

Addressing the ethical problem of underdiagnosis in the post-pandemic Canadian healthcare system

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Abstract

Proper diagnosis is essential for effective treatment, yet in Canada health conditions are commonly underdiagnosed at all levels of the health system, meaning that they go undiagnosed or are diagnosed only after a delay. Underdiagnosis leads to inadequate treatment and potentially insufficient recovery and rehabilitation, as well as costly inefficiencies, such as repeat medical visits. Moreover, disparities in underdiagnosis in which vulnerable groups, such as women and Indigenous persons, are properly diagnosed at lower rates worsen existing inequities, which threatens the overall health of the general population. As health leaders and policy-makers seek to strengthen Canada's strained healthcare system, it will be important to address underdiagnosis and its causes, including systematic bias. Providing timely and accurate diagnoses for all patients is an essential component of delivering high quality, efficient, ethical, and cost-effective healthcare. The Canadian College of Health Leaders' Code of Ethics offers a framework for addressing underdiagnosis equitably. Utilizing the framework, suggestions are made for actions that can be taken at all levels of the health system to reduce underdiagnosis.

The underdiagnosis problem

Receipt of an accurate diagnosis is essential to maintaining and restoring health, yet there is evidence that a range of health conditions either go undiagnosed or are underdiagnosed by practitioners at all levels of care and that patients from already vulnerable populations are more likely to suffer from underdiagnosis contrary to healthcare ethics.¹ The underdiagnosis problem results in poorer health, worse health outcomes, loss of patients' trust, administrative waste, and higher costs, which further burden an already strained healthcare system.

The importance of an accurate diagnosis in healthcare

An accurate diagnosis is critical to treating illness since treatment hinges upon this step.² Once a diagnosis is made, a treatment protocol—which could consist of the administration of therapy, prescribing of medication(s), referrals to specialists, scheduling of appointments, and arrangement of supports—can be developed and pursued. Along with a treatment plan, diagnosis triggers the allocation and release of resources by the health system, such as approval of insurance coverage or reimbursement of related services, as well as assignment of health human resources like nurse navigators or social workers to the patient. In fact, given that most healthcare hinges on diagnosis, health policies related to payment, reimbursement, and authorization of services are typically based on diagnosis. The delivery of a diagnosis also provides information that helps a patient manage personal affairs, such as work obligations. Additionally, diagnoses often trigger the provision of important social benefits, such as workers compensation or disability assistance.

Underdiagnosis is a diagnostic error

Diagnosis is a clinical decision at the end of a complex process involving the patient, clinicians, technicians, and

other healthcare professionals to identify a disease or healthcare condition by reasoning through information obtained from a clinical history and patient examination, an environmental scan, consultation, and diagnostic testing.² The process can be initiated by a patient who presents to a provider upon noticing symptoms of illness, or by health professionals who otherwise encounter the patient, perhaps when the patient presents with unrelated symptoms.²

Diagnostic error is a remarkably understudied medical topic, but “underdiagnosis” can be categorized as one type of diagnostic error characterized by ignored, missed, or delayed recognition of a condition or disease and distinct from misdiagnosis (a wrong or inaccurate diagnosis) or overdiagnosis (a diagnosis that is unlikely to impact a patient's health).^{3,4}

Underdiagnosis is often the product of systemic bias whereby diagnostic team members' personal or social biases inform early steps in the diagnostic process that determine later steps. For example, a physician disregards reported symptoms based on assumptions about the patient's ethnicity, so fails to input all symptoms into a clinical decision support tool.⁵ Or, a clinical decision support tool cannot provide guidance regarding a patient's potential condition because no research has been conducted on how the condition manifests in that patient's demographic group (for example, gender, sexual orientation, and age cohort).

