Ontario Medical Association

NORTH AMERICAN OBSERVATORY on Health Systems and Policies

White Paper on: Patients' Views of the Canadian Health-Care System

A study prepared by the North American Observatory on Health Systems and Policies for the Ontario Medical Association.

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OMA*Thoughts*

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Executive Summary

Patient-centred care is currently a priority area of inquiry among researchers, decision-makers, and health system planners. The COVID-19 pandemic has reinforced the importance of ensuring health and social care services are delivered to users in a meaningful and effective manner that meets their needs and preferences. In order for patient-centred care to be meaningfully implemented, we first need to understand the needs, preferences and desires of all patient groups. Current patient engagement efforts tend to rely on a generic somewhat simplistic view of patient perspectives, limiting our capacity to understand the full range of preferences needed to move toward truly patient-centred care. Additionally, we have limited insight into how patient perspectives on health care can be used to inform system reform. This scoping review of the literature was conducted to gain insight into the nuances of patient and caregiver preferences or desires across a variety of health and life stages.

This study reveals similarities in desires across all patient health and life stages, which can be categorized into five broad themes: a desire for personalized care; a desire for information on resources available and how to navigate the health system; a desire for choice in treatment, care setting and/or care provider; a desire for holistic care and non-medical supports; and a desire for care co-ordination and care continuity. However, even with these similarities across health stages, the way these preferences and needs were expressed, and the examples of changes to health care systems that were suggested, dramatically differed across patient groups. These findings are novel as they highlight nuances in preferences and desires that are both similar and different across health stages. Findings from this study are timely as jurisdictions internationally aim to deliver patient/caregiver-focused models of integrated health service delivery. Thus, these findings will be particularly helpful to inform the following efforts:

1. **Planning**: through understanding the detailed experiences and preferences of a variety of target populations. This may inform which providers to consider being a part of the integrated care team.
2. **Patient Involvement**: in offering insight into the diversity of patient views across population groups and inform patient engagement efforts.
3. **Quality Improvement**, **Metrics and Evaluation**: in informing the development of metrics that reflect the desires and preferences of patients and caregivers.
4. **Targeting Investments**: in identifying areas for investment that are relevant to, and important for, a variety of target populations.

“The good physician treats the disease; the great physician treats the patient who has the disease.”

Sir William Osler (1849–1919)

Introduction and Background

Given the diversity of experiences, values and expectations that reflect the broader socio-demographic profile of Canada, we undertook a scoping review of the literature to provide insight into the experiences, both positive and negative, of patients and unpaid caregivers across multiple health and life stages. In doing so, we aim to present a comprehensive picture of patient and caregiver experiences that both acknowledges this diversity and provides practical insights into the ways in which the Canadian health system may be shaped or reshaped to better meet their needs.

This study addresses the following research question: “how do the needs, values, preferences, and experiences of patients and unpaid caregivers differ across various health and life stages?” Answering this research question will help system leaders and providers reshape the design and delivery of health care in a manner that is tailored to each and every Ontarian.

Increasingly, policy-makers and health system managers are considering the perspectives and experiences of patients in reforming health systems.[1-5] Consecutive Ontario governments have emphasized the importance of “patient-centred care” that places patients (and caregivers) at the forefront in the planning, delivery, and evaluation of healthcare services.[2,6,7] The recent establishment of the 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 in decision-making and system planning.[7,8]

The idea of organizing health care around patients seems simple, yet the concept of patient-centred care is multifaceted. The 2001 definition by the Institute of Medicine (IOM)[5] informs much of the current policy discourse, where *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” (p. 3). As described by the IOM, the concept applies not only to care delivery, but also to system planning and research.[4] It also relates closely to patient experience and engagement.[4,9] While *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]

Alongside the increasing interest among policy-makers in patient-centred care, there is a growing body of scholarly research that aims to understand patient experiences with, and their perspectives of, the health system. However, these studies are often specific to a disease group or sub-population, or they may be so general that they lack the necessary insight to inform meaningful system reform or redesign.

The COVID-19 pandemic, which has disproportionately affected vulnerable populations in Canada, further highlights the importance of targeted measures to meet the needs of different sub-populations. Moreover, the health system adaptations and reforms that are put in place in response to the COVID-19 pandemic should consider the preferences, perspectives, needs, and desires of patients across different health and life stages. Our aim is to build on this knowledge base by drawing attention to the similarities and differences in experiences across life and health stages.

Conceptual Foundation

For this study, we considered two categories of subpopulations to organize patient groups: health stage and life stage. These two categories allow us to identify and understand differences and similarities in the experiences of various patient groups that could inform health system improvement.

We categorized health stages into five main groups:

1. Walking well (which would include preventive care);
2. Chronic conditions;
3. Acute life-threatening conditions;
4. Mental/cognitive health and addictions; and
5. Palliative/end-of-life care.

The walking well group included those who use primary, preventive and alternative care to maintain health and well-being. The chronic conditions group comprised of those who live with one or more chronic conditions and often see more than one provider. Those who seek care in emergency departments or have short intervals in hospitals were included in the acute life-threatening conditions group. The mental/cognitive health and addictions group encompassed those who seek care for mental health issues and/or addictions in any setting. The palliative/end-of-life care group covered those who use end-of-life support in any setting.

Life stages were grouped into six primary categories:

1. Infant and pediatric (<12 years old);
2. Children and youth (12-21);
3. Young adult (22-30);
4. Adult (31<65);

5. Older adult (often defined as 65 years and older); and
6. Caregivers (families, partners, parents).

This review aims to understand patient and caregiver experiences from the perspectives of health stage and life stage simultaneously, as well as determine if this categorization of health and life stages is supported by the literature. To account for the diversity within health and life stages, we also aimed to draw attention to the experiences of specific populations including immigrants, Indigenous Peoples, LBGTQ+, vulnerably housed, and other populations that were identified in the literature.

Methods

A scoping review was conducted to identify English-language studies to answer the following research question: "*how do the needs, values, preferences and experiences of patients and caregivers differ across various health/life stages?"* Our secondary question: *how should the Canadian health care system be shaped or reshaped based on the needs, values, preferences and experiences of patients and caregivers?* 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: 1) develop a broad guiding question, 2) conduct a comprehensive literature search, 3) follow inclusion/exclusion criteria to select articles, 4) organize articles thematically or topically, and 5) summarize findings.[12] All steps were overseen by the supervising author and reviewed on an ongoing basis by the research team and the Ontario Medical Association (OMA).

Search Strategy

The PICo (population, interest, context) framework for qualitative studies[13] was used to operationalize the research question into searchable keywords (Appendix A). Four databases were searched in January 2019 – OVID Medline, CINAHL, EMBASE and PsycInfo – to capture literature from health/medical, nursing/allied health, pharmaceutical, and psychology disciplines, respectively. For each database, four independent searches were conducted of various combinations of life stage, health stage, and population of interest (as discussed in the conceptual framework) to maximize search results. 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

Various search operators, including truncation, phrase searches, wildcards and Boolean operators, were applied to maximize search results and translate keywords for each database.

Where applicable, keywords were matched to Medical Subject Headings (MeSH). Search restrictions were imposed on date of publication (January 2013 to December 2019) to obtain articles that are both manageable in number and reflective of current Canadian opinions of the health system; language (English); and setting (Canada, provinces/territories). To ensure a valid and reliable search, this search process was guided by a trained medical sciences librarian. Appendix B presents a search schema applied to OVID Medline (*Search 1*).

Study Selection

Two reviewers performed a title/abstract screening of all articles following the removal of duplicate articles (deduplication). Articles were included based on study setting (Canada and/or a Canadian province/territory), study participants (patient and/or caregiver), and study topic (study addresses patient/caregiver perceptions of the health system and/or elements of how the health system can be structured or restructured). Two independent reviewers then performed a full-text screening on all remaining articles using the same criteria for inclusion as in title/abstract screening.

Articles were excluded for a number of reasons: 1) full text could not be located; 2) health-care providers (HCPs) are the only study subjects who speak as a proxy for patients/caregivers; 3) HCPs and patients and/or caregivers are study subjects, but the results do not distinguish between them; 4) systematic or scoping reviews present data from articles published before 2013; 5) randomized controlled trials, protocols and cross-sectional analyses that compare Canada to other jurisdictions did not present findings on what the health system should look like; 6) article was about perceptions of personal health behaviours and health management, not about experiences with the health system; 7) article focused on a sample of one individual (personal narrative), which limit opportunities to make meaningful/discernable generalizations about the health system for the purpose of this review; and 8) articles on community health were about healthy communities, not community health as a sector of health-care delivery.

Article Selection

Appendix C presents the PRISMA flow diagram for article selection. 12,341 studies were pulled across all databases searched; 7,763 articles were removed following deduplication. 4,127 studies were excluded following title/abstract screening as they did not meet the inclusion criteria described in the methods. Full-text screening was then performed on the remaining 451 studies and 193 were included for analysis. Agreement was moderate between reviewers (Cohen's kappa, κ, 0.54). Any disagreement was reconciled by the supervising author.

There was much heterogeneity in terms of study setting. Study settings included all of Canada, specific provinces/territories or cities, or hospitals/health care facilities. Several studies took place across multiple settings. Hence, the following thematic analysis is a geographically agnostic account of salient themes across studies, based on the assumption that learnings about the health system are relevant across Canada. For reference, Appendix D presents a table summarizing articles by year of publication, study aim, and study setting, and Appendix E presents a matrix tally of articles based on life stage and health stage. Study subjects in many studies fall under more than one life stage so a single study may fall in more than one category/cell.

Data Extraction and Analytic Framework

We developed a data extraction template including the following data points of interest: study title, authors, year of publication, study aim, study population, sample characteristics, sample size, study methodology/methods, key findings, and representative quotes. Two reviewers independently extracted data from all articles following a pilot extraction of two articles. An inductive thematic analysis was then conducted by three reviewers to summarize findings and themes across the studies within each health and life stage.[14]

Limitations

All literature we included was peer reviewed; thus, the results are inclusive of those populations of interest to researchers and may not be representative of broader population needs and experiences. Moreover, experiences with, and perspectives of, the health system presented in this review do not necessarily represent the full or comprehensive characterization of people who could fall within the respective health or life stages. For example, much of the literature focused on specific subpopulations. In addition, much of the literature extracted was reflective of patients and caregivers living in urban settings with few that focused on the perspectives of patients and caregivers living in rural and/or remote locations of Canada.

Findings

Findings are presented below based on each health stage. Within each health stage we highlight key themes that were identified from the literature and describe any differences across life stages.[1] Themes are characterized as needs, desires or preferences of what the health system should look like. Within themes we note experiences of patients and caregivers as they interact with the health system.

Across all life and health stages five broad themes were identified:

1. **A desire for personalized (person-centred) care:** Personalized care refers to a combination of care that is culturally competent and culturally sensitive, free of language barriers, racism, and discrimination toward religions, cultures, gender identities and socioeconomic status by medical and health professionals. Personalized care also refers

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[1] A full review of the relevant studies based on medical and life stages can be reviewed in a technical appendix (available upon request). Also, we did not identify the term “walking-well” in the literature. This label was applied by the researchers during the data abstraction phase to categorize populations that were physically or mentally well.

to timely service delivery that minimizes wait times and recognizes that medical urgency may not be the only criteria to promptly being seen. Lastly, personalized care approaches include interdisciplinary care (a range of care and health service providers both within and outside the health system).

2. **A desire for information on resources available and how to navigate the system:** Knowledge deficits and gaps among HCPs related to community resources available for patients and caregivers. There was also a desire for increased information around disease trajectory, and what sources of support could be accessed to ensure patients can manage their illnesses. In addition, personal health information should be accessible, and information presented online should be comprehensive and easy to find.

3. **A desire for choice in treatment, care setting and/or care provider:** Choice around treatment includes vaccination/screening, natural health products, health prevention programs, and medical assistance in dying. Choice around care setting includes care at home and involving other sectors like the education sector (e.g., schools). Choice around care provider includes expanding roles of pharmacists, increasing access to midwives, and including caregivers as partners in care.

4. **A desire for holistic care and non-medical supports to overcome barriers to accessing care:** Holistic care recognizes that care must continue outside hospital walls (e.g., primary care, community care, social care), and that social determinants of health, including income, geographic access to health services, and education are important factors influencing health. Barriers to accessing care include the monetary costs of some health care services and medications, geographic or transportation-related barriers, difficulties finding a provider, the referral process, and wait times.

5. **A desire for care co-ordination and care continuity:** Care co-ordination and continuity refer to regular contact with the same team of HCPs, co-ordination of services, and co-ordination in various types of care transitions.

Findings within Health Stages

Walking Well

A total of 78 articles focus on the “walking well” health stage, which includes those who use primary, preventive and alternative care to maintain health and well-being. Of these articles, five focused on infant and pediatric, four on children and youth, three on young adult, 44 on adult, nine on older adult, and eight on caregiver/parent life stages. Specific similarities and differences in themes across life stages within the walking well population are presented below.

A DESIRE FOR PERSONALIZED (PERSON-CENTRED) CARE

Culturally Competent and Culturally Sensitive Care

Across life stages, there exist examples of care delivery that is impersonal and lacks sensitivity and cultural awareness. Lack of sensitivity, for example, is noted commonly by certain populations. Transgender adults express concern that their HCPs lack sensitivity and awareness of trans-identity when they misgender transgender patients.[15] Transgender adults also perceive a disconnect between trans-inclusive policy and practice. For example, intake and registration forms do not reflect gender and sexual identities,[16,17] and washrooms/change rooms in health facilities are gender-segregated.[16] Overcoming these challenges is important in fostering equitable treatment.[17] LGBTQ+ adults note that HCPs should ask directly and early in the doctor-patient relationship about sexual identity to facilitate trust and reinforce a system in which people do not feel judged, marginalized and/or excluded.[18]

In terms of culturally competent training, Indigenous adults note this requires training in non-discriminatory practices that highlight social and historical factors in Indigenous health care delivery.[19,20]

Adult immigrants also discuss examples of lack of sensitivity and cultural awareness. For example, immigrants from African nations and immigrant women who self-identify as Muslim express a desire for HCPs to provide culturally appropriate care (not having to undress in front of a male doctor; access to interpreters; tailored services to address specific needs of immigrants, including special clinics, health education, and awareness forums).[21-23] Immigrant older adults from Korea perceived racial discrimination in the health system and felt "left behind…through language…age…and visible minority status." They express a desire for proper translation of medical terms and physicians' instructions.[24] The need for interpreters and culturally and linguistically competent HCPs who are open and sensitive to cultural diversity is also echoed by immigrants from China who are expectant mothers.[25] Immigrant adult women from sub-Saharan African countries note that not having access to an interpreter during health emergencies or during serious medical procedures like surgeries is emotionally taxing. For these patients, calling an ambulance was seen as the better option than trying to get to the hospital and navigating emergency care by themselves.[26] Failure to provide culturally competent, linguistically accessible care limits access to the health system for immigrant women seeking maternity services[27] and immigrant women from the Middle East seeking health care.[28] Older adult immigrants living in assistive living facilities desire ethnolinguistically congruent services to address their needs, foster a sense of familiarity, and communicate their thoughts.[29]

Cultural and linguistic barriers are also noted by Indigenous adults. Many cultural rituals, including those in death and dying, do not align with hospital rules (for example, exceeding the maximum number in a hospital room is prohibited).[19] Other Indigenous adults suggest that nurse educators should receive education on culturally safe care and Indigenous culture.[30] These sentiments contrast with Indigenous adults living in small communities, who express satisfaction with their health services. In these small communities, some adults prefer having a non-

Indigenous HCP and the associated cultural and linguistic barriers because it creates a more "confidential" care situation.[31]

Several patient populations (i.e., vulnerably housed or older adults) felt some form of discrimination and perceived a need for a broader perspective when HCPs were caring for them. Vulnerably housed adults perceive unfair discrimination from the health system: they are unable to get a health card number because of their vulnerably housed status, and often feel looked down upon by HCPs because of underlying drug addictions, or judged for having a criminal record.[32] Older adults perceive ageism among HCPs[33] and note feeling dismissed by their HCP who will often speak directly to the adult child caregiver. Older adults also note concerns about HCPs overprescribing, their narrow viewpoint around caring (not looking beyond specific illnesses or conditions), patient-blaming where HCPs expect patients to overcome shortcomings in their behaviours, and failure to initiate discussion of emotional and psychological needs.[34] New adult fathers note feelings of exclusion in maternity care units. For example, the structure of the maternity unit does not enable fathers to stay overnight with their spouse.[35]

Care avoidance as a consequence of care that is not culturally competent

Youth and adults both expressed care avoidance behaviours and difficulties in accessing medical care. This is noted specifically by sub-groups as a result of HCPs' limited education on patient-specific issues. For example, the young transgender community highlights avoidance of medical care due, in part, to health care delivery that continues to be gender binary (male and female), perpetuated by HCPs who continue to disregard preferred pronouns of transgender patients and gender-binary medical intake forms.[36] This is corroborated by adult transgender patients seeking HIV/sexually transmitted infection (STI) screening, who note: cis-normative assumptions among testing providers; a disconnect between trans-inclusive policy and practice (e.g., intake and registration forms); gender-segregated services; and lack of knowledge among testing providers (lack of knowledge of trans identities, including appropriate communicative terminology, and trans-specific health-related concerns).[16] These negative encounters discourage LGBTQ populations from accessing regular check-ups and preventive care, and only seeking health care services when they become ill.[37]

> *"I feel some anxiety around the health care system but I believe that doctors should be aware of transgender people and I shouldn't be shamed of asking questions regarding me being transgender and how that affects my general health."*
>
> —Heard, 2017

Care avoidance is also noted by adult immigrant women. Due to language barriers and failure to provide culturally competent care, immigrant women in both rural and urban settings seeking maternity care drop out of antenatal classes.[27] Adult immigrant women seeking maternity services note an aversion to seeking care due to a lack of female providers, which could contribute to care that is not culturally competent. Women also note how language barriers create difficulties seeking care, and the need for comprehensive and readily available interpretive services to improve effective, therapeutic communication if patient confidentiality can be preserved. Other adult immigrants actively sought a family physician that spoke the same language because they lacked comfort or had fears of missing or misunderstanding important information about their health. In many cases, finding a local physician who spoke the same language was challenging, so they had to bring their own translator or friend to the office visit.[38]

