HEALTHCARE

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Politiques de Santé

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

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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.

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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.

Bien que *Politiques de Santé/Healthcare Policy* encourage l'envoi d'articles ayant un solide fondement théorique et innovateurs sur le plan méthodologique, nous privilégions la recherche appliquée plutôt que les travaux théoriques et l'élaboration de méthodes. La revue veut maintenir une saveur distinctement canadienne en mettant l'accent sur les questions liées aux services et aux politiques de santé au Canada. Nous publions aussi des travaux de recherche et des analyses présentant des comparaisons internationales qui sont pertinentes pour le contexte canadien.

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sdey@longwoods.com

DESIGN
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CREATIVE
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* * *

HOW TO REACH THE EDITORS AND PUBLISHER
Telephone: 416-864-9667; fax: 416-368-4443

ADDRESSES
All mail should go to: Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

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EDITORIAL

Health Services Research and Government's Spending on Healthcare Programs: A Welcome Misalignment?

Excluding capital projects, spending on hospitals, physicians and drugs makes up more than two thirds of provincial and territorial governments' healthcare spending (CIHI 2019). One expects that health services and policy research would be aligned with where the money flows and yet, there is a misalignment. For example, research as published by *Healthcare Policy*, is not so neatly aligned with provincial and territorial governments' healthcare spending patterns. In this issue, for instance, there are only two such articles – one related to medication adherence and cost, and another related to payment policy associated with a hospital's alternative level of care utilization. The previous issue of *Healthcare Policy* was similarly focused, with only two articles the study settings of which were primary care.

What does this misalignment mean? Is something important missing between research and governments' emphases?

There are several possible reasons for the mismatch that bear careful evaluation: Canadian hospital-, physician- and drug-related health services and policy research is being published elsewhere; these three sectors are not as attractive to researchers because there is little policy movement in them; provincial and territorial governments have not aligned their research imperatives with local research centres very well; or research funders – including the Canadian Institutes of Health Research – are not aligning their funded projects with the governments' policy imperatives or programs. Some or all of these reasons may be true.

Irrespective of the causal factors associated with applied health services and policy research outputs, one thing is certain: contemporaneous topics being generated by the Canadian health services research community are conclusively oriented in directions other than hospitals, physicians or drugs.

Provinces' and territories' recent initiatives on integrating care, strengthening allied sectors and between-sector innovations are rightly drawing attention from researchers. This activity is now paying dividends to government decision makers and policy makers with applied research outputs. Publications in these areas represent an important new emphasis on health and healthcare beyond the medicare-funded hospital and physician sectors. *Healthcare Policy* welcomes these developments and will continue to provide a forum for peer review, engagement and dissemination.

In the editorial of the previous issue of *Healthcare Policy*, I noted that all of the articles came from Ontario (Sutherland 2020). This issue has the same provincial bias – most of the articles' settings are in Ontario. I will work to encourage authors to address important issues of generalizability and diversity in other settings so that all provincial, territorial and federal decision and policy makers feel compelled to think through the implications of *Healthcare Policy*'s manuscripts in their settings.

In this issue

Leading this issue of *Healthcare Policy* is a commentary by Thomas and Flood (2020), which presents the contemporaneous issue of falling rates of childhood vaccination, the concept of vaccine hesitancy and mass immunization. Underlined with examples drawn from Ontario, the authors make a case for elimination of non-medical exemptions to vaccination due to religion or conscience. Describing that more data is needed, the authors posit that mandatory vaccinations, albeit controversial, can withstand *Charter* challenges.

The commentary is followed by a rejoinder (Beaman 2020). The author agrees that additional data is needed to inform the balance between individual and societal interests and potential harms. Beaman also adds that the COVID-19 pandemic and the rights of children may similarly affect the court's possible positions regarding mandatory vaccinations.

Guerriere et al. (2020) used a qualitative design-based study to explore relationships between a family caregiver's labor force transitions during a patient's phase of palliative care. Based in two of Ontario's palliative care programs, primary caregivers of palliative care patients were interviewed and changes in employment status measured. The study found changes reported by the participants – some described working more and others, working less – possibly associated with episodes of intense caregiving demand.

In their paper, Wong et al. (2020) explore public funding of alternate level of care (ALC), a chronic issue affecting cancer surgery patients among provinces' hospitals. Using population-based data, and in the context of episode-based funding for cancer surgery, the study found that hospitals' volume of ALC days among cancer surgery patients was small and that the per day cost of ALC is not far from $1,000. The authors posited that a combination of policies that integrate sectors is needed to improve ALC within Ontario.

Leadership in digital innovation in healthcare is complex; federal agencies, provincial programs and a hospital's local priorities and initiatives muddy the waters about who is responsible for identifying and implementing innovations. Desveaux et al (2020) from Ontario leveraged a digit health symposium to conduct a qualitative study examining the role of academic medical centres in vetting and promulgating digital health innovations. The authors concluded that academic medical centres can play a unique role as catalysts of adoption of digital health innovations.

Identifying residents of retirement homes is challenging. Gaps in administrative data mean that residents of retirement homes cannot be confidently identified. These gaps have significant implications for health services research aimed at the elderly and frail. Addressing this problem, Brath et al. (2020) developed methods for using postal codes to identify retirement home residents in Ontario. This method-oriented paper provides a roadmap for other provinces' researchers and governments to develop similar tools for measuring health- and healthcare-seeking behaviours of these residents.

Using repeated cross-sectional design and data from the Canadian Community Health Survey, Amoud et al. (2020) studied the association between prescription medication cost coverage and type 2 diabetes and hypertension oral medication adherence among adults in Ontario and New Brunswick. Adjusted results found that lacking insurance for drug costs was associated with poorer adherence over the study period. The authors conclude that this study provides additional evidence that medication costs are likely associated with medication adherence and impacting disease progression.

Feldman et al. (2020) report the results of a survey of Canadian rheumatologists' perceptions regarding a physical therapist's ability to appropriately refer patients. According to the findings, rheumatologists acknowledged that physical therapists could appropriately refer patients for specialty care. However, this conclusion was offset by the finding that a low proportion of respondents would accept a therapist's referrals. The authors concluded that a financial lever was needed: rheumatologists would be more likely to accept referrals from physiotherapists if they could bill for full consultations.

In a cross-sectional study conducted in Ontario, Veloce et al. (2020) explored whether the general public distinguished between the terms *nutritionist* and *dietitian*. The study found that there was substantial confusion regarding the difference between the terms, and concluded that this confusion had the potential to cause harm to Ontarians because dietitians have a regulatory responsibility for standards of care. The authors proposed legislative amendments to clarify the use of terms to reduce confusion about the respective roles and training.

JASON M. SUTHERLAND, PHD
Editor-in-Chief

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ÉDITORIAL

Recherche sur les services de santé et dépenses publiques pour les programmes de soins de santé : un désalignement bienvenu?

LES DÉPENSES POUR LES HÔPITAUX, LES MÉDECINS ET LES MÉDICAMENTS représentent à elles seules – si on exclut les projets d'immobilisation – plus des deux tiers des dépenses des gouvernements provinciaux et territoriaux pour la santé (ICIS 2019). On s'attendrait à ce que les services de santé et la recherche s'alignent sur les flux d'argent, et pourtant, il y a désalignement. Par exemple, la recherche, comme celle publiée par *Politiques de Santé*, n'est pas parfaitement alignée sur les régimes de dépense en santé des gouvernements provinciaux et territoriaux. Dans le présent numéro, par exemple, il n'y a que deux articles de ce type : l'un sur l'observance thérapeutique et le coût des médicaments, l'autre sur les politiques de paiement associées à l'utilisation d'un autre niveau de soins par un hôpital. Le même phénomène s'observait dans le numéro précédent de Politiques de Santé : seulement deux articles concernaient les soins primaires.

Que signifie ce désalignement? Manque-t-il des choses importantes entre la recherche et les intérêts des gouvernements?

Plusieurs raisons pouvant expliquer cette inadéquation méritent une attention particulière : on publie ailleurs de la recherche sur les politiques et les services de santé dans le contexte des hôpitaux, du travail des médecins ou des médicaments au Canada; ces trois secteurs ne sont pourtant pas très attrayants pour les chercheurs, car il y a peu de dynamiques politiques en eux; les gouvernements provinciaux et territoriaux n'ont pas su bien harmoniser leurs impératifs de recherche avec les centres locaux de recherche; ou encore, les bailleurs de fonds – notamment les Instituts de recherche en santé du Canada – n'alignent pas leurs projets financés sur les impératifs ou programmes politiques des gouvernements. Certaines ou toutes ces raisons peuvent être vraies.

Indépendamment des facteurs de causalité associés aux extrants de la recherche sur les politiques et les services de santé, une chose est certaine : les sujets actuels abordés par la communauté de la recherche sur les services de santé au Canada sont définitivement orientés dans des directions autres que les hôpitaux, les médecins ou les médicaments.

Les récentes initiatives des provinces et territoires sur l'intégration des soins, le renforcement des secteurs connexes ou les innovations intersectorielles attirent à juste titre l'attention des chercheurs. Cette activité rapporte des dividendes aux responsables gouvernementaux et aux décideurs grâce aux résultats de la recherche appliquée. Les publications dans ces domaines témoignent de la nouvelle importance accordée à la santé et aux soins de santé, au-delà du secteur des services hospitaliers et des consultations médicales financés par l'assurance maladie. *Politiques de Santé* se réjouit de ces développements et continuera de fournir un forum pour l'examen par les pairs, l'engagement et la diffusion.

Dans l'éditorial du dernier numéro de *Politiques de Santé*, j'observais que tous les articles provenaient de l'Ontario (Sutherland 2020). On constate le même biais pour le présent numéro : la plupart des contextes étudiés concernent l'Ontario. Je m'efforcerai d'encourager les auteurs à se pencher sur l'importance de la généralisabilité et de la diversité dans d'autres contextes afin que tous les décideurs provinciaux, territoriaux et fédéraux soient portés à réfléchir aux répercussions des articles de notre revue dans leur propre contexte.

Dans le présent numéro

Le commentaire de Thomas et Flood (2020), qui ouvre ce numéro, présente le problème actuel de la baisse des taux de vaccination des enfants, du concept de réticence à la vaccination et de la vaccination de masse. Forts d'exemples tirés de l'Ontario, les auteurs plaident en faveur de l'élimination des exemptions non médicales à la vaccination pour motifs religieux ou de conscience. Tout en indiquant que davantage de données sont nécessaires, ils affirment que la vaccination obligatoire, bien que controversée, peut résister aux contestations judiciaires qui invoquent la *Charte*.

Le commentaire est suivi d'une réplique (Beaman 2020). L'auteure convient qu'il faut obtenir plus de données pour bien définir le point d'équilibre entre, d'une part, les intérêts individuels et sociétaux et, d'autre part, les préjudices potentiels. Beaman ajoute également que la pandémie de COVID-19 et le droit de l'enfant pourraient aussi affecter la position d'un tribunal face aux vaccinations obligatoires.

Guerriere et coll. (2020) ont eu recours à une étude qualitative pour explorer la transition de la main-d'œuvre chez les proches aidants dans le contexte des soins palliatifs. Dans le cadre de deux programmes de soins palliatifs en Ontario, les proches aidants ont été interrogés et les changements de statut d'emploi mesurés. L'étude a révélé des changements signalés par les participants – certains ont indiqué travailler plus et d'autres, travailler moins – et possiblement associés à des épisodes de demande intense de soins.

Dans leur article, Wong et coll. (2020) explorent le financement public d'un autre niveau de soins (ANS), un problème chronique qui touche les patients en chirurgie oncologique dans les hôpitaux. En utilisant des données basées sur la population, et dans le contexte du financement pour la chirurgie oncologique, l'étude révèle que le volume de journées ANS chez les patients ayant subi une chirurgie oncologique était faible et que le coût journalier des ANS n'était pas loin de 1 000 $. Les auteurs avancent qu'une combinaison de politiques intégrant les divers secteurs est nécessaire pour améliorer l'ANS en Ontario.

La question du leadership en innovation numérique dans les soins de santé est complexe : les organismes fédéraux, les programmes provinciaux ainsi que les priorités ou initiatives hospitalières locales ne permettent pas de déterminer qui est responsable de l'identification et de la mise en œuvre des innovations. Desveaux et coll. (2020), de l'Ontario, ont profité d'un symposium sur la santé numérique pour mener une étude qualitative examinant le rôle des centres médicaux universitaires dans la vérification et la promulgation d'innovations en santé numérique. Les auteurs concluent que les centres médicaux universitaires peuvent jouer un rôle particulier en tant que catalyseurs de l'adoption des innovations.

Identifier les résidents des maisons de retraite est un défi. Les lacunes dans les données administratives ne facilitent certainement pas la tâche. Ces lacunes ont des répercussions importantes sur la recherche visant les personnes âgées et fragiles. Pour résoudre ce problème, Brath et coll. (2020) ont mis au point une méthode d'utilisation des codes postaux pour identifier les résidents des maisons de retraite en Ontario. Leur article fournit une feuille de route pour les chercheurs et les gouvernements d'autres provinces afin de développer des outils similaires pour mesurer les comportements de santé et d'accès aux soins chez ce type de résidents.

Au moyen d'une méthode transversale répétée et des données de l'Enquête sur la santé dans les collectivités canadiennes, Amoud et coll. (2020) ont étudié le lien entre la couverture du coût des médicaments sur ordonnance et l'observance de la médication contre le diabète de type 2 et l'hypertension, chez les adultes en Ontario et au Nouveau-Brunswick. Les résultats ajustés révèlent que l'absence d'assurance pour le coût des médicaments est associée à une moins bonne observance, pour la période à l'étude. Les auteurs concluent que cette étude fournit des données supplémentaires démontrant que le coût des médicaments est probablement associé à l'observance de la médication, et cela a des répercussions sur la progression de la maladie.

Feldman et coll. (2020) font état des résultats d'une enquête sur la perception des rhumatologues canadiens concernant la capacité d'un physiothérapeute à aiguiller les patients de manière appropriée. Selon les résultats, les rhumatologues reconnaissent que les physiothérapeutes peuvent orienter de manière appropriée les patients vers des soins spécialisés. Cependant, en contrepoids, on constate qu'une faible proportion de répondants accepteraient les références d'un physiothérapeute. Les auteurs concluent qu'un levier financier est nécessaire : les rhumatologues seraient plus enclins à accepter les références des physiothérapeutes s'ils pouvaient facturer les visites comme des consultations complètes.

Dans une étude transversale menée en Ontario, Veloce et coll. (2020) cherchent à savoir dans quelle mesure la population distingue les termes *nutritionniste* et *diététiste*. L'étude révèle qu'il y a une grande confusion quant à la différence entre ces termes et conclut que cela pourrait nuire aux Ontariens car les diététistes, contrairement aux autres, ont des obligations réglementaires en matière de normes de soins. Les auteurs proposent des modifications législatives pour clarifier l'utilisation des termes afin de réduire la confusion concernant leur rôles respectifs et la formation requise.

JASON M. SUTHERLAND, PHD
Rédacteur en chef

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DISCUSSION AND DEBATE

Eliminating Religious and Philosophical Exemptions: The Next Step in Ontario's Campaign against Vaccine Hesitancy

Mettre fin à l'exemption pour motifs religieux ou philosophiques : prochaine étape de la campagne ontarienne contre la réticence à la vaccination

BRYAN THOMAS, SJD, MA
Senior Research Associate and Adjunct Professor
Centre for Health Law, Policy and Ethics
University of Ottawa
Ottawa, ON

COLLEEN M. FLOOD, SJD, FRSC, FCAHS
University Research Chair and Director
Centre for Health Law, Policy and Ethics
University of Ottawa
Ottawa, ON

Abstract

Ontario families are required to provide up-to-date vaccination records as children begin schooling. Exemptions are allowed on both medical and nonmedical (religious or philosophical) grounds. In a recent report, Toronto Public Health (2019) called for an end to nonmedical exemptions – a proposal some allege infringes the *Canadian Charter of Rights and Freedoms* right to freedom of religion and conscience. This paper explores whether and to what extent vaccine refusal is protected under the *Charter* and argues that the elimination of nonmedical exemptions can be justified under Section 1 of the *Charter*. The issue of mandatory vaccination may take on special urgency in the coming months and years, if and when a vaccine is found for COVID-19.

Résumé

Les familles ontariennes doivent présenter un carnet de vaccination à jour au moment où les enfants commencent l'école. Certaines exemptions sont toutefois accordées, que ce soit pour des raisons d'ordre médical ou pour des motifs religieux ou philosophiques. Dans un rapport récent, l'organisme de santé publique Toronto Public Health (2019) demande la fin des exemptions non médicales; proposition qui, selon certains, enfreint la liberté de conscience et de religion protégée par la *Charte canadienne des droits et libertés*. Dans cet article, on cherche à savoir dans quelle mesure le refus à la vaccination est effectivement protégé par la *Charte*. On y avance aussi que l'article 1 de ladite *Charte* peut être invoqué pour l'élimination des exemptions non médicales. La question de la vaccination obligatoire pourrait prendre une importance particulière dans les mois ou années à venir, si un vaccin contre la COVID-19 est mis au point.

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Introduction

Mass immunization is one of the great triumphs of modern medicine – so much so that it risks becoming a victim of its own success. Through a complex mix of complacency about infectious disease outbreaks, mistrust of mainstream medicine and a consumerist orientation toward healthcare, a growing number of parents are declining to have their children immunized (Dubé et al. 2016). This exposes the individual child to infection and weakens "herd immunity," raising the ambient risk for groups that cannot be vaccinated for medical reasons, such as infants, pregnant women and those with compromised immune systems. Failure to vaccinate costs our healthcare system as well: every dollar invested in immunizing children against measles, mumps and rubella returns $16 in healthcare savings down the road (Public Health Agency of Canada 2016). In recent years, Ontario and other provinces have wrestled with outbreaks of measles, mumps, whooping cough and other preventable-by-vaccine diseases, as Canada fails to meet targets for childhood vaccinations (OECD 2020).

Discussion

As we write, the issue is again making headlines in Ontario, with reports that over 10% of students at 12 Toronto alternative schools have not received their vaccinations (Brockbank 2019). This is despite the fact that Ontario is one of the handful of provinces that have made childhood immunization compulsory: under the *Immunization of School Pupils Act* (*ISPA* [1990]), parents must furnish vaccination records at the time of school enrolment, or the students must face a 20-day suspension from school and $1,000 fine. Students can be exempted from the aforementioned penalty if they submit a form signed by a physician or a registered nurse either stating that an immunization would be dangerous or an unnecessary by-reason of past infection, or showing laboratory evidence of immunity. More controversially, parents who object to vaccination on grounds of religion or conscience can request a nonmedical exemption. While only 2.5% of Ontario children receive such nonmedical exemptions (Public Health Ontario 2019), they can be clustered geographically, or gravitate to alternative schools, presenting an outsized risk of outbreak – as is now the case at Toronto's alternative schools.

This has been an ongoing challenge, and Ontario has enacted previous legislative reforms in an effort to overcome vaccine hesitancy and reach the target rates of 95% vaccination. A 2017 amendment to the *ISPA* requires parents to attend education sessions and learn the facts on immunization before receiving a nonmedical exemption. Yet, the number of parents seeking nonmedical exemptions continues to rise, according to the head of the Ontario Medical Association (Payne 2019). Thus, Toronto Public Health (2019) recently made a controversial recommendation that Ontario eliminate nonmedical exemptions altogether.

Two questions come to mind in evaluating this proposal. First, will the elimination of nonmedical exemptions be *effective* in meeting the target rates for vaccination? Second, supposing this approach holds promise, can the elimination of nonmedical exemptions be squared with the *Charter of Rights and Freedoms* Section 2(a): protections for freedom of religion and freedom of conscience? The two questions are interrelated, of course – if eliminating the exemptions is demonstrably ineffective, government will have a very difficult time answering a *Charter* challenge. Let us nevertheless take the questions in turn.

About the *effectiveness* question, skeptics worry that eliminating the exemption will make vaccine-hesitant parents all the more strident (Sibbald 2016). Yet, it is not clear how this increased stridency will undermine the effectiveness of mandatory vaccination – on the face of it, the options would be home-schooling or seeking out a (possibly falsified) medical exemption.

In 2015, California eliminated nonmedical vaccine exemptions for students entering school and saw vaccination rates rise from 92.8% to 95.1% over two years as the use of religious and philosophical exemptions dropped (Mohanty et al. 2018); an earlier systematic review of evidence from all US states likewise found a correlation between allowing nonmedical exemptions and decreased vaccination (Wang et al. 2014). True, it appears that some percentage of these California families sought out *medical* exemptions from sympathetic doctors to replace nonmedical exemptions, but this trend was not enough to offset the overall improvement in vaccination. Moreover, if it appears that students previously exempted on nonmedical grounds are making illegitimate use of medical exemptions, there is always the option of tightening up the rules governing medical exemptions. Indeed, California's experiment has been criticized precisely for allowing too many loopholes, loosening criteria for medical exemptions and allowing unvaccinated students already enrolled in school to be grandfathered. There may, however, be subtler effects worthy of consideration – such as the policy wisdom of having school administrators put in an adversarial position toward vaccine-hesitant parents (Mello et al. 2015).

Accepting, for the sake of argument, that eliminating nonmedical exemptions shows promise for improving vaccination rates, our second question is whether the change can withstand the *Charter* scrutiny. There are multiple *Charter* values at stake here, arguably, such as the Section 7 guarantee of "life, liberty and security of the person" and the Section 15 right to "equal benefit of the law … without discrimination based on … religion." However, the most directly applicable *Charter* protection – and the focus of our discussion – is the Section 2(a) right to freedom of religion and freedom of conscience.

A preliminary point here is that the majority of nonmedical exemptions do not appear to be *religiously* motivated – as explained, the rise in vaccine hesitancy is primarily rooted in philosophical skepticism, incorporating concerns about the safety of vaccines and the pharmaceutical industry's trustworthiness. This difference may matter to the *Charter* analysis. The Supreme Court has granted very wide protections for bona fide *religious* convictions – requiring that claimants merely show a "nexus" between the impugned legislation and their beliefs about the divine (*Syndicat Northcrest v. Amselem* 2004). There is scant Supreme Court jurisprudence on freedom of conscience, but it seems doubtful to us that vaccine hesitancy will qualify.

Though it lacks the precedential force of a Supreme Court ruling, consider, by analogy, the 2004 Alberta Provincial Court ruling, *R. v. Locke* (2004), where the plaintiff, skeptical of the science behind seatbelts, claimed that mandatory seatbelt laws infringed his freedom of conscience. The court rejected the claim, reasoning that the *Charter*'s protection of conscience extends only to "comprehensive value systems," reflecting "profoundly personal beliefs that govern one's perception of oneself, humankind, nature." This language draws from the Supreme Court of Canada's jurisprudence on religious freedom, in *R. v. Edwards Books and Art Ltd* (1986). Seatbelt hesitancy does not meet this test, according to the court, and we suspect that similar reasoning might apply to knock down claims by vaccine-hesitant parents at the infringement stage.

Of course, it is possible (and even likely) that the claimants in a *Charter* challenge will be a mix of religious and philosophical objectors to vaccination. If so, the Supreme Court may be inclined to acknowledge an infringement and proceed to a Section 1 analysis: the rights set out under the *Charter* are not absolute trumps – impugned legislation can be saved if government can show that it is "reasonably justified in a free and democratic society." The onus will be on government lawyers to show that mandatory vaccination of school children, with no religious or philosophical exemptions, is a proportionate response to the threat posed by vaccine-preventable diseases.

Charter proportionality analysis proceeds in four stages, interrogating whether the government action is (1) in pursuance of a "pressing and substantial" objective; (2) rationally connected with that objective; (3) minimally impairing the *Charter* right in question; and (4) whether the impact on the *Charter* right is proportionate overall to the importance of the objective. Government lawyers will have no difficulty in establishing that meeting vaccination targets is a pressing and substantial objective – the protection and promotion of public health is a core responsibility of the government. Likewise, the "rational connection" test will be easily met, it seems – not least because outbreaks of measles and other diseases have coincided with a documented increase in Ontario parents' use of nonmedical exemptions (Wilson et al. 2015).

The government's attempts to defend legislation against the *Charter* challenge often fail at the "minimal impairment" stage, as the plaintiffs' lawyers may present evidence from other jurisdictions – other provinces or comparator countries – that have achieved the sought-after objective with lesser or no infringement of rights. Of course, this is a complex question with plenty of confounding factors at play. Across Canada, provinces vary significantly in their approach toward encouraging childhood vaccination, with Alberta using a scheme that tracks children from birth and relies on a series of reminders from public health nurses to encourage vaccination; Alberta has not made vaccination compulsory at school entry. While Alberta has achieved slightly higher childhood vaccination rates (Public Health Agency of Canada 2019), there are a host of contextual factors – immigration levels and the geographic distribution of vaccine-hesitant people – that caution against apples-and-oranges comparisons to Ontario. Whether courts are up to the task of sorting out these nuances is an open question.

There is also a risk that the government – in its effort to *minimize* its application of coercion in this area – may run afoul of other *Charter* values. One way to minimize coercion is to target compulsory vaccination – and deny religious and philosophical exemptions – only in communities or schools that fall dangerously below the target vaccination rates. This was the approach taken by New York State recently, as the state targeted mandatory vaccination at the zip codes that are home to the Hasidic Jewish communities that had seen a measles outbreak. The move invited charges of discrimination, including those from prominent public health advocates who worried that it might be "challenged as unequal and arguably unfair" (Gostin and Hodge 2019). An attempt by the Ontario Government to impose mandatory vaccination in a manner that targeted religious or immigrant communities would invite a challenge under Section 15 of the *Charter*.

Should the Ontario Government opt to eliminate nonmedical exemptions and weather a constitutional challenge, its attempts to justify the move as minimally impairing will be bolstered by evidence showing that past less-coercive measures – for example, the requirement that parents participate in an education session before receiving a nonmedical exemption – have not succeeded in bringing childhood vaccination rates in line with targets for herd immunity. At the fourth and final stage of Section 1 analysis, the overall proportionality of eliminating nonmedical exemptions can be supported by evidence linking nonmedical exemptions to disease outbreaks (Wilson et al. 2015) as well as evidence from the US showing a correlation between nonmedical exemptions and lower rates of vaccination (Wang et al. 2014). Ontario's effort to demonstrate that mandatory vaccination is evidence-based and proportionate overall may be hamstrung by its haphazard and anachronistic approach toward tracking childhood vaccination, relying on yellow cards collected by parents and shared with school administrators. As a first step, the province would be wise to adopt a more rigorous approach to record keeping, commensurate with this issue's importance to public health and the gravity of the human rights implicated by mandatory vaccination.

Conclusion

The issue of mandatory vaccination may take on a special urgency in the coming months and years, if and when a vaccine is found for COVID-19. There, the potential legal challenges will extend beyond the classroom, as individuals may be compelled to be vaccinated as a precondition of returning to work, visiting long-term care facilities, travelling by air, and so on – engaging *Charter* rights and human rights protections that apply to the private sector. Our analysis, suggesting that mandatory vaccination can withstand *Charter* scrutiny does not necessarily carry over to these other contexts. As explained, the devil is very much in the details when it comes to assessing the proportionality of mandatory vaccination for various diseases in varying contexts.

Correspondence may be directed to: Bryan Thomas, SJD, MA, 55 Aziel St., Toronto, ON M6P 2N8. He can be reached by e-mail at bryanpaulthomas@gmail.com.

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Commentary: Cautionary Notes on Exemption Elimination

Commentaire : Mise en garde au sujet de l'élimination des exemptions

LORI G. BEAMAN, PhD, FRSC
Canada Research Chair, Religious Diversity and Social Change
Director, Nonreligion in a Complex Future
Department of Classics and Religious Studies
University of Ottawa
Ottawa, ON

Abstract

A flourishing democracy should have a great deal of space for a wide range of beliefs and practices. The issue of vaccine hesitancy requires that we have as much data and information as possible in order to determine the precise point at which those beliefs and practices may endanger others or the population as a whole. Imposing restrictions before determining that point is about power rather than protection, and ultimately alienates portions of the population.

Résumé

Une démocratie saine doit prévoir suffisamment d'espace pour une vaste gamme de croyances et de pratiques. La question de la réticence à la vaccination demande que nous ayons en main toutes les données possibles afin de déterminer le point précis où ces croyances et pratiques peuvent mettre en danger des individus ou l'ensemble de la population. Imposer des restrictions avant de connaître ce point est plus une question de pouvoir que de protection et, en bout de ligne, peut aliéner des segments de la population.

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Introduction

Dozens of vaccines for COVID-19 are reportedly at some stage of development. Hopes for success are high as the global community longs for a return to "normalcy." It is in this context that vaccine hesitancy attracted renewed attention and has taken on a new urgency. In their article *Eliminating Religious and Philosophical Exemptions: The Next Step in Ontario's*

Campaign against Vaccine Hesitancy, Thomas and Flood (2020) take up the issue of vaccination exemption. Taking Ontario as their point of entry, they discuss issues that have applicability beyond the province of Ontario. There are many reasons why people avoid or refuse vaccinations, including a mistrust of medical science and the pharmaceutical industry. As Thomas and Flood (2020) note, the majority of non-medical exemptions do not seem to be religiously motivated.

Discussion

Only 2.5% of Ontario children receive non-medical exemptions, but as Thomas and Flood (2020) point out, they are clustered geographically in what they refer to as "alternative schools." This, of course, increases the risk of disease outbreaks, and leads us to ask the following questions: What precisely are these alternative schools? Are they primarily religion-based, or is there some other commonality that inspires vaccine hesitancy? Moreover, are there cohorts of people within those alternative schools who are vaccine hesitant, and what is their demographic? If we wish to maximize the "persuasion" route rather than the "force" approach, it is vital that these details be understood. Thomas and Flood (2020) note that mandatory education for vaccine-hesitant people does not seem to be producing an effect. It is important to consider to what extent that education has been developed with the resisting cohorts in mind and whether it has been prepared in collaboration with those within the alternative community who are vaccine positive. It is possible that there are elements of the education that alienate the hesitators rather than engage them. There may be minor tweaks to the education that would open the door to greater information and ultimately persuade vaccine-hesitant people of the value in choosing to be vaccinated.

