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Health Services, Management and Policy Research
Services de santé, gestion et recherche de politique

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Data Matters • Discussion and Debate • Research Papers

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Healthcare Policy/Politiques de Santé seeks to bridge the worlds of research and decision making by presenting research, analysis and information that speak to both audiences. Accordingly, our manuscript review and editorial processes include researchers and decision makers.

We publish original scholarly and research papers that support health policy development and decision making in spheres ranging from governance, organization and service delivery to financing, funding and resource allocation. The journal welcomes submissions from researchers across a broad spectrum of disciplines in health sciences, social sciences, management and the humanities and from interdisciplinary research teams. We encourage submissions from decision makers or researcher–decision maker collaborations that address knowledge application and exchange.

While *Healthcare Policy/Politiques de Santé* encourages submissions that are theoretically grounded and methodologically innovative, we emphasize applied research rather than theoretical work and methods development. The journal maintains a distinctly Canadian flavour by focusing on Canadian health services and policy issues. We also publish research and analysis involving international comparisons or set in other jurisdictions that are relevant to the Canadian context.

Politiques de Santé/Healthcare Policy cherche à rapprocher le monde de la recherche et celui des décideurs en présentant des travaux de recherche, des analyses et des renseignements qui s'adressent aux deux auditoires. Ainsi donc, nos processus rédactionnel et d'examen des manuscrits font intervenir à la fois des chercheurs et des décideurs.

Nous publions des articles savants et des rapports de recherche qui appuient l'élaboration de politiques et le processus décisionnel dans le domaine de la santé et qui abordent des aspects aussi variés que la gouvernance, l'organisation et la prestation des services, le financement et la répartition des ressources. La revue accueille favorablement les articles rédigés par des chercheurs provenant d'un large éventail de disciplines dans les sciences de la santé, les sciences sociales et la gestion, et par des équipes de recherche interdisciplinaires. Nous invitons également les décideurs ou les membres d'équipes formées de chercheurs et de décideurs à nous envoyer des articles qui traitent de l'échange et de l'application des connaissances.

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EDITORIAL

Spending on Healthcare: What Is the Right Number?

Healthcare is Canada's favourite punching bag. Admittedly, Canadian healthcare has many problems and, sometimes, it feels as though the system cannot get anything right. But is all the criticism fair?

Many Canadians experience the underbelly of provinces' and territories' publicly funded healthcare systems, which results in a perception that governments are spending too little money to fix the problems. This perception is in stark contrast with healthcare policy wonks' debates regarding whether Canada spends too little or too much. This editorial takes aim at the question of whether provinces and territories spend enough money on healthcare.

What Does Canada Currently Spend on Healthcare?

Canada was projected to spend $344 billion on healthcare in 2023, an annual increase of 2.8%. This is a lot of money. The spending is split into 70% public spending by governments and 30% private spending (CIHI 2023). The former includes spending on hospitals and physician services while the latter includes individuals' out-of-pocket costs for uninsured physical and mental health services, therapies and devices.

The big-ticket items are well known. Approximately 25% is spent on hospitals, 14% on prescribed medicines and 14% on physician services. The remaining 44% is spent on home and community care, allied health professionals, public health, capital for building and so on. Approximately 3% is spent on administration (CIHI 2023).

The financing of public healthcare spending comes from two sources. Approximately $47.1 billion is financed through the Canada Health Transfer from the federal government to provinces and territories (Department of Finance Canada 2024). The remaining $190 billion of public funding is generated through taxes, fees and levies by the provinces and territories.

How Does Health System Performance Compare With Other Nations?

Provinces' and territories' health systems perform well on some measures. Canada has among

the best population health outcomes across the Organisation for Economic Co-operation and Development (OECD) nations (OECD 2023). For instance, Canada comparatively has a low number of avoidable deaths and a low percentage of people who self-report their own health as bad or very bad (OECD 2023).

On measures of health system performance, provinces' and territories' health systems perform dismally. Canada has among the worst outcomes on measures of access to primary care and timely access to advanced imaging or non-life-threatening surgeries (Schneider et al. 2021).

To address the question of whether the provinces and territories spend enough money on healthcare, there are two pieces to the puzzle. The first is whether the trade-offs related to spending on healthcare outweigh the benefits of spending on other provincial and territorial programs. Second, once the budget for public spending on healthcare is set by the government, what are the trade-offs regarding how the funds are spent?

Overall Spending on Healthcare

If we consider how much should be spent on healthcare in Canada, the options are unlimited. At one end, provinces and territories could devote their entire budget to healthcare. In fact, some argue that this outcome is approaching since healthcare spending is growing as a proportion of all government expenditures. We argue that this is implausible since Canadians also highly value other public programs, such as education.

At the other end of the spectrum, governments could spend as little as possible on healthcare. This could be achieved by restricting public spending to mandatory services outlined in the *Canada Health Act* (1985). This option is equally implausible since it would do away with provinces' drug insurance plans for seniors, for example.

The middle ranges of the spectrum leave a lot of room for governments to determine how to spend their revenues – and how much on healthcare. Framing the allocation between programs in this way lays bare that government programs are competing for the available funding.

The question is then this: What is the *best* allocation of taxpayers' dollars to healthcare?

The *best* allocation is measured with opportunity costs. In other words, what are the benefits to Canadians of spending on other programs that compete with healthcare for the government's dollars? For instance, what are the potential gains to Canadians of spending more on new bridges to alleviate traffic or spending on libraries, schools and parks in growing communities as compared with spending the same amount on healthcare?

The analysis to determine the opportunity costs of government spending in areas other than health – even within health – are beyond current data and information. This means that there are few evidence-based tools available to governments, their analysts or the public to determine whether healthcare spending is providing health benefits of comparable value in lieu of spending on other programs.

One of the few points of comparison is whether other OECD countries spend similar amounts on healthcare after adjusting for population size. Surprising to many Canadians, our country's spending on healthcare is among the highest when compared with other OECD nations (OECD 2023).

The other point of comparison is whether some provinces are meaningfully spending more or less than others on healthcare. The data indicate that, as a proportion of government spending, provinces tend to spend around the same amount on healthcare. The absence of outliers suggests that provinces and territories are not out of line with each other in their spending.

From these, albeit limited, perspectives, provinces and territories are spending what they ought to on healthcare. Canadians can draw little solace from this flawed comparison since nobody knows whether comparator countries or provinces spend too little or too much. That is only the beginning of the story though.

Spending Within Healthcare

Once the dust has settled and budget negotiations are over, there is still much hard work ahead in terms of deciding which healthcare programs receive the money. Should spending on hospitals or home care be prioritized? It turns out that nobody knows how to spend the money to get the highest benefit in terms of patients' health relative to the amount of spending. That is, the opportunity costs of spending between sectors, settings, providers or products are unknown. Since we are unable to reliably quantify the benefits across all these sectors, we do not know what we are trading off with the spending decisions.

Not knowing the opportunity costs of different healthcare programs means there is no insight into whether additional spending on surgeries *buys* more health than spending the same amount on homecare services or funding new assisting living spaces, for example. The uncertainty causes programs' allocations to be based on combinations of incomplete data, advocacy and political expediency, with some exceptions. The results are unpredictable – uncertainty regarding what spending *buys* more health can result in inappropriately downsizing capital projects, such as with hospitals, in rapidly growing communities.

Not knowing how to best spend the money has meaningful implications within provinces and territories since the numbers are so big – they impact budgets and the people whose livelihoods rely on them.

The Trajectory of Healthcare Spending

Perhaps the best we can hope for is to slow the trajectory of spending on healthcare. This is not a novel concept. *Bend the curve* was all the rage 10 years ago and then disappeared during the profligate COVID-19-related healthcare spending surge. "Bend the curve" means slowing the rate of growth of healthcare spending so it does not consume too much of the government's revenue (Marchildon and Di Matteo 2014). Given the implausibility of other options,

the "bend the curve" concept offers potentially the best achievable outcome for Canada, slowing the rate of healthcare spending growth.

Fortunately, there are many good ideas on how to slow down spending growth. Some are legislative, others are technology- or policy-based. All require a significant shift from the current approach of the status quo. We name a few ideas here:

- *The federal government, the provinces and the territories legislate a cap on healthcare spending growth*. This approach has been tried in the UK, where multi-year growth caps would provide predictability and create incentives for robust budget management. This approach could be twinned with commitment between political parties to put caps on healthcare spending growth.
- *Expanding non-hospital-based models of care*. Since hospitals are the most expensive locations to receive care and, in many cases, not the optimal location, there would be a commitment to building outpatient care centres, community care and virtual care delivery.
- *Focus spending on the social determinants of health*. Since the cheapest hospitalization is the one that never happens, more funding should be directed into affordable housing, basic income support, accessible education, climate change and public health.
- *Working at or near the top of skill levels*. Spending on human resources is estimated to be 63% of hospital expenditures (CIHI 2022). Drawing from evidence, there is untapped potential to reconsider the type of skills required to provide specific kinds of care. This will provide support for highly trained care providers to focus on activities or *scopes of practice* that they are trained for.
- *Continue focusing on medicine price negotiation and management*. The rate of growth of spending on medicines is outstripping other programs. Governments should continue to focus on applying and expanding cost management tools, such as mandatory generic substitution, mandatory biosimilar switching and price negotiation for individual medicines.

Conclusion Regarding Healthcare Spending

This editorial is not able to provide a definitive judgement regarding whether Canada's spending on healthcare is enough or appropriate.

There are no easy answers regarding the level of public spending on healthcare. Absent revenue increases, increases to healthcare spending come at the cost of investments in other programs – this cannot go on for too much longer. Provinces and territories could shift more spending to the private sector though this shift negatively affects those without the means to pay privately, increases inequities over time and decreases the overall health of Canadians over time.

The most viable option is to slow the trajectory of healthcare spending growth. The status quo cannot be maintained for much longer so governments need to move quickly.

In This Issue

This issue's Discussion and Debate article highlights Canada's patchwork approach to funding expensive drugs for rare diseases. Given the mismatch between available funds and the need for spending on effective treatments, Lexchin and Sirrs (2024) advocate for the development of standardized principles to guide coverage and spending polices, whose elements may include defining evidence generation, risk-sharing agreements with manufacturers or de-emphasizing spending on products with slight or very limited therapeutic benefit.

A rejoinder to the proposed principles for coverage and spending policies on expensive drugs for rare diseases is offered by Gagnon (2024). The rejoinder states that spending on expensive drugs is important, but a broader question regarding the allocation of public funding for rare diseases should also consider other aspects of health-related quality of life, such as the provision of medical equipment and home modifications. The rejoinder also describes that developing and producing expensive drugs for rare diseases has a place in Canada. It concludes that funding rare diseases is important and is an area that needs new policies.

In the Data Matters category in this issue, Keefe et al. (2024) present research regarding the quality of work life and mental well-being among staff at Nova Scotian long-term care homes. The research analyzed survey data from a cross-section of continuing care assistants, registered nurses and licensed practical nurses working in 10 licensed long-term care homes in Nova Scotia. The results highlight that improving the work environment of continuing care assistants should be a priority focus in order to augment the stability of the Nova Scotian long-term care workforce.

In a second Data Matters article in this issue, Ruangsomboon et al. (2024) highlight changes in Ontario's primary care health services during the COVID-19 pandemic using a repeated cross-sectional study of audit and feedback reports for academic practices associated with the University of Toronto. Based on a number of quality-of-care indicators, the study concluded that primary care services were disrupted during the pandemic and associated with missed and delayed care.

This issue offers a research manuscript by Dion et al. (2024) assessing reasons for high emergency department utilization among people with common mental disorders or substance-related disorders in Quebec. Based on a sample of high users, common reasons for high emergency department utilization included barriers to accessing outpatient care and co-occurring disabilities. The research highlighted problems with patients' trust in the health system, unmet healthcare needs and problems with care coordination.

A research manuscript by Lexchin (2024) investigates conflicts of interest among deans of medical schools in Canada. Using publicly available information, the investigation found that no conflict-of-interest statements were available for over 10 deans while six deans had

conflicts with industry. The research highlights the complex roles of medical school deans, a lack of transparency regarding conflict declaration and involvement with pharmaceutical companies.

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ÉDITORIAL

Dépenses de santé : quel est le bon chiffre?

Le secteur de la santé est le bouc émissaire de prédilection du Canada. Il est vrai que les soins de santé sont confrontés à de nombreux problèmes et, parfois, on a l'impression que le système ne peut rien faire correctement. Mais toutes les critiques sont-elles justes?

Plusieurs Canadiens se heurtent aux failles des systèmes de santé publics provinciaux et territoriaux, ce qui donne l'impression que les gouvernements dépensent trop peu d'argent pour régler les problèmes. Cette perception contraste fortement avec les débats politiques qui portent sur la question de savoir si le Canada dépense trop ou pas assez dans la santé. Le présent éditorial vise à déterminer si les provinces et les territoires dépensent suffisamment d'argent pour les soins de santé.

Que dépense le Canada actuellement en soins de santé?

Le Canada devrait dépenser 344 milliards de dollars en soins de santé en 2023, soit une augmentation annuelle de 2,8 %. C'est beaucoup d'argent. Les dépenses sont réparties entre 70 % de dépenses publiques et 30 % de dépenses privées (ICIS 2023). Le premier pourcentage comprend les dépenses gouvernementales pour les hôpitaux et les services médicaux, tandis que le second comprend les frais des particuliers pour des services, des thérapies ou des dispositifs médicaux en santé physique et mentale non assurés.

Les articles à gros prix sont bien connus. Environ 25 % des fonds sont consacrés aux hôpitaux, 14 % aux médicaments d'ordonnance et 14 % aux services médicaux. Les 44 % restants vont aux soins à domicile et communautaires, aux professionnels paramédicaux, à la santé publique, au capital pour le bâtiment, etc. Environ 3 % sont destinés à l'administration (ICIS 2023).

Le financement des dépenses publiques de santé provient de deux sources. Environ 47,1 milliards de dollars sont financés par le Transfert canadien en matière de santé du gouvernement fédéral aux provinces et territoires (ministère des Finances Canada 2024).

Les 190 milliards de dollars restants proviennent des impôts, des frais et des redevances des provinces et territoires.

Comment se compare la performance du système de santé par rapport aux autres pays?

Les systèmes de santé des provinces et territoires ont un bon rendement dans certaines mesures. Le Canada est l'un des pays de l'Organisation de coopération et de développement économiques (OCDE) qui affiche les meilleurs résultats en matière de santé de la population (OCDE 2023). Par exemple, le Canada a comparativement un faible nombre de décès évitables et un faible pourcentage de personnes qui déclarent que leur santé est mauvaise ou très mauvaise (OCDE 2023).

En ce qui concerne les mesures du rendement des systèmes de santé, les provinces et les territoires affichent un rendement déplorable. Le Canada a l'un des pires résultats en ce qui concerne les mesures d'accès aux soins primaires et l'accès en temps opportun aux examens d'imagerie avancés ou aux opérations chirurgicales non urgentes (Schneider et al. 2021).

Pour ce qui est de savoir si les provinces et les territoires dépensent suffisamment d'argent pour les soins de santé, il y a deux pièces du puzzle. La première est de savoir si les compromis liés aux dépenses en santé l'emportent sur les avantages des dépenses dans d'autres programmes provinciaux et territoriaux. La deuxième a trait aux compromis quant à la façon dont les fonds sont dépensés, une fois que le budget des dépenses publiques en santé est fixé par le gouvernement.

Dépenses globales en soins de santé

Si l'on considère combien il faudrait déposée pour les soins de santé au Canada, les choix sont illimités. D'un côté, les provinces et les territoires pourraient consacrer tout leur budget aux soins de santé. En fait, certains affirment que cette possibilité approche puisque les dépenses de santé augmentent face à toutes les autres dépenses gouvernementales. Nous soutenons que cela est invraisemblable, puisque les Canadiens accordent aussi une grande valeur à d'autres programmes publics, comme l'éducation.

À l'opposé, les gouvernements pourraient dépenser le moins possible pour les soins de santé. Cela pourrait se faire en limitant les dépenses publiques aux services obligatoires décrits dans la *Loi canadienne sur la santé* (1985). Cette option est tout aussi improbable, car elle éliminerait les régimes d'assurance-médicaments des provinces pour les aînés, par exemple.

Entre ces deux extrêmes, les gouvernements disposent d'une vaste marge pour déterminer comment dépenser leurs revenus – et combien ils consacrent à la santé. En encadrant la répartition entre les programmes de cette façon, on observe que les programmes gouvernementaux sont en concurrence pour le financement disponible.

La question est donc la suivante : quelle est la *meilleure* façon d'affecter l'argent des contribuables aux soins de santé?

La *meilleure* allocation se mesure avec les coûts d'opportunité. En d'autres termes, quels sont les avantages pour les Canadiens de dépenser dans d'autres programmes qui rivalisent avec les soins de santé pour l'argent du gouvernement? Par exemple, quels sont les gains potentiels des dépenses pour des nouveaux ponts visant à alléger la circulation, ou encore ceux des dépenses dans les bibliothèques, les écoles et les parcs dans les collectivités en croissance, comparativement aux mêmes montants pour les soins de santé?

Les analyses visant à déterminer le coût d'opportunité des dépenses du gouvernement dans des domaines autres que la santé, et même au sein de la santé, dépassent les données et l'information actuelles. Cela veut dire qu'il existe peu d'outils fondés sur des données probantes à la disposition des gouvernements, des analystes ou du public pour déterminer si les dépenses de santé offrent des avantages comparables en matière de santé plutôt que de financer d'autres programmes.