> *"Nurse ask me, 'You know about that HVP test?' So I said, 'I don't know.' She said to me, 'You suggest yes or no?' So I said no because I can't understand so that's why I said no."*
>
> —Higginbottom 2015

Difficulties accessing care and care avoidance were highlighted frequently by Indigenous Peoples. All studies including Indigenous Peoples highlight the need for culturally centred care and improved cultural awareness among HCPs. Indigenous youth note how a lack of "culturally safe" health care has contributed to resistance in care-seeking behaviours. Specifically, they highlight how colonialism and structural racism continue to exist in health care delivery. As a result, they resist going to counselling, particularly for concerns regarding their mental health problems. Indigenous adults note feelings of differential treatment from HCPs when HCPs find out they are Indigenous and low income. This leads to HCPs not listening or believing patients, and patients being provided insufficient information on, and explanation about, their diagnosis and treatment, which discourages future care-seeking behaviours.[19] Indigenous adult women confirm this, noting racism, prejudice, discrimination and the fear of child apprehension in mainstream health care agencies impact their decisions to seek health care services for themselves.[30,39] Indigenous-specific health care centres, such as the Indian Friendship Society Health Centre, are therefore considered highly important.[40]

Mistrust as a consequence of care that is not person-centred

Specific populations note a history of discrimination and mistreatment from their HCPs, which has contributed to a sense of mistrust. For the adult transgender community, mistrust of HCPs arises when HCPs refuse to provide care.[16] Among Indigenous adults, mistrust is the result of: delays in diagnosis of health problems; denial of medication (namely pain medication due to HCPs perceived concerns about substance misuse among Indigenous populations, which leads to feelings of judgement and discrimination;[39] lack of confidentiality, especially in smaller communities where care is serviced by community health workers, which has led to a preference for non-Indigenous HCPs with cultural and linguistic differences as they create a more "confidential" situation;[31] and the impersonal nature of Indigenous health delivery, involving *"doctors [who] just throw stuff at us, so many papers [brochures]."*[41]

Wait Times

For all life stages, patients experienced barriers to access due to long wait times. Discontent with wait times in the health system is expressed by individuals across all life stages and population groups (immigrant/ethnic minority adults,[21,23,24,26,42] LGBTQ groups,[15,36,43] vulnerably housed,[44] and Indigenous Peoples.[31,39] Wait times are associated with the referral process and access to specialists,[22,46] as well as finding a family doctor.[23] For LGBTQ or vulnerably housed adults, wait times and lack of availability hinder or delay access to care,[43,45] sometimes to the point of requiring hospitalization.[45] For vulnerably housed who identify as working poor, work conditions may not afford them the opportunity to wait for a medical appointment, forcing them to forgo care altogether.[44]

Newcomer/immigrant Canadians are more likely to report difficulties accessing specialist care in Ontario in comparison with the Canadian-born population, citing long wait times.[42] For this population, wait times were exacerbated by use of provincial health insurance or care access programs, including the three-month waiting period for OHIP and use of the Healthcare Connect Program to find a physician.[38,47] For other newcomer Canadians, long wait times in Canada for disease diagnosis, treatment and/or operation are surprising to patients and contrast with shorter wait times in their countries of origin.[24]

> *"It's hard to find a family doctor because I phoned everyone … it took me a while, and then you can't go with him because his appointment [book] was full. I phoned a lot of clinics and then they cannot accommodate. It might take up to one year to find a family doctor. Moreover, after finally getting a family doctor and referral to a specialist clinic there was often another long waiting period because of the shortage of gynecologists or obstetricians. Some women complained that they received their first appointment in the advanced stages of their pregnancy. The issue of long wait periods was a greater barrier to accessing care at an appropriate time"*
>
> —Higginbottom 2016

Indigenous adults also note long wait times for emergency, walk-in, and non-urgent services due to geographic barriers.[31,39] In remote settings, some Indigenous adults wait weeks for nurses to arrive.[31] Some Indigenous adults believe these wait times represent a health system that is uncaring and disrespectful toward the Indigenous communities in Canada; however, some Indigenous adults understand that the capacity of HCPs or services may be limited,[39] and the provision of completely equal and equitable access to primary health-care services in remote areas (e.g., Northwest Territories) is unrealistic due to geographical characteristics and the small population size of remote communities. Still, there is an expression for timely, risk- and barrier-free, and appropriate primary health care as close to home as possible.[31]

A DESIRE FOR INFORMATION ON RESOURCES AVAILABLE AND HOW TO NAVIGATE THE HEALTH SYSTEM

HCP Knowledge Deficits and Gaps

Many populations are often unaware of community-based resources and supports available to them that would facilitate appropriate care-seeking behaviours. HCPs play an important role in filling these knowledge gaps; however, vulnerably housed adults note their HCPs lack the necessary knowledge and training to communicate effectively with them around resources or supports available, highlighting a desire for HCPs to identify supports that would encourage care-seeking behaviours rather than discourage such behaviours.[44] Similarly, among older adults living in poverty, there is a desire for HCPs to provide information on mental health resources and community-based services and programming for mental health.[48]

A desire for more information from HCPs was also expressed by caregivers of older adults and older adults in rural and remote locations, who note that poor information exchange has resulted in difficulties navigating the health system (e.g., limited awareness of community-based resources).[49] Adult immigrant women from Korea note that information gathering was easier in their country of origin than in Canada. In Korea, the government and HCPs recognize their role in delivering information on health behaviour expectations to families.[50]

Funding Information

Overcoming informational barriers around medical coverage and funding options is viewed as important. Both adult immigrant and adult non-immigrant populations note a desire for adequate and timely information on navigating funding options.[46,47,51] LGBTQ adult immigrants and refugees from African and Caribbean nations note difficulties understanding health care costs that are not publicly covered, and how to gain access to physician services, medication and dentists.[52] Social support groups help clarify some of the questions around this complexity, which enhances these populations’ ability to access health care.

Parents of refugee-claimant children report not understanding online information around federal health insurance options available, for example, the Interim Federal Health Program (IFHP). The IFHP provides limited, temporary coverage of health care benefits to protected persons, including resettled refugees; refugee claimants; and certain other groups who are not eligible for provincial or territorial health insurance.[53] As a result, they avoid seeking medical care for their child unless their child becomes severely ill, due to financial difficulties in paying for care. Parents also lack information regarding health care rights and services, and an understanding of IFHP online renewal procedures.[51]

Multiple Sources of Information

Adult immigrants from China note a desire for multiple resources to obtain pregnancy information.[25] New adult mothers report a desire for more informational support in neonatal follow-up, namely, what to expect, what is needed to guide their child's development, and how to navigate the health system (assistance with referrals, expenses and applications for disability funding).[46] Within the expectant mother population, although birth plans aim to provide new parents' instructions on how to care for a new baby, many mothers note that such plans could lead to inflexibility and rigidity, potentially leading to poor outcomes.[54]

Indigenous adults highlight how HCPs in community settings must connect with Indigenous Peoples to establish a collaborative strategy for delivering health information appropriately.[55] Many Indigenous adults believe inadequate information and explanation about their diagnosis and treatment is a consequence of individuals not being listed to, being ignored, or not being believed.[19] Other Indigenous adults' express frustration with HCPs' dependence on written materials and neglect of the importance of oral transmission of knowledge. They offer suggested changes in the future transmission of information, including videos that feature different Elders communicating health information in traditional languages, as well as English, and sharing accurate and respectful illustrations of the body.[41]

A DESIRE FOR CHOICE IN TREATMENT, CARE SETTING AND/OR CARE PROVIDER

Vaccination

Across life stages, there is trust of HCPs and the health system generally. Young adults, adults and older adults view public health authorities as responsible toward citizens and view recommendations on vaccination as trustworthy.[56] Adult immigrants echo this sentiment: they trust the Canadian government to ensure vaccine safety during development, manufacturing and delivery, as well as their HCP's recommendations on vaccination.[50] Older adults note their willingness to put ownership of their health in their physician's hands. For this population, family doctors strongly influence decisions to receive vaccines.[57] For other older adults, having been offered the pneumococcal vaccine by their HCP or being told about it by their HCP, or believing their HCP thought receiving this vaccine was a good idea are factors positively associated with vaccine receipt.[58] Among parents of young children who strongly intended to vaccinate, as well as those with a lower intention of doing so, expressed a high level of trust in doctors to do what is in the best interest of the public.[59]

Screening

Similar sentiments around trust exist in terms of screening. Among adult women, the most frequent reason provided for having a first mammogram was "my HCP's recommendation."[60] Among adult immigrants, physicians are considered trusted and authoritative figures whose recommendations they would follow around testing and screening (e.g., cervical cancer screening).[23] This sentiment is echoed by other adult immigrants (from China and South Asia), who note the importance of a physician recommending and facilitating screening. Female gender of the HCP was paramount in facilitating access to cervical cancer screening for almost every informant.[61] Vulnerably housed women seeking prenatal care also spoke of the importance of trusting their providers and feeling that they were not being judged. They valued HCPs who took time to make a connection with them and who provided emotional and psychological support.[20]

Natural Health Products

Among adults, there is a desire for alternative treatment modalities, particularly natural health products (NHPs). While adults recognize that NHPs are not prescription drugs.[62] many adults (47% of adults surveyed) believe NHPs are safer than prescription medications because they are less likely to cause adverse events.[63] Among immigrant adults, there is also a preference for herbal and natural remedies. However, these adults do not seek advice from their primary care physician about alternative treatments due to a perceived misalignment in preferences. There is a belief that if physicians were more open-minded to such treatment modalities, care would be more comprehensive.[38] Among other immigrant adults (Korean newcomers), traditional Chinese medicine is considered effective, but the high cost of such treatments and lack of coverage in provincial health plans means these treatments are only available to those who can afford it.[24] Indigenous youth note the importance of cultural approaches to health and natural healing ceremonies, and a desire to learn Indigenous medicine.[40]

> *"I want to learn how to make Indian medicine, because one time I was heating up and I felt like I was cold to being really hot. I had to go to the hospital for a day, but I felt better after taking the Indian medicine." (Youth Participant)*
>
> —Natalie, 2013

Health Prevention Programs

Adult parents of infants support strengthening early intervention programs to include more health care treatment programs, as well as health prevention programs, including nutrition interventions (subsidies for nutritious food).[64] Indigenous adults express a lack of preventive health programs, particularly concerning traditional practices.[31]

Medically Assisted Death

The majority of adults (70%) support medically assisted death as a viable treatment option for patients facing imminent death.[65] This is supported by other adults who believe that "dying adults should be able to request and get help from others to end their life," and that "every competent adult should have this right," or, in "certain cases or situations."[66]

Health-Care Personnel

Adults strongly support expanding the scope of practice of pharmacists to authorize refills of medications, offer advice for the treatment of minor ailments, administer vaccinations, and conduct certain health screening or monitoring services, such as blood pressure monitoring.[67]

Expectant mothers choosing a birth centre express an appreciation for midwifery care during the birthing process. Women who were having their second (or more) birth after having their first birth in a hospital prefer birth centres for a more natural experience while avoiding interventions and the clinical environment of a hospital birth.[68] This preference is also expressed by other expectant mothers in both rural and urban settings who view birth centres as safe and more comfortable than hospitals, and a setting where they can control their surroundings (lighting, smell, noise, extent of interruptions). Again, midwifery services are highly valued as midwives are perceived to be more open-minded about birthing options (e.g., in hospital or at home).[69]

While one study found that Indigenous youth do not prefer an Indigenous provider over a non-Indigenous provider,[40] another study found that Indigenous adults express a specific preference for Indigenous HCPs and an increase in Indigenous HCPs overall.[55]

Care Settings

Community: Among HIV-status LGBTQ immigrants, there is a desire for access to community-support groups. Existing community services have been noted to help in coping with challenging times, reduce isolation, foster kinship in Canada, and offer a judgement-free, safe space.[52] Chinese and South Asian adult immigrants also support an expansion of care into the community, suggesting that primary care and screening outreach should be based in community hubs (e.g., apartment complexes and community centres), where newcomers can receive screening services provided in their own language.[61]

Involvement of Education Sector: There is a desire to move childhood vaccination into the community, namely schools. For many parents, school-based immunization programs are important and outweigh potential monetary costs of vaccinating many Canadian children outside school in terms of resources used,[70] and decreasing spread of disease and subsequent health care utilization.[71] Other parents disagree, suggesting implementing school-based immunization programs would increase the pressure to have children immunized, forcing parents to make a decision. These parents note that the decision to vaccinate should be personal, and implementation of school-based immunization would lead to what was considered an inappropriate external influence on the parents' decision-making process .[71]

Choice can be Constrained

Power dynamics between patients and HCPs exists and can impact on a patients' willingness to speak out regarding various treatment preferences, that they may prefer. Vulnerably housed adults express a need to agree with physician opinions around treatment even though prior experience suggested a drug was not effective. Trust was based on a need to protect and preserve their ongoing relationship with their physicians.[45]

A DESIRE FOR HOLISTIC CARE AND NON-MEDICAL SUPPORTS TO OVERCOME BARRIERS TO ACCESSING CARE

Many themes presented thus far highlight challenges in navigating various aspects of the health system due to limited information, knowledge gaps among HCPs, and language barriers. This section describes additional barriers to care that relate to challenges navigating the health system and general unfamiliarity with the health system.

Financial Barriers

Many groups are highly favourable of Canada's system of universal health care coverage. Immigrant populations express a favourable attitude toward Canada's "socialist" health care system, which they understand as "free basic care" regardless of socioeconomic status.[24]

> *"The fact that the vaccine is free for all confirms that this protection is not limited to the rich alone and that the principle of equality is properly applied in our health system."*
>
> —Kowal, Jarine & Bubela 2015

Concerns regarding the deficits in universal coverage stem from the design of provincial health insurance programs. These concerns are raised largely by adult immigrant and refugee populations.[21,38,47,51] For example, many such populations note prohibitive costs of medication and non-basic care, despite obtaining provincial health insurance. For refugees in particular, there is a perceived gap between government services available for government-assisted refugees and privately sponsored refugees, the latter being unable to access interpretation services during health care visits or access social programs to support families with children. This resulted in feelings of alienation.[21] This is echoed by caregivers (parents) of refugee-claimant children, who note a lack of continuous health insurance in the Interim Federal Health Program (IHFP), often resulting in denial of care of children. Services are refused if refugee claimants are unable to pay, forcing parents to seek care for their children only when the child becomes ill.[51] Cost as a determinant of whether or not to seek care resonates with other adult immigrant populations. In Ontario, the three-month waiting period preceding OHIP eligibility means landed immigrants in Ontario deter standard medical visits or limit testing or treatments used.[38,47]

Immigrant populations note additional economic barriers to health care, including the lack of extended health insurance to cover pharmaceuticals, eye care, dentistry and other essential services.[24,72] As a result, particularly for those seeking natural medicine approaches will engage in transnational care seeking (seeking care in country of origin) is common among this population in response to the high cost of services such as dentistry.[24]

Caregivers also note specific financial difficulties. For example, older adults and caregivers of older adults in rural and urban communities note limited access to services and holistic care due to various policy issues and funding restraints with respect to home visits. In addition, current funding reimbursement models in Ontario discourage physicians from practicing preventive care and home visits, since the compensation provided for these services is minimal compared to medical interventions provided in a clinical setting. There are also limits placed on funding for services deemed “non-essential” by provincial health insurance, such as physiotherapy, forcing patients to exhaust their coverage before treatment is complete.[49] New mothers on neonatal follow-up programs also note financial barriers, citing a desire for greater assistance with expenses and in applying for disability funding.[46]

> *“…but that requires a change in the structure of the OHIPs remuneration system. Because a doctor who visits someone at home, it will take that doctor five times as long than if the doctor was in her office – she could see five patients in that time and she would get paid five times as much. So the OHIP and the other provinces have got to restructure their system if any system of home visiting is going to have any hope of success.” (urban patient)*
>
> —LaFortune, 2015

Worth noting is that vulnerably housed adults express that the inadequacy in benefits provided by Quebec's Social Assistance Program make it impossible for persons living in poverty to maintain good health when living on social assistance, as it hinders good nutrition and the ability to follow a dietician's recommendations. This represents an incompatibility of certain HCP’s recommendations with their lived reality.[44]

Transportation

Older adults express a desire for transportation to reach medical appointments. When medical services are not within walking distance or on-site for those living in assistive living facilities, when getting to a transit stop or boarding a bus without help is challenging, or when weather conditions pose a risk of falling, older adults must rely on caregivers to reach medical appointments, or they avoid medical appointments altogether.[27,29,48,49]

Referral Process

Many note the complicated nature of the referral process and difficulties obtaining referrals to specialists in Canada as barriers to care. For example, older adults and their caregivers note that access to a specialist is complicated due to the referral process.[49] This sentiment is supported by mothers in neonatal support programs who express frustration with wait times associated with referrals, and desire assistance with navigating the referral process in the community. One mother notes, *"In the community, it’s not always easy to get the resources to help, such as occupational therapy, physical therapy and dieticians. They (Neonatal Follow-up [NFU]) were able to get us hooked up with services in a timely manner . . . getting referrals is difficult. Some parents are finding they need to wait sometimes years for services."*[46] Immigrant populations also note their lack of understanding in the referral process around seeing a specialist in Canada.[23]

> *"In our country we go to specialist directly but everything has to go through the GP here [Canada]. It takes 19 time to get the referral and see a specialist. It took me like more than four months to see an Orthopedic."*
>
> —Vahabi, 2016

Some adults are skeptical about the referral process and desire primary care providers to be transparent about their motivations for screening referral practices, noting their belief that performance incentives are tied to referrals to screening such as mammography.[60] By contrast, other adults (vulnerable housed women seeking prenatal care) noted their appreciation of care providers' referrals to other professionals.[20]

Finding a Provider

Challenges finding a family doctor or specialist is noted commonly by adult immigrant populations. Issues in finding a suitable provider relate to language barriers;[22,24,25,27,38,72] a preference for female doctors;[21,23,61] geographic barriers;[38] and perceived physician shortages.[21,27] Vulnerably housed adults also note challenges finding HCPs, including midwives and obstetricians, due to a perceived shortage.[20,44] For older adults, there is a belief that physicians prefer younger patients and express concern in finding a replacement and establishing a relationship with a new doctor when their current doctor retires.[33]

Mental and Cognitive Health

This section summarises the 31 articles that addressed mental and cognitive health. The majority of the articles (16) focused on adult populations and 10 focused on children and young adults. Specific similarities and differences in themes across life stages within the mental and cognitive health population are presented below.