Although Thomas and Flood (2020) point out that the majority of vaccine exemptions do not seem to be religiously motivated, it is important to understand the constellation of beliefs and practices associated with vaccine hesitancy. "Philosophical objection" does not tell us much. By better understanding the rationale behind their position, we are better able to meet their objections. It is true that in this era of "fake news" all data can be claimed as tainted, but this should not prevent the dissemination of data-based information that might move some people to a deeper understanding and a subsequent shift in their position.

Thomas and Flood (2020) note that the number of exemption requests continues to rise despite the education. But what is the magnitude of that increase and is it meaningful (i.e., an increase of 10 people or 100)? What is the tipping point for overall herd immunity, and how close do we come to that point considering the number of exemption requests currently being granted? This takes us back to the issue raised above – low immunization within a particular population creates an outsized risk outbreak but, nonetheless, it is important to know the numbers in order to understand the precise level of increased risk. This brings us to an important recommendation made by Thomas and Flood (2020): there is an urgent need for better vaccination record-keeping that will tell us who has accessed vaccinations and who has not. It is also possible that some people seek exemption unevenly – in other words, they may have an objection to a specific vaccine, but not to all. This, too, offers an opening to overcome resistance. Better record-keeping will also give an accurate picture of where herd immunity stands in any given disease. This information is crucial for the development of sound (and legally supportable) vaccination policies and practices. It will allow for a precise calculation of how much flexibility we actually have, and when the risk of harm is too great. This, in turn, allows for the development of a strategy that avoids legal challenges, and, equally as important, is inclusive enough to not unnecessarily alienate people who are vaccine hesitant.

When considering mandatory vaccinations, it is important to avoid throwing the baby out with the bathwater. We, as a society, must ask what are the beliefs and practices that we want to protect, even if it means protecting something with which we strenuously disagree. Take for example the case of *A.C. v. Manitoba* (2009) involving a Jehovah's Witness girl who was assessed as a mature minor and wished to refuse a blood transfusion. In his dissenting judgment, Justice Binnie stated, "The *Charter* is not just about the freedom to make what most members of society would regard as the wise and correct choice" (para. 163). Disagreement is not a lawful reason to override a decision, Justice Binnie later noted (para. 175). Courts often assess harm to others or a society in cases involving religious practices and beliefs, which seem to go against what most members of society would choose. Of course, harm itself is a slippery concept; however, in the case of vaccine hesitancy, we might argue that harm can be assessed at that point where herd immunity is scientifically shown to be at risk because a sufficient number of people have not been immunized.

Thomas and Flood (2020) focus their remarks on two important questions: first, if exemptions are eliminated, will this result in an effective meeting of target rates for vaccination? After reviewing evidence from the US, they conclude that elimination of non-medical exemptions shows promise. Politics aside, there are many differences between Canada and the US that make it challenging to compare data about social behaviour and impacts. For example, the rhetoric of freedom has much greater purchase south of the border, and although we see it in recent Canadian demonstrations about mask wearing, there is a stronger tradition of social balancing in Canada – indeed, it is built in to the Section 1 provision of the *Charter* discussed in detail by Thomas and Flood (2020).

The second question posed by the authors is whether or not the elimination of non-medical exemptions is defensible under the *Charter*. To answer this question, they divide religious and non-religious non-medical exemptions and conclude that the former are more likely to receive *Charter* protection than the latter. They then outline the likely *Charter* analysis, with an infringement of Section 2(a) (freedom of religion and conscience) being found with a state policy of forced immunization, but supported on a Section 1 proportionality analysis, which essentially balances individual and societal/state interests. In other words, the Section 1 analysis offsets the infringement argument based on Section 2.

Thomas and Flood (2020) note that a religious objection or justification for vaccine exemption may have a greater likelihood of being supported by the courts than those based on conscience. They may be correct about this, but not necessarily so. The Supreme Court decisions on religion also include some cases, such as *Alberta v. Hutterian Brethren of Wilson Colony* (2009), that suggest that the Court is willing to override religion in some circumstances. The Hutterian Brethren requested an exemption from having their photographs on their drivers' licenses for religious reasons. The basis of the request was clear. But the majority of the Court was unwilling to support the request, with the justification being that public security was at risk. It is entirely conceivable that in the current pandemic situation, the Court would decide that vaccine exemptions cannot be justified even if forcing vaccinations is in fact a *Charter* violation. In other words, public harm would outweigh the right protected under Section 2(a). This discussion also raises a broader issue that is controversial in religious and law circles: to what extent is religion "special"? Why should someone who has a strenuous opposition to vaccines for reasons of conscience be less protected by the *Charter* than someone who invokes a religious reason? In other words, if the courts would not support an exemption on the basis of conscience, are there compelling reasons to support an exemption on the basis of religious beliefs?

Interestingly, although the vaccination exemption issue is primarily related to children, there has been little consideration of the rights of children themselves. Legal approaches to children's rights are evolving, and the question of what children themselves want is important and increasingly being taken into consideration. We see parallel discussions around contraceptives, for example, and the right of people who are legally classified as children to access reproductive information and resources. Parental practices that demonstrably put children at risk or are harmful may not be upheld, and children themselves may access their *Charter* rights to be vaccinated. The question of children's legal agency and personhood and parents' right to harm is one that will inevitably come up in this issue.

Conclusion

Ultimately, a flourishing democracy should have a great deal of space for a wide range of beliefs and practices. The issue of vaccine hesitancy requires that we have as much data and information as possible to determine the precise point at which those beliefs and practices may endanger others or the population as a whole. Imposing restrictions before that point can be determined is about power rather than protection, and ultimately alienates those who hold unpopular beliefs.

Correspondence may be directed to: Lori G. Beaman. She can be reached by e-mail at lbeaman@uottawa.ca.

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RESEARCH PAPER

Transitions in Labour Force Participation over the Palliative Care Trajectory

Transition de la main-d'œuvre au cours de la trajectoire des soins palliatifs

DENISE GUERRIERE, PhD
Adjunct Professor
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

AMNA HUSAIN, MD, CCFP, MPH
Clinician Scientist
Temmy Latner Centre for Palliative Care
Lunenfeld Tanenbaum Research Institute
Sinai Health System
Toronto, ON

DENISE MARSHALL, BSc, MD, CCFP (PC), FCFP
Medical Director
Niagara West Palliative Care Team and
McNally House Hospice
Grimsby, ON
Professor, Department of Family Medicine
Division of Palliative Care,
David Braley Health Sciences Centre
McMaster University
Hamilton, ON

BRANDON ZAGORSKI, MS, PSTAT
Adjunct Professor
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

JULIA KENNEDY, MHSc, MSc
Consultant
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

PETER C. COYTE, PhD
Professor of Health Economics
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

Abstract

Background: Home-based palliative programs rely on family caregivers, who often miss time from employment. This article identified changes in caregivers' labour force participation over the palliative trajectory.

Methods: Family caregivers (n = 262) were interviewed biweekly to measure transitions across four employment categories.

Results: More than half of the caregivers had one employment transition and 29% had three or more. The highest proportion of transitions occurred for caregivers who were employed part-time.
Interpretation: Understanding these transitions is critical to the development of strategies tailored to caregivers to contain labour force losses and to support caregivers during a time of high caregiving demands.

Résumé

Contexte : Les programmes de soins palliatifs à domicile comptent sur la contribution des proches aidants qui, souvent, doivent s'absenter du travail. Cet article identifie les changements dans l'activité de la main-d'œuvre au cours de la trajectoire des soins palliatifs.
Méthode : Des proches aidants (*n* = 262) ont été interviewés au deux semaines afin de mesurer les transitions dans quatre catégories d'emploi.
Résultats : Plus de la moitié des proches aidants ont connu une transition d'emploi et 29 % en ont connu trois ou plus. La plus forte proportion de transition touche les proches aidants qui occupent un emploi à temps partiel.
Interprétation : La compréhension de ces transitions est essentielle pour le développement de stratégies sur mesure pour les proches aidants afin de freiner la perte de main-d'œuvre et d'aider les proches aidants en période de grande demande pour ce type d'aide.

Introduction

With a rapidly growing aging population and an increased emphasis on ambulatory and home-based palliative care, dependence on family members to provide care will continue to grow and intensify (Quality Hospice Palliative Care Coalition of Ontario 2010). Palliative care aims to improve quality of life and reduce pain and suffering for patients with a life-threatening illness and their families (Hall et al. 2011). Although palliative care recipients receive multidisciplinary care from publicly and privately financed services (Carstairs 2000), this care context relies greatly on family members to provide the majority of the day-to-day care (Munck et al. 2008; Rabow et al. 2004; Thomas et al. 2002; Wolff et al. 2007). Many family caregivers of palliative care patients miss time from work or remove themselves entirely from the labour market (Brazil et al. 2003; Covinsky et al. 1994; Eldh and Carlsson 2011; Grunfeld et al. 2004; Stommel et al. 1993; Wolff et al. 2007) to meet high caregiving demands, which has economic consequences for the family, the labour force and the society at large.

The temporal fluctuations in labour force participation (LFP) in the palliative care context have not been assessed extensively among caregivers in Canada. LFP refers to an attachment to labour market work compared to no engagement. The LFP transitions considered herein may take on one of two forms: first, adjustments in the intensity of labour market engagement, which reflect shifts between full- and part-time employment, and second, decisions to entirely withdraw or remove oneself from the labour market. Each of these employment adjustments may be temporary (e.g., when taken over a part or all of the palliative care trajectory) or permanent (e.g., when caregivers retire). Although studies have characterized some aspects of caregivers' employment while caring for a family member, these assessments were embedded within studies where the primary focus was not transitions in LFP (Addington-Hall et al. 1992; Covinsky et al. 1994; Cui et al. 2014; Grunfeld et al. 2004; Rossi et al. 2007; Rowland et al. 2017). These studies measured time missed from employment rather than transitions (Addington-Hall et al. 1992; Covinsky et al. 1994; Grunfeld et al. 2004; Rossi et al. 2007), going on leave or being unemployed at one or two time points (Covinsky et al. 1994; Grunfeld et al. 2004; Rossi et al. 2007) and employment status at the start of caregiving without consideration of subsequent transitions (Rowland et al. 2017). Furthermore, these studies did not assess whether caregivers moved back to full- or part-time employment after being unemployed or on leave. One study conducted multiple assessments with caregivers over the palliative care trajectory; however, their focus was on productivity while at work and hours missed from employment; the study did not measure LFP transitions (Mazanec et al. 2011). While the effects of caregiving on LFP have been characterized outside of the palliative care context (Alpass et al. 2017; Berecki-Gisolf et al. 2008; Bittman et al. 2007; Carmichael and Charles 2003; Carmichael et al. 2008; Carr et al. 2018; Covinsky et al. 2001; de Moor et al. 2017; Gonzales et al. 2017; Heitmueller 2007; Jacobs et al. 2017; Kotsadam 2012; Lilly et al. 2010; Longacre et al. 2016; Nguyen and Connelly 2014; Pavalko and Henderson 2006; Schneider et al. 2013; Spiess and Schneider 2003; Van Houtven et al. 2013; Wakabayashi and Donato 2005), they do not assess all possible transitions nor do they evaluate movement between employment categories. Furthermore, application to the palliative setting may be limited, as this context is unique and fraught with intense caregiving needs and psychological stress during the final days with a family member. Further empirical work into the concept of LFP in the palliative context is necessary, as the trajectory is typically shorter and more immediate than general caregiving contexts.

Accordingly, the main purpose of this study was to estimate and describe LFP transitions of unpaid caregivers across the palliative care trajectory. Tracking the transitions that occur is very important because caregiving demands can change frequently and dramatically as a patient's status stabilizes or worsens with approaching death. A comprehensive assessment of the scale, frequency and form of labour force adjustments will inform policy responses that simultaneously advance labour, social and health policies such as improving the provision of effective care while at the same time enabling caregivers to remain in the labour force.

Methods

This study was a prospective, longitudinal cohort study that assessed caregiver LFP from admission to death for two palliative care programs in Ontario, Canada: (1) Toronto's Temmy Latner Centre for Palliative Care and (2) Niagara West Palliative Care Team.

These programs provide community- and team-based multidisciplinary palliative care, including symptom and case management, and practical/emotional support to individuals at home 24 hours per day, seven days per week. Care components include home care (medicine, nursing, personal support), outpatient clinics, hospice care and coordinated acute and tertiary palliative care. These programs offer care in ethnically diverse regions of the province and have been in existence for several years; therefore, these programs reflect current practices in home-based palliative care in Ontario.

The potential participants were: (1) primary caregivers of patients admitted to one of the two palliative care programs within the past seven days; (2) fluent in English; and (3) ≥18 years of age. At each palliative care program, the records clerk identified all the admissions that met the eligibility criteria. Then the research officer telephoned the eligible caregivers to screen them for inclusion and to inquire about their interest in the study. The research officer then explained the study to all the interested participants and mailed a written consent form to those who indicated that they would participate.

Data were obtained from telephonic interviews with the participants and from the palliative care program databases. The study participants were interviewed every two weeks from admission into the palliative care program until the death of the care recipient. A biweekly data-collection period was selected because the interval is short enough to minimize recall bias (Severens et al. 2000), but not so short that it overburdens the caregivers.

The caregiver LFP variables were measured using a demographic questionnaire that we developed (Guerriere et al. 2008, 2010, 2015) and adapted for this study. Respondents were asked if they were employed, and if so, whether any changes had occurred and the number of hours worked over the prior two weeks. In the first interview, the demographic questionnaire was applied, and respondents were also asked if they had made changes (as described in the previous sentence) prior to their family member entering the palliative care program. Caregivers were classified under four employment categories: Full-Time (including self-employed individuals working >30 hours per week); Part-Time (including self-employed individuals working <30 hours per week) based on the Statistics Canada's Labour Force Survey or LFS (https://www.ccsd.ca/resources/ProgressChildrenYouth/pdf/pccy_notes.pdf); On-Leave; and Not-Employed (including retirees and students).

Patient age and gender were obtained from the palliative care program databases at each of the two data collection sites. Caregiver age, gender, marital status, education and co-residence status were obtained from participant interviews using our demographic questionnaire. This demographic questionnaire is part of the Ambulatory and Home Care Record, a costing tool that assesses health and social care utilization, out-of-pocket costs and caregiving time, that we developed and have used extensively in our past work (Cai et al. 2017; Chai et al. 2013; Guerriere et al. 2008, 2015, 2016; Masucci et al. 2013) and the psychometrics have been evaluated (Guerriere et al. 2006). All data obtained in this study were entered into Excel and analyzed using SAS (SAS version 9.0, SAS Institute Inc., Cary, North Carolina, US). An SQL server database housed the data behind enterprise class Cisco Firewalls to protect against unauthorized access.

Employment status across the palliative care trajectory was operationalized using the employment state transitions between interviews (changes per two weeks) and by the amount of time spent in each employment state over the trajectory. For the latter, proportions of time spent in each state were estimated for the entire sample. Using the four unique employment categories, 16 unique transitions between two time periods over the palliative trajectory were captured, four of which represent no change in employment categories. We quantified these employment transitions across the palliative trajectory in two ways. First, among caregivers with two or more interviews, we estimated a transition probability for each of the 16 potential unique transitions for each interview period (Time 2) relative to the preceding period (Time 1). Second, we estimated the cumulative proportion of time spent in each employment category across the palliative trajectory relative to the one reported at the baseline for all caregivers in aggregate.

Statistical significance was tested to assess for differences in transitional probabilities between spouses and adult-child caregivers using the Chi-square test.

Results

During the 26-month participant recruitment period (February 1, 2014, to April 5, 2016), 1,456 caregivers were identified as being potentially eligible for the study. Of these, 964 (66%) were contacted by the research officer, and the remainder were unreachable by telephone (*n* = 492). Consent to participate was given by 273 (28% of 964); 634 (65.7%) potential participants declined; and 57 (5.9%) care receivers died before the research officer could contact the potential caregiver participant. Of the 273 consenting participants, 11 were excluded because employment data were missing. Our results are therefore based on a sample of 262 caregiver–patient dyads, yielding a total of 1,962 interviews, consisting of 27,632 patient days. While this period is right-skewed and varies from days to over 6.4 months for the upper 25%, the length of the follow-up (study entry until death) was a median of 2.6 months and the IQR was 81 days (35–197). At times, we recruited patients close to the time of entry into the palliative care program (within two weeks) and followed them until close to their death.

Tables 1 and 2 describe the samples of patients and caregivers, respectively. The sample of patients (care recipients) comprised an almost equal number of males and females. Almost 70% of the patients were 71 years or older. Most lived with at least one other person, and the majority were married.

The caregivers mainly comprised women (around 70%). More than half of the caregivers were between 51 and 70 years of age. The majority were married, and close to 75% had obtained post-secondary school education. An almost equal number of caregivers were the spouse or the adult-child of the patient. On average, caregivers dedicated six hours per day to caregiving activities.

TABLE 1. Care recipient characteristics

Variable *N*	Value	Total cohort *N* = 262
Age (yrs.)	Mean ± SD	76.13 ± 14.38
	Median (IQR)	79 (67–87)
	≤40	5 (1.9%)
	41–50	8 (3.1%)
	51–60	29 (11.1%)
	61–70	42 (16.0%)
	71+	178 (67.9%)
Gender	Male	133 (50.8%)
	Female	129 (49.2%)
Marital status	Married	169 (64.5%)
	Divorced/Widowed	82 (31.3%)
	Never married	11 (4.2%)
Education	High school or less	197 (75.2%)
	Any university or vocational course	65 (24.8%)
Living arrangement	Lives alone	30 (11.5%)
	Lives with others	232 (88.5%)
Number of days observed in study	Mean ± SD	162.39 ± 194.95
	Median (IQR)	81 (35–197)
Days from death at baseline	Mean± SD	137.06 ± 177.99
	Median (IQR)	64 (21–168)

SD: Standard Deviation, IQR: Interquartile Range

Overall, we observed many transitions among the LFP categories across the palliative care trajectory. Among these transitions, 57% of the caregivers had one transition, 14% had two transitions and 29% had three or more transitions. Figure 1 presents the average percentage of caregivers who transitioned between employment categories every two weeks. These changes occurred both while moving in and moving out of three of the categories (Full-Time [FT], Part-Time [PT] and On-Leave; Figure 1). The percentage reported for each employment category represents the proportion of caregivers who reported remaining in that employment category without making an employment transition at each interview over the whole palliative care trajectory (Figure 1 legend).

The highest proportion of two-week transitions occurred for caregivers who were PT employed. On average, 10% of caregivers in the PT employed category transitioned to FT employment every two weeks. Equal percentages transitioned from PT to On-Leave (1.4%) and from PT to Not-Employed (1.4%).

The second highest transition average was observed within the On-Leave employment category. In this category, 6.8% moved to PT and 5.1% transitioned into the Not-Employed category, every two weeks over the trajectory. No movement was observed from On-Leave to FT employment.

TABLE 2. Primary caregiver characteristics at first interview

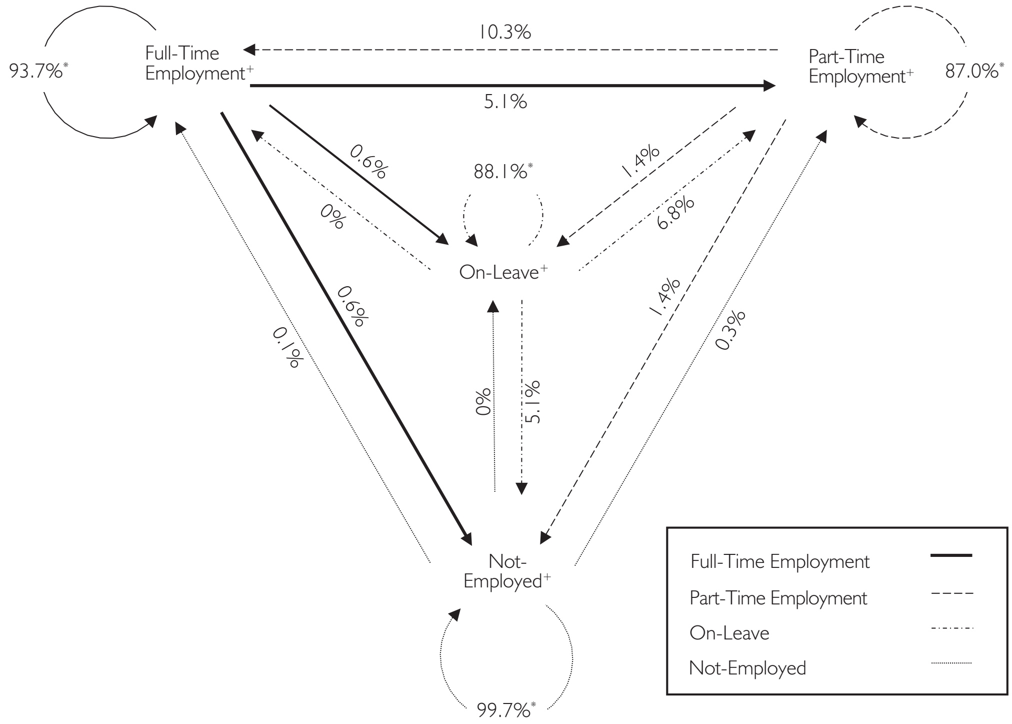
Variable	Value	Total *N* = 262
Age (yrs.)	Mean ± SD	59.15 ± 13.08
	Median (IQR)	59 (52–68)
	≤40	21 (8.0%)
	41–50	37 (14.1%)
	51–60	91 (34.7%)
	61–70	67 (25.6%)
	71+	46 (17.6%)
Gender	Male	79 (30.2%)
	Female	183 (69.8%)
Marital status	Married	189 (72.1%)
	Divorced/Widowed	27 (10.3%)
	Never married	46 (17.6%)
Education	High school or less	67 (25.6%)
	Any university or vocational course	195 (74.4%)
Relationship to care recipient	Spouse	113 (43.1%)
	Child	129 (48.1%)
	Other	20 (7.6%)
Employment status*	Not-Employed	140 (53.4%)
	Part-Time	32 (12.21%)
	Full-Time	62 (23.6%)
	On-Leave	28 (10.7%)
Caregiver's time (number of hours per day)	Mean ± SD	6.29 ± 3.62
	Median (IQR)	6 (4–9)

SD: Standard Deviation, IQR: Interquartile Range
Note: *At baseline

Transitions also occurred in the FT category, however, to a lesser extent than in the PT and On-Leave categories. Although the overwhelming majority (93.7%) of caregivers who were employed FT stayed in this employment category every two weeks over the trajectory, there was some movement in both directions. The highest average transition for those in the FT category was movement to PT employment (5.1%). Finally, the least amount of transitions, and thereby the largest amount of inertia, occurred in the Not-Employed category. On average, 99.7% of caregivers remained in this category every two weeks.

Overall, 93.7% of caregivers employed FT stayed FT, and this was true for both spouses (92.8%) and adult-child caregivers (94.1%; $p = 0.61$). Differences were observed for PT caregivers, with a higher proportion of transitions among adult-child caregivers (90.9%) compared to spousal caregivers (83.1%) who stayed as PT ($p = 0.21$) and the proportion of adult-child caregivers transitioning from PT to FT was also insignificant ($p = 0.14$). Just over half (51%) of all interviewees were spouses and 43% were adult-child caregivers.

FIGURE 1. Changes in LFP over study trajectory (two-week transitions from baseline to end of follow-up; n = 1,700 interviews)

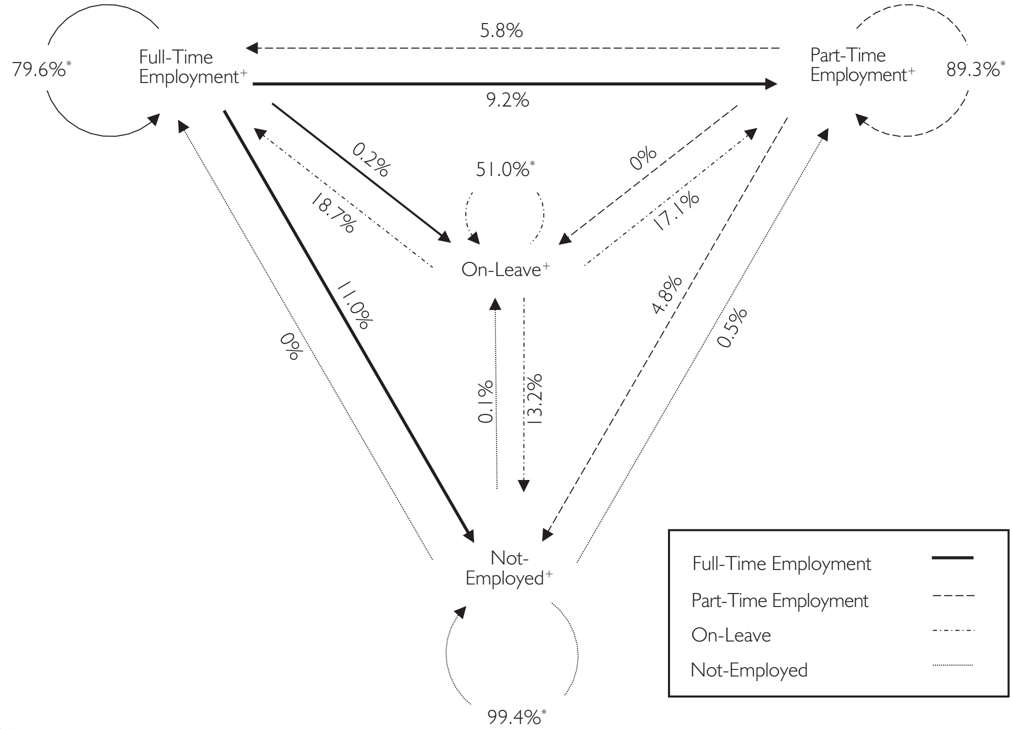


* Stayed in category and did not transition
\+ Employment category at baseline

Figure 2 presents the cumulative proportion of time spent by a caregiver in each of the four employment categories over the two-week observation periods (i.e., from admission into the palliative program until death) relative to baseline employment. These data reflect calculations of the average transition in employment, every two weeks, over the palliative trajectory. Caregivers who were On-Leave at the start of the observation period spent the least amount of time in this category, compared to the other employment categories. These individuals spent half of their time staying On-Leave (51.0%), 35.8% of their time being employed either FT or PT and 13.2% of their time in the Not-Employed category over the course of the palliative care trajectory. Those caregivers who started in FT employment spent 11.0% of their time being Not-Employed and 9.2% of their time in PT employment. In contrast, all of the caregivers who were Not-Employed at the baseline spent almost all of their time (99.4%) in this initial state throughout the trajectory.

Figure 3 presents the transitions in employment categories that occurred prior to admission to palliative care, which is also consistent with their entry into the study. The largest percentage of change was observed for caregivers employed FT, where 50% of caregivers who were FT in the past had subsequently made an employment change prior to entering the study; almost equal percentages moved into PT (14.5%), On-Leave (18.6%) and Not-Employed (16.9%). While 50% of those who were FT did not make a transition prior to

FIGURE 2. Cumulative proportion of time spent in each of the four employment categories relative to baseline employment



* Stayed in category and did not transition
+ Employment category at baseline

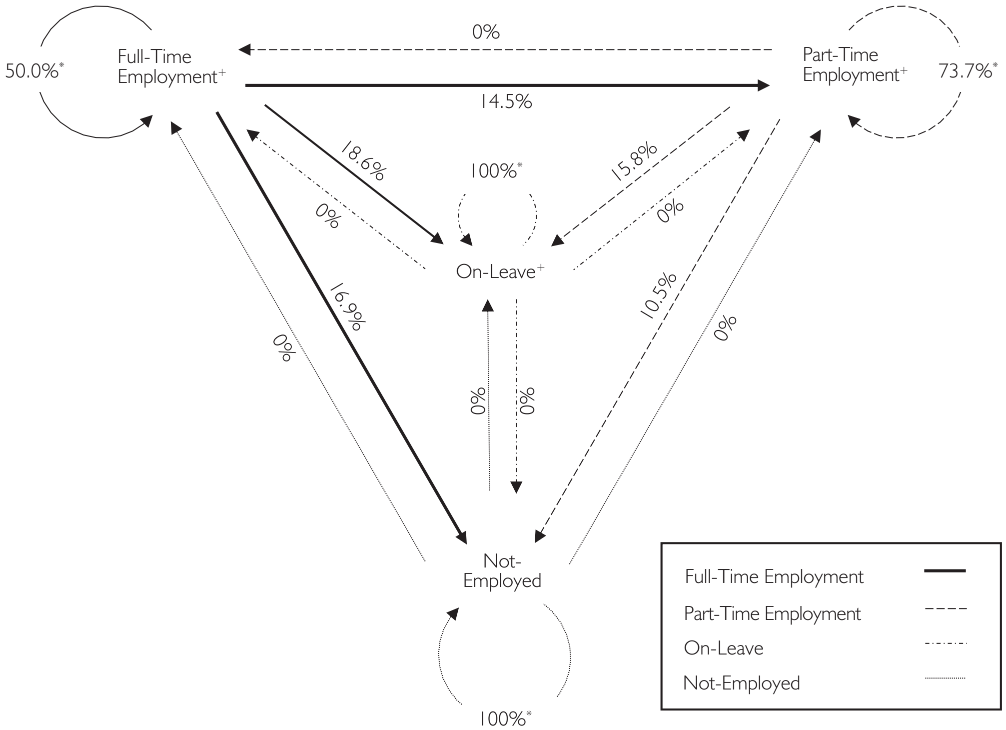
study entry, more inertia was observed for PT employed caregivers, where 74% did not transition into another employment category prior to the baseline. Of those who did transition out of PT employment, 15.8% went On-Leave and 10.5% became Not-Employed. No change in employment status occurred for caregivers who were either On-Leave or Not-Employed prior to entering the study.