Un des rares points de comparaison est de savoir si d'autres pays de l'OCDE dépensent des montants similaires pour les soins de santé après ajustement en fonction de la taille de la population. Étonnamment, les dépenses de santé de notre pays figurent parmi les plus élevées par rapport à celles des autres pays de l'OCDE (OCDE 2023).

L'autre point de comparaison est de savoir si certaines provinces dépensent plus ou moins que d'autres en soins de santé. Les données indiquent que, en proportion des dépenses publiques, les provinces ont tendance à dépenser environ le même montant pour les soins de santé. L'absence de valeurs aberrantes laisse entendre que les provinces et les territoires ne sont pas en décalage les uns par rapport aux autres dans leurs dépenses.

Dans ces perspectives, bien que limitées, les provinces et les territoires dépensent ce qu'ils faut pour les soins de santé. Les Canadiens ne peuvent guère tirer de réconfort de cette comparaison erronée, car personne ne sait si les pays ou les provinces de comparaison dépensent trop ou trop peu. Ce n'est que le début de l'histoire.

Dépenses dans le secteur des soins de santé

Une fois que la poussière s'est déposée et que les négociations budgétaires sont terminées, il reste encore beaucoup de travail à faire pour décider quels programmes de soins de santé recevront l'argent. Les dépenses consacrées aux hôpitaux ou aux soins à domicile devraient-elles être prioritaires? Il s'avère que personne ne sait comment dépenser l'argent pour obtenir le plus grand bénéfice en termes de santé des patients par rapport au montant des dépenses. Autrement dit, les coûts d'opportunité des dépenses entre secteurs, milieux, fournisseurs ou produits sont inconnus. Comme nous ne sommes pas en mesure de quantifier de façon fiable les avantages dans tous ces secteurs, nous ne savons pas ce que nous sacrifions avec les décisions de dépenses.

Ne pas connaître les coûts d'opportunité des différents programmes de soins de santé signifie que nous n'avons aucune idée si les dépenses supplémentaires pour les chirurgies permettent *d'obtenir* plus de santé que le même montant pour les services à domicile ou le

financement de nouveaux espaces de vie avec service, par exemple. L'incertitude fait en sorte que l'allocation des programmes se fonde sur une combinaison de données incomplètes, de plaidoyers et d'opportunisme politique, à quelques exceptions près. Les résultats sont imprévisibles – l'incertitude quant aux dépenses qui permettent *d'obtenir* plus de santé peut entraîner une réduction inappropriée des projets d'immobilisations, comme ceux des hôpitaux, dans des collectivités en croissance rapide.

Ne pas savoir comment dépenser l'argent de la meilleure façon possible a des répercussions importantes au sein des provinces et des territoires, car les chiffres sont si importants – ils ont une incidence sur les budgets et sur les personnes dont les moyens d'existence dépendent de ces fonds.

La trajectoire des dépenses de santé

Le mieux que nous puissions espérer est de ralentir la trajectoire des dépenses en soins de santé. Ce n'est pas un concept nouveau. « Faire fléchir la courbe » était une idée à la mode il y a 10 ans, puis elle a disparu lors de l'augmentation des dépenses de santé liée à la COVID-19. « Faire fléchir la courbe » signifie ralentir le taux de croissance des dépenses de santé afin qu'elles ne consomment pas trop les recettes du gouvernement (Marchildon et Di Matteo 2014). Étant donné l'invraisemblance des autres choix, le « fléchissement de la courbe » présente peut-être le meilleur choix possible pour le Canada, grâce à un ralentissement du taux de croissance des dépenses de santé.

Heureusement, il existe de nombreuses bonnes idées pour ralentir la croissance des dépenses. Certaines sont législatives, d'autres technologiques ou politiques. Toutes demandent un changement important par rapport au statu quo actuel. En voici quelques-unes :

- *Le gouvernement fédéral, les provinces et les territoires imposent un plafond à la croissance des dépenses de santé*. Cette approche a été testée au Royaume-Uni, où des plafonds de croissance pluriannuels permettraient d'assurer la prévisibilité et de créer des incitations pour une gestion budgétaire robuste. Cette approche pourrait être jumelée à un engagement entre les partis politiques de plafonner la croissance des dépenses de santé.
- *Élargir les modèles de soins non hospitaliers*. Étant donné que l'hôpital est l'endroit le plus coûteux pour recevoir des soins – et dans plusieurs cas ce n'est pas l'endroit optimal –, il serait avisé de construire des centres de soins ambulatoires et de soins communautaires ainsi que de mettre de l'avant la prestation de soins virtuels.
- *Concentrer les dépenses sur les déterminants sociaux de la santé*. Puisque l'hospitalisation la moins chère est celle qui n'arrive jamais, il faudrait consacrer davantage de fonds au logement abordable, au soutien du revenu de base, à

l'éducation accessible, aux changements climatiques et à la santé publique.

- *Travailler au niveau de compétence ou près du niveau de compétence le plus élevé*. Les dépenses en ressources humaines sont estimées à 63 % des dépenses hospitalières (ICIS 2022). Les données probantes montrent qu'il existe un potentiel inexploité en reconsidérant le type de compétences requises pour fournir des types particuliers de soins. Cela permettra de soutenir les fournisseurs de soins hautement qualifiés afin qu'ils se concentrent sur les activités ou les champs d'exercice pour lesquels ils sont formés.
- *Continuer de mettre l'accent sur la négociation et la gestion des prix des médicaments*. Le taux d'augmentation des dépenses en médicaments dépasse celui des autres programmes. Les gouvernements devraient continuer à mettre l'accent sur l'application et le développement d'outils de gestion des coûts, comme la substitution générique obligatoire, le passage obligatoire aux biosimilaires et la négociation des prix pour les médicaments.

Conclusion concernant les dépenses de santé

Cet éditorial ne permet pas de porter un jugement définitif sur la question de savoir si les dépenses du Canada en matière de santé sont suffisantes ou appropriées.

Il n'existe pas de réponses faciles concernant le niveau des dépenses publiques en matière de santé. En l'absence d'une augmentation des recettes, l'augmentation des dépenses de santé se fait au détriment d'investissements dans d'autres programmes – cela ne peut pas durer trop longtemps. Les provinces et les territoires pourraient transférer davantage de dépenses au secteur privé, mais ces transferts auraient des répercussions négatives sur ceux qui n'ont pas les moyens de payer de leur poche, accroîtraient les inégalités avec le temps et diminueraient éventuellement la santé globale des Canadiens.

La meilleure option consiste à ralentir la trajectoire de croissance des dépenses de santé. Le statu quo ne peut être maintenu plus longtemps, les gouvernements doivent donc agir rapidement.

Dans ce numéro

L'article de la section Discussions et débats du présent numéro met en lumière l'approche disparate du Canada pour le financement des médicaments onéreux destinés aux maladies rares. Étant donné le décalage entre les fonds disponibles et la nécessité de dépenser pour des traitements efficaces, Lexchin et Sirrs (2024) préconisent l'élaboration de principes normalisés pour guider les politiques de couverture et de dépenses, dont les éléments peuvent inclure la définition de la production de données, les accords de partage des risques avec les fabricants ou la dévalorisation des dépenses sur des produits ayant un bénéfice thérapeutique faible ou très limité.

Une réplique aux principes proposés pour la couverture et les politiques de dépenses sur les médicaments coûteux pour les maladies rares est proposée par Gagnon (2024). On y

indique que les dépenses en médicaments coûteux sont importantes, mais la question concernant l'allocation de financement public pour les maladies rares devrait également prendre en compte d'autres aspects de la qualité de vie liée à la santé, comme la fourniture d'équipements médicaux ou les modifications apportées au domicile. La réplique indique également qu'il y a place au canada pour le développement et la production de médicaments coûteux pour les maladies rares. Il conclut que le financement pour les maladies rares est important et qu'il s'agit d'un domaine qui nécessite de nouvelles politiques.

Dans la section Questions de données, Keefe et al. (2024) présentent des recherches sur la qualité de vie au travail et le bien-être mental du personnel des foyers de soins de longue durée en Nouvelle-Écosse. Les auteurs ont analysé les données d'une enquête menée auprès d'un échantillon représentatif d'assistants de soins continus, d'infirmières autorisées et d'infirmières auxiliaires autorisées travaillant dans 10 foyers de soins de longue durée agréés en Nouvelle-Écosse. Les résultats indiquent que l'amélioration de l'environnement de travail des assistants de soins continus devrait constituer une priorité afin d'accroître la stabilité de la main-d'œuvre des soins de longue durée en Nouvelle-Écosse.

Un deuxième article de la section Questions de données, présenté par Ruangsomboon et al. (2024), met en évidence les changements survenus dans les services de soins primaires en Ontario pendant la pandémie de COVID-19, et ce, au moyen d'une étude transversale répétée des rapports de vérification et de rétroaction pour les pratiques universitaires associées à l'Université de Toronto. D'après un certain nombre d'indicateurs de la qualité des soins, l'étude conclut que les services de soins primaires ont été perturbés pendant la pandémie et certains soins ont été manqués ou retardés.

Ce numéro présente un article de recherche rédigé par Dion et al. (2024) qui évalue les raisons du recours fréquent aux services d'urgence par les personnes atteintes de troubles mentaux courants ou de troubles liés à la consommation de substances psychoactives au Québec. Selon un échantillon de grands utilisateurs, les raisons courantes d'une utilisation élevée des services d'urgence comprennent les obstacles d'accès aux soins ambulatoires et les incapacités concomitantes. La recherche met en évidence les problèmes de confiance des patients envers le système de santé, les besoins non satisfaits en matière de soins de santé et les problèmes de coordination des soins.

Un article de recherche de Lexchin (2024) examine la question des conflits d'intérêts chez les doyens des facultés de médecine au Canada. Au moyen de renseignements publiquement accessibles, l'enquête révèle qu'aucune déclaration de conflit d'intérêts n'était disponible pour plus de 10 doyens, alors que six d'entre eux présentaient une situation de conflits d'intérêts avec l'industrie. La recherche met en évidence les rôles complexes des doyens de faculté de médecine, le manque de transparence concernant la déclaration de conflit d'intérêts et l'implication avec les compagnies pharmaceutiques.

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Federal Funding for Expensive Drugs for Rare Diseases: How Do We Pick and Choose?

Financement fédéral pour les médicaments onéreux pour les maladies rares : comment choisir?

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Abstract
The number of expensive drugs for rare diseases (EDRDs) approved by Health Canada and their contribution to healthcare costs have been rapidly increasing. The federal government has announced a three-year funding commitment of $1.4 billion for EDRDs, but principles need to be developed for how that funding will be allocated, especially in cases where insufficient data are available to guide decision making. Here, we review the role of evidence quality in making choices and draw on the experience from other countries to put forward five principles about how the money should be spent.

Résumé
Le nombre de médicaments onéreux pour les maladies rares (MOMR) approuvés par Santé Canada et leur contribution aux coûts des soins de santé ont rapidement augmenté. Le gouvernement fédéral a annoncé un engagement de financement triennal de 1,4 milliard de

dollars pour les MOMR, mais il reste à élaborer les principes sur la façon dont ces fonds seront alloués, surtout dans les cas où les données disponibles sont insuffisantes pour orienter la prise de décisions. Ici, nous examinons le rôle de la qualité des données dans les choix et nous nous appuyons sur l'expérience d'autres pays pour proposer cinq principes sur la façon de dépenser l'argent.

Introduction

Expensive drugs for rare diseases (EDRDs) are an exploding subset of health expenditures with rapid increases in the number of such drugs approved by Health Canada and their share of total Canadian drug spending (PMPRB 2022). Expensive drugs are those with "estimated treatment costs exceeding $100,000 per year for non-oncology drugs or $7,500 per 28 days for oncology drugs" (PMPRB 2022: 38). The definition of a "rare disease" used by both the European Medicines Agency and the Canadian Organization for Rare Disorders is one affecting five or fewer in 10,000 people (Health Canada 2021).

Canada does not have a formal EDRDs policy despite a decades-long debate on the need for a national orphan drug policy (ODP) but it compares favourably with some countries with ODPs on how many of these drugs come to market and how fast. For example, Australia has had an ODP since 1997, but a higher percentage of orphan drugs approved in the US are marketed in Canada than in Australia and are marketed at the same time with similar lengths of time spent in regulatory processes (Lexchin and Moroz 2020).

However, having drugs approved for the Canadian market does not help patients unless the drugs are reimbursed. Delays and discrepancies in listing marketed drugs on provincial formularies are a challenge for patients. In March 2023, the government acted on this point with a three-year plan to spend over $1.5 billion on the National Strategy for Drugs for Rare Diseases (Health Canada 2023). Most of the money ($1.4 billion) is targeted to a cost-sharing program with the provinces to provide coverage of a common set of new and emerging drugs, while also enabling provinces and territories to enhance coverage for existing drugs and supporting improvements in screening and diagnostics (Health Canada 2023). However, that level of federal funding will leave gaps in coverage even for highly effective drugs. For example, five EDRDs that were rated as offering substantial improvements and/or breakthrough status had total annual Canadian sales of over $1.2 billion (Table 1) (PMPRB 2022). Federal funding would not cover even these five drugs, let alone any upcoming drugs. Therefore, we need principles to decide which drugs to cover.

International Experience Can Inform the Use of Federal Funds

The federal funds for EDRDs are unique given that healthcare services in Canada are traditionally provided by the provinces, with drug manufacturers having to navigate separate systems of the 13 provinces and territories. Other countries have experience that could be used to inform the use of the federal funds. In most jurisdictions, EDRDs are treated in

TABLE 1. Top 10 EDRDs: Sales and therapeutic ratings

Generic name	Brand name	Sales (2021, $ millions)	PMPRB therapeutic rating[¶]	Indications
Lenalidomide	Revlimid	537.7	Breakthrough*	**Multiple myelomas in combination with dexamethasone,** myelodysplastic syndromes
Pembrolizumab	Keytruda	525.7	Slight to none[†]	**Melanoma**, Hodgkin lymphoma, B-cell lymphoma, urothelial carcinoma, bladder cancer, lung cancer, renal cell carcinoma, colorectal cancer, endometrial carcinoma, squamous cell cancer, gastric adenocarcinoma, esophageal carcinoma, breast cancer, cervical cancer
Ibrutinib	Imbruvica	349.5	Substantial[‡]	**Chronic lymphocytic lymphoma**, mantle cell lymphoma, Waldenström's macroglobulinemia, graft versus host disease
Daratumumab	Darzalex	254.3	Moderate[§]	**Multiple myelomas**, amyloidosis
Nivolumab	Opdivo	249.6	Slight to none	**Melanoma**, Hodgkin lymphoma, colorectal cancer, urothelial cancer, non-small cell carcinoma, mesothelioma, renal cell carcinoma, squamous cell cancer, gastroesophageal cancer
Eculizumab	Soliris	180.1	Breakthrough	**Paroxysmal nocturnal hemoglobinuria**, atypical hemolytic uremic syndrome, myasthenia gravis, neuromyelitis optica spectrum disorder
Osimertinib	Tagrisso	178.4	Moderate	**Non-small cell lung cancer**
Nusinersen sodium	Spinraza	97.2	Breakthrough	**Spinal muscular atrophy**
Durvalumab	Imfinzi	92.1	Slight to none	**Urothelial carcinoma**, non-small cell lung cancer, small cell lung cancer, biliary tract cancer
Ipilimumab	Yervoy	75.2	Substantial	**Melanoma**, colorectal cancer, renal cell cancer, non-small cell lung cancer, mesothelioma, esophageal carcinoma

EDRDs = expensive drugs for rare diseases; PMPRB = Patented Medicine Prices Review Board.
Initial approved indication in bold.

¶ Therapeutic rating based on initial approved indication.

* First drug to be sold in Canada that effectively treats a particular illness or effectively addresses a particular indication.

† Relative to other drug products sold in Canada, provides slight or no improvement in therapeutic effects or provides slight or no savings to the Canadian healthcare system and/or to patients and/or caregivers.

‡ Relative to other drug products sold in Canada, provides substantial improvement in therapeutic effects or provides substantial savings to the Canadian healthcare system and/or to patients and/or caregivers.

§ Relative to other drug products sold in Canada, provides moderate improvement in therapeutic effects or provides moderate savings to the Canadian healthcare system and/or to patients and/or caregivers.

Source: PMPRB 2022.

the same manner as other medicines, but some countries have established separate mechanisms. In Australia, drugs may be considered through a separate Life Saving Drugs Program. In the UK, the National Institute for Health and Care Excellence has a program that evaluates the benefits and costs of a limited number of drugs for very rare conditions. France, Germany and Sweden allow validated surrogate endpoints as measures of clinical efficacy/effectiveness for EDRDs. Scotland makes EDRDs available through a Patient Access Scheme for up to three years while further evidence on their effectiveness is generated. After that evidence is available, the drug undergoes a reassessment that includes a Patient and Clinician Engagement meeting (Stafinski et al. 2022).

Beyond just receiving submissions from individual patients and patient groups, Germany, England and Scotland have formal patient involvement teams within review bodies (Stafinski et al. 2022). In Germany, topic-specific patient representatives are appointed to committees for a single review. Generally, there is only indirect patient involvement in the development of terms and conditions of contractual agreements that tie reimbursement to evidence generation (Stafinski et al. 2022).

How Is Canada Responding to the Challenges of EDRDs?