A DESIRE FOR PERSONALIZED (PERSON-CENTRED) CARE

HCP Knowledge of Cultural and Social Groups

HCPs were perceived to lack an understanding of various cultural and social groups. The adult LGBTQ population note that prescription refills is the extent of their HCPs' mental health care knowledge. HCPs also lack knowledge of trans-affirming mental health care, resulting in misgendering and transphobia in treatment. This is, in part, due to professional protocols that do not reflect trans identities.[73]

> *"They would refer to me as [given (male) name] or Mr. [last name]. . . It's the sort of thing where it's very subtle, but it's just an indication that it's what's on your OHIP [provincial health insurance] card that matters, not who you are. . . Like when you're sitting in emergency looking like this [female gender presentation] and they call out [given name] or Mr. [last name], and you stand up and there's people sitting there all around you, you feel weird. You almost don't want to be in the emergency department, right?"*
>
> —Ross, 2018

Similarly, among adult Korean immigrants seeking help for suicidal behaviours, primary HCPs are limited in their knowledge on how to pick up on suicidal behaviours, as some cultures are more likely to downplay or deny the severity of these behaviours.[74] Among adult Indigenous groups seeking addictions care, patients stress the need for HCPs to be trained on how to deal with Indigenous patients living with addictions, as HCPs are noted to be indifferent to their specific health needs.[75]

Wait Times and Referral Processes are not Person-Centred

Patients and caregivers (parents) across all life stages express concern with wait times and care processes, including referrals. Youth and young adults note difficulties in navigating the mental health system in terms of finding the appropriate place to get treatment and having to wait to see someone regarding their health concerns, as one young patient notes, *''It's the waiting that's really hard (and I got in very quickly). It feels like your whole life is on hold.''*[76] For young adult substances users, the long wait time for an initial consultation with a substance misuse professional is often exacerbated by the long referral process and evaluations that must be done before accessing care. For many young patients, this results in continued substance misuse.[77] Adult mothers seeking perinatal mental health (PMH) express a desire to "*cut out the referrals piece because you end up getting a referral from somebody that has no idea what you actually require.*"[78] These mothers also report long wait times for already limited existing specialized services, reflecting the inadequate capacity to meet the needs among mothers for timely access to psychiatrists, psychologists, and other counsellors with specialized skills in perinatal mental health.[78] This is corroborated by patients with coexisting mental illness and chronic disease in primary care, who note that referral to external services by HCPs is occasionally inadequate due to HCPs' lack of knowledge of existing resources.[79] In addition to wait times, there are concerns among adult cancer patients seeking psycho-oncology about availability in terms of clinic office hours, as appointments are only scheduled on weekdays during working hours. One patient notes, *"Cancer and its support shouldn't be nine to five."*[80]

Care Avoidance as a Consequence of Non-Personalized Care

Patients and caregivers (parents) across life stages note how certain HCP qualities facilitate care-seeking behaviours. These include: good communication skills;[79,81,82] interdisciplinary collaboration;[79] and compassionate, non-judgmental, knowledgeable, respectful, and prompt care.[77] However HCP qualities may also discourage care-seeking behaviours; for example: HCPs passing judgement related to substance misuse during initial consults;[77] prejudice, racism and discrimination by any HCP[83] toward ethnic minorities,[84] LGBTQ adults,[73] and Indigenous adults;[75] feeling stigmatized by HCPs, thereby influencing the extent to which patients disclose symptoms and their preferred treatment options;[79,80,82] poor interactions with hospital staff such as imaging technicians and nursing staff, who may be non-communicative with patients, conduct assessments that are physically painful to the patient, or disrespectful to patients;[85,86] lack of trust in HCPs when they provide care that is perceived to be non-personalized and when HCPs offer a multitude of screening procedures without proper explanation;[85] and lack of cultural sensitivity by HCPs,[82] particularly for Indigenous youth,[87] LGBTQ adults,[73] and Canadian newcomers.[74] Vulnerably housed adults seeking mental health care note that clerical staff should receive sensitivity and awareness training.[85] Barriers in all cases contributed to care avoidance or an unwillingness to return to the clinic for follow-up care.

A DESIRE FOR INFORMATION ON RESOURCES AVAILABLE AND HOW TO NAVIGATE THE HEALTH SYSTEM

HCP Knowledge Deficits and Gaps Around Mental Health-Care and Supports

Patients across all life stages note knowledge gaps among primary HCPs about various aspects of their mental health care. Youth seeking mental health-care believe their family doctor is not knowledgeable about youth mental health services.[88] Similarly, mothers seeking PMH care note a lack of knowledge on community-based PMH services.[78] Other young adults note their HCP's knowledge of substance misuse treatment facilities is missing or unclear.[77] Young adult parents note knowledge gaps among HCPs on their role in the transition process.[89] For some young adults, the most helpful thing a HCP can do is demonstrate an understanding of the patient's problem.[77]

Adult patients with coexisting mental disorders and chronic diseases who are seen in primary care note that family physicians hesitate to take time to discuss mental health due to perceived knowledge gaps. These adults express that HCPs make inadequate referrals to external services due to their limited understanding of available mental health resources.[79] Other adult recipients of mental health services note similar knowledge deficits from their primary HCP and social agencies, namely around the side effects of prescriptions for mental illness, and healthy living while living with mental illness.[90] Adult cancer patients seeking psycho-oncology (psycho-oncology is an interdisciplinary field at the intersection of physical, psychological, social, and behavioral aspects of the cancer experience for both patients and caregivers. The psycho-oncology programs offer emotional and supportive care to cancer patients and their caregivers), note challenges in accessing timely counselling services: dissemination of information about counselling services does not occur when they need it (either too early, or too late when they are in distress). When they do receive information, they are overwhelmed. Despite these challenges, patients note they are able to access counselling services and are satisfied with them and the information provided.[80]

> *"I went on this medication, I was over three hundred pounds, the doctor's saying 'well you're overweight'; well I wasn't when I started it . . . if I just stopped taking my medication I'd probably lose a lot of weight. So, am I going to be fat and sane or skinny and nuts?"*
>
> —Graham, 2013

Alternative Sources of Information

As a result of these knowledge deficits, many patients seek mental health-related information elsewhere. Among children and young adults, their parents are considered useful sources of information and support when they first seek treatment.[77] Other youth and young adults seek information from the Internet on mental health, symptoms and treatment options. These youth express a specific desire for more web-based mental health resources, including contact with an online professional (e.g.,. a therapist or coach).[91] These online resources would include a range of information, for example, descriptions of interventions and treatments, evidence-based research articles, a resource list to access help based on area of residence, self-help interventions and tools, and informative pictures and videos.[91] Among mothers seeking PMH services, specialized psychiatrists and midwives are very helpful in filling knowledge gaps.[78] Some adult LGBTQ groups seeking mental health care note seeking information and care outside the health sector altogether, for example, at church.[73]

A DESIRE FOR CHOICE IN TREATMENT, CARE SETTING AND/OR CARE PROVIDER

Health and Social Care Personnel

Patients, largely from the adult life stage, and caregivers (parents) note a range of care and service providers involved in mental health care, including case managers,[88] probation officers,[77] midwives,[78] nurses and psychologists,[79,80] and individuals who serve as companions during medical appointments when a patient is alone.[85]

Parents desire someone to provide case management to co-ordinate services available to their child seeking mental health care, thereby ensuring their child does not fall through the cracks. These parents, however, do note that some children do fall through the cracks because they do not fit into existing programs and cannot access appropriate services.[88] Mothers seeking perinatal mental health services express a strong appreciation for midwives. Midwives assume an advocacy role and take on the responsibility of ensuring that mothers become connected to all the services they need. Midwives take a proactive role in supporting mothers and are able to perceive the mother's need for care, even when they cannot ask for help themselves. Mothers also value that midwives provide postpartum home visits.[78] Adult patients with coexisting mental disorders and chronic diseases seeking primary care appreciate the involvement of HCPs other than family physicians, including nurses and psychologists.[79] Psychologists, in particular, are seen as important among adult cancer patients given their ability to "help the whole person," and their holistic, non-judgemental approach to care.[80] Among adult immigrant populations, there is a desire to have providers, particularly counsellors, who are proficient in the patient's language,[74] as this would increase care-seeking behaviours by a population that often downplays mental health concerns.

> *"…they don't say it out loud, many Koreans would actually consider seeking counselling if we have Korean Counsellors available here."*
>
> —Han, 2015

Vulnerably housed adult women with mental health challenges desire an individual, e.g., a volunteer, to provide supportive accompaniment (companionship) during medical appointments.[85] Along similar lines, low-income, adult LGBTQ mental health care users express a desire for support, but post-treatment, noting that it would be helpful if someone checks in periodically, as self-care strategies to maintain well-being are often ineffective.73 Adult LGBTQ newcomers note that their mental health improved after attending support groups, which helped them cope, reduced their isolation, provided a judgment-free safe space, and provided guidance in navigating the Canadian health care system, namely around the health care costs that are covered in Canada's health care system.[52] More support by HCPs in navigating the health care system was also expressed by parents of children with intellectual disabilities.[92]

In terms of physicians, patients and caregivers (parents) view the role of specialist and non-specialist physicians differently. Parents desire their primary care provider specifically to communicate and co-ordinate care to ensure care continuity.[88] Young adult substance users in the criminal justice system generally trust physicians.[77] Vulnerably housed women with mental health challenges note that family physicians should be open to accepting clients who have complex histories.[85]

While child and youth perceptions on this theme are scant, youth seeking mental health services do note their appreciation of having more than one HCP involved in their care. As one youth notes, *"…we can brainstorm more."*[88] Young adults seeking treatment for substance abuse and mental health view probation officers as important. These individuals straddle the health, social and criminal justice systems, and guide imprisoned substance abusers to treatment, which represents an important supportive role for substance users.[77] This highlights a subsequent theme of care continuity, as well as the idea that mental health care goes beyond the medical care sector. Young adults belonging to ethnic minorities seeking community mental health care view case workers/managers as important in their health, as these individuals represent a catalyst to improving their health. They encourage medication compliance, stabilize patient conditions, help patients lead productive lives, and check-in with patients on a regular basis.[84]

Caregivers as Partners in Care

Parents acknowledge their significant role in their child's care and express a desire to be involved in their own child's treatment and care team.[88] As previously mentioned, parents often assume the role of health care expert and system navigator.[89,92] Indigenous youth express a desire for their parent or guardian's involvement in school-based interventions.[87]

> *"…the way [provider] included me-that was the model that we should all follow with kids in mental health."*
>
> —Tobon, 2015

Services

Patients and caregivers (parents) across life stages identify a range of services that would help to optimally manage their own or their child's mental health care. For example, parents of young adults with an intellectual disability want better accessibility to health and rehabilitation services in the adult sector, increased availability of opportunities in community-based activity centres, and daycares specialized in intellectual disability. Youth engaged in online mental health resources desire online platforms with access to online professionals (e.g., a therapist or coach), and highlight the importance of privacy.[91] Similarly, mothers seeking perinatal mental health express a desire for online services that can be accessed at their convenience at home, as one mother notes, *"…trying to find mechanisms that are not so intensive in terms of booking appointments and getting out of the house and all that."* Mothers also note a desire for more mother-oriented services in addition to existing baby-oriented services, as maternal well-being should be a prerequisite for the health of babies.[78]

Screening

Vulnerably housed women with mental health challenges who are concerned about breast and cervical cancer screening desire improved outreach in screening practices; for example, screening should ask about sexual history, explain what will happen during the procedure, and arrange for a female nurse to be in attendance for reassurance purposes. Resource materials should also be accessible: in plain language, in multiple languages, in large print, produced on Braille and on audio cassettes and/or DVDs.[85]

A DESIRE FOR HOLISTIC CARE AND NON-MEDICAL SUPPORTS TO OVERCOME BARRIERS TO ACCESSING CARE

Social Determinants of Health

Many patients across life stages and caregivers acknowledge the relevance of the social determinants of health (education, income, transportation) in mental health care. For example, a desire for counselling psychology to focus on social determinants of health and family issues is expressed by adult (Korean) immigrants seeking self-management of suicidal behaviours.[74] Vulnerably housed women with mental health challenges note that living in the context of poverty makes it difficult to maintain good nutrition, exercise, and a healthy lifestyle as recommended by HCPs. Simple health promotion messages that fail to attend to these realities (e.g., reliance on food banks) can be ineffective and discouraging to marginalized poor women.[85]

> *"I was very irritated because they only focused on suicide, nothing else. They don't focus on family issues, they don't focus on poverty, they don't focus on my mom who I was caring for…they were like "how many times do you think of suicide"…they only cared about the suicide part but if…I didn't mention suicide then they would just put me in a waiting list like two months later…so I just stopped going."*
>
> —Han, 2015

Involvement of Education Sector: Parents of young adults with intellectual disabilities highlight the importance of communication between rehabilitation centres, public specialized schools, health and social service centres, and parents themselves.[89] Parents of youth seeking mental health care desire involvement of the education sector (schools) to accommodate children's emotional, behavioural and learning needs.[88] Similarly, Indigenous youth desire school-based interventions and co-ordination of mental health care, specifically Indigenous-specific, culturally informed, gender- and sex-specific developmental services addressing sex work, substance use and the social determinants of health.[87]

***Transportation*:** Among adults who frequently visit the emergency department for mental health-related reasons, there is consensus that lack of transportation is an important determinant of health. Patients felt their needs were not met by the care received as they were being discharged without transportation or a plan, which exacerbated their symptoms, leading to a worsened mental state or self-destructive behaviours that would necessitate further emergency care.[86] Transportation barriers to accessing care is also noted among youth substance users.[87]

Overcoming Financial Barriers: While patients and caregivers (parents) appreciate Canada's publicly funded health care system, they note several challenges. Patients across life stages note limitations to the extent of mental health care they receive, often rooted in funding constraints. Young adult substance users, for example, do appreciate that substance misuse treatment is publicly covered, but expressed a specific need for psychological support for substance misuse which is difficult to access in the public system and expensive in the private sector. Although funding through social assistance or workplace health insurance is available, some group insurance policies restrict choice of treatment, especially in private sector facilities (residential facilities).[77]

Adult mothers who seek perinatal mental health services note that, while PMH care provided by physicians is publicly funded, PMH services by nurses, social workers and psychologists is not completely publicly funded. In Ontario, midwives can refer mothers to mental health professionals who are paid privately and to family physicians, but not directly to psychiatrists. Patients of midwives must see their family physician in order to obtain a psychiatric referral.[78] Additional costs that are incurred out-of-pocket, or through private health insurance, prevent access to preferred methods of treatment for perinatal mental illness, such as individual counselling sessions, postpartum doulas, and community-based psychotherapy.[78] Cancer patients seeking psycho-oncology note that access to free counselling is valued and means they can continue with their counselling program. These patients highlight the need for emotional support following treatment, when the reassurance of the "medical safety net" gives way to anxiety and fears of recurrence.[80]

The prohibitive cost of mental health care is also noted by adult patients with coexisting mental disorders and chronic diseases,[79] and by adult LGBTQ patients regarding prescription medication for their mental health,[73] and, to a lesser extent, by vulnerably housed adults with unmet mental health care needs including the need for affordable mental health care.[93]

A DESIRE FOR CARE CO-ORDINATION AND CARE CONTINUITY

Contact with Health Care Providers

Parents of children and youth seeking mental health care express satisfaction with the consistency of contact with their HCPs and the continuity of care received across providers.[88]

> *"Continuity of care would be…if my daughter [goes] from [here] …to wherever she may end up, there's somebody liaising between each of those services."*
>
> —Tobon, 2015

Other groups express a desire for greater continuity in care. Adult mothers seeking PMH say that an ongoing relationship with a known HCP is necessary in order to comfortably disclose PMH concerns and reduces the need for women to have to repeat their health history and symptoms to multiple HCPs.[78] Similarly, mothers of children with intellectual disabilities highlight the importance of relationships between HCPs and children. Continuity in these relationships (namely, working with the same nurses and other HCPs when visiting a health facility) creates familiarity and, like mothers seeking PMH, reduces the frustration of having to repeat clinical history.[81]

Co-ordinated Care During Care Transition

The importance of co-ordinated services is expressed by parents of young adults transitioning from pediatric to adult care.[89] Parents often act as system navigators as a result of a perception that HCPs know little about care transitions, the lack of transition planning services available, and the lack of consultation between services.[89] Similarly, parents of children with intellectual disabilities feel like they move between the parent/learner role, and educator/expert role due to gaps in information and care co-ordination.[92] For parents, added responsibilities to compensate for gaps in service delivery and poor co-ordination between institutions and services increase their levels of stress. Parents express a need for material support, information support (better understanding of complexity of health need), cognitive support (adapted services for patients with more severe intellectual disability), and emotional support.[89]

Acute Life-Threatening

A total of 18 articles focused on acute life-threatening populations. Of the four articles that spoke to youth and young adult populations, two focused specifically on vulnerably housed populations while the other two on the general youth/young adult populations. The remainder of articles fell within the adult (six), geriatric (one) and caregiver (seven) groups with one of the articles focusing on adult LGBTQ populations. There was relative consistency across life stages within this health stage, which are summarized below.

A DESIRE FOR PERSONALIZED (PERSON-CENTRED) CARE

Personable, Open, and Clear Communication by HCPs

Patients and caregivers in the emergency room (ER) wanted to have HCPs who were willing to listen to them and communicate in a manner that was easy to understand.[94-97] They would also like HCPs to work as a team and not contradict one another,[94-96,98] which aligns with a desire for greater care co-ordination.

