HEALTHCARE
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Volume 14 ◆ Number 4

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Politiques de Santé

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

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

* * *

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

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

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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EDITORIAL

Nothing About Me Without Me

Active and effective partnerships with patients are increasingly recognized as key to improving the design, delivery and organization of health services and policy. Co-designing for improvement yields new insights and tends to lead to better results than healthcare providers, researchers, or policy makers acting on their own.

(For convenience, I use the term "patient" here since it has been identified as a term of choice in several Canadian focus groups. I intend it in an inclusive sense, not only referring to those who have a particular health problem or who use specific health services, but also family, friends, and other caregivers, as well as those who bring other important perspectives from their lived experience of interactions with the health and social sectors.)

Of course, that doesn't mean that moving in this direction is always straightforward. While much has been written about how patients' perspectives and leadership can change care, research, education, and policy, this is a journey where we are collectively learning by doing.

Several articles in this issue of *Healthcare Policy/Politiques de Santé* add to our understanding in this regard. James Shaw and colleagues reflect on the importance of considering the complementary perspectives of public representatives and potential users on health innovation policy. They explore the added dimensions that personal and collective lenses offer to these conversations. Iris Gorfinkel and Joel Lexchin take us into the world of patient portals, addressing their potential to improve collaboration in care between patients and primary care providers. And Josée Lavoie and colleagues take a deep dive into how best to support the care needs of people living with end-stage kidney disease in Northern Manitoba. I appreciate the many insights that these authors offer, as well as those writing on topics as diverse as dementia care reform, deprescribing, and fertility consultations in this issue.

As this is the final issue for this volume of the journal, I would like to extend my sincere thanks to everyone involved in the publication process over the last year. Authors are, of course, central to this process. Papers that pass initial triage are then assigned to one of the journal's editors. S/he oversees the review process. Over the past year, I have been fortunate to work with a talented and committed team of editors from across the country: François Béland, Roger Chafe, Raisa Deber, Mark Dobrow, Eric Latimer, Joel Lexchin and Claude Sicotte, as well as Contributing Editor Steven Lewis.

The lead editor for each paper works with Ania Bogacka, the journal's Managing Editor, to select reviewers. We depend on reviewers' insights, expertise and professionalism to help assess and improve submissions and their relevance for the journal's readers. I would like to take this opportunity to thank all those who have served as reviewers during the past year (see page 79). Special thanks are due to those who provide timely reviews – and to authors who respond to reviews as quickly as possible – so that we can achieve the time-to-publication goals that we have set for the journal. This goal also depends on the continued efforts of the team at Longwoods Publishing who produce the journal.

On behalf of myself and all others who benefit from the insights published in *Healthcare Policy/Politiques de santé*, collective thanks to all those who make the journal possible.

JENNIFER ZELMER, PhD
Editor-in-Chief

ÉDITORIAL

Participation des patients aux études qui les concernent

On reconnaît de plus en plus l'importance des partenariats actifs et efficaces avec les patients pour améliorer la conception, la prestation et l'organisation des services et politiques de santé. Cette coopération ouvre en effet de nouvelles pistes et orientations qui donnent lieu à de meilleurs résultats que si les fournisseurs de services, les chercheurs ou les responsables de politiques travaillaient seuls de leur côté.

(Aux fins de simplification, j'emploie le mot « patient » puisqu'il a été désigné comme terme de choix par plusieurs groupes de discussion au Canada. L'emploi ici est inclusif et ne réfère pas uniquement aux personnes qui ont un problème de santé, mais aussi aux familles, amis et autres aidants, de même qu'aux personnes qui apportent d'importants points de vue tirés de leur expérience de vie et de leurs interactions avec les secteurs de la santé et des services sociaux.)

Bien sûr, il n'est pas toujours simple d'appliquer ce principe. Bien qu'on ait beaucoup écrit sur la façon dont le leadership et le point de vue du patient apportent des changements dans les soins, la recherche, la formation et les politiques de santé, il s'agit d'un domaine où l'on apprend collectivement au fur et à mesure.

Plusieurs articles du présent numéro de *Politiques de Santé/Healthcare Policy* s'ajoutent aux connaissances en ce sens. James Shaw et ses collaborateurs s'intéressent à la complémentarité entre, d'une part, le point du vue du représentant de la population et, d'autre part, celui de l'usager potentiel dans l'avancement des politiques touchant aux innovations en santé. Ils explorent les aspects que les points de vue personnels et collectifs peuvent apporter à ces débats. Iris Gorfinkel et Joel Lexchin se penchent, pour leur part, sur le monde des portails en ligne destinés aux patients, portails qui permettent d'améliorer la collaboration entre patients et prestataires de soins primaires. De leur côté, Josée Lavoie et ses collaborateurs s'intéressent aux façons de couvrir les besoins des personnes atteintes d'insuffisance rénale terminale dans le Nord du Manitoba. Les pistes que proposent ces auteurs sont fort appréciables, tout comme le sont celles des autres auteurs de ce numéro qui nous présentent leur travail sur des sujets comme la réforme des soins en matière de démence, la déprescription et les consultations en infertilité.

Puisqu'il s'agit du dernier numéro pour ce volume de la revue, j'aimerais sincèrement remercier les personnes qui ont contribué à sa publication au cours de l'année. Les auteurs constituent, évidemment, des éléments essentiels de ce processus. Les articles sélectionnés au départ sont remis à un de nos rédacteurs, qui supervisent le processus de révision. Au cours de la dernière année, j'ai eu le plaisir de travailler avec une équipe de rédacteurs talentueux et dévoués provenant de partout au pays : François Béland, Roger Chafe, Raisa Deber, Mark Dobrow, Eric Latimer, Joel Lexchin et Claude Sicotte, ainsi que le collaborateur à la rédaction Steven Lewis.

Les rédacteurs travaillent de pair avec Ania Bogacka, directrice de rédaction, pour le choix des examinateurs. Nous comptons sur les commentaires, l'expertise et le professionnalisme de ces derniers pour évaluer et améliorer les articles soumis, ainsi que pour en assurer la pertinence aux yeux du lectorat. Je profite de l'occasion pour remercier tous ceux et celles qui ont agit à titre d'examinateurs au cours de l'année (voir page 79). Un remerciement tout spécial à ceux qui remettent leur évaluation dans les temps alloués – et aux auteurs qui y répondent rapidement –, ce qui nous permet d'atteindre les échéanciers établis. La réussite dépend aussi des efforts constants de l'équipe de Longwoods Publishing qui produit la revue.

En mon nom et au nom de tous ceux et celles qui bénéficient des pistes de solutions publiées dans *Politiques de Santé/Healthcare Policy*, j'aimerais remercier toutes les personnes qui rendent possible la parution de la revue.

JENNIFER ZELMER, PhD
Rédactrice en chef

DISCUSSION AND DEBATE

Achieving the Goals of Dementia Plans: A Review of Evidence-Informed Implementation Strategies

Atteindre les objectifs fixés dans le cadre des plans contre la démence : revue des stratégies de mise en œuvre éclairées par les données probantes

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Abstract

A 2019 report by the Canadian Academy of Health Sciences identified the importance of evidence-informed implementation strategies in reforming dementia care. Such implementation strategies may be relevant to changing clinical practice in the wake of Canada's impending federal dementia plan (initiated by Bill C-233). As this federal dementia plan is elaborated, there may be value in looking ahead to some of the implementation challenges likely to be faced "on the ground" in healthcare settings. We thus conducted a rapid review of provincial and national dementia plans from high-income countries and reviewed studies on implementation strategies to dementia care. We advance seven key implementation strategies that may be useful for future dementia care reform.

Résumé

Un rapport publié en 2019 par l'Académie canadienne des sciences de la santé met en relief l'importance des stratégies éclairées par les données probantes pour la mise en œuvre des réformes des soins en matière de démence. Ces stratégies de mise en œuvre peuvent permettre de changer la pratique clinique dans le contexte imminent du plan fédéral canadien en matière de démence (au moyen du projet de loi C-233). Dans le contexte de ce plan, il est intéressant d'envisager certains défis liés à la mise en œuvre auxquels devront faire face « sur le terrain » les établissements de santé. Nous avons ainsi mené une revue rapide des plans provinciaux et nationaux contre la démence dans les pays à revenu élevé. Puis nous y avons examiné les stratégies de mise en œuvre pour les soins en matière de démence. Nous proposons sept stratégies de mise en œuvre qui pourraient être utiles pour d'éventuelles réformes des soins en matière de démence.

The Alzheimer Society of Canada (2010) reports that by 2038 over 1.1 million Canadians will have dementia. This represents 2.8% of the total Canadian population, with 9% of Canadians over age 60 and 50% of Canadians over age 90 having dementia (Alzheimer Society of Canada 2010). Ultimately, this prevalence of dementia will lead to a cumulative economic burden of $293 billion per year by 2040 (Alzheimer Society of Canada 2018). In response to rising global dementia rates, the World Health Organization (WHO 2012) has identified dementia as a global health priority. In Canada, this priority has been addressed provincially: beginning with Ontario in 1999 (MOHLTC 1999), provinces have gradually developed plans to address the overwhelming scale, impact and cost of dementia. While provincial stewardship in this arena is logical (Flood and Choudhry 2002), calls for a federal dementia strategy that is complementary to provincial stewardship – involving investment in research, increasing awareness of dementia risk factors and supporting and inspiring local clinicians to improve care practices for dementia – persist (Alzheimer Society of Canada 2018).

Canada's recent passage of Bill C-233, an Act respecting a national strategy for Alzheimer's disease and other dementias, suggests that a federal dementia plan may soon be established. Bill C-233 identified five priorities for dementia care reform: (1) developing national objectives, (2) encouraging investment in research, (3) coordinating with international bodies (e.g., WHO), (4) assisting provinces with the development and dissemination of diagnostic treatment guidelines and best practices for dementia care management; and (5) making recommendations for standards of care. A National Dementia Conference (PHAC 2018) and a report conducted by the Canadian Academy of Health Sciences (CAHS 2019) were organized in response to Bill C-233. Both the conference and report allowed for diverse stakeholders to share perspectives on dementia care and support, research and public education. They also suggested that implementing a dementia strategy is easier said than done. Accordingly, the CAHS recommended that evidence-informed implementation strategies be considered to achieve stated goals of dementia care reform (CAHS 2019). To respond to this final recommendation – and to support the clinic-level objectives identified by Bill C-233 and the National Dementia Conference – a synthesis of existing implementation strategies specifically relevant to dementia care is needed.

In this article, our aims are (1) to highlight why implementation strategies are essential components downstream of any dementia plan, (2) to examine the implementation strategies referenced in dementia plans of peer high-income countries and provinces; and (3) to review and propose evidence-informed implementation strategies that national and provincial governments in Canada may use as they further reform dementia care at the clinical level. To do so, we conducted a rapid review as defined by Tricco et al. (2016), examining provincial and national dementia plans from around the world. In addition, we reviewed studies on implementation strategies that are specific to dementia care reform. Note that while a dementia plan should ideally be broad, including supportive housing, community programs, caregiver support, dementia-friendly cities, transportation and anti-stigma campaigns, this paper will specifically focus on the healthcare delivery system for dementia care.

Why Implementation Strategies Matter

The inclusion of implementation strategies in dementia care reform is important for countries to reap the benefits – improved care and reduced cost – of dementia plans (Milstein and Shortell 2012). Studies have shown that the dissemination of healthcare initiatives is challenging. For example, Damschroder et al. (2009) report that only one-third of healthcare improvement initiatives successfully transition from adoption to sustained implementation across organizations. Even if implementation strategies to change clinical practice are only enacted after high-level policy is negotiated, understanding implementation challenges likely to be faced by healthcare professionals is relevant to the negotiation of funding mechanisms and resource allocation by federal and provincial governments.

Whereas many implementation strategies are applicable to any healthcare policy, specific implementation strategies matter for dementia because of the complex nature of dementia diagnosis, care and affected population. First, dementia is notoriously underdiagnosed in primary care, with rates between one-half (Bradford et al. 2009) and two-thirds (Valcour et al. 2000). The challenges of primary care physicians to diagnose dementia stem from a lack of confidence (Foley et al. 2017) and/or uncertainty about whether the diagnosis of an incurable disease such as dementia will improve the care or quality of life of a patient (Borson and Chodosh 2014). Second, optimal dementia care requires a wide range of personnel and services, which change as the needs of dementia patients evolve (Borson and Chodosh 2014). Third, patients with dementia suffer from high degrees of comorbidity, with one-third of patients experiencing five or more additional chronic conditions (Mondor et al. 2017). Acute exacerbations of these co-existing diseases often make dementia care too rare of a priority. Finally, optimal dementia care requires engaging both the patient and their caregiver(s), which is specific to dementia care (Borson and Chodosh 2014).

Shedding Light on the Lack of Implementation Strategies in Published National and Provincial Plans for Dementia

National and provincial plans for dementia have been published in 29 countries and eight Canadian provinces, according to *Alzheimer's Disease International* (2018). We analyzed the 24 strategies that were written in either English or French (16 countries plus all eight Canadian provinces). These reports generally share a common form: the reports define dementia and describe its prevalence and impact, underscore the purpose for a national or provincial dementia strategy and outline strategic priorities for dementia reform. These priorities typically include (1) increasing awareness and understanding of dementia, (2) promoting timely diagnosis through workforce development; and (3) improving dementia management and care. Of the 24 national and provincial plans for dementia examined, *only 12* addressed the implementation strategies for the programs. The plans either introduce implementation strategies throughout the documents (i.e., tying individual strategies to specific objectives) or through explicit "stand-alone" chapters on implementation strategies, typically located towards the conclusion of the documents (Table 1).

More critically, even among the national and provincial plans for dementia that include sections on implementation strategies, very few plans actually articulate strategies for the diffusion or implementation of dementia care reform. They tend to state objectives but not how such objectives will be achieved or measured (e.g., "educating more people earlier about the risks of developing dementia"). The few implementation strategies that have been articulated remain vague. Strategies like "investing in research" (United Kingdom) (United Kingdom Department of Health 2009), "diversifying pedagogical approaches" (France) (Ministère des Affaires sociales, de la Santé et des Droits des femmes 2014) and "involving individuals living with dementia and their caregivers" (Switzerland and Malta) (Office fédéral de la santé publique 2013; Scerri 2014) form inadequate foundations upon which governments can orchestrate targeted and consequential steps towards achieving dementia plan goals.