To deal with situations where there is both an unmet need and insufficient data at the time of market entry to determine the benefits of a drug, two new programs were launched in September 2023. The Canadian Agency for Drugs and Technologies in Health (CADTH, now Canada's Drug Agency) created a new category known as "time-limited recommendations (TLRs)" to facilitate early access to drugs for patients with rare diseases (Canada's Drug Agency 2023b). To be eligible, drugs must have "robust" evidence-development plans to fill the gaps identified at the time of health technology assessment (HTA). Importantly, the manufacturer of the drug seeking TLRs must commit to having its drug reassessed within a defined timeline, even if this means the recommendation may be withdrawn. Drugs with a TLR have price negotiations through a second new temporary access program offered by the pan-Canadian Pharmaceutical Alliance where risk sharing is part of the negotiation process (pCPA 2023). Decisions about how robust evidence should be defined will need to be contextualized to reflect, among other things, the severity and long-term consequences of the condition and the availability of other therapies. One approach to doing so could involve the use of a national expert panel as suggested in a discussion paper released in 2021 (Health Canada 2021) and could draw on a national data system that incorporates both already existing disease registries (Inform Rare n.d.) and new ones that provide comprehensive and consistent information about how treatments for rare diseases are used by Canadians and how they are working.

What Is the Role of Evidence Quality in Making Choices?

High-quality evidence should be the gold standard for making therapeutic choices, but

pivotal studies for rare diseases that form the basis for regulatory approval often exhibit methodological flaws; for example, they lack quality-of-life measures, may not be blinded and depend on surrogate endpoints (Lexchin 2023). Some of these deficiencies are inherent in trials for rare diseases where small patient numbers limit power. If there is no existing therapy to give to a control group, enrolling a placebo group may be considered unethical for debilitating or fatal diseases. Finally, the limited understanding of the relationship of biomarkers to disease pathology may decrease study validity (Shah et al. 2021).

Real-world evidence (RWE) can complement other types of studies (Sirrs et al. 2023), but the time needed to generate data leaves patients waiting for options. CADTH recently developed recommendations for the use of RWE but it will take time to assess the impacts of these new guidelines (Canada's Drug Agency 2023a). Regardless of when the evidence is available (pre- or post-market), ultimately decision makers need evidence that a drug provides a clinically meaningful improvement in the quality and/or quantity of life. Judgements about what is clinically meaningful should be made with input from experts in the disease area plus people with lived experience of the disease.

What Principles Can Be Used to Aid Decision Making Around Federal Funds for EDRDs?

We should not pay for drugs that do not work. As with all drugs, the therapeutic value of EDRDs is variable. Out of 46 drugs that had a therapeutic evaluation by the Patented Medicine Prices Review Board between 2010 and 2019, 22 were rated as offering slight to no therapeutic benefit compared with existing drugs, while only 10 were considered substantial improvements or breakthroughs (NPDUIS 2022). For those EDRDs where high-quality clinical evidence was generated prior to market entry, separate routes for reimbursement are not needed. The first principle we suggest is that in these cases, instead of using federal funds, existing HTA infrastructure should inform value-based price negotiations as the basis for listing on provincial/territorial formularies when evidence sufficient for HTA is available prior to market access. Federal funds should only be considered for use in situations where there are convincing reasons why high-quality evidence is not possible prior to market entry (e.g., in rare patient subsets of a given disease), rather than as a means for manufacturers to avoid doing a rigorous pre-market clinical trial.

Second, new drugs for diseases where good therapeutic alternatives are already available in Canada should not be unconditionally reimbursed until such time as high-quality data about clinically relevant outcomes are available. With some EDRDs, only limited knowledge about their effectiveness (Kennedy-Martin et al. 2015) and safety (Singh and Loke 2012) are available at the time of market entry. Risk-sharing agreements are one tool for regulators to balance the challenge of timely access to drugs when considerable uncertainties remain at the time of market access and have been used in Australia mainly for oncology products (Tuffaha and Scuffham 2018). For this reason, we suggest that federal EDRD funds should

be prioritized for those drugs where manufacturers are amenable to meaningful risk-sharing agreements. These agreements can help with common challenges faced by payors such as patient subsets not included in clinical trials. For example, elexacaftor/tezacaftor/ivacaftor (Trikafta) is a breakthrough therapy for cystic fibrosis (CF) approved in Canada for patients who have at least one copy of the most common CF mutation, p.Phe508del (CADTH 2021). Some, but not all, of the rare CF mutations may respond to therapy and trials of treatment for patients with rare mutations could be negotiated on a pay-for-performance basis. Those manufacturers who do not have enough confidence in their drug to put it to the test in risk-sharing agreements should not benefit from the federal EDRD funds.

It follows then that the third principle underlying the use of the federal EDRD funds should be a willingness by the manufacturer to participate in post-market generation of high-quality evidence. This principle does carry some risk for manufacturers in that funding should be withdrawn if post-market trials fail to provide convincing evidence of the drug's value or if the trials fail to be completed. Adherence to this principle will also require changes in Canada's regulatory structures to mandate the reassessment of drugs across their life cycle and, more importantly, to act on the results of this reassessment.

The TLR process specifies that the manufacturer must have a plan for a phase III clinical trial but simply having a plan for a phase III trial should not be sufficient. Not all phase III trials are of similar quality – one worrisome trend has been the explosion of clinical trial structures such as single-arm trials (which are more subject to confounders than to traditional randomized controlled trials) in the oncology field (Agrawal et al. 2023). The excuse for these lower-quality studies is the size of the rare disease population, but size does not guarantee quality – even large patient datasets must be combined with good clinical trial design or else the trial simply becomes a marketing tool. Research in rare diseases requires international collaboration to gain sufficient patient numbers and such collaboration has been recently prioritized by the Canadian Institutes of Health Research (CIHR 2023). We suggest that the fourth principle is that the quality of the evidence-generation plan should be used to choose drug candidates that can take advantage of the federal EDRD funds, thus prioritizing those drugs whose plans optimize clinical trial design and maximize patient numbers through international collaborations where necessary.

Perhaps the most important and final principle around the use of federal EDRD funds is that of fairness. Spending on EDRDs has far outpaced spending in other areas of healthcare, effectively shifting limited healthcare resources from common diseases toward rare diseases (Sirrs et al. 2023). The high opportunity costs for EDRDs make it just as important to engage the public as a stakeholder as it is to engage patients, healthcare providers, manufacturers, regulators and payors. Engaging the public requires transparency around the decision-making processes, opportunity costs and the results of reassessment of the drug across its life cycle. Such transparency has largely been lacking for EDRDs (Sirrs et al. 2023), and moves to enhance transparency are complicated by Canada's proximity to the lucrative

US drug market. Transparency does not mean that governments and manufacturers have to release specific details of negotiated agreements. However, the broad strokes of those agreements can be made public, as they are in other jurisdictions such as the UK (NICE 2019). Drugs where manufacturers are unwilling to allow for this degree of transparency should not be considered as candidates for the funds.

Summary

In order to spend the $1.4 billion in federal money responsibly for EDRDs, drawing on the evidence that we reviewed here and the practices in other countries, we recommend the following five principles:

1. Drugs where high-quality evidence is available prior to market entry should be handled through the existing infrastructure with the federal funds reserved for drugs where the development of high-quality evidence is not possible prior to market entry.
2. Risk-sharing funding agreements should be in place until high-quality evidence showing clinically relevant outcomes is available.
3. Manufacturers should be willing to participate in meaningful evidence-generation with the understanding that if the results of post-market trials do not provide convincing evidence of value, funding will be withdrawn.
4. The quality of the research plan should be used to prioritize candidates for federal funding.
5. There must be meaningful public engagement in order to promote transparency in decision making and all parties have to accept the need for transparency.

Disclaimer

The views expressed in this article are those of the authors and not official positions of their affiliated institutions.

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Commentary: Which Principles Should Apply for a National Strategy on Rare Diseases?

Commentaire : Quels principes devraient s'appliquer à une stratégie nationale pour les maladies rares?

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Abstract

Lexchin and Sirrs (2024) proposed five relevant principles to guide the use of federal funding for expensive drugs for rare diseases, including funding of outcomes-based risk-sharing agreements (OBRSAs) and proactive commitment and participation in the generation of high-quality evidence in a transparent way. This rejoinder, however, questions whether the federal funding should be used only to buy new drugs or whether it could be used to develop new drugs as well. It also examines what OBRSAs would require in terms of institutional capacities to allow the collection of real-world evidence.

Résumé

Lexchin et Sirrs (2024) proposent cinq principes pertinents pour guider l'utilisation du financement fédéral pour les médicaments onéreux pour les maladies rares, dont le financement des ententes de partage des risques axées sur les résultats ainsi qu'une participation proactive à la production de données de qualité de manière transparente. Cette réplique pose toutefois la question à savoir si le financement fédéral devrait être utilisé uniquement pour acheter de nouveaux médicaments ou s'il pourrait également être employé pour développer de nouveaux médicaments. Il examine également ce dont les ententes de partage des risques auraient besoin en matière de capacités institutionnelles afin de permettre la collecte de données probantes concrètes.

Overview

Lexchin and Sirrs (2024) have identified a serious problem with the Canadian government's announcement (Health Canada 2023) of a national strategy for high-cost drugs for rare diseases (DRDs): money is being provided without any guidelines on how it should be used. Lexchin and Sirrs (2024) propose five principles that they assert should guide the use of federal funding for expensive drugs for rare diseases (EDRDs), including funding of outcomes-based risk-sharing agreements (OBRSAs) and proactive commitment and participation in the generation of high-quality evidence in a transparent way. While the proposed principles are sound, some additional nuance seems necessary.

Should a national strategy for rare diseases be limited to drugs?

Patients with rare diseases (and their families) have important needs beyond pharmaceuticals that must also be taken into account. Key issues for families dealing with a rare disease go beyond accessing medication: they may need to obtain appropriate medical equipment, adapt the house or the car or cope with lost income because of constant hospital visits or because one parent needs to stay at home with a sick child (Awada 2023). It is odd that governments are willing to pay $300,000 per year for a drug that will slow the progress of a rare disease by 15%, yet ensuring that even a small fraction of that amount is available to pay for adequate social support apparently remains unviable. A national strategy should focus on how to best help patients with rare diseases in all areas of their lives, not only on costly pharmaceutical provision.

Should we only buy drugs or also develop them?

In March 2023, the federal government announced a three-year plan to spend $1.5 billion over three years on high-cost rare disease drugs, but most of the money ($1.43 billion) was meant to boost the ability of public drug plans to purchase EDRDs (Health Canada 2023). Another $36 million of the $1.5 billion will be spent to help the Canadian Drug Agency, the Canadian Institute for Health Information and Health Canada to support the implementation of the strategy and improve the collection of information. Lastly, only $32 million of the $1.5 billion will go to the Canadian Institutes of Health Research to advance rare disease research and establish a rare disease clinical trials network. In many ways, this focus on buying drugs marketed by corporations instead of advancing institutional capacity to develop drugs ourselves is baffling. The market system is not well adapted for DRDs; the term "orphan drugs" describes drugs that lack market incentives for their development (Mikami 2019: 609). Why then are efforts so focused on buying drugs marketed by private interests?

The stories of two DRDs developed in Canada – Strensiq and Glybera – help illustrate the point. Strensiq is a drug for an ultra-rare bone disease called hypophosphatasia and was developed in Montreal's universities and by a start-up company, Enobia. The drug was then acquired by the company Alexion, as Enobia did not have the capacity to bring the drug to market (Gagnon 2021). At the time, Alexion was selling only one drug, Soliris, considered

the world's most expensive drug. Alexion marketed Strensiq in 2014 at a prohibitive price; consequently, most Canadians who stood to benefit from the drug could not access it. Following the acquisition and the successful marketing of Strensiq, in 2014, Alexion's chief executive officer, Leonard Bell, became the world's highest paid pharmaceutical executive ever with a total compensation of $217 million (Lazonick et al. 2017), an amount larger than the total payroll for all non-executive employees at the company. If we only make policy decisions that encourage paying more for EDRDs instead of developing alternative ways to bring these drugs to the market, are we really incentivizing relevant research or are we simply fattening shareholders?

Glybera is a gene therapy that treats a genetic condition called lipoprotein lipase deficiency. It was the first-ever gene therapy, developed by academics at the University of British Columbia in partnership with a small European drug company called Amsterdam Molecular Therapeutics (AMT). The company went bankrupt during the drug's regulatory approval process time and was acquired by the company uniQure. uniQure attempted to market the drug at $1 million per treatment, the highest price ever seen at the time. No drug plan was willing to reimburse the drug and, instead of selling the drug at a lower price, the company shelved the drug entirely (Crowe 2018). In 2019, the National Research Council (NRC) announced that they would start producing the drug themselves through their public labs (Crowe 2019) and would sell the drug at a portion of its initial price (NRC 2020). This example makes the case that the national strategy for DRDs should also support alternative ways to bring drugs to the market, such as the public production of DRDs by the NRC. As it currently stands, however, we only have significant additional funding for buying DRDs, not developing them ourselves.

Which principles should apply for the purchase of DRDs?

Because of the lack of guidelines on how this money should be spent, the principles proposed by Lexchin and Sirrs (2024) are relevant and deserve a closer look. According to the authors, no additional funding should be used for drugs that already have high-quality evidence, meaning that the purpose of the funding ought to be associated with securing OBRSAs for new DRDs entering the market without high-quality evidence of risks and benefits, under the condition of a commitment by the manufacturer to transparently generate the missing evidence. This approach provides sound principles for the national strategy based on existing literature about OBRSAs (Dabbous et al. 2020; Facey et al. 2021; Kim et al. 2020; Mendell et al. 2023; Thanimalai et al. 2021). However, some challenges remain for the implementation of such principles.

While some DRDs are offered only in hospital settings, which is a suitable environment for the generation of real-world evidence (RWE), many DRDs are only offered as prescription drugs taken outside hospital settings. This requires additional institutional capacity to collect real-world evidence (Gonçalves et al. 2018). While this work would normally fall on the shoulders of the prescribing physician, it is worth noting that community pharmacists

in Quebec showed considerable capacity to collect RWE for Paxlovid in the context of the COVID-19 pandemic, based on a provincial not-for-profit patient-support program (Accessa 2022). Such capacity could be of interest for the implementation of OBRSAs for DRDs.

Moreover, OBRSAs are agreements between the payer (the drug plan) and the manufacturer in which the funding of the drug can be withdrawn if post-market trials fail to provide clear evidence of the drug's therapeutic value (Thanimalai et al. 2021). OBRSAs are easier to achieve when the whole population is covered through one national drug plan. However, in Canada, there are more than 100 public drug plans and more than 100,000 private drug plans (Advisory Council on the Implementation of National Pharmacare 2019). While public drug plans collaborate in negotiating financial risk-sharing agreements (confidential rebates) through the pan-Canadian Pharmaceutical Alliance and could develop better capacity to negotiate OBRSAs, most private plans have no capacity to negotiate such OBRSAs. Do the principles proposed by the authors imply full public coverage for DRDs without high-quality evidence? If this is the case, this assumption should be explicit.

These caveats should not be interpreted as obstacles to implementing the suggested principles. On the contrary, by setting down clear principles regarding how this new federal funding for DRDs should be used, Lexchin and Sirrs (2024) have started an important discussion on how to make this funding work in the best interest of patients.

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DATA MATTERS

Quality of Work Life and Mental Well-Being for Long-Term Care Staff in Nova Scotia

Qualité de la vie au travail et bien-être mental chez le personnel des soins de longue durée en Nouvelle-Écosse

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Abstract

This study assesses the quality of work life for Nova Scotian continuing care assistants (CCAs) (n = 266), nurses (n = 144) and managers (n = 45) from 10 long-term care (LTC) homes in late 2021. CCAs scored significantly worse than nurses and managers on measures of mental health and anxiety. All groups reported high levels of cynicism and emotional exhaustion; CCAs' scores were higher than nurses or managers. CCAs scored significantly higher on professional efficacy than other groups. CCAs can derive a strong sense of accomplishment from their work, but results raise concerns of a potential breaking point. This suggests the need for continued action to support LTC staff.

Résumé

Cette étude évalue la qualité de l'équilibre entre vie professionnelle et vie privée chez les assistants de soins continus (ASC) (n = 266), chez les infirmières (n = 144) et chez les gestionnaires (n = 45) dans 10 foyers de soins de longue durée (SLD) de la Nouvelle-Écosse, à la fin de 2021. Les résultats pour les mesures de la santé mentale et de l'anxiété sont nettement moins bons chez les ASC que chez les infirmières et les gestionnaires. Tous les groupes ont signalé des niveaux élevés de cynisme et d'épuisement émotionnel; les scores étaient plus élevés chez les ASC que chez les infirmières ou les gestionnaires. Les ASC ont obtenu un score significativement plus élevé sur l'efficacité professionnelle que les autres groupes. Les ASC peuvent tirer un fort sentiment d'accomplissement au travail, mais les résultats soulèvent des préoccupations quant à un point de rupture potentiel. Cela suggère la nécessité d'une action continue pour soutenir le personnel des SLD.

Introduction

Long-term care (LTC) staff are a vital part of the healthcare system in Canada, especially as LTC demand continues to increase. Nova Scotia has one of the oldest populations in Canada (Statistics Canada 2023), and can expect increased need for LTC with rising rates of those with the highest LTC use, such as people aged 85 years and older (Hallman et al. 2022); and those living with dementia (Alzheimer Society of Canada 2022; Garner et al. 2018). Nova Scotian LTC homes, similar to those in other provinces, experienced significant challenges with staffing turnover and recruitment efforts before the COVID-19 pandemic; these challenges were exacerbated during and after the pandemic. A better understanding of the Nova Scotian LTC workforce will assist both the government and LTC providers in stabilizing the current workforce and ensuring healthy staffing levels to meet the projected demand.