> *"They let me know that they're all here as a team and that they work together . . . everyone had their own way of explaining tube feeding to me: how it works and how much. And it was nice. It made me feel more comfortable and relaxed because they all came to a common conclusion, that it's for me and my benefit."*
>
> —Green et al., 2016

Patients agree that they need to receive timely, appropriate, transparent information especially about discomfort with therapy or other details. They want to know the full truth, but they also want this full truth to be presented in a compassionate manner. Mainly because being in hospital with acute symptoms and pain already provokes fear and uncertainty among them.[97] They expect that HCPs go an extra mile when asking about sensitive issues like pain management[94] and end-of-life decisions.[99]

Emergency Room Avoidance as a Consequence of Stigma

Although many people who found themselves in a crisis would go to the ER, other groups (LGBTQ, vulnerably housed and socially isolated youth) choose to avoid the ER as a result of fear of stigmatization, judgment, or having to experience long wait times which was perceived to be associated with their appearance of looking homeless.[95,100] Long wait times to see a HCP in the ER was problematic for vulnerably housed people who may be unable to obtain a space in a shelter if they are waiting in the ER.[95,101]

> *"Homelessness just in itself has sort of a stigma or even looking homeless or not having average clothing, just being bulky or having a coat. It's big and it's kind of old. Just gives that stigma and they're like, 'Oh, he's homeless, we can make him wait. He didn't really have anything to get back to, he doesn't pay taxes, he doesn't do this, he doesn't do that.'"*
>
> —Newton, 2016

A DESIRE FOR INFORMATION ON RESOURCES AVAILABLE AND HOW TO NAVIGATE THE HEALTH SYSTEM

Emergency Room Becomes First Resort When Other Options are not Presented

Individuals living with acute life-threatening illness often access the ER as a result of not knowing where else to go when they find themselves in a precarious position. Patients perceive a sense of frustration from HCPs about attending the ER as they are told to avoid it but lack an understanding of alternative resources to support them in a time of crises.[96]

> *"It was suggested that I avoid ER, but at the same time I don't know what to do when the symptoms come. There's no education. I would go back to the ER because it's the only place that I can find a solution when I'm sick"*
>
> —Vaillancourt, 2017

Community Resources and Discharge Planning

Informing patients and caregivers of available support services within the community and support navigation across the health care system is valued.[94-96] There is an overall lack of thorough discharge planning from the perspectives of patients and caregivers. There is a need to improve information sharing and planning for patients and caregivers, so they feel confident in knowing what to expect when they return home or know who to contact if something were to happen. Parents value clear communication and information provided to them.[96,102,103]

A DESIRE FOR HOLISTIC CARE AND NON-MEDICAL SUPPORTS TO OVERCOME BARRIERS TO ACCESSING CARE

Patients and caregivers expect an in-depth assessment of the root causes of their acute symptoms rather than just treatment of flare-ups and other patchwork solutions. They also expect some sort of attention to their non-medical needs, for example, providing food if patients need it or subsidized medications if they do not have money to pay for prescriptions. They also appreciate if their individualized needs are taken into consideration, like being seen by a female physician or HCPs speaking to them in their native language.[95]

> *“We had very clear instructions about what medications to give, what prescriptions to get, when to give them. The surgeon spoke with me afterwards about things that she could and could not do, activities she could and couldn’t participate in, if there were any foods she could or couldn’t have, all of those sorts of parts. The nurse reviewed all of the medications before we left. . .The pharmacist also reviewed all those things.” (Participant 9)*
>
> —Longard, 2016

Chronic Conditions

There were 97 articles that focused on people living with chronic conditions. The majority of the articles focused on the adult, older adult, and caregiver life stages.

Specific similarities and differences in themes across life stages within the chronic condition’s population are presented below.

A DESIRE FOR PERSONALIZED (PERSON-CENTRED) CARE

Like the themes that were identified within the other health stages, people living with chronic conditions in all life stages desire respectful and personalized approaches to care. Overall the literature highlights that there is an over-reliance on the medical aspect of illness and a lack of support focusing on patients’ mental and emotional needs.[104-115] To provide more person-centred care and engage meaningfully with patients, HCPs need to have non-judgmental attitudes, open and clear communication (e.g., no medical jargon), kindness and a genuine character.[116,117]

> *“[the MCC are all interrelated anyway…they’re all me… it begins to sound like the rheumatoid arthritis ‘me’ and the diabetic ‘me’ but they’re all me.”*
>
> —Ploeg, 2017

Several studies note the importance of assessing patients’ needs and capacity by considering their physical, mental, social, financial, and personal features; assessments need to be based on the whole person, not exclusively on the diagnoses.[110-114,118] Patients believe in HCPs’ clinical competence, but urge that biomedical care is insufficient on its own.[119] Patients desire HCPs to be empathetic and open in their communication. Patients note that, when given permission to suffer, they feel their needs and experiences are being validated. HCPs who allow patients to be vulnerable leads to trusting relationships, and without this connection, patients feel lonely and frustrated.[120] Parents report unmet need for their children's preferred services, including psychological counselling because such services were unavailable at their local clinics.[121]

> *"Some providers go the extra mile while others seem to do the bare minimum. Respect and dignity are important and looking beyond the ailment to the person. A good listener. They actually listen to what you're saying. Non-judgmental. They actually are there to help you. Whereas some of them, they're just here for the buck […] It's hard to describe it but there's no rapport, and a bit of a chip on the shoulder. That's about it."*
>
> —Kuluski, 2013

Relatedly, patients express a desire for HCPs to be non-judgmental and provide thoughtful care by being supportive and offering preventive supports, advocating for patients within the health care system, and being compassionate, honest and making time for their patients.[113] Patients who are LGBTQ, vulnerably housed, and Indigenous all desire culturally sensitive and appropriate care. Fear of stigmatization affect willingness to access care and self-disclose relevant parts of their lives .[122]

> *"I'd like to be treated the way professional staff would treat anybody. I wouldn't accept any special treatment, but I wouldn't accept substandard treatment because of my sexuality"*
>
> —Furlotte et al., 2016

Patients undergoing cancer treatment highlight a desire for HCPs to have conversations with them about sexuality, noting they are less likely to initiate the topic, but if a HCP did, they would be more likely to talk about it.[123] Patients recognize this topic as being important to have in regular routine procedures. Patients value more forthright communication from providers around sexual vitality, which is part of maintaining a normal life for many.[124,125]

> *"I asked my gynecologist before and after surgery, then mentioned [trouble with having intimate relationships] at the first visit at the cancer centre to the oncologist, and then with a resident in the family practice unit. And no one ever followed up with me… I was disappointed that nobody went any further."*
>
> —Fitch et al., 2013

Mistrust as a consequence of HCP behaviour: Most of the pediatric population and their parents appear to value the expert opinion of HCPs, often choosing to defer decisional burdens to HCPs.[126] However, some feel that physicians withhold treatment options and important information, or they would not be willing to discuss new treatments.[126] Most adults living with chronic conditions do not have high levels of trust in HCPs; for example, some patients do not trust that hospitals adequately control and manage infections.[127] Similarly, Indigenous populations describe HCPs as being too prescriptive or authoritarian, making them feel "tired of being told what to do."[128] However, another study highlights that some patients prefer to be "guided by the health care staff," where "guided" means receiving information and being given the opportunity to express their own views.[129]

> *"They know what they're doing, I feel really comfortable with that."*
> *(mother of 13-17-year-old)*
>
> —Gutman et al., 2018

> *"all that she told me at the hospital about the services was useful; because, I did not know about all these possibilities"*
>
> —Keller et al., 2017

Wait Times

For parents of youth living with chronic conditions (e.g., Autism Spectrum Disorder [ASD]) wait times were particularly problematic. Parents dislike waiting to see a staff member and to receive treatment. Additionally, for children living with ASD, wait times are especially challenging given the sensory-intense environment of health care settings.[123] Thus, parents propose that medical urgency not be the only factor determining access to care and triage; for example, salient care-relevant issues should be considered that reflect the child's special needs, and children with ASD should be fast-tracked. Cancer patients also find wait times to be a cause of frustration and note a desire for clear information on anticipated wait times for initial treatment and subsequent surgery/treatment/follow-up.[130] Others living with chronic conditions express they are rarely considered a priority in hospital settings.[131]

Interdisciplinary Teams

People living with chronic conditions value having access to interdisciplinary teams with providers who work to their full scopes of practice.[79,132-135] Patients feel more confident in understanding their health care needs if they have access to a team, and appreciate having a team to speak to post-diagnosis.[136]

Patients also spoke to the value that teams can offer in clinical settings. Physicians are perceived as always needing to rush, and as a result of these relationships, patients report feeling stigmatized by providers, which causes anxiety and influences their willingness to disclose symptoms and their treatment choice. Involvement of HCPs other than physicians is one way to reduce this barrier to care. It is considered to be acceptable to have less time with a physician so long as it is complemented with more time with another HCP. Team-based environments are seen to support patient-centred relationships and are valued.[79,135]

A DESIRE FOR INFORMATION ON RESOURCES AVAILABLE AND HOW TO NAVIGATE THE HEALTH SYSTEM

Access to Information on Supports and Resources

Patients living with complex chronic conditions value access to information; for example, a care plan that offers emergency care guidelines, list of HCPs with contact information, and details on how conditions may deteriorate in crises or over time.[137] Similarly, cancer survivors value information to understand signs of recurrence or staying well after treatment.[130] There are also difficulties in accessing services (challenges connecting with organizations, being put on waitlists, not understanding eligibility). Patients who are discharged note feeling unprepared, relying on services identified by word-of-mouth.[115,138,139]

> *"And with Crohn's, I always wait till the last minute before I go to hospital. I dread [emphasis added] going, because it's the same thing all the time, you have to wait hours to get in to see somebody, and half of the time you're waiting in the waiting room, you're vomiting and you're going to the bathroom with diarrhea. And I don't think that they're triaging people the way they should be."*
>
> —Griscti et al., 2016

There is an overall lack of understanding among patients about availability of resources, treatment options, care trajectory and severity, and service offerings,[115,124,130.138.140] and an overall feeling that patients receive incomplete information, are rushed, and that some illnesses may have been diagnosed incorrectly (e.g., bronchitis rather than asthma).[139,141] Cancer patients similarly experience informational gaps and note feeling as though questions were never addressed due to being rushed by HCPs.[130] Indigenous youth and parents believe that their cultural identity impedes their access to needed services and supports. There is an overall lack of information and resources offered to understand conditions, medication, and side effects. Most seek emotional and practical support from Elders, but this support is not available at health care facilities or through formal education.[141]

> *"I think the clinic should be mandatory because it explains things like, for example, blood clots. I thought blood clots were pieces that would form and break off but they show you a video of exactly what they are. Then you understand…It would have been nice if someone [earlier] said, "You know what? Live normally. It's not life-threatening. Don't worry about it." But I was never told that"*
>
> —Webster, 2015

Patients who enter the hospital without home supports are often unaware that home supports are available or are waiting for an HCP to connect them to home supports. Some patients express feelings of abandonment post-discharge; for example, rehab services are often short during hospital stays and patients are unaware of additional rehab services that may be available in the community.[142,143]

Constrained Access to Resources

Access to resources is a challenge for Indigenous patients living on-reserve; for example, limited access to human resources like physicians, or limited access to necessary supplies such as insulin pumps as a result of the complexity of government funding forms and physicians unwilling to fill these forms.[128] In urban settings with more resources, patients criticize the lack of respectful care for Indigenous patients. Both cancer survivors and caregivers stated they had received differential treatment, which perpetuated their silence and limited their access to care.[144]

Access to resources is also challenging for populations living in rural and remote locations. Some patients believe that city-dwelling patients are those who are well-educated are the only people who are referred to specialists.[141,145] Overall, cancer patients are satisfied with the health care system despite perceived gaps and lack of resources. Patients would like a better understanding of the disease, prognosis, and treatment plan with a HCP who confirms that patients understand the information that was just delivered to them.[145-147] One patient described having an ex-patient who has lived experience come in and talk to them about their experience was helpful and offered information around the operation, approach, and what to expect.[140]

> *"They're doing their best. They're doing what they can. They can't do more without more tools."*
>
> —Melhem, 2017

Appropriate use of Electronic Health Records and Other Technologies

Patients and caregivers from across life stages see value in both patients and HCPs having access to health information.[148-153] Patients believe they should have access to medical information. Anxiety about medical results is not considered a major concern with only 9.7% of participants suggesting that it may be anxiety provoking.[149] Although, one study notes that 31.6% of participants agree or strongly agree that they would be less likely to get tested for sextually transmitted infections (STI) if they knew their personal health information would be included in a provincial database.[154]

> *"I had some severe complications during surgery; in fact, I almost died. Two weeks later I went to see my medical oncologist and he didn't know anything about this. When he went to look it up in the system, the reports hadn't even been scanned into the system yet. I mean, my medical oncologist not being able to access reports when I almost died 2 weeks ago, like that's a big deal."*
>
> —Easley et al., 2016

A DESIRE FOR CHOICE IN TREATMENT, CARE SETTING AND/OR CARE PROVIDER

Care at Home

Patients and caregivers across all life and health stages value home-based supports.[124,132,138,155] For youth living with chronic conditions, home supports require additional training for families which can reduce apprehension and foster close relationships between family members and HCPs. Home visits also help to engage other members of the family and reduced feelings of exclusion.[155]

For some, homecare is a better location for hemodialysis.[124] For others, it is a more affordable alternative to living in long-term care, with the cost-sharing aspect of facility-based long-term care being described as unaffordable.[138] Toronto Local Health Integration Networks (LHINs) Telehomecare program is helpful to patients as it allows people the opportunity to manage conditions in a home setting.[156]

> *"The program gave my mother the opportunity to recover in the comfort of her home. This was a major contributor to her recovery. It was also a great relief and support as a caregiver to be able to recognize and control potential crisis/anxiety with this condition."*
>
> —Barbita et al., 2017

While home-based support is considered a positive aspect of the health care system, patients and caregivers note some areas of concern. For example, patients express that HCPs should be required to participate in sexual and gender diversity training for home workers and companies.[122] Additionally, patients highlight the challenges of having a lack of consist homecare providers, noting that this often becomes overwhelming and adds to responsibilities rather than alleviates them. Caregivers who felt that they had to educate or supervise homecare staff are more likely to refuse assistance.[133]

Caregivers and Patients as Partners in Care

Patients and caregivers who felt as though they were a member of the care team see the experience as positive and their contribution valued. Patients and caregivers become increasingly frustrated when kept in the dark.[114,116,157] Family centred approaches are appreciated and seen as necessary. HCPs should listen to parents and caregivers and recognize them as partners in care, as developing a targeted and comprehensive care plan cannot be accomplished without feedback from family or caregivers.[108,135,140,157]

> *They did it [family-centered approach] for my liver transplant, but not for my stroke, where my wife fell into a depression."*
>
> —Rochette, 2014

There is an overall desire for more involvement in health care decisions, supporting access to mental health care, and focusing on quality of life. Reciprocal exchange is important; caregivers fill in health system gaps and can offer information guidance, problem solving, resources, and accompaniment. Patients and caregivers believe these qualities are important and should be valued by HCPs.[115,133,158]

Relatedly, caregivers and older adults note a desire for caregiver supports that facilitate socialization, including opportunities to engage in social activities and leisure that foster community engagement and interpersonal relationships.[159]

Online Care and Support

While face-to-face support is almost always preferred, online supports are a positive alternative that can bridge care gaps (particularly for those in rural communities).[151] Others highlight their desire to have online support groups, online access to trustworthy and relevant health information (i.e., how to treat highs and lows of glucose levels),[160] online access to necessary medical equipment , and the ability to make medical appointments online and communicate via text message.[150]

Use of technologies and access to medical information is clearly desired among patients, but there are concerns around the lack of integration of medical information, which is believed to cause redundancies and delayed access to services.[148]

A DESIRE FOR HOLISTIC CARE AND NON-MEDICAL SUPPORTS TO OVERCOME BARRIERS TO ACCESSING CARE

Spiritual elements of health care are lacking within the health care system. For persons diagnosed with cancer, spiritual care is a necessary component to comprehensive care. Basic spiritual care could be provided by all members of the care team. A lack of spiritual support can be associated with HCPs tendency to conflate spirituality with religion. One suggestion is to incorporate nature within cancer centres to enhance spiritual well-being.[161]

A DESIRE FOR CARE CO-ORDINATION AND CARE CONTINUITY

Care Transitions

Transitions, primarily from hospital to home, is highlighted as a great challenge for patients and caregivers. The challenges around care setting transition relate to limited channels of communication and limited understanding of what to expect post-discharge.[112,114] Patients want to have discharge meetings that are meaningful, stressing that discharge meetings are only helpful if they are not rushed and involve patient engagement and planning. [112] Another study notes that even with comprehensive discharge plans (that consider the whole person), people still experience problems once they return home and start to access and receive services. [142] Parents underscore the value of having accessible channels of communication post-discharge. With this support, parents do not feel overwhelmed or the need to rush back to the hospital.[114]

In terms of pediatric-to-adult care transition, there are differences among youth and their caregivers with respect to youth transitioning into the adult health care system. Youth feel they are able to independently manage their health needs and report increased self-management during the transition. By contrast, parents feel there should be a more gradual and balanced transition from youth-to-adult health systems and that 18 years of age is too young for adolescent patients to be making independent decisions about their care.[162,163]

Need for A Navigator Role due to a Lack of System Co-ordination

Patients living with chronic conditions and their caregivers express displeasure with the overall lack of co-ordination and continuity in information within the health care system.[118,164] This overall lack of co-ordination has left caregivers,[79,115,118,153,164,165] First Nations and Métis women,[158] and other patients feeling as though they are responsible for managing their own care and navigating the larger health care system, which can be an overwhelming feeling.[145] Patients suggest that if providers are connected to each other, this would likely improve the burden of navigation experienced by patients and caregivers. HCPs are seen to be lacking a knowledge on what services are offered in their communities (i.e., counselling services).[79] Similarly, patients discuss that seeing many providers often results in contradictory advice and inconsistent service provision, which passes responsibility onto the patient.[158] In these cases, patients feel like providers are always “passing the buck.”[164]

> *“And then all of a sudden [genetics specialist] dropped me like a hot potato. She says, you have to deal with your pediatrician. And the pediatrician, like I said, he’s retiring. Every time I ask him for a referral or something, I can’t do it. They have to do it. The specialist has to do it. They have to do this. It’s not mine. Always passing the buck to somebody else.”*
>
> —Baumbusch et al., 2018

For patients in the cancer care system, those who had an oncology nurse navigator felt this role to be vital.[120] Others who did not receive navigator support suggest that a navigator would be a pivotal aspect to their care by assisting patients at point of treatment entry and throughout the treatment process, offering contact during times of uncertainty (i.e., transitions in care), offering various modes of communication (i.e., email, telephone calls, face-to-face meetings, text messages), and providing useful information regarding other resources that may be helpful to patients and caregivers (i.e., financial support, transportation trips).[118,132,138]

Palliative Care

Within the palliative care literature there were 12 articles. Most of these articles focused on adult, older adult and caregiver populations, and only one focused on rural and remote and Indigenous populations. Specific similarities and differences in themes across life stages within the palliative care population are presented below.