TABLE 1. A list of reviewed national and provincial dementia plans, and how they address implementation strategies

Region	Implementation	Integrated throughout plan	Stand-alone section
Country			
Australia	✔	•	
Finland			
France	✔	•	
Greece	✔	•	
Indonesia	✔	•	
Ireland	✔		•
Israel			
Italy			
Korea	✔	•	
Luxembourg			
Malta	✔		•
Netherlands			
Norway			
Switzerland			
United Kingdom	✔	•	
United States	✔	•	
Canadian Province			
Alberta			
British Columbia			
Manitoba	✔	•	
Newfoundland & Labrador			
Nova Scotia			
Ontario			
Quebec	✔		•
Saskatchewan	✔	•	

A Review of Successful Implementation Strategies in Dementia Care

The literature suggests that any implementation of dementia reform, like any innovation, should target both individual adopters (healthcare professionals and informal caregivers) and whole organizations (Greenhalgh et al. 2004). Individual adopters benefit from pragmatic guidelines that target the confidence and expertise of individuals, address their concerns and encourage them to engage with dementia reform over an extended period. Implementation strategies should also be conceived at the organizational level, where integrating reforms with the current organizational context, identifying and valourizing a "champion" of dementia reform and providing additional resources and incentives may facilitate improved dementia care.

Successful Strategies at the Individual Level: Putting People First

Disseminating pragmatic guidelines and training through active, concise and varied formats

Traditional didactic and passive strategies (lecture-style meetings, printed materials and guidelines) are usually ineffective strategies for increasing healthcare professionals' knowledge of dementia and their confidence in managing patients (Aminzadeh et al. 2012; Burgio et al. 2001; Gifford et al. 1999). Healthcare professionals benefit most from *problem-based* and *solution-focused* dementia training (Yaffe et al. 2008). Whatever the intervention, strategies that focus on *pragmatic benefit* and *usability* should be developed (Aminzadeh et al. 2012). Guidelines must recognize the importance of the patient–caregiver dyad, which is specific to dementia (CAHS 2019). For example, caregivers benefit from specialized training including practice opportunities, personalized feedback and collaboration with practitioners (Chesney et al. 2011; Mazmanian and Davis 2002; Soumerai 1998). Guidelines to healthcare professionals and informal caregivers should be communicated in succinct and synchronized trainings to minimize "guideline fatigue" (Aminzadeh et al. 2012). These guidelines should also include recent recommendations from the Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (Gauthier et al. 2012). Finally, guidelines should be encompassing of the comorbidity associated with dementia that often compounds physicians' difficulty with diagnosing and providing care for dementia and patients' difficulty with living with the disease while managing other chronic conditions (Borson and Chodosh 2014; Mondor et al. 2017).

Promoting confidence and expertise

Implementation strategies must be designed to target the confidence of healthcare professionals who feel ill-equipped to diagnose and care for dementia in Canada (Aminzadeh et al. 2012). Confident healthcare professionals are more likely to take a keen interest in dementia and dementia care reform and to diagnose dementia in a timely way (Aminzadeh et al. 2012; Moore and Cahill 2012). Confidence and expertise may be self-initiated, but governments can also furnish this capacity by providing funding and resources to train additional staff, such as geriatric nurses, who can collaborate and mentor closely with other clinicians (Aminzadeh et al. 2012).

Addressing concerns of potential adopters

Similarly, many healthcare professionals approach dementia diagnosis and care from a nihilist perspective (Pentzek et al. 2009). Family physicians are concerned about whether a diagnosis will improve the quality of life of a patient (Borson and Chodosh 2014) and whether dementia care interventions will result in improved care (Black and Fauske 2007; Netting and Williams 1999; Seddon and Robinson 2001). Studies show that when healthcare professionals maintain negative attitudes towards dementia interventions, the interventions are less likely to be adopted (Khanassov et al. 2014). A final unique barrier remains the reluctance of some family physicians to be trained in dementia care by non-physicians (Cameron et al. 2010).

Encouraging adopters to engage with the intervention over an extended period

Interventions take time to implement, and practices take time to change. This is especially true in dementia care, which mobilizes multiple health and social service organizations. Accordingly, benefits of dementia diagnosis and management take time to emerge. Persistence with interventions is thus particularly important in the context of dementia care. When healthcare professionals engage with new dementia programs for longer durations, their adherence to, and confidence in, the interventions increases (Cherry et al. 2004; Gladman et al. 2007; McCrae and Banerjee 2011; Netting and Williams 1999; Van Eijken et al. 2008). Eventually, as outcomes become perceivable, healthcare professionals feel increased self-worth and accomplishment (Grinberg et al. 2008).

Successful Strategies at the Organizational Level: Teamwork and Resources

Integration with current context

Dementia interventions that are implemented in ways that are compatible with the current healthcare structure are more likely to be well-received by healthcare professionals (Khanassov et al. 2014). This can be challenging, since dementia care is often time-consuming, especially for solo practitioners (Hinton et al. 2007). Team-based care, with a clear division of labour, is needed. For example, nurses (referred to as *infirmières pivots*, "pivot nurses") are particularly suited to conduct cognitive screening, assessment and functional evaluation (Bergman 2009).

Identifying and valourizing a "champion" of dementia reform

As is usually the case for any policy or program implementation, a critical predictor for the successful implementation of a strategy is the presence of a physician or nurse who serves as a "clear champion" for dementia reform (Gifford et al. 1999). This champion, who recognizes the potential benefits of new recommendations, including timely diagnosis of dementia and interdisciplinary management, takes an active role in convincing other colleagues to use the guidelines (Gifford et al. 1999). If the champion is knowledgeable in dementia management, they may also provide support and guidance to peers. Championing dementia reform can be individual- or team-based.

Resources, incentives and culture

Governments must also fund and support dementia-specific resources beyond the clinic: home-based care, community services, transportation, long-term care and assistive devices. Healthcare professionals should be trained to know which of these options or services are available in the region, how efficient and organized these resources are and how to refer patients to them (Yaffe et al. 2008). Governments should also consider personal incentives (such as remuneration and other motivations) and cultural differences (unique perceptions of dementia and caregiving, especially in rural, Northern or immigrant communities) when developing strategies for implementation (Braun and Browne 1998; Khanassov et al. 2014; Martindale-Adams et al. 2017).

Limitations

This rapid review serves as a brief overview of the current state of dementia plans, vis-à-vis implementation strategies, across Canada and other high-income countries. However, our analysis is limited. First, untranslated dementia plans (written in languages other than English or French), or those not available in the public domain, were not examined. Also, this review was limited to national and provincial plans. Grey literature (including future policy enforcement documentation) was not examined. Accordingly, we may have missed more applied guidelines (including implementation strategies) in subsequent years.

Summing Up: Implementation Strategies for Dementia

Even if implementation strategies are not included in national and provincial dementia plans, they will ultimately be relevant to transforming dementia care practice "on the ground." This article advances several dementia-specific implementation strategies that can be leveraged to improve the diagnosis and management of dementia. These strategies should be considered as future dementia plans are translated from policy to action.

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DISCUSSION AND DEBATE

Enabling Patient Portals to Access Primary Care Medical Records: Maximizing Collaboration in Care between Patients and Providers

Faciliter les portails d'accès aux dossiers médicaux de soins de première ligne : maximisation de la collaboration entre patients et fournisseurs de soins

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Abstract

Portals to allow patients to access their primary care medical records are necessary to achieve true collaborative care between doctors and patients. In this article, we outline a practical approach to achieving this goal that involves Ministries of Health, electronic medical record vendors, physicians and patients. Patient portals to primary care records could make possible an entirely new world of on-the-spot, customized learning. Patient portals ideally should be designed with the goal of optimizing patients' to better their ability to help themselves. Delaying implementation of these portals exacts a continued financial and personal hardship on patients and their families.

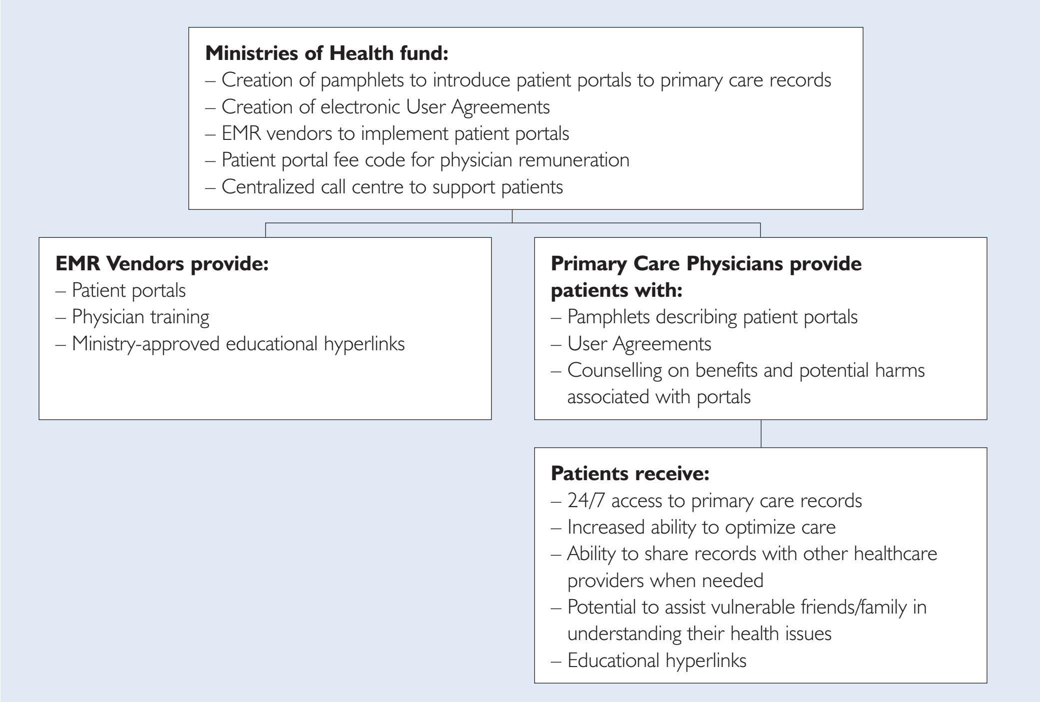
Résumé

Les portails qui permettent aux patients d'accéder à leur dossier médical de soins de première ligne sont nécessaires pour favoriser une véritable collaboration entre les médecins et les patients. Dans cet article, nous mettons de l'avant une démarche pratique pour atteindre cet objectif – démarche qui met à contribution les ministères de la Santé, les fournisseurs de dossiers médicaux électroniques, les médecins et les patients. Ces portails ouvrent la porte à un tout nouveau monde d'apprentissage personnalisé sur-le-champ. Les portails devraient idéalement permettre aux patients d'optimiser la prise en charge de leurs propres soins. Les délais de mise en œuvre de ces portails se traduisent par des difficultés financières et personnelles pour les patients et leurs familles.

There currently exists a largely untapped potential to enable patients to be better informed and more proactively involved in optimizing their primary care. With over 85% of primary care providers currently using electronic medical records (EMRs; Statistica: The Statistics Portal 2018), enabling patients to access their primary care records via a patient portal represents a key component in achieving better health for patients (Gorfinkel and Lexchin 2018). A patient portal is an online application that allows patients to view personal primary care records and to securely communicate with their primary care provider. However, with only 1 in 10 Canadians currently having access to even the most rudimentary online services (Showing Results for Resources and Web Pages Tagged: Patient Portals 2018), patient portals to primary care records remain a critical but vastly underutilized resource. Once armed with easily accessed primary care records, patients are better enabled to advocate for their needs as well as those of vulnerable dependents. However, in Canada, a patchwork of EMR systems that lack interoperability presents significant challenges to establishing universal patient portals of access to primary care records.

There are a variety of functions that patient portals serve, including allowing patients to access their clinicians, see their medical records, book appointments and obtain prescriptions written online, but due to space limitations, we focus on the value of patients having access to their clinical information. We propose a collaborative model for the creation and implementation of patient portals into primary care records (Figure 1) within the patchwork of EMRs and provide an overview of essential steps needed to implement them in Canada. We define distinct and coordinated roles that Ministries of Health, EMR vendors and physicians could embrace to help make patient portals a reality. By selectively reviewing key articles from the literature and the experiences with patient portals in other countries and some Canadian provinces, we demonstrate the educational and other benefits that can be realized from patients having ready access to their clinical information, and we outline the difficulties that could be encountered. Finally, we want to emphasize that we are advocating for preliminary steps in a process of initiating patient portals at scale and acknowledge that there remain significant challenges that will need to be worked out over time.

FIGURE 1. Roles and responsibilities of different stakeholders in patient portals



Ministries of Health fund:
- Creation of pamphlets to introduce patient portals to primary care records
- Creation of electronic User Agreements
- EMR vendors to implement patient portals
- Patient portal fee code for physician remuneration
- Centralized call centre to support patients

EMR Vendors provide:
- Patient portals
- Physician training
- Ministry-approved educational hyperlinks

Primary Care Physicians provide patients with:
- Pamphlets describing patient portals
- User Agreements
- Counselling on benefits and potential harms associated with portals

Patients receive:
- 24/7 access to primary care records
- Increased ability to optimize care
- Ability to share records with other healthcare providers when needed
- Potential to assist vulnerable friends/family in understanding their health issues
- Educational hyperlinks

Patient portals need not be passive entry points to access medical data. Kildea and colleagues (Kildea et al. 2019) describe a "participatory stakeholder co-design" to expand the role of patient portals that involved patients, computer scientists, clinicians and medical physicists in their ongoing development of a smartphone app used in an oncology setting in Quebec. Their stakeholder co-design approach incorporated six core elements: (1) equal co-leadership, including a patient on treatment, (2) patient preference determination, (3) security, governance and legal input, (4) continuous user evaluation and feedback, (5) continuous staff input; and (6) end-user testing.

Drawing on the experience of in-patient portals may help to optimize the design of outpatient portals. In the in-patient setting, researchers interviewed patients provided with a patient portal during their hospitalization. Patients were taught to use the portal and to access health information as well as to learn about their care team members. As a result, patients reported feeling more independent, having reduced anxiety, feeling that their families were better informed and having an increased sense of empowerment (McAlearney et al. 2019).