The workplace conditions and well-being of LTC staff have received minimal research focus, though research in this area has increased in recent years due to the COVID-19 pandemic, revealing that working conditions have worsened and LTC staff have been pushed to their limits (Reynolds et al. 2022). Research on staff in LTC – such as continuing care

assistants (CCAs), nurses and managers – reports that each staff type had unique experiences and stressors during the COVID-19 pandemic and was under severe duress, as shown in outcomes such as poor mental health (Fisher et al. 2021; Havaei et al. 2021, 2022; Reynolds et al. 2022) and burnout (Boamah et al. 2023; Estabrooks et al. 2023; Leskovic et al. 2020; Navarro Prados et al. 2022).

Despite the importance of supporting this workforce, Nova Scotia has limited data about the health and well-being of LTC staff at both the local LTC home and the provincial level. Thus, the primary aim of this project was to provide a snapshot of the mental well-being and quality of work life (QWL) for Nova Scotia's LTC staff during the COVID-19 pandemic. This study also examined the differences in mental health between types of LTC staff. Establishing baseline data will help in measuring the potential impact of LTC policy changes on the workforce in the future. These findings, especially in the context of the post-COVID-19 pandemic era, will be informative to help meet the needs of this important workforce as policy and practice change.

Method

Study design and setting

Data used in this analysis were collected between October 2021 and December 2021 in 10 Nova Scotian licensed LTC homes. This voluntary convenience sample of homes was mostly not for profit, small- to mid-sized (<120 beds) and located in rural and urban areas. Each LTC home received a monetary stipend in recognition of their participation in this study.

Participants

Study participation within each home was voluntary and convenience-based with a small reimbursement offered for survey completion. Within each home, CCAs, registered nurses and licensed practical nurses were eligible to complete the survey if they had worked in the facility for longer than three months and worked at least six shifts over the past month. Managers had to be in their role for longer than three months. In addition, CCAs had to be able to identify one unit where they worked at least 50% of their shifts. For CCAs, surveys were computer-assisted interviews administered by trained interviewers over video-conferencing software during their work hours, with interviews taking 25–30 minutes to complete; for nurses and managers, surveys were self-directed online questionnaires with completion times of 20–25 minutes. Prior protocol development found that data quality and survey length using online surveys were acceptable for regulated staff such as nurses and managers, but care aides (such as CCAs) provided higher quality data in shorter survey times when surveys were administrated using computer-assisted interviews (Estabrooks et al. 2009). Further research on this method of data collection concluded a high level of data quality (Squires et al. 2012).

Ethics

Ethics approval was obtained from Mount Saint Vincent University Research Ethics Board (REB) File # 2021-016 and Nova Scotia Health REB #1027057.

Measures

Demographic variables were single questions asking for direct information about the participant. Well-being and QWL variables were diverse. Cynicism, emotional exhaustion and professional efficacy are subscales of the Maslach Burnout Inventory (MBI) (Maslach et al. 1996). Physical and mental health are derived from the Short Form 8 (SF-8) health measurement scale (Yiengprugsawan et al. 2014). Anxiety scores use the Generalized Anxiety Disorder (GAD-7) screening tool for general anxiety disorder (Spitzer et al. 2006), and job satisfaction is a modification of the Michigan Organizational Assessment Questionnaire-Job Satisfaction Survey (MOAQ-JSS-3) (Cammann et al. 1979). Further information on measures is provided in Appendix 1 (available online at www.longwoods.com/content/27348).

Analysis

For demographic variables, frequencies and percentages were calculated for categorical variables and a chi-squared test of independence was performed. Where results were significant at $\alpha = 0.05$, post-hoc analysis was conducted between care staff types again using a chi-squared test of independence. For continuous variables, means and standard deviations were calculated and an analysis of variance was conducted to compare results across care staff, and where results were significant at $\alpha = 0.05$, post-hoc analysis was conducted using Welch's two-sample *t* test (Welch 1947).

Means and standard deviations were calculated for well-being and QWL variables and were compared using a two-level random intercept linear regression model, with separate regressions run between each staff type. The LTC home was used as the class factor in order to control for the clustering of LTC staff nested within the same homes. An adjusted model was then created that controlled for years in the role and whether or not the respondent lived with a partner.

Results

Demographic characteristics

Table 1 summarizes the demographic comparisons between CCAs ($n = 266$, 46% RR [response rate]), nurses ($n = 144$, 39% RR) and managers ($n = 45$, 71% RR). Across all groups, staff tended to be middle-aged, female and Canadian-born. They typically worked 70–80 hours in the two weeks before the survey. CCAs were less likely to live with a partner than nurses ($p < 0.05$) and managers ($p < 0.001$), and managers had less experience in their staff role type than CCAs ($p < 0.001$) and nurses ($p < 0.001$).

TABLE 1. Demographic measures compared between care staff type and post-hoc analysis results

Measure		CCA	N	M	Total	Chi-square (*p*)	Post-hoc Chi-square (*p*)		
Age [*n* (%)]	<30	42 (15.8)	24 (16.7)	4 (8.9)	70 (15.4)	3.383 (0.908)	N/A		
	30–39	54 (20.3)	32 (22.2)	10 (22.2)	96 (21.1)				
	40–49	75 (28.2)	32 (22.2)	13 (28.9)	120 (26.4)				
	50–59	69 (25.9)	40 (27.8)	13 (28.9)	122 (26.8)				
	>60	26 (9.8)	16 (11.1)	5 (11.1)	47 (10.3)				
Sex [*n* (%)]	Male	26 (9.8)	10 (6.9)	5 (11.6)	41 (9.1)	1.123 (0.570)	N/A		
	Female	240 (90.2)	130 (90.3)	38 (88.4)	408 (90.9)				
Born in Canada [*n* (%)]	Yes	236 (88.7)	121 (84.0)	42 (93.3)	399 (88.9)	2.399 (0.301)	N/A		
	No	30 (11.3)	18 (12.5)	2 (4.4)	50 (11.1)				
Living with a partner [*n* (%)]	Yes	144 (54.1)	94 (65.3)	37 (84.1)	275 (61.5)	17.777 (<0.001)	**CCA-N*** 6.564 (0.010)	**CCA-M***** 12.566 (<0.001)	**N-M** 3.466 (0.063)
	No	121 (45.5)	44 (30.6)	7 (15.9)	172 (38.5)				
		CCA	**Nurse**	**Manager**	**Total**	**ANOVA *F* (*p*)**	**Post-hoc Welch's t (*p*)**		
Hours worked in two weeks [*mean* (*SD*)]		75.8 (14.6)	69.4 (19.8)	79.8 (11.0)	74.1 (6.5)	0.533 (0.466)	N/A		
Years in role [*mean* (*SD*)]		12.1 (9.7)	13.0 (12.1)	5.1 (6.9)	11.7 (10.5)	7.56 (0.006)	**CCA-N** −0.761 (0.447)	**CCA-M***** 5.962 (<0.001)	**N-M***** -4.478 (<0.001)

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.
ANOVA = analysis of variance; CCA = continuing care assistant; M = manager; N = nurse; SD = standard deviation.
Post-hoc analysis only ran when chi-squared test of independence showed significance at $\alpha = 0.05$.

QWL characteristics

Table 2 summarizes QWL outcomes across the sample and comparisons between LTC staff types. Intra-class correlation coefficients (ICCs) (see Table 3) were typically low, implying little consistency in scores within each care home, with only job satisfaction (ICC = 0.31) showing a small level of per-home consistency. Cronbach's alpha for each scale can be found in Appendix 1; coefficients were acceptable and ranged from 0.72 to 0.91 with the exception of professional efficacy that had a Cronbach's alpha of 0.52. As evidenced in Table 3, generally, CCAs showed worse QWL outcomes than both managers and nurses, while nurses showed poorer QWL than managers on some measures and comparable outcomes on others.

Physical and mental health were both lower for CCAs than for managers with moderate-strength differences reported. Nurses also had lower physical and mental health scores than managers but with weaker differences. CCAs reported higher levels of anxiety than both nurses and managers, with stronger differences between CCAs and managers. CCAs scored higher (higher being worse) than both nurses and managers on the MBI subscales for cynicism and emotional exhaustion, with the strongest differences observed between CCAs and managers. CCAs scored higher (higher being better) on the MBI subscale for professional efficacy compared with both nurses and managers. Job satisfaction was consistently high with no significant differences among LTC staff types.

TABLE 2. Outcome means and standard deviations, by care staff type

Measure	*Mean (SD)*		
	CCA	N	M
SF-8 physical health (0–100)	**45.2** (9.31)	**47.4** (8.50)	**51.7** (9.17)
SF-8 mental health (0–100)	**42.9** (11.6)	**45.0** (11.3)	**47.6** (11.25)
Anxiety (0–21)	**8.19** (5.56)	**5.20** (5.19)	**4.67** (4.65)
MBI cynicism (0–6)	**2.77** (1.76)	**2.32** (1.56)	**1.89** (1.60)
MBI emotional exhaustion (0–6)	**3.66** (1.58)	**2.54** (1.64)	**2.15** (1.67)
MBI efficacy (0–6)	**4.91** (0.98)	**4.15** (1.06)	**4.37** (0.98)
Job satisfaction (1–5)	**3.99** (0.70)	**4.00** (0.75)	**4.25** (0.65)

CCA = continuing care assistant; M = manager; MBI = Maslach Burnout Inventory; N = nurse; SF-8 = Short Form 8.

TABLE 3. Well-being and QWL differences between care staff type using adjusted mixed-effects regression

Measure	Regression coefficient (95% CI)					Intra-class correlation
	N – CCA	M – CCA	M – N	Years in role	Living w/ partner	
SF-8 physical health (0–100)	**2.37***** (0.48 – 4.25)	**5.82***** (2.84 – 8.80)	**3.46*** (0.31 – 6.60)	**-0.07** (-0.15 – 0.01)	**0.32** (-1.44 – 2.08)	0.02
SF-8 mental health (0–100)	**1.45**** (-0.91 – 3.82)	**5.71***** (1.97 – 9.45)	**4.26*** (0.32 – 8.20)	**0.20***** (0.10 – 0.31)	**1.17** (-1.04 – 3.37)	0.01
Anxiety (0–21)	**-2.76***** (-3.89 – -1.63)	**-3.87***** (-5.65 – -2.10)	**-1.11** (-2.98 – 0.76)	**-0.05*** (-0.10 – 0.00†)	**-0.30** (-0.81 – 0.22)	0.02
MBI cynicism (0–6)	**-0.42**** (-0.77 – -0.07)	**-0.73***** (-1.28 – -0.19)	**-0.31** (-0.86 -0.26)	**0.01** (0.00 – 0.03)	**-0.06** (-0.38 – 0.27)	0.12
MBI emotional exhaustion (0–6)	**-1.12***** (-1.45 – -0.79)	**-1.43***** (-1.96 – -0.91)	**-0.31** (-0.86 – 0.24)	**0.00** (-0.01 – 0.01)	**-0.16** (-0.47 – 0.15)	0.12
MBI efficacy (0–6)	**-0.73***** (-0.94 – -0.52)	**-0.60***** (-0.93 – -0.27)	**0.13** (-0.22 – 0.48)	**-0.01** (-0.01 – 0.00)	**-0.03** (-0.22 – 0.17)	0.13
Job satisfaction (1–5)	**0.01** (-0.14 – 0.15)	**0.21** (-0.02 – 0.44)	**0.21** (-0.03 – 0.45)	**0.00** (-0.01 – 0.00)	**0.06** (-0.07 – 0.20)	0.31

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.
† Presents as 0.00 due to rounding, 95% CI does not include 0.
CCA = continuing care assistant; CI = confidence interval; M = manager; MBI = Maslach Burnout Inventory; N = nurse; SF-8 = Short Form 8.

Discussion and Policy Implications

To the best of our working knowledge, our research demonstrates for the first time in Nova Scotia that nurses and managers working in LTC were comparable on most QWL measures, but CCAs tended to experience a poorer QWL than both nurses and managers when controlling for LTC home of origin, time spent in staff role and support at home (living with a partner). Apart from job responsibilities, staff roles also differ importantly in the kind of work they do in LTC homes (Berta et al. 2013), in the level and type of training and education (Andersen 2009), in access to professional development opportunities and in income (Van Houtven et al. 2020). These differences may account for some staff handling stressors better than others. Most of the direct care for residents such as hygiene, mobility and mealtime support is performed by CCAs (Chamberlain et al. 2019), resulting in higher physical demands. Thus, it is not surprising that they reported lower self-perceived physical health. CCAs also have lower education and training requirements, have a lower position on the care hierarchy and lower income compared to nurses and managers, as well as different demands on their time due to shift scheduling (Berta et al. 2013; Chamberlain et al. 2019, Van Houtven et al. 2020), which could account for some of the differences in mental health and burnout outcomes. In addition, since CCAs provide the majority of direct care (Chamberlain et al. 2019), the risk of exposure to COVID-19 through resident cases would be higher for CCAs (Greene and Gibson 2021), implying a different level of burden caused by the pandemic.

In this study, all groups scored high on efficacy with CCAs reporting higher scores on efficacy than both nurses and managers. The coexistence of high efficacy and personal accomplishment with negative burnout symptoms such as emotional exhaustion, cynicism and depersonalization has been documented before among LTC staff pre-COVID-19, implying worrying symptoms but still showing overall moderate to low burnout levels (Chamberlain et al. 2016; Costello et al. 2019; Estabrooks et al. 2015a). This was also reported during the COVID-19 pandemic in Western Canada, where, despite a decrease in efficacy when entering the COVID-19 pandemic, care aides still showed overall high efficacy levels (Song et al. 2023). While the ability of CCAs to derive a sense of accomplishment from their work even when facing challenging working conditions seems high, it raises concerns of a potential breaking point for this workforce.

These data suggest that CCAs should be a priority focus for Nova Scotian LTC staff initiatives at both the local care home and provincial levels. In 2022, intervention efforts mainly focused on the recruitment of more CCAs by increasing provincially funded care hours per resident day, increasing the rate of pay for CCAs and covering tuition and textbook costs for students enrolling in upcoming CCA programs, as well as expanding the capacity of the program (Campbell 2023; Government of Nova Scotia n.d.). While improving staffing levels is one way to improve conditions of care (Silas and Armstrong 2021), other important

aspects of the work environment such as staff feedback mechanisms and structural resources also play a significant role in the use of best practices in LTC (Estabrooks et al. 2015b); workplace culture, social capital and slack/flexibility in use of staffing were associated with missed and rushed care tasks (Song et al. 2020). There is more to improving working conditions and quality of care than maintaining staffing levels alone.

Conclusion

This research and a subsequent planned wave of data collection in 2024 will enable monitoring of the impact of recent LTC staffing initiatives. The understanding of LTC staff's physical and mental health, well-being and QWL in Nova Scotia during the COVID-19 pandemic suggests a workforce in need of support; in particular, CCAs reported a significantly worse QWL in Nova Scotian care homes during the COVID-19 pandemic than their nurse and manager counterparts. These poorer outcomes for CCAs could be related to a variety of background and professional factors. Due to the cross-sectional nature of this study and lack of pre-COVID-19 data, we cannot say definitively that the COVID-19 pandemic contributed to these poorer outcomes; however, Song et al. (2023) found in their longitudinal study of care aides in two Canadian provinces that MBI cynicism increased and SF-8 mental health decreased in comparison with pre-pandemic reports. Longitudinal tracking of mental well-being and QWL will provide important insights into the experience of LTC staff following the COVID-19 pandemic, help monitor the success of LTC staff interventions and aid in designing further supports and interventions.

Regardless of the reasoning behind the worsened QWL outcomes, concerns for the stability of the Nova Scotian LTC workforce and especially CCAs need to be addressed. As demand for LTC reaches unprecedented highs, current efforts to recruit and retain more LTC staff will play an important role in relieving the pressure experienced by these front-line care workers. In addition, further initiatives focusing on other aspects of QWL will be necessary to improve the work environment and, subsequently, quality of care.

Limitations and Future Directions

This research has some important limitations. We had a convenience sample of 10 LTC homes whose characteristics (size, location, owner-operator model) were not proportional or representative of the provincial LTC sector. A subsequent wave of data collection (2023–2024) will replicate this study across the four Atlantic provinces. This research will utilize a stratified random control design (using characteristics identified earlier) to enable generalizability of the results and ultimately provide evidence of where policies and practices are most needed to improve LTC staff well-being (ARCLTC 2023).

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DATA MATTERS

Changes in Primary Care Health Services During the COVID-19 Pandemic: A Longitudinal Analysis of Data From Ontario

Changements dans les soins de santé primaires pendant la pandémie de COVID-19 : une analyse longitudinale des données de l'Ontario

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Abstract

The COVID-19 pandemic significantly impacted primary care, but its effect on quality of care is not well understood. We used health administrative data to understand the changes in quality-of-care measures for primary care between October 2018 and April 2022. We examined the following domains: cancer screening, chronic disease (diabetes) management, high-risk prescribing, continuity of care and capacity of primary care services. Colorectal and breast cancer screenings declined after the pandemic and had not returned to baseline by study end. In patients living with diabetes, in-person visits and up-to-date retinopathy screening rates declined after the pandemic declaration and did not return to baseline by study end, while statin prescribing remained stable. High-risk opioid prescribing decreased over time and was not affected by the pandemic. Physician continuity remained stable, though new patient enrollments decreased over the pandemic but returned to baseline by study end. Existing disparities in colorectal cancer screening by income and recent registration widened during the pandemic. In summary, COVID-19 had a variable impact on primary care, with the strongest influence on preventive and chronic disease care that was dependent on in-person visits.