A DESIRE FOR PERSONALIZED (PERSON-CENTRED) CARE

Relational Connectedness and Empathetic Support

Patients and caregivers value consistent relationships with HCPs. These relationships allow trust to build overtime. This aligns with a desire for co-ordinated care and continuity in care. Strong relationships are built through the HCP's use of eye contact in communication with patients/caregivers, and HCPs giving patients/caregivers their full and undivided attention when engaging with them. Communication and engagement do not need to be long but does require an element of meaningful and personable connection. In the final days of life, caregivers express not wanting to have the long-standing team that had been working with them to be replaced by specialized providers.[166]

A DESIRE FOR INFORMATION ON RESOURCES AVAILABLE AND HOW TO NAVIGATE THE HEALTH SYSTEM

Knowledge and Information Sharing

The need for better knowledge and information sharing was present across identified life stages. It was clear that patients respect direct and clear communication that is informative so they are able to make clear care decisions and understand care trajectories and what to expect over the course of an illness, or at the very least, who to call or what to do in an emergency.[167,168] Information should be shared with families and patients, who note often feeling "out of the loop" and desiring a shared decision-making relationship, open communication, proper care co-ordination and follow-up.[166] The idea of candid communication that involves empathy and respect was highlighted by both patients and caregivers.

> *"If a doctor honestly believes that I am so far advanced in an illness that I couldn't possibly live very much longer, then I would appreciate him saying to me, 'Well, it looks as though we've come to the end of the road but I'll make you as comfortable as possible, make your going out as good as I can." (Participant 8: male, age range >80 years old, non-cancer diagnosis)*
>
> —Abdul-Razzak et al., 2014)

A DESIRE FOR CHOICE IN TREATMENT, CARE SETTING, AND/OR CARE PROVIDER

Palliative Care at Home

> *"Having a palliative care program allows for that community to bring their loved one's home, to die where they were born…Certainly in an aboriginal community that is the one thing that is key, to be born on the territory and to pass away on the territory. Having a palliative care program helps them to feel comfortable leaving the hospital." (community facilitator)*
>
> —Kelley et al., 2018

The desire to have palliative care at home was solely expressed by rural and remote living Indigenous geriatric populations. There was a desire presented among this population to have access to local services that was appropriate to their needs (particularly for the Indigenous communities).[169]

Findings across Health Stages

A theme was generated if it was identified within two or more of the health stages. Table 1 summarizes the key themes identified by health stages. Personalized care and information followed by holistic care were the three most salient themes, with the majority of health stages identifying these as important aspects of the health care system.

Table 1		HEALTH STAGE				
		Walking Well	Mental & Cognitive Health	Acute Life-Threatening	Chronic Conditions	Palliative Care
OVERLAPPING THEMES	Personalized Care	✓	✓	✓	✓	✓
	Information	✓	✓	✓	✓	✓
	Choice	✓	✓		✓	✓
	Holistic Care and Non-Medical Supports	✓	✓	✓	✓	
	Co-ordinated Care and Continuity of Care		✓		✓	✓

Table 2 highlights the nuances of the overlapping theme “personalized care.” The walking well, those living with mental and cognitive illnesses and those with chronic conditions all saw value in personalized care that was non-discriminatory. Those with acute life-threatening illnesses, chronic conditions, and those in palliative care all saw the value of having personalized care that was compassionate, empathetic and non-judgmental. There were three consequences, identified within the literature, associated with care that was not personalized. For example, the walking well, those living with mental and cognitive illnesses and those living with acute life-threatening illnesses would avoid care as a result of care not being personalized or culturally sensitive.

Table 2			**HEALTH STAGE**				
			Walking Well	**Mental & Cognitive Health**	**Acute Life-Threatening**	**Chronic Conditions**	**Palliative Care**
OVERLAPPING THEME	**Personalized Care**	HCP and health system awareness of trans-identity in policy and practice	✓	✓			
		Non-discriminatory HCPs for cultural and social groups (aging, Indigenous, immigrants, LGBT)	✓	✓		✓	
		Culturally appropriate procedures (privacy when undressing)	✓				
		Tailored services for immigrant populations	✓				
		Interpreters and translation services	✓				
		HCPs initiating discussion of non-physical needs (emotional and psychological)	✓			✓	
		HCPs initiative discussion about sexuality				✓	
		Wait times reflect that care is not person-centred		✓		✓	
		Compassionate, empathetic and non-judgmental care and communication by HCPs			✓	✓	✓
		Interdisciplinary care valued		✓		✓	
		Consequence: Care avoidance	✓	✓	✓		
		Consequence: Difficulty accessing medical care	✓				
		Consequence: Mistrust in HCPs and health system	✓			✓	

Table 3 below highlights that all health stages value a health care system that provides, shares or offers access to valuable information. Namely, the walking well, those living with mental and cognitive health illnesses, those with acute life-threatening illnesses and those living with chronic conditions all value HCPs who have knowledge of, and an understanding around, community-based resources. Another area of overlap among the walking well, those living with acute life-threatening illnesses, chronic conditions and those who are palliative, is around a desire to have a clear care outline and information to understand disease trajectory and possible therapy complications.

Table 3			**HEALTH STAGE**				
			Walking Well	**Mental & Cognitive Health**	**Acute Life-Threatening**	**Chronic Conditions**	**Palliative Care**
OVERLAPPING THEME	**Information**	HCP knowledge deficits around community-based resources	✓	✓	✓	✓	
		Mental health resources and programming	✓	✓			
		Health information easier to obtain in country of origin	✓				
		Difficulties navigating health system due to poor information exchange	✓				
		Challenges understanding online information around insurance options	✓				
		Medical coverage and funding options	✓				
		Information in multiple languages	✓				
		Interest in understanding disease trajectory and therapy complications	✓	✓		✓	✓
		Multiple sources of information (e.g. online, video) would be helpful (beyond oral)	✓	✓			
		Challenges filling out funding applications	✓			✓	
		Health information often sought outside health system (friends, family, online)		✓			
		HCP gaps in transition knowledge (pediatric-to-adult care)		✓			
		Gaps around care/ER discharge procedures/ planning			✓	✓	
		Dissemination of counselling information should happen early		✓			
		Content with counselling services		✓			
		Emergency Room default care setting when other options not presented			✓		
		Perceived differences in urban vs. rural access to specialists				✓	
		Access to personal electronic health information				✓	
		Shared decision-making important					✓

Table 4 presents a detailed portrayal of what the theme “choice’ “looked like across health stages. The most common desired choice was to have a choice for female HCP among the walking well, those living with mental and cognitive illnesses and those living with acute life-threatening illnesses.

Table 4			HEALTH STAGE				
			Walking Well	Mental & Cognitive Health	Acute Life-Threatening	Chronic Conditions	Palliative Care
OVERLAPPING	Choice	Vaccination	✓	✓			
		Screening	✓	✓			
		Use of natural health products	✓				
		Engagement in health prevention programs	✓				
		Medically assisted death	✓				
		Expanded delivery and use of private services	✓				
		Visiting a pharmacist for treatment	✓				
		Indigenous HCPs	✓				
		Female HCPs	✓	✓	✓		
		Birth centres	✓				
		Midwifery care	✓	✓			
		Mother-only services		✓			
		Seeking care in the community (non-hospital settings)	✓	✓			
		Companionship during medical appointments		✓			
		Caregivers as partners in care		✓		✓	
		Online services and support groups		✓		✓	
		Home-based care and supports (including telehome care)				✓	✓

Table 5 summarizes the key findings across health stages as it relates to care that is holistic and non-medical in nature. The two most common elements of this overarching theme relate to an appreciation of universal health care as well as the financial challenges that people can experience around services that are considered "non-essential."

Table 5			**HEALTH STAGE**				
			Walking Well	**Mental & Cognitive Health**	**Acute Life-Threatening**	**Chronic Conditions**	**Palliative Care**
OVERLAPPING THEME	**Holistic Care and Non-Medical Supports**	Universal health care appreciated	✓	✓	✓	✓	
		Extending coverage for pharmaceuticals	✓	✓			
		Extending coverage for eye care	✓				
		Extending coverage for dentistry	✓				
		Extending coverage for home visits	✓				
		Extending coverage for mental health care	✓				
		Preference for non-Western medicines (traditional Chinese, natural)	✓				
		Financial difficulties (exhausting non-essential coverage)	✓	✓		✓	✓
		Complicated, time-consuming referral process	✓	✓			
		Finding a suitable provider is a challenge	✓			✓	
		Long wait times to access a specialist		✓			
		Long wait times in emergency		✓			
		Addressing root cause (not patchwork solution)			✓	✓	
		Spiritual care and support		✓			
		Care should focus on SDOH (transportation)		✓			
		Care should focus on SDOH (family issues)			✓		
		Care should focus on SDOH (nutrition/exercise programs)				✓	
		Care should focus on SDOH (education)				✓	

Table 6 presents findings around a desire for “co-ordinated care” and “care continuity.” The primary element of this theme that related to all five of the health stages was a desire to have an ongoing relationship with HCPs (continuity of relationships).

Table 6			HEALTH STAGE				
			Walking Well	**Mental & Cognitive Health**	**Acute Life-Threatening**	**Chronic Conditions**	**Palliative Care**
OVERLAPPING THEME	**Co-ordinated Care and Continuity of Care**	Ongoing relationship with HCP	✓	✓	✓	✓	✓
		Co-ordinated transition process (pediatric-to-adult care)	✓	✓			
		Co-ordinated transition process (hospital to home)	✓				
		Consequence: Parents and caregivers are system navigators	✓				
		Consequence: Gaps in information	✓				
		Consequence: Stress among caregivers and parents	✓				

Table 7 Comparing Desires of the Health System for each Health Stage

		HEALTH STAGE				
		Walking well	**Mental/Cognitive Health**	**Acute Life-Threatening**	**Chronic Health**	**Palliative Care**
THEME	**PERSONALIZED CARE**	- Treat all patients equitably (do not discriminate based on income, prior history of crime, sexual identity, Indigenous status) - Ask about sexual identity early on - Undergo training in non-discriminatory practices around Indigenous health care delivery - Tailored services that address specific needs of immigrants (e.g., special clinics, health education, awareness forums) - Ensure care remains confidential	- Offer emotional support - Demonstrate sympathy, compassion and understanding of patient's problem - Undergo training in trans identities, how to pick up on suicidal behaviours, and Indigenous addictions - Cut out referral processes that contribute to long wait times for specialized services	- More female physicians - Communication in native language - Compassionate presentation of information about disease and therapy discomforts	- Provide empathetic care (validate patient experiences) - Provide culturally sensitive care - Initiate sensitive topics (sexuality) - Address spiritual care and spiritual well-being - Involve unpaid caregivers in health care decisions - Less sensory-intense emergency rooms (lights)	- Provide empathetic care (eye contact by HCP, full engagement during clinical encounters) - Timely and consistent follow-up
	" I Statements"	• People need follow-up.[78,125] • I will not accept substandard treatment because of my sexuality.[170] • Family centred approach is necessary when your life is falling apart and when sexual health is a concern.[125,140] • When I am waiting it feels like my entire life is on hold…I don't want to have to run around from clinic to clinic when I am sick, very sick to find someone who will take me.[44,76] • As a newcomer or someone who doesn't speak English I would like to learn how to access a doctor and other health care providers who speak my language, one doctor who speaks another language is always busy so I would like other health care providers who also speak that language.[21]				

	INFORMATION	- Interpreters / interpretive services - Online information around health insurance and health care rights - Illustrative, video-based information in traditional languages - Information on mental health resources and community-based services and programming - Information on navigating the health system (referral process, expenses, applications for disability funding) - Information transparency (patients want to know the benefits of prescribed screening, and rationale for primary care provider's referral to a specialist)	-Early dissemination of information on counselling services - Web-based mental health resources and contact with online professional - Information on how to navigate health system - Plain language resources in multiple languages, large print, and on multiple forms of media	- Information transparency (i.e., around potential discomforts and side-effects associated with medicine or therapy) - Information on community supports - Information on how to navigate health system - Improved information sharing at discharge (what to expect when patients return home)	- Information on wait times for initial and subsequent treatments - Information on community services (e.g., counselling) - Information on care planning (HCP contact information, how condition may deteriorate over time, guidelines when visiting the emergency room) - Post-discharge information - Modes of communication (email, telephone, text) - Information on non-medical resources (financial support, transportation) - Access to an interdisciplinary team with knowledge of patient history	- Information on course of illness - Information should be shared with families and patients
	" I Statements"	I don't want to just be asked if I know about something, I would like an explanation about what it is, it is the responsibilities of health care providers to offer pamphlets and information to patients and families, and it is the patients and families responsibilities to read the information.[23,123,171] I would like to fully be taught the consequences and benefits of different health care decisions I might make.[90,103,172] I like to be included in health care processes and decisions (family members and patients) and if I am dying, I would like my provider to be honest with me about what that looks like.[88,167]				

<table>
<tr><td>CHOICE</td><td colspan="5">- Alternative treatment modalities (natural health products)
- Early intervention programs for infants (e.g., nutrition interventions)
- Medically assisted death as a viable treatment option for patients facing imminent death
- Expanding scope of practice of pharmacists
- More birth centres and availability of public funding for midwives
- Move childhood vaccines into the community (schools)
- Expand delivery of private services</td></tr>
<tr><td>“ I Statements”</td><td>I want to learn how to make Indian medicine…[40]
I want a doctor who visits someone at home…the best way is for it to be done at the school…allow for the continuity to die where they were born.[49,70,169]</td><td>- Specialized psychiatrists and midwives
- Case managers to co-ordinate services available for children
- Supportive accompaniment (companionship) during medical appointments
- Community-based screening practices (e.g., community centres and apartment complexes)</td><td></td><td>- More home-based supports to manage chronic conditions in home setting
- Online support groups to bridge care gaps
- Recognizing caregivers as partners in care</td><td>-Expanding palliative care at home for rural populations</td></tr>
<tr><td>HOLISTIC CARE AND NON-MEDICAL SUPPORTS</td><td colspan="5">- Expanded coverage of natural health products, pharmaceuticals, eye care, dentistry, disability funding
- Subsidies for nutritious foods for infants
- Reimbursing rural physician home visits</td></tr>
<tr><td>“ I Statements”</td><td colspan="5">I don’t want to become a “suicide me” an “arthritis me” a “diabetic me” – they are all me and I would like other concerns like family, finances, my own caregiving duties to be considered with my overall health.[74,115]</td></tr>
</table>

	CO-ORDINATED CARE AND CONTINUITY OF CARE		- Ongoing relationship with HCP important to disclose mental health concerns - Continuity (same) nurses and HCPs - Improved co-ordination of care during care transition	- HCPs should not contradict one another	- Discharge meetings should involve engagement and planning - Continuity in homecare providers - Emergency room triage navigator	-Continuity in health care team during final days
	" I Statements"	I would like somebody to work with me or my daughter between each service and let me know that they are all here and working as a team. It makes me feel more comfortable and relaxed because they all came to a common conclusion that is for me and my benefit.[32,88]				

Discussion

The purpose of this review was: 1) to identify the gamut of patient and caregiver perspectives of the Canadian health system, where "perspectives" included their needs, values, preferences and experiences (whether positive or negative); and 2) to thematically organize these perspectives based on patients' health stage and life stage (including caregivers).

The typology we used for organizing perspectives of the health system implicitly assumes that there should be differences in the needs, values and preferences between various health and life stages. Indeed, across both health and life stages, we note important differences in how each of the five themes are interpreted by patients and caregivers.

In summary, we present common themes, as desires of the health system, across health stages. These themes include: a desire for choice in treatment, care setting and/or care provider; personalized (person-centred) care; information on resources available and how to navigate the system; holistic care and non-medical supports to overcome barriers to accessing care; and care co-ordination and care continuity. Although each theme is shared by at least two health stages (Table 1), there are noteworthy differences in the interpretation of these themes (Table 2-6).

The **desire for personalized care** was a common theme across all health and life stages. However, the meaning of personalized care differs. For the walking well, personalized care is fairly broad, representing patient respect, providing care in the preferred language, provider awareness about the needs of vulnerable populations, and delivery of care that considers both social and medical needs. Patients and caregivers consistently identified a desire for care that is holistic, individualized, and culturally competent. Since care avoidance was often attributed to a fear of being stigmatized or judged, patients saw value in HCPs receiving diversity training. On the other hand, for the palliative care group, personalized care represents direct interaction with care HCPs, and compassionate, empathetic and non-judgmental communication by HCPs.

All the health and life stages expressed a **desire for information** and specifically a desire for HCP to have an understanding about the available resources beyond the hospital walls. However, perspectives around what information to receive and how best to receive it varied across the health stages. Information about funding was particularly important for the walking well group. Availability of online resources was perceived as important by the walking well group and the mental health and addictions groups. Being given the necessary information in order to make an informed decision was underscored by the walking well and palliative care groups. A desire for information before making a decision was perceived to be relevant for less sensitive decisions (the decision to get screened or receive a vaccination) as well as more sensitive decisions (those related to end of life).