Problem areas in developing portals are recognized in the literature; however, there are only a few studies that systematically report on the patient portal development process. Ongoing work in this area is necessary to ensure that portals are a success for patients, clinicians and the healthcare system (Otte-Trojel et al. 2016). In the collaborative model that we envision, Ministries of Health would fund EMR vendors and resources for both physicians and patients. EMR vendors would receive Ministry funding to incorporate patient portals into their software and to educate physicians on their utilization. Participating physicians would be provided with a novel "patient portal fee code" by Ministries to compensate them for counselling patients about the benefits and potential risks of portals. Ministries would fund patient resources, including the production, updating and dissemination of pamphlets to educate patients on patient portals. Ministries would create and provide EMR vendors with an electronic user agreement that would formalize patients' access to their primary care records. Finally, Ministries would fund centralized call centres to address patients' questions regarding portal access.

EMR vendors would be responsible for providing and maintaining the required software infrastructure for patient portals. This would include the implementation of preset standards defined by the Ministry that are compliant with the *Ontario Personal Health Information Protection Act* (Government of Ontario 2018) or its equivalent in other provinces. EMR vendors would be incentivized to participate through funding from Ministries and annual fees paid by physicians for EMR support. In return, EMR providers would be responsible for supporting physicians' implementation of patient portals, including providing doctors and their staff with training in their use.

Physicians would be expected to ensure that patients are provided with the necessary tools to enable them to successfully use their portals. They would provide patients with the Ministry-produced pamphlet, review this information with them and obtain their consent to the electronic user agreement. An example of such a user agreement is the one in systems such as MyChart (MyChart User Agreement nd). Physicians would also be responsible for counselling patients on the advantages and potential disadvantages of using patient portals, including the potential for a security breech. The new fee code mentioned earlier would compensate physicians for these activities. This same model could be utilized for other primary care providers, for example, nurse practitioners, but with payment models appropriate to the individual profession.

Although such a collaboration endeavours to minimize potential pitfalls, difficulties in implementing patient portals are expected. Ministries may be concerned about the initial cost outlay, especially at a time when provinces are struggling to control their budgets. Over time, this initial cost outlay is expected to be more than compensated by greater patient satisfaction and improved outcomes (Sorondo et al. 2017). EMR vendors may be concerned about whether the funding that they are provided with is adequate to support the various functions that they are being asked to undertake, including dealing with cyber-security issues. Physicians may be hesitant to pay additional fees to support EMR vendors. There may also be concerns that when patients see abnormal test results, they may experience increased patient stress.

Fortunately, this concern has not been borne out by retrospective studies examining the effects on patients of patient portals. These studies have not demonstrated a major increase in patient anxiety related to the direct release of laboratory results through patient portals (Christensen and Sue 2013). On the contrary, patients consistently find the test result feature among the most useful on patient portals and express interest in obtaining further information about interpreting the relevance of results (Giardina et al. 2015). To obtain this help, patients should be provided with opportunities to get additional health information. This engagement could come from physicians; clinicians could provide a hyperlink to explain the utility of tests that they have ordered and mark abnormal results as "clinically significant" or "not clinically significant" on the EMR, so that patients are able to see this information. Some physicians may have concerns about the potential additional workload that patient portals could represent. To mitigate this worry, abnormal results could be directly addressed by utilizing other healthcare professionals such as nurse practitioners to help explain information to patients.

The experience of some countries implementing patient portals has been variable. Australia initially struggled with low rates of adoption with My Health Record. Four years after its introduction in 2012, only 17% of Australians had registered when it was an "opt-in" system (van Kasteren et al. 2017). Since switching to an opt-out model, national participation is now in the 90% range (Australian Digital Health Agency 2019), but there remains ongoing criticism from both clinicians (Janakiramanan 2019) and academics (Kemp et al. 2018), who point out that it is not up-to-date, that it creates a security risk and that My Health Record does not seek patients' express consent because of its "opt-out" system. Other criticisms include that patients may edit their own records, thereby reducing their reliability. A further major concern is that My Health Record was not designed to be compatible with existing medical programs (Kemp et al. 2018).

In contrast, Denmark's National eHealth Portal is an example of success in the implementation of patient portals. There is near complete clinician engagement, with 98% of primary clinicians and all pharmacists having access to a centralized database accessible to patients. Citizens are empowered to log in to a personal web space to book appointments, renew prescriptions, review medication records and health data and communicate with healthcare authorities. Clinicians are able to obtain records from hospitals, laboratory results and data from electronic patient records (Khan et al. 2018).

Here in Canada, Ministries of Health in Alberta and in Quebec have demonstrated their willingness to work with EMR vendors, physicians and patients to generate patient portals. Although still in its infancy, Alberta currently is leading the way with its investment in a unified EMR that incorporates patient portals with Alberta Netcare (Alberta Netcare EHR 2019). Connect Care, the bridge between information, healthcare teams and patients, will allow healthcare providers a central access point to patient information, common clinical standards and best healthcare practices. Implementation is expected to be gradually rolled out over the next three to four years to minimize disruptions for patients and healthcare providers (Alberta Health Services nd).

Quebec has instituted a patient portal through Quebec Health Record (Québec Health Booklet 2019). The portal is to be introduced over two years and will allow patients to view their medications, lab results, medical imaging results, doctors' and hospital billings and wait lists for surgery. This system will further enable nurse practitioners, nurses and pharmacists to optimize follow-up of chronic conditions. The eventual goal is to incorporate patient health information and information regarding tests and treatments. Because the regulation of the delivery of healthcare is a provincial function, precisely what information a patient will have access to when using the patient portal will be determined at the provincial level. Differences may also exist between what information is available through hospital and primary care patient portals. Our focus here is on the latter, and it is our belief that it should include their social, medical and surgical histories, current medication list, prescription history, drug allergies/intolerances, laboratory and radiology reports and consultation notes.

The development of universal access to patient portals in Canada should be understood as an ongoing and evolving process. Patient portals need to first be implemented before they can be further developed with efforts that will optimize the provision of patient health information and relevant educational material.

Despite possible roadblocks, we strongly advocate for provinces to proceed with implementing patient portals using the model we have outlined or some variation of it. Patient portals to primary care records make possible an entirely new world of on-the-spot, customized learning. Each problem listed in a patient's electronic medical history could be directly linked to educational resources that are specific to that problem. Such resources would be available to patients precisely at the moment that they are most needed, when patients are reading their chart. Accurate and reliable hyperlinks for patients to topics such as smoking cessation, insomnia, exercise, diet, hypertension, support groups, depression and anxiety, to name a few, could be accessed by simply clicking on that problem in their medical history. The information contained in these hyperlinks could be customized according to the patient's language of preference and level of education. Patient portals ideally should be designed with the goal of optimizing patients' ability to help themselves. The combined experience of countries that have implemented patient portals demonstrates the critical need for clinical engagement about health record content and standards (Khan et al. 2018). Much of the value that patients derived from the use of portals will be directly affected by the attitudes and actions of physicians, nurse practitioners, nurses and pharmacists (Shah and Liebovitz 2017).

The time has arrived for all stakeholders in Canada – provincial Ministries, EMR providers, clinicians and patients – to embrace patient portals. Delaying implementation of patient portals exacts a continued financial and personal hardship on patients and their families. Having the will to implement a collaborative model of care centred on patient portals moves us closer to achieving truly patient-centric care.

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RESEARCH PAPER

Deliberating as a Public Representative or as a Potential User? Two Complementary Perspectives that Should Inform Health Innovation Policy

Participer aux délibérations en tant que représentant de la population ou en tant qu'usager potentiel? Deux points de vue qui devraient éclairer les politiques d'innovation en santé

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Abstract

While public involvement in health policy is gaining traction around the world, deciding whether practitioners of public involvement should encourage participants to deliberate from a personal or a collective perspective remains an object of contention. Drawing on an empirical study, the aim of this article is to generate methodological insights into these two perspectives. Our qualitative analyses illustrate how members of the public contributed differently to deliberations about the value of health innovations by alternatively sharing views as public representatives and as potential users. When engaging as public representatives, participants raised important collective concerns, and, when engaging as potential users, participants brought concrete details and contextual nuances to the group exchanges. Because these perspectives entail different yet mutually challenging ways of appraising health innovations, public engagement practitioners should foster both personal and collective perspectives.

Résumé

La participation du public gagne du terrain dans les politiques de santé partout au monde, mais il y a débat à savoir si ceux qui mettent en pratique une telle participation devraient encourager les participants à délibérer d'un point de vue personnel ou plutôt collectif. L'objectif de cet article, fondé sur une étude empirique, est de proposer des éléments de méthodologie pour ces deux points de vue. Notre analyse qualitative illustre comment les représentants de la population alternent – au cours de leurs contributions aux délibérations portant sur l'évaluation des innovations en santé – entre un rôle de représentant du public et un rôle d'usager potentiel. Quand ils adoptent le point de vue du représentant de la population, les participants font valoir d'importantes préoccupations d'ordre collectif, alors qu'ils apportent des détails concrets et des nuances contextuelles aux échanges du groupe quand ils adoptent le rôle d'usager potentiel. Puisque ces points de vue entraînent des façons différentes – quoique réciproquement enrichissantes – d'évaluer les innovations en santé, les responsables de la participation du public devraient favoriser tant le point de vue personnel que le point de vue collectif.

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With the aim of informing difficult policy decisions, public involvement in health policy and Health Technology Assessment (HTA) (Bombard et al. 2011; Degeling et al. 2015; Facey et al. 2010; Gagnon et al. 2011) is gaining traction. As Burgess (2014: 48) puts it, public engagement "emphasizes inclusiveness so that a range of social perspectives are included beyond that of established stakeholders." Inspired by deliberative democracy theory (Gutmann and Thompson 2009), public engagement mechanisms may rely on face-to-face group discussions and online platforms that support interactions between participants. In such mechanisms, both patients and members of the public are invited to ponder the complex social and ethical issues that are raised by existing and new health technologies, thereby complementing more traditional expert-based assessment approaches (Gagnon et al. 2011, 2016; Wortley et al. 2016, 2017).

However, the multifaceted nature of lay opinions poses significant methodological challenges to practitioners of public involvement (Degeling et al. 2015; Wortley et al. 2016). One key object of contention is deciding whether participants should be contributing on the basis of their own personal perspective (i.e., as patients or users of health services) or whether they should be encouraged to talk on behalf of the broader collective (i.e., as citizens or public representatives; Delgado et al. 2010; King et al. 1998). While deliberative democracy emphasizes a form of exchange that values reasoned dialogue between various parties, defining what *well-argued* exchanges are remains challenging. Richard-Ferroudji (2012) and Charles (2012) observed that personal and collective concerns may receive unequal treatment by practitioners of public involvement. Warning against poorly designed public involvement mechanisms, Young (2001) underscored that participants do not engage similarly in a deliberative process because they may not *care* about the same issues and may not express these issues in a similar way. For Degeling and colleagues (2015: 119), when participants are not given a clearly defined role in a deliberative setting, it "only leads to a shallow articulation of public participation in policymaking processes." Yet, should a collective perspective be considered more meaningful than a personal one?

The aim of this article is to provide methodological insights into this question by drawing on an empirical research in which we asked members of the public to ponder both personal and collective issues when deliberating about the desirability of three prospective health technologies. Following Boenink and colleagues (2010), we developed a scenario-based method to illustrate the context in which these fictional technologies would be used in a not-so-distant future (2030–2040). Four deliberative workshops followed by an online forum were organized in Quebec, Canada, and a total of 57 participants of different age groups were recruited.

While we analysed *what* issues participants shared regarding the value of these technologies in other publications, this current paper focuses on *how* they shared their views and contributed to group discussions. Our qualitative findings illustrate how participants raised collective concerns when engaging as public representatives and how they added concrete details and contextual nuances to the deliberations when engaging as potential users. Our analyses suggest that the two perspectives are necessary and complementary.

Methods

Our prospective deliberative study was designed to explore how the public perceives the value of three fictional innovations: a "smart" sweater to support cognitive enhancement in teenagers, a cardiac implant for genetically at-risk adults and an assistive robot for the elderly. We created short videos (three minutes) to explain how these technologies would work and short story-like dilemmas (500 words) to illustrate the prospective contexts in which they would be used in the period from 2030 to 2040. The videos were discussed in four face-to-face workshops (8–10 participants, 3.5 hours each), and the dilemmas were debated through an asynchronous online forum with additional participants (the protocol is described in greater detail here: Lehoux et al. 2014).

The study sample was constituted in accordance with qualitative research principles in which the primary intent is to generate rich and diversified data, targeting more specifically young adults (18–25 years), adults (30–55 years) and older adults (>60 years). We fostered the participation of individuals from all walks of life but excluded individuals who worked in healthcare. All participants provided their consent and were attributed a pseudonym at the outset of the study. The University of Montreal's Research Ethics Board approved the study.

The workshops and forum were facilitated by a professional moderator, while an observer from the research team recorded field notes. The video describing the first technology was shown, and then each participant was asked to share two to three desirable and two to three undesirable features with the group. Group interactions were then prompted by asking "How should this technology be improved?" This structure, which fosters an equal opportunity to speak, as well as deliberations among participants, was repeated with the second and third technology in each workshop. The online forum started after the last workshop and was hosted on a login/password-secured blog platform (WordPress®). Participants were invited to read the scenarios and respond to questions to start the online deliberations (available in French upon request).

The workshop discussions were audio-recorded and transcribed verbatim. The content of the online forum (355 comments) was downloaded into an Excel spreadsheet. Using the web-based qualitative analysis software Dedoose®, we applied an iterative thematic analysis strategy (Hansen 2006). This web-based platform enabled both authors to code the whole data set, starting with pre-defined categories (e.g., nature of the judgment made: favourable or unfavourable; kinds of issue raised: social, ethical, ease of use, discomfort) and gradually identifying emerging categories. The field notes provided insights into the "serious playfulness" and respect that characterized the deliberations.