Résumé

La pandémie de COVID-19 a eu un impact significatif sur les soins primaires, mais son effet sur la qualité des soins n'est pas bien compris. Nous avons utilisé les données administratives sur la santé pour comprendre les changements dans les mesures de la qualité pour les soins primaires entre octobre 2018 et avril 2022. Nous avons examiné les domaines suivants : dépistage du cancer, gestion des maladies chroniques (diabète), prescription à risque élevé, continuité des soins et capacité des services de soins primaires. Le dépistage du cancer colorectal et du cancer du sein a diminué après la pandémie et n'est pas revenu au niveau de référence à la fin de l'étude. Chez les patients atteints de diabète, les visites en personne et les taux de dépistage de la rétinopathie à jour ont diminué après la déclaration de pandémie et ne sont pas revenus au niveau de référence à la fin de l'étude, tandis que la prescription de statines est demeurée stable. La prescription d'opioïdes à risque élevé a diminué au fil du temps et n'a pas été touchée par la pandémie. La continuité chez les médecins est demeurée stable, même si le nombre de nouveaux patients a diminué au cours de la pandémie, mais est

revenue au niveau de référence à la fin de l'étude. Les disparités en matière de dépistage du cancer colorectal en fonction du revenu et d'un enregistrement récent se sont accrues pendant la pandémie. En résumé, la COVID-19 a eu un impact variable sur les soins primaires, avec une plus forte influence sur les soins préventifs et les soins pour les maladies chroniques qui dépendent des visites en personne.

Introduction

Providing high-quality primary care is fundamental to establishing robust health systems as it is linked to better health, decreased mortality rates and enhanced health equity (Starfield 2009). The COVID-19 pandemic has had a profound impact on primary care service delivery with initial reduction in visit volumes and a pivot to virtual care (Glazier et al. 2021). Early in the pandemic, clinicians and patients were instructed to defer preventive care activities and routine chronic disease management (Walker et al. 2021). The pandemic disproportionately affected marginalized groups, and there is concern that existing inequities in preventive care and chronic disease management (Smith et al. 2019; Upshaw et al. 2021) widened over the pandemic. Despite these concerns, there is little published research providing a comprehensive look at changes in recommended care and related changes in care disparities. Previous evidence from Ontario (Kiran et al. 2022) only addressed the pandemic's impact on select indicators over a brief time frame, with limited focus on disparities. Therefore, we sought to use administrative data to understand the impact of COVID-19 on a comprehensive list of quality-of-care measures in Ontario and related changes in disparities in care over a four-year period encompassing both pre-pandemic and pandemic periods. Measures corresponded to four of six Institute of Medicine's quality dimensions (access, effectiveness, safety, and equity) (AHRQ 2022) and were informed by other measurement initiatives as advised by clinicians (Shuldiner et al. 2023).

Methods

We conducted a repeated cross-sectional study using health administrative data. We assessed quality-of-care measures in six-month increments between October 2018 and April 2022. We included patients living in Ontario and eligible for the Ontario Health Insurance Plan (OHIP) as of March 31 of the respective year. We excluded infants aged less than one year old and those in long-term and palliative care.

We leveraged data collected for audit and from feedback reports for academic practices affiliated with the University of Toronto, available on the CareCanvas dashboard (https://www.carecanvas.ca/clinic). Accordingly, we examined quality of care in the following domains: cancer screening, chronic disease management, high-risk prescribing, continuity of care and capacity of primary care services. A full list of indicators, definitions and data

sources is presented in Table 1. Datasets were linked using unique encoded identifiers and analyzed at ICES. ICES is an independent, non-profit research institute whose legal status under Ontario's health information privacy law allows it to collect and analyze healthcare and demographic data, without consent, for health system evaluation and improvement (https://www.ices.on.ca/).

TABLE 1. List of variables, data sources and definitions

Variable name	Data source	Definition
Colorectal cancer screening	PCPOP dataset	Percentage of patients aged 52 to 74 years at index date who had a fecal occult blood test within the past two years, other investigations (i.e., barium enema, sigmoidoscopy) within the past five years or a colonoscopy within the past 10 years
Breast cancer screening	PCPOP dataset	Percentage of female patients aged 52 to 69 years at index date who had a mammogram within the past two years
In-person visits by patients with diabetes	OHIP claims database	Percentage of diabetic patients aged 18 years and older who had an in-person visit to their physician for any reason within the last 12 months from index date
Retinopathy screening in patients with diabetes	OHIP claims database	Percentage of diabetic patients aged 18 years and older who had at least one retinal exam with an ophthalmologist or optometrist in the last 24 months from index date
Statin prescription in patients with diabetes	OHIP claims database	Percentage of elderly diabetic patients aged 66 years and older who had a statin medication dispended within the last 12 months from index date
Opioid prescription	NMS	Percentage of non-palliative patients dispensed an opioid prescription within the last six months (excluding opioid agonist therapy) from index date
New opioid prescription	NMS	Percentage of non-palliative patients newly dispensed an opioid prescription within the last six months (excluding opioid agonist therapy) from index date
Opioid prescription with benzodiazepine or z-drugs	NMS	Percentage of non-palliative patients dispensed an opioid prescription with a benzodiazepine (or z-drug) prescription within the last six months (excluding opioid agonist therapy) from index date
New patient enrollments	OHIP claims database	Percentage of all patients who are new enrollments, calculated from new patient enrollments among all rostered patients in the last six months prior to index date as captured through OHIP billing code Q200 for rostering
Visit to rostered physician	ICES physician database, OHIP claims database	Percentage of in-person visits to a patient's rostered physician, calculated from total number of in-person visits in the two years prior to index date to a patient's rostered physician among all non-focused, comprehensive general practitioner in-person outpatient visits in the two years prior to index date

NMS = Narcotics Monitoring; OHIP = Ontario Health Insurance Plan; PCPOP = primary care population; System.

We only focused on in-person visits for diabetes follow-up as we hypothesized that these were the most affected by the COVID-19 pandemic, and diabetes guidance during the pandemic recommended a minimum of one in-person visit per year to perform the needed physical exam manoeuvres (Kiran et al. 2020). We calculated the aggregate data for each quality-of-care indicator for each time point. We stratified two indicators – colorectal cancer screening and in-person follow-up for diabetes – by sex, age, neighbourhood income, recent registration for OHIP and rurality, as we hypothesized a priori that there could have been changes to these practices over the pandemic (Cauch-Dudek et al. 2013; Kiran et al. 2017). Patients' sex and postal code were derived from the registered person's database. Registration with OHIP in the past 10 years has been used as a proxy for immigration but is also influenced by interprovincial migration (Kiran et al. 2017; Ray et al. 2007). Patients' postal code was used to calculate rurality using the Rurality Index of Ontario (big city, small town and rural area) (Kralj 2000) and neighbourhood income quintile. We calculated the absolute difference between the group with the highest and the lowest quality of care at the start and end of the study.

The use of the data in this project to improve the quality of care was authorized under section 45 of Ontario's *Personal Health Information Protection Act*, 2004, and does not require review by a research ethics board.

Results

Cancer screening

The percentage of screen-eligible patients who were up to date on breast cancer screening was steady before the beginning of the COVID-19 pandemic, then decreased to a nadir by October 2021 and has been increasing since (Figure 1a). The same pattern was seen for colorectal cancer screening, with the percentage of patients with up-to-date screening significantly decreasing after the pandemic.

Chronic disease care

The percentage of patients with diabetes with an in-person visit within the past 12 months had a similar pattern as those of cancer screening but with a more prominent negative trend (Figure 1b). The percentage of patients with diabetes with retinopathy screening in the past 24 months showed a steady decrease over time since the pandemic, while the percentage of older diabetic patients with a statin prescription within the past 12 months remained stable overall regardless of the pandemic.

High-risk prescription

The percentage of patients dispensed an opioid, newly dispensed an opioid and dispensed an opioid with a benzodiazepine all showed an overall decreasing trend over time, including during the pandemic (Figure 1c).

FIGURE 1. Changes in primary care indicators between October 2018 and April 2022

Figure 1a: Cancer screening

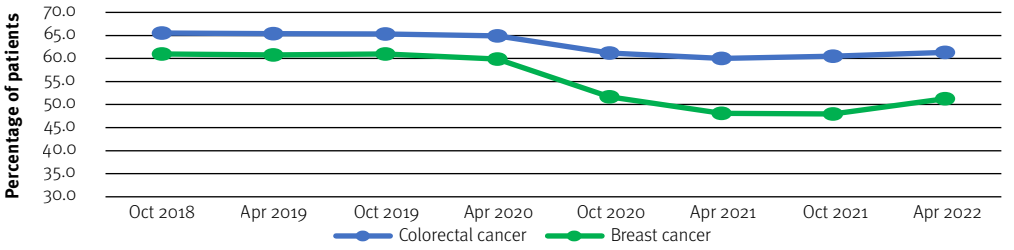


Figure 1b: Chronic disease (diabetes) management

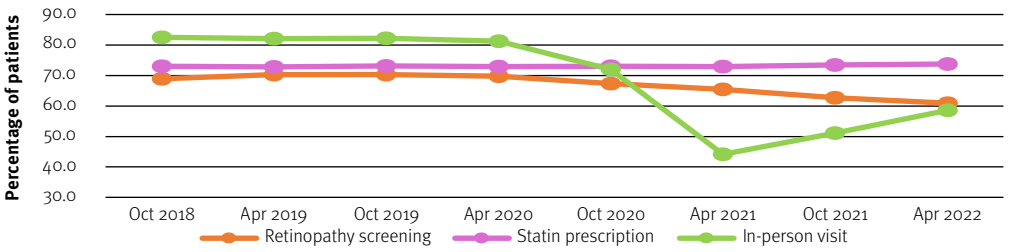


Figure 1c: High-risk prescription

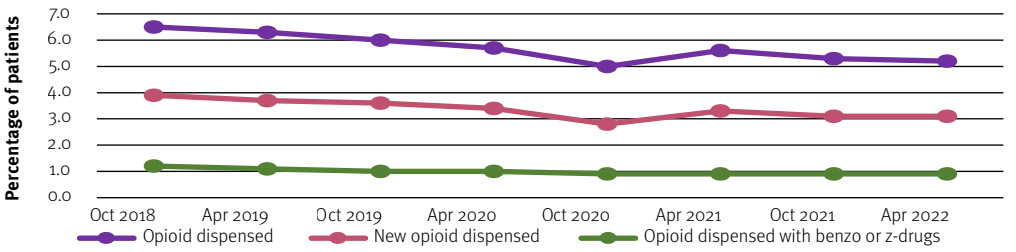


Figure 1d: New patient enrollment

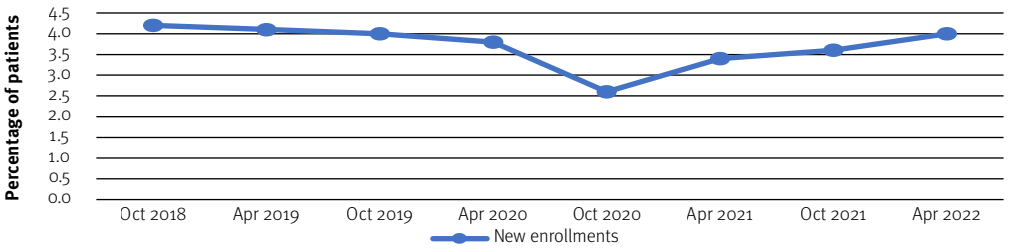
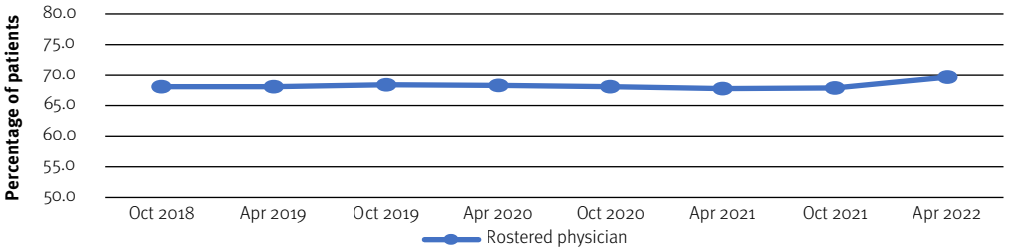


Figure 1e: Continuity of care



New patient enrollment and continuity of care

The percentage of newly enrolled patients was decreasing prior to the pandemic and then dropped significantly right after (Figure 1d). Regardless, it has been increasing back toward pre-pandemic measures. However, the percentage of in-person visits to a patient's rostered physician remained stable overall (Figure 1e).

Stratifications

The percentage of patients with up-to-date colorectal cancer screening and patients with diabetes with an in-person visit was higher among female than male patients (Figures 2a and 3a). Older patients had higher colorectal screening and in-person visit rates for diabetes than patients of younger age groups, with the highest rates among those aged at least 65 years for both variables (Figures 2b and 3b). When stratified by neighbourhood income quintile, the percentage of colorectal cancer screening showed a stepwise increase as income quintile increased (Figure 2c). Prior to the pandemic, the percentage of in-person visits for diabetes was also persistently lowest in patients from the lowest-income neighbourhoods; however, those from the highest-income neighbourhoods went from having the highest percentage before the pandemic to the lowest after the pandemic (Figure 3c). Patients in rural areas generally had lower colorectal cancer screening and in-person follow-up rates for diabetes than those in big cities and small towns (Figures 2d and 3d). Similarly, recent registrants had lower rates of both indicators compared with other Ontarians (Figures 2e and 3e).

The disparity between the highest and lowest groups for colorectal cancer screening across all stratifications widened over time except for age (Figures 2a to 2e). In contrast, the disparity for in-person visits for diabetes mostly followed the pattern of the indicators, and all decreased at study end compared to the start (Figures 3a to 3e).

Discussion

The COVID-19 pandemic disrupted overall primary care delivery in Ontario, resulting in missed and delayed care (Mangin et al. 2022). Our study documents and emphasizes the impact of the pandemic on a comprehensive range of quality-of-care measures in primary care. We also provided an equity lens to facilitate a deeper understanding of the shifts in quality of care associated with disparity. We found that preventive and chronic disease care that was dependent on in-person visits – namely, colorectal and breast cancer screening, retinopathy screening and in-person follow-up for people with diabetes – declined after the COVID-19 pandemic and still had not returned to the pre-pandemic baseline by study end. In contrast, physician continuity and statin prescribing among patients with diabetes remained the same as pre-pandemic baseline. High-risk prescribing decreased prior to the pandemic and that trajectory was maintained. The percentage of new patient enrollments decreased but returned to the pre-pandemic baseline by study end.

Our findings align with previous reports detailing the adverse impact of COVID-19 on diabetes care and cancer screening in Ontario shortly after its onset (Moin et al. 2022;

FIGURE 2. Stratifications for colorectal cancer screening

Figure 2a: Colorectal cancer screening by sex

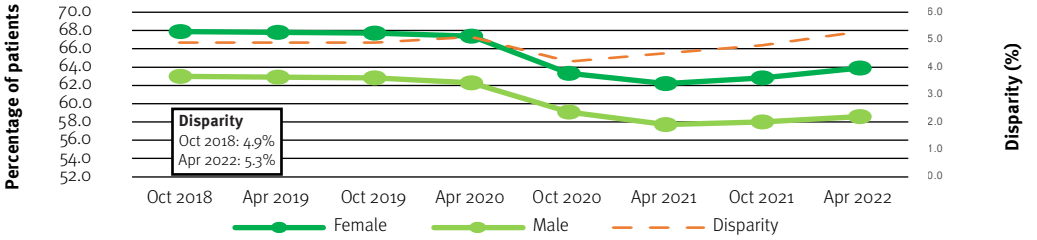


Figure 2b: Colorectal cancer screening by age

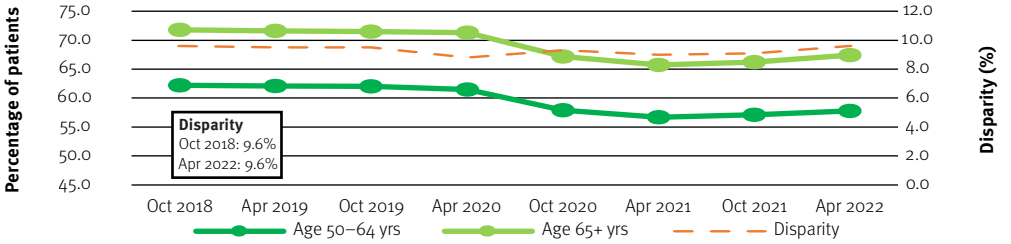
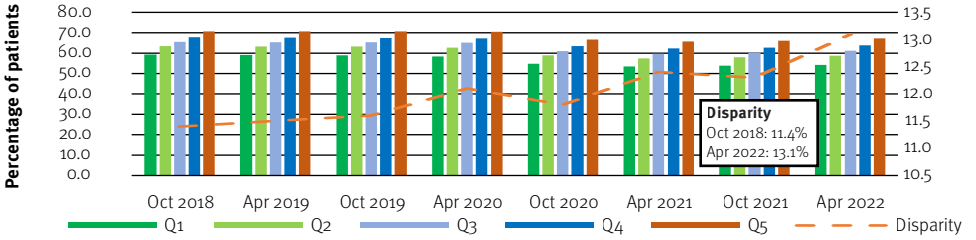


Figure 2c: Colorectal cancer screening by income quintile



Q = quarter.