An ability to choose was desired among all health stages. The walking well group expressed the need to be able to choose in all aspects of health care (e.g., vaccination, screening, health-care providers, care setting and treatment options/modality). 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 which care setting to receive care.

A **desire for holistic care that includes non-medical supports** to overcome barriers to accessing care. The relationship between HCPs and patients was important to those across all health stages. Desires of HCPs were described positively in some cases, represented by the trusting relationship that patients (namely older patients) and caregivers have with their HCPs. However, some areas of improvement were also emphasized. For example, the ability of the HCPs to communicate in a way that is easy to understand by patients, respecting patients' needs and treatment preferences, being non-judgmental, allowing more time to listen to patients, treating patients as persons by attending to their social needs and helping patients better navigate the health-care system (discussing next steps, available resources, and treatment options). This highlights the need for new strategies to be included in medical education that can enable HCPs to better meet patient needs and expectations.

Co-ordinated, continuous care was an important theme across all health stages. A continuous relationship with the same primary care provider was important for all health stages particularly given their critical role as the gatekeepers and the first point of contact with the health-care system. Additionally, for the two stages who often receive care from more than one HCP—chronic conditions and mental health and addictions—co-ordinated transitions across various care setting was considered to be vital.

Our approach to assessing and analyzing the available literature was unique in that it involved comparing similarities and differences both within and across health and life stages. This work brings together a breadth of literature focusing on a variety of populations accessing a broad range of services. As such, this work expands upon previous works as it goes beyond specific target populations or specific care settings.[2,3,4] In addition, our inclusion of the "walking well" fills a gap within the literature that rarely speaks to consumers who are not vulnerable or medically complex.

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Strategies to redesign the health system with current or future users in mind should not be one-size-fits-all. For example, the walking well population may have similar desires of the health system as persons living with chronic illness, but how these desires are interpreted differs between these health stages. Furthermore, we attempt to include positive perspectives of the health system. While such perspectives are not as salient as negative perspectives in our findings, these are important to highlight to avoid reinventing aspects of the health system that are currently succeeding as perceived by patients and caregivers.

Conclusion

This review identifies a range of patient and caregiver preferences in how the Canadian health care system could be shaped or reshaped. We identified five common desires that are consistent across health and life stages. However, these themes were expressed with subtle nuances between them and therefore may have different implications for how the health system should be shaped or reshaped, for different target populations.

Many of the desires echo features of successful integrated patient-centred care models.[172,173] At the forefront of integrated care models are the real-life needs of patients and caregivers. Health systems across many provinces/territories in Canada are at the cusp of change, with integrated care at the forefront of the health policy agenda.

In Ontario, for example, we are seeing efforts toward integrated care, through the development of Ontario Health Teams which intend to bridge the gap between various sectors of the health system including home care. Improving care navigation by linking patients discharged from hospitals to community service groups, engaging patients and caregivers in health system design, improving access to virtual care options for patients, and connecting teams of providers and services to patients and families in the community[174,175] is desired by patients and health systems. Certainly, findings from this review are timely as provinces like Ontario continue to make strides toward a more integrated, patient/caregiver-focused model of health service delivery. Specifically, these findings could be used to support the implementation and development of care models through:

1. **Planning**: improved understanding of the detailed experiences and preferences of a variety of target populations. Additionally, dependent upon the selected priority population, this study could inform which partners to include as part of the integrated care team.
2. **Patient Involvement**: offering insight into the diversity of patient views across population groups and inform patient engagement efforts.
3. **Quality Improvement**, Metrics and Evaluation: informing the development of metrics that reflect the desires and preferences of patients and caregivers.
4. **Targeting Investments**: identifying areas for investment that are relevant to, and important for, a variety of target populations.

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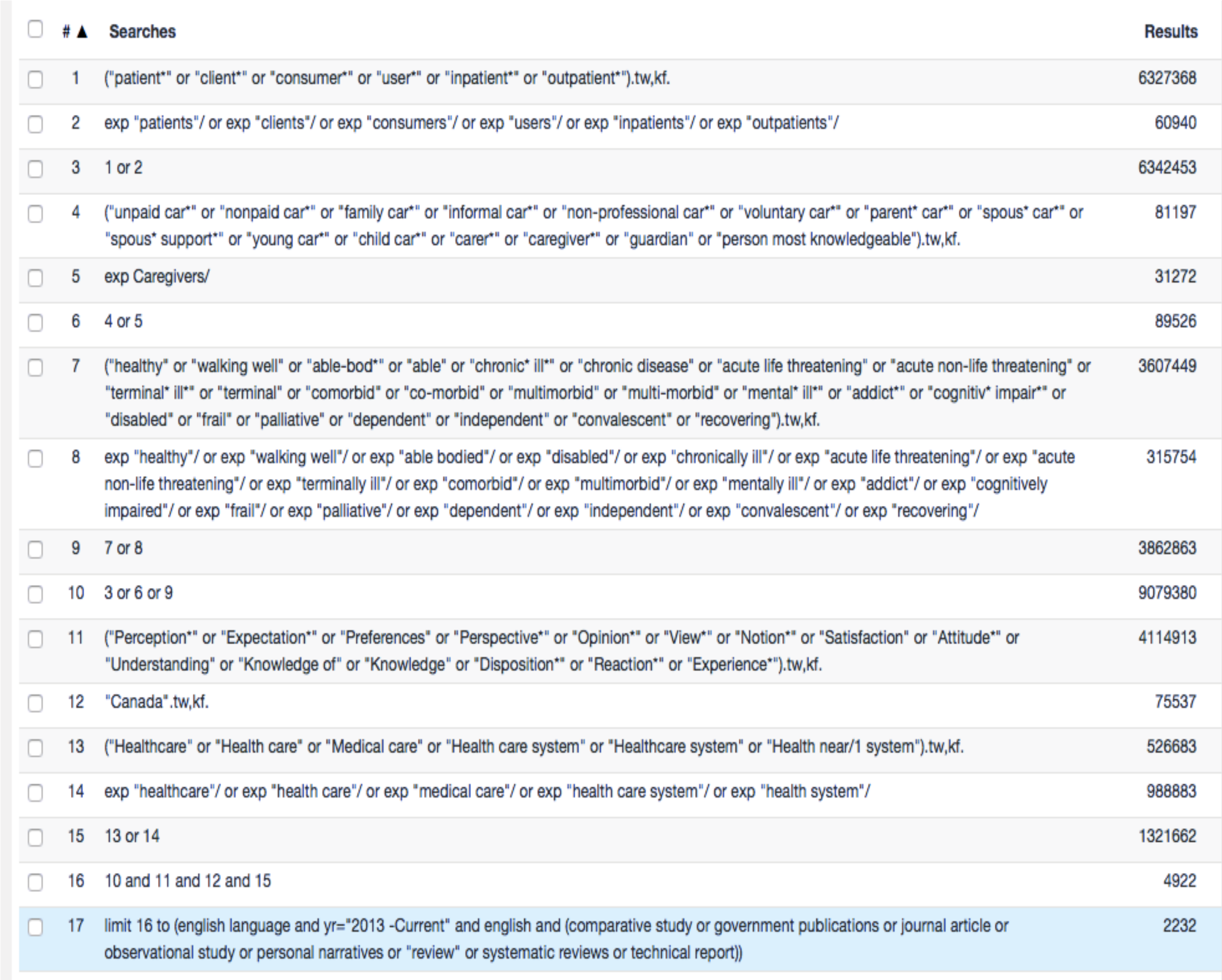
Appendix A: Search Terms

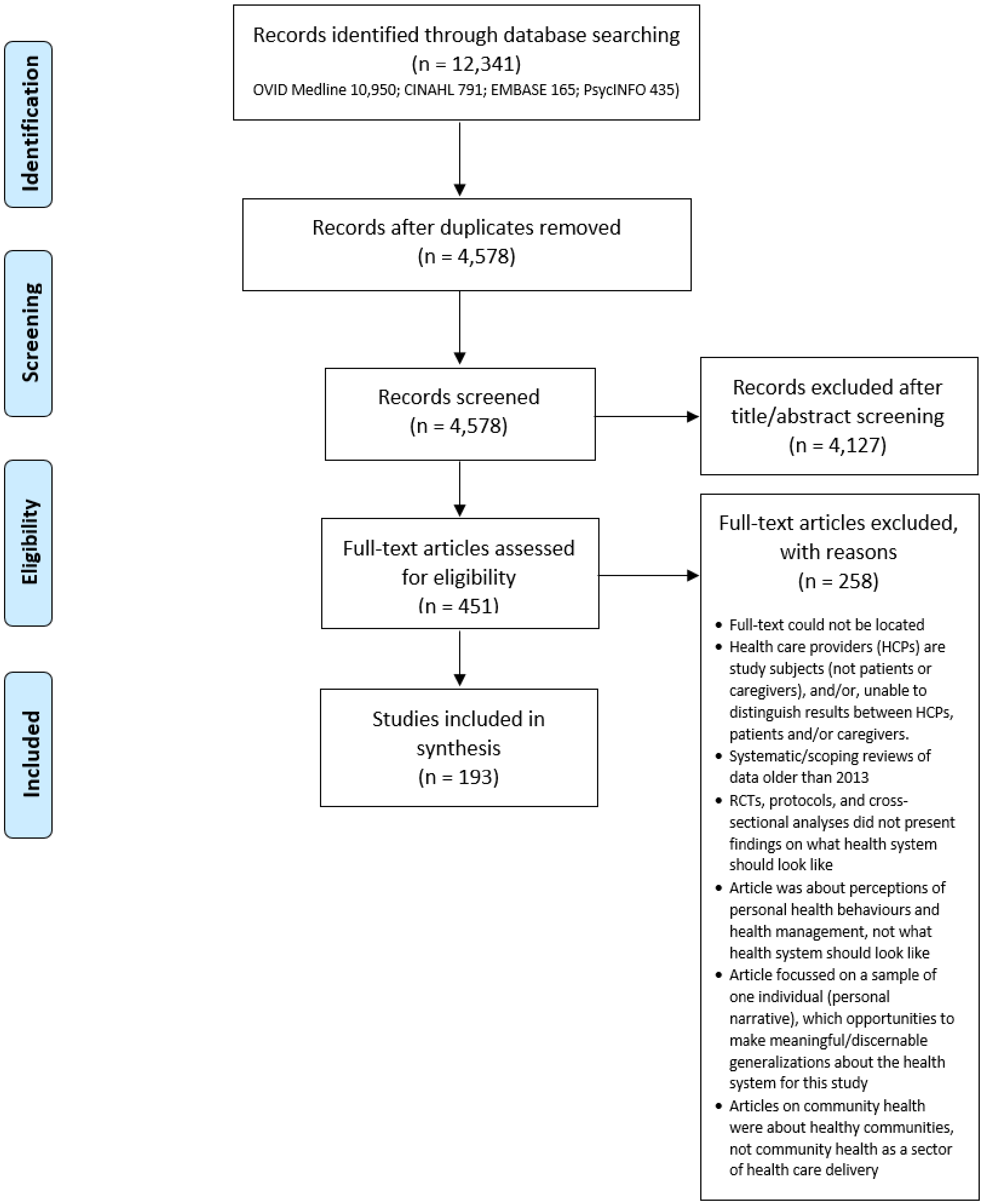
Population or Problem				Interest	Context
Patients: -Patient* -Client* -Consumer* -User* -Inpatient -Outpatient Caregivers: -Carer -Care *near/2* partner -Unpaid car* -Nonpaid car* -Family car* -Informal car* -Non-professional car* -Voluntary car* -Parent car* -Guardian -Person most knowledgeable -Spousal car* -Spousal support -Young car* -Child car*	Life (Biological) stage: -Pediatric / Infant -Children/Child /Adolescent/ Youth/School-aged -Young Adult -Adult/Middle Aged -Older Adult /Elder/Senior/ Aged/ Geriatric	Health (Medical) stage: -Healthy -Walking well -Able, able-bodied -Chronic* ill* OR disease -Acute life threatening -Acute non-life threatening -Terminal, terminally ill -Comorbid, multimorbid -Persons with mental illness -Persons with addiction -Persons living with cognitive deficits, cognitively impaired -Disabled -Frail -Palliative -Hospitalized -Institutionalized, non-community-dwelling -Community-dwelling/homebound -Dependent -Independent -Convalescent / Recovering	Social Status (sub-populations): -Vulnerable -Marginalized -Immigrant -Newcomer -Refugee -LGBT -Homeless -Veteran -Ethnic minority -Substance user/abuser -Unemployed	-Perceptions -Expectations -Preferences -Perspectives -Opinions / Views -Notions -Satisfaction -Attitudes -Understanding / Knowledge -Dispositions -Reactions -Experiences	Geography: Canada General: -Heathcare -Health care -Medical care -Health care system -Health near/1 system -Medicare, coverage -Health care delivery Care context: -Medical Care -Primary Care -Secondary, Specialty Care -Tertiary Care -Quaternary Care -Hospital Care -Ambulatory Care -Community, Home Care -Assisted living -Institutional, long-term, nursing home, residential care -Palliative care -Hospice, end-of-life care -Transitional care -Nursing care -Allied health care -Rehabilitation, rehabilitative care -Virtual, mobile health care Others: -Drug therapy, drug coverage -Diagnostic services (imaging)

Appendix B: Search Strategy



☐	# ▲	Searches	Results
☐	1	("patient*" or "client*" or "consumer*" or "user*" or "inpatient*" or "outpatient*").tw,kf.	6327368
☐	2	exp "patients"/ or exp "clients"/ or exp "consumers"/ or exp "users"/ or exp "inpatients"/ or exp "outpatients"/	60940
☐	3	1 or 2	6342453
☐	4	("unpaid car*" or "nonpaid car*" or "family car*" or "informal car*" or "non-professional car*" or "voluntary car*" or "parent* car*" or "spous* car*" or "spous* support*" or "young car*" or "child car*" or "carer*" or "caregiver*" or "guardian" or "person most knowledgeable").tw,kf.	81197
☐	5	exp Caregivers/	31272
☐	6	4 or 5	89526
☐	7	("healthy" or "walking well" or "able-bod*" or "able" or "chronic* ill*" or "chronic disease" or "acute life threatening" or "acute non-life threatening" or "terminal* ill*" or "terminal" or "comorbid" or "co-morbid" or "multimorbid" or "multi-morbid" or "mental* ill*" or "addict*" or "cognitiv* impair*" or "disabled" or "frail" or "palliative" or "dependent" or "independent" or "convalescent" or "recovering").tw,kf.	3607449
☐	8	exp "healthy"/ or exp "walking well"/ or exp "able bodied"/ or exp "disabled"/ or exp "chronically ill"/ or exp "acute life threatening"/ or exp "acute non-life threatening"/ or exp "terminally ill"/ or exp "comorbid"/ or exp "multimorbid"/ or exp "mentally ill"/ or exp "addict"/ or exp "cognitively impaired"/ or exp "frail"/ or exp "palliative"/ or exp "dependent"/ or exp "independent"/ or exp "convalescent"/ or exp "recovering"/	315754
☐	9	7 or 8	3862863
☐	10	3 or 6 or 9	9079380
☐	11	("Perception*" or "Expectation*" or "Preferences" or "Perspective*" or "Opinion*" or "View*" or "Notion*" or "Satisfaction" or "Attitude*" or "Understanding" or "Knowledge of" or "Knowledge" or "Disposition*" or "Reaction*" or "Experience*").tw,kf.	4114913
☐	12	"Canada".tw,kf.	75537
☐	13	("Healthcare" or "Health care" or "Medical care" or "Health care system" or "Healthcare system" or "Health near/1 system").tw,kf.	526683
☐	14	exp "healthcare"/ or exp "health care"/ or exp "medical care"/ or exp "health care system"/ or exp "health system"/	988883
☐	15	13 or 14	1321662
☐	16	10 and 11 and 12 and 15	4922
☐	17	limit 16 to (english language and yr="2013 -Current" and english and (comparative study or government publications or journal article or observational study or personal narratives or "review" or systematic reviews or technical report))	2232

Appendix C: PRISMA Flow Diagram



- Full-text could not be located
- Health care providers (HCPs) are study subjects (not patients or caregivers), and/or, unable to distinguish results between HCPs, patients and/or caregivers.
- Systematic/scoping reviews of data older than 2013
- RCTs, protocols, and cross-sectional analyses did not present findings on what health system should look like
- Article was about perceptions of personal health behaviours and health management, not what health system should look like
- Article focussed on a sample of one individual (personal narrative), which opportunities to make meaningful/discernable generalizations about the health system for this study
- Articles on community health were about healthy communities, not community health as a sector of health care delivery

Appendix D: Summary of Articles

Author	Year	Study Location	Study Aim
Abdul-Razzak et al	2016	Hamilton, Ontario and Calgary, Alberta (3 academic tertiary hospitals)	The objective of this study was to understand patient perspectives on physician behaviours that help or hinder EOL communication.
Abdul-Razzak et al	2014	Hamilton, Ontario and Calgary, Alberta 3 Canadian academic tertiary hospitals)	The objective of this qualitative study is to understand patient perspectives on physician behaviours during EOL communication. The results are intended to provide practical knowledge and insights that can be incorporated into a physician's clinical practice.
Abelson et al	2018	Ontario, Canada	Addressing gaps in current evidence on mammography/questions about the net benefits of organized screening, about women's current screening practices, knowledge, attitudes and values toward screening to support informed decision making in this area.
Abelson et al	2018	Ontario, Canada	Capture citizens' perspectives about mammography screening, and how-to best support informed decision-making within the context of organized screening programs.
Adams et al	2013	Ontario, Canada-Hospital for Sick Children	Understand the usefulness and desired content of comprehensive care plans by exploring the perceptions of parents and HCPs of CMC.
Albrecht et al	2017	Edmonton, Alberta (specialized pediatric ED)	Describe caregivers' experiences of pediatric AGE and identify their information needs, preferences, and priorities.
Aragon et al	2013	British Columbia, Canada	Understand the perspectives of women, health-care providers, and support persons regarding the use of birth plans.
Ashworth et al	2018	Canada	Aims to identify the factors affecting Aboriginal peoples' attitudes toward and experiences in accessing oral health services in Canada in an attempt to contribute to the discussion of how oral health professionals can better support this population's oral health.