While Figure 1 shows that little biweekly movement occurred into the On-Leave category during the observation period, Figure 3 demonstrates that 18.6% of FT employed caregivers and 15.8% of PT employed caregivers moved to the On-Leave category prior to the baseline.

Discussion

This prospective, longitudinal study examined transitions in a caregiver's employment status over the course of a palliative care episode and makes two main contributions. First, changes over time in the state of employment and the effect of family caregiving in palliative care on both the ability to work and the intensity of LFP (FT/PT) can be assessed (Hyslop 1999). Second, characterization of the transitions that occur permits estimation of longer term effects on employment categories that, in turn, incorporate the effects of employment interruptions on those states. While the aim of palliative care has evolved over time and now often

FIGURE 3. Changes in LFP prior to study entry ($n = 262$ caregivers)



* Stayed in category and did not transition

includes early intervention, it is crucial to understand the associated implications for caregivers and the impacts on their employment transitions after adjustment for other covariates.

In our study, there were transitions between employment categories as well as between hours of work, from more hours to fewer or no hours of work. As a caregiver becomes more comfortable with the palliative care environment, and as patients become clinically stable, caregivers might feel able to return to higher levels of employment. On the contrary, during intense caregiving demands, caregivers might reduce their hours of work or resign.

While it would be useful to compare our findings concerning caregiver employment transitions to other studies, this is challenging as most other studies obtained only a one-time assessment of LFP without consideration of specific changes in either employment or hours of work, and most were not in the palliative setting. With these differences in mind, we briefly discuss previous research herein to contextualize and highlight our results.

In our study, we observed that on average, 5.1% of FT caregivers transitioned to PT employment over each two-week period (Figure 1). To our knowledge, no previous study in palliative care has assessed this particular transition. In the non-palliative care context, de Moor et al. (2017) found that 2.5% of caregivers of cancer survivors transitioned from FT to PT (de Moor et al. 2017). This discrepancy in findings may be explained by the difference in the period of caregiving. Caregivers of palliative patients may be more willing to move into part-time work, as the transition is temporary, in contrast to that for caregivers with long-term responsibilities.

In our study, transitions into the Not-Employed category were observed both during the observation period (Figure 1) and prior to the patients entering palliative care (Figure 3). Three end-of-life care studies found that the impact of caregiving on labour market attachment was much lower than that in our study. According to the three studies, only 2% of caregivers quit their job due to caregiving (Grunfeld et al. 2004), 11% quit or took time off work (Covinsky et al. 1994) and 8% resigned (Rossi et al. 2007). This contrast to our findings may be because of the transitions over time and the movement in and out of employment categories that we observed and that were not assessed in the other three studies.

In our study, we observed movement into On-Leave for caregivers in both the FT and PT categories (Figure 1). In the literature, 8–13% of caregivers reported going on-leave while caregiving for individuals with life-threatening illness (Covinsky et al. 1994; Cui et al. 2014) and in the non-palliative context (de Moor et al. 2017). Although these findings were higher than those in our study, it is important to note that in these studies, transitions were not captured at regular intervals and transitions going in both directions between not-employed and employment were not measured.

One important public and private policy goal is to foster an environment in which caregivers, including palliative caregivers, are able to either maintain their attachment to the labour force during episodes of caregiving or return to work (and/or enhance their intensity of LFP) once their episode of caregiving has concluded (Employer Panel for Caregivers 2015). Both public service agencies and private businesses have roles to play to advance this goal. First, employers can introduce flexible workplace attachment procedures that would be beneficial for all parties. Identifying which employees are caregivers and understanding the factors that influence employment transition among them is essential for planning. This is especially pertinent in the context of palliative care, as caregiving tends to occur over a relatively short period of time, compared to chronic, long-term caregiving contexts. During that critical window, support to employees in terms of workplace and leave flexibility have the potential to be beneficial to both businesses and employees. Second, by identifying how the provision of health and social care services impact caregivers' employment transitions, opportunities to simultaneously advance social and health policy as well as labour policy exist. Indeed, the judicious targeting of social and healthcare services, such as respite care, may assist palliative caregivers in their maintenance of employment. The provision of a broad range of business and public service supports may allow caregivers to move into PT employment so that they may balance their work responsibilities and their caregiving demands. This highlights the potential for important public–private partnerships in the caregiving arena rather than merely a singular public or private sector solution.

As family caregivers are fundamental to the delivery of effective home-based palliative care, it is important to ensure that they are supported. Previous research in oncology and palliative care have pointed to the fact that family caregivers are still an underserved population (Zavagli et al. 2019). Developing and implementing policies and procedures that help to alleviate the burden for family caregivers is crucial to the delivery of compassionate palliative care. Employers who support transitions during the palliative trajectory not only enhance the well-being of caregivers but also allow palliative patients to receive effective, compassionate care from their loved ones.

Developing better models of palliative care that recognize the needs of family caregivers is an important focus for governments and healthcare institutions. Although employment insurance for compassionate care benefits exist, further attention to the role of employers is essential to support employed caregivers. Incorporating employment supports for family caregivers into home palliative care programs will allow for a more systematic and comprehensive approach to substantiate the critical role played by family caregivers.

Effective (multi-way) communication between health and social care providers and family caregivers is well recognized in the literature to advance a range of goals (Seow and Bainbridge 2018). Such discourse may address the well-being of the caregiver, including actions and supports to help them sustain employment. Ensuring that health and social care providers consider the employment status of the primary family caregiver when assessing and planning the formal care needs of palliative patients will contribute to the maintenance of employment. In addition to communicating about the patients' care, healthcare professionals can include discussion on caregivers' employment obligations and needs when planning formal care delivery. Directives are needed specifically for family caregivers in the palliative care realm. Programs such as short-term paid leave allow caregivers to provide home-based care to their ailing family member, with the assurance that they can return to the same level of employment after they fulfill their responsibilities. Furthermore, the reassurance that employees can leave to provide care without compromising their employment position and stability acts as an incentive for them to fulfill their responsibilities and return to work. These actions are likely to reduce substantially the number of caregivers who retire early due to caregiving responsibilities (Jacobs et al. 2017).

Limitations

There are three main limitations to this study. First, the data collected through interviews relied on self-reports by the participants, which introduced the possibilities of social desirability bias and non-response bias (Norman and Streiner 1986; Zarit et al. 1980). However, all the interview data were kept confidential, and we found that telephonic interviews minimized the chance of missing data, thereby reducing the possibility of non-response bias. The second limitation lay in the potential lack of generalizability of the findings. The participants were drawn from two palliative care programs, and therefore, the findings may not necessarily apply to patients receiving services outside of these programs. However, the populations served are quite diverse in terms of their clinical, demographic and ethnic backgrounds, which may help to improve the generalizability of the findings. The third limitation was the potential for selection bias. But this bias was likely negligible given the similarity between the caregivers in the study and both the broader population of all caregivers in Canada based on gender, age and marital status (Government of Canada 2004) and the caregivers in other studies based on age, gender and relationship to the patients (Holley and Mast 2009; Macchi et al. 2020; Pinto et al. 2018).

The transitions that occurred between the various categories of LFP identified in our study are quite noteworthy. Our study shows that there are significant opportunities open to healthcare professionals, employers and public policy makers to support employed caregivers balance their twin roles in employment and at home. As the number of working family caregivers increases and their caregiving trajectories become longer, employers will need to adapt and accommodate their needs and work in partnership with health and social care agencies. Our study was designed to inform strategies that evaluate and enhance the delivery of home-based palliative care services, which may lead to the containment of labour force losses.

Correspondence may be directed to: Denise Guerriere, PhD, Institute of Health Policy, Management and Evaluation, University of Toronto, 155 College Street, Toronto, ON, M5T 3M6. She can be reached by e-mail at Denise.guerriere@utoronto.ca.

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RESEARCH PAPER

Reallocating Cancer Surgery Payments for Alternate Level of Care in Ontario: What Are the Options?

Réaffectation des paiements pour les chirurgies oncologiques à un autre niveau de soins en Ontario : quels sont les choix?

JUDITH WONG, MA
Methodologist
Ontario Health (Cancer Care Ontario)
Toronto, ON

SHANNON MILROY, MA, MSc
Health Economist
Ontario Health (Cancer Care Ontario)
Toronto, ON

KATHERINE SUN, MPH
Senior Analyst
Ontario Health (Cancer Care Ontario)
Toronto, ON

PIERRE IORIO, MSc
Methodologist
Ontario Health (Cancer Care Ontario)
Toronto, ON

MAY SETO, MLT
Group Manager
Funding Unit
Ontario Health (Cancer Care Ontario)
Toronto, ON

JULIA MONAKOVA, PhD, MPP
Group Manager
Funding Unit
Ontario Health (Cancer Care Ontario)
Toronto, ON

JASON M. SUTHERLAND, PhD
Faculty, UBC Centre for Health Services
and Policy Research
Professor, UBC School of Population and Public Health
University of British Columbia
Vancouver, BC

Abstract

This article examines how alternate-level-of-care (ALC) days are funded through the cancer surgery funding model in Ontario and evaluates policy options to better address ALC days. The contribution of ALC days to hospital funding and the impact of removing or reallocating this funding from cancer surgery is measured. Though costs associated with ALC days in cancer surgery are low, this article highlights the need for policy options that would realign funding across the healthcare system in Ontario to better meet the needs of patients waiting for ALC, reduce pressure on inpatient bed capacity and improve value for money.

Résumé

Cet article examine comment les journées d'hospitalisation d'autres niveaux de soins (ANS) sont financées grâce au modèle de financement pour les chirurgies oncologiques en Ontario et évalue les choix stratégiques pour mieux traiter la question des journées ANS. On y mesure la contribution des journées ANS au financement des hôpitaux ainsi que l'impact de la suppression du financement pour les chirurgies oncologiques ou de sa réaffectation. Bien que les coûts associés aux journées ANS en chirurgie oncologique soient faibles, cet article met en évidence le besoin de stratégies politiques pour réaligner le financement dans l'ensemble du système de santé de l'Ontario afin de mieux répondre aux besoins des patients en attente d'ANS, de réduire la pression sur la capacité des lits d'hôpital et d'améliorer l'optimisation des ressources.

* * *

Introduction

In Canadian provinces, when a patient no longer requires the intensity of resources or services provided in acute care, but is waiting to be discharged to a more appropriate care setting, the patient is designated as needing alternate level of care or ALC (CIHI 2009, 2012; Sutherland and Crump 2011, 2013). ALC is a long-standing challenge across hospitals in Ontario, with negative impacts including patients not receiving care most suited to their needs, decreased hospital capacity to admit new patients and higher costs to the health system. ALC is not exclusive to Canada; the Netherlands, England, Spain and Italy have all reported issues with delayed discharge (Landeiro et al. 2017; National Audit Office 2016).

There are significant health and financial impacts of not discharging patients who no longer need the intensity of care provided in an acute-care hospital bed (Costa and Hirdes 2010). In the fiscal year 2015–2016 (April 1, 2015, to March 31, 2016), 13.9% of inpatient bed days in Ontario, Canada, were occupied by patients waiting for an alternate setting of care (Health Quality Ontario 2017). This percentage equates to an average of 3,961 hospital beds per day in Ontario (Health Quality Ontario 2017) at a cost of over $4 million per day or over $1.5 billion per year (based on an estimated cost of C$1,090 [as of 2016] per ALC bed day; Sutherland et al. 2019).

Excessively long hospitalizations are an ineffective use of scarce hospital resources, leading to denial of beds to waiting patients; recent statistics from a number of Canadian provinces have shown hospital occupancy rates at over 100% (CBC News 2016; Grant 2017; Ontario Health Coalition 2017). In Canadian hospitals with the highest occupancy rates, up to one-third of the beds are filled with patients designated ALC (Lavergne 2015; McCloskey et al. 2014), and some small community hospitals have reported even higher rates. For patients, longer hospitalization while waiting for ALC is associated with increased risk of functional decline (Manville et al. 2014; McCloskey et al. 2014) and adverse events (Baker et al. 2004). Moreover, patients designated ALC have reported feelings of guilt, being undeserving of staff attention (McCloskey et al. 2015), stress due to the uncertainty of the discharge process (Cressman et al. 2013; Kuluski et al. 2017), social isolation and physical and mental stagnation due to prolonged hospital stays (Wilson et al. 2013).

The causes of ALC days are complex, including potential patient, hospital and community factors. A lack of adequate community care is often cited as the most common cause because hospitalized patients may not have a discharge location in the community where their care needs can be safely met, or their preferred discharge location may not have beds available (Afilalo et al. 2014; Costa and Hirdes 2010; Jutan et al. 2013; McCloskey et al. 2014). Processes within hospitals may play a role as well, including the underestimation of patients' potential for independence, the deconditioning of patients while in hospital and hospital staff's lack of understanding of home care (Bender and Holyoke 2018).

Hospital funding in Ontario

In Ontario, the Ontario Ministry of Health (MOH) provides funding for hospitals through regional health authorities called Local Health Integration Networks (LHINs). Cancer Care Ontario (CCO), now a division of Ontario Health – an agency funded by the MOH – finances hospitals for cancer and renal care.

Approximately 55% of hospitals' public revenues are based on global budgets set by the MOH (Palmer et al. 2018). Approximately 30% of revenues are based on Ontario's Health-Based Allocation Model, a proportional allocation of funding based on hospitals' case mix, relative cost-efficiency, market share and volume (Ontario Ministry of Health and Long-Term Care 2011). The final 15% of revenues are funded by the MOH or CCO on a per-case basis for 20 service groups, called Quality-Based Procedures (QBPs) (Palmer et al. 2018).

The cancer surgery QBP is one of the volume-based QBPs funded by CCO. The scope of QBP-funded cancer surgery activity spanned four cancer disease sites in the fiscal year 2016–2017: colorectal, prostate, breast and thyroid surgeries. The transition of all cancer surgery disease sites to volume-based QBP funding was completed in fiscal year 2019–2020 (Ontario Ministry of Health and Long-Term Care 2019).

For the Cancer Surgery QBP, hospitals receive per-case funding from CCO based on the provincial price per weighted unit and the hospital's average weight per case for each disease site. CCO sets the provincial price per weighted unit following MOH guidelines (Ontario Ministry of Health and Long-Term Care 2013). For inpatient surgeries, the funding amount remunerates the hospital for the episode of care, including the procedure and inpatient stay. The funding amount does not include community-based health services such as post-discharge home care or long-term care, which are funded separately by the MOH.

Funding and incentives

Given that Ontario hospitals operate within a system of multiple decision makers, including patients, clinicians and senior administrators, and varying incentives created through different revenue sources, Ontario's hospital funding policies may contribute to the problem of ALC days.

The per-case funding calculation includes incremental hospital funding for ALC days, as each patient's case weight increases with additional ALC days. This policy has two undesirable consequences. First, the funding models do not address the issue of ALC directly as funding is spread across multiple envelopes, making the financial incentives to the hospitals unclear and giving no direct incentive to home care or long-term care to take on ALC patients. Second, by including ALC days in QBP funding for cancer surgery, the distribution of funding to hospitals is distorted, increasing funding to hospitals with more ALC days rather than for more complex cancer patient or surgery characteristics.

ALC days do not provide good value for money, as patients are not being served in the most appropriate setting for their care needs and acute care is costlier than community care. In many countries, value-for-money concepts have been embedded in funding formulas and nonpayment based on quality measures is becoming more common. In the US, a medicare policy reduces payments to hospitals for excessive readmissions (Desai et al. 2016; Zuckerman et al. 2016), and the National Health Service in England uses a similar hospital-based policy (Kristensen et al. 2014). In Germany, hospital readmissions for the same reasons or for complications of treatment are not remunerated (Kristensen et al. 2014), and in Australia, incremental hospital costs attributable to avoidable events are not remunerated (Independent Hospital Pricing Authority 2018).

Given the provincial policy goals of reducing ALC days and increasing acute inpatient bed capacity, there is a need for policy options that would realign funding to better meet the needs of patients waiting for other settings of care, reduce pressure on inpatient bed capacity and improve value for money. The purpose of this study is twofold: first, to untangle the financial impact of funding ALC days within cancer surgery episodes and, second, to assess funding policy options. Aligning funding policies with improving patient and health system outcomes aims to generate renewed interest in policy and decision makers to tackle an endemic problem in Canada.

Data and Methods

For QBP-funded cancer surgeries, inpatient hospital discharge summaries from the Discharge Abstract Database (DAD) are used for the fiscal year 2015–2016. Breast and thyroid surgeries may also be performed in an outpatient setting, but as these cases are not relevant to ALC, they have been excluded from the analysis.

Eligible QBP-funded cases are identified from the DAD dataset using diagnosis and intervention codes (Ontario Ministry of Health and Long-Term Care 2019). Each discharge summary includes a variable for whether the hospitalization was scheduled or emergent. Cases ineligible for QBP funding are excluded (pediatric cases, non-residents of Ontario, those ineligible for provincial insurance and those whose surgeries were cancelled or abandoned; Ontario Ministry of Health and Long-Term Care 2019).

Each inpatient discharge summary includes variables for length of stay and the number of ALC days. ALC designation is defined the same way for cancer-related hospitalizations as for non-cancer-related hospitalizations. Each hospitalization includes a case weight assigned by the Canadian Institute for Health Information's (CIHI) case mix algorithm. The financial impact of removing ALC days from cancer surgery QBP funding cannot be calculated by simply multiplying the average cost of an ALC bed day by the number of ALC days – it requires recalculating each component of the QBP funding methodology, excluding costs associated with ALC.

Cancer surgery QBP pricing

Funding per case for each cancer disease site in the cancer surgery QBP is based on the product of the provincial price per weighted case ("base" price) and each hospital's average weight per case or case mix index (CMI). The base price is set for each disease site based on average costs reported in Ontario Case Costing Initiative (OCCI) data, which is Ontario's repository of retrospective patient-level cost data generated by a sample of hospitals (Wodchis et al. 2013). This case costing data includes patients' costs for each applicable cost centre (department). CCO adjusts the cost data to remove hospital-specific factors expected to impact cost, including teaching hospital status, proportion of tertiary cases and rurality. Eligible patients' hospitalization costs are then divided over the sum of their weighted cases to obtain the cost per weighted unit (base price) and scaled to fit the available funding envelope.

Hospital CMIs

The CMI is a continuously valued variable that reflects a hospital's case mix, or the average weight of its cases in the same QBP and disease site. For each disease site, each hospital's CMI is calculated as the average weight per case among eligible cancer surgery cases. Hospitals' CMIs are updated each fiscal year for each disease site.

Removing ALC costs

First, the case weights are recalculated excluding ALC days from patients' hospitalization weight calculation. This calculation is achieved by using CIHI's case weight calculation algorithm and subtracting the ALC portion of the stay from the total length of stay.

There are three ways by which the removal of ALC days impacts inpatient case weights: the category into which each case is assigned determined by length of stay (long stay outlier status), the number of days beyond the length of stay trim point and additional case weight adjustments for flagged interventions that are based on the length of stay percentile. Revised case weights are applied to hospitals' activity to calculate hospitals' average CMIs while excluding ALC days.

The second step is to remove ALC costs from the base price calculations. The base price is recalculated by removing ALC costs from the total cost calculations in OCCI and by dividing these costs with the revised total weighted cases. Finally, the available funding envelope is recalculated based on the revised total weighted cases, and the base price is then scaled to fit the revised total available funding for cancer surgery.

To remove patients' costs associated with their ALC days, ALC days are assumed to occur at the end of each stay. This assumption is necessary because the DAD does not distinguish acute days of stay from ALC days. It is possible that ALC days may not occur at the end of the patient's stay if, for example, they are designated ALC but subsequently experience a deterioration in health that designates them acute for a second time during the same hospitalization. The cost of ALC could then increase if some of the acute days' costs are assumed to be costs of ALC days. Also, in the OCCI data, a number of inpatient departments' costs, such as laboratory and pharmacy expenses, could not be separated from the ALC days' costs. These costs were retained in the patients' hospitalization costs, which may understate the impact of removing ALC.

In a third step, the funding amounts received from QBP for hospitals' cancer surgeries are recalculated based on the hospitals' revised CMI values and revised base price multiplied by their case volumes, and the difference between the original and revised funding amounts are noted as the impact of removing ALC days. The total number of QBP-funded cancer surgeries and the sum of ALC days are calculated to illustrate the magnitude of the impact on cancer surgery funding. The policy's effect on QBP prices and hospitals' funding is examined by region (i.e., the LHIN) to measure impact.

A simplified version of this methodology is then applied to all cancer and non-cancer QBPs in the fiscal year 2016–2017, for which technical specifications were available (as of fiscal year 2017–2018) to estimate total provincial spending on ALC days through QBP payment models. The simplified methodology recalculates CMIs for each QBP when excluding ALC days and multiplies the change in CMI by the base price and total cases for each QBP. The QBP base prices are not recalculated, given the negligible change in base price observed after recalculating the base price for colorectal cancer surgery.

Results

As shown in Table 1, the number of ALC days included in cancer surgery cases ranged from zero to 2,369 in the fiscal year 2015–2016, with QBP-funded colorectal cancer surgeries having the highest number of ALC days among cancer surgery disease sites. For colorectal cancer surgery, 4.3% of the total days of stay were designated ALC in 2015–2016, less than half the overall Ontario proportion of 13.9% of acute inpatient bed days. Subsequent analyses focused on the impact of ALC days associated with QBP-funded colorectal cancer surgery, as the number of ALC days associated with the other QBP-funded cancer surgeries was negligible.

TABLE 1. Number of ALC days by disease site for fiscal year 2015–2016

QBP-funded cancer surgery disease site	Number of eligible QBP cases	Total days of stay	ALC days	Ontario Average CMI
Colorectal	6,501	54,937	2,369	2.58
Prostate	2,405	5,726	0	1.44
Breast (with immediate reconstruction)	616	1,458	0	1.71
Breast (without immediate reconstruction)	2,299	3,405	70	0.98
Breast (delayed reconstruction)	378	1,093	5	1.78
Thyroid	3,451	5,436	42	0.83

As shown in Table 2, patients undergoing emergency, rather than elective colorectal surgery, were most likely to be designated ALC ($p < 0.01$). This finding is consistent with that of some other studies, which report that emergent cases have longer lengths of stay and are more likely to have complications such as surgical site infection, evisceration and anastomotic leakage (Bayar et al. 2016).

TABLE 2. Admission category for colorectal cancer surgery cases with and without ALC days, fiscal year 2015–2016

Admission category	Cases without ALC days	Cases with ALC days	Total	*P*-value
Scheduled/Elective	5,254 (83.8%)	108 (46.8%)	5,362	<0.01
Urgent/Emergent	1,016 (16.2%)	123 (53.2%)	1,139	

Changes in the CMI associated with the removal of hospitals' ALC days from QBP-funded colorectal cancer surgery resulted in a decline in the average CMI of 0.05 (1.94%), from 2.58 to 2.53. As shown in Table 3, there was variation in average CMI between regions.

Removing ALC days from the payment amount resulted in an increase in the base price of $0.76 (from $5,203 to $5,204 or 0.01%). The small increase is attributable to removing ALC from the numerator and denominator in recalculating the cost per weighted unit.

As shown in Table 4, Ontario spent over $87 million on hospitals' colorectal surgeries in fiscal year 2015–2016. Removing QBP funding for ALC days would reduce spending on QBP-funded colorectal cancer surgery by almost $2 million for fiscal year 2015–2016 activity, or 2.25% of CCO's total payments to hospitals for their QBP-funded colorectal cancer activity. Divided across the 2,369 ALC days associated with these surgeries, the funding amount was $829 per ALC day.

TABLE 3. Effect of removing ALC days on hospitals' and LHINs' CMI, fiscal year 2015–2016

Local Health Integration Network (LHIN)	Average CMI – including ALC days	Average CMI – excluding ALC days	Average Hospital change	Range of hospital change (min., max.)
Overall	2.58	2.53	-0.06	(0, -0.67)
Erie St. Clair	2.54	2.46	-0.04	(0, -0.14)
South West	2.52	2.48	-0.05	(0, -0.24)
Waterloo Wellington	2.56	2.54	-0.01	(0, -0.04)
Hamilton Niagara Haldimand Brant	2.90	2.81	-0.08	(-0.01, -0.25)
Central West	2.42	2.33	-0.05	(0, -0.10)
Mississauga Halton	2.48	2.42	-0.09	(-0.02, -0.17)
Toronto Central	2.68	2.65	-0.04	(-0.00, -0.18)
Central	2.51	2.40	-0.10	(-0.04, -0.16)
Central East	2.56	2.54	-0.02	(-0.00, -0.03)
South East	2.56	2.51	-0.11	(0, -0.37)
Champlain	2.57	2.48	-0.07	(0, -0.41)
North Simcoe Muskoka	2.45	2.43	-0.02	(0, -0.10)
North East	2.47	2.43	-0.12	(0, -0.67)
North West	2.27	2.26	-0.00	(0, -0.01)

The largest absolute change in cancer surgery funding was in the Central LHIN, the region with the highest amount of ALC days, corresponding to a total decrease of over $400,000 and approximately 4.5% of CCO's funding for colorectal cancer surgery in this region. At the same time, a number of regions, such as the North West LHIN, had few ALC days and the absolute and relative impact would be small, less than $5,000 and less than 0.30% of funding.

Total provincial spending on ALC days across all cancer and non-cancer QBPs was estimated at over $100 million per year in Ontario, with wide variation between QBPs in the proportion of inpatient days that were designated ALC and the proportion of QBP funding attributable to ALC days.

Discussion

CCO spends $829 per ALC day or about $2 million per year on QBP-funded colorectal cancer surgery. This funding amount is based on 4.3% of days being designated ALC among QBP patients, a proportion substantially lower than the provincial average of 13.9% of total inpatient days. The proportion of ALC days was even lower for the other cancer surgery disease sites examined in 2015–2016. It should be noted that this study did not examine factors such as age or comorbidities of patients, and it is possible that ALC rates among cancer surgery patients may be higher than the provincial average after accounting for these factors.

TABLE 4. Financial impact of removing payment for ALC days from colorectal surgery funding, fiscal year 2015–2016

Local Health Integration Network (LHIN)	Funding for colorectal surgery, including ALC days	ALC days	Impact of removing ALC Days	Percentage impact of removing ALC days
Overall	**$87,414,461**	**2,369**	**-$1,963,757**	**-2.25%**
Erie St. Clair	$4,049,585	137	-$137,210	-3.39%
South West	$7,798,469	67	-$93,776	-1.20%
Waterloo Wellington	$4,369,091	50	-$34,783	-0.80%
Hamilton Niagara Haldimand Brant	$12,256,171	453	-$372,746	-3.04%
Central West	$2,797,318	86	-$104,520	-3.74%
Mississauga Halton	$5,614,399	152	-$116,380	-2.07%
Toronto Central	$11,447,313	145	-$120,905	-1.06%
Central	$8,983,965	469	-$402,853	-4.48%
Central East	$9,365,382	152	-$74,224	-0.79%
South East	$3,339,292	63	-$63,907	-1.91%
Champlain	$8,836,149	416	-$334,309	-3.78%
North Simcoe Muskoka	$3,072,856	47	-$30,366	-0.99%
North East	$4,093,162	115	-$73,551	-1.80%
North West	$1,391,303	17	-$4,220	-0.30%

Although QBP funding increases with increased ALC days, the myriad funding and cost incentives faced by hospitals and care providers make it difficult to assess the impact of any single funding policy. The variation in ALC rates between both disease sites and regions suggests that the QBP funding model is not a primary driver of ALC days among QBP patients.

Though this study did not find evidence that the QBP funding model is driving worse outcomes than the provincial average with respect to ALC days, it is also clear that the funding model does not fully align with its stated goals. Because the CCO Cancer Surgery QBP funding model aligns with the methodology for all MOH-managed QBPs, the implications of this model apply to all CMI-based QBP funding models. The QBP Clinical Handbook states that "QBPs incent healthcare providers to become more efficient and effective in their patient management by adopting clinical best practices that ensure Ontarians get the right care, at the right time, and in the right place" (Ontario Ministry of Health and Long-Term Care 2019). For hospitals, incremental funding for ALC days does not incent either efficiency or ensuring that their patients get care in the right place. For CCO and the MOH, a policy of removing ALC from QBP funding would disentangle funding on QBPs from funding for ALC days, which are a health system challenge much broader in scope than individual procedures. Embedded funding for ALC days means that, should the broader issues of unmet ALC needs persist or worsen, CCO and the MOH risk rising per-case

QBP costs, which would in turn reduce the number of cases that can be funded within a finite funding envelope.

An advantage of working to realign funding policies to better address ALC needs among QBP patients is that the funding policy is already designed to provide incremental per-case funding, and the amount currently spent on ALC days can be estimated using the methodology developed in this study. Policy options framed in terms of better allocation of current spending may be politically more feasible than options where additional investment is required and potential cost savings are unknown. This study estimated that funding for ALC days across all cancer and non-cancer QBPs is over $100 million per year. Realigning QBP funding models to better address ALC could improve funding efficiency and care outcomes for QBP patients, and potentially yield lessons for how to better support the non-QBP patient population waiting for ALC.

There are several policy options for realigning QBP funding to better address ALC needs. Given the relatively small proportion of ALC days funded through any individual QBP, and the complexity of the funding and other incentives at work, coordinated provincial action to reduce ALC is needed, including applying multiple funding and non-funding policy changes in concert. Policy options include removing incremental funding for ALC days from QBP funding formulas, redirecting current QBP spending to the home and community care sectors and creating bundled payments for acute and post-acute care.