Figure 2d: Colorectal cancer screening by rurality

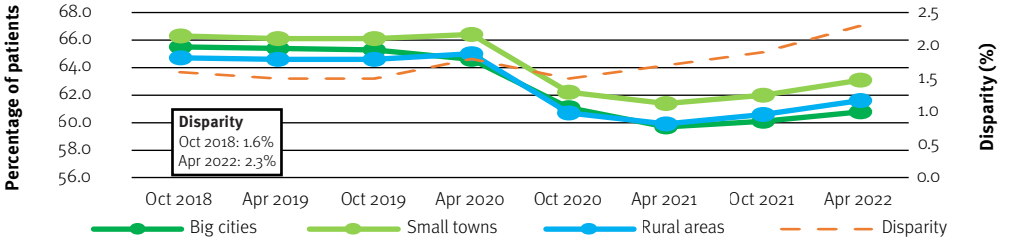


Figure 2e: Colorectal cancer screening by recent registration

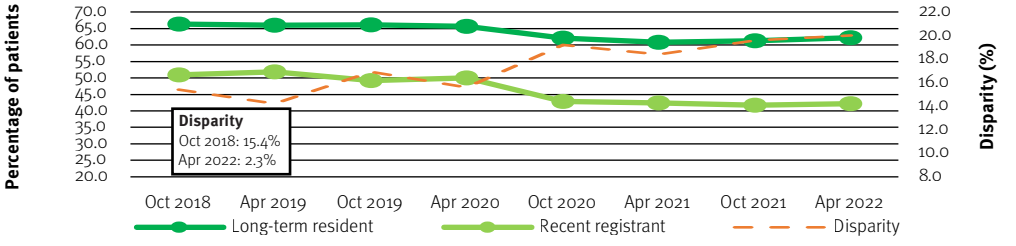


FIGURE 3. Stratifications for in-person visits for diabetes

Figure 3a: In-person follow up in diabetes patients by sex

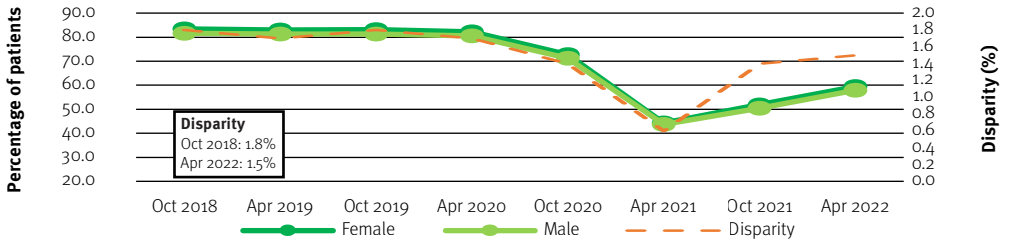


Figure 3b: In-person follow up in diabetes patients by age

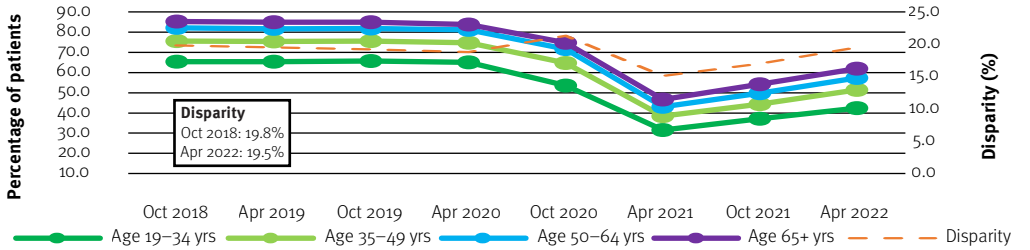
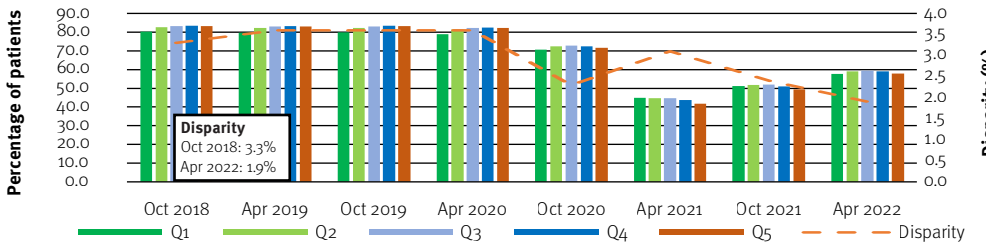


Figure 3c: In-person follow up in diabetes patients by income quintile



Q = quarter.

Figure 3d: In-person follow up in diabetes patients by rurality

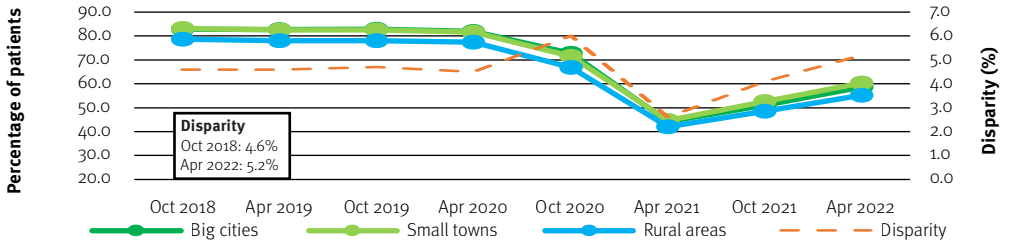
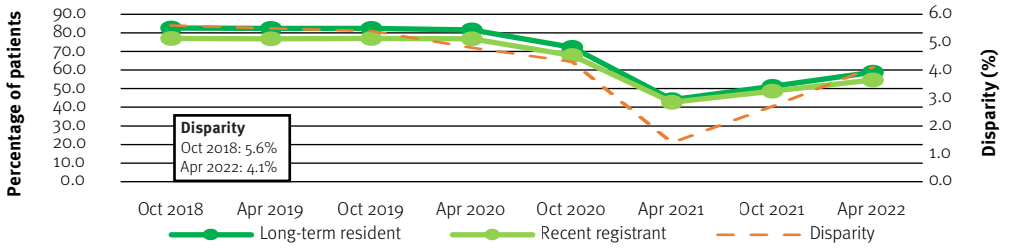


Figure 3e: In-person follow up in diabetes patients by recent registration



Walker et al. 2021). However, we could also demonstrate that such impacts have persisted for at least two years following the pandemic. Our findings also highlight the importance of targeted catch-up of preventive and chronic condition management that is contingent on in-person visits (Stephenson et al. 2021) in family practice and other outpatient settings, such as optometry offices. The total number of primary care visits rebounded to pre-pandemic levels by fall 2021, but 49% of the visits remained virtual (Kiran et al. 2023). The sustained drop in in-person visits is likely related to many factors, including provincial guidance, patient preferences for care given circulating COVID-19, availability of personal protective equipment and deferral of non-acute concerns (Glazier et al. 2021; Kiran et al. 2022).

It was reassuring that many aspects of care that did not require an in-person visit were maintained. For example, prescription patterns for opioids and statins remained stable and were not contingent on in-person visits. Colorectal cancer screening was an exception. Screening for colorectal cancer declined over the pandemic and most disparities widened despite a provincial screening program that distributes fecal immunochemical testing (FIT) via mail (Cancer Care Ontario n.d.); family physicians could assess the need for a FIT virtually and order a kit to be mailed to the patient's home. There were known disparities in colorectal cancer screening for new immigrants and people in low-income neighbourhoods even before the pandemic (Kiran et al. 2017). Reasons vary from competing priorities, histories of trauma, cultural norms to lack of access to primary care (Honein-AbouHaidar et al. 2016; Kiran et al. 2016; Lofters et al. 2020). The widening disparities underscore the importance of ensuring that catch-up efforts prioritize recent registrants, most of whom are new immigrants, and low-income neighbourhoods (Persaud et al. 2021; Vanden Bossche et al. 2023). Targeted approaches are also needed for males, those under 65 years of age, and people from rural areas given their relatively low screening rates. We found that the pandemic did not impact the elderly differently from younger patients, with minimal changes in disparities for both colorectal cancer screening and in-person visit for diabetes.

Data suggest that the number of people without a family doctor in Ontario has increased since the pandemic (Lavergne et al. 2023). Our study found that the percentage of new enrollments initially declined but went back to baseline. However, even the temporary decrease in new enrollments was likely enough to create a backlog of unattached patients. The pandemic may have also created more churn in the system, with more people moving, which may require an even higher proportion of new enrollments to keep people attached to primary care (Thomson Reuters 2022). In keeping with our study findings, recent data suggest that the number of patients without a regular family doctor in Ontario has increased substantially over the pandemic, from 1.8 million in 2020 to 2.3 million in 2023 (OCFP 2023). Research has also demonstrated that a lack of a regular family physician is a major determinant to receiving recommended preventive and chronic disease care and is worse for patients who have lower income or are new to Canada (Kiran et al. 2016). Improving attachment to primary care should be a key priority (Kiran 2022).

Limitations

This study had some limitations. We only had aggregate quality-of-care data available so were unable to do a patient-level analysis. We did not have sufficient time points to do a more rigorous statistical analysis for trend changes. We only assessed quality-of-care indicators that could be measured accurately using administrative data so were missing important aspects of care such as cervical cancer screening (some of which are processed in hospitals and not captured in administrative data), blood pressure readings and smoking counselling. We did not assess patient experience or outcomes or assess the specific impact of virtual visits on the quality of care. Finally, we did not have access to data from other provinces so could not assess whether people received care elsewhere – a possibility given out-of-province migration during the pandemic (Bruce 2022).

Conclusion

COVID-19 had a variable impact on primary care quality. Preventive and chronic disease care that was dependent on in-person visits declined but quality of care was maintained for aspects that were not dependent on in-person visits. An exception was colorectal cancer screening, which declined through the pandemic with worsening of existing disparities related to recent registration and income. Targeted catch-up efforts are needed to support marginalized groups in accessing recommended care and match unattached patients to a primary care clinician.

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RESEARCH PAPER

Reasons for High Emergency Department Use Among Patients With Common Mental Disorders or Substance-Related Disorders

Les raisons expliquant le recours fréquent aux services d'urgence par les patients souffrant de troubles mentaux courants ou de troubles liés aux substances psychoactives

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Abstract

Aims: This study examined the reasons for high emergency department (ED) use among patients with common mental disorders (MDs), substance-related disorders (SRDs) or co-occurring MDs-SRDs.
Method: Following content analysis, 42 high ED users (three-plus visits/year) recruited in two Quebec EDs were interviewed.
Results: The reasons included barriers to outpatient care, patient disabilities and professional practices. Patients with SRDs trust outpatient services less, those with MDs had important unmet needs and those with MDs-SRDs faced care coordination issues.
Conclusion: Improvements such as ED use monitoring, consolidating MD-SRD practices and continuous training are needed in EDs and outpatient services to enhance access and continuity of care.

Résumé

Objectifs : Cette étude examine les raisons de recours fréquent aux services d'urgences (SU) chez les patients ayant des troubles mentaux courants (TMC), des troubles liés aux substances psychoactives (TLS) ou des TMC-TLS concomitants.
Méthode : Fondée sur l'analyse de contenu, les données de 42 grands utilisateurs des SU (plus de trois visites/an), recrutés dans deux SU du Québec, ont été collectées.
Résultats : Les raisons d'utilisation fréquente sont liées, notamment, aux obstacles d'accès aux soins ambulatoires, aux limitations des patients et aux pratiques professionnelles. Les patients avec des TLS font moins confiance aux services ambulatoires, ceux avec des TMC ont des besoins importants non satisfaits et ceux avec des TMC-TLS sont confrontés à des problèmes de coordination des soins.
Conclusion : Des améliorations telles que la surveillance de l'utilisation des SU, la consolidation des pratiques pour les TMC-TLS et la formation continue sont nécessaires dans les SU et les services ambulatoires pour améliorer l'accès et la continuité des soins.

Introduction

Emergency departments (EDs) are used as a first or last service resort when seeking help for acute conditions or when outpatient resources have been exhausted (Fleury et al. 2019; Navas et al. 2022). A significant number of patients account for a disproportionate amount of ED use; they are referred to as high ED users, defined by three-plus ED visits/year – the lowest standard for high ED use (Pines et al. 2011). High ED use is costly and contributes to ED overcrowding (Morley et al. 2018). Patients with mental disorders (MDs), including substance-related disorders (SRDs), are often reported as high ED users (Moe et al. 2021; Roennfeldt et al. 2021). Most studies on high ED users with MDs are based on hospital health records and investigate socio-demographic and clinical patient characteristics predicting high ED use (Kromka and Simpson 2019). High ED users with MDs are more likely to

have a low income, limited social networks, multi-morbidity, recurring health issues and serious MDs (e.g., schizophrenia) or co-occurring MDs-SRDs (Casey et al. 2021).

Few qualitative studies have explored the reasons why patients with MDs repeatedly use EDs. For these patients, the decision to use the ED instead of outpatient care is rarely taken lightly, nor perceived as desirable (Schmidt et al. 2018). Reasons for disproportionate ED use include difficulty in accessing effective treatment (Wise-Harris et al. 2017), limited alternatives to ED use when in crisis (Aagaard et al. 2014), previous negative outpatient experiences and lack of continuous care (Vandyk et al. 2018). Patients included in these studies usually experienced acute mental distress or complex health conditions (Wise-Harris et al. 2017) or displayed disruptive behaviours that led relatives, the police or other clinicians to refer them to EDs (Poremski et al. 2020).

To our knowledge, no previous qualitative study has investigated reasons for high ED use among patients who exclusively have common MDs (e.g., anxio-depressive disorders). Only two have studied patients with SRDs (McCormack et al. 2015; Parkman et al. 2017) and they found that few were inclined to receive SRD treatments, mostly because of motivational barriers or engagement issues. Common MDs are the most prevalent type of MDs (McGrath et al. 2023), though MDs are known to often co-occur with SRDs (Huỳnh et al. 2020). MD treatments, usually provided in primary care, have been consolidated in current reforms (NCCMH 2011). Historically, services have, however, focused on patients with serious MDs (Fleury et al. 2016). Patients with co-occurring conditions are found to be more difficult to treat, turning alternately to mental health or addiction services without much integration between these (Gaulin et al. 2019). Ascertaining reasons for high ED use, especially for patients with common MDs, SRDs or MDs-SRDs, could offer insights to improve services, especially as these patients may display different needs and different patterns of service use and experience different barriers to care.

This study is based on a conceptual framework adapted from an existing implementation model (Fleury et al. 2019) integrating mental healthcare system features (adequacy, accessibility and continuity of care), patient profiles (urgent and recurrent biopsychosocial problems, support systems and individual disabilities) and professional practices (knowledge of and comfort in treating MDs or SRDs, quality of exchanges with patients and collaboration between clinicians) influencing ED use. It examined reasons for high ED use by comparing the perspectives of patients with common MDs, SRDs or co-occurring MDs-SRDs and aspects that patients identified as helpful in decreasing ED use.

Methodology

Study context

In Quebec, health and social services are mostly public, covering medical and some psychosocial services (Martin et al. 2018). Primary mental healthcare relies on general practitioner clinics and community healthcare centres (mainly providing psychosocial services). The mental healthcare system is complemented by helplines, crisis centres, suicide prevention

centres and detox centres mostly operated by community-based organizations, and counselling services dispensed by psychologists mostly working in private practice. Specialized care is provided in psychiatric departments of general or psychiatric hospitals or, in the case of SRDs, in addiction treatment centres (MSSS 2022). Patients access public MD-specialized services mostly through one-stop services in community healthcare centres.

Study setting, data collection and analytical dimensions

Data from this qualitative study came from a larger mixed-methods research study on high ED users with MDs, conducted in Quebec health territories serving roughly one-fourth of the province's population (Fleury et al. 2020). Two health territories were selected for the present study, including a psychiatric ED in a university region with specialized care, teaching and research mandates and a general ED from a peripherical region with MD staff but less specialized care. Participants had to be 18 years or older, be high ED users (three-plus ED visits/year for MD or SRD issues), speak French or English, be functional enough to be interviewed – if intoxicated or in psychosis, their interview was postponed – and grant the research team access to their medical records. Randomized recruitment was done between March 1, 2021, and May 13, 2022, through a list of 1,008 ED users (identified by ED staff) meeting the aforementioned criteria. Of the first 308 patients reached, 247 agreed to be referred to the research team and be contacted for an interview. To be selected for the qualitative study, patients had to have common MDs or SRDs only or co-occurring common MDs-SRDs. All patients with such diagnoses were included in this study, with an equal number of patients coming from each of the two ED sites. Patients provided prior consent and received a $20 compensation. The multisite protocol was approved by the human research ethics board of the Douglas Mental Health University Institute.