Aston et al	2014	Canada	Better understand the personal, social, and institutional hospital experiences of children with IDs, their parents, and the nurses who cared for them (focus on relationships and how participants interacted with others in the hospital including health-care professionals, clients, and family members).

Bainbridge et al	2017	Ontario, Canada	Assess the usefulness of qualitative survey data for quality improvement.
Bainbridge et al	2018	Ontario, Canada (22 hospices)	Capture the end-of-life care experiences across various settings from bereaved caregivers of individuals who died in residential hospice.
Ballantyne, M. et al	2015	Calgary, Alberta and Hamilton, Ontario	Investigate the barriers and facilitators to attendance at Canadian NFU programs taking into consideration both mothers' and HCPs' perspectives.
Banner, D. et al	2015	British Columbia, Canada (2 rural hospitals)	Examines the qualitative findings from 16-month mixed methods randomized controlled trial examining the impact of a virtual CRP (vCRP).
Barbita, J. et al	2017	Ontario	Highlighting patient and caregiver perspectives on Telehomecare.
Barnieh, L. et al	2014	Atlantic, British Columbia, Ontario, Prairies, Quebec, Territories, Canada	To synthesize the views of Canadian patients on or nearing dialysis, and those who care for them (in order to support treatment decision-making, enhance communication, address psychosocial well-being and improve patient satisfaction).
Barry, A.R.	2018	Burnaby and Surrey, British Columbia	Determine patients' perception of the efficacy, safety and quality of NHPs and to characterize NHP use.
Bauer, G.R. et al	2014	Ontario, Canada	Document the extent of trans-specific negative emergency department (ED) experiences, and of ED avoidance.
Baumbusch, J. et al	2018	Western and Central Canada (British Columbia, Ontario, Manitoba, Quebec)	Experiences of parents of children with rare diseases.

Benoit, C., et al	2016	St. John's, NL; Montréal, QC; Kitchener (including Waterloo and Cambridge), ON; Wood Buffalo (Fort McMurray), AB; Calgary, AB; and Victoria, BC.	Examines unmet health-care needs of adult sex workers and investigates whether their reasons for not accessing health care are different from those of other Canadians.
Blanchette, P.S. et al	2014	Toronto, Ontario (Princess Margaret)	Describe patients' knowledge, attitudes, and expectations toward GTC.
Bombard, Y. et al	2013	Ontario, Canada	Explore citizens' informed and reasoned values and expectations of personalized medicine, a timely yet novel genomics policy issue.
Brazil, K. et al	2014	Ontario, Canada (Sudbury, Sault Saint Marie, North Bay and Timmins)	Formal comparisons between the rural and the urban experience of family caregiving.
Brownlie, E.B. et al	2017	Ontario, Canada	Enhancing youth services addressing substance use in Ontario.
Brunings, P. et al	2013	British Columbia, Canada (rural/small urban areas)	Explore and describe patients' perspectives on quality of HCV healthcare in rural viral hepatitis clinics in British Columbia.
Bungay, V.	2013	Western Canadian inner-city neighbourhood	(a) Examine women's experiences of and decision-making about engagement with the health-care system, and (b) Analyze these experiences within a wider sociopolitical context to understand how these contexts shape health care and opportunities for health among street-involved women.
Burge, F. et al	2014	Nova Scotia, Canada	Examine the relationship between the location where the decedent received the majority of care during their last 30 days of life and the informant's perception of the extent of unmet need experienced.

Bye, A. et al	2016	Nova Scotia, Canada	Share one mother's (child with ID) personal story about her journey through the Canadian health care system in Nova Scotia.
Cable-Williams, B. et al	2017	Ontario, Canada (3 LTC facilities)	Identify the influence of the culture in Canadian long-term care facilities on the awareness of impending death and initiation of a palliative approach to care for residents aged 85 years and older.
Carusone, S.C. et al	2017	Toronto, Canada (Casey House)	Identify gaps in hospital discharge practices and design interventions to improve outcomes.
Coffey, M. et al	2017	Ontario, Canada	Explores parent preferences around disclosure and views on including children.
Colpitts, E. et al	2016	Truro (rural) and Halifax (urban), Nova Scotia	Offer an overview of the findings of a scoping review and community consultations aimed at developing strengths-based approaches to understanding LGBTQ+ pathways to health in Nova Scotia.
Corosky, G.J. et al	2016	Arviat, Nunavut	Generate youth-focused evidence on experiences of SRHR relating to access to care in Arviat in order to better inform locally authored interventions geared toward improving youth SRHR.
Dale, C.M. et al	2017	Vancouver General Hospital (British Columbia), The Hospital for Sick Children (Ontario) and the Children's Hospital of Eastern Ontario (Ontario)	To get a better understanding of the needs of Canadian mechanical ventilator-assisted adolescents (VAAs) so as to provide transition services responsive to VAAs and caregiver-identified needs.
Dalpe, G. et al	2017	Quebec, Canada	Analyzing perspectives of women as well as decision-makers about genetic testing and insurance as well as general insurability questions in the context of a risk-stratification approach to breast cancer screening and prevention.
Davison, S.N. et al.	2014	Canada	Knowledge and Attitudes of Canadian First Nations People Toward Organ Donation and

			Transplantation: A Quantitative and Qualitative Analysis.
Denison, J. et al	2014	Northern region of a Western Canadian province (2 urban Aboriginal health centres)	Report findings from a study examining the impact of the threat of child removal on Aboriginal women's experiences accessing of healthcare services.
Dhaliwal, J. et al	2017	Pediatric Weight Centres in Edmonton, AB, Shapedown BC, Vancouver, BC, and Hamilton, ON.	Explore parents' reasons for discontinuing tertiary-level care for paediatric weight management.
Digel Vandyk, A. et al	2018	Ontario, Canada	Explore the experiences of persons who frequently visit the emergency department (ED) for mental health-related reasons.
Donnelly, L.R. et al	2016	Vancouver, British Columbia, Canada	Explore the roots of stigma and its impact on health services and resource seeking as experienced by HIV-infected members of marginalized communities in Vancouver.
Downie, K. et al	2017	Ontario, Canada	Explore personal difficulties in the patient experience with recurrent C. difficile infection in Canada.
Du Mont, J. et al	2017	Ontario, Canada	Explore the presentation, sociodemographic, assailant, assault, and service use characteristics of Indigenous women, as compared to non-Indigenous adult and adolescent women.
Dube, E. et al	2018	Canada	Explore vaccine hesitancy among Canadian parents and to examine factors associated with a parent's intention to vaccinate his/her child.
Duhoux, A. et al	2017	Toronto and Ottawa, Ontario Vancouver, British Columbia	Aims (a) to determine the reasons contributing to having unmet mental health-care needs (UMHCN) among adults who are homeless or vulnerably housed in three Canadian cities and (b) to examine the determinants of UMHCN.
Durocher, E. et al	2017	Canadian university-	Examine how the intersection of various social and political influences shapes discharge planning and rehabilitation

		affiliated teaching hospital;	practices in ways that may not meet the espoused aims of rehabilitation programs or the preferences of older adults and their families.
Duthie, K. et al	2017	Montreal, Quebec	Explore cancer patients' experience with multimodal treatments, that is, treatments for multiple chronic conditions, as well as issues related to navigating the health-care system.
Dyason, C. et al	2015	Calgary, Alberta	Describe who participates in advance care planning (ACP) and decision-making for patients in long-term care and designated assisted living.
Easley, J. et al	2016	Canada	To explore patient perspectives on, and experiences with, the co-ordination and continuity of cancer care.
Easley, J. et al	2013	Canada (majority from Ontario)	Describe the survivorship experience of young adult patients with thyroid cancer.
Etchegary, H. et al	2013	St. John's and Grand Falls-Windsor, Newfoundland, Canada	Aimed to provide information about research programs in the province, provide the public with a space for asking questions, and solicit their opinions about genetic testing and research.
Farjou, G. et al	2014	Canada (3 pediatric oncology centres)	Describe the health-care experiences of teenagers with cancer.
Fitch, M.I. et al	2013	Canada	Explore the perspectives of cancer patients concerning the conversations that happen about sexuality following a cancer diagnosis in daily practice.
Floyd, A. et al	2017	Vancouver, British Columbia	Show lived experiences of refugees and the strategies these people might develop in their efforts to access health care.
Freeman, T. et al	2013	Southwestern Ontario	Examine the health care-related experiences of individuals who have lost their FPs.
Furlotte, C. et al	2016	Ontario, British Columbia, and Alberta, Canada	Describes expectations, concerns, and needs regarding long-term care (LTC) homes and home care services of 12 older lesbian and gay couples living in Canada.

Gauthier-Boudreault, C. et al	2017	Eastern Townships , Montérégie , Mauricie and Centre-du-Québec , Quebec	Document the needs of parents and young adults with profound ID during and after the transition to adulthood by exploring their transitioning experience and factors that influenced it.
Gemmell, A.P. et al	2017	Southern Manitoba	Assess Hutterites’ views of genetic counseling services. A secondary aim was to compare their views to those obtained in a study of rural Midwestern U.S. residents.
Gervais, C. et al	2016	Quebec, Canada	Where do fathers fit within the observations, concerns, and actions of perinatal health-care providers, according to parents’ perceptions and the analysis of institutional documents? What are fathers’ needs in terms of services and formal support during the perinatal period?
Ghazzawi, A. et al	2016	Ontario, Canada (Stroke rehabilitation facility)	Fully understand the dynamic complexity of the stroke rehabilitation system and how to better integrate inpatient and community settings to support continuity of care.
Goel, R. et al	2013	Ontario, Canada	Describe the experiences of a group of new immigrants and caregivers of new immigrants who were subject to the three-month waiting period for the Ontario Health Insurance Plan and needed to access health-care services during that time.
Goodman, A. et al	2017	Vancouver, BC (inner city)	Explore the health-care experiences of Aboriginal peoples who use illicit drugs and or illicit alcohol (APWUID/A) living in Vancouver's inner city.
Graham, C. et al	2013	Northern British Columbia, Canada	Explore the meaning of a healthy lifestyle for this population and the barriers they experience to healthy living.
Green, C. et al	2016	Northwestern, Ontario	Explore patients’ needs and experiences with receiving this therapy.
Green, S. et al	2016	Southwestern Ontario, Canada	Describe the primary care experience of adults in custody in a provincial correctional facility in Ontario in the 12 months prior to admission.
Gregory, D.M. et al	2013	Newfoundland, Canada (large	Explore patients’ perceptions of waiting for bariatric surgery, the meaning and experience of waiting, the psychosocial and

		tertiary care hospital)	behavioral impact of waiting for treatment and identify health-care provider and health system supportive measures that could potentially improve the waiting experience.
Grigorovich, A.	2015	Ontario, Canada	Examine experiences outside of primary health-care contexts or the perspectives of older health-care users.
Grigorovich, A.	2015	Ontario, Canada	Deepen existing knowledge by demonstrating how chronic illness and sexual minority status can further exacerbate the consequences of rationing public care.
Griscti, O. et al	2016	Nova Scotia, Canada (regional hospital)	Understand the experiences of chronically ill patients and registered nurse in negotiating patient care in hospital.
Grohmann, B. et al	2017	Ontario, Canada (diabetes education programs in 11 primary care sites)	Explore patients' perspectives on care received from diabetes education teams (a registered nurse and a registered dietitian) integrated into primary care.
Gucciardi, E. et al	2015	Southern Ontario, Canada	Explores the implementation processes of integrating specialized diabetes teams into primary care in southern Ontario, Canada.
Guilcher, S.J.T. et al	2013	Northern Ontario, Canada	Explore the experiences of participants in a chronic disease self-management program via telehealth (tele-CDSMP) and to identify facilitators and barriers to inform future tele-CDSMP delivery models.
Gutman, T. et al	2018	Canada	Describe the perspectives of children with chronic kidney disease (CKD) and their parents with regard to communication and decision-making.
Hammond, C. et al	2017	Canada (4 First Nations communities)	Explores survivorship experiences of First Nations women with cancer and their caregivers. Drawing from a larger data set on survivorship, we identify several major barriers to cancer communication and support in First Nations communities.
Han, C.S. et al	2015	Greater Vancouver Area, British Columbia	Describe Korean-Canadian immigrants' help-seeking and self-management for their suicidal behaviour.

Harrington, D.W. et al	2013	Ontario, Canada	Examining the factors associated with difficulty accessing specialist services, and the reasons why particular subpopulation groups report experiencing difficulties.
Harrison, T.G. et al	2015	Calgary, Alberta, Canada (multidisciplinary CKD clinic)	Understand perceptions of CKD patients about ePHRs, and describe characteristics associated with their expressed intent to use an ePHR.
Hayeems, R.Z. et al	2015	Greater Toronto, Ontario and Montreal, Quebec	Investigate Canadian public expectations and values regarding the types of conditions that should be included in NBS and whether parents should provide consent.
Heaman, M.I. et al.	2015	Winnipeg (inner city), Canada	Explore the perceptions of women living in inner-city Winnipeg, Canada, about barrier, facilitators and motivators related to their use of prenatal care.
Heard, J. et al	2017	Manitoba, Canada	Describe the paediatric transgender population accessing health care through the Manitoba Gender Dysphoria Assessment and Action for Youth (GDAAY) program, and report youth's experiences accessing healthcare in Manitoba.
Henderson, R. I et al	2018	Alberta, Canada	Optimize HPV vaccination rates and, thereby, decrease the burden of HPV-related illness, including high-morbidity surgical procedures and chemo-radiotherapy.
Herron, R.V. et al	2013	Peterborough, Ontario, Canada	Understand the multifaceted ways in which emotions shape and are shaped by experiences of aging and caring at the interpersonal, household and community scales.
Heyland, D.K. et al	2017	Canada (12 Acute care hospitals)	To explore the internal consistency of patients' (or their family members') stated values, and the relationship between these values and expressed preferences.
Higginbottom, G.M. et al	2016	Canadian province (metropolitan city and rural town)	(1) Generate new understanding of the processes that perpetuate immigrant disadvantages in maternity health care, and (2) Devise potential interventions that might improve maternity experiences and outcomes for immigrant women in Canada.

Higginbottom, G.M.A. et al	2015	Alberta, Canada	Identify the nature of communication difficulties in maternity services from the perspectives of immigrant women, healthcare providers and social service providers in a small city in southern Alberta, Canada.
Hodgetts, S. et al	2013	Alberta, Canada	Increase knowledge and understanding of how families with children with autism spectrum disorder (ASD) experience FCC in Alberta, Canada
Hole, R.D. et al	2015	Interior of British Columbia	Interrogate practices within one hospital to see whether and how CS (cultural safety) for Aboriginal patients could be improved.
Holroyd-Leduc, J.M. et al	2017	Alberta, Canada	Review current research evidence and conduct multi-stakeholder dialogue on the potential gaps, facilitators, and barriers to the provision of caregiver supports.
Hulme, J. et al	2016	Central Toronto, Ontario, Canada	Better understand how Chinese and South Asian immigrants – the largest and most under-screened immigrant groups according to national and provincial statistics - conceive of breast and cervical cancer screening
Huynh, E.	2018	Manitoba, Canada	Explore youth's perceptions of diabetes management.
Jacklin, K.M. et al	2017	British Columbia, Alberta, Ontario, Canada	Examine the health-care experiences of Indigenous people with Type 2 diabetes to understand how such determinants are embodied and enacted during clinical encounters.
James-Abra, S. et al	2015	Ontario, Canada	What are the experiences of trans persons in health care.
Jessri, M. et al	2013	Edmonton, Canada	Explore from the Middle-Eastern mothers' perspective, the experience of breastfeeding and their perceptions of attributes of the health-care system, community and society on their feeding decisions after migration to Canada.
Kalocsai, C. et al	2018	Toronto, Ontario	Offer a novel analysis of the complexities involved in building positive family-provider relationships in the ICU through the consideration of not only communication

			but other important aspects of family-provider interactions, including family integration, collaboration, and empowerment.
Katz, J.E. Et al	2014	Quebec, Canada	Understand how patients wish to communicate or to be communicated with (looking into E-patients).
Keller, G. et al	2017	Eastern Canada (supra-regional hospital)	Examine patient experiences of hospital-based discharge preparation for referral for follow-up home care services. To identify aspects of discharge preparation that will assist patients with their transition from hospital-based care to home-based follow-up care.
Kelley, M.L. et al	2018	Ontario and Manitoba, Canada	Generating the knowledge required to implement health promoting PC in First Nations communities.
Kelly, D.V. et al	2014	Newfoundland and Labrador, Canada	Explore the public's knowledge and attitudes regarding the role of the community pharmacist and to determine their likelihood of using expanded pharmacist services.
Kingston, D.E. et al	2015	Alberta, Canada	The purpose of this study was to describe women's reported willingness to disclose mental health concerns during screening and factors associated with this.
Kirst, M. et al	2017	Ontario, Canada	Examine Ontarians' support and predictors for targeted health equity interventions versus universal interventions.
Koehn et al	2016	British Columbia	How do ethnically diverse older adult residents of assisted living (AL) facilities in British Columbia (B.C.) experience quality of life? And, what role, if any, do organizational and physical environmental features play in influencing how quality of life is experienced?
Kowal et al	2015	Edmonton, Alberta	To understand information-gathering and decision-making processes of immigrant mothers for scheduled childhood vaccines, vaccination during pregnancy, seasonal flu and pandemic vaccination.