Removing incremental funding for ALC days from QBP case weight calculations would disentangle patients' ALC needs from their QBP episode needs, separating and making transparent the funding drivers. Making this policy change alone shifts the financial risk associated with the ALC portion of hospital care from QBP funding envelopes to hospital budgets. Hospitals may in turn work to transfer this risk to the MOH through requests for increased non-QBP funding, or to patients through increased discharge pressure. Among QBPs with a higher risk of ALC days, it is also possible that hospitals may choose to avoid the financial risk by not accepting QBP patients or funding.

A complementary funding policy change redirecting current QBP funding for ALC days to the home and community care sectors has the advantage of boosting capacity in the areas where patients with ALC needs would be more appropriately served. Long-term care is the most common discharge location for patients designated ALC, but home care and supportive housing play an important role too (Health Quality Ontario 2017). As costs of delivering care are generally lower outside the acute hospital setting, cost savings per patient day could potentially be achieved. However, increased funding to home and community care providers alone does not remove the financial risk that hospitals would incur if ALC funding is removed from hospital funding formulas. As previously noted, QBP funding accounts for a minority of ALC days, so redirecting QBP funding alone is unlikely to fully meet the broader capacity challenges in home and community care. Hospitals may still incur financial risks when treating QBP patients with a high probability of waiting for ALC.

One potential resolution to the competing financial risks and incentives between CCO, the MOH, hospitals and community providers may lie with the recent initiatives to pilot bundled payments covering acute and community care. The current health system funding is predominantly siloed, with separate funding streams for hospital services and other aspects of the patients' continuum of care. Making hospitals the primary fund-holders for bundled payments may allow them to more effectively manage the financial risks associated with long waits for ALC by purchasing post-acute care for patients in a variety of settings, such as long-term care and home care. Care providers would also have the flexibility to invest bundled payments in other ways that could potentially reduce hospital length of stay, such as enhanced discharge planning or rehabilitation services.

The finding that patients undergoing emergency rather than elective colorectal cancer surgery were more likely to have ALC days suggests that there may also be areas for improvement in patients' pre-surgery care. Improvements in the screening and diagnosis stages of the cancer care path may reduce the frequency of emergency surgeries, leading to improved patient outcomes in many areas, including ALC. This finding may also indicate a correlation of multiple access issues for subgroups of patients (i.e., weaknesses in access and referral to cancer services, as well as home and community supports). Although further research should be undertaken to explore the needs of these patients, it should also be noted that the majority of ALC days for colorectal cancer surgery patients were among patients who had elective surgery, as these comprise the majority of QBP patients.

This discussion has focused on realignment of funding policies to better serve QBP patients. These policy changes would help to remove funding as a potential barrier to providing more efficient and appropriate care. However, they will be ineffective if non-funding barriers such as patient capacity assessments or hospital staff knowledge of home care are driving ALC days (Bender and Holyoke 2018). A comprehensive policy solution will need to explore and address any non-financial barriers to providing patients with care in the most appropriate setting.

Limitation

This study is limited by its focus on cancer surgery cases across four disease sites, primarily colorectal cancer surgery. Relatively few ALC days were observed for these patients; however, an extension of the study's methodology found a larger magnitude of ALC days and QBP funding across all provincial inpatient QBP funding, which rely on the same patient weight calculations. Further research could examine patterns of ALC days across multiple QBPs and explore patient, hospital and regional characteristics that may be driving ALC days.

Conclusion

This study sought to approach the long-standing challenge of ALC days in Ontario hospitals from the perspective of QBP funding policy. The analysis demonstrates that funding for ALC days through QBP-funded cancer surgeries is relatively low. However, there are opportunities to realign QBP-funding policies by removing incremental funding ALC days from the QBP funding formula and reallocating this funding to the home and community care sectors or by combining these two changes by implementing bundled payments that would cover both acute and post-acute care. Funding policy changes implemented across multiple QBPs could create larger financial incentives, and lessons learned from these changes could potentially be applied to ALC days among non-QBP patients. Reducing the number of patients designated ALC and the wait times for ALC would serve both the health system, through more efficient care, and ALC patients, through improved care outcomes.

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Correspondence may be directed to: Jason M. Sutherland, UBC Centre for Health Services and Policy Research, 201–2206 East Mall, Vancouver, BC. He can be reached by phone at 604-822-6812 or by e-mail: Jason.sutherland@ubc.ca.

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RESEARCH PAPER

Catalyzing Digital Health Innovation in Ontario: The Role of an Academic Medical Centre

Catalyser l'innovation en santé numérique en Ontario : le rôle d'un centre médical universitaire

LAURA DESVEAUX, PhD, PT
Scientist, Women's College Hospital
Institute for Health Systems Solutions and Virtual Care
Women's College Hospital
Assistant Professor, Institute for Health Policy
Management & Evaluation
University of Toronto
Toronto, ON

LEAH T. KELLEY, HBSc
Research Coordinator, Women's College Hospital
Institute for Health Systems Solutions and Virtual Care,
Women's College Hospital
Toronto, ON

R. SACHA BHATIA, MD, MBA
Director, Women's College Hospital
Institute for Health Systems Solutions and Virtual Care
Women's College Hospital
Cardiologist, Women's College Hospital
University Health Network
Toronto, ON

TREVOR JAMIESON, MD, MBI
Chief Medical Informatics Officer
Unity Health Toronto, St. Michael's Hospital Site
Medical Director, Virtual Hospital
Women's College Hospital
Toronto, ON

Abstract

Overcoming barriers to health system innovation is an ongoing challenge in Canada. A total of 51 participants attended a digital health symposium in October 2017 to discuss the role of an academic medical centre (AMC) in advancing innovation. The conversation centred around (i) the current state of innovation in healthcare; (ii) the need for an innovation catalyst; and (iii) the roadmap for an AMC to drive change. AMCs can address the barriers to digital health innovation in Canada by providing a centralized network and infrastructure that supports innovation throughout its journey from "bench to bedside" as well as supporting educational reform.

Résumé

Surmonter les obstacles à l'innovation dans le système de santé est un défi constant au Canada. En tout, 51 participants ont assisté à un symposium sur la santé numérique, en octobre 2017, pour discuter du rôle des centres médicaux universitaires (CMA) dans la promotion de l'innovation. La conversation a porté sur (i) l'état actuel de l'innovation dans les soins de santé, (ii) le besoin d'un catalyseur d'innovation et (iii) la feuille de route qui permet à un CMA de provoquer le changement. Les CMA peuvent affronter les obstacles à l'innovation numérique en santé au Canada en mettant en place un réseau et une infrastructure centralisés qui soutiennent l'innovation tout au long de son parcours – du laboratoire au chevet du patient – et en appuyant les réformes de l'enseignement.

Background

Resource constraints and system reform have shifted health system innovation from a want to a need (Becker et al. 2010; Bhatia et al. 2020; Dzau et al. 2013). Implementing innovations, defined as new products, processes, business models, methods of communication or origination of new markets (Bloch 2007; Organisation for Economic Co-operation and Development and Statistical Office of the European Communities 2005), has proven challenging, with few demonstrated examples of successful scale or sustainability. Academic medical centres (AMCs) operate at the intersection of scientific research, implementation and clinical care and are uniquely positioned to become hubs for health system innovations (Dzau et al. 2010). Direct access to patients, derived data and direct insight into unmet clinical needs provide an ideal foundation for meaningful innovation (Dzau et al. 2013).

The need for AMCs to play a role in health system innovation is well-acknowledged (DePasse et al. 2014; Dzau et al. 2013; Ellner et al. 2015; Mann et al. 2019; Ostrovsky and Barnett 2014; Speck et al. 2015). Several strong examples exist across the US (Bhattacharyya et al. 2018; Ellner et al. 2015), where numerous emerging innovations have been adopted nationally and internationally (Ellner et al. 2015). However, operationalizing the role of AMCs in health innovation is challenging: ensuring that resources and infrastructure exist to support the innovation lifecycle across the continuum is a common institutional barrier, especially at the transition from prototype/pilot project to scaled implementation (Speck et al. 2015).

This challenge is exacerbated in digital health, where innovation complexity is driven in part by the collision of fast-paced and dynamic consumer technologies with a conservative, highly regulated and risk-averse healthcare system (Desveaux et al. 2017; Elenko et al. 2015; Peterson and Harrington 2018; Shaw et al. 2018). The evolution of digital innovations in healthcare is stifled by an education system that respects traditional models of care (to the detriment of new models; Carter et al. 2018; Dzau et al. 2013; Ostrovsky and Barnett 2014), lacks formalized implementation training (Carter et al. 2018) and operates in an environment that does not provide the space (physical or otherwise) for innovators to interact with the system (Dzau et al. 2013; Marvel et al. 2018; Mathews et al. 2019).

Despite efforts to detail the nature of these barriers to digital health innovation (Desveaux et al. 2017; Ostrovsky and Barnett 2014; Peterson and Harrington 2018), overcoming them in Canada is an ongoing challenge (Canadian Medical Association 2020), and the role of an AMC in promoting digital health innovation remains unclear. Context-sensitive considerations and relevant stakeholder discussions are critical to advancing the health innovation agenda. To address this need, we invited system leaders involved in digital health innovation to a symposium held in October 2017. The objective of the symposium was to define the role(s) of an AMC in promoting digitally enabled innovation in health, with an emphasis on the Canadian healthcare context.

Method

Setting

The University of Toronto (UofT) Departments of Medicine and Computer Science partnered with the Women's College Hospital Institute for Health System Solutions and Virtual Care (WIHV), to develop a strategy to locally catalyze digital health innovation.

The findings of this study are the result of a policy symposium jointly hosted by UofT and WIHV in Toronto, ON. WIHV is an academic organization based at the Women's College Hospital focused on designing, implementing, evaluating and scaling innovative solutions to healthcare challenges in Ontario, Canada. The Faculty of Medicine at UofT has over 800 faculty members working across nine fully affiliated hospitals, 12 community hospitals and three hospital organizations (Temerty Faculty of Medicine 2018). The Department of Computer Science is one of the top departments in the world, with over 140 faculty members across 16 research areas (University of Toronto 2018). This dialogue coincided with the introduction of a 10-point implementation plan by the Ontario Ministry of Health for a digital health strategy promoting both consumer-focused and health system–focused initiatives (Hussain 2017).

STAGE 1: PRE-SYMPOSIUM INTERVIEWS

To identify the most pressing digital health policy issues in Ontario around which to structure the symposium, brief interviews were conducted, with key informants purposively sampled for their familiarity with the interaction between AMCs, digital health innovation and the public health system in Toronto, ON (Appendix 1, available online at longwoods.com/content/26353). These individuals included leaders in digital health research, health policy, computer science, data analytics, and health system innovation. Interviews explored barriers to successful spread and scale of digital health innovations to help the research team identify priority areas for discussion during the symposium. Rapid inductive coding was used to identify key barriers that informants felt should be prioritized: (i) the lack of infrastructure around innovation; (ii) the need for evidence to link into decision making, (iii) funding challenges; and (iv) the unclear role of AMCs. These themes shaped the topics to be discussed during the symposium.

STAGE 2: SYMPOSIUM

To support the development of a strategy to address the barriers identified in the pre-symposium interviews, the researchers took a qualitative deliberation approach in which relevant participants are engaged to discuss reasons for and against various courses of action (Abelson et al. 2003). Deliberation techniques are commonly used for health priority setting and governance and planning of health services, including digital health (Degeling et al. 2015). Deliberations share a common structure, in which participants are presented with information about the issue at hand; they discuss and debate that issue and, in consideration of all participants' input, they conclude with strategic recommendations moving forward (Abelson et al. 2003).

Participants

A total of 51 participants attended the symposium by invitation only. There are three potential types of participants in public deliberation of health policy: citizens, consumers and advocates (experts and interest groups; Degeling et al. 2015). This symposium involved deliberation among advocates. Purposive sampling was used to identify key stakeholders with expertise in relevant areas, including healthcare administration, healthcare policy, healthcare delivery, digital health implementation and the development of digital health technologies (Table 1). Transcripts were de-identified so that no identifying information was noted beyond participants' work sectors. Participants in the symposium provided explicit, written consent to participate.

Data collection

The topics discussed during the symposium addressed the four themes identified from the pre-symposium interviews. The symposium aimed to further explore these barriers to identify solutions and a possible role for an AMC in those solutions. The morning focused

TABLE 1. Participant characteristics

Organizational sector	Number of representatives
WIHV (Host)	14
Clinical practice/hospital sector	9
Technology incubator[1]	2
Ministry of Health and Long-Term Care	3
Non-profit research organization	12
Technology company (vendor)	4
Academic sector[2]	7
Total	51

[1] An incubator is an all-encompassing term for organizations that provide an environment supportive of the development of new firms.
[2] Included researchers from the University of Toronto and the University of Sydney.

on exploring high-level challenges preventing development, evaluation, implementation and scaling of digital health innovations (Appendix 2, Symposium Agenda, available online at longwoods.com/content/26353). The afternoon involved breakout groups that explored key drivers of success, potential solutions and how these solutions might be operationalized. Participants self-selected into one of four breakout sessions to discuss how an AMC may contribute toward one of four aspects of digital health innovation: academics (research and education), innovation (developing new tools), economics (commercializing digital health ventures) and care (improving population and personal healthcare). Each group then presented its proposed model to all attendees, followed by open discussion regarding its feasibility. Resultant priorities for an AMC-driven innovation model were identified through group consensus.

In addition to audio recording the symposium, three note takers were appointed to create field notes that captured key information throughout the day. The note takers were trained to ensure that they recorded information verbatim where possible and that diverse perspectives were accurately represented when notes reflected a synthesis of information. Following the symposium, audio was transcribed, and a team member (Leah T. Kelley) reviewed the transcripts to produce summary notes outlining the key takeaways from group discussions.

Data analysis

Analysis was conducted by the primary author (Laura Desveaux), a scientist experienced in qualitative methods, and the second author (Kelley), a research coordinator. Both individuals were familiar with the data before the analysis as either a symposium participant (Desveaux) or note taker (Kelley). Qualitative data sources (i.e., field notes and the summary notes from the audio transcripts) were consolidated to create the full data set. Kelley and Desveaux reviewed the data set independently to inductively identify themes using the principles of thematic analysis outlined by Braun and Clarke (2006). We included only findings and recommendations that achieved consensus from the group and thus represented the perspectives of multiple participants. Several strategies were used to ensure fidelity and credibility of the data, such as using multiple sources of data (field notes and symposium transcripts), having key collaborators who attended the symposium participate in the triangulation analysis and the refinement of the themes (construct and external validity), examining points of convergence and divergence within and among the data set (internal validity) and having a stepped analysis process whereby there was an initial independent review of the data by two reviewers (Kelley and Desveaux), who then met to reach consensus around individual codes and common themes (Judd et al. 1991). Two additional members of the research team (R. Sacha Bhatia and Trevor Jamieson) and the note takers reviewed the emerging themes to confirm their accuracy and clarity. One member of the team (Kelley) then listened to the audio recordings to identify any divergent themes or insights that were not captured in the data. Finally, the authors met to discuss the final themes and refine their description to ensure that they were representative of the dialogue and generalizable to other academic and policy contexts.

Results

Structured discussions provided participants with an opportunity to elaborate upon the barriers identified in the pre-symposium interviews (Table 2) and propose a role for an AMC in overcoming these barriers.

TABLE 2. Refinement of themes across project stages

Stage 1. Pre-symposium interviews: Barriers identified	Stage 2. Symposium structure: Topics for discussion	Results: Key strategic direction from deliberation
i) The lack of infrastructure around innovation ii) The need for evidence to link into decision-making iii) Funding challenges iv) The unclear role of AMCs	i) Adapting innovation models from the US in Canada ii) The current state and strategies for digital health in Ontario iii) Prioritizing strategic directions for an AMC in digital health innovation	i) The current state of the system suppresses innovations ii) Capitalizing on the unmet need for centralized infrastructure iii) The AMC as an innovation catalyst

We outline the key symposium insights corresponding to each theme in the following sections: how the current health system suppresses innovation, how there is a need for centralized infrastructure to facilitate connection between innovators and the health system and how an AMC can be the catalyst for innovation by filling this gap and addressing some of those system barriers (refer to Table 3 for representative quotes).

The current state of the system suppresses innovation

Participants highlighted a range of barriers that impede digital health innovation, including current perceptions of quality and risk, misaligned incentives and a lack of infrastructure to support digital health evaluation and implementation.

There was consensus that the highly regulated, risk-averse healthcare culture was at

TABLE 3. Key themes and representative quotes emerging from the symposium

Theme	Representative quote
The current state of the system suppresses innovation	
Incentives misalignment, preventing clinicians from engaging in digital health innovation	"Basically, everyone came to the conclusions that … incentives misalignment, … available capital and funding, and that no one, everyone wants to say they do [innovation], but no one actually wants to be the person who holds the pen to give permission to do it. It's a huge problem as are a lot of logistical issues like privacy and data governance and data access … one of the comments just at the very end was like, 'You know, I'd do this for free if someone would just give me permission to work within their system'."
Lack of funding for innovation, which requires iteration	"From within the health system, it's not the risk about failing, there's no money to, there's operational budgets, capital budgets, there's so many demands in a public health system, there's no room to speculate."
Cost savings are not realized by those who fund innovation (e.g., hospitals invest in innovations that reduce readmissions, which realizes cost savings at the system level)	"Care is siloed, but also the costs and potential cost savings are siloed. So, in order to incentivize the system, we would really have to address those ways in which we're developing new mechanisms to realize cost savings across silos … as we all know right now, we don't have a great way of doing that."
Capitalizing on the unmet need for centralized infrastructure	
Need for someone to connect those with problems (e.g., hospitals and clinicians) to people developing solutions (e.g., digital health vendors)	"[There is] need for a clearinghouse in terms of problem identification and ideas. [Someone to] both to identify the problems but also to validate those problems … perhaps a group of hospitals or a group of similar, you know, type of organizations."
The AMC as an innovation catalyst	
Opportunity to create cross-disciplinary expertise in health and technology	"Looking across the faculties and departments that would be involved, [curriculum design] needs to include things like practical experiences across different sectors but there also needs to be courses in med school on digital health and courses in computer science on healthcare."
Opportunity for curriculum changes to teach health professional students about system forces and how innovation can empower patients	"[We need to help] our health professional students broadly to think about the system and to think about the forces that are shaping it, including how to restructure it to promote digital health and very importantly, self-care and patient empowerment, because to me, digital health is very much about empowering patients. So, there's a curriculum challenge that I think can be taken on. We can fix the context but if we don't change the basic wiring of the people who are entering the system, I'm not sure that they will change the way they behave, no matter what we do in context."
Opportunity to connect academics and clinicians from across a variety of disciplines	"The function is bringing people and data together … and embedding, kind of creating the networks to embed some of this innovation within a kind of healthcare community group or population."

odds with the inquisitive and experimental nature of innovation, which embraces "failure" as a necessary means of refinement. This may be due in part to healthcare organizations' social responsibility to manage the allocation of publicly funded resources; however, this was believed to restrict the progress of innovations that have the potential to improve the quality of care delivered to patients as an unintended consequence.

Healthcare stakeholders must accept a reframing of this less conservative approach as a required step in developing effective digital health innovations, if innovation is truly the goal. Current regulations and system incentives stifle innovation by reinforcing the status quo, effectively disincentivizing innovation across all levels of the healthcare system. The unintended consequences of fruitless competition, costly repetition and redundancy greatly reduce the amount of collaboration across the system. While individuals and organizations endeavour to encourage innovation, they function independently of one another and often compete for the same pool of resources, resulting in further fragmentation and the distributed nature of digital health activities.

Capitalizing on the unmet need for centralized infrastructure

Amidst the risk aversion, misaligned incentives and fragmented activity, there has yet to be a coordinated effort to encourage digital health innovation, evaluation and implementation. Participants acknowledged the presence of incubators and accelerators that encourage the development of a new tool, but highlighted the myriad of ad-hoc mechanisms by which these tools attempt to enter the market. Clinics and hospitals are reluctant to engage with innovations in the absence of both a clear vetting process and a financial mechanism to support uptake. The result is a landscape of perpetual pilot projects (Bégin et al. 2009), which is further exacerbated by a lack of appropriate evaluation standards (Desveaux et al. 2017). Participants expressed a critical need for an organization or centralized network to address fragmented organizations, activities and expertise.

Collaboration across the key players would allow for an integrated continuum from incubation to evaluation to implementation, thereby closing the gaps and allowing effective digital innovations a streamlined mechanism to enter the healthcare system. Such an organization would be able to facilitate the connection of clinical settings with defined problems to innovators with the ability to generate solutions. This centralization would enable more seamless integration of the innovation into the system, ensure a more targeted use of organizational resources, facilitate appropriate collaborations, assist in the development of an innovation infrastructure and promote the development of scientific frameworks to standardize evaluation and assist in decision making.

The AMC as an innovation catalyst

Symposium participants spent the afternoon brainstorming the role of an AMC in facilitating change. The overarching role of an AMC would be to balance patient-centred, economic and evaluation priorities within an innovation portfolio. Key objectives included building healthcare-specific information technology (IT) capacity, supporting educational reform, organizing a central network of diverse expertise to facilitate cross-collaboration, developing evaluation standards and creating a process to plug innovations into the system. The development of healthcare-specific IT requires the integration of digital health principles into entry-level training programs as well as improved cross-collaborations between medical and IT fields.

Academic institutions are positioned to address these factors with modifications to entry-level curricula, thereby normalizing the role of innovation and shifting the culture at its foundation. Participants believed that changes in these areas have the potential to shape professional perspectives and practice – a key enabler of shifting culture toward a system that supports digital innovation and digitally enabled care delivery. Most notably, an AMC has a natural academic network from which to draw in order to promote collaboration across relevant disciplines (e.g., law, business and engineering, among others). By centralizing activity and leveraging this existing network, an AMC is ideally positioned to catalyze digital health innovation.

The development of standardized evaluation methods builds an applied evidence base while simultaneously improving efficiency through the provision of practical guidance, helping to accelerate the innovation process. Given the established nature of the technology sector, it is not a central role of an AMC to invest resources in creating new technologies (and they may avoid such activities entirely). Rather, an AMC's role would be to identify problems in the healthcare system and match pre-existing innovations or innovators to that problem. The AMC's clinical affiliates would then provide outlets to test that solution and feedback to refine it, and co-develop new workflows that maximize the value of the technology in practice.

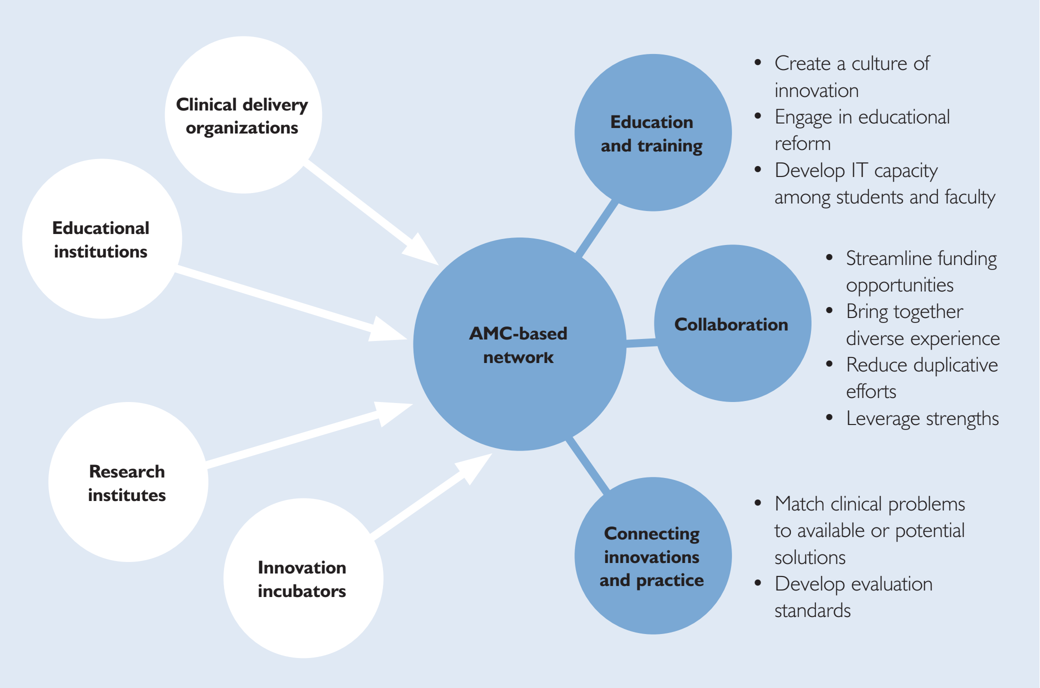
Discussion

These findings illustrate an overarching vision for an AMC that aligns with existing centres in the US (Khuntia et al. 2014). Specifically, there is a need to catalyze digital health transformation through the provision of education, research and service (e.g., facilitating the clinical testing of digital innovation). Despite persisting barriers, a promising opportunity exists to learn from numerous exemplars (Bhattacharyya et al. 2018; DePasse et al. 2014; Speck et al. 2015; Tseng et al. 2018).

The most essential function of an AMC in our local context is to act as a central hub within a coordinated network that integrates distributed and fragmented activities. A centralized hub would help to navigate cross-sector gains and explore how to realize gains in one sector at multiple levels – an issue that is likely to resonate with health systems across the globe. We propose the following model for an AMC to optimize existing networks and expertise, foster collaborations, modernize training and connect innovations with the problems and populations that are likely to yield benefit (refer to Figure 1).

AMCs also need to "provide structured opportunities and processes for innovations to be introduced, evaluated, and disseminated" (Dzau et al. 2013) as well as provide systematic mechanisms for innovators to connect with individuals. Connecting innovators with AMCs provides an opportunity for internal validation, translating into reduced risk and higher return on investment, and mitigates the likelihood of the innovation's failure due to premature transfer into the clinical environment (Toner and Tompkins 2008). It is important to move beyond simple endorsement and to engage with actual reorganization of resources, as operational success relies on individuals' ability to congregate to support multidisciplinary collaboration (Speck et al. 2015).

FIGURE 1. A proposed model for AMCs to overcome barriers to innovation



Our findings align with the overarching roles of an AMC in other contexts, including incorporating innovation into entry-level education, dedicating resources and funding to innovation efforts and fostering an innovation-friendly environment (Dzau et al. 2013). Training for health system innovators necessitates a different set of skills and competencies than those that are currently cultivated by the medical curriculum (Dzau et al. 2010; Holmström and Höglund 2007; Kijsanayotin et al. 2009; Konttila et al. 2019; Snooks et al. 2008), highlighting the role educational institutions play in achieving transformation. Key competencies include knowledge of digital technology and the associated skills required to deliver digitally enabled, high-quality patient care (i.e., ethical considerations, appropriate social behaviour and communication; Holmström and Höglund 2007; Kijsanayotin et al. 2009; Konttila et al. 2019; Snooks et al. 2008). Successful acquisition of these skills requires that healthcare providers are motivated to develop these competencies, underscoring the importance of an overarching culture shift. The lack of established pathways for academic career advancement outside of research (Dzau et al. 2010; Ostrovsky and Barnett 2014) presents an opportunity for academic institutions to lead this culture shift by reviewing current promotion criteria and to expand their view of scholarship in order to shape an environment that provides advancement opportunities for health system innovators (Dzau et al. 2010). By necessity, innovation encompasses a suite of highly academic, pragmatic and applied activities, all of which must be strongly represented within the expertise of an AMC.

Like all health systems, the Canadian context is not without barriers that are beyond the purview of an AMC. Issues relating to reimbursement, policies/regulations and system infrastructure may require governmental intervention to promote certain categories of innovation (Weinstein et al. 2014). Digital health is simultaneously an academic endeavour, a business opportunity and a clinical enterprise. Understanding how these roles relate to each other is critical, illustrating that above all else, coordinated leadership is key (Desveaux et al. 2017; Tinker and Donatelli 2009). Organizational culture presents a greater barrier than innovation-specific factors (Bunting 2012), requiring that leaders attend to the context and culture that tend to drive changes in the form and use of technology, rather than the other way around (Leonardi and Barley 2010).

Policy Implications

Many healthcare systems in Canada and beyond face rising costs and resource constraints while simultaneously pursing increased quality through innovative modification of current delivery systems (Wiener et al. 2012), highlighting the broad relevance of our findings. To empower AMCs to play the suggested role would require coordination from several entities. Financial incentives are needed to support implementation and use, which requires a collaborative effort between provincial ministries of health and respective professional associations (e.g., the Ontario Medical Association and the Ontario Hospital Association). Leadership at academic institutions and their associated departments must update definitions of impact and modernize advancement pathways to reflect the cross-disciplinary nature of this work. Currently, academics in computer sciences and medicine have incompatible academic advancement structures that make mutually productive collaboration challenging. Post-secondary institutions and affiliated academic sites must collaborate to update training programs to integrate technological curricula into healthcare curricula, and vice versa, to promote the necessary competencies. Finally, AMCs themselves would need to develop the infrastructure to promote a cross-disciplinary collaborative network for digital health innovation in practice, to connect those with problems (e.g., clinicians and healthcare organizations) to those who can develop solutions (e.g., digital health vendors). In addition to the key participating institutions (Figure 1), it is critical to engage community organizations and patients in such efforts, with an emphasis on representation from traditionally marginalized groups. Health innovation that ignores the diversity of the public it serves precludes the ability to achieve meaningful and sustainable transformation.

Conclusion

This study highlights the importance of understanding local barriers and context to identify unmet needs within the system. AMCs can address the barriers to digital health innovation in Canada by providing a centralized network and infrastructure that supports innovation throughout its journey from "bench to bedside" as well as by supporting educational reform. The specific strategies outlined will inform the development of an AMC and its subsequent activities focused on accelerating digital health innovation. Although it is based primarily on expertise from Toronto, Canada, the themes are relevant to health systems facing similar barriers, demands and operating constraints. The present work also suggests the potential of transplanting successful organizational models into health systems looking to advance digital health innovation.

