manitoba's creation of "shared health" is an attempt to centralize services and offer an integrated clinical services plan. In Ontario, this has manifested as Ontario Health Teams (OHTs). It is hoped that OHTs will coordinate care at an organizational level (shared governance, shared medical information and streamlined approaches to funding, with local regions' spending autonomy based on patient demographics and regional needs). However, the degree to which these efforts align with patient desires, as well as how all of these approaches will consider patients' needs and preferences in health service delivery, remains unknown. The results from our study align with notions of integration proposed by Singer et al. who view integrated care as a concept that should be built around the patient and as composed of two pillars: coordinated care across time and between settings (which OHTs aim to address) and patient- or person-centredness (210). The latter is where the results from our study are particularly relevant in the ongoing evolution of health systems to be integrated. Additionally, with the effort to achieve Quadruple Aim outcomes to improve patient/caregiver experience, population health and provider experience and to maintain per capita costs, this research becomes increasingly relevant to inform evaluative efforts to ensure that measurements are capturing the identified desires of patients and caregivers depending on the priority population.

Patient-centred care improves health outcomes and is instrumental to addressing racial, ethnic and other healthcare inequities. We identified four areas where this work could be used to inform the development, implementation and evaluation of integration efforts across Canada. This includes how patients, specifically members of each of the different health states, should be *engaged in planning and improvement efforts*. Additionally, depending on the targeted priority population, these findings could help inform which partners and/or care providers should be considered part of the integrated care team (i.e., having caregivers included as part of the care team for those living with chronic conditions) and support *public and patient involvement*. As Canadian jurisdictions transition toward more integrated health systems, they will require measurement and evaluation plans. These findings will inform the development of *quality improvement plans* and the construction of *meaningful outcome measures* that consider the differences and needs between and among health states (i.e., access to transparent information with treatment plans for individuals living with acute life-threatening illnesses). Finally, *targeted investments* to improve the system must consider the potential magnitude of any benefits given that different patient populations will benefit to different degrees (i.e., directing resources toward online information for individuals living with mental health illnesses).

Limitations

First, the experiences with and perspectives on the health system presented in this review do not necessarily represent a full or comprehensive characterization of people who could fall within the respective health states. Relatedly, we recognize that patient populations may fall into multiple health states. This reinforces complexities in addressing gaps in health service delivery, particularly for Canadians living with multiple morbidities. Second, our characterization of health states was based on the literature, but other groupings or subgroupings would likely identify further distinctions. However, the hypothesized categorization comprehensively described the identified literature, with few exceptions. Third, much of the literature was reflective of patients and caregivers living in urban settings, with few studies focusing on the perspectives of patients and caregivers living in rural and/or remote locations of Canada. The collective literature was also relatively less reflective of certain social groups, including racialized populations, non-English-speaking communities, the unemployed or underemployed and persons living across the income and education spectrum. This underrepresentation makes it challenging to discern how health inequities may impact patient and caregiver desires of the health system. Finally, given the heterogeneity of study types, we could not make any assertions on the relative importance of one desire over another. Instead, the desires captured in this study are a composite of those most commonly expressed across all studies.

Conclusion

There were similarities in desires expressed across health states. However, the way these preferences and desires were expressed, and the examples of how to adapt health systems, varied across health states. If the healthcare system is going to be truly patient-centred, then one size does not fit all. The patient groups in our study – the walking well, those with mental and cognitive health challenges, those with life-threatening or more chronic conditions and those needing palliative care in the final stages of life – have varying preferences for and different perspectives on personalized care, health system information, choice, non-medical supports and the coordination and continuity of care. These findings can be used to inform patient-centred integrated care efforts on how the health system can be shaped or reshaped for identifiable patient groups. We highlight four particular ways this could work to support the development, implementation and evaluation of integration efforts. First, the results can support policy and practice planning by offering an improved understanding of the preferences of a variety of potential target populations; they could also, depending on the priority population, inform as to which partners should be included as part of the care team. Second, central to the effective development of patient-centred models is the meaningful engagement of patients, and these results provide some insight into differing experiences of patients based on their health state. Third, the results of this scoping review could be used to inform quality improvement efforts and evaluation strategies that reflect the desires of patients and caregivers. Finally, these results can inform the worthwhile targeting of investments, highlighting areas that are relevant and important for a variety of priority populations.

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