Our preliminary analyses indicated that participants easily adopted a public representative and a potential user perspective. The former perspective articulates what theorists of deliberative democracy are typically looking for, that is, a collective viewpoint, whereas the latter illustrates a personal viewpoint, which is not always seen as relevant to policy making (Young 1996). Yet, because both perspectives enabled participants to share their understanding of a broad set of social and ethical issues, we decided to further examine what these perspectives entailed. Our analyses gained more depth when we fleshed out these perspectives with the help of Thévenot's "modes of engagement," which can account for the way individuals deepen and transform their appraisal of a given situation by mobilizing various cognitive and experiential resources (Blokker and Brighenti 2011; Thévenot 2007). We carefully examined how certain values, ideas and experiences were shared and considered by participants when they engaged as a public representative and a potential user. Our findings are structured around these two perspectives, showing how group deliberations could "switch" from one perspective to another and how each of these perspectives supported different kinds of judgment.

Results

A total of 38 individuals participated in the workshops and were invited to join 25 additional participants on the forum; 32 accepted, and hence, a total of 57 individuals contributed to the forum. Using data gathered through our end-of-study survey (response rate: 81%), Table 1 summarizes participant characteristics.

TABLE 1. Characteristics of the participants

	n	%
Age		
18–29	9	20
30–39	6	13
40–49	3	7
50–59	7	15
60–69	17	37
>70	4	8
Gender		
Women	33	72
Men	13	28
Education		
High school	4	9
Collegial	5	11
University	37	80
Household income		
<CDN$20,000	4	9
$20,000–$39,999	9	19
$40,000–$59,999	17	37
>$60,000	16	35

Note: A total of 46 participants completed the demographic survey.

Our findings are structured around the two modes of engagement described earlier, which we argue support different yet mutually challenging appraisals of health technologies. As public representatives, participants raised public policy concerns such as the proper handling of data privacy. By contrast, when adopting the perspective of a potential user, participants' judgments centred on concrete details that clarified their willingness or reluctance to use the technology (e.g., fit with one's daily routine, value of certain functionalities, etc.). But in both cases, the deliberations moved forward productively: Personal preferences and insights were (re)located within a broader social and political context, and vice versa.

Engaging as a public representative

When engaging as public representatives, participants addressed or disputed the social values underlying the fictional technologies. For instance, in one of the workshops, Jeanne (pseudonym) brought forward a putative collective gain that emphasized the social desirability of the smart sweater. She saw in this innovation a means to increase equality between students and reduce the social costs associated with teenagers who drop out of school:

> We know that dropping out of school is a scourge, which causes all sorts of consequences: low self-esteem, violence, gang phenomena, drug use. Also, from an economic standpoint, they may possibly cost more to society in terms of care, low income, hence a lesser contribution in terms of taxes (Jeanne, Workshop 1*).

In contrast, Éloïse claimed on the online forum that the smart sweater fostered an undesirable social norm of performance. She criticized the idea of "a smooth world, virtuous without virtues, constipated and artificially harmonious where conflicts subside on the spot, where individual capacities are pushed to their maximum" and feared that teachers or parents would be tempted to "get rid of young people by telling them to put on their 'smart' plasticized chainmail and calm the cake, even before any conflict breaks out" (Éloïse, Forum 2030). Like many other participants, Éloïse refused to envision a behaviourally homogeneous community where only one form of intelligence is acknowledged and valued.

Hence, the judgments regarding the desirability of the smart sweater of Jeanne and Éloïse differed, but they both relied on and made explicit their own beliefs regarding the social and moral values their community should seek. In other words, they bring to the fore the social and moral values they would like to see promoted from a collective perspective. As a result, this mode of engagement enables the group to challenge each other's assumptions. For instance, during a workshop discussion, many participants found the assistive robot to be undesirable on the assumption that elderly people would not be at ease with such a technological device. Malik offered nuances to such a critique:

> I'd like to come back on the issue of the capability of using [the robots]. I believe it depends on the horizon time frame that it takes us to develop them. […] I've a little boy who at two years old was on the phone and able to figure out how it works. I mean, people of this generation, when they'll approach retirement, operating robots, teaching them stuff, that'll be their day-to-day. Myself, I'm really not worried. [But if] we provide this technology tomorrow, it's clear that it won't work. All depends upon the moment we implement it and whether people in society already live in proximity with robots or other technologies (Malik, Workshop 3).

Malik's comment invited others to reflect on the innovation by considering implementation issues that went beyond the current state of things. Sarah, who was in the same workshop, picked up on his comment and introduced additional social and political considerations:

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* All quotes from participants were translated from French to English.

> Malik referred to his two-year-old son, but would he prefer that his little guy takes care of him when he gets old or that a robot does so? These are the questions that must be asked as human beings, as a society. Yes, [the robot] surely could help caregivers, those who have to travel [to provide home care]. But, from a legal point of view, I think it'd really create a lot of problems, for insurance or things like that, or if the robot has a bug. It's someone's life that's at stake: what happens if the robot forgets to give a medication? … I think it opens the door to many problems (Sarah, Workshop 3).

Sarah thus both challenged and complemented Malik's argument, inviting the group to reflect upon the importance for technology developers to consider and anticipate the evolving capacities of users as well as the values underpinning home care for the elderly people.

Overall, this mode of engagement enabled participants to address the desirability of health innovations by referring to fundamental rights, social costs, privacy, individual freedom, environmental protection, responsibilities of private and public actors, etc. These arguments thus shed light on collective concerns in regard to technological advances in health.

Engaging as a Potential User

When participants engaged as potential users, they judged the fictional technologies through resources that differed from those described earlier and enabled them to react to what they saw as potential flaws in a technology. For instance, Adrian referred to his own preferences and feelings to question the integration of the smart sweater in the daily life of its users: "even if I had such a device, I wouldn't be interested to look at it when I'd be stressed. I know when I'm stressed! I think it'd get on my nerves even more to look at it!" (Adrian, Workshop 2). By sharing his personal discomfort, Adrian evoked the problem of intrusion and brought participants to think about the world people want to live in. Similarly, Walter shared on the online forum an intimate personal reflection, explaining why he did not consider the smart sweater desirable:

> I'd say that family support and a positive and constant encouragement could have the same, if not a better, impact than the smart sweater. We tend to forget that we are responsible for our successes as much as our failures. We deny our responsibility, evoking factors that are unrelated to the events. We reduce our feelings of guilt for not having tried hard enough, and it's increasingly common to also see parents attributing the cause of their child's failures on other things or other people to avoid acknowledging that, in fact, they're responsible (Walter, Forum 2030).

By engaging as potential users, participants also pondered the value of various technical functionalities and their likely impact on the user. One key problem with the assistive robot was to determine what functionalities would be beneficial and to which user:

> On our telephones, we enter the numbers in the directory and we no longer practice our memory. I don't even know my daughter's phone number. I know it's programmed "6". […] It can go even further with this kind of robot ... not only it won't improve autonomy, it will diminish it. […] For someone who starts to do some arthritis, it's recommended to walk a little. Well, with this robot, the person will say "Good! the robot can do everything for me." I think we should decompose the functions of the robot, remove those that are superfluous, which don't support autonomy (Fabien, Workshop 1).

Although several participants considered that the robot should not to be introduced as a substitute for home-care services and human interactions, Jeanne did not hesitate to draw on her own situation to provide a counterpoint:

> We raised the issue of the human, the human, the human ... But we must also think that ... that we could use it wisely […]. Myself, I live alone and I often say to myself: "If my kids don't call me" – because they don't call me very often – I say to myself: "Shit, what will happen to me if I die right there! Anything can happen and they won't know because they don't call or they don't come" (Jeanne, Workshop 1).

Jeanne's reference to her daily life thus invited the group to consider how the robot could increase older people's safety and reduce their isolation, thereby pushing them to reflect on what caring may mean in such context. Similarly, Theresa responded to the participants of her own group who criticized the device for being dehumanizing. She mobilized her own experience as a blind person to explain why such technology should be considered valuable:

> Personally, I find that quite brilliant. […] Since I'm blind myself, I know that people are often exhausted when helping us out all the time. I think it could offer a moment of rest that would be very interesting to the people around us. Otherwise, it is true that there are inconveniences. It's very nice to be with other human beings, the contact is certainly different, this bothers me a little, but for those moments where people do need respite, I think it could be marvellous (Theresa, Workshop 2).

Addressing the others as someone whose autonomy is compromised, Theresa not only explained why she, as a potential user, would appreciate the technology but also brought to the debate caregiver respite. She called the attention of other participants to an issue they might not had fully understood otherwise, bringing meaningful nuances to the deliberations.

Overall, when engaging as potential users, participants shared their thoughts about how the innovations might affect their daily life, and enabled the group to ponder social and ethical issues that may surface through a more intimate understanding of the context of use (e.g., isolation, dependence upon relatives, adverse effects of certain functionalities, sense of safety, etc.).

Discussion

Untangling the multiple social and ethical issues arising from health innovations is a complex program (Wortley et al. 2017). It implies not only acknowledging "hard" impacts like risks for human health and safety but also looking at "soft" impacts that may affect daily routines and collective identity (Swierstra and Molder 2012). This partly explains why specific attention has been given to the relationship between HTA and democratic governance. In a deliberative democracy, the voices of non-experts need to be heard and inform policy making (Gutmann and Thompson 2009). Hence, important research efforts have been devoted in the past decades to experiment with and assess the impact of different public and user engagement mechanisms (Degeling et al. 2015; Sanders and Stappers 2008).

In this paper, our aim was to generate methodological insights on the deliberative processes themselves because the issues being emphasized by participants depend upon the perspective they adopt or are told to adopt. Notwithstanding the fact that our sample comprised more women and educated individuals, our findings showed how two contrasting modes of engagement characterized our participants' deliberations. Their ability to shift from one mode of engagement to another generated rich debates about the social and ethical issues raised by health innovations, and both modes of engagement brought to the group discussions concerns that were complementary. In particular, participants adopting a user mode offered counterpoints to the claims of participants adopting a public representative mode: personal anecdotes refocused the discussion on concrete aspects.

Although further conceptual and methodological insights into public involvement in HTA are needed (Gagnon et al. 2011; Krinks et al. 2015; Wortley et al. 2016), our findings can inform the design of deliberative mechanisms and the way group discussions are moderated. Because the two modes of engagement entail different yet mutually challenging ways of appraising health innovations, we suggest that deliberative processes be designed so as to deliberately solicit both personal and collective reflections. For instance, participants could be asked to sequentially share and ponder personal and collective concerns. To support more challenging group discussions, the moderator could also explicitly solicit arguments from one standpoint and then invite participants to think about and raise potential counterpoints from the other standpoint.

The respective limitations of these modes of engagement should also be carefully considered because public involvement is increasingly seen as a way to enhance the legitimacy of public policies (Gagnon et al. 2016; Wortley et al. 2017). While engaging as a public representative is typically considered the ideal to be pursued within a deliberative democracy framework, such a mode of engagement may contribute to the problem critics of deliberative democracy call the authenticity problem (King et al. 1998). This problem is understood as a limit induced when participants would, among other things, "lack sufficient expertise to understand, articulate, and form meaningful judgments on the relevant issues" (Degeling et al. 2015: 115). Engaging as a potential user enables participants to draw on concrete details and contextual elements, but it may, on the other hand, lead them to downplay key aspects of the common good (Burgess 2014; Krinks et al. 2015). For instance, as a user, one may accept short-term benefits despite the fact that long-term risks remain unknown, or one may support certain trade-offs between individual and collective concerns (Montesanti et al. 2016). Another element that may undermine the authenticity of an argument is related to the ways in which individual beliefs and commonly shared concerns are intertwined (Innes and Booher 2004). For instance, there is a thin line between one's own beliefs and the beliefs of the collective within which this person is evolving. From a deliberative standpoint, assuming that one's way of seeing the world is shared by a broader group is problematic because such claims may easily gain the approval of other participants, closing down the discussion too rapidly.

Conclusion

While public involvement is gaining traction in many public policy domains, knowing how to handle the multifaceted nature of the lay opinions that are gathered through deliberative processes is methodologically challenging. One key object of contention is deciding whether participants should be contributing on the basis of their own personal perspective or whether they should be encouraged to talk on behalf of the broader collective. Acknowledging how the two modes of engagement we described enable participants to share opinions that not only complement but also challenge those of each other is important for practitioners of public involvement. Enabling both modes of engagement to coexist in a given public involvement mechanism could help to develop a richer understanding of the social and ethical issues raised by health innovations. This would be more consistent with the deliberative democracy ideal wherein difficult decisions need to be carefully pondered by a broad and diversified set of citizens.

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RESEARCH PAPER

Policies for Deprescribing: An International Scan of Intended and Unintended Outcomes of Limiting Sedative-Hypnotic Use in Community-Dwelling Older Adults

Politiques de déprescription : analyse internationale des résultats attendus ou non d’une limitation de l’utilisation de sédatif hypnotique chez les personnes âgées vivant dans la communauté

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Abstract

Policies have been put in place internationally to reduce the overuse of certain medications that have a high risk of harm, such as sedative-hypnotic drugs for insomnia or opioids for chronic non-cancer pain. We explore and compare the outcomes of policies aimed at deprescribing sedative-hypnotic medication in community-dwelling older adults. Prescription monitoring policies led to the highest rate of discontinuation but triggered inappropriate substitutions. Financial deterrents through insurance scheme delistings increased patient out-of-pocket spending and had minimal impact. Pay-for-performance incentives to prescribers proved ineffective. Rescheduling alprazolam to a controlled substance raised the street drug price of the drug and shifted use to other benzodiazepines, causing similar rates of overdose deaths. Driving safety policies and jurisdiction-wide educational campaigns promoting non-drug alternatives appear most promising for achieving intended outcomes and avoiding unintended harms. Sustainable change should be supported with direct-to-patient education and improved access to non-drug therapy, with an emphasis on evaluating both intended and unintended consequences of any deprescribing-oriented policy.