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Correspondence may be directed to: Laura Desveaux, Women's College Hospital, Institute for Health Systems Solutions and Virtual Care, 76 Grenville Avenue, Toronto, ON M5S 1B2. She can be reached by phone at 416-323-6400 x4302 or by e-mail at laura.desveaux@wchospital.ca.

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RESEARCH PAPER

Co-Locating Older Retirement Home Residents: Uncovering an Under-Researched Population via Postal Code

Localisation des résidents de maisons de retraite : découvrir une population sous-étudiée grâce au code postal

HANA BRATH, BHSc (H)
Medical Student
Women's College Research Institute
Women's College Hospital
Toronto, ON
Faculty of Medicine
University of British Columbia
Vancouver, BC

SANGHUN J. KIM, BMSc
MSc Candidate
Women's College Research Institute
Women's College Hospital
Toronto, ON
Nuffield Department of Population Health
University of Oxford
London, UK

SUSAN E. BRONSKILL, PhD
Senior Scientist and Program Leader
ICES
Institute of Health Policy, Management and Evaluation
University of Toronto
Women's College Research Institute
Women's College Hospital
Toronto, ON

PAULA A. ROCHON, MD, MPH
Vice President, Research and Senior Scientist
Women's College Research Institute
Women's College Hospital
Institute of Health Policy, Management and Evaluation
Division of Geriatric Medicine, Department of Medicine
University of Toronto
Toronto, ON

NATHAN M. STALL, MD
Geriatrician and Research Fellow
Women's College Research Institute
Women's College Hospital
Institute of Health Policy, Management and Evaluation
Division of Geriatric Medicine, Department of Medicine
University of Toronto
Toronto, ON

Abstract

Background: Retirement home residents represent a growing proportion of older Ontarians who cannot be identified within existing administrative databases.
Objective: This article aims to develop an approach for determining, from an individual's postal code, their likelihood of residing in a retirement home.
Methods: We identified 748 licensed retirement homes in Ontario as of June 1, 2018, from a public registry. We developed a two-step evaluation and verification process to determine the probability (*certain*, *likely* or *unlikely*) of identifying a retirement home, as opposed to other dwellings, within a postal code.
Results: We identified 274 (36.7%) retirement homes within a postal code *certain* to indicate that a person was residing in a retirement home, 200 (26.7%) for which it was *likely* and 274 (36.7%) for which it was *unlikely*. Postal codes that were *certain* and *likely* identified retirement homes with a capacity for 59,920 residents (79.9% of total provincial retirement home capacity).
Conclusion: It is feasible to identify a substantive cohort of retirement home residents using postal code data in settings where street address is unavailable for linkage to administrative databases.

Résumé

Contexte : Les résidents des maisons de retraite représentent un segment croissant du nombre d'aînés en Ontario qui ne peuvent être identifiés avec les bases de données administratives actuelles.
Objectif : Cet article vise à développer une approche pour déterminer, à partir du code postal d'une personne, sa probabilité de résider dans une maison de retraite.
Méthode : Nous avons repéré, grâce à un registre public, 748 maisons de retraite titulaires d'un permis en Ontario en date du 1^er^ juin 2018. Nous avons élaboré un processus d'évaluation et de vérification en deux étapes afin de déterminer la probabilité (certaine, probable ou improbable) d'identifier une maison de retraite, par opposition à d'autres types de logement, dans la zone d'un code postal.
Résultats : Nous avons repéré 274 (36,7 %) maisons de retraite dans la zone d'un code postal où il est certain qu'une personne réside dans une maison de retraite, 200 (26,7 %) où cela est probable et 274 (36,7 %) où cela est improbable. Les codes postaux qualifiés de certains ou probables permettaient d'identifier des maisons de retraite pouvant accueillir 59 920 résidents (79,9 % de la capacité totale des maisons de retraite dans la province).
Conclusion : Il est possible d'identifier une cohorte importante de résidents de maisons de retraite grâce au code postal dans les milieux où l'adresse municipale n'est pas disponible pour le couplage aux bases de données administratives.

Background and Objective

It is well recognized that the health of people living in a shared place of residence may be interdependent (Christakis and Allison 2006). A shared place of residence, also known as co-location, can be a valuable tool for health services research to understand how social determinants and the built environment can shape health, and to support health system capacity planning. Co-location has proven useful for studying relationships between married or cohabiting couples, parents and their children, and family caregivers and their care recipients (Christakis and Allison 2006; Kjaer et al. 2014; Moriarty et al. 2015; Smits et al. 2010). Within the existing administrative databases in Ontario, Canada (and other Canadian and international jurisdictions), there can be challenges to co-locating individuals due to the methods through which data are collected, linked and protected; these include the current unavailability of individuals' registered street addresses.

Health systems' administrative data are generated whenever an individual has an encounter with the healthcare system (Cadarette and Wong 2015). While these data are generally collected for administrative and billing purposes, they are frequently leveraged for health services research (Cadarette and Wong 2015). The Canadian healthcare system includes universal access to a publicly funded provincial health insurance program that covers medically necessary physician services, diagnostic testing services and ambulatory and hospital care; in the province of Ontario, children and older adults receive additional coverage for prescription medications. Services that are not directly tied to the provision of healthcare, such as accommodation, are frequently privatized and are therefore not captured in health administrative data (Palley et al. 2011). Consequently, health services researchers and policy makers must turn to creative solutions to identify recipients of supportive care and services not covered by public funding; these include the co-location of individuals residing in privately funded retirement homes (also known as residential care or assisted living facilities; Sloane et al. 2003; Statistics Canada 2017).

In Ontario, roughly 92% of individuals live in private households, while the remaining 8% live in collective dwellings, including provincially financed long-term care (LTC) facilities and privately financed retirement homes (Milan et al. 2014). Whereas LTC facilities place a greater focus on medical care, provide 24-hour supervision of their residents and provide the majority of institutional end-of-life care to older adults, retirement homes tend to provide limited supportive care and services to assist with activities of daily living while allowing residents to maintain independence in the community (National Institute on Aging 2017; Roblin et al. 2019). While retirement homes have become an increasingly common place of residence for older adults in Ontario when they can no longer support themselves independently, there is currently limited information on the public health system use of retirement home residents at a population level (Poss et al. 2017, 2019). Retirement homes have been regulated in Ontario since 2010, when the government passed the *Retirement Homes Act 2010*, granting the Retirement Homes Regulatory Authority (RHRA) of Ontario the authority to license homes in the province (Government of Ontario 2010). The licensing of retirement homes in Ontario resulted in the development of a public registry of homes available through the RHRA of Ontario website and presents an opportunity to co-locate retirement home residents via shared address information (RHRA of Ontario 2018).

The purpose of this pilot study was to develop an approach identifying privately funded retirement homes with geographically unique postal codes in order to support capacity planning for provincial health services. Limited evidence from a single jurisdiction in Ontario highlights how – compared to older adults in private residences – retirement home residents have higher proportions of dementia and moderate cognitive impairment, less support from family and friend caregivers, higher rates of depression and loneliness as well as more private personal care and nursing services (Poss et al. 2017, 2019). Evidence from other jurisdictions, including Alberta, has focused on publicly funded assisted living facilities and demonstrated that residents in these facilities have high rates of LTC placement, acute care utilization and antipsychotic use (Hogan et al. 2014; Maxwell et al. 2013, 2015; Stock et al. 2017).

Despite an increasing number of older adults turning to retirement homes for residential care, the sociodemographic and clinical characteristics of retirement home residents and the ways in which they access and interact with the healthcare system is still largely undescribed. To comprehensively study the unique healthcare system needs and services of retirement home residents, it is necessary to generate a population-based cohort that can be linked to the existing health administrative databases. The coronavirus disease (COVID-19) pandemic has accelerated the need for population-based research on retirement home residents, with large outbreaks occurring in retirement home settings (Roxby et al. 2020; Zimmerman et al. 2020). This pilot study determines the probability of identifying a retirement home resident by using six-digit postal code information alone.

Methods

Data sources

We identified all 748 licensed retirement homes in the province of Ontario as of June 1, 2018, from the public registry available through the RHRA of Ontario website (RHRA of Ontario 2018). Information was collected from the public registry on geographic location (including postal code), resident capacity and service provision.

Using postal codes to co-locate individuals

Postal codes and map-based technologies were used to co-locate individuals, a methodology that has been used in previous health services research to geospatially map population distributions and data (Ray et al. 2008; Romanski et al. 2015). To co-locate individuals within a retirement residence using postal codes, we had to be reasonably certain that the facility postal code was not substantially shared with other residences. In some instances, a postal code was unique to a given address. In other cases, postal codes were shared by multiple addresses within a region, making it difficult to ascertain whether individuals within a postal code belonged to any one particular residence; the multiple addresses included commercial buildings that were non-residential and multiplexes that were private residences housing multiple individuals.

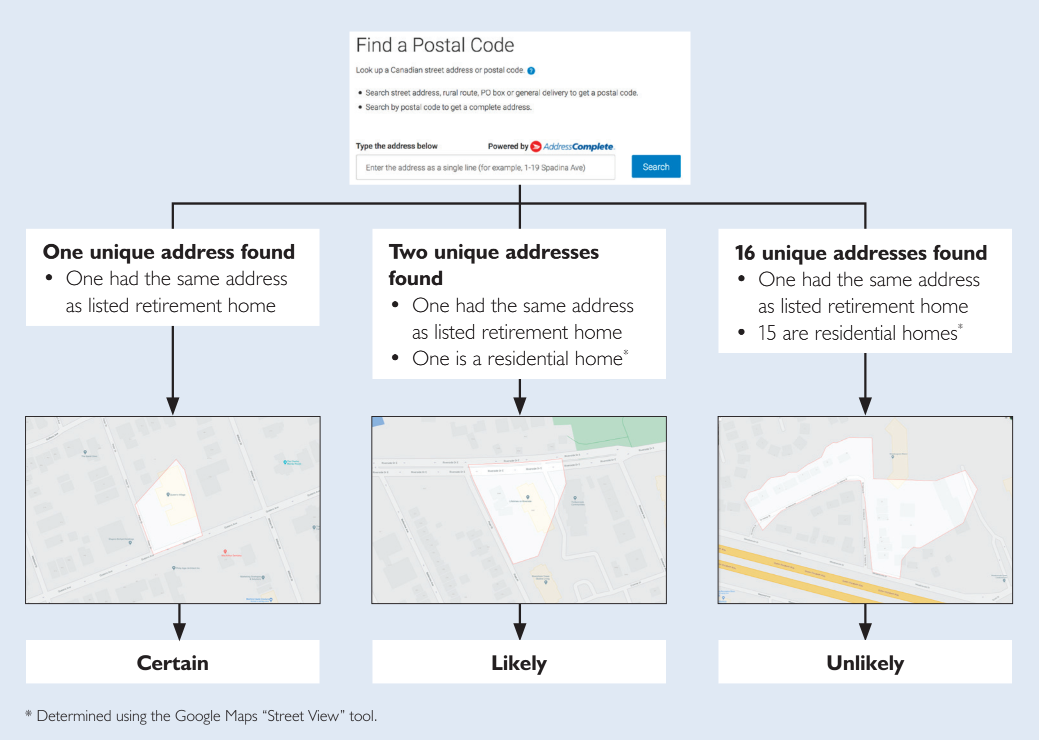
Outcomes

We developed a screening method to determine the probability (*certain*, *likely* or *unlikely*) of identifying a retirement home resident using postal code information alone. Because we anticipated linking the cohort of *certain* and *likely* retirement home postal codes to administrative databases, these categories were combined, and publicly available licensing data were used to compare the characteristics of *certain* and *likely* facilities to those of the facilities with *unlikely* postal codes. Publicly available licensing data were used to provide context on the resident capacity, location (urban or rural) and service provision of retirement homes.

Analysis: Two-stage approach

To determine whether retirement home addresses shared a postal code with other non-retirement home addresses, we developed a two-step verification process (Figure 1). First, we inputted postal codes from the RHRA of Ontario public registry into the online Canada Post (n.d.) "Find a Postal Code" tool (RHRA of Ontario 2018). Canada Post is the primary postal operator in Canada, and their publicly available "Find a Postal Code" tool enables users to search by a postal code and returns a complete list of street addresses that share that postal code. Postal codes were classified as unique to a retirement home only when Canada Post displayed one street address per postal code.

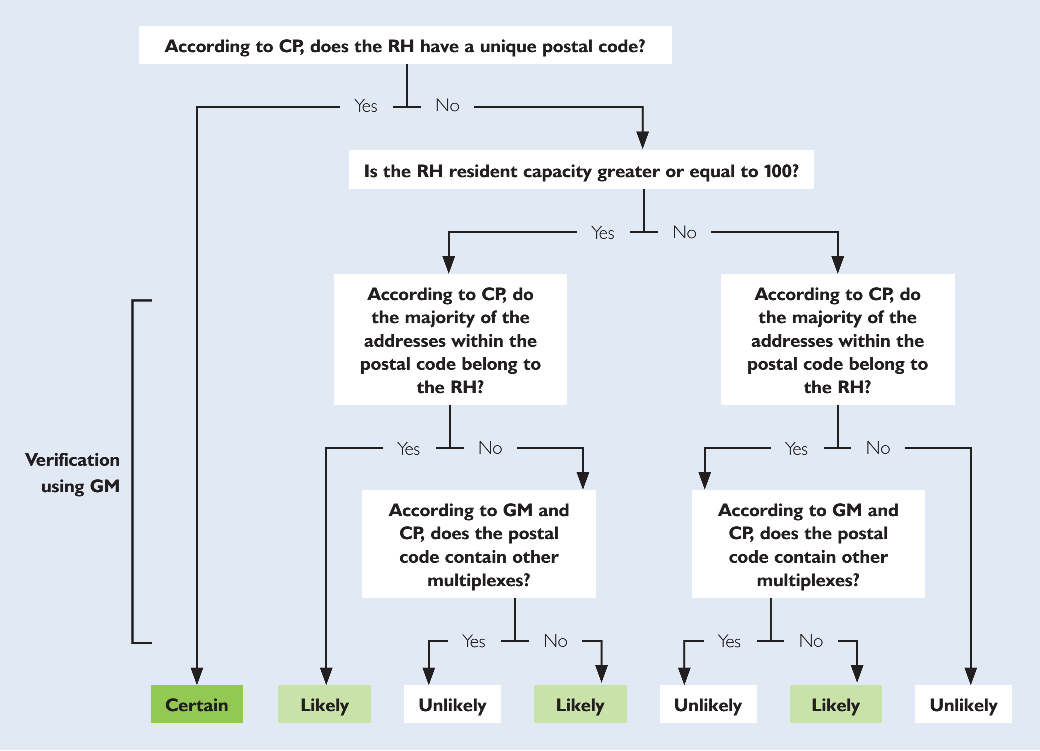
FIGURE 1. Examples of how postal codes were classified using Canada Post's "Find a Postal Code" tool and then Google Maps' Satellite and Street View tools



* Determined using the Google Maps "Street View" tool.

Second, if a retirement home postal code shared multiple addresses, the postal code was investigated using Google Maps Satellite and Street View technology (Google n.d.). Inputting postal codes into Google Maps provides the user with a visual and spatial representation of the estimated geographic area captured by a postal code; Google Maps has excellent validity and reliability for virtual measures of geoprocessing (Silva et al. 2015). Using this technology, we developed a standardized algorithm to differentiate between postal codes that were *likely* and *unlikely* to be uniquely attached to retirement homes. If a retirement home capacity was large (>100 residents), and the majority (>50%) of addresses sharing a given postal code belonged to retirement home residents while accounting for the presence of other residential multiplexes, the home would be classified as *likely* (because it was assumed that the majority of individuals with that postal code were residents of the retirement home). If the retirement home capacity was small (<100 residents), and the majority (>50%) of addresses sharing a given postal code belonged to other residential addresses or multiplexes, the postal code would be classified as *unlikely* to uniquely belong to retirement home residents (because it was assumed that the majority of residents with that postal code were not retirement home residents). The resulting algorithm for classifying retirement home postal codes is illustrated in Figure 2. Two reviewers (Hana Brath and Sanghun J. Kim)

FIGURE 2. Flowchart algorithm for classifying postal codes: unique, likely unique or unlikely unique



Notes: CP = Canada Post; RH = Retirement Home; GM = Google Maps independently assessed postal codes and classified them as *likely* and *unlikely* unique to retirement homes. Discrepancies between the two reviewers in classifying the postal codes were resolved through consultations and discussions with a third reviewer (Nathan M. Stall).

After classifying retirement home postal codes based on the likelihood of identifying a retirement home resident using postal code information, we compared facilities with *certain* and *likely* postal codes to those with *unlikely* postal codes. Retirement homes were compared, for context, on the basis of resident capacity, rurality and service provision to facilitate future research and planning opportunities.

Results

After screening the 748 licensed retirement homes listed in the RHRA of Ontario public registry as of June 1, 2018, 274 (36.7%) postal codes were categorized as *certain*, 200 (26.7%) as *likely* and 274 (36.7%) as *unlikely* to uniquely belong to a retirement home (Table 1). See Appendix Tables A1–A3 for the full list of retirement home names and postal codes (available online at longwoods.com/content/26352).

Retirement home capacities

Retirement homes with *certain* and *likely* postal codes had a capacity for 59,920 residents, which represents 79.9% of Ontario's retirement home collective resident capacity. The full sample of the 748 retirement homes had a median resident capacity of 87 (interquartile range [IQR] = 50–140) residents, whereas the 474 *certain* and *likely* retirement homes had a higher median resident capacity of 115 (IQR = 77–159.25) residents.

Retirement home locations

Retirement homes classified as *certain* and *likely* were all located in either urban or suburban areas, while a high proportion of *unlikely* homes were located in rural areas (43.8%).

Discussion

This study presents a feasible screening method to co-locate retirement home residents by postal code in Ontario, Canada. In the absence of more specific address location information, we were able to identify 474 *certain* and *likely* retirement homes based on their postal codes, which accounted for a population of 59,920 retirement home residents, or 79.9% of total provincial capacity.

While retirement homes have been licensed by the RHRA of Ontario since 2010, there is little published information on the collective characteristics of retirement homes, despite the collection of information from individual facilities required for licensing. The absence of this information and related quality metrics likely results from the fact that retirement homes are not publicly funded; this contrasts with LTC facilities, which are part of the province's healthcare system and publicly funded on a cost-shared basis with residents (Ontario Long Term Care Association 2018). Licensing data indicate that the 748 retirement homes in Ontario have a capacity for over 75,000 residents (with a median resident capacity of 87 residents [IQR = 50–140]), and the majority provide supportive care with some instrumental and basic activities of daily living, including bathing, personal hygiene, ambulation, meal preparation and medication management. Interestingly, nearly one-third (31.6%) of all homes have no direct access to physician services, and the minority of homes assist with feeding (37.3%) and have dementia care programs (16.8%).

An algorithm to determine the probability (*certain*, *likely* or *unlikely*) of identifying a retirement home resident using postal code information at the facility level represents an important tool that can be used in other jurisdictions where direct linkage of health administrative databases to street address is not available. This algorithm's output will allow health service researchers and policy makers in Ontario to identify individuals as residing in specific retirement homes, facilitating linkages to administrative databases. In the province of Ontario, linkages permit the capture of all medically necessary physician services, ambulatory and hospital care and prescription medications that are covered under a publicly funded provincial health insurance program. These linkages will allow researchers to describe the sociodemographic and clinical characteristics of retirement home residents, investigate their specific healthcare needs and service utilization and describe their changing health status and residence over time. In particular, research questions of interest include the inappropriate use of acute care services and medications, the way in which retirement home residents access physician services and transition through residential care settings as well as variations in the care of retirement home residents by both region and facility.

Indeed, retirement home residents are a potentially vulnerable population who have received little attention to date. Relatedly, the identification of LTC residents in health administrative databases in Ontario has permitted the undertaking of a large body of important research that has advanced the understanding of this population and improved health outcomes, something that could be similarly translated to future studies among retirement homes. Most recently, the COVID-19 pandemic has revealed the extreme vulnerability of congregate care including retirement homes, and the ability to effectively identify and link retirement homes residents to existing health administrative databases could facilitate timely analysis of COVID-19 outcomes (Roxby et al. 2020, Zimmerman et al. 2020).

There are important health policy implications that stem from improving our understanding of which older adults reside in retirement homes and how these individuals use the health system. Emerging evidence suggests that the characteristics and needs of retirement home residents may be very different from those of other community-dwelling individuals, and perhaps closer to those of LTC residents (Poss et al. 2017, 2019; Roblin 2017). In particular, the ongoing demand and waiting lists for beds in provincially funded LTC homes can overflow into other residential care settings, including private retirement homes; despite this, retirement homes are still largely perceived as serving the needs of more independent older adults (Roblin et al. 2019). As the characteristics of retirement home residents and the services provided in these facilities increasingly become similar to those of nursing homes, experts in healthcare policy have advocated for a more careful consideration of how retirement homes are funded, regulated and incorporated into planning for the provision of LTC in Canada (National Institute on Aging 2019; Roblin 2017; Roblin et al. 2019; Sinha 2012).

Any new healthcare policy involving retirement homes will rely, in part, on robust population-based health services research with the capability of linking retirement home residents. Currently, health services research in Ontario relying on administrative claims data can only differentiate between LTC-dwelling older adults and community-dwelling older adults; the latter category includes both individuals living in their own homes and those living in retirement homes. The methodology developed and reported in our study presents an opportunity to both uncover the under-researched population of retirement home residents using postal code and support the evaluation of a much-needed healthcare policy related to the residential care sector.

Limitations

We must also acknowledge some limitations to this study. Our reliance on postal code data for future linkage to health administrative databases meant that it was not possible to include all the 748 Ontario retirement homes in our cohort. We created a cohort of 474 retirement homes with *certain* and *likely* postal codes, resulting in the exclusion of 274 homes with *unlikely* postal codes. These excluded retirement homes that shared postal codes with multiple addresses, mainly because they had smaller residential capacities and were located in rural areas. While we were able to create a cohort with a capacity for 59,920 *certain* and *likely* retirement home residents (representing 79.9% of Ontario's retirement home collective resident capacity), the retirement homes in our cohort exist disproportionately in urban and suburban areas, reflecting the challenges faced by residents of rural settings in accessing health services data (Lavoie et al. 2016). An ideal solution to this issue would be to link retirement homes to individuals by street address. However, at present, many research-ready administrative databases in Canada do not include street address. This is due, in part, to the highly identifiable nature of street address data and the need for appropriate privacy protections. More broadly, research on retirement home settings might best be accomplished by multi-method approaches using a variety of data sources. For example, supplementing the health administrative data with health survey methods would potentially mitigate the exclusion of data from retirement home residents of rural settings and help identify other health and social service needs incompletely captured by administrative data.

Another limitation of our study is the lack of validation work, including the calculation of interrater agreement between reviewers as well as the determination of sensitivity and specificity of cut-offs used, which could help determine the accuracy of our classification (*certain*, *likely* or *unlikely*) of identifying a retirement home resident using postal code information at the facility level. In particular, we acknowledge the real possibility that postal codes classified as *likely* unique to a retirement home may capture a proportion of individuals who are not actually retirement home residents.

There are some potential approaches to validation that could help overcome the aforementioned limitations. One method would involve linking the subset of Ontario residents receiving publicly funded home care who have registered addresses containing *certain* and *likely* postal codes to health administrative databases, notably the RAI-Home Care database (Poss et al. 2017). The RAI-Home Care database is a standardized, reliable, valid and comprehensive clinical assessment system designed for home care, the use of which has been mandated in Ontario for all long-stay home care clients (≥60 days) since 2002 (Landi et al. 2000; Morris et al. 1997; Poss et al. 2017). The RAI-Home Care tool contains a mandatory data entry field (Section CC, Item 5) about the place of living, which could be used to investigate the proportion of individuals (who would all have registered addresses with *certain* and *likely* postal codes belonging to retirement homes) classified as living in a retirement home. An alternate approach would be using probabilistic record linkage methodology, whereby a wider range of potential identifiers could be used to identify likely retirement home residents in administrative databases (Sayers et al. 2016). These variables could include age more than 65 years (especially because this is one of the criteria used to define a retirement home in Ontario) or identifying individuals who receive primary care services from a physician known to serve a specific retirement home (the latter identifier would involve contacting each retirement home to help identify the physician; Government of Ontario 2010).

Conclusion

In Ontario – Canada's most populous province – a substantial proportion of older adults lives in 748 licensed retirement homes that have a combined capacity for 75,020 residents. While retirement home residents represent a growing subpopulation of older Ontarians, there is very limited information about their health and well-being because of the inability to link them to large administrative databases. Furthermore, because retirement homes are not publicly funded, there is little published information on the characteristics of these facilities and the care services available to residents. This study presents a novel method to co-locate Ontario retirement home residents in health administrative databases using postal code information at the facility level. The creation of this retirement home cohort will create data to best support the health needs of aging communities.

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Conflict of Interests

The authors have no financial relationships with any organizations that might have an interest in the study and have no other relationships or activities that could appear to have influenced the study.

Correspondence may be directed to: Nathan M. Stall, Women's College Hospital, 76 Grenville Street, Toronto, ON M5S 1B2. He can be reached by phone at 416-351-3732 x2711 or by e-mail at nathan.stall@mail.utoronto.ca.

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RESEARCH PAPER

The Impact of Prescription Medication Cost Coverage on Oral Medication Use for Hypertension and Type 2 Diabetes Mellitus

Impact de la couverture du coût des médicaments d'ordonnance sur l'utilisation des médicaments oraux pour l'hypertension et le diabète sucré de type 2

RAZAN AMOUD, BSc PHARM, MSc, PhD(c)
School of Pharmacy, Faculty of Science
University of Waterloo
Waterloo, ON

KELLY GRINDROD, MSc, PHARMD
Associate Professor
School of Pharmacy, Faculty of Science
University of Waterloo
Waterloo, ON

MARTIN COOKE, PhD
Associate Professor
School of Public Health and Health Systems, Faculty of Applied Health Sciences
Department of Sociology and Legal Studies, Faculty of Arts
University of Waterloo
Waterloo, ON

MHD WASEM ALSABBAGH, BSc PHARM, PhD
Assistant Professor
School of Pharmacy, Faculty of Science
University of Waterloo
Waterloo, ON

Abstract

Background: No previous study, to the best of our knowledge, has examined both the time trend and impact of not having insurance or prescription medication cost coverage (PMCC) on the usage of type 2 diabetes and hypertension oral medications in Ontario and New Brunswick, Canada.

Methods: We used data from the Canadian Community Health Survey (CCHS) from 2007 to 2014 to examine the time trend and impact of PMCC. A multivariable-adjusted logistic regression model was fitted.

Results: The pseudo-cohort included 23,215 individuals representing a population of approximately 8.7 million people. Overall, 20.0% of respondents reported absence of PMCC. This proportion increased slightly from 19.6% (95% confidence interval [CI] 95% CI [17.5, 22.5]) to 20.7% (95% CI [16.9, 23.1]). Adjusted odds ratios (OR) showed that uninsured individuals were 23% less likely to use their medications (OR = 0.77, 95% CI [0.657, 0.911]).

Conclusion: There was a slight decline in PMCC over time and this decline was associated with reduced use of medications for type 2 diabetes and hypertension.

Résumé

Contexte : Aucune étude, à notre connaissance, n'a examiné à la fois la tendance temporelle et l'impact de l'absence de régime d'assurance ou de couverture du coût des médicaments d'ordonnance (CCMO) sur l'utilisation des médicaments oraux contre le diabète de type 2 et l'hypertension en Ontario et au Nouveau-Brunswick, au Canada.

Méthode : Nous avons utilisé les données de l'Enquête sur la santé dans les collectivités canadiennes (ESCC) de 2007 à 2014 pour examiner la tendance temporelle et l'impact de la CCMO. Un modèle de régression logistique ajusté à plusieurs variables a été employé.

Résultats : La pseudo-cohorte comprenait 23 215 individus représentant une population d'environ 8,7 millions de personnes. Dans l'ensemble, 20,0 % des répondants ont signalé ne pas avoir de CCMO. Cette proportion a légèrement augmenté, passant de 19,6 % (intervalle de confiance [IC] à 95% [17,5; 22,5]) à 20,7 % (IC à 95% [16,9; 23,1]). Les rapports de cote (RC) corrigés montrent que les personnes non assurées sont moins susceptibles, dans une proportion de 23 %, d'utiliser leurs médicaments (RC = 0,77, IC à 95% [0,657; 0,911]).

Conclusion : Il y a eu une légère baisse de la CCMO au fil du temps et cette baisse est associée à une réduction de l'utilisation des médicaments pour le diabète de type 2 et l'hypertension.

Background

Prescription medications are the cornerstone of hypertension and type 2 diabetes management (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee et al. 2013; Daskalopoulou et al. 2015). These include oral medications that not only slow the progression of hypertension and type 2 diabetes but also reduce adverse clinical outcomes. Despite the availability of effective medications, there are barriers to optimizing therapy (Brown and Bussell 2011). Particularly important is poor medication adherence, which is the main contributor to the poor management of these conditions (Burt et al. 1995; Canadian Diabetes Association Clinical Practice Guidelines Expert Committee et al. 2013).

Adherence is defined as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider" (Sabaté 2003). The World Health Organization (WHO) has estimated that in developed countries, almost half of the patients are non-adherent to their medications (Sabaté 2003). The WHO's theoretical framework conceptualized five main adherence barriers, including social and economic factors, healthcare team–related and system-related factors, condition-related factors, therapy-related factors and patient-related factors (Sabaté 2003).