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The scope of underdiagnosis

The scope of underdiagnosis is by its nature difficult to estimate,^{6,7} but evidence shows that many conditions are underdiagnosed by healthcare professionals working in a range of settings (such as, primary care and hospitals).⁸ Multiple papers explain that cardiovascular diseases are underdiagnosed in women across the globe,^{9,10} as is chronic obstructive pulmonary disease by general practitioners.¹¹ A recent CBC News report cites work that shows that Canadians who were born with uteruses face significant barriers in getting diagnoses for pelvic pain, especially by family doctors and walk-in clinics.⁷ Multiple studies from Canada demonstrate that breast cancer, which was already underdetected by provincial screening programs, has been increasingly underdiagnosed since the outbreak of COVID-19 pandemic due to restrictions on in-person interaction at screening sites.^{12,13} Additionally, several stigmatized diseases are underdiagnosed in Canada, including syphilis and substance use disorder in seniors.^{14,15} Diseases also go underdiagnosed in younger patients; for example, Lindbloom showed that First Nations children with asthma in British Columbia have not been represented in research publications, which suggests a history of misdiagnosis or underdiagnosis, possibly due to data limitations or cultural bias on the part of clinicians.¹⁶

Underdiagnosis' impacts, including on treatment

Underdiagnosis is by definition ineffective and inefficient, and it can be harmful. Undiagnosed patients with continuing or progressing symptoms might seek additional physical examinations or diagnostic tests from the same provider, request second opinions, or even present at urgent care centres or emergency departments with the hope that healthcare professionals working there will properly diagnose their conditions. Each patient contact with the health system draws upon health human resources and exacts a financial cost. Additionally, underdiagnosis is often correlated with undertreatment,¹⁷ in part because the systematic biases that contribute to the former lead clinicians to fail to present all treatment possibilities and to explore individualized treatment options. At its worst, underdiagnosis costs some Canadians their lives because their undiagnosed conditions progress to a point, such as late stage cancer, at which they are incurable.¹³

The ethical consequences of underdiagnosis

Underdiagnosis in vulnerable groups could worsen existing inequities. In 2003, the United States' Institute of Medicine's Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care published a Congressionally mandated report assessing differences in the kinds and quality of healthcare received by racial and ethnic minorities and non-minorities.¹⁸ The Committee found that disparities—generally defined as “differences in the quality of healthcare that are not due to access-related factors or clinical needs, patients' preferences, and appropriateness of intervention—in diagnosis were often accompanied by disparate, lower quality treatment decisions.¹⁸ There is even evidence in Canada that treatment for women is

disincentivized—a comparative study of surgical procedures in Canada found that the health systems of eight provinces and territories reimbursed surgeons at significantly lower rates for procedures performed on female patients than for similar procedures performed on male patients.¹⁹

The state of the post-pandemic Canadian healthcare system

A comprehensive, standardized review of Canada's health system performed immediately prior to the COVID-19 pandemic found that Canadians generally had access to and financial coverage of hospital and physician services and that the quality of hospital and physician care was close to the average of comparable countries, but that Canadians were experiencing difficulties accessing non-covered services like mental healthcare and were dissatisfied with specialist and surgical wait times. In addition, there were large gaps in Canadians' health outcomes, particularly between income groups and Indigenous and non-Indigenous people.²⁰ The review also found that Canada's health expenditures as a share of gross domestic product were growing relative to the shares in similar countries.²⁰

A snapshot of Canadian healthcare in 2023 by the Canadian Institute for Health Information (CIHI) shows that the COVID-19 pandemic combined with record population growth²¹ have placed enormous strain on the Canadian healthcare system.²² The report's conclusions on priority improvement areas (primary care, mental health and substance abuse, health workforce, and health information) agreed to by the Government of Canada and the provincial and territorial governments are concerning:

“...many Canadians struggle to access a regular healthcare provider when they need healthcare or advice...Hospitals are at or over capacity, surgeries and procedures have been delayed and there is increasing need for mental health services...The decline [in surgeries] was more pronounced for those living in lower-income neighbourhoods... Many must wait to get the [mental health] care they need, while others don't get any care or don't get enough—with young people particularly hard hit by lack of services...Adding to the pressures, healthcare providers are burned out and some are leaving their profession...Despite the drop in surgeries, overtime hours in Canada's public hospitals in 2020-2021 increased by 15% over the previous year—a stark example of the pressure COVID-19 put on healthcare workers...Racism in health systems and unequal access to high-quality healthcare have been identified by First Nations, Inuit and Métis Peoples as key priorities. [Governments] must be modernizing healthcare information systems to enhance Canadians' ability to see their health information on-line.”²²

The strain on the healthcare system is unlikely to subside in the short run as population growth will likely outpace health workforce recruitment.²³ Also, initiatives to privatize additional health services²⁴ could pull resources away from the public provincial health plans, thus making it more difficult for patients with less financial and social capital to access services, including diagnostic assessments. Health leaders will need to be creative

and resourceful in addressing underdiagnosis. The imperative to reform systems during a crisis is an opportunity to consider a broad range of policy solutions.