Kuluski et al	2013	Ontario	The types of goals that were important for older persons with multi-morbidities were explored from the perspectives of patients, their caregivers and physicians. Comparisons of goals were made across each patient, caregiver and physician triad to determine alignment.
Kuluski et al	2013	A continuing care/rehabilitation hospital in Canada	This study investigated what is important in care delivery from the perspective of hospital inpatients with complex chronic disease, a currently understudied population.
Kuluski et al	2017	Northwestern Ontario	Understand the hospital experience of carers (e.g., family members) of patients with alternate levels of care, ALC (delayed hospital discharge), and cognitive impairment who were waiting for long-term care from the hospital.
Lafortune et al	2015	Mid-sized urban and rural communities in Ontario	Older persons are often poorly served by existing models of community-based primary health care (CBPHC). We sought input from clients, informal caregivers, and health-care providers on recommendations for system improvements.
Law et al	2015	Toronto, Ontario	Understand LGBQ patients' perceptions of their experiences related to disclosure of sexual identity to their primary care provider (PCP).
Le Dorze et al	2014	Montreal, Quebec	Explore the factors that facilitate or hinder participation according to people who live with aphasia.
Lee, T.-Y. et al.	2014	Toronto, Canada	To explore immigrant Chinese women's experiences in accessing maternity care, the utilization of maternity health services, and the obstacles they perceived in Canada.
Lind et al	2014	Calgary, Alberta	Parents' perspectives on the acceptability of adding an annual influenza immunization to the immunization program that is currently delivered in Alberta schools, and obtained suggestions for structuring such a program.
Lindsay et al	2016	Greater Toronto Area, Ontario	To explore gender and sex differences in experiences of transitioning to adult health

			care among young adults with acquired brain injury (ABI) who take part in a co-ordinated model of transitional care.
Liu et al	2015	Ontario (GTA)	Chinese family caregiver experiences, including challenges, needs and service gaps in providing care for immigrant seniors with heart disease and stroke.
Logie et al	2016	Toronto, Ontario	Explore experiences of social support group participation among LGBT African and Caribbean newcomers and refugees in an urban Canadian city.
Loignon et al	2015	Quebec, Canada	Explore barriers to responsive care for undeserved persons (poverty) with a view to developing equity-focused primary care.
Longard et al	2016	Eastern Canada (tertiary care centre)	To understand parents' experiences of managing their child's postoperative pain at home.
Lukewich et al	2015	Across Canada	Describe chronic pain self-management from the perspective of individuals living with chronic pain in the context of primary care nursing.
Lum et al	2016	Greater Niagara Region, Ontario	Examine the lived experiences of immigrants living in a small urban centre with regards to the primary health-care system.
MacDougall et al	2014	Ontario, Canada	To understand the perspectives of Ontario parents regarding the advantages and disadvantages of adding influenza immunization to the currently existing Ontario school-based immunization programs.
MacRae et al	2015	Nova Scotia, Canada	Investigate older women's perceptions of their interactions with physicians and to identify what older women want from physicians.
MacRae et al	2016	Nova Scotia, Canada	Older women's experiences with and views of, physicians.
Marchand et al	2016	Canada (2012 CCHS Mental Health data)	Using data from a nationally representative survey, the Canadian Community Health Survey-Mental Health, this secondary analysis aimed to determine the prevalence of perceived prejudice by health-care

			providers (HCPs) and its relationship with mental disorders.
Marsh et al	2014	Toronto, Ontario	We determined (1) patient satisfaction and (2) patients’ preferences for follow-up method (web-based or in-person) after total joint arthroplasty.
Masse et al	2014	Quebec, Canada	(i) To analyze the receptiveness of the population of French-speaking Quebecers to certain ethical principles promoted by public health authorities during the AH1N1 vaccination campaign. (ii) To add to the limited number of empirical studies that examine the population’s perception of ethical values.
McCloskey et al	2015	New Brunswick, Canada	The experiences and opinions of those who must wait in hospital for alternate services.
McIntyre et al	2014	London, Ontario	Explore the self-perceived influences among older adults in deciding whether to take or not take the seasonal influenza vaccine.
Melhem et al	2017	Montreal, Quebec	To explore the needs of cancer patients in palliative care and to determine how care providers, including family physicians, could meet these needs more fully.
Mfoafo-M'Carthy et al	2014	Toronto, Ontario	Presents findings from research on the lived experiences of individuals from ethnic minority backgrounds who have been the subjects of community treatment orders (CTOs) in Toronto, Canada, and their perceptions of its impact on their lives.
Miedema et al	2013	New Brunswick, Canada and GTA, Ontario	Large administrative data set analyses demonstrate that geography has a significant impact on access to health care and subsequent health outcomes. In general, rural populations have poorer access to health-care services. This article explores the reality of this issue for young adult cancer survivors.
Molinaro et al	2018	Southern Ontario	This secondary data analysis examines the caregiving responsibilities of mothers from Southern Ontario, Canada, during the time from diagnosis to after their children’s

			pediatric cancer treatment (how mothers provide care during child's treatment).
Montague et al	2017	Canada (2016 HealthCare in Canada Survey)	To define stakeholders' perceptions on all contemporary end-of-life options.
Moore et al	2017	Canada	Opinions about how-to best approach anticipated extremely preterm birth.
Moravac	2018	Toronto, Ontario	Perceptions of women living in homeless shelters and women with severe mental health challenges about the factors influencing their decision-making processes regarding breast and cervical cancer screening.
Morgan et al	2014	Saskatoon, Saskatchewan (Rural and Remote Memory Clinic)	Experiences of rural family caregivers in the period leading up to a diagnostic assessment of dementia at a Canadian memory clinic, their hopes and expectations of the assessment, and their experiences in the six months following diagnosis.
Murray-Davis et al	2014	Ontario, Canada	Understand how pregnant women in Ontario decide to give birth at home or hospital and why they choose one birthplace over another (sample drawn from 85 midwifery practices in Ontario across six Ontario geographical regions determined by the Association of Ontario midwives).
Natalie et al	2013	Kamloops, British Columbia	Determine how urban Aboriginal youth identify their health needs within a culturally centred model of health and wellness; create new knowledge and research capacity by and with urban Aboriginal youth and urban Aboriginal health care providers.
Nekolaichuk et al	2013	Canada - 2 unspecified hospital sites	Understand patients' experiences of attending an individual psycho-oncology counselling service in a comprehensive cancer centre in Canada.
Nelson et al	2018	Prince George, British Columbia	Examines perceived barriers to health care access for urban Indigenous peoples in light of how colonialism impacts Indigenous peoples in their everyday lives.

Nguyen et al	2016	Ontario, Canada	Explore self-management from the perspectives of youth, parents and health-care providers in transition to adult health care.
Nicholas, Gutwin et al	2013	3 Canadian cities: Fredericton, NB; Edmonton, AB; Saskatoon, SK	Examines parents' interest and perspectives related to online diabetes resources.
Nicholas, Newton et al	2016	Large city in Western Canada	Examine experiences of street-involved (SI) youth who use hospital emergency departments and factors affecting ED use.
Nicholas, Zwaigenbaum et al	2016	Two Canadian tertiary-level pediatric hospitals	Perspectives of ED care among children with parents of children with autism spectrum disorder.
Oosterveer et al	2015	Northwest Territories	Document and analyze the challenges in accessing PHC services by Indigenous peoples in remote communities in Canada's Northwest Territories from the perspective of users and providers of PHC services.
Pedersen A. et al	2014	Winnipeg, Manitoba	To delineate the role of the oncology patient navigator, drawing from the experiences and descriptions of younger women with breast cancer.
Pederson H. et al	2015	Vancouver, British Columbia	To assess attitudes toward sharing of personal health information through a provincial EHR.
Perez et al	2016	Four Canadian cities: Edmonton AB, Hamilton ON, Montreal QC, Vancouver BC	Explore reasons for and facilitators of enrolment in pediatric weight management from the parental perspective.
Pighini et al	2014	Western Canada	Experiences of parents of children deemed at risk for developmental delays or disabilities who had received early intervention (EI) services (birth to age 3) in a large urban location in Western Canada.
Pike et al	2013	Newfoundland and Labrador, Canada	To gain a more thorough understanding of why parents choose to give their children natural health products (NHPs), parents' sources of information about NHPs, and the extent of disclosure and conversation with family doctors about the use of NHPs.

Pitt et al	2016	Montreal, Quebec (food bank)	To identify low-income working families' health challenges and understand their barriers and facilitators to navigating those challenges.
Ploeg et al	2017	Hamilton, ON and Edmonton, AB	Explore the experience of managing multiple chronic conditions in the community from the perspectives of older adults with MCC, family caregivers and HCPs working in a variety of settings.
Potestio et al	2015	Public venue in Calgary, Alberta	To engage the public to understand how to improve the care of critically ill patients.
Premji et al	2017	Calgary, Alberta, Canada	Explores mothers' experience of caring for their late preterm infants in the community.
Prorok et al	2017	Ontario, Canada (Kingston, Bancroft, Belleville)	Examining the primary care healthcare experience of persons with dementia and their caregivers in Ontario, Canada.
Rice et al	2017	Northern Ontario	Examines the challenges involved in providing and receiving primary care for complex chronic conditions in two remote resource communities in Northern Ontario.
Rink et al	2017	Montreal, Quebec	1) Report the narrative experiences of refugee claimant families who were denied health-care services in Montreal following June 2012 when the government of Canada severely restricted the scope of the Interim Federal Health Program that had hitherto provided coverage for the health-care needs of refugee claimants; and 2) describe the predominant barriers to accessing health-care services and understanding their impact using thematic analysis, and 3) derive concrete recommendations for child health care providers to improve access to care for refugee claimant children
Roberge et al	2016	Quebec, Canada (3 primary care clinics)	Explore the perceived needs, barriers and facilitators for the delivery of mental health care for patients with coexisting common mental disorders and chronic diseases in primary care from the clinician and patient perspectives.

Robinson et al	2017	British Columbia, Canada	Describe the experiences of bereaved family caregivers whose terminally ill family members with advanced cancer were successful in achieving a desired home death.
Rochette et al	2014	Montreal, Quebec	To document the ethical issues regarding the systematic inclusion of relatives as clients in the post-stroke rehabilitation process.
Ross et al	2018	Ontario, Canada	Barriers in accessing mental health care among low income LGBTQ people.
Roulston et al	2018	Edmonton, Alberta; Toronto, Ontario; Montreal, Quebec	Understand the steps that need to be taken to ensure Canadians can access high-quality palliative care services as part of Canada's universal health-care model.
Royall et al	2017	Hamilton, ON	Insights for new obesity management services were sought from both provides and patients in 1 progressive citywide organization.
Saroa et al	2018	Alberta, Canada (two large cancer centres), English-speaking	To determine the information needs and preferences of patients who had human papillomavirus-associated head and neck cancer (HNC) and who were aged 18-65 years in the post-treatment phase of recovery.
Scheim et al	2016	Ontario, Canada	Identify trans men who have sex with men (MSM)'s perspectives on barriers and facilitators to HIV and STI testing.
Schneeberg et al	2014	Eight vaccination centres across Canada (B.C., Manitoba, Ontario, Quebec, Nova Scotia)	Improving understanding of factors influencing pneumococcal vaccination among older adults to improve vaccine uptake.
Shaw et al	2015	Calgary, Alberta, Canada	Explore patient perspectives on the responsiveness of the Alex Seniors Clinic (a clinic that offers a patent-centred multidisciplinary care team model for primary care) to their stated health needs.
Simon et al	2015	12 acute-care hospitals in Canada	To explore seriously ill, older hospitalized patients' and their family members'

			perspectives on the barriers and facilitators of advanced care planning (ACP).
Sinclair et al	2015	Bone marrow transplant clinic of a large urban outpatient cancer care centre in Western Canada (Calgary, Alberta)	Use a qualitative approach to better understand the importance and efficacy of addressing spiritual issues within an interdisciplinary bone marrow transplant clinic from the perspectives of patients and health-care providers.
Smith-Carrier et al	2017	Toronto, Ontario	Explore unpaid caregivers' perceptions of and experiences with home-based primary care programs in Toronto.
Stacey et al	2016	Nova Scotia, Ontario, Quebec (three ambulatory cancer programs)	Assess patient and family member experiences with telephone cancer treatment symptom support.
Stewart et al	2013	Canada (specific location unspecified)	Assess the health and health care inequities experienced by affected children and by their parents.
Summerhurst et al	2017	London, Ontario	Adolescent perceptions of what was most helpful and most challenging about mental health treatment for mood and/or anxiety disorders.
Tait Neufeld	2014	Winnipeg, Manitoba	Describe the experiences of First Nations and Métis women with gestational diabetes mellitus (GDM).
Tamaian et al	2017	Canada	Qualitatively assess patients' negative experiences with the medical system that may lead to feelings of institutional betrayal.
Taneja et al	2018	London, Ontario (mid-size Canadian urban community)	To describe how lay people understand and make decisions for life-sustaining interventions when engaging in advance care planning.
Throndson et al	2016	Winnipeg, Manitoba	Explore the factors that influence the perceptions and health behaviours of patients after elective ad-hoc percutaneous coronary interventions (PCI).
Tobon et al	2015	One of five CMH agencies in Ontario, Canada	Examining continuity of care in children's mental health care.

Tomasone et al	2017	All of Canada, including Quebec (Quebec City)	Explore factors related to service adoption among non-users of counselling services offered to facilitate physical activity participation among persons with physical disabilities, and the barriers and facilitators to maintaining service participation among adopters.
Topf et al	2013	Western Canada	Gain a better understanding of the experiences of family caregivers when circumstances prevented a desired home death for a family member with advanced cancer.
Torti et al	2017	Alberta, Canada	Explore patients' perspective on the role of primary care in obesity management and their experience with existing resources, with a view to develop an improved understanding of this perspective, and more effective management strategies.
Tremblay et al	2016	4 Canadian tertiary-level, multidisciplinary weight management clinics (Edmonton, AB; Shapedown, BC; Hamilton, ON; Montreal, QC)	Characterize parents' recommendations for enhancing tertiary-level health services for managing pediatric obesity in Canada.
Turcotte et al	2015	Quebec, Canada	Explores the participation needs of older adults having disabilities as perceived by the older adults themselves, their caregivers and health-care providers.
Vahabi et al	2016	Greater Toronto Area, Ontario	Explored Muslim immigrant women's views on cervical cancer screening and the acceptability of HPV self-sampling.
Vaillancourt, S., et al.	2017	Toronto, St. Michael's Hospital and Ottawa Montfort Hospital, Canada	To define outcomes of emergency department care that are valued by patients discharged from the ED, with the goal of informing the development of a patient-reported outcome measure for ED care.
Vermeir et al	2018	Nova Scotia, Canada	Explore the barriers trans adults encounter when pursuing primary and emergency care in Nova Scotia, Canada.

Viveiros et al	2018	Ottawa, Ontario	To explore what factors midwifery recipients perceive to prevent or facilitate access to mental health care in the perinatal period.
Wagner et al	2016	"A multicultural Canadian city" (likely Toronto)	Examines the attitudes and beliefs of health-care providers toward people living with HIV through the use of focus groups.
Wagner et al	2017	Quebec, Canada	Explore young adults' initiation of substance misuse treatment.
Wang et al	2015	Toronto, Ontario	Analyzes the health care-seeking behaviour of South Korean immigrants in Toronto, Canada, and how transnationalism shapes post-migration health and health-management strategies.
Watt et al	2013	Canada (6 Canadian pediatric oncology centres)	Describe Chinese and South Asian immigrant parents' experiences of family-centred care (FCC) in pediatric oncology settings in Canada.
Webster et al	2015	Ontario, Canada	Provide new insights on the perspectives, needs and preferences of patients with complex health and social needs.
Weingarten et al	2014	Edmonton, Alberta	Children's perspectives of and satisfaction with their pain management in the emergency department (ED).
Wetterlin et al	2014	Canada-wide	Explore youth experiences with traditional and online mental health resources and investigate youth expectations for mental health websites.
Wilson et al	2013	Alberta, Canada	Public opinion on the controversial topic of death hastening and end-of-life plans.
Wood et al	2016	Winnipeg, Manitoba	Explore women's experiences of choosing to plan a birth at an out-of-hospital birth centre; how do women make the choice to plan for an out-of-hospital birth and the meaning that women ascribe to this decision-making process.
Woodgate et al	2017	Manitoba, Canada	Examine the experiences of access to primary health care by African immigrant and refugee families.
Zheng et al	2018	Hamilton, Ontario (McMaster	To understand patient, family caregiver, and clinician impressions of early mobilization,

	Children's Hospital PICU)	and the use of in-bed cycling as a method of mobilization.

Appendix E: Matrix of Included Articles

Life Stage			HEALTH STAGE				
			Walking Well	**Acute Life-threatening**	**Mental/Cognitive Health & Addictions**	**Chronic Health**	**Palliative Care**
Pediatric	Broadly Defined Results		IIIII		I		
	Sub-Population Results	LGBTQ+					
		Ethnic Minorities, Immigrants, Refugees					
		Vulnerably Housed					
		Rural and Remote					
		Indigenous					
Youth/ Children	Broadly Defined Results		I	II	III	IIII	
	Sub-Population Results	LGBTQ+	I				
		Ethnic Minorities, Immigrants, Refugees					
		Vulnerably Housed		I			
		Rural and Remote					
		Indigenous	II		I	I	
Young Adult	Broadly Defined Results		I		IIII	III	
	Sub-Population Results	LGBTQ+					
		Ethnic Minorities, Immigrants, Refugees			I		
		Vulnerably Housed		I			
		Rural and Remote				I	
		Indigenous	II		I		
Adult	Broadly Defined Results		IIIII, IIIII, IIIII, IIII	IIIII	IIIII, III	IIIII, IIIII, IIIII, IIIII, IIIII, IIIII, IIIII, II	II
	Sub-Population Results	LGBTQ+	IIIII, I	I	II	IIII	
		Ethnic Minorities, Immigrants, Refugees	IIIII, IIIII, III		III		
		Vulnerably Housed	IIII		II	I	
		Rural and Remote	I			II	
		Indigenous	IIIII, I		I	III	I
Geriatric/ Older Adult	Broadly Defined Results		IIIII, II	I	I	IIIII, IIIII	IIIII
	Sub-Population Results	LGBTQ+					
		Ethnic Minorities, Immigrants, Refugees	I			I	
		Vulnerably Housed					
		Rural and Remote	I			I	
		Indigenous					
Caregivers/ Parents	Broadly Defined Results		IIIII, I	IIIII, II	III	IIIII, IIIII, IIIII, IIIII, IIIII, I	III
	Sub-Population Results	LGBTQ+					
		Ethnic Minorities, Immigrants, Refugees	I			I	
		Vulnerably Housed					
		Rural and Remote	I			I	I
		Indigenous				I	

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