Medication cost is one of the economic factors that can impact medication adherence (Law et al. 2012). In a national survey carried out by Angus Reid (2015), 23% of Canadians reported that they did not adhere to their prescription regimen due to the cost of the medication. Similarly, in a survey of Medicare beneficiaries in the US, 56% had not filled at least one prescription medication because they "thought it would cost too much," and 20% had chosen to not fill a prescription because the "medicine was not covered by insurance" (Kennedy et al. 2008). Notably, cardiovascular medications accounted for 18% of unfilled prescription medications, and endocrine/metabolic agents accounted for 7% (Kennedy et al. 2008). These and similar studies suggest that relieving patients from high medication cost through prescription medication cost coverage (PMCC) could help improve adherence (Viswanathan et al. 2012).

Canada is the only developed country with a universal health insurance system that does not offer universal coverage for medications (Morgan et al. 2015). Although provincial governments generally cover the cost of prescription medications for people who meet certain criteria (such as people who are on social assistance or people whose medication cost exceeds a certain percentage of their income; Lewis 2020), this coverage does not include the whole Canadian population. Previous research has identified a medication coverage gap in Canada, whereby a significant number of Canadians do not have the needed support for the cost of their prescription medications through their employment (Health Canada 2019). As such, the Advisory Council on the Implementation of National Pharmacare recommended implementing universal prescription coverage to all Canadians (Health Canada 2019). It is estimated that about two thirds of Canadian households face out-of-pocket expenses for their prescription medications and that about one in 10 Canadians have cost-related medication non-adherence (Law et al. 2012). Although previous research has looked at this issue at single points in time (Gee et al. 2012), trends in PMCC in Canada, and their impact on medication use and adherence, are still unknown. Examining the changes in PMCC over time is essential for understanding whether the medication-coverage gap is widening in Canada.

The aims of this study were to measure the recent trends in PMCC and to examine the association between absence of PMCC and the use of oral hypertension and type 2 diabetes medications among adults in Ontario and New Brunswick. Because it seems that fewer Canadians are employed as full-time employees with health benefits, we hypothesized that the percentage of Canadians without PMCC had increased over the study period (Evans 2019; Morissette 2015). This increase may balance out the aging population that becomes eligible for PMCC (i.e., becoming eligible for drug plan coverage because of their age). Measuring the magnitude of association between PMCC and non-medication use helps us understand whether lack of insurance has a significant impact on Canadians and their medication use behaviour. Shedding light on this trend and association can contribute to the national discussion of the potential benefits of providing universal medication coverage.

Method

Study design

To perform this study, we examined the self-reported medication use of a large sample of respondents with two specific chronic diseases (hypertension and type 2 diabetes) from the provinces of Ontario and New Brunswick, using cycles from the Canadian Community Health Survey (CCHS). We included data from a seven-year period (2007–2014) and used a repeated cross-sectional study design.

Data source

The CCHS is a cross-sectional survey of a representative sample of community-dwelling Canadians 12 years of age and older. The collection period for the CCHS is divided into 12 two-month periods and spans two years. This facilitates the option of combining cycles and examining time trends. The risk of respondents' re-inclusion (appearing in more than one annual cycle) is very low (Thomas and Wannell 2009). The CCHS excludes populations living on First Nations reserves in the provinces, full-time members of the Canadian Armed Forces, institutional residents and persons living in the Inuit and Cree regions of Quebec. Altogether, these excluded populations account for less than 3% of the Canadian population (Statistics Canada 2011).

This survey uses a complex sampling design (stratified and clustered) to provide estimates at the health region (sub-provincial) level. To calculate accurate estimates of variance and to account for design effects, Statistics Canada provides a set of weights to be used with bootstrap re-estimation procedures (Chatrchi et. al 2015).

The design of the CCHS allows provinces to purchase or opt in to its optional modular content. The PMCC question was available for patients of Ontario and New Brunswick in the years 2007, 2008, 2013 and 2014. This combination of provinces/years allowed us to examine the trend over the longest available period.

Cohort

Respondents were included in this study if they were 18 years of age or older on the date of the survey, had type 2 diabetes or hypertension and had answered the questions about oral medication use and PMCC status. Type 2 diabetes was identified using the derived variable specifications provided by Statistics Canada (Ng et al. 2008). Respondents who were pregnant at the time of diagnosis with hypertension or diabetes, had Alzheimer's disease or did not respond to the questions regarding hypertension or type 2 diabetes or their PMCC status were excluded.

Measurements and confounding variables

In the CCHS survey, the exposure of interest was absence of PMCC. This was assessed using the question "Do you have insurance that covers all or part of the cost of your prescription medications?" Respondents who answered "no" were considered exposed, while respondents who answered "yes" were considered not exposed. The outcome of interest was the use of oral hypertension and type 2 diabetes medications. Medication use for hypertension was assessed using the following question: "In the past month, have you taken any medicine for high blood pressure?" For type 2 diabetes oral medication, the question was as follows: "In the past month, did you take pills to control your blood sugar?" Respondents who answered "yes" were considered to be using their medication, while respondents who answered "no" were considered to not be using their medication. The validity of these questions has been previously established (Allin et al. 2013). For respondents who had both hypertension and type 2 diabetes, they were classified as not using their medication if they indicated they were not using medications for either disease (hypertension or type 2 diabetes). A sensitivity analysis was also conducted to examine the robustness of this consideration by requiring a "no" answer to both questions in order for the respondent to be classified as not using medication.

We considered several independent variables as potential confounders based on the WHO's theoretical framework that includes sociodemographic characteristics, healthcare-system use, condition-related and therapy-related factors and patient-related factors (Sabaté 2003). Table A1 in Appendix 1 (available online at longwoods.com/content/26351) shows the definition of each variable and the corresponding CCHS coding considered for this study.

Sociodemographic characteristics included age (18–29, 30–44, 45–64, or 65+), sex (male or female), education level (less than secondary school graduation, secondary school graduation and post-secondary school graduation), household income quintile, main source of household income (employment, government support or other) and province (Ontario or New Brunswick). In addition, because racial inequalities affect health behaviour beyond socioeconomic factors (Ramraj et al. 2016), we also included race (Aboriginal, White, other) as a potential confounder. Indicators for healthcare-system use included whether the respondent had a regular medical doctor (yes or no) and had taken a flu shot (yes or no). Condition-related and therapy-related factors included smoking status (smoker/non-smoker) and alcohol consumption (regular drinker, occasional drinker or did not drink in the last

12 months), diagnosis of the diseases of interest (hypertension alone, type 2 diabetes alone or hypertension and type 2 diabetes together). Our analysis also considered including self-reported presence of other health problems, including asthma (yes/no), arthritis (yes/no), back problems (yes/no), migraine (yes/no), cardiovascular disease (heart disease/stroke or none), cancer (yes/no), gastrointestinal disease (yes or no), mental health issues (yes or no) and having stayed overnight in hospital in the past 12 months (yes or no). For patient-related factors, hospital stay in the past 12 months and self-reported general health were included. General health was categorized as a three-level indicator where "excellent," "very good" and "good" were considered as "good" and collapsed into one category, and the other two categories were "fair" and "poor."

Statistical analyses

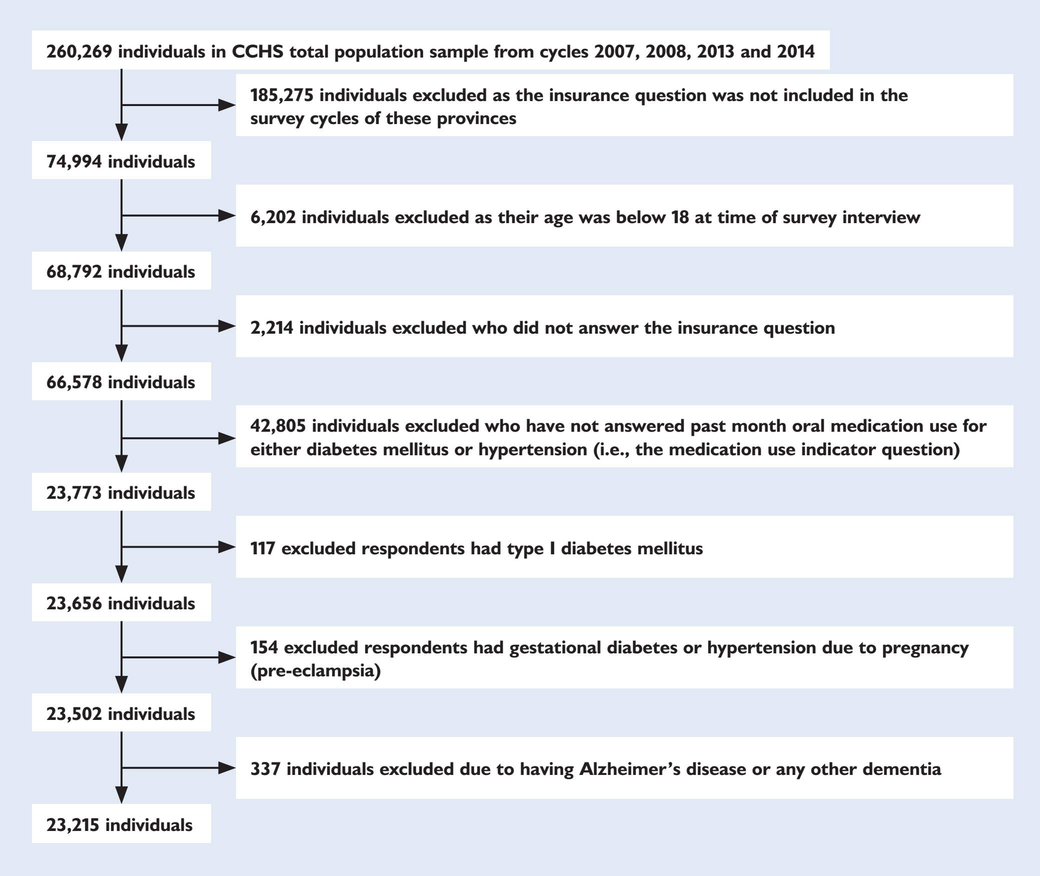
First, we examined relationships between each independent variable and PMCC status, using χ^2 tests of independence. Then, a multivariable logistic regression model was constructed to examine the relationship between PMCC and hypertension/type 2 diabetes medication use following a stepwise forward-selection approach (Bursac et al. 2008).

All of the independent variables mentioned were included based on goodness of fit in the full model. However, variables including province, year and household income were forced into the model to control for potential confounding imposed by geographical, time and income factors. To factor total household income as a potential confounder, we used the imputed and derived national-level deciles income variable, which provide a relative measure of a respondent's household income to that of all other respondents' household income on a national level, and is adjusted each year based on the consumer product index (Yeung and Thomas 2013). This income variable is derived by adjusting respondents' reported household income by the low-income cut-off corresponding to their household size and population size. If a respondent's household income was not reported, it was imputed based on the characteristics of respondents. The respondents' adjusted income is then categorized into deciles within all respondents (Statistics Canada 2014). Deciles were collapsed to quintiles to simplify analyses and inferences. The year (of survey) variable was coded as 2007 to 2008 (combined), 2013 and 2014. While the PMCC question was asked in New Brunswick in all years, it was only asked in Ontario starting in 2008. Therefore, combining 2007 and 2008 simplified comparison and inference and balanced the sample size in the three periods. Models were estimated using the bootstrap weights and re-estimation procedure provided by Statistics Canada, to account for the complex design of the survey and to produce more conservative confidence intervals (Shao 2003). We handled independent variables missingness using three strategies and compared the results (Appendix 2, [Amoud 2018]). First, we calculated the percentage of missing data and conducted regression analyses by including only the respondents who had complete data (Sterner 2011). Second, we followed the educated guessing approach for imputation of missing data (Allison 2002). For example, if the smoking status was unknown, we assumed the respondent as a non-smoker. Third, we carried out five multiple imputations by fitting a logistic regression to predict the missing variable's value, using all other covariates and following the fully conditional specification method (Berglund 2015).

All results presented are weighted. We performed several sensitivity and subgroup analyses within the province of residence, age group, income level, and insurance type.

SAS®, version 9.4 (SAS Institute Inc, Cary, NC) was used. Main model outputs were reproduced using STATA® version 14. Data were provided by Statistics Canada through the South-West Ontario Research Data Centre at the University of Waterloo. Because these are anonymous secondary data subject to the confidentiality procedures of Statistics Canada, no research ethics board approval was necessary.

FIGURE 1. Steps taken to achieve study respondents



Results

Descriptive statistics

Our study sample included 23,215 records, from a total of 74,994 responses in CCHS cycles

2007, 2008, 2013 and 2014 in Ontario and New Brunswick. This translates to 31% of the sample from Ontario and New Brunswick combined. Figure 1 illustrates the steps taken in forming the study sample. Using the population weights provided on the data sets, this final sample represents a weighted population of 8,696,520 Canadians in Ontario and New Brunswick. Overall, 20.0% of the study population indicated that they did not have any drug insurance that covered all or part of the cost of their prescription medication.

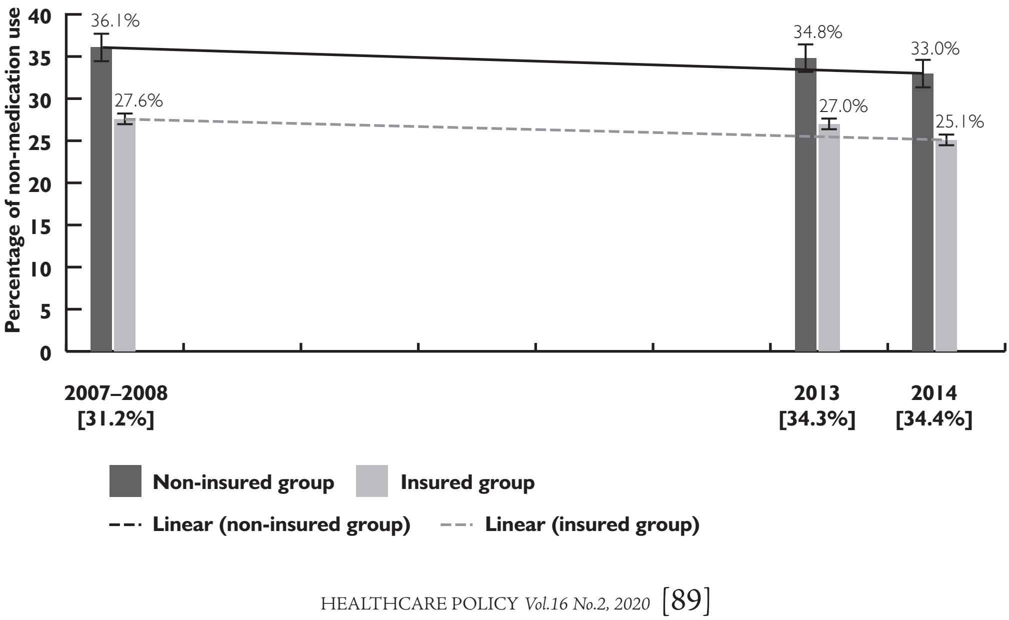
Table 1 (available online at longwoods.com/content/26351) illustrates the characteristics of the sample, weighted to population. Over half of the study population was male (51.2%), and 39.7% were 65 years of age or older. The prevalence of non-medication use was 28.2%. Respondents who did not have insurance had a significantly higher rate of non-medication use compared to those who had insurance (34.6% vs. 26.6%, $p < 0.0001$).

Trend in PMCC

Over the seven-year (2007–2014) study period, the proportion of respondents who did not have PMCC increased slightly by almost 1%, from 19.6% (95% CI [17.5, 22.5]) to 20.7% (95% CI [16.9, 23.1]). While the percentage of non-medication use among people with hypertension and type 2 diabetes decreased over the study period by 8.9% (29.3% to 26.7%), those without insurance showed less improvement in their medication use (8.3% change, from 27.6% to 25.1%) compared to those who had insurance (10.8%, change from 36.1% to 33.0%; Figure 2). In other words, medication use improved over time.

The final multivariable logistic regression model controlled for age, sex, household income, respondent's highest acquired level of education, having either or both diseases

FIGURE 2. Weighted percentage of Canadians with non-medication use by PMCC from 2007 to 2014

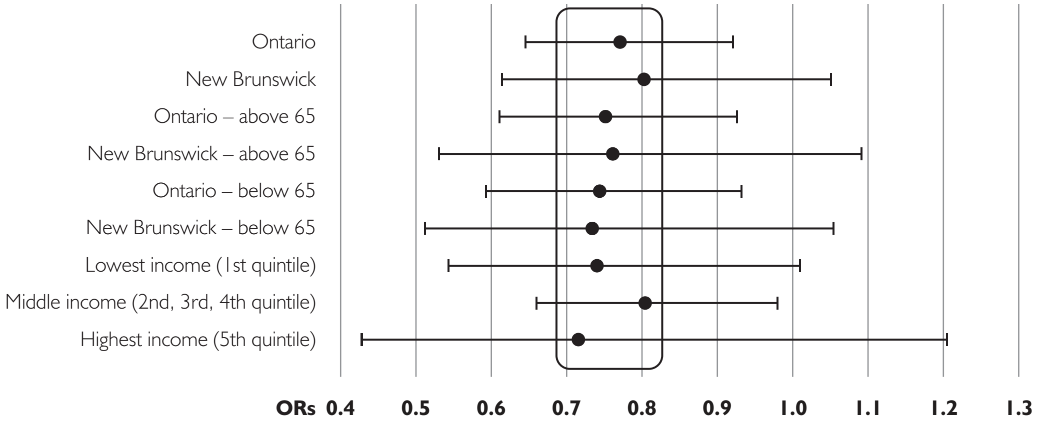


(hypertension/type 2 diabetes or both), smoking status, province of residence, the year the survey was taken as well as not having cancer, a cardiovascular disease, a flu shot or a regular medical doctor. Respondents who did not have PMCC had an adjusted odds ratio (OR) of 0.774 (95% CI [0.66, 0.91]) for either type 2 diabetes or hypertension oral medications use, compared to those who did have insurance. The factors controlled for in the model were statistically significant except for the forced variables (province, income and year). These include age, sex, education level, smoking status, not taking a flu shot, not having a regular medical doctor, not having stroke or heart disease (cardiovascular disease) and not having cancer. Other variables, such as race, were not statistically significant and hence were not included in the final model. The ORs of all included variables are shown in Table 2, available online at longwoods.com/content/26351.

Subgroup analyses

The subgroups analyses showed consistent results in all groups and yielded medication use ORs ranging from 0.7 to 0.8 as shown in Figure 3. The association between PMCC and medication use did not change significantly depending on province of residence, age group or income level. Among Ontarians who were 65 years of age or older (i.e., who are eligible for the public drug plan), the estimated OR of medication use with not having PMCC for this subgroup was 0.75 (95% CI [0.61, 0.93]). Having more than one plan was associated with better medication use. Those who had more than one type of insurance (private/employer with governmental) had a higher odds of medication use (OR = 1.44, 95% CI [1.12, 1.86]) as compared with having only governmental insurance. Additionally, results of further subgroup analyses are illustrated in Table A3 of Appendix 2 (available online at longwoods.com/content/26351).

FIGURE 3. ORs of medication use with no PMCC in subgroups with 95% CI



Sensitivity analyses

Unlike the main analysis, in which respondents who had both hypertension and type 2 diabetes had to have answered "yes" to using both medications to be classified as using their medication, we carried out sensitivity analyses with four different approaches to identifying medication use, to test the robustness of our definition of medication use (Models 2–5, Table 3, available online at longwoods.com/content/26351) (Lyles and Lin 2010). None of the analyses resulted in substantial changes to the ORs. Remarkably, 17.1% (n = 1,819) of Ontario seniors answered "no" to having PMCC, in spite of having an automatic PMCC through the Ontario provincial plan (Government of Ontario 2016). We carried out further sensitivity analyses by considering all Ontario seniors to have PMCC, and the odds did not shift substantially. The results of these analyses are illustrated in Table 3 (Models 6–7).

Misclassification of type 1 diabetes respondents as type 2 was suspected, as some respondents with diabetes reported using insulin at a very young age but also answered questions about their oral medication use. We observed that all respondents who answered "yes" to having type 2 diabetes were provided with the question for adhering to oral medication for diabetes, and the question was not restricted to those who had type 2 diabetes. Statistics Canada's algorithm to differentiate type 2 diabetes from type 1 classified respondents who answered "yes" to using oral anti-diabetic medications as being type 2. This misclassification was found to affect 1% (289) of the study population. We performed sensitivity analyses by removing those diagnosed with type 2 diabetes at an age less than 30 years (Shields et al. 2015). The resulting OR was very similar to the ORs in the main analysis. Model 8 in Table 3 shows the OR after this removal.

Considering the methods for addressing missing values, the ORs produced by the three different strategies did not differ substantially from the main analysis (OR = 0.77, 95% CI [0.66, 0.91]). See Table A2 in Appendix 2 (available online at longwoods.com/content/26351).

Discussion

Similar to previous studies (Law et al. 2012; Men at al. 2019; Tamblyn et al. 2014), we used regression analysis to adjust for confounding effects. Several other methods are available, such as propensity score matching (Kratzer et al. 2015) or utilizing instrumental variables (Angrist et al. 1996); however, no one method can be considered as the most advantageous in observational research (Elze et al. 2017; King and Nielsen 2019; Linden 2014).

We studied PMCC in a representative sample of two Canadian provinces, Ontario and New Brunswick, over seven years. Over that study period (2007–2014), the percentage of respondents without PMCC in these two provinces may have increased slightly, from 19.6% (95% CI [17.5, 22.5]) in 2007–2008 to 20.7% (95% CI [16.9, 23.1]) in 2014. As for the confounding variables, the results of the statistical model were consistent with previous research showing that smoking, not having a flu shot, not having a medical doctor and being female decreases the odds for medication use (Meichenbaum and Turk 1987; Sherman and Lynch

2014; World Health Organization 2014). On the other hand, increase in age increased the odds for medication use. Medication use was also found associated with having less disease burden such as one disease (hypertension or diabetes) instead of both, or no other cardiovascular diseases (heart disease or stroke), or not having cancer (Brown and Bussell 2011; Yang et al. 2009). People who did not have PMCC were 23% less likely to use their oral medications for type 2 diabetes and/or hypertension compared to people who had PMCC (medication use OR 0.77, 95% CI [0.66, 0.91]). This translates into an 8% absolute decrease in use of oral type 2 diabetes and hypertension medications. As such – assuming a causal relationship – providing PMCC to 13 patients, may help one patient use their medication. In a subgroup analysis, for those who had PMCC, having more than one type of insurance would increase the odds of medication use by 44%.

The Canadian Institute for Health Information (CIHI [2019]) reported a continuous increase in household out-of-pocket health expenditure between 1988 and 2017; the annual growth rate for this expenditure – including prescription medication cost – for patients was 2.2%. Our findings of 1% more people not having PMCC cannot sufficiently explain this increase in out-of-pocket health expenditure. In fact, this increase in the percentage of respondents who did not have PMCC over the study period may be due to natural variability (i.e., noise). As such, the increase in chronic diseases prevalence (Public Health Agency of Canada 2019), the aging of the population and the availability of more new expensive medications may explain some of this trend (CIHI 2011). From 1988 to 2017, an increase of 4.1% in private insurance expenditure was reported (CIHI 2019). Increased cost of chronic medications may have contributed to this rise in expenditure. For example, between 2014 and 2015, spending for diabetes medications increased by 10.2% within private insurance (Welds 2017). Nevertheless, our findings confirm that financial burden is still a major obstacle that prevents patients from taking full advantage of chronic medications, including those for type 2 diabetes and hypertension (Law et al. 2018). Almost 20% of Canadians do not have PMCC. This represents a substantial number of Canadians without insurance.

PMCC in Canada is closely related to the state of the economy (Sanmartin et al. 2014), and therefore, economic conditions might offer some explanation for this trend of staying at the same level (Sutherland and Dinh 2017), if not increasing. Specifically, the "working poor," who are the most vulnerable to economic cycle changes (Bernard 2014), are also mostly affected by the burden of drug cost (Caldbick et al. 2015). Thus, it can be speculated that the economic crisis of 2008, which was associated with increased unemployment rates, might have trumped any improvement in PMCC. As such, a national Pharmacare program has been suggested as an effective intervention to fill gaps in PMCC while providing overall cost savings to the system.

Our results support previous studies that show that older Canadians who have hypertension use their medication more than their younger counterparts and that people with cardiovascular diseases (such as heart disease or stroke) have higher odds of using their medication (Campbell et al. 2008; DiMatteo et al. 2007). Thus, the increase in age and chronic disease burden over time may explain increased medication use in people with a chronic disease such as hypertension or type 2 diabetes.

Matching with previous studies, we found that medication use is increasing over time (Fang 2020; Montvida et al. 2018; Tajeu et al. 2016; Tajeu et al. 2019). However, although we found a trend toward improvement in medication use over time, the extent of improvement among uninsured patients was lesser and may have been hindered by the absence of PMCC (Gai and Gu 2009). This is because not having PMCC can add to the financial struggle of cost-related non-adherence (Goldsmith et al. 2017; Gupta et al. 2018; Kennedy and Morgan 2009; Morgan and Lee 2017). The lack of PMCC may divest patients from fully benefiting from the positive improvement in medication use. As such, we suggest that PMCC is important for ensuring that Canadians have equitable access to treatments that can prevent some of the devastating clinical outcomes of hypertension and type 2 diabetes.

Consistent with previous findings, in the subgroup analysis of those who had PMCC, having two types of insurance, rather than only one type, increased the odds for medication use (Kratzer et al. 2015). This implies a dose–response or exposure–response relationship. That is, an increase in insurance coverage increases the odds for medication use. We think that this is evidence that public and private insurance programs can complement each other to provide patients with more comprehensive coverage. Universal public coverage could be seen as coverage that provides basic access to medication. Private insurance could extend medication access by working with public coverage to increase accessibility to a wider range of medications beyond the basic needs.

Policy implications

Universal coverage for medications was intended to be added to the Canadian universal healthcare system (Medicare; Brandt et al. 2018). Over the past 50 years, since the inception of the Canadian Medicare, the introduction of universal PMCC (i.e., Pharmacare) was discussed repeatedly in Canada. Recently, the final report of the Advisory Council on the Implementation of National Pharmacare, A Prescription for Canada: Achieving Pharmacare for All, recommended a PMCC in Canada that covers all essential medication to all Canadians (Health Canada 2019). On the other hand, in November 2019, 1,300 health professionals and public policy experts wrote a letter directed to members of the 43rd Parliament of Canada, advocating and asking for necessary legislation and budget commitments in 2020 for a comprehensive public Pharmacare plan (Pharmacare 2020).

The Canadian Pharmacists Association advised governments and policy makers to examine the evidence on financial barriers to medication adherence, to gain a better understanding of what is impeding optimal health outcomes of effective medications (Canadian Pharmacists Association 2015). Non-adherence is a significant problem for cardiovascular and diabetic patients. Quantifying the association between PMCC and non-medication helps explain the impact of the lack of PMCC on Canadians and their medication adherence behaviour. Non-adherence is significantly associated with all-cause hospitalization in older people (adjusted OR = 1.17, 95% CI [1.12, 1.21]) and mortality (adjusted hazards ratio = 1.24, 95% CI [1.14, 1.35]; Walsh et al. 2019). In fact, medication non-adherence can incur annual economic costs to the healthcare system. Costs attributed to non-adherence in cardiovascular diseases ranged from $3,347 to $19,472 per patient annually (Cutler et al. 2018), when all costs were added. Medication non-adherence also increases healthcare costs for diabetes patients (Kennedy-Martin et al. 2017). Thus, increasing the use of medications by removing patients' financial barriers is expected to be cost-saving. Although improved adherence increases drug costs, this adherence offsets non-drug costs (i.e., healthcare costs). Therefore, the net total costs are decreased as a result of medication adherence (Muszbek et al. 2008). Creating drug-coverage programs for treating chronic conditions such as diabetes and hypertension can be beneficial and cost-saving and a step forward toward including more Canadians with PMCC (Brandt et al. 2018; Lewis 2020). In Ontario, there are incentive fees for primary healthcare providers for chronic disease management, including diabetes and congestive heart failure (Ontario Ministry of Health 2020). This is because providing better care for patients with chronic diseases is a robust approach to improve health and save cost. As such, implementing PMCC, even if starting with chronic diseases (such as hypertension and diabetes), should complement systems already in place that aim to enhance chronic disease managements by primary healthcare providers. Finally, starting with provision of PMCC for patients with hypertension and diabetes is of best interest for the healthcare system offsetting dire consequences of non-adherence due to prescription cost barriers. Results from this study can assist policy makers and administrators in evaluating the pressing need for improvement of medication use. The results also convey the characteristics of people, within the population, at a disadvantage from lack of PMCC.

Our use of repeated cross-sectional survey data is an advantage over other designs for answering the questions ((Kelsey et al. 1986). First, this design provides a valuable glimpse of the real-world association between no PMCC and medication use in the Canadian population with type 2 diabetes and hypertension at multiple points in time. Second, this design provides a clear examination of the trend in the impact of lack of PMCC on medication use related to two of the most important chronic diseases in Canada.

Limitations

Despite these advantages, there are some limitations to this study. Most are related to the self-reported nature of the surveys. For example, some respondents with type 1 diabetes seem to have answered "yes" to adhering to oral medications, which they are unlikely to have been prescribed. This may have led to some respondents being misclassified as having type 2 diabetes. Also, some respondents might have also misreported their PMCC status by not considering copayment to be PMCC (Grootendorst et al. 2003). This potential misreported PMCC status represents 6.2% of the total study population who were classified as having no PMCC. In Ontario, the Ontario Drug Benefit plan is activated on the first day of the month after residents turn 65 years (Government of Ontario 2016). As for people from New Brunswick, we were unable to quantify the potential misclassification. In New Brunswick, seniors turning 65 years or older have a 60-day mail notice notifying them to apply for provincial coverage for prescription medication (Government of New Brunswick 2018). Numerous sensitivity analyses were carried out and revealed that these possible misclassifications had minimal influence on our results. Furthermore, respondents could have been classified as not using their medication, while in reality they may have initially not been prescribed any. This limitation is challenging to quantify. However, this is probably non-differential misclassification and hence could not have affected the estimated OR of the association between PMCC and medication use. Due to the nature of this study in using self-reported data, some variables that could have an impact on the relationship between PMCC and medication use could have been missed. For example, according to the health belief model (Becker 1974; Glanz et al. 2008), patients' attitude and perception of the severity and susceptibility to diabetes and hypertension affect medication use (Harrison et al. 1992). However, such variables were unmeasured in the CCHS. Lastly, because the medication use question asked about past month use, some respondents might have overestimated their monthly use of medication. Arguably, this overestimation could have increased the odds for medication use, and our final results may be an underestimation of the actual underuse of medication due to the absence of PMCC. It is also possible that some respondents may have had hypertension and/or type 2 diabetes but were never prescribed any medication. The extent of this limitation could not have been sought out, although an update about the epidemiology of hypertension in Canada found that about 90% of respondents who reported having high blood pressure also indicated that they were receiving treatment (Padwal et al. 2016).