An ethical framework for addressing underdiagnosis

The Canadian College of Health Leaders' (CCHL) Code of Ethics²⁵ offers a framework for addressing underdiagnosis equitably. First, it makes ethics central to healthcare practice by highlighting the ethical dimensions of activities that health professionals perform in the course of duty, such as communicating with patients and handling personal information. Ethical practice recognizes the diverse populations in the community and society; respects differences and intersectionality (the interconnected nature of social categories, such as race and income class); promotes equity, diversity, and inclusivity; and advocates for changes to policies and practices that adversely affect the health of certain populations. Second, the framework conveys a broad view of health leaders as individuals working in a variety of roles in healthcare, including possibly as government policy analysts and patient partner researchers. Third, the framework reminds health leaders that they simultaneously work in multiple levels of the health system—individual, organizational, professional, and community—and that they must fulfill ethical responsibilities at each level.

Following are specific, practical strategies that health leaders can implement at the respective levels, as well as at an additional level—the mega, or intersectoral, level. This is not an exhaustive list and leaders are encouraged to pursue additional ideas.

Individual or micro level (the level where individual patients, their representatives/advocates, individual providers, and other healthcare stakeholders interact with one another²⁶).

- Require staff to periodically complete the CCHL ethics self-evaluation tool, which assists the user in thinking about his or her own ethics-related leadership and actions.²⁷
- Utilize community-based patient advocates in health practices to provide culturally specific, evidence-informed consultations regarding potentialities for patients to fail to present and clinicians to fail to diagnose certain conditions, as well as to develop culturally sensitive materials to support patients in communicating their symptoms.
- Establish programs whereby clinicians mentor peers in making culturally-informed diagnoses for pertinent patient groups.

Organizational and professional or meso-level strategies (the level responsible for service areas/clinical programs providing care for a similar group of patients, typically part of a larger organization²⁶).

- Establish a system for reporting, identifying, and analyzing incidents of underdiagnosis similar to adverse events reporting systems.

- Form a counterpart to Choosing Wisely Canada²⁸ to provide a voice for minimizing underdiagnosis and educating about underdiagnosed conditions and patient groups.
- Implement a social accountability mandate requiring employees to serve the health needs of diverse populations.

Community or macro level (the level at which different components of a single healthcare system intersect²⁶).

- Recruit students and healthcare workers from each of the diverse populations in the community and support their residency in the community.
- Using medical claims/payment data, perform and report detailed surveillance of conditions by community population groups.
- Engage in Strategy for Patient Oriented Research (SPOR) initiatives to fund and perform research into underdiagnosis in the community.

System or mega level (the level at which different sectors of the health system interact²⁶).

- Conduct communication campaigns, to include public service announcements, to educate the public about identifying and communicating health symptoms to their healthcare providers.
- Develop and disseminate school curricula to educate youth and young adults about identifying and communicating health symptoms to their health professionals.
- Similar to the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP), develop a national (pan-Canadian) reporting system for tracking underdiagnoses.²⁹

Conclusions

Underdiagnosis is an underexamined problem in the Canadian health system that health leaders should not overlook when working to improve healthcare for all Canadians in the four priority areas jointly identified by the federal, provincial, and territorial governments: improving access to primary care; increasing the supply of healthcare workers and decreasing backlogs; improving access to mental health and substance use services; and modernizing health information systems and digital tools for sharing electronic health information.²² Reducing inefficient diagnostic error is an essential means of decreasing the service backlogs that discourage patients and providers alike; as such, it is an important means of increasing access to services. Enhancing health information systems and tools will facilitate the reduction of diagnostic error.

Actions to reduce underdiagnosis should be taken at the health system level, but can also be independently pursued by providers, patients, and community members at the individual,

organizational, and community levels. These actions should be guided by the ethical imperative to promote the health of all of Canada's diverse populations.

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