Résumé

Des politiques ont été adoptées, un peu partout au monde, afin de réduire la surutilisation de certains médicaments qui présentent un risque élevé pour la santé, tels que les sédatifs hypnotiques pour traiter l'insomnie ou les opioïdes pour la douleur chronique non cancéreuse. Nous étudions et comparons les résultats des politiques qui visent la déprescription des sédatifs hypnotiques chez les personnes âgées vivant dans la communauté. Les politiques de surveillance des prescriptions ont mené aux plus hauts taux d'abandon, mais elles ont aussi donné lieu à des solutions inappropriées. Les moyens de dissuasion financière – par révision des listes d'assurance – ont poussé les patients à défrayer davantage les coûts à même leur poche et ont eu des impacts minimes. Les incitatifs de type « rémunération au rendement » visant les prescripteurs se sont montrés inefficaces. Le remplacement de l'alprazolam par une substance contrôlée a fait augmenter le prix du médicament sur le marché clandestin et a déplacé l'usage vers d'autres benzodiazépines, ce qui a causé des taux similaires de mortalité par surdose. Les politiques de sécurité et les campagnes de sensibilisation nationales, qui favorisent le recours à des choix non médicamenteux, s'avèrent les plus prometteuses pour atteindre les résultats escomptés et pour éviter les effets néfastes. Pour un changement durable, il faut offrir une éducation directement aux patients et assurer un meilleur accès aux thérapies non médicamenteuses, en mettant l'accent sur l'évaluation des répercussions souhaitées ou non de toute politique orientée vers la déprescription.

* * *

Background

Discontinuing potentially inappropriate medications is a foundational element of the broader de-adoption movement, which aims to use evidence-based health policy as one of several strategies to promote safe and appropriate prescribing (Baicker and Chandra 2017;

Tannenbaum et al. 2017). National health and professional organizations have drawn attention to the overuse of antibiotics (Dar et al. 2016), opioids (Barnett et al. 2017; Califf et al. 2016), antipsychotics (Choosing Wisely 2018a; Desveaux et al. 2015), sedative-hypnotics (Bachhuber et al. 2016; Budnitz et al. 2011; Choosing Wisely 2018b; Hampton et al. 2014; Lembke et al. 2018) and polypharmacy (Mangin et al. 2018; Scott et al. 2015; Scottish Government 2018). Policies have been put in place to reduce the overuse of medications but have produced mixed outcomes. Careful assessment of the policy mechanisms that have failed is needed to avoid future implementation of pharmaceutical policies that may be ineffective or counterproductive, burdening health providers, consuming taxpayer resources and inconveniencing patients (Larochelle et al. 2015).

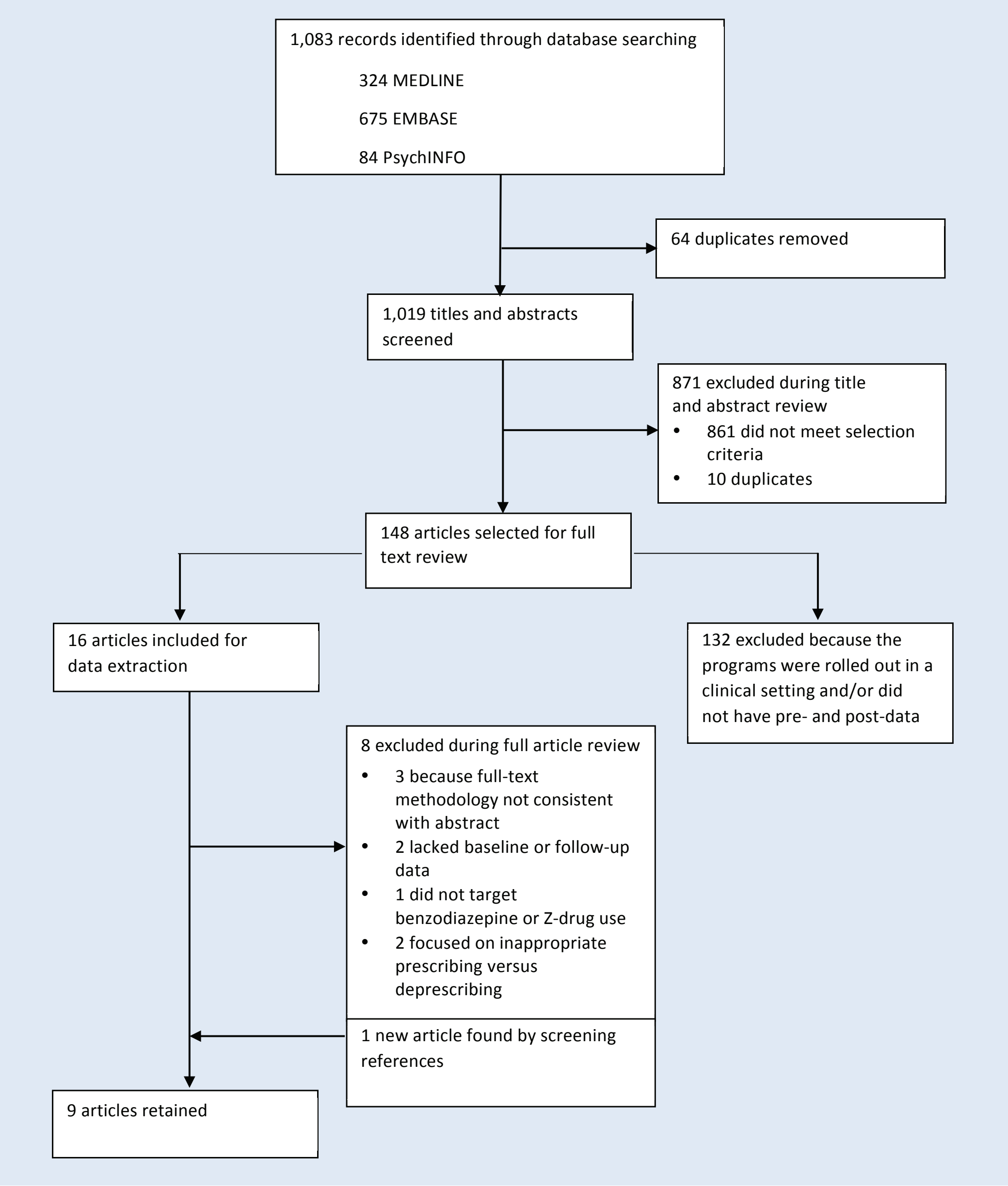
Sedative-hypnotic drugs, especially benzodiazepine receptor agonists such as alprazolam, diazepam, lorazepam, zolpidem and zopicolone, have been identified as a priority area for deprescribing among older adults (Tannenbaum et al. 2017). Benzodiazepines and Z-drugs are among the most frequently prescribed potentially inappropriate medications, especially for older women (Bachhuber et al. 2016; Brett et al. 2018; Tannenbaum et al. 2017). The harms associated with their short- and long-term use are well documented (Glass et al. 2005) and include falls and fractures (Donnelly et al. 2017; Woolcott et al. 2009), cognitive impairment (Billioti de Gage et al. 2012; Tannenbaum et al. 2012), automobile accidents (Hansen et al. 2015) and higher mortality alone and in combination with opioids (Kripke 2016; Lembke et al. 2018; Sun et al. 2017). There is a substantive body of clinical research assessing interventions to reduce benzodiazepine and Z-drug use that are amenable to implementation (Martin et al. 2018; Reeve et al. 2017; Smith and Tett 2010; Tannenbaum et al. 2014). Policy initiatives in support of clinical interventions should be informed by previous assessment of effectiveness and unintended harm (Kollen et al. 2012; Rat et al. 2014). Here we examine and compare the outcomes of different jurisdictional-wide policies on the reduction of benzodiazepine and Z-drug use among community-dwelling adults.

Study Data and Methods

Search strategy

A search was conducted for published articles evaluating the impact of regional or regulatory jurisdiction-wide policies aimed at limiting sedative-hypnotic use among community-dwelling older adults using Medline, Embase and PsychINFO from inception to January 2017, with search terms related to drug class policy and age and restricted to the English language. For drug class, we limited the MeSH terms and keywords specific to benzodiazepines and specific Z-drugs (eszopiclone, zopiclone, zaleplon and zolpidem). The policy concept was split into two related and required component terms. First, we included terms concerning "legislation," "policy," "public policy," "health policy," "program(s)," "patient education," "campaign(s)" and "practice guidelines" to broadly identify studies of policies. Second, we included terms suggestive of an intended outcome related to discontinuation or deprescribing of inappropriate or unnecessary medications: "deprescriptions," "inappropriate prescribing," "drug utilization," "drug prescriptions," "withdraw*," "discontinu*," "appropriate*," "optim*" and "prescri*." To ensure that the policy targeted individuals aged 65 years and older, we included the search terms "aged" and "over 65." Through hand-searching of references, we identified additional papers and grey literature sources. We limited our results to studies published in English. Figure 1 details the results of the search and the subsequent screening process.

FIGURE 1. Flowchart of study identification, screening, eligibility and inclusion



Article screening and selection

Article titles and abstracts were each screened independently by two reviewers for policies or programs that targeted a reduction in benzodiazepine and Z-drug use among older adults. Article selection criteria included applicability of a jurisdictional-level policy to reduce the use of benzodiazepines and Z-drugs, clear documentation of pre- and post-policy population rates of sedative-hypnotic use to evaluate the policy's effectiveness and inclusion of community-dwelling individuals over the age of 65. Exclusion criteria included long-term care settings, programs that were rolled out in clinical settings, individuals solely under the age of 65 and baseline and follow-up data not available in the publication or via follow-up with the author directly. Article selection was completed by one investigator and reviewed by a second investigator. Disagreements were addressed through dialogue until agreement was reached among the authors.

Data extraction

Data were extracted from full-text articles by two members of the investigator team using a data extraction form, which included fields for the nature of the policy intervention, the relevant contexts, the time frame and the baseline and follow-up change metrics in drug use.

Outcomes

The primary outcome was the comparative effectiveness of each policy on reductions in population-based rates of benzodiazepine and Z-drug prescriptions. Absolute prescription change was calculated by comparing rates of sedative-hypnotic use pre- and post-policy implementation. The relative effectiveness of each policy was recorded as the relative change in prescription rates (absolute difference in post- vs. pre-policy rate/pre-policy rate). Although the unintended consequences of each policy were of interest, unintended outcomes were not always documented in the article or related articles and therefore were considered as a secondary outcome. We hand-searched the literature for each policy that was identified to ensure that, where possible, we captured the published unintended outcomes.

Study Results

The search returned 1,083 titles and abstracts. We excluded 74 duplicates and retained 148 full articles for review. One article was added from an external source. Of these, nine independent studies evaluating seven different policies for reducing the use of benzodiazepine and Z-drug medications in community-dwelling adults were included in the final analysis.

Comparative effectiveness

The comparative effectiveness of each policy on a change in sedative-hypnotic drug use is shown in Table 1 (available at www.longwoods.com/content/25857). Prescriber monitoring was most effective during a two-year follow-up of New York State's benzodiazepine triplicate prescribing policy for seniors (McNutt et al. 1994; Wagner et al. 2003). The policy required physicians to obtain, pay for and transmit one of three copies of a serialized prescription form to state health authorities for surveillance for any senior receiving a benzodiazepine prescription. A 35% reduction in the number of seniors receiving monthly benzodiazepine prescriptions was reported after the first year post-policy, and a cumulative 53%–58% decrease was recorded over two years (McNutt et al. 1994; Wagner et al. 2003). Following a successful state-wide intervention involving prescriber monitoring and education in 2007, in 2014, Australia made a national regulatory change that involved the rescheduling of alprazolam from a "schedule 4" designation, like other benzodiazepines, to a "schedule 8" controlled substance designation, which led to its inclusion as a monitored drug (Schaffer et al. 2016). As with the New York triplicate prescription policy, this regulatory change introduced surveillance by state and territory health authorities for any patient prescribed alprazolam. In New South Wales, a 28% reduction in alprazolam use was achieved among 65–79-year-olds one year post-policy implementation and 39% for those 80 years and older.

Denmark implemented a number of public awareness campaigns designed to reduce the use of sedative-hypnotics beginning in 2003, and in 2008, the Danish National Board of Health introduced a driver's license restriction policy for seniors. The driving license policy diminished the use of long-acting and short-acting benzodiazepines and Z-drugs by 54% and 35%, respectively, over five years (Eriksen and Bjerrum 2015). Physicians were required to report patients taking a benzodiazepine or Z-drug based on duration of use and drug half-life guidelines. Driving safety regulations included that all long-acting benzodiazepine users have their driver's license revoked, short-acting benzodiazepine users have a one-year limited renewal imposed with mandatory cognitive testing, new users refrain from driving for four weeks and episodic users not drive the morning after ingestion.

An Australian regional awareness campaign aimed to promote non-pharmacological therapy for insomnia. The multifaceted campaign included healthcare provider engagement and education, public education and the development and distribution of patient education materials relating to non-drug alternatives for the treatment of insomnia. A 19% reduction in benzodiazepine use was observed and sustained over a two-year period (Dollman et al. 2005).

The effect of delisting benzodiazepines from public insurance programs varied by country and by specific policy. The Netherlands experienced an 11%–14% reduction over a two-year period (Hoebert et al. 2012; Kollen et al. 2012) and a one-year 5% reduction was observed in the US (Chen et al. 2008). France's financial incentive program for physicians was the least effective, with a 1.4% increase in the number of patients initiating benzodiazepines over the course of one year (Rat et al. 2014).

Unintended consequences

Two follow-up studies examined the consequences of the national rescheduling of alprazolam in Australia (Deacon et al. 2016; Lloyd et al. 2017). The first reported an overall reduction in alprazolam and total benzodiazepine use among a small sample of patients enrolled in an opioid substitution program (Deacon et al. 2016). The street drug price of alprazolam doubled from $5 to $10 per two-milligram tablet over the 12-month period. The second report examined coroner records to assess a change in overdose due to alprazolam and other benzodiazepines (Lloyd et al. 2017). Although overdose deaths involving alprazolam declined, there was a steady increase in any overdose death where a benzodiazepine contributed, suggesting that limiting access to individual benzodiazepines might not impact on overall benzodiazepine-related mortality. Similarly, the US Medicare Part D restriction of reimbursement policy for benzodiazepines in the US led to high rates of substitution with zolpidem, which was still covered under the policy program, and a significant increase in out-of-pocket spending for benzodiazepines (Chen et al. 2008; Chen and Kreling 2014). A parallel rise occurred in prescriptions for other classes of sedative-hypnotics such as antipsychotics (Briesacher et al. 2010). There was an increase in fracture rates observed among patients admitted to nursing homes, presumably because of substitutions with these other sedatives (Briesacher et al. 2010).