Conclusion

Our study found that people without PMCC are more likely to underuse their medications. We were able to quantify these odds, which we estimate are 23% less than for those who do have PMCC with hypertension and/or type 2 diabetes. Over a seven-year time period (2007–2014), the percentage of respondents without PMCC increased slightly. Medication use improved over time, yet, despite this improvement, respondents without PMCC had limited improvement in medication use compared with those with PMCC. Overall, this study provides evidence that a lack of PMCC is a barrier to proper medication use. In addition, this study provides necessary real-world evidence for the argument that PMCC is indeed likely to improve oral medication use for hypertension and type 2 diabetes in Canada.

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Correspondence may be directed to: Mhd Wasem Alsabbagh, Assistant Professor, School of Pharmacy, Faculty of Science, University of Waterloo, 10A Victoria St. S., Kitchener, ON N2G 1C5. He can be reached by phone at 519-888-4567 x21382 or by e-mail at wasem.alsabbagh@uwaterloo.ca.

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RESEARCH PAPER

Rheumatologists' Acceptance of Patient Referrals from Physical Therapists

Acceptation par les rhumatologues des recommandations de patients faites par des physiothérapeutes

DEBBIE EHRMANN FELDMAN, BSCPT, MSc, PhD, PHT
Professor, School of Rehabilitation
Physiotherapy Program and School of Public Health
Department of Social and Preventive Medicine
University of Montreal
Researcher, Centre for Interdisciplinary Research in Rehabilitation
Centre for Public Health Research
University of Montreal, Montreal, QC

MICHEL ZUMMER, MD, FRCPC
Associate Clinical Professor, University of Montreal
Department of Rheumatology
Maisonneuve-Rosemont Hospital
Montreal, QC

TATIANA OROZCO, BSCPT, MSc
School of Rehabilitation
Faculty of Medicine, University of Montreal
Montreal, QC

JONATHAN EL-KHOURY, MD (C)
Faculty of Medicine and Health Sciences
University of Sherbrooke, Sherbrooke, QC

FRANÇOIS DESMEULES, PT, PhD
Associate Professor, School of Rehabilitation
Faculty of Medicine
University of Montreal
Orthopaedic Clinical Research Unit
Maisonneuve-Rosemont Hospital Research Center
Montreal, QC

MAUDE LALIBERTÉ, PT, PhD
Assistant Clinical Professor, School of Rehabilitation
University of Montreal, Montreal, QC

KADIJA PERREAULT, PT, PhD
Associate Professor, Department of Rehabilitation
Centre for Interdisciplinary Research in Rehabilitation and Social Integration
Laval University, Quebec, QC

ROLAND GRAD, MD, MSc
Associate Professor, Department of Family Medicine
McGill University
Herzl Family Practice Centre
Jewish General Hospital
Montreal, QC

LINDA WOODHOUSE, PT, PhD
Professor and Head of School
School of Physiotherapy and Exercise Science
Faculty of Health Sciences, Curtin University
Perth, Australia
Adjunct Professor, Department of Physical Therapy
Faculty of Rehabilitation Medicine
University of Alberta, Edmonton, AB

SASHA BERNATSKY, MD, PhD
Professor, Department of Medicine
Faculty of Medicine, McGill University
Department of Medicine
Division of Rheumatology
McGill University Health Centre
Montreal, QC

Abstract

We surveyed Canadian rheumatologists regarding beliefs about physical therapists' (PTs) ability to refer patients appropriately to rheumatologists and whether they would accept such referrals. Most (86.9%) believed that PTs can appropriately refer to rheumatologists. However, only 48.2% of rheumatologists would be very or extremely likely to accept a referral from a PT they knew, and 23.5% would accept a referral from a PT they did not know. Conversely, 90.5% would accept a referral from a PT if they could bill it as a full consult. We conclude that being able to bill PT referrals as full consults may potentially enhance the acceptance of PT referrals.

Résumé

Nous avons sondé les rhumatologues canadiens au sujet de leur confiance en la capacité des physiothérapeutes à aiguiller les patients de manière appropriée vers des rhumatologues et au sujet de leur acceptabilité de tels aiguillages. La plupart des répondants (86,9 %) estiment que les physiothérapeutes sont en mesure de faire des aiguillages appropriés vers les rhumatologues. Cependant, seulement 48,2 % des rhumatologues seraient très ou extrêmement susceptibles d'accepter l'aiguillage proposé par un physiothérapeute qu'ils connaissent, et 23,5 % accepteraient l'aiguillage d'un physiothérapeute qui leur est inconnu. À l'inverse, 90,5 % accepteraient l'aiguillage d'un physiothérapeute s'ils pouvaient le facturer comme une consultation complète. Nous concluons que le fait de pouvoir facturer les aiguillages provenant de physiothérapeutes comme des consultations complètes pourrait potentiellement améliorer l'acceptation de tels aiguillages.

Introduction

Optimal care for patients with inflammatory arthritis requires rapid access to a rheumatologist (Raza 2010; van der Linden et al. 2010). In Canada, rheumatologists represent a limited resource (Brophy et al. 2016), and inappropriate referrals could actually impair rheumatology access for those who need it the most. Therefore, it is important that referrals are appropriate and correctly prioritized. Typically, persons with joint problems consult a family doctor, who then refers them to a rheumatologist if they suspect inflammatory arthritis. Canadian residents may also consult a physical therapist (PT) as their first contact, an important option for individuals with joint problems, given that approximately 15% of Canadians do not have a regular family physician (CIHI 2016).

A recent study indicated that PTs in the provinces of Quebec and Alberta, where PTs are permitted to refer cases to rheumatologists (Ordre professionnel de la physiothérapie du Québec 2015; Physiotherapy Alberta College and Association 2009), were able to distinguish between inflammatory and non-inflammatory cases and were aware that new-onset inflammatory arthritis cases should be referred to rheumatologists (Feldman et al. 2019). With the currently evolving roles of allied healthcare practitioners, such as the successful model of primary care PT in the US military and health maintenance organizations

(McGill 2013; Murphy et al. 2005) and the agreement by some Canadian provinces (Ordre professionnel de la physiothérapie du Québec 2015; Physiotherapy Alberta College and Association 2009), rheumatologists are faced with the new possibility of accepting referrals from nonphysicians. Potential barriers to the success of this new referral model may relate to rheumatologists' concerns regarding communication, consultation fees and other factors. These have never been investigated.

Our objectives were to (1) determine whether rheumatologists believe that PTs are able to refer patients appropriately to rheumatology; (2) explore whether rheumatologists would be willing to accept referrals made by PTs; and (3) investigate factors associated with rheumatologists' willingness to accept PT referrals.

Method

The study design was a cross-sectional survey of Canadian rheumatologists – members of the Canadian Rheumatology Association (CRA) – and was conducted in June 2018. We designed a questionnaire with 17 questions, 10 related to demographics and practice characteristics and seven regarding the acceptability of PTs referring patients directly to rheumatologists. The latter group of questions included items regarding the rheumatologists' past experiences with referrals from PTs and beliefs in PTs' abilities to refer appropriately: Would they accept a referral from a PT whom they knew or one whom they did not know? Would they accept a referral from a PT if they could bill it as a regular consult? The questionnaire was translated into French by a bilingual member of our research team and back-translated by another bilingual member. It was then pretested on two rheumatologists (in each language), and minor adjustments were done. The survey was distributed by the CRA and sent to all their rheumatologist members using the platform Survey Gizmo. Two reminders were sent regarding the survey. The study was approved by the ethics committees of the University of Montreal and the University of Alberta and also by the subcommittee of the CRA.

Analysis consisted of a description of the sample, comparison with national statistics of Canadian rheumatologists using 95% confidence intervals (CI) (CMA 2018), and logistic regression to explore factors associated with rheumatologists' willingness to accept PT referrals. Factors included in the regression model were other provinces versus Alberta and Quebec, sex, experience (>10 years versus ≤ 10 years), type of practice (group versus solo), practice setting (hospital versus nonhospital) and target population (adult versus pediatric). Age was excluded from the regression because it was highly correlated with experience (Spearman $r = 0.8$). We used SPSS statistical software Version 25 (IBM) to analyze the data.

Results

In all, 90 out of 471 rheumatologist members of the CRA responded to the survey, for a 19.1% response rate. The majority ($n = 50$) of respondents worked at university-affiliated

TABLE 1. Description of sample of rheumatologists

Characteristic	Characteristic levels	Sample		National statistics
		N	Percentage [95% CI]	Percentage [95% CI]
Province	British Columbia Prairie provinces* Ontario Quebec Nova Scotia and Newfoundland Other§	17 17 25 15 2 2	21.8 [12.6–31.0] 21.8 [12.6–31.0] 32.1 [21.7–42.5] 19.2 [10.5–27.9] 2.6 [0–6.1] 2.6 [0–6.1]	14.2 [11.0–17.4] 16.3 [13.0–19.6] 39.3 [34.9–43.7] 24.4 [20.5–28.3] 4.7 [2.8–6.6] 5 [3.0–7.0]
Age	<45 ≥45	34 55	38.2 [28.1–48.3] 61.8 [51.7–71.9]	36.0 [31.7–40.3] 64.0 [59.7–68.3]
Sex	Male Female	37 52	41.6 [31.4–51.8] 58.4 [48.2–68.6]	46.0 [41.5–50.5] 54.0 [49.5–58.5]
Experience	≤10 years >10 years	33 56	37.1 [27.1–47.1] 62.9 [52.9–72.9]	N/A
Clientele age	Pediatric Adult	12 73	14.1 [6.9–21.3] 85.9 [78.7–93.1]	N/A
Practice setting	Private clinic University hospital Other	30 50 5	35.3 [25.1–45.5] 58.8 [48.3–69.3] 5.9 [0.9–10.9]	45.0 [40.5–49.5] 46.0 [41.5–50.5] 9.0 [6.4–11.6]
Practice type	Solo Group Other	31 52 2	36.5 [26.3–46.3] 61.2 [50.8–71.6] 2.4 [0–5.6]	41.0 [36.6–45.4] 57.0 [52.5–61.5] 2.0 [0.70–3.3]
Clinical or research	Clinical Research Mixed Other (administrative, teaching)	58 1 25 3	66.7 [56.8–76.6] 1.1 [0–3.3] 28.7 [19.2–38.2] 3.4 [0–7.2]	N/A
Number of patients per week	0–30 ≥31	27 60	31.0 [21.2–40.6] 69.0 [59.2–78.6]	N/A

Note: CI = confidence interval.

* Alberta, Saskatchewan, Manitoba

§ New Brunswick, Prince Edward Island, Territories

hospitals, and 35% of the respondents (*n* = 31) had more than 25 years of experience. Table 1 contains a description of the sample and comparisons with Canadian rheumatologists (CMA 2018). There were more rheumatologists working in academic hospital settings in our sample than the sample defined by the national descriptors. We also saw trends for more respondents who were female, <45 years of age and from Western Canada (British Columbia and the Prairie Provinces), although the 95% CIs overlapped for these categories.

Among the respondents, only 11 (13%) had received referrals from a PT in the past six months, of which nine accepted these referrals. Most respondents (*n* = 73; 86.9%) believed that PTs can appropriately refer patients to rheumatology. Nonetheless, only 41 respondents (48.2%) said that they would be very or extremely likely to accept a referral from a PT they knew, and this proportion went down by more than half (*n* = 20, 23.5%) for a PT they did not know. However, 76 respondents (90.5%) would accept a referral from a PT if they could bill it as a regular consult from a physician, i.e., receive the same remuneration as a referral from a physician (which includes an additional premium versus a standard patient visit).

Results of logistic regression analyses are presented in Table 2. Male rheumatologists and rheumatologists with ≤10 years of experience were more likely to accept referrals from PTs, especially if the PT was known to the rheumatologist. Pediatric rheumatologists (versus adult rheumatologists) appeared more likely to accept a PT referral, particularly when the PT was not known to the rheumatologist.

TABLE 2. Factors associated with referral acceptance from a PT: Odds ratio (95% CI)

Factor	Accepting referral from a known PT (as opposed to not accepting)	Accepting referral from an unknown PT (as opposed to not accepting)
Province other than Quebec and Alberta	0.34 [0.08–1.38]	1.57 [0.34–7.20]
Male rheumatologist	6.45 [1.85–22.50]	3.50 [0.95–12.86]
Experience >10 years	0.10 [0.02–0.42]	0.28 [0.07–1.13]
Group practice vs. solo	0.90 [0.17–4.74]	1.31 [0.17–10.16]
Hospital setting vs. outside clinic/office	0.71 [0.12–4.09]	0.77 [0.10–6.15]
Adult vs. pediatric clientele	0.17 [0.03–1.05]	0.15 [0.03–0.89]

CI: confidence interval

Discussion

Our results demonstrate that although rheumatologists believe that PTs can appropriately refer patients, only between a quarter (PT not known) and a half (PT known to rheumatologist) of the rheumatologists who responded would accept referrals from PTs under present conditions (i.e., they cannot bill the visit as a full consult). Rheumatologists with less experience, those who were males and those working with a pediatric clientele were more likely to accept a PT referral.

It is not surprising that billing is a factor in physician specialists accepting referrals. Most rheumatologists in Canada are paid fee-for-service, also work outside an academic teaching centre (CMA 2018) and are responsible for paying their own overhead costs. Specialists in Ontario can bill a consultation visit for patients who are referred by a nurse practitioner, but PT referral is not reimbursed in this province (INFOBulletin 2016). Although there is a code for specialists to bill for consults of patients referred by PTs in Alberta, many rheumatologists may not be aware that this is allowed.

The fact that rheumatologists would be more open to accepting referrals from a PT who they know likely reflects confidence in that PT's judgment. Rheumatologists with less experience are younger and were more willing to accept PT referrals; this may be because they have smaller patient rosters than older, more experienced rheumatologists or because they have received more interprofessional training. Many medical schools have recently instituted interdisciplinary courses where there is exposure to other health professionals, which can foster better communication and respect among the different professions (Apramian et al. 2015). Also, pediatric rheumatologists were more receptive to PT referrals: the multidisciplinary team model is favoured in pediatric rheumatology. There are fewer pediatric rheumatologists overall; however, patient rosters in the pediatric clinic are smaller and more fluid (i.e., patients move out to the adult rheumatology world, eventually making way for other patients), which may also be a factor (Davies et al. 2010).

Male rheumatologists were also more likely to accept referrals than female rheumatologists. This disparity may be related to financial loss of the consultation premium, which may be more of a concern for a female rheumatologist because, according to an American study, male rheumatologists already earn 16% more than female rheumatologists (Quinn 2017), although we do not know if this is the case in Canada as well.

Referral from a PT directly to a rheumatologist can speed up the consultation process instead of having to advise the patient – after seeing the patient – to go to a family physician in order to be referred to a rheumatologist. An Australian study (Byrnes and Comans 2015) suggested that direct referral to medical specialists by PTs could reduce initial costs.

Limitations include the small sample and issues related to representativeness. Our 19% response rate is higher than the 16% response rate of the National Physician Survey (2014) in Canada. Further, we do not have data from rheumatologists who are not members of CRA. With the small number of pediatric rheumatologists, it is unknown whether respondents in that group specifically are representative of pediatric rheumatologists, which may be important, given how differently this group responded to the survey (versus rheumatologists who treat adults). Also, our sample showed more rheumatologists working in university-affiliated hospitals, where they may work more closely with PTs. This may have resulted in an overestimation in our study regarding acceptance of PT referrals. We also did not ask about methods of remuneration; salaried rheumatologists may be more likely to accept PT referrals than those paid on a fee-for-service basis. However, the majority of Canadian rheumatologists are paid fee-for-service, with only 9% reportedly paid a salary (CMA 2018).

Referral to a rheumatologist may emanate from a PT working in either the public or the private sector. However, more PTs with outpatient musculoskeletal clienteles work in the private sector today (The Conference Board of Canada 2017). Because many Canadians do not have insurance that would pay for physical therapy, the proposed pathway may exclude persons who are unemployed or in the lower socio-economic levels. An earlier Canadian study indicated that persons with higher socio-economic status were more likely to bypass primary care with regard to specialist contact (Glazier et al. 2009).

Policy Implications

To optimize the pathway of referrals from PTs to specialists, provincial health ministries (health insurance boards) in Quebec and Alberta (where PTs are already permitted to refer directly to specialists) could enact a policy regarding equal remuneration for consultations when referrals originate from PTs, similar to those originating from family physicians. In other provinces, agreements to enable PT referrals will need to be negotiated between physician organizations (college of physicians and surgeons and/or specialists associations) and provincial physiotherapy associations (responsible for licensing, public protection, ensuring that quality services are dispensed by PTs and professional development of its members). Subsequently, provincial physiotherapy associations will need to negotiate agreements with the provincial health ministries regarding remuneration for consultations originating from PTs, in order to enable this pathway of direct referral by PTs. Finally, once these new policies are established, there will be a need for knowledge translation among practising physicians and PTs on the part of their professional associations. Although newer PT graduates may be more aware of new policies, many practising PTs and physicians may not be. In order for this new policy to be successful, the knowledge translation aimed at both rheumatologists and PTs will need to include the following: (1) the advantages of enabling the pathway of PT referral to rheumatologists, which includes rapidity of access and cost-saving since patients who opt to go to a PT do not need to subsequently go to a family physician just to get the referral; (2) the high ability of PTs to distinguish between inflammatory and non-inflammatory cases; and (3) the ability to bill these consultations the same way as physician referrals.

There are several potential barriers to adopting this new policy. For example, there can be resistance from physicians (both specialists and family physicians), since traditionally, specialists only accept referrals from other physicians, and the proposed pathway would represent an expansion of nonphysician roles and changes in their scope of practice. This may be especially problematic to accept for family physicians and rheumatologists who are more "traditionalistic" in their approaches – that is, those who prefer the gate-keeping role of family physicians making decisions about referring patients. Furthermore, family physicians' roles include coordination of care for their patients, while rheumatologists deal with symptoms of the rheumatic disease. For persons with a chronic disease such as rheumatic disease, the family physician's role is vital to ensure that the patient's health needs are looked after (Goldenberg 2017). Thus, for patients who see a PT first, it is imperative that the patient has (or finds) a regular source of primary healthcare. There have been problems in Canada regarding finding a family physician (CIHI 2016), and this is a barrier to optimal care, especially for persons with chronic disease conditions. Another barrier may be the lack of confidence in PTs' abilities in discerning cases that are important to be referred. The fact that rheumatologists were much more likely to accept referrals from PTs who they know may support this contention. There is a need for knowledge translation with respect to PTs' abilities to refer appropriately. Hence, negotiations between regulatory bodies of physicians and physiotherapists (professional orders/associations/colleges) should include a presentation of evidence affirming that PTs are experts in musculoskeletal evaluation and management, and are capable of distinguishing between cases that require a referral (inflammatory disease) and those that do not (e.g., osteoarthritis, mechanical lower back pain or neck pain).

From the ministry's perspective, lobbying by professional bodies can influence policy.

However, policies are frequently influenced by economic/funding considerations, and not only potential, to improve health outcomes (Hutchison et al. 2011). This new pathway can serve as a cost-cutting measure, as patients who are seen by a PT can be referred directly without having to visit a family physician to be referred (Byrnes and Comans 2015). Physicians who doubt PTs' abilities may contend that they will be receiving unnecessary referrals (that would inflate costs); however, there are doubts about appropriateness of family physicians' referring practices as well (Mehrotra et al. 2011; Wong et al. 2019). Moreover, family physicians' training in musculoskeletal evaluation and management is often lacking (Akesson et al. 2003), and as shown by our previous work, PTs who are well-trained in care of musculoskeletal conditions are quite adept in discerning inflammatory and non-inflammatory conditions (Feldman et al. 2019), potentially performing better than family physicians in providing appropriate referrals to rheumatologists.

Finally, patients who consult a PT usually have private insurance that covers (in part or all of) their visit to the PT. Some patients who do not have private insurance must pay for their PT sessions themselves. This may pose a barrier to those who do not have private insurance or who cannot afford PT. Nonetheless, they are covered by their provincial insurance plan to access a physician who would then refer them if need be.

Conclusion

Rheumatologists appear to have confidence in PTs' abilities to refer appropriately. However, acceptance of referrals from a PT in the present scenario is low. Being able to bill PT referrals as full consultations (i.e., at the same rate as they would bill consultations from family physicians) may enhance the acceptance of PT referrals. Enabling the pathway of an appropriate referral by a PT to a rheumatologist can potentially enhance the rapidity of rheumatology consultation for some patients with inflammatory rheumatic disease and ultimately improve health outcomes for these patients.

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Correspondence may be directed to: Debbie Ehrmann Feldman, École de réadaptation, Université de Montréal, Pavillon 7077 du Parc, C.P. 6128, Succ. Centre-ville, Montréal, QC H3C 3J7. She can be reached by phone at 514-343-6111 x 1252 or by e-mail at debbie.feldman@umontreal.ca.

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RESEARCH PAPER

The Ontario Public Does Not Understand the Difference Between Registered Dietitians and Unregulated "Nutritionists": Results from a Cross-Sectional Mixed Methods Study

La population ontarienne ne comprend pas la différence entre diététiste autorisé et « nutritionniste » non réglementé : Résultats d'une étude transversale mixte

DEANNA VELOCE, BSc, RD
Registered Dietitian
School of Food and Nutritional Sciences
Brescia University College, Western University
London, ON

MARLEY FISHER, BSC, RD
Registered Dietitian
School of Food and Nutritional Sciences
Brescia University College, Western University
London, ON

COLLEEN O'CONNOR, PHD, RD
Associate Professor
School of Food and Nutritional Sciences
Brescia University College, Western University
Lawson Health Research Institute
London, ON

BRENDA HARTMAN, PHD, RD
Assistant Professor
School of Food and Nutritional Sciences
Brescia University College, Western University
Lawson Health Research Institute
London, ON

JUSTINE R. HORNE, PHD, RD
Registered Dietitian
Health and Rehabilitation Sciences
Western University
London, ON
East Elgin Family Health Team
Aylmer, ON

Abstract

Background: Current Ontario healthcare policy permits anyone to use the title "nutritionist" and practice as a clinician regardless of education and training. The title "dietitian," on the other hand, is protected under the *Dietetics Act* (1991) for use exclusively by individuals who undergo rigorous education and training in evidence-based nutrition.

Objectives: The objectives of this study were to: identify whether the Ontario general public understands the difference between a registered dietitian (RD) and an unregulated "nutritionist;" understand experiences with RDs and "nutritionists;" and determine if the current nutrition landscape arising from gaps in healthcare policy has the potential to harm the public.

Methods: A cross-sectional mixed methods survey study was carried out using inductive content analysis, descriptive statistics and chi-square tests.

Results: Respondents (n = 402) did not understand the difference between RDs and "nutritionists." Overall, public experiences have been significantly more positive when nutrition information/advice stemmed from an RD.

Implications: This study provides justification for proposed legislative amendments to the *Dietetics Act* (1991) and the *Regulated Health Professions Act* (1991). These proposed amendments have been detailed in the full-text manuscript.

Résumé

Contexte : La politique de santé actuelle en Ontario permet à quiconque d'utiliser le titre de « nutritionniste » et d'exercer en tant que clinicien, et ce, indépendamment de son éducation et de sa formation. Le titre de « diététiste », quant à lui, est protégé en vertu de la *Loi de 1991 sur les diététistes* et ne peut être utilisé que par des personnes qui ont reçu une éducation et une formation rigoureuses en nutrition.

Objectifs : L'objectif de cette étude était de déterminer si la population ontarienne comprend la différence entre un diététiste et un « nutritionniste » non réglementé, afin de mieux comprendre l'interaction avec les diététistes et les « nutritionnistes ». L'étude cherchait aussi à déterminer si le paysage nutritionnel actuel, résultant de lacunes dans les politiques de santé, peut être nuisible pour la population.

Méthode : Une étude transversale mixte a été réalisée au moyen d'une analyse inductive de contenu, de statistiques descriptives et de tests du chi carré.

Résultats : Les répondants (n = 402) ne comprennent pas la différence entre diététiste et « nutritionniste ». Dans l'ensemble, l'expérience de la population est nettement plus positive lorsque les informations et conseils nutritionnels *proviennent d'un diététiste.*

Répercussions : Cette étude justifie les modifications législatives proposées à *la Loi de 1991 sur les diététistes* et à *la Loi de 1991 sur les professions de la santé réglementées.*

Introduction

Safe, evidence-based and effective nutrition advice is essential for the health and wellness of the general public. With rising chronic disease and obesity rates, emerging diet trends and increasing use of complementary and alternative medicine (CAM) in Canada (Caulfield and Rachul 2011; Statistics Canada 2014, 2016), it is vital that consumers understand where to seek credible nutrition information. According to the Canadian Foundation for Dietetic Research, the public is relying less on traditional sources of health information, such as family physicians, and relying more on the internet, social media and blogs, as well as friends, relatives and colleagues for health information (Kennedy 2015).

Healthcare is legislated provincially in Canada (McMillan 2010). In Ontario, registered dietitians (RDs) are the only regulated nutrition professionals in the province (College of Dietitians of Ontario 2018b). The title "nutritionist" is not protected by Ontario law, allowing anyone to legally refer to themselves as a "nutritionist," offer nutrition advice and provide *medical nutrition therapy* regardless of education or training. While the definition of the term "medical nutrition therapy" can be interpreted in different ways, for the purposes of this study, this term refers to the provision of nutrition information and advice aimed to help prevent, manage or treat a medical disease or condition, manage food allergies/intolerances or improve health and nutritional status during pregnancy/lactation. This is in line with the proposed definitions provided by the American Dietetic Association and the Center for Medicare and Medicaid Services (Carey and Gillespie 1995; Michael 2001). Peer-reviewed scientific research has yet to study consumer comprehension of the difference between an RD and an unregulated "nutritionist," but grey literature indicates that significant confusion from the general public is likely (DieteticAdvocacy 2013). The provinces of Alberta, Nova Scotia, Quebec and Prince Edward Island have responded to this issue with provincial legislation requiring that the title "nutritionist" be used exclusively by RDs (College of Dietitians of Alberta 2018; Ordre professionnel des diététistes du Québec 2017; Prince Edward Island Legislative Counsel Office 2018; The Nova Scotia Dietetic Association 2018).

More than 70% of Canadians regularly use CAM as part of their health regime. This includes taking vitamins and minerals, herbal products, homeopathic medicines, and other natural health products in an effort to maintain and improve health and quality of life (Public Health Agency of Canada 2008). With the common use of these products in Canada, there is the possibility of a number of issues that may adversely affect health, including CAM/nutrient/drug interactions, direct clinical risks of adverse events (including hepatoxicity of CAM products) and inefficacy of these treatments leading to the delay or outright refusal of evidence-based conventional treatments (Johnson et al. 2018; Wardle and Adams 2014). Given that the provision of CAM and *medical nutrition therapy* are not considered controlled acts under Ontario's *Regulated Health Professions Act* (*RHPA* 1991), "nutritionists" in Ontario are permitted to recommend vitamins and minerals, herbal products, homeopathic "medicines" and other natural health products regardless of their knowledge and training in this area. Essentially, anyone in the province can sell or endorse CAM and *medical nutrition therapy* services as a result of gaps in the current healthcare policy and legislation. This, in turn, puts the public at risk of nutrition misinformation, which could result in health-related harms.

Social media has become a frequently used tool for delivering health and nutrition information, with blogs being a particularly popular "source" of information (Dumas et al. 2017). A recent study focusing on detox diet blogs found that "nutritionists" in Ontario are providing false, misleading and potentially harmful nutrition information, while RDs in Ontario are providing safe, evidence-based information about detox diets (Toth et al. 2019). These diets can have many serious adverse effects, such as changes in electrolyte levels, dehydration or water overdosing, interactions with medications and nutritional deficiencies (Acosta and Cash 2009; Dietitians of Canada 2014; Klein and Kiat 2015; Zeratsky 2020). Fad diets, including detoxes, have resulted in several harmful health outcomes including the development of serotonin syndrome (Bryant and Kolodchak 2004), lactic acidosis (Johnstone 2007) and even death (Isner et al. 1979). Interestingly, one study noted that blogs written by non-RDs displayed more results on Google and therefore could have higher readership (Dumas et al. 2017). Consequently, non-RD blogs could influence readers' dietary behaviours to a greater extent than RD blogs. These findings are especially concerning, given that about 50% of Canadians seek nutrition information and advice online (Kennedy 2015). Furthermore, Ontario "nutritionists" provide recommendations with no accountability to uphold safe standards of practice for the quality of their service and are not mandated and overseen to ensure patient confidentiality or security of personal health information (UnlockFood 2020). In comparison, RDs in Ontario are legislated under the *RHPA* (1991) and the *Dietetics Act* (1991) to help ensure that safe, competent and ethical care is provided to patients at all times.