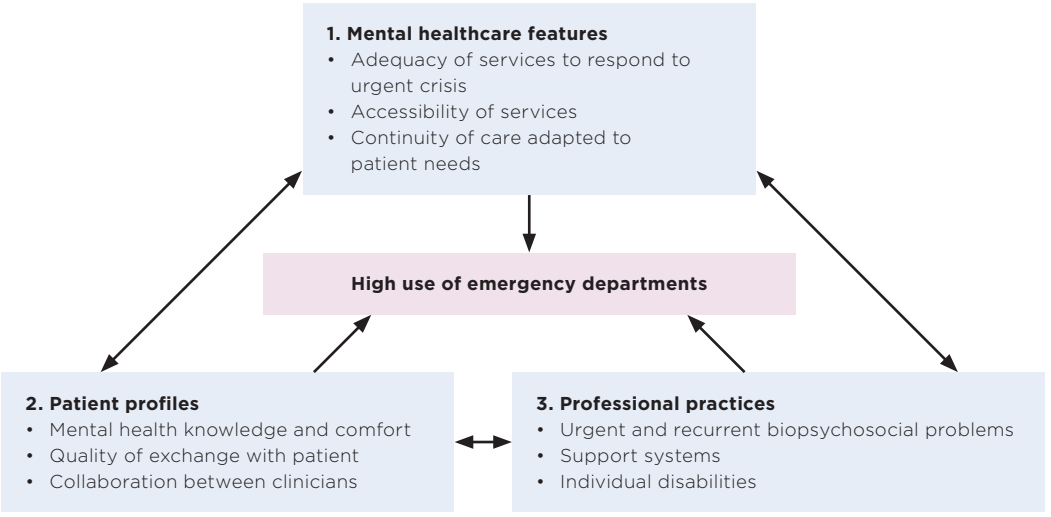
Phone interviews for the larger project lasted about one hour. They included closed and open-ended questions and were conducted by trained staff using an online platform. Medical records for 12 months preceding the interviews were used to confirm high ED use and MD or SRD diagnoses. ED use was measured using data from an ED use database (BDCU [*banque de données communes des urgences*]) (Institut national de santé publique du Québec n.d.), while MD or SRD diagnoses came from a hospitalization database (MED-ECHO [*maintenance et exploitation des données pour l'étude de la clientèle hospitalière*]) (Institut de la statistique du Québec n.d.). Common MD and SRD diagnosis codes were based on the *International Classification of Diseases, Tenth Revision* (ICD-10) (CIHI 2022). Common MDs included anxiety, depressive, adjustment and attention deficit/hyperactivity disorders; and SRDs included alcohol and drug use – induced, abuse, addiction, intoxication or withdrawal (Appendix 1, available online at www.longwoods.com/content/27333). As SRDs tend to be underdiagnosed in medical records (Huỳnh et al. 2021), two standardized scales were included in the interviews and merged with results from medical records: the Alcohol Use Disorders Test (AUDT) (Bohn et al. 1995) and the Drug Abuse Screening Test-20 (Skinner 1982) (see Appendix 2, available online at www.longwoods.com/content/27333).

Self-reported quantitative patient socio-demographic variables included sex, age group, education, civil and employment status, personal income and housing situation. The open-ended questions (Appendix 2) took about 20 minutes to complete out of the one-hour interview time. The interview guide was validated by a steering committee of ED experts, including clinicians and managers, created to support the study design. The open-ended questions, which were recorded and then transcribed, focused on reasons explaining high ED use, the other services patients had used before the ED, recommendations to avoid high ED use, services that would better respond to their needs and what most helped with recovery.

Analyses

Descriptive analyses were produced from the quantitative data, while content analysis was used for the qualitative data, allowing themes to emerge (Vaismoradi et al. 2013). The process involved six steps: (1) familiarization with the data; (2) generating initial codes and the analysis grid; (3) combining codes into themes; (4) reviewing verbatim transcripts for consistency and completeness; (5) presenting and describing themes clearly, with relevant quotes; and (6) interpreting the data. The aforementioned conceptual framework guided the analysis, categorizing the reasons contributing to high ED use into mental healthcare features, patient profiles or professional practices (Figure 1). Themes were examined according to their frequency and percentage of patients reporting them. Data saturation was reached when themes were found to represent enough of the data (Saunders et al. 2018). Study rigour was ensured by combining different strategies: training and close monitoring of the research team, research tools validation by the steering committee and keeping a reflective journal (Patton 2015). Three team members produced the analysis involving an inter-judge agreement on 10% of the verbatim transcripts to minimize the impact of personal biases.

FIGURE 1. Conceptual framework of reasons reported by patients for high emergency department use



Results

Of the 247 ED users referred to the research team, 31 were unreachable, 61 declined to participate and 155 had completed the larger study's interview – a 72% response rate. Of these, 42 had common MDs and/or SRDs (n = 21 per site) and were classified in one of three groups: 43% (n = 18) common MDs only; 40% (n = 17) SRDs only; and 17% (n = 7) co-occurring MDs-SRDs. Of these patients, 43% were women, median age was 42 years, 48% had a post-secondary diploma, 74% were single, 74% were on welfare and 10% were living in supervised housing (Table 1). About half the patients with MDs reported trying to reach a general practitioner before using the ED. In contrast, very few patients with SRDs or co-occurring MDs-SRDs reported seeking help in outpatient services. Reasons leading to high ED use and aspects identified as helpful in decreasing such use are summarized in Table 2. Quotations from patients are presented in Table 3. Both tables are available online at longwoods.com/content/27333.

Mental healthcare system

For all patients, the main reasons for high ED use were associated with accessibility to the mental healthcare system and its adequacy to respond to urgent MD or SRD crises. The ED was considered the most accessible (free, open 24/7), responsive, safe and appropriate service for patients facing a crisis. Many talked about the lack of alternative services; other services were usually closed between 5:00 p.m. and 9:00 a.m. and on weekends and lacked resources. Patients were often referred to the ED by relatives or outpatient care providers. Most participants had trouble accessing regular outpatient care, such as family doctors, social workers, psychiatrists and free public psychologists. For patients with MDs and MDs-SRDs especially, procedures to access MD services via one-stop services were found to be complex and lengthy, with wait times of over six months not being uncommon.

Most patients mentioned lack of continuity of care as another reason for high ED use, with many lacking a regular care provider offering close follow-up care. Patients with a regular care provider often felt follow-up care was not adapted to their needs and that their provider's responses to urgent requests were not swift enough. Patients did not consider this optimal for recovery, as it left them alone and could worsen their health conditions. The few patients who received public psychosocial counselling criticized the limited number of sessions available to them.

Contrasts emerged in patients with SRDs and MDs-SRDs who were more anxious to receive adapted follow-up care from a trusted provider. They found having to deal with different clinicians (general practitioners, MD and SRD specialists) and to constantly repeat their personal history disruptive, which negatively impacted their hopes of progress and recovery. Outpatient services that, when available, were identified as helpful included psychosocial services for patients with MDs and SRDs and specialized addiction treatments for those with SRDs or MDs-SRDs, along with case management for the latter.

TABLE 1. Socio-demographic characteristics of patients with common MDs, SRDs or co-occurring common MDs-SRDs

	Common MDs		SRDs		Co-occurring MDs-SRDs		Total	
	n = 18	42.86	*n* = 17	40.48	*n* = 7	16.67	*n* = 42	100
	N	%	*N*	%	*N*	%	*N*	%
Sex								
Women	8	44.44	6	35.29	4	57.14	18	42.86
Men	10	55.56	11	64.71	3	42.86	24	57.14
Age (years)								
19–35	11	61.11	3	17.65	1	14.29	15	35.71
36–73	7	38.89	14	82.35	6	85.71	27	64.29
Education								
Secondary	11	61.11	8	47.06	3	42.86	22	52.38
Post-secondary	7	38.89	9	52.94	4	57.14	20	47.62
Civil status								
Single, separated, divorced	10	55.56	14	82.35	7	100	31	73.81
Common-law, married	8	44.44	3	17.65	0	0	11	26.19
Employment status								
Work or study	2	11.11	3	17.65	1	14.29	6	14.29
On welfare	16	88.89	11	64.71	4	57.14	31	73.81
Retired	0	0	3	17.65	2	28.57	5	11.9
Personal income ($/year) (*n* = 39)								
0–19K	1	6.25	7	46.67	3	42.86	11	28.95
20–39K	6	37.5	5	33.33	3	42.86	14	36.84
40+K	9	56.25	3	20	1	14.29	13	34.21
Housing situation								
Owned housing	7	38.89	2	11.76	1	14.29	10	23.81
Rented housing	11	61.11	12	70.59	5	71.43	28	66.67
Supervised housing	0	0	3	17.65	1	14.29	4	9.52

K = thousands of Canadian dollars; *N* = number of patients within a group.
MD = mental disorder; SRD = substance-related disorder.

Patient profiles

Patient profiles explaining high ED use were mostly associated with urgent and recurrent biopsychosocial problems. Patients viewed their high ED use as inevitable considering their multiple, complex health issues. Most reported ED visits were due to psychological and physical distress – panic attacks and acute gastro-intestinal issues, among others. More than half reported intoxication problems or issues with medication, while a few had social problems – grievances and interpersonal conflicts, among others. EDs were used as a last resort when patients could no longer self-regulate and had no one else to turn to. Most participants talked about lacking emotional and psychological support from their relatives, clinicians or peers.

Compliance aside, patients with MDs complained more about medication being prescribed too hastily, with no adequate information nor consideration for their overall conditions, which could lead to adverse events.

Disabilities or limitations related to the patients' conditions and lack of health literacy were also driving high ED use. Most struggled with impairment symptoms linked to their conditions (loss of stamina/autonomy) and had trouble recognizing and communicating their symptoms, triggers and needs. That was especially true of patients experiencing new acute symptoms and patients with ongoing SRDs or MDs-SRDs. Many of those participants explained how feeling misunderstood and stigmatized isolated them, leading to periods of withdrawal, low self-esteem and risky behaviours and how they would wait for their conditions to become acute and overwhelming before seeking help, all of which could heighten ED use. More contrast emerged from patients with SRDs who were especially preoccupied about feeling autonomous, to the best of their ability, and anxious about returning to their previous living environment after addiction treatment. This tension was a key reason for relapsing and led to repeated ED use.

For all patients, having a non-judgemental social network was viewed as helpful for maintaining good mental health and reducing ED use. Proper medication, providing patients with more information on their conditions and available resources (especially for those with MDs) and helping them develop symptom management capabilities were identified as key components for decreasing ED use.

Professional practices

High ED use reasons linked to professional practices were mostly associated with the patients' perception of the clinicians' lack of knowledge or comfort toward treating MDs and SRDs. This was especially true of general practitioners, nurses and emergency doctors and in complex crises, which favoured revolving-door services and discouraged patients. About half the patients felt their biopsychosocial conditions were not fully evaluated and care not appropriately planned for their multiple needs. They felt they were being evaluated for acute symptoms only, which did not support recovery and led to high ED use. It often took several outpatient or ED visits to be referred to appropriate outpatient services.

Patients were also critical of the quality of communication with some clinicians, mentioning that they felt judged, not taken seriously, were hastily sent home, thus contributing to the stagnation of their conditions and high ED use. Patients with SRDs or MDs-SRDs particularly felt they were being treated differently. Clinicians were perceived as working in silos, leading to patient confusion on prognosis and treatments and subsequent high ED use. Destigmatization and better-informed assessments were identified as key drivers to improving professional practice. Finding trustworthy, stable healthcare providers who did not judge patients and receiving patient-centred treatments that catered to their needs contributed to lower ED use.

Discussion

This qualitative study explored reasons for high ED use in patients with MDs, SRDs or co-occurring MDs-SRDs. Factors leading to high ED use were mostly linked to mental healthcare features, followed by patient profiles and professional practices. The main reasons found in this study were close to those uncovered in previous ones, which included all types of MDs and SRDs (Poremski et al. 2020; Wise-Harris et al. 2017). ED use was mainly driven by a complex interplay of factors whose cycles led to high ED use. A few notable differences were identified in this study's results, distinguishing needs and barriers to recovery for patients with MDs, SRDs or co-occurring MDs-SRDs. Patients with MDs felt that they should receive more comprehensive MD care from general practitioners and psychosocial resources, integrating patient-centred care and self-management strategies (Menear et al. 2020). Echoing a previous study (McCormack et al. 2015), patients with SRDs showed less interest and trust in outpatient services, preferring to self-manage until needing acute care. Patients with SRDs, including those with MDs-SRDs, were lacking integrated care and experiencing more stigmatization and lower self-esteem (Huỳnh et al. 2020).

Overall, high ED use was mostly found to be justified by insufficient access to outpatient care, lack of ED alternatives in outpatient care when in crisis and insufficient care continuity. Underlying reasons explaining insufficient access to appropriate care by patients echoed challenges reported in other studies on mental healthcare systems, such as insufficient resources, restrictive opening hours and poor care integration (CMHA 2023). Several past reforms have aimed to improve access, continuity and quality of mental health services; mental health services were integrated with primary care in 2005 (Fleury et al. 2016). However, requests for help exceed available resources, and long waiting lists prioritizing the least functional patients persist (Vérificateur général du Québec and MSSS 2023), which explains why patients are frequently being referred to the ED. In Quebec, it may be appropriate to increase the mental healthcare budget, which represents 5–7% of the province's global healthcare budget, to a figure closer to 13% as in the UK (Bartram 2019). Outpatient care, community-based services and early interventions (Colizzi et al. 2020) could also be consolidated.

Even patients who received outpatient services often felt that these lacked patient-centred (Walsh et al. 2022) and recovery-oriented treatments (Mousavizadeh and Bidgoli 2023), thus contributing to negative care experiences, distress and high ED use. While studies have shown that patients with common MDs often favoured psychosocial services over medication (Casey et al. 2021) and that public coverage for psychotherapy has proven effective in countries such as the UK and Australia (Clark 2018; Cromarty et al. 2016), most of these services are not covered in Quebec (Vasiliadis et al. 2015). Psychosocial services, including psychotherapy, should be more accessible to the province's population, as an approach combining psychotherapy and medication is often recommended (van Weeghel et al. 2019).

Study results also outlined the overall vulnerability of high ED users who were mostly poor, had limited networks, a low sense of self-efficacy and a strong feeling of hopelessness.

These patients' difficulty to prevent, recognize or communicate distress were commonly mentioned as barriers to recovery, leading to high ED use – as shown in other studies (Slankamenac et al. 2020). As previously noted (Schmidt et al. 2018), patients turned to the ED when they were no longer able to self-regulate and sought emotional relief (feeling safe and heard), short-term solutions (diagnosis and medication) and recovery planning. To prevent ED use, primary care organized according to the chronic care model (Wagner et al. 2001), including better MD and SRD detection, should be implemented, with integration of the stepped-care model along with patient symptoms management training. EDs should better monitor high ED users and embrace known strategies to reduce high ED use – e.g., individual care plans, case management, peer-support initiatives (Gabet et al. 2023) and short-stay crisis units (Gabet et al. 2020; Wheeler et al. 2015). Several new ED strategies are being deployed in Quebec's current mental healthcare plan (MSSS 2022) to reduce acute care use (e.g., short-stay crisis units [Anderson et al. 2022]), but no initiatives are promoted or prioritized to reduce high ED use. Addiction liaison teams (Blanchette-Martin et al. 2016; Musgrave et al. 2018) that use motivational approaches (Schwenker et al. 2023) could be more consolidated in EDs and better integrated with other key community partners to reinforce treatment adherence among patients with SRDs.

Providing adequate outpatient care was also found to be a key factor protecting against high ED use. In this study as in previous ones (Gentil et al. 2021; Vandyk et al. 2018), many patients felt misunderstood and not properly evaluated by primary care clinicians, which contributed to treatment delays. Studies exploring clinician perspectives on high ED users also reported challenges regarding complex case assessments, mentioning insufficient time spent with patients, lack of best practices guidelines and the inclination to transfer patients to more specialized care (Bodenmann et al. 2021; Li et al. 2022). These findings support the need to develop evidence-based clinical practices in line with Quebec's From Self-Care to Psychotherapy program (MSSS 2021) for MD management and continuous training on MDs and SRDs (Karazivan et al. 2017) for primary care clinicians and other psychosocial care providers. Teamwork (Rosen et al. 2018) and collaborative care between psychiatrists and primary care clinicians (Fleury et al. 2021) may also be better implemented to address complex biopsychosocial issues. Ultimately, EDs should not replace outpatient care.

Limitations

This study has limitations. First, given the stigma patients with MDs or SRDs encounter, participants may not have disclosed all pertinent information and memory bias may have hindered such information. Second, the studied EDs had specialized psychiatric staff and were in large urban territories, limiting generalization to other EDs or areas. Third, the perspectives of high ED users' relatives and clinicians were not accounted for; seeking those perceptions could provide additional insights. Finally, the study results may not be generalizable to other mental healthcare systems, notably those without universal healthcare coverage.

Conclusion

This study found that patients identified multiple barriers to outpatient care, disabilities related to their conditions and professional practices that explained their high ED use. Patients with MDs were faced with important unmet needs, while patients with SRDs mostly differentiated themselves by their lack of trust in outpatient services, and those with MDs-SRDs especially struggled with care coordination issues. This led to potentially disruptive cycles in patient recovery, with the ED being used to alleviate distress and inadequate care. Study findings support the need to improve outpatient services for high ED users. Greater investments are needed in Quebec's mental healthcare system to enhance access to and continuity of diversified care, especially as it pertains to psychosocial services. Extending teamwork and collaborative care with continuous training may help consolidate mental health evidence-based practices in primary care, contributing to the reduction of ED use. High ED users might be monitored more extensively and strategies such as integrated MD-SRD treatments deployed to help these patients. Breaking the cycles leading to high ED use will require efforts from all parties involved in the mental health system.

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Ethics Approval

The Douglas Mental Health University Institute Ethics Committee approved the study protocol. The analyses reported in this paper were also approved by the Comité d'éthique de la recherche en science de la santé of the University of Montreal. Research procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2008.