The New York State triplicate prescribing policy also had unintended outcomes (Fisher et al. 2012). Within one year of the policy, prescriptions for barbiturates, meprobamate and other medications climbed, in contrast to the rest of the US, where their use was trending downward (Weintraub et al. 1991). Greater reductions in sedative-hypnotics were observed among women and individuals who were black and living in urban or low-income areas (Fisher et al. 2012). Data also suggest that the policy detrimentally affected some clinically vulnerable populations (e.g., persons with chronic psychiatric and neurological disorders) (Fisher et al. 2012).

Patient perceptions and physician receptivity in response to the administrative burden associated with prescription monitoring and other policies programs were analyzed (Fisher et al. 2012; Rodriguez 1991). A survey was conducted of 302 physicians and 103 patients from a Hispanic community in New York State two years after implementation of the benzodiazepine triplicate prescription policy (Rodriguez 1991). Forty-nine per cent of physicians reported that the policy affected their prescribing patterns, with 86% citing the increased administrative burden as the main reason for diminishing prescriptions, and 78% expressing opposition to prescription monitoring. Sixty-eight per cent of patients surveyed were dissatisfied with the triplicate prescription policy owing to the need for government documentation, breach of confidentiality and increased costs because of additional physician visits. In Denmark, sharing of information occurred between government departments during the driver's license restriction policy but was framed in the context of new public driving safety legislation implemented in 2007 that targeted prescribed medications together with illicit substances that can impair driving (Steentoft et al. 2010).

Limitations

Many of the reports relating to policy interventions are observational and retrospective, and only a small number purposively assessed unintended outcomes. In some cases, publication of the primary outcome and unintended outcomes was completed separately. We hand searched the literature to ensure that, where possible, we could present the published unintended outcomes. Our search did not find any negative outcomes from the drivers' license policy in Denmark nor the educational campaign in Australia; it is possible that negative consequences occurred but remain undocumented. Furthermore, unintended outcomes may have occurred at a clinical level and these would not have been captured. We limited our review to published peer-reviewed papers and did not scan government websites or the grey literature for other policies that were implemented. As policies do not have fixed evaluation periods and are situated within different contexts, it is difficult to compare the effectiveness of each policy, even with a generic calculation such as the relative reduction in use. We chose to study pharmaceutical policy for community-dwelling older adults. Policies that have been applied to reduce benzodiazepine use in acute or long-term care settings were not included, and the results of this analysis may not be generalizable to other contexts.

Other potentially effective solutions may exist that were not captured in this review. For instance, we did not find any jurisdictional-wide interventions that examined the effectiveness of policies to restrict pharmaceutical industry-based product promotion, for example via direct-to-consumer advertising (Becker and Midoun 2016). Policies that aim to reduce the promotion of prescription drugs to prescribers and directly to patients require further investigation (Gaffney and Lexchin 2018; Gardner et al. 2003). Nor did we find any assessments of jurisdiction-wide deprescribing initiatives that occurred at the patient level, rather than at the drug level. Medication reviews and deprescribing frameworks that address the patient's goals of care should be applied more broadly to patients with multimorbidity and polypharmacy in the clinical setting (Scott et al. 2015). Patient-specific interventions to deprescribe demonstrate a significant reduction in mortality (Page et al. 2016).

Discussion

The benefits of deprescribing policies may be diminished by a host of unanticipated consequences. Prescription monitoring policies such as the New York triplicate prescription policy led to the highest rates of discontinuation, but substitution with other inappropriate medication classes and the emergence of inequities undermined the intended effect. Financial deterrents through insurance scheme delistings were only minimally impactful and increased patient out-of-pocket spending. Financial incentivization in the form of a pay-for-performance supplement to prescribers was ineffective. Rescheduling alprazolam to a controlled substance that requires monitoring raised the street drug price of the drug and shifted use to other medications from the same class that caused similar rates of overdose deaths. Denmark's driver license policy and Australia's regional educational campaign on non-drug alternatives for treating insomnia were the only two policies that did not report unintended harms.

Extrapolation of the findings from policies targeting sedative-hypnotics to other drug classes such as opioids – given the current opioid abuse epidemic – would be useful, but is challenging to do. Prescription monitoring to reduce opioid prescribing has been shown to be modestly effective in some but not all jurisdictions in the US, particularly when it is part of a mandated program and covers the full range of prescription opioids (Barnett et al. 2017). Similar to the Australian alprazolam policy, however, substitution with other medications from the same class and a rise in illicit access and street drug costs can occur when a single opioid drug is targeted for restriction (Larochelle et al. 2015). Intensive and inclusive educational awareness programs that target the public, patients and health professionals to encourage use of non-drug substitutes appear to be moderately effective, at least for reducing sedative-hypnotics in the short term. The long-term sustainability and unforeseen consequences of time-limited education and awareness campaigns targeting sedative-hypnotics, opioids or other medication classes have yet to be fully elucidated (Califf et al. 2016). Widespread availability of opioids, while emphasizing alternative approaches and tools for the treatment of chronic pain, emerges as a promising approach associated with a substantially lower population-wide usage of opioids in Japan (Fischer et al. 2016).

Because opioids are implicated in three-quarters of benzodiazepine-related overdose deaths (Jones and McAninch 2015), parallel educational policies should be entertained and examined for sedatives and opioids. The EMPOWER study, that distributed direct-to-patient educational material on the harms of benzodiazepines, easy-to-follow tapering protocols and suggestions for non-drug alternates, yielded a 27% termination in chronic benzodiazepine use at the six-month follow-up versus 5% in the treatment as usual group (Tannenbaum et al. 2014). Additional benefit occurs with the combined use of patient education and pharmacist-initiated distribution of evidence-based pharmaceutical opinions to physicians to support patients to deprescribe and adopt non-drug therapies for symptom relief (Martin et al. 2018). Opportunities exist to encourage dialogue and legislation around drugs and driving safety when entertaining policies to reduce motor vehicle accidents. Patient-oriented policies have been proposed in the context of brain health and dementia strategies (Daiello and Tannenbaum 2018). The Canadian Deprescribing Network serves as a national hub in Canada for the promotion of evidence-informed initiatives and partnerships with policy makers, healthcare providers and the general public to reduce medication-related harm and improve access to non-drug therapies (Tannenbaum et al. 2017).

Challenges exist when comparing pharmaceutical policies to reduce medication overuse both within and across drug classes. To evaluate the magnitude of effect of each policy on medication reduction, methodological considerations include the use of different metrics and length of follow-up periods for each policy evaluation, the inability to evaluate policies that are not recorded in the medical literature, the lack of adequate explanation of contextual and cultural factors impacting the policy and widely different indications and determinants of use. Evidence-based policy also requires a hard look at downstream consequences, assessing trade-offs between specific goals (Baicker and Chandra 2017). Although prescriptions plummeted with prescriber monitoring and medication rescheduling policies, substitutions with equally and more harmful medications increased and the demand for street drug availability rose, leading to higher rates of morbidity and mortality. Direct and indirect costs are rarely ascertained in the real-world setting, though economic simulations suggest that access to and coverage of non-drug therapies may prove cost-effective, particularly for older adults with insomnia (Morgan et al. 2016; Tannenbaum et al. 2015).

The effort to generate policies that are effective at reducing the overuse of particular prescription drugs, that do not lead to pernicious consequences and that are acceptable to stakeholders requires close attention to political and health system contexts. Success will depend on the design, drug class, implementation details and the program particulars for each jurisdiction. Health promotion educational interventions that target specific patients may be the safest and most reasonable solution.

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RESEARCH PAPER

Is Assisted Peritoneal Dialysis a Solution for Northern Manitoba?

La dialyse péritonéale assistée est-elle une solution pour le Nord du Manitoba?

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Abstract

Background: End-stage kidney disease (ESKD) continues to fundamentally impact the lives of First Nations (FN) patients. Home peritoneal dialysis (PD) offers patients more mobility and flexibility, but few Manitoba FNs have availed themselves of this option.
Objective: This paper discusses Manitoba FNs' experience of PD, to highlight enablers and barriers to expanding the use of PD in rural and remote Manitoba communities.
Methods: We analyzed interviews of individuals living with ESKD ($N = 14$), family caregivers ($N = 14$) and healthcare providers and administrators ($N = 27$).

Results: Barriers to PD uptake include medical suitability, patients' distrust of home modalities and fear in their ability to manage. Other factors include limited family support and lack of appropriate housing.
Conclusions: Assisted peritoneal dialysis (APD) is an emerging model where PD supplies are centrally located, and where a cohort of PD patients can provide mutual support with added assistance from an APD worker. This model could mitigate existing treatment barriers.

Résumé

Contexte : L'insuffisance rénale terminale (IRT) continue d'avoir un impact fondamental sur la vie des patients chez les Premières Nations. La dialyse péritonéale (DP) à domicile donne au patient plus de mobilité et de flexibilité, mais peu de membres des Premières Nations se prévalent de cette option.
Objectif : Cet article fait état de l'expérience des Premières Nations manitobaines quant à la DP et met en relief les facteurs favorables et les obstacles à l'expansion du recours à la DP dans les communautés manitobaines rurales et éloignées.
Méthode : Nous avons analysé des entrevues menées auprès de personnes atteintes d'IRT (*N*=14), d'aidants naturels (*N*=14) ainsi que d'administrateurs et de fournisseurs de services de santé (*N*=27).
Résultats : Les obstacles à l'adoption de la DP comprennent l'aptitude médicale, la méfiance des patients face aux modalités à domicile et la crainte envers leur habileté à gérer le traitement. Parmi les autres obstacles se trouvent le faible soutien familial et le manque d'hébergement adéquat.
Conclusion : La DP assistée constitue un modèle émergent dans lequel les installations pour la DP sont centralisées et où les patients peuvent s'entraider sous la supervision d'un professionnel de la DP. Ce modèle pourrait servir à atténuer les obstacles aux traitements.

* * *

Background

Indigenous populations experience a high burden of chronic kidney disease (CKD) and poorer outcomes internationally (Yeates et al. 2009). Important outcome inequities remain between Canadian Indigenous and non-Indigenous peoples (Canadian Institute for Health Information [CIHI] 2013). In 2004–2005, 30.9% and 22.4% of dialysis patients in Manitoba and Saskatchewan were Indigenous, respectively (Indigenous people constitute 15% and 11% of the population of Manitoba and Saskatchewan, respectively) (CIHI 2008).

A diagnosis of renal failure is devastating to anyone. For those living in rural and remote communities, this diagnosis may also involve relocating to an urban or a smaller regional centre, increased physical distance from family and community at a time where support is much needed and severe financial hardship because relocation and/or treatment demands often result in loss of employment. The development of satellite hemodialysis units in rural communities, which has been the main innovation of the past three decades, had provided opportunities for some patients to dialyze closer to home. In Manitoba, dialysis modality uptake favours institution-based (in-centre) hemodialysis (ICHD) available primarily in urban centres and some rural communities, which results in high numbers of First Nations (FN) patients requiring relocation to access treatment.

Home dialysis (which includes home hemodialysis or HHD, and peritoneal dialysis or PD) uptake remains limited. This is largely due to inconsistent access to a consistent clean water source and the influence of other social determinants of health, which make this option less viable in FN communities.

In this paper, we discuss evidence garnered from Manitoba FN patients who have undergone PD, as well as from healthcare providers who support them, to extract lessons and inform potential assisted peritoneal dialysis (APD) developments in FN communities. APD is performed at the patient's home or in a central community-based shared location, with the assistance of a healthcare professional or a family member (Dimkovic et al. 2009; Lobbedez et al. 2012). APD is an emerging modality that can mitigate community infrastructure limitations. Our paper begins with a discussion of current dialysis modalities and of the need for alternatives. We highlight key contextual issues that create barriers to the successful adoption of PD in FN communities. These findings then inform key factors that should be considered in the development of an FN-centric APD model.

The Importance of Exploring Treatment Alternatives

Interventions to support patients with end-stage kidney disease (ESKD) are divided into three main options: transplantation, dialysis or palliative care. This paper focuses on dialysis only, a medical treatment required when a patient's kidney function has stopped. Dialysis replaces some of the regular functions of healthy kidneys by cleaning blood and removing waste and excess water from the body.

Dialysis care is most often provided in ICHD, either in larger urban dialysis centres or rural satellite centres. ICHD is usually scheduled three times a week. The process takes approximately four hours per treatment. This time commitment does not, however, include travel time, which for residents of remote communities can be considerable to the point of requiring relocation.

Independent or semi-independent (assisted) home dialysis options include HHD and PD. HHD is performed at home, using a hemodialysis machine and a water filtration system, which in Manitoba are provided by the Manitoba Renal Program at no cost to the patient. Dialysis can be done overnight or adapted to fit the patient's schedule and preferences. Once training is complete, patients only need to visit the home dialysis clinic once every one to two months for assessment by healthcare team members. The process for PD is slightly different, in that the blood is cleaned inside the body, using the peritoneum within the abdominal cavity as a natural filter, rather than being cleaned outside in a machine. PD requires access to the dialysis solution and equipment, also provided free of charge by the

Manitoba Renal Program. A patient choosing PD dialyzes seven days a week, usually overnight during sleep. Patients only need to visit the PD clinic every two to four months for assessment by healthcare team members.

Across Canada, most provinces have large urban dialysis units offering ICHD, staffed with large multidisciplinary teams that include nurses, nephrologists, pharmacists, social workers and dietitians. Satellite ICHD centres, staffed with smaller teams of nurses and sometimes nurse practitioners, exist in most provinces to serve a limited number of rural communities.

Capital investments are considerable for rural satellite ICHD centres (Ferguson et al. 2015), coverage of remote communities is variable to inexistent (Manns et al. 2007) and beds are limited. Few rural patients, including FN patients, currently have the opportunity to dialyze in their home community. In the fall of 2017, the Manitoba Renal Program reported that 116 people were on the Manitoba Renal Program's waiting list for a dialysis bed in rural Manitoba: of these, 99 (or 85%) were FN patients (Zacharias 2017, personal communication). A few FN communities have developed transportation systems to support patients' access to ICHD sites in rural communities (1–3 hours away). Most communities cannot afford such a service. Reliance on HHD and PD is low to nonexistent in Canadian remote communities (Manns et al. 2007).