When nutrition advice is not backed by robust scientific evidence, there is a higher risk of harm. An example includes the case of an 11-year-old boy in Ontario who followed a highly restrictive diet (consisting of only potato, pork, lamb, apples, cucumber and Cheerios™) in an effort to relieve his severe eczema and allergies (Jacobson et al. 2017). Due to the severe vitamin A deficiency that developed over the course of eight months, the boy suffered from severe dry eyes, light sensitivity, night blindness and progressive vision loss, leading him to become legally blind (Jacobson et al. 2017). Another example comes from a recent study that assessed the utilization and efficacy of alternative medicine for patients with common types of curable cancer (Johnson et al. 2018). This study found a significantly increased risk of death in patients who chose alternative medicine as treatment, without conventional cancer treatment (chemotherapy, radiotherapy, surgery and/or hormone therapy; Johnson et al. 2018). Given that CAM practices are highly prevalent in Canada (Wardle and Adams 2014), this is a significant public health concern.

While patients should have the option to access various healthcare practitioners, their choice should be informed (Caulfield and Rachul 2011). Noted concerns with medical or lifestyle advice that lacks scientific evidence includes costly, ineffective and inappropriate dietary recommendations – this has been noted particularly with respect to certain types of allergy testing (Caulfield and Rachul 2011). In addition to the abovementioned risks, there is a risk of harm to the public when the advice they receive is not evidence-based, as this can delay effective scientific-based treatment, resulting in unnecessary monetary costs and wasted time and effort for patients.

There is currently no peer-reviewed published literature assessing the public's comprehension of the differences between RDs and "nutritionists" in Ontario, and minimal research exists assessing patients' experiences working with each of these nutrition providers. If Ontarians are unaware of the differences between an RD and "nutritionist," they are at great risk by unknowingly trusting those who provide nutrition advice with no credibility or scientific evidence (Caulfield and Rachul 2011). Accordingly, the objectives of the present study were: to identify whether members of the Ontario general public who have an interest in nutrition understand the difference between RDs and "nutritionists" in Ontario; to assess their experiences of obtaining nutrition information from various nutrition providers; and to determine if the current Ontario nutrition landscape arising from gaps in healthcare policy and legislation has the potential to harm the public.

Methods

This was a cross-sectional, mixed methods study, which utilized both online and in-person data collection methods. The recruitment methods aimed to capture an accurate and representative sample of members of the Ontario general public who have an interest in nutrition. To achieve this, a non-probability voluntary sampling strategy was used. The sampling strategy aimed to target a variety of age groups, genders and locations when reaching out to organizations and social media pages. Two main strategies were used for data collection. First, the online survey link was shared on social media with Ontario-based followers via a variety of Facebook and Twitter pages, upon obtaining the consent of page administrators (Appendix 1, available online at longwoods.com/content/26349). Social media pages were strategically selected to recruit subjects from a variety of locations within Ontario, with followers accurately representing the Ontario general public. To minimize response bias (e.g., aiming to avoid recruitment of a large number of friends/family of dietitians and/or nutritionists), social media pages of practising dietitians and nutritionists were not contacted to share the survey link. To capture individuals who may not use social media, in-person surveys were conducted in various public spaces within Southwestern Ontario with permission from the respective establishment (Appendix 1). Non-RD and non-nutritionist Ontario residents aged 13 years and older met the inclusion criteria. Residents aged 13 years and over were included, given that research demonstrates that dieting and attention to nutrition in adolescence is becoming increasingly common in Ontario (Findlay 2004). A chance to win a $50 grocery store gift card was provided as an incentive to participate in the study. Voluntary and anonymous survey responses were collected from the online format between August and November 2018, and from the in-person format throughout November 2018. This study was approved by the Western University Research Ethics Board (Protocol #112252).

Instruments

An electronic survey was developed using Qualtrics Survey Software, Version 4.02. The same questions were included in the in-person survey. The survey consisted of two open-ended questions and 14 closed-ended questions, which were developed to screen for eligibility criteria, obtain demographic data from the sample population and achieve the three abovementioned objectives of the study (Appendix 2, available online at longwoods.com/content/26349). All authors reviewed and revised the survey before implementation. All surveys were voluntary and anonymous.

Data analysis

Qualitative responses to Questions 6 and 16 were analyzed using inductive content analysis (Elo and Kyngäs 2008). Responses were independently coded by two researchers (Fisher and Horne), who then identified overarching themes. The final themes were agreed upon through consensus by discussion.

To determine the public's understanding of the differences between RDs and "nutritionists," two questions were analyzed (Appendix 2). First, respondents were asked if there is a difference between RDs and "nutritionists." If they selected "no" or "not sure," they were coded as "did not understand." If respondents selected "yes," they were asked to specify what the difference is. These open-ended responses were further analyzed for accuracy based on pre-determined criteria for a correct response (Appendix 3, available online at longwoods.com/content/26349). Upon analyzing the responses, one additional criterion was added to the list for determining a correct response (Appendix 3). Using this criterion, each response was independently coded by two researchers (Fisher and Horne) as "correctly understood (the differences)," "did not understand (the differences)" or "cannot determine." Discrepancies in coding were resolved by reaching consensus through discussion. Those who indicated that there was a difference between RDs and "nutritionists" and who were able to correctly identify at least one difference (Appendix 3) were determined to have a correct understanding of the difference between RDs and "nutritionists." All others were grouped as those who did not understand the difference.

Quantitative responses were summarized using descriptive statistics. Chi-square tests were used to test associations ($p < 0.05$) between the type of nutrition provider (RD, "nutritionist" or other) and whether (1) specific recommendations about food were provided, (2) specific recommendations about supplements were provided, (3) health and nutrition concerns were addressed and (4) nutrition recommendations were followed.

Results

Of the 430 participants who started the survey, 93.5% ($n = 402$) met the predetermined inclusion criteria and were therefore included in the analyses. Participants were primarily female adults (Table 1). Due to the nature of online surveys, the number of responses varied for different questions. This could have been because respondents closed the survey before

TABLE 1. Characteristics of study participants ($n = 402$)

Age (years)	13–17	18–45	46–65	Over 65
Frequency, n (%)	22 (5.5)	189 (47.0)	131 (32.6)	60 (14.9)

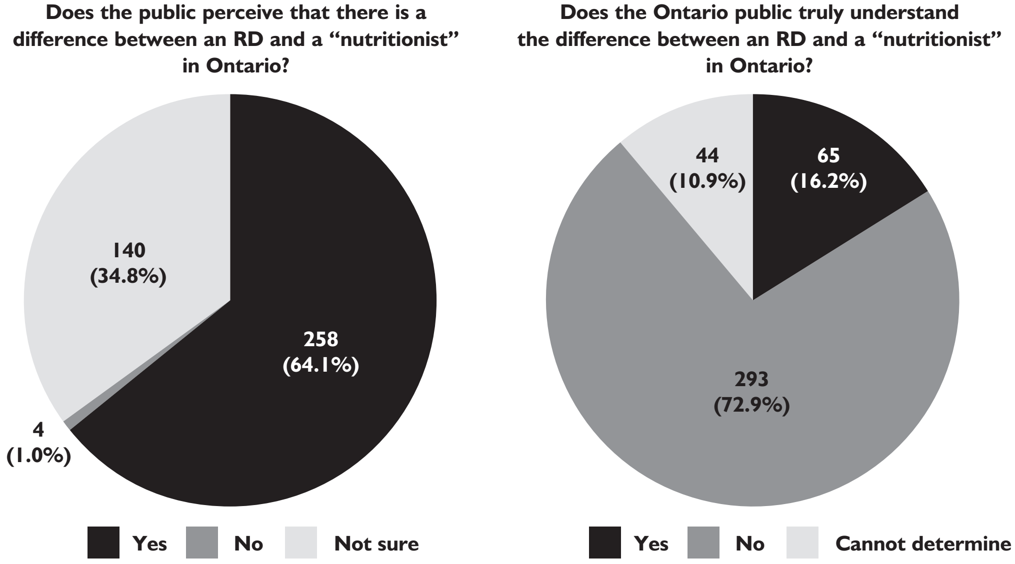
Gender	Male	Female	Non-binary	Prefer not to say
Frequency, n (%)	68 (16.9)	331 (82.3)	0 (0.0)	3 (0.8)

answering all questions and submitting, did not need to respond to questions that were not applicable based on their previous responses or skipped questions. For reference, the number of respondents for various results is indicated in each table/figure.

Limited understanding of the difference between RDs and nutritionists

While 64.1% ($n = 258$) of survey respondents indicated that there was a difference between an RD and "nutritionist" in Ontario, only 25.2% ($n = 65$) of these individuals correctly identified the difference (Figure 1). The vast majority comprising 72.9% of the entire sample of 402 respondents ($n = 293$) either did not understand that there is a difference, stated that they were not sure if there is a difference between RDs and "nutritionists" in Ontario, or stated that there was a difference but did not correctly identify it. Therefore, only 16.2% (of the entire sample of 402 respondents) correctly understood the difference(s). A total of 10.9% of the open-ended survey responses could not be analyzed as the responses were vague and did not refer to the type of nutrition provider, or the responses were left unanswered.

FIGURE 1. Public perceptions and understanding of the difference between an RD and a "nutritionist" in Ontario



Examples of vague responses included "degree," "schooling" and "skills." Four overarching themes were identified from the inductive analysis of perceptions of the difference(s) between RDs and "nutritionists": education/training, scope of work, regulation and uncertainty.

THEME: EDUCATION/TRAINING

With respect to education/training, the differences were incorrectly identified by most respondents. For example, one respondent incorrectly stated that, "Nutritionists are more educated in the biochemistry area of how food is absorbed and what fuels your body." Conversely, a few respondents correctly identified differences in education/training, such as one who correctly stated that, "Dietitians have a degree in foods and nutrition from an accredited university program and undergo comprehensive and rigorous training."

THEME: SCOPE OF WORK

Interestingly, many respondents perceived that RDs and "nutritionists" could be differentiated by the scope of their work. With a lack of regulation around nutrition practices in Ontario, both RDs and "nutritionists" are permitted to practice within similar scopes of work. One respondent incorrectly noted, "Dietitians are more focused on eliminating sugars, fats, etc. Nutritionists are more focused on wholesome, natural ways of taking in all food groups including healthy fats and carbs." Another stated that a "dietitian helps modify your diet to match your health needs and a nutritionist provides supplements outside of what you actually eat." A different participant believed that "a nutritionist could create a diet specific to your needs, and costs much more. Registered Dietitians seem to be more about public education and teaching the Canada Food Guide."

THEME: REGULATION

While correct responses were minimal, a more common correct response about regulation was that "dietitians are regulated health professionals." When regulation was mentioned, responses were often correct. Another participant noted that "a registered dietitian is a regulated profession under Ontario law and requires specific educational pathways. Nutritionist is a more open profession with less governance." These perceptions were accurate overall.

THEME: UNCERTAINTY

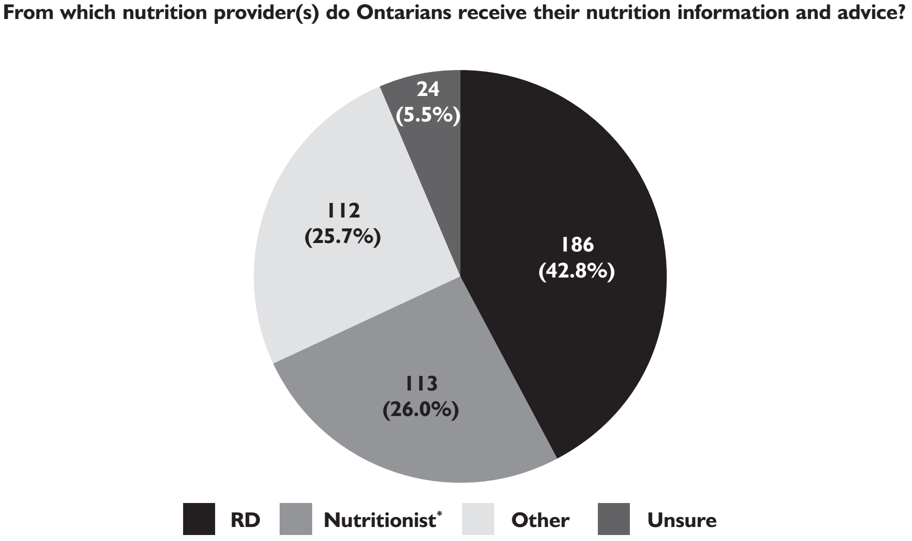
Uncertainty was often expressed by respondents in the open-ended responses to Question 6 (Appendix 2). Participants may have perceived that there was a difference between RDs and "nutritionists," but they failed to explain the difference. Examples of uncertain responses include the use of some of the following phrases: "not sure," "don't know" and "I could be wrong."

Reported experiences with nutrition providers

Ontarians reported having had experiences with a variety of nutrition providers, including

RDs, "nutritionists" and "other" nutrition providers. When asked who/what the "other" nutrition providers included, the most common responses were doctors, the internet, coaches or fitness trainers and naturopaths. In total, 84.0% of respondents attested having sought information, advice or counselling about nutrition (in person/online/blog post/magazine/newsletter/social media) at some point in their lives. When asked where/who they seek out for nutrition information, 42.8% of respondents indicated an RD, 25.7% reported a "nutritionist," 26.0% reported "other" nutrition providers and 5.5% were not sure (Figure 2). Therefore, the majority of respondents sought nutrition information from sources other than an RD.

FIGURE 2. Proportion of Ontarians receiving nutrition information and advice from different sources



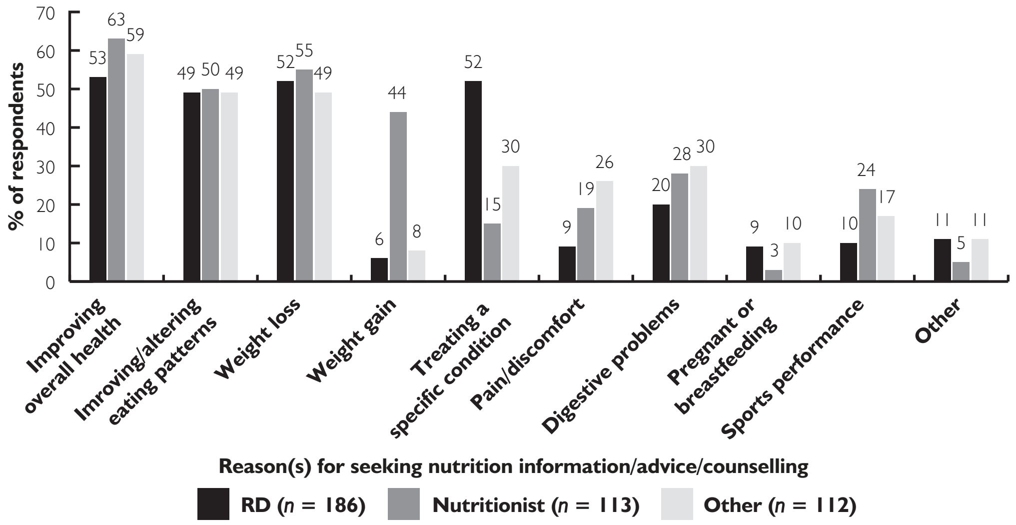
*Nutritionist may include: Holistic nutritionist, personal trainer, nutrition specialist, certified nutritionist, sports nutritionist, certified health coach, certified nutrition consultant and others.

Participants were only asked this question if they responded "yes" to the previous question: "Have you ever sought out information, advice or counselling about nutrition (in person or online through blog posts/magazines/newsletters/social media)?"

The top five reasons for seeking out information from an RD and "other" nutrition providers were for improving overall health, improving/altering eating patterns, losing weight, treating a specific condition and managing digestive problems (Figure 3). The top five reasons for seeing a "nutritionist" were for improving overall health, improving/altering eating patterns, losing weight, gaining weight and managing digestive problems (Figure 3).

When receiving nutrition advice from an RD, 75.7% of respondents reported an increased perception or belief that their nutrition concerns were addressed, which is significantly greater ($p = 0.03$) than that of those who received nutrition advice from a "nutritionist" (59.4%) and those who received nutrition advice from "other" nutrition providers (62.2%). When seeking out information from an RD, 91.3% of respondents reported

FIGURE 3. Reasons for seeking out nutrition information, advice or counselling, stratified by type of nutrition provider



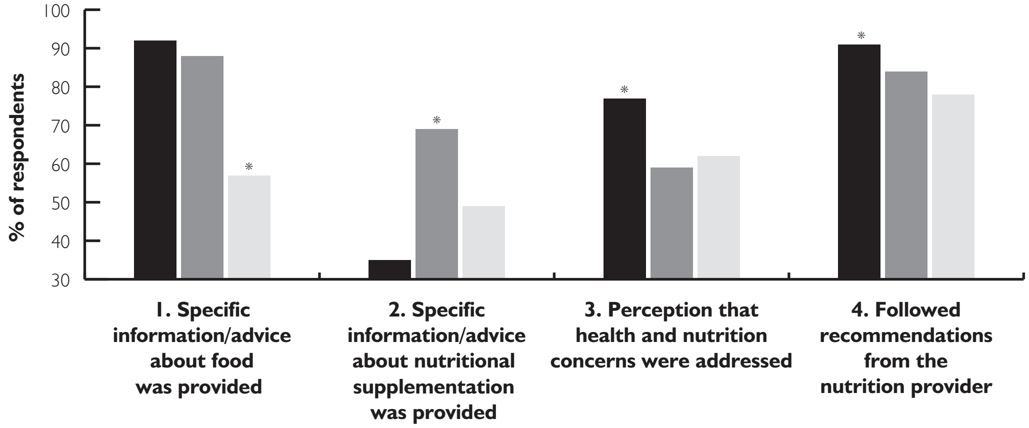
following nutrition advice, compared to 83.8% for those who sought out information from a "nutritionist" and 78.0% for those who sought out information from "other" nutrition providers. Those who received the advice from RDs were significantly more likely to have reported following the advice ($p = 0.007$). Furthermore, respondents were significantly less likely to be given specific recommendations regarding nutrition from food from "other" nutrition providers at 57.0% ($p < 0.001$) compared to 91.8% of respondents who received advice from RDs and 88.3% who received advice from "nutritionists." Finally, 68.9% of respondents who sought out nutrition information from "nutritionists" said that they were given specific recommendations regarding nutritional supplements (natural products, vitamins/minerals, powder, drinks), which was significantly higher ($p < 0.001$) than 49.5% who received information from "other" nutrition providers or 35.3% who received information from RDs (Figure 4).

Potential for harm

Overall, 66.5% of the respondents identified that nutrition-related conditions improved after following advice from a nutrition provider, 30.4% of the responses reported no change and 3.1% reported that the condition worsened. As a result of following nutrition advice from a nutrition provider, 9.8% of the respondents reported having adverse/negative side effects.

When asked to specify these experienced side effects, the following three themes arose from the qualitative analysis: *weight gain*, *physiological stress* and *diminished mental health*. Self-reported "unnecessary/unwanted weight gain" was the most prevalent theme. With regard to *physiological stress*, respondents wrote about medication reactions, gastrointestinal

FIGURE 4. Self-reported experiences with different nutrition providers: percentage of sample indicating "yes" to survey questions



* $P < 0.05$

Percentage of sample indicating "yes" to the following survey questions (number of respondents by category indicated in brackets below):

1. Were you given specific recommendations regarding nutrition from food by one or more of the nutrition professionals? (RD: $n = 182$; Nutritionist: $n = 103$; Other: $n = 93$).
2. Were you given specific recommendations regarding nutrition from nutritional supplements (natural products, vitamins/minerals, powder, drinks) by one or more of the nutrition professionals? (RD: $n = 179$; Nutritionist: $n = 103$; Other: $n = 97$).
3. Were your health and nutrition concerns addressed by one or more of the nutrition professionals? (RD: $n = 181$; Nutritionist: $n = 106$; Other: $n = 98$).
4. Did you follow any recommendations you were given by one or more of the nutrition professionals? (RD: $n = 183$; Nutritionist: $n = 105$; Other: $n = 100$).

problems, "dizziness" and "hair loss." *Diminished mental health* often included comments related to disordered eating such as "I ended up binge eating," or participants noted that their experience "worsened [their] relationship with food, [they] felt guilty about eating anything that was not part of the strict and restrictive meal plan." Others noted adverse side effects such as "depression" and "social anxiety" and noted that they were "hungry *all the time* and miserable." This suggests that the current nutrition landscape in Ontario has the potential to harm the public and highlights the need for improved regulation of *medical nutrition therapy*.

Discussion

Overall, this study highlights a concerning lack of understanding of the difference between unregulated "nutritionists" and RDs among the Ontario general public. This is the first study to formally assess this public confusion and confirms the confusion that has been indicated in grey literature (DieteticAdvocacy 2013). The public's inability to differentiate between nutrition providers is concerning, given that RDs are the only regulated nutrition professionals in Ontario. Thus, the public is at risk of mistakenly seeking and following nutrition advice from unregulated nutrition providers, whose training and education in nutrition may be limited, of poor quality and not science-based (College of Dietitians of Ontario 2018b). Furthermore, only RDs have a regulatory college that is responsible for ensuring that high standards of safe, ethical and science-based nutrition care are being provided to the public (College of Dietitians of Ontario 2018b).

Our results indicated that 84.0% of the respondents have sought nutrition information, advice or counselling at some point, with less than half disclosing that they have sought information or advice from an RD. More than half of the general public appears to be turning to "nutritionists" and "other" nutrition providers or internet sources that may be unregulated, unsanctioned or lacking evidence-based nutrition expertise. Many of the top reasons for seeking nutrition advice from "nutritionists" and other nutrition providers can be considered *medical nutrition therapy*, such as losing weight, gaining weight, treating a specific condition and managing digestive issues (Dietitians of Canada 2018). Ontarians also sought *medical nutrition therapy* from these providers for potentially higher risk considerations such as nutrition for pregnancy, breastfeeding or pain/discomfort (Figure 3). This finding is interesting, as significantly more respondents felt that their health and nutrition concerns were addressed, and were more likely to follow nutrition advice when the information/advice came from an RD, compared to a "nutritionist" or "other" nutrition provider. It was further notable to find that the majority of Ontarians are not turning to RDs for nutrition information/advice. This is, however, not surprising, given the public confusion. Reports of higher rates of health and nutrition concerns being addressed and increased likelihood of following through with recommendations provided by RDs suggest that RDs should be the primary provider of nutrition information and advice in Ontario. Furthermore, the highly reported incidences of "nutritionists" recommending supplements (with no accountability to a regulatory body) is cause for concern due to possible CAM–nutrient interactions, direct clinical risks, adverse events and inefficacy of these treatments, leading to delayed or refusal of evidence-based conventional treatments (Johnson et al. 2018; Wardle and Adams 2014).

Although most respondents self-reported that their condition(s) improved, it cannot be neglected that 30.4% of the responses showed "no improvement," and 3.1% reported "worsened" conditions, highlighting the notion that following nutrition advice has the potential to result in undesirable outcomes and may cause harm. The potential for risk of harm was further demonstrated in the 10% of participants who indicated that they experienced adverse or negative side effects, such as unwanted weight gain, diminished mental health and physiological stressors. Given that there is potential for nutrition information/advice to cause harm, any nutrition provider offering *medical nutrition therapy* should be regulated in a manner similar to that of an RD. RDs are overseen by a regulatory body, which has a process in place for the public to report negative experiences with dietitians. In cases where harm stems from the nutrition information/advice provided by an RD, disciplinary measures are taken (College of Dietitians of Ontario 2018a). No such regulatory body exists for "nutritionists." A promising solution is for *medical nutrition therapy* to be added as a controlled act for dietitians under the *RHPA* (1991) and for the term "nutritionist" to be legally protected under the *Dietetics Act* (1991) for use exclusively by the only regulated health professional in the area of nutrition — RDs. These two legislative changes could help protect the Ontario public and promote optimal nutrition and overall health considering that (1) the public is confused about the difference between "nutritionists" and RDs, (2) unregulated "nutritionists" are practising *medical nutrition therapy* and (3) there is a risk for harm with the provision of nutrition information/advice. In addition, the legislative amendments may spark media attention, which could help inform the public of the education and training differences among different nutrition providers.

While these proposed legislative amendments aim to help improve the current nutrition landscape with respect to public protection, there are some limitations to note. First, if the title "nutritionist" was protected, these nutrition providers could still refer to themselves using other unprotected titles such as "nutrition coach" or "nutrition clinician". However, we hypothesize that the title "nutritionist" is perceived as having greater credibility than other titles such as "nutrition coach." Indeed, future research should explore this. Second, amending legislation can take several years, and thus other strategies to protect the public against false, misleading and potentially harmful nutrition information and advice should be employed in the meantime. Moreover, if/when legislation is amended, a transition plan should be put in place. Transition plans have been used in other provinces, such as Alberta. Alberta's transition plan included a two-year period in which the college worked to inform non-RD nutrition providers of the new legislation by sending cease-and-desist letters to individuals using the title "nutritionist." In an effort to avoid any further public confusion around title use, following this two-year transition period, RDs plan to begin using the title "nutritionist" (D. Cook, personal communication, January 21, 2020). The College of Dietitians would ultimately be responsible for overseeing title protection, which is the current situation in provinces where title protection has been achieved (College of Dietitians of Alberta 2018; Ordre professionnel des diététistes du Québec 2017; Prince Edward Island Legislative Counsel Office 2018; The Nova Scotia Dietetic Association 2018). Similar strategies can be used with respect to protection of the term "registered." However, in this case, various healthcare regulatory colleges would be responsible for overseeing the new legislation, depending on the type of healthcare provider misusing the term. For example, the College of Physiotherapists would be responsible for overseeing the titular use of a "registered athletic therapist." In terms of implementation costs, indeed, there can be some costs associated with the enforcement of these legislative changes. However, following protection of the title "nutritionist" in Alberta, costs were primarily limited to postage fees of mailing >100 cease-and-desist letters (D. Cook, personal communication, January 21, 2020). Therefore, we posit that Ontario would similarly experience low costs; however, it is possible that costs could differ substantially from province to province.

The findings of this study provide convincing evidence of Ontarians' confusion surrounding who to approach for evidence-based nutrition information. This study included a wide range of age groups and used robust data analysis methods to examine the results. The accessible, anonymous and voluntary design of the online and in-person survey allowed for participants to be open and honest regarding feedback. This survey design also allowed for a representative collection of responses from people who seek out nutrition information across Ontario. In addition, the survey was advertised virtually on social media pages based in

Ontario and advertised in-person in public spaces within Ontario's densely populated southern region (Appendix 2), further contributing to the representative sample. Furthermore, samples from a variety of genders and age groups, in both urban and rural settings, were gathered for this study.

While the majority of respondents were female, previous research demonstrates that females are more likely than males to seek out nutrition information/advice (Ek 2015). Therefore, our results are generalizable to those seeking out nutrition information and advice.

Some limitations to the study should be noted. Due to the nature of the survey data collection, response bias cannot be completely eliminated, nor can self-selection bias or fraudulent responses. Misunderstandings and misinterpretation of questions are inherent limitations of all survey-based research (Alderman and Salem 2010). In addition, respondents were asked, "Is there a difference between a Registered Dietitian and Nutritionist in Ontario?" The use of the term "registered" preceding dietitian may have biased respondents' perceptions of the difference between the terms RD and "nutritionist." Because the term "registered" is not regulated, it is possible that asking about the difference between registered nutritionists and dietitians in Ontario may have elicited different responses and results, particularly related to which nutrition provider is regulated. Thus, our finding that 72.9% of respondents do not understand the difference between these nutrition providers may be an underestimation of the degree of public confusion. Future research should assess public perceptions of various terms such as "registered," "licensed" and "certified," which are not legally protected in Ontario under the *RHPA* (1991) and, therefore, are available for anyone to use. Furthermore, future research should aim to determine if there is greater potential for harm when nutrition advice stems from an RD or "nutritionist."

Our research is the first to provide insight into the public's perception of the terms "nutritionist" and RD, as well as the public's experiences with different nutrition providers in Ontario. Future research similar to this in other provinces in Canada would be beneficial to compare the perceptions and experiences of Canadians, especially in provinces where the title "nutritionist" has been protected. Additional research should focus on the education, training and experience of unregulated nutrition providers and how these factors influence the quality of nutrition care they provide to the public. In addition, creating a database of cases of harm that have stemmed from following the nutrition advice of "nutritionists," RDs and other nutrition providers, would provide greater insight into the possible adverse events arising from poor nutrition care. This database could be used to guide recommendations for policy and legislative changes to help reduce the risk of harm and protect the health of Ontarians.

Implications for Research and Practice

This study provides justification for several proposed legislative amendments. A positive step toward ensuring that Ontarians receive the highest quality nutrition information would be to amend two Ontario Acts. The first recommendation is to amend the *Dietetics Act (*1991) to protect the title of "nutritionist" exclusively for RDs. The second recommendation is to amend the *RHPA* (1991) to protect the title "registered" exclusively for regulated healthcare professionals and to protect *medical nutrition therapy* as a controlled act for RDs. These amendments would minimize confusion for the general public regarding the education levels and experiences of "nutritionists" in comparison to RDs. This is especially significant, given the role that optimal nutrition plays in the management of chronic disease and obesity rates, which are continuously rising in Canada (Statistics Canada 2014, 2016).

Conclusion

Although some of the general public may perceive that there is a difference between an RD and a "nutritionist" in Ontario, the vast majority are unaware of what the difference is, demonstrating an overall lack of understanding. With this lack of understanding, the potential risk for harm, and no regulation around the provision of *medical nutrition therapy*, it is evident that the current state of nutrition care in Ontario needs to be improved. The aforementioned proposed legislative amendments have the potential to dramatically improve the health and nutritional status of Ontarians. These proposed amendments are timely; reducing the risk for chronic disease and managing health conditions through healthy lifestyle behaviours is fundamental, now more than ever and will continue to be in the future.

Disclosures

Justine R. Horne is the chair of the Professional Titles for Dietitians in Ontario Advocacy Group.

Correspondence may be directed to: Justine R. Horne. She can be reached by e-mail at jhorne5@uwo.ca.

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