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RESEARCH PAPER

Conflicts of Interest of Canadian Medical School Deans: A Cross-Sectional Study

Les conflits d'intérêts des doyens des facultés de médecine du Canada : une étude transversale

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Abstract

Background: Medical school deans wield considerable influence over research, clinical and educational missions at their institutions. This study investigates conflict of interest (COI) of Canadian medical school deans.

Method: The websites of all 17 Canadian medical schools were searched for any mention of relationships between deans and pharmaceutical or medical device companies.

Results: No COIs were discovered for 11 of the deans. Six had COIs, including participating in research funded by pharmaceutical companies and received consulting and speaker fees.

Discussion: A minority of deans had COIs with healthcare industry companies. Whether deans' COIs affect policies at the medical schools they lead should be the subject of further investigation.

Résumé

Contexte : Les doyens des facultés de médecine exercent une influence considérable sur les missions de recherche, cliniques et éducatives de leurs établissements. Cette étude porte sur les conflits d'intérêts des doyens des facultés de médecine du Canada.

Méthode : Les sites Web des 17 facultés de médecine du Canada ont fait l'objet d'une recherche pour toute mention des relations entre les doyens et les sociétés pharmaceutiques ou les entreprises de dispositifs médicaux.
Résultats : Aucun conflit d'intérêts n'a été ainsi découvert pour 11 des doyens. Six d'entre eux présentaient une situation de conflits d'intérêts, notamment la participation à des recherches financées par des sociétés pharmaceutiques et la perception d'honoraires pour des consultations ou des conférences.
Discussion : Une minorité de doyens présentent une situation de conflits d'intérêts en lien avec des entreprises du secteur de la santé. La question de savoir si les conflits d'intérêts des doyens influent sur les politiques des facultés de médecine qu'ils dirigent devrait faire l'objet d'une enquête plus approfondie.

Introduction

Medical school deans wield considerable influence over all aspects of the institutions that they lead, including research, clinical and educational missions. By virtue of their authority, their actions (or non-actions) can play a significant direct and indirect role in defining the relationships between their institutions and companies in healthcare industries, primarily pharmaceutical and medical device companies; in teaching activities; and in the research done by faculty in their schools.

Relationships between deans and for-profit healthcare industries constitute a conflict of interest (COI), where a COI is defined as "a risk that [an individual's] professional judgment or actions regarding a primary interest … will be unduly influenced by a secondary interest (such as financial gain)" (IOM 2009: 6). The critical issue is whether COIs will consciously or subconsciously bias the decisions that the deans take, given that the missions of medical schools and industries are substantially different (Table 1). The lack of disclosure of COIs can create the impression that decisions or actions were based on the COI, whether that conclusion is accurate or not, and ultimately erode public confidence in an institution.

TABLE 1. Differences in the missions of medical schools and for-profit healthcare industry companies

Mission of medical schools	Mission of for-profit healthcare industry companies
Conduct research to understand the mechanisms of disease and human functioning	Develop new products that will generate profits for the company
Train students to become doctors who will care for patients	Encourage students to think about carrying out research on the company's promising products once they are in independent practice
Promote evidence-based medicine and independent critical judgement by students	Develop marketing strategies to improve sales and profits

Source: Adapted from Lo 2010.

Previous research from 2011 has shown a wide range in the strength of COI policies at Canadian medical schools (Shnier et al. 2013). In each policy, 12 items were examined, including those on accepting gifts from industry, restrictions on participation in industry-funded speaking relationships and speakers' bureaus, restrictions on on-site education activities and disclosure of COIs by faculty. Only five of 17 schools had a score of greater than 50%, and when individual item scores from all schools were combined, the highest mean score was 0.9 out of 2 (Shnier et al. 2013). These scores suggest that there may be a lack of control about how industry activities affect the functioning of medical schools.

COIs between people in leadership positions in medical schools and industries have been researched to some extent in the US (Anderson et al. 2014, 2015; Campbell et al. 2007; Freshwater and Freshwater 2011), but examination of this issue in other countries, including Canada, is non-existent. This study is a first step in investigating the COIs of Canadian medical school deans as one factor that may contribute to the relationship between the schools and healthcare industries. In addition, it looks at whether the COIs are publicly disclosed.

Method

The websites of all 17 Canadian medical schools were searched for the names of the deans, their biographical information, date of appointment, any mention of relationships with pharmaceutical or medical device companies, research by the deans that was funded by companies from those industries and COIs with companies from those industries. Searches for the same information about the deans and pharmaceutical and medical device companies were undertaken by entering the name of the dean and the phrase "dean x faculty of medicine" into a Google search. The first 20 sites were examined for any mention of relationships with healthcare companies. A search of PubMed between January 2012 and September 2023 scanned for any publications listing the dean as an author. These publications were read to look for funding sources for the research and any declared COIs (only a maximum of the five most recent publications for each dean are listed in Appendix 1, available online at www.longwoods.com/content/27349). Mergent Intellect was searched using the dean's name to look for whether a dean held an executive or board position at any healthcare-related company (Mergent Intellect n.d.). Mergent is a publicly accessible, web-based application offering business data for a collection of over 1.6 million private and public Canadian corporations. Finally, the websites of the medical schools were searched for the presence of COI policies, including whether COI declarations by faculty, including deans, were publicly available.

Bélisle-Pipon et al. (2018) developed a five-point ordinal ranking scale based on declared COIs to assess individuals' independence from industry, ranging from zero interaction = 0 (100% independent of industry) to employed by a pharmaceutical company or a pharmaceutical organization-representing industry = 5 (0% independent of industry) (Table 2). The scale was developed by examining the COIs declared by members of the Quebec's immunization

expert advisory committee on vaccines, grouping those COIs into eight broad types describing different types of payments that the experts received from industry and then using those eight types to modify a previous scale based on COIs of experts associated with the agri-food industry (Newton et al. 2016). No other similar scale exists for grading individuals' relationships with the pharmaceutical industry. The deans' COIs were ranked based on this scale. If their activities resulted in more than one score, then the highest score was used.

TABLE 2. Level of independence from industry

Ranking	Description of conflict of interest
0	Zero interaction (100% independent of industry)
1	Reimbursement of travel or registration fees for a congress from a private company
2	Research funding from a private company Research funding awarded to an affiliated institution or organization
3	Honoraria for lectures or presentations
4	Honoraria as a consultant Member of the board of directors Has investment in the capital of a private enterprise
5	Employed by a pharmaceutical company or an organization representing industry (0% independent of industry)

Source: Bélisle-Pipon et al. 2018.

Only publicly available information was gathered based on the principle that transparency around relationships with industry should be public knowledge (Rosenthal and Mello 2013).

All information was entered into an Excel spreadsheet. All data were gathered between September 9 and 10, 2023, by a single individual. Ethics approval was not required since all the data were public. The methods are reported according to the STROBE reporting guidelines (https://www.equator-network.org/wp-content/uploads/2015/10/STROBE_checklist_v4_cross-sectional.pdf).

Results

Deans were appointed between July 2014 and September 2023 (two were interim appointments). Six of the deans were women. Table 3 (available online at longwoods.com/content/27349) summarizes the COI information gathered from all four sources, the requirement for public disclosure and the ranking of independence from industry. No COIs were discovered for 11 of the deans. The full data are available in Appendix 1.

COI information on biographical webpages

The dean of Dalhousie University was a founding member and former chair of a research group focused on clotting disorders. He is still listed as a member of the research group. It is not clear whether this is a non-profit or for-profit enterprise, but its current website lists seven industry partners. The dean of McMaster University had been the leader of

an industry-sponsored research collaborative before his appointment. The dean of the University of British Columbia (UBC)'s Faculty of Medicine is a non-executive director of a contract-based research organization that provides consulting and outsourced development and commercialization services to pharmaceutical, biotechnology, medical device and government and public health organizations.

COI information from Google searches

The UBC dean who was associated with the contract-based research organization was also a co-founder of a drug development company that went into liquidation in 2019.

COI information from PubMed

Four deans participated in research funded by pharmaceutical companies. Three deans declared COIs with multiple pharmaceutical companies within the past three years. These COIs consisted of consulting and speaker fees as well as payments for manuscript writing and educational events and receiving funding for research. The names of the companies that the deans had a COI with were only available from their declarations in their publications. The payment amounts were not disclosed. No publications could be found for one dean.

COI information from Mergent Intellect

No dean was a company executive or held a board position.

Requirement for public disclosure of COI information

All the medical schools had policies requiring faculty to report COIs, but none of the policies stated whether the information in the disclosures was publicly available or could be requested.

Ranking of independence from industry

Four of the deans received a rank of four out of five for dependence on industry based on one or more of the following criteria: receiving honoraria as a consultant and/or having investments in the capital of a private enterprise. Two other deans had a ranking of two due to receipt of research funding from industry.

Discussion

Six of the 17 deans had COIs with a healthcare industry company and for three of those deans, their relationships – including payments for various activities from multiple companies and the names of those companies – were only discovered through their declarations in publications. In the absence of any requirement by medical schools for public disclosure of COIs, finding detailed COI information, therefore, requires extensive searching. Four of the deans were ranked four on a scale of 0–5 for their dependence on industry, where zero is completely independent and five is completely dependent.

No dean held a leadership position (executive or board member) in a Canadian healthcare company. In this respect, the Canadian situation is different from that in the US. Out of 161 deans investigated in a study in 2009, nine were directors of 13 public companies, with two deans being directors of two companies and one dean being a director of four companies (Freshwater and Freshwater 2011). In another study, 19 of 47 pharmaceutical companies had at least one board member who concurrently held a leadership position at an academic medical centre (Anderson et al. 2014). Directors of 180 US healthcare companies were affiliated with 85 non-profit academic institutions, including 19 of the top 20 medical schools funded by the National Institutes of Health. Included among the directors were eight medical school deans or presidents (Anderson et al. 2015).

Medical school deans and COIs

Medical school deans cannot be expected to micromanage their institutions, but their leadership should set the overall tenor for their schools, including how to deal with the COIs that will inevitably arise in undergraduate and postgraduate teaching, the relationship with pharmaceutical companies and research. Over the years, the attitude of Canadian deans to COIs has been variable. According to Martin Hollenberg, the dean of medicine at UBC in the early 1990s, in the past, industry funding was viewed as a threat to the autonomy of universities but "the view is much more positive now" and the relationship was seen as "a true partnership with very high standards" (Rich 1992). At a meeting in 1992, he advocated for the formation of a joint university-pharmaceutical industry council to coordinate future planning about medical research in Canada (Rich 1992). A similar attitude came from John Kelton, the dean of McMaster's Faculty of Health Sciences in the mid-2000s. Although the university required full-time faculty members to declare their consultancy work for industry once a year, some McMaster researchers indicated that they were not required to reveal their pharmaceutical company connections to the university for things such as honoraria, speaking fees or consultancies. Kelton seemed to adopt a laissez faire attitude toward disclosures. When asked by a reporter from the *Hamilton Spectator* about relationships between faculty at the medical school and industry, his response was that "the university has never tried to keep track of faculty members' relationships [and] McMaster has no plans to change the way things are done" (Buist et al. 2005: A1). In 2015, Richard Reznick, the then dean of Queen's University, commented that when he became dean, "[t]he pendulum, with respect to industry-academic relationships had swung far to the left [i.e., were too restrictive], communications were not open, relationships were fractured" (Reznick 2015). His response was to recruit the previous chief executive officer of the Canadian subsidiary of GlaxoSmithKline to "proactively buil[d] relationships with senior executives of pharmaceutical and medical device companies" (Reznick 2015).

At the other end of the spectrum, the Temerty Faculty of Medicine at the University of Toronto released a set of guidelines for the ethical conduct of research in 1994. According to the guidelines, "Clinical researchers must not permit their clinical practices to be swayed by

such [industry] support and they must be free to think independently, to conduct research freely and to publish negative as well as positive results promptly" (Dahlin 1994: 9).

These attitudes about COIs are reflected in how they have impacted undergraduate teaching, the introduction of industry-funded research centres in medical schools and rules around how research is managed in them. Three separate studies of COI policies at Canadian medical schools done around 2010 all concluded that, in general, policies were relatively weak or, in many cases, non-existent (Beyaert et al. 2013; Mathieu 2012; Shnier et al. 2013). A 2019 survey by *Global News* seemed to indicate that some medical schools had strengthened their policies, but there was no formal scoring of their rigour (Hensley and Young 2019).

Undergraduate teaching

The relationship between the University of Toronto and Purdue Pharma was a highly public issue (Persaud 2014; News Staff 2010). Starting in 2000, the university has been giving a one-week course on pain management to all its health science students. Between 2002 and 2006, the course was funded by $117,000 in unrestricted educational grants from four pharmaceutical companies, including Purdue Pharma, makers of OxyContin (extended-release oxycodone). Up until 2010, students were given a book on pain management that was funded by Purdue (Jovey 2002). Roman Jovey, the editor of the book and an unpaid guest lecturer for the course, was on the speakers' bureau for Purdue.

At the University of Toronto, the Amgen Foundation is currently funding undergraduate medical and pharmacy students for 10-week hands-on research placements, a program that is enthusiastically supported by the university's vice-president of research and innovation (Temerty Faculty of Medicine, University of Toronto 2019).

Faculties of medicine have the primary responsibility for training medical students and play a major role in training house staff. Medical students and trainees who are exposed to policies that restrict interactions with the pharmaceutical industry are less reliant on information from companies once they are engaged in independent practice than those who attended institutions with no policies (Epstein et al. 2013; King et al. 2013; McCormick et al. 2001).

Pharmaceutical industry-sponsored research centres

When Sanofi-Aventis gave money to Queen's University in 2007 for a new obesity centre, Robert Ross, the Queen's University researcher who headed the obesity centre, said the money was coming to the university through an unrestricted educational grant and that "We have no accountability [to the company] … We make no reports. We have no advice to give them or them us … They do not sit on our council. They no not advise us on any issue" (Tripp 2007). Ross was a speaker for, on the advisory board of and received consulting fees from Sanofi-Aventis.

Novo Nordisk, the maker of semaglutide (Ozempic, Wegovy), an injectable drug for type 2 diabetes and obesity, is contributing $20 million (matched by $20 million from the University of Toronto) over a 10-year period for the establishment of the Novo Nordisk Network for Healthy Populations (U of T News 2021). The network is a partnership between the Dalla Lana School of Public Health, the Temerty Faculty of Medicine and the University of Toronto Mississauga and will "aim to find solutions that address the root cause of rising type 2 diabetes and other serious chronic diseases" (U of T News 2021). In 2022, Novo Nordisk was suspended from the industry association in the UK because of violating the industry code of marketing in its promotion of another drug for diabetes and weight loss (*AUTH/3525/6/21*).

Management of research

A mid-2000 survey of Canadian medical schools enquired about the presence of institutional policies on a series of topics relating to research, including royalties from the sale of the investigational product that is the subject of the research; equity interest or an entitlement to equity of any value in a non-publicly traded sponsor of human subjects research at the institution; ownership interest or an entitlement to equity in a publicly traded sponsor of human subjects research at the institution; and whether institutional officials with direct responsibility for human subjects research could hold a significant financial interest in a commercial research sponsor or investigational product. Only a minority of schools had policies on any of these issues (Rochon et al. 2010).

Systematic reviews have found that research sponsored by pharmaceutical companies is more likely to end in positive results and conclusions compared with sponsorship from any other source (Lundh et al. 2017), and the same conclusion applies to trials led by researchers who have a COI with the industry (Ahn et al. 2017). Since faculty members within medical schools are often the primary investigators in research funded by pharmaceutical companies, strong leadership in developing policies about how the research is conducted is needed to help ensure that the trials yield unbiased information.

Recommendations

In an editorial in the *Canadian Medical Association Journal* in 2010, Paul Hébert, the editor-in-chief, argued that medical school faculty should make a full public disclosure of the income generated from pharmaceutical companies in order to avoid a situation where revelations of undisclosed COIs could create public mistrust in the medical profession and its institutions (Hébert et al. 2010). That call has, so far, gone unheeded.

The US Institute of Medicine (now the National Academy of Medicine) recommended that the chairs and co-chairs of clinical practice guidelines (CPG) committees should be completely free of COIs because of their influence over the entire process of guideline development (IOM 2011). Medical school deans are in an even more authoritative position than

CPG chairs, and the same policy should apply to them and ideally more generally to all medical school faculty. In addition, Canada should follow the lead of the US (Rosenthal and Mello 2013) and some European countries (Ozieranski et al. 2021) and make disclosure of any transfer of value between industry and healthcare professionals a requirement. Ontario was poised to implement that kind of requirement until the 2018 election of a Progressive Conservative government stopped that initiative (Owens 2019).

Limitations

More extensive Google and publication searches may have uncovered further COIs, changing the ranking of the deans on the scale of independence from industry. Information was only gathered by a single individual and may have resulted in relevant information being missed. However, both these limitations would have decreased the number of COIs identified. The scale ranking independence from industry only has face validity and how the scores translate into actions and decisions by individuals has not been investigated. This study did not investigate how the various levels of COI independence of the deans translated into policies and actions at different medical schools. The results are not generalizable to other healthcare settings or healthcare professionals.

There is no evidence that the relevant deans were directly responsible for any of the three COI situations described earlier or even approved of them, but they occurred under their watch. Practices at medical schools may have changed in the interim since the various events occurred.

Conclusion

A minority of Canadian medical school deans have COIs with healthcare companies and most of those COIs are not found on their institutional biographical pages or through Google searches; they were only available after searching declarations in their publications. The COIs of the deans should be easily found and publicly available. Whether deans' COIs affect policies at the medical schools that they lead should be the subject of further investigation. Ideally, deans should not have any COI.

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