Evidence suggests that it is not the distance travelled but relocation itself that is problematic for FN peoples (Tonelli et al. 2006), with reports of loneliness; role reversal between parents and children, with children becoming caregivers; alienation and, in some cases, stigmatization (Salvalaggio et al. 2003; Wilson et al. 1994). Colonization, historical trauma, culturally unsafe care, ill-informed assumptions by healthcare providers and racism remain huge barriers to accessing responsive care for FN peoples (Lavoie et al. 2015, 2016) and may explain the faster progression from CKD to ESKD.

Canadian data show that, nationally, ICHD remains the most prevalent modality used (44.2%), followed by transplants (41.5%), PD (11.5%) and then HHD (2.8%). Figures for Manitoba are sensibly the same, with a slightly higher use of ICHD and lower reliance on transplants (55.1% and 30.1%, respectively) (Tonelli et al. 2004). CIHI data show a 43.3% unadjusted five-year patient survival for patients on ICHD, compared with 51.0% for patients on PD (CIHI 2017, p. 3). Caution should, however, be exercised in interpreting these data, as unadjusted data do not account for the possibility of a selection bias: PD candidates are more likely to be younger and healthier than ICHD candidates, as a whole. CIHI does not provide an urban/rural breakdown when reporting data.

The literature we reviewed suggests that PD is less expensive to deliver than ICHD for patients living in remote locations (Newfoundland and Labrador Centre for Applied Health Research 2008; Tonelli et al. 2007). A recent health and technology report from the Canadian Agency for Drug and Technology Assessment (Canadian Agency for Drugs and Technologies in Health [CADTH] 2017) shows the estimated lifetime cost of PD at $600,808 and APD at $670,452, compared with HHD at $561,962 and ICHD at $637,101.

The cost of offering ICHD in rural and remote jurisdictions was, however, estimated to be 1.6–2.5 times higher than that in urban centres. When locality was factored in, the annual costs of PD and APD were estimated to be considerably lower than that of ICHD (with annual savings ranging from $62,352 to $271,592) (CADTH 2017, p. 69).

Several studies in Australia and Canada have found increased rates of peritonitis, technique failure and mortality among Indigenous people undergoing PD (Bello et al. 2012; Buob-Corbett and Blundon 2007; Couchoud et al. 2012; Golper et al. 2011; McCarthy and Martin-McDonald 2007). These results were attributed to poor housing quality, overcrowding, periodic or no access to clean water and poorly designed sewage utilities (Hildebrand et al. 2010; Lim 2004; Lim et al. 2011; Sood et al. 2012). In addition, Manitoba Renal Program nephrologists observed that some FN patients express considerable discomfort and fear of PD, reporting that they believe it to be a substandard option. An Alberta study reported that Indigenous patients were 50% less likely to initiate PD compared with Caucasian patients (Tonelli et al. 2005).

PD's acceptability is influenced by systemic and personal factors. For example, patients living further away from points of care were found less likely to accept PD as their treatment modality (Wang et al. 2017) and less likely to have access to a nephrologist and good-quality renal care (Bello et al. 2012). A large US cohort study found that patients who opted for PD were more likely to have completed high school compared with those who opted for ICHD (Kutner et al. 2011). Maaroufi and colleagues also documented that limited awareness of PD was an important barrier (Maaroufi et al. 2013). The generalizability of these findings to FN patients is, however, unknown.

Further, the influence of previous experiences of trauma and neglect on patients' attitude towards PD remains undocumented. Previous poor experiences may have created a long-lasting fear and distrust of health systems (Lux 2016; McCallum and Perry 2014). In addition, the burden of self-managing a modality where errors may have life-threatening consequences is a likely deterrent.

Methods

This paper draws on a subset of interviews from a larger study focused on the challenges associated with FN peoples relocating for medical reasons, for which we partnered with *the First Nations Health and Social Secretariat of Manitoba* and four FN communities.[1] As shown in Table 1, a total of 129 people participated in the larger study. Findings from the broader data set have already been published (Lavoie et al. 2015, 2016). The main reason for relocation was the need for FN patients to access renal care. This paper is informed by an overall analysis of interviews conducted with FN patients, their family caregivers and healthcare providers with experience of renal care. This included in-depth, open-ended interviews with 29 patients or family members (19 women and 10 men) who spoke about their own healthcare experiences or those of family members with whom they were closely involved and 26 healthcare providers and program managers. We used the renal data set to contextualize findings from a smaller data set (20 interviews) focused on PD.

TABLE 1. Participants' characteristics

	All interviews		Renal-related interviews		Peritoneal dialysis-related interviews	
	Male	**Female**	**Male**	**Female**	**Male**	**Female**
Patients	11	23	5	9	1	4
Family member, parent, guardian	9	27	5	10	0	4
Healthcare provider, including social workers, physicians, nurses, navigators	4	21	4	18	3	8
Managers/decision-makers	1	4	4		0	
Focus group with program managers/decision-makers	29		0		0	
Total	129		55		20	

A partnership agreement was signed by the research team and the community leadership in each of the four FN communities, detailing the purpose and process of the study. Community-based healthcare providers with long-standing knowledge of the community invited patients and family members to participate in the research project. These workers identified potential participants, based on their knowledge, and contacted them to discuss the study and gauge interests. They then booked an appointment with the researchers. A consent form was provided and explained by a member of the research team to participants. Most interviews lasted 1–1.5 hours. In Winnipeg, potential patients and family members were identified and contacted through the AMC's Patient Navigation Unit and other key informants known to the health research team. Community-based and other healthcare providers were approached by the research team, and informed consent was secured if interested. Additional providers were identified using a respondent-driven sampling process. Ethical oversight was provided by the University of Manitoba Research Ethics Board.

Interviews were digitally recorded with permission, transcribed verbatim, cleaned of any personal identifiers and compared with the audio recordings for technical accuracy. Using interpretive thematic analysis for qualitatively derived data (Thorne 2008), the research team reviewed the transcripts to identify concepts, processes and linkages to theoretical perspectives as well as any recurring and contradictory patterns in the data. NVivo 10, a qualitative data analysis software, was used by two research assistants to independently code and organize the interview data, using the code book developed by the research team. The code books were periodically reviewed and discussed by the research team, and compared to independent coding of transcripts completed by research team members for validation. Over time, analysis shifted to a more abstract and conceptual representation of the processes and themes reflected in the data. Credibility of the analysis was continually evaluated by members of our research team, which included experts in ethnographic research, healthcare services, FN health and health equity. Preliminary results were presented to FN Health Directors to seek advice on interpretation. In these meetings, on-reserve healthcare providers affirmed that the themes reflected in the data resonated with their experience of working with families and patients in the healthcare sector.

Findings

Participants clarified that all dialysis is initiated in Winnipeg, no matter where the patient is from, whether a satellite centre exists in their community or whether they qualify for home modalities. Dialysis initiation generally requires a six-to-eight-week stay in Winnipeg. The modality chosen at the time of initiation is most often ICHD, but a minority of patients may initiate home dialysis, either HHD or PD.

> [A] patient will come in, in renal failure and they'll be at a really critical state. So we get them stabilized and, then, we'll put them on hemodialysis (Healthcare provider 25).

Once training is completed, a patient's ability to dialyze in their home community may be contemplated, but there are important barriers impeding this option:

- ICHD beds in satellite sites are limited, and often in use. It may take one to two years for a bed to become available (Patient 407; Healthcare providers 001 and 40).
- Limitations to the local infrastructure (crowding, lack of safe running water, limited storage for the dialysis solution, over/underheated house, insufficient water pressure to the house, etc.) may simply exclude the option to dialyze in the patient's home (Patient 407, for example).

Limited opportunities to go home might lead individuals to decide to go home, and endanger their life, to be able to attend to their family, community and ceremonial obligations:

> You know, someone in the community who's prominent dies, everyone wants to go to the funeral and it's a big deal. So these patients put themselves at risk. And I've seen patients die from this – where they go for a funeral … and there's no way to always provide them with dialysis (Healthcare provider 40).

Understanding the decision-making process

From the Manitoba Renal Program's perspective, decision-making surrounding the choice of a dialysis modality is based on a number of key factors related to patient characteristics that go beyond *clinical suitability*. PD requires considerably more commitment and patient investment in the treatment process than ICHD. *Ability to self-manage* is, of course, key.

> [F]or the patient to go home … [t]hey've got to be able to grasp the needles and the tubes to be able to connect, disconnect – those kinds of things (Healthcare provider 36).

Another key factor is *social and family support*.

> Depending on what kind of supports they have in community, they may be able to just go home, right? … [I]t doesn't matter what the state of the family is; they still need them … (Healthcare provider 25).

A number of patients and caregivers recounted their/their loved one's journey on PD. In this first story, family caregivers' reticence was overcome through the continued support of healthcare providers. This patient was on dialysis for a decade, and then passed away in his teen years. He lived in Winnipeg.

> [T]he nurses and doctors were very supportive there. And they did everything they can to help us … [B]efore he got discharged from the hospital, both my husband and I went on training … because he was on [PD]. [W]e both went for the training to look after him at home … And we brought him home with – after we got trained and we were *brave* enough to bring him home … I guess that's the best – what I can do because *it was scary*. I took him and I said, "Well, what if I do something wrong?" You know? There was *a lot of fear* … But the nurses came and … [t]hey helped us through the process – like, letting us do the dialysis, them being there, supervising it. And they done that for about 2 months and then finally we went on our own (Patient 44, emphasis added).

In this second story, related by a patient's mother, the patient also lived in Winnipeg. He chose PD but eventually switched to ICHD in Winnipeg. At the time of the interview, he was waiting for a dialysis bed to open in one of the satellite units closer to his home community.

> He was on home [PD]. He didn't want to go to the hospital for dialysis. *He wanted to do it on his own* because he was okay … He was feeling good; he – he wanted to work, besides that, doing his dialysis at night time, and then maybe do something – find work or maybe part-time, maybe – but they were in the evening – day-time, because he was on dialysis at night. And then, he got sick … *I don't trust that home dialysis* (Patient 218, emphasis added).

The next two stories are of patients who were using PD in their own community. Patient 30 initiated PD while living in her community, which is remote. The family's involvement in ensuring that she remained on PD in her community is remarkable. She, unfortunately, had to relocate to Winnipeg because of recurrent health issues that forced her to travel frequently to Winnipeg to receive care.

> She did [PD in her home community] by herself in the beginning. I went for training along with her. And then I helped on the side here and there. And eventually, like, she couldn't – like, her pain. So eventually I did the dialysis for her. And then, eventually, I would teach, like, my children. They were about, like, maybe 10 at the time. And then they would learn it also … the nephews and the nieces. And they all learned it; they were all under 15. So we just took turns and the sisters. I taught them how to do it, and my brothers, as well. So we all shared the responsibility … And then, when she got really sick … That's when she did the relocation to Winnipeg. We had to move (Patient 30).

In the following story, as in the one above, moving to Winnipeg was eventually required for other health reasons.

> I looked after my mom and dad when they were sick ... My dad [f]irst he started off with … [PD] … And then, after a while, it didn't work. He got really sick and we had to relocate. He had no choice (Patient 203).

According to one healthcare provider, key reasons for PD failure include "improper training and not enough people looking after them" (Healthcare provider 26).

Unsuitable housing conditions can be a decisive factor on the choice of a modality. In our sample, seven patients had experienced PD. PD was considered for two more patients but not pursued. In one case, the patient reported being advised that PD was not a suitable option, but the rationale was not documented (Patient 007). In contrast, PD would have been the option of choice for Patient 407, but this was not possible because of substandard housing:

> [H]ome dialysis: I could do that at home. But I don't have running water in my house at home. I've got those options still and I'm still thinking about – trying to make up my mind … I'd go home first chance I get (Patient 407).

This patient reflected that "I used to want to come to the city a lot," but that his priority was to get home. At the time of the interview, he reported that he had been waiting for two years for an ICHD bed in a site closer to his home community.

A healthcare provider contributed the following scenario:

> A good example is one person who'd be perfect for [PD] up North but wants to live with their daughter. But the housing won't be provided for both of them together … So that person didn't sign the papers or could have had an apartment by themselves that was big enough for PD but ended up having to move to Winnipeg to start [ICHD] because they wanted to live with their daughter. They wanted to live in a family group, which isn't always something that the system, then, is sensitive to and provides. So, they don't always provide the unique circumstances or for the extended family that, often, people want to live with or the context of the extended family (Healthcare provider 40).

The successful use of PD in an FN community is thus linked to a number of factors beyond clinical suitability. These factors are largely structural and contextual.

Discussion

Expanding access to home-based options in rural and remote communities is evidently complex, because of the limited local support available (support group, renal clinics, limited local primary care) and the distance required to access more complex care if needed. Our results show that barriers to home modalities in rural and remote FN contexts include intrinsic and extrinsic factors. Intrinsic factors include medical suitability and patients' fear in their ability to manage a complex disease previously only treated by doctors and nurses. There appears to be an important lack of trust in home modalities.

Extrinsic factors include the support of family and friends and lack of appropriate housing (space for storage and running water). These findings echo those on patients' perspectives documented in the CADTH report (CADTH 2017), although the context and the scale are different. The housing crisis in FN communities has been well documented (Carriere et al. 2017; Larcombe et al. 2011; Wearmouth and Wielandt 2009; Webster 2015). A 2017 Canada Mortgage and Housing survey documented that one in three houses on-reserve was below acceptable standards. This percentage was as high as one in two in the prairie region, which counts as the highest number of FN families living on-reserve (Canada Mortgage and Housing Corporation 2011). Likewise, the lack of access to safe drinking and running water in many communities has attracted the attention of James Anaya, the Special Rapporteur on Indigenous Human Rights to the United Nations (Anaya 2014).

Finally, the devastating impact of former and current policies on FN families continues to undermine some families' ability to support individual members, as is the case for those on home dialysis (McKenzie et al. 2016), leaving those family members to depend more readily on public services, which in turn may be prejudiced towards FNs (Browne et al. 2010, 2011; 2015; Nelson et al. 2016).

To date, most research works documenting models of APD have related the existence of urban-based models, which function primarily on the basis of home visits (Bevilacqua et al. 2017; Brown and Wilkie 2016; Dimkovic et al. 2009; Giuliani et al. 2017; Lobbedez et al. 2012). We found no evidence of patient engagement in the development of the model. Further, no attention has been paid to the need of patients from rural and remote settings and to the specific needs of FN patients.

Conclusions

Our analysis suggests that developing APD sites in FN communities might expand options for eligible FN patients. The mutual support of a group of patients undergoing PD together, assisted by a healthcare professional, with a central and temperature-controlled location to house supplies, could create opportunities that help to not only overcome the infrastructure and housing issues but also mitigate the intrinsic barriers of the patient's concerns and fears associated with current PD models.

Our decades of experience working in FN communities, and providing renal healthcare services to FN patients, suggest that success will require a) developing a service with strong coordination, b) wrap-around supports in terms of the mental, emotional, spiritual and physical care; and c) a strong culturally appropriate education and empowerment components. These are, in our view, essential to successfully support the individual and their family through the adjustment to APD.

Implementing an APD program within an Indigenous context would also help build local expertise in this complex disease. Expanding local expertise may prove to be the most important factor in not only expanding local knowledge of treatment but also preventing the disease and could perhaps also shift current trends towards increased CKD and ESKD diagnoses at very early ages. Fundamentally, effective models of APD must build on the needs and wants of FN patients themselves and be context-relevant.

Australia and New Zealand have successfully implemented models of APD in rural and remote Indigenous contexts. An APD pilot was also successfully implemented in BC non-FN communities (Bevilacqua et al. 2017). An urban APD site exists in Winnipeg. Although we readily admit that greater research in this area is needed, and will be undertaken by our team over the next five years, APD appears promising.

Note

[1] The Assembly of Manitoba Chiefs (AMC) was formed in 1988 to act as an advocate on issues that commonly affected all First Nations of Manitoba. The First Nations Health and Social Secretariat of Manitoba was established in 2014 with the staff from AMC's Health and Social Secretariat.

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RESEARCH PAPER

The Impact of the Ontario Fertility Program on Duplicate Fertility Consultations

Impact du Programme de procréation assistée de l'Ontario sur les demandes d'un second avis en consultation

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Abstract

Objectives: The Ontario Fertility Program (OFP) funds 5,000 annual in vitro fertilization (IVF) cycles. We hypothesized that after introduction of the OFP, there would be an increase in duplicate infertility consultations by patients attempting to increase chances at obtaining publicly funded IVF through enlisting at multiple fertility clinics.
Methods: This retrospective observational study included women eligible for healthcare services in Ontario from 2014 to 2016 and compared infertility consultations pre- and post-initiation of the OFP.
Results: Post-OFP, the average number of consultations per patient and the proportion of patients with more than one consult increased (1.04 vs. 1.05, $p = 0.015$ and 3.8% vs. 4.2%, $p = 0.027$, respectively). Total consultations for infertility increased from 24,565 to 27,714 post-OFP. The OFP had the largest impact in the Greater Toronto Area (GTA).
Conclusion: The OFP resulted in a statistically significant increase in duplicate consultations, although unlikely to be of clinical relevance. The disproportionate impact seen in the GTA highlights the inequitable access to fertility care in Ontario.

Résumé

Objectif : Le Programme de procréation assistée de l'Ontario (PAO) permet de financer, chaque année, 5000 cycles de FIV. Notre hypothèse est qu'afin d'accroître les chances d'obtenir une FIV financée par les deniers publics, il y aurait un accroissement des demandes d'un second avis pour les consultations en infertilité suite à la mise en œuvre du PAO, ce qui augmenterait les coûts pour le système de santé publique.
Méthode : Cette étude observationnelle rétrospective porte sur des femmes admissibles aux services de santé ontariens entre 2014 et 2016 et compare le nombre de consultations en infertilité avant et après la mise en œuvre du PAO.
Résultats : Après la mise en œuvre du PAO, le nombre moyen de demandes de règlement pour les patientes qui ont obtenu plus d'une consultation s'est accru (1,04 contre 1,05; p=0,015 et 3,8% contre 4,2%; p=0,027, respectivement). Le nombre total de consultations en infertilité est passé de 24 565 à 27 714 après la mise en œuvre du PAO. L'impact le plus important du PAO touche la Région du Grand Toronto (RGT).
Conclusion : La mise en place du PAO a donné lieu à un faible, quoique statistiquement significatif, accroissement des demandes d'un second avis en consultation. La disproportion observée dans la RGT met en évidence l'iniquité d'accès aux services de fertilité en Ontario.

* * *

Introduction

Infertility is defined clinically as a disease of the reproductive system characterized by the inability to achieve a pregnancy after 12 months of regular intercourse (Zegers-Hochschild et al. 2009). Approximately one in six couples in Ontario will experience infertility and require assisted reproductive technology (ART) to achieve pregnancy (Greenblatt 2015). ART can include controlled ovarian hyperstimulation, intrauterine insemination (IUI), in vitro fertilization (IVF) and intracytoplasmic sperm injection. In Ontario, 1%–2% of live births are achieved with ART (Greenblatt 2015). As more people delay childbearing, and given the documented decline in fertility with age, a growing number of people are turning to IVF as a means of achieving a pregnancy. IVF is also used by single individuals and many lesbian, gay, bisexual, transgender, and queer (LGBTQ) people to achieve pregnancy, and a growing number of couples are also using ART for the purpose of preimplantation genetic diagnosis to prevent the transmission of known genetic conditions to offspring.

The Ontario Health Insurance Plan (OHIP) initially covered all fertility treatments until 1994. In 1994, IVF was delisted from OHIP requiring individuals to pay out of pocket, apart from persons with bilateral tubal obstructions who remained covered under OHIP until 2015 (Ikonomidis and Dickens 1995). A cycle of IVF typically costs upwards of CAD$15,000 for treatment and medication, making cost a major barrier to access.

On July 24, 2014, the Ontario Legislature passed *The Building Opportunity and Securing Our Future Act* promising to expand fertility coverage (Sousa 2014). The goal was to increase access to fertility treatments to all Ontarians, regardless of gender, sexual orientation or ability to pay (McGuinty 2007). In keeping with these goals, the Ministry of Health and Long-Term Care (MOHLTC) launched the Ontario Fertility Program (OFP) on December 21, 2015 (Ontario MOHLTC 2015a). The OFP introduced $70 million of funding annually for fertility treatments including cycle monitoring with IUI and IVF (Ontario MOHLTC 2015b). The program is limited to 5,000 IVF cycles per year, with capped cycles per year allocated to each fertility clinic based on their historical demand (Ontario MOHLTC 2015a). However, historical demand was primarily based on patients accessing private IVF, and thus, the increase in demand observed for publicly funded IVF is much greater than the supply, resulting in long wait lists reported up to 1.5 years at the onset of the program (Blackwell 2016). The average wait time for publicly funded OFP in the 2017/2018 fiscal year was 12 months (personal communication, OFP Team 2019). Under the OFP, each person under the age of 43 with a uterus and a valid OHIP card is entitled to one funded cycle, regardless of gender, sexual orientation or presence of a medical diagnosis of infertility (Ontario MOHLTC 2015b). A person is entitled to an additional cycle of IVF if she is acting or has acted as a gestational carrier (Ontario MOHLTC 2015a). There continues to be an option for privately funded IVF with no age restriction, for patients able to afford it, which creates a two-tiered system. Physician consultations at fertility clinics have continued to be covered under OHIP with no restrictions.

At the time of data collection in 2016, there were 51 fertility clinics participating in the OFP: 18 received funding for IVF cycles, whereas the other 33 sites were provided with funding for IUI only. However, many of these non-IVF sites are associated with IVF clinics, and thus, patients from these non-IVF sites could be entered on their affiliated centre's IVF wait list. Currently, in 2019, there are 50 fertility clinics participating in the OFP, with

18 providing IVF (Ontario MOHLTC 2018a). With a limited number of publicly funded cycles available to each of the IVF clinics in Ontario, they have been required to determine their own strategies for resource allocation. No principles of prioritization were suggested by the MOHLTC, and there is no standardization across the province, except for prioritization of cancer patients for fertility preservation. To see a fertility specialist who performs IVF, patients must be referred by another physician and wait for a scheduled consultation before they will have the opportunity to be placed on the clinic's funded IVF wait list. Some clinics post information about their wait list process on their websites, but most patients must wait for their first consultation to learn the clinic's process. Individuals benefit differently based on the fertility clinic's allocation strategy, and most patients would not know which clinic is best suited for them or that discrepancies exist. For example, a younger patient would benefit from attending a clinic that prioritizes successful outcomes versus one that prioritizes women approaching the maximum age for funding under the OFP. Without knowing a clinic's allocation method, a patient cannot choose a clinic with their most advantageous outcome, and it is likely that their family physician is also not aware of these discrepancies between clinics.

When fertility clinics were surveyed in 2016, eight clinics reported using first come, first served, two using lottery and 11 using multiple factors, some of which favoured younger patients and some that favoured older patients, to determine publicly funded IVF allocation (Gotz and Jones 2017). In the 2017/2018 fiscal year, most clinics also reported using a first come, first served wait list policy, often with some additional clinical considerations (e.g., priority for patients requiring fertility preservation) (personal communication, OFP Team 2019).

Given the lack of transparency of IVF wait list prioritization and differing methods of prioritization at different fertility clinics, we hypothesized that patients would be motivated to attend multiple, different clinics to be placed on several waiting lists at the same time. When the OFP was announced, media outlets reported on people attending multiple consultations at different fertility clinics and placing their names on multiple wait lists, trying to maximize their chances of receiving funded IVF as quickly as possible (Zlomislic 2015). The goal of the study was to assess whether there was an increase in the number of multiple consultations per patient by different fertility specialists in Ontario, following the introduction of the OFP. This study aims to obtain relevant information for healthcare policy makers to improve the function of the OFP and inform development of similar programs in the future.

Methods

This was a retrospective observational study. Residents of Ontario who were eligible for OHIP from 2014 to 2016 were included in this analysis. Eligible subjects were women under the age of 43 receiving consultations for infertility in Ontario. Women are defined as individuals who identify as a woman on their Ontario health cards.

Fertility clinics were identified from the OFP's website, which listed all 51 participating clinics at the time. Fertility specialists were identified through a comprehensive search strategy. Fertility clinics' websites were reviewed to determine the names of practicing physicians at their site, regardless of speciality. When this information was not available online, individual clinics were called. Any physician who stated they were a fertility specialist with access to ART was included. Gynaecologic Reproductive Endocrinology and Infertility (GREI)-certified physicians were also identified through searching on the College of Physicians and Surgeons of Ontario (CPSO) online directory. CPSO numbers for all physicians identified through this comprehensive search were obtained from the CPSO.

Consultations by specialists who work at OFP-associated fertility clinics were ascertained by examining the OHIP physician billing claims for the identified physicians. Infertility consultations were identified as claims with a diagnosis code of 628 and a fee code of A205 (OBGYN consultation), A935 (OBGYN special surgical consultation), A135 (internal medicine consultation), A005 (family medicine consultation), A905 (family medicine limited consultation) and A285 (medical biochemistry consultation). These speciality codes were used in accordance with the specialists identified as providing fertility care.

The government announced the OFP implementation plans in October 2015 prior to its initiation on December 21, 2015. The data were analyzed, eliminating the October–December 2015 period when the OFP was introduced and implemented to avoid overestimating the results solely because of the hype of the OFP announcement. Thus, the total number of consultations for infertility by OFP-associated specialists and the average number of consultations by different specialists per patient were compared between January 1, 2016 and December 31, 2016 and the year prior, October 1, 2014 to September 30, 2015. Subgroup analyses of patients aged 40–42 and those living in the Greater Toronto Area (GTA) were performed for the same parameters.

Secondary outcomes were the per cent of repeat consultations over 180-day increments. In each quarter between April 2014 and December 2016, the number of women who had their first consultation was determined, and then, the proportion who had a second consultation with a different specialist within 180 days was assessed. A subgroup analysis looking specifically at women who live within the Toronto, Halton, Peel, York and Durham regions was performed to assess whether duplicate consultations were a phenomenon specific to the GTA.

A logistic regression model was performed looking for relationships between duplicate consults and the following factors: age, income, rurality of locale and pre- or post-OFP implementation period. Effect modification of GTA residence on duplicate consults pre- and post-OFP implementation was tested using an interaction term.

Approval for the study was obtained from the Sunnybrook Health Sciences Research Ethics Board.

Results

The comprehensive search resulted in 129 physicians identified as practicing GREI in Ontario with access to ART, of which 122 hold billing numbers. Table 1 demonstrates the average number of consultations pre- and post-OFP, and the proportion of duplicate consultations. There was an overall increase in total number of consults (24,565 vs. 27,714). Out of all women who had a consult, there was a statistically significant increase in the average number of consultations per patient (1.04 ± 0.21 vs. 1.05 ± 0.23, $p = 0.015$), and a statistically significant increase in the per cent of patients with more than one consultation (3.8 vs. 4.2%, $p = 0.027$). Pre-OFP, the absolute number of duplicate consultations was 933 out of a total of 24,565 consultations. Post-OFP, the absolute number of duplicate consultations was 1,164 out of a total of 27,714 consultations. If the 3.8% rate stayed constant, there would have only been 1,053 duplicate consults; thus, an extra 111 duplicate consults were performed. The absolute increase in duplicate consultations was 231.

TABLE 1. Assessment for duplicate consultation eliminating the announcement period and subgroup analysis

Subgroup	Period	Patients with consults*	Number of consults per patient†			Patients with multiple consults§		
			Mean	SD	*p*	Total number	%	*p*
All patients	Oct 2014–Sep 2015	24,565	1.04	0.21		935	3.8	
	Jan 2016–Dec 2016	27,714	1.05	0.23	0.015	1,160	4.2	0.027
Age 40–42	Oct 2014–Sep 2015	2,277	1.05	0.24		110	4.8	
	Jan 2016–Dec 2016	2,919	1.06	0.26	0.3	152	5.2	0.54
GTA	Oct 2014–Sep 2015	15,008	1.04	0.21		555	3.7	
	Jan 2016–Dec 2016	16,848	1.05	0.74	<0.0001	767	4.6	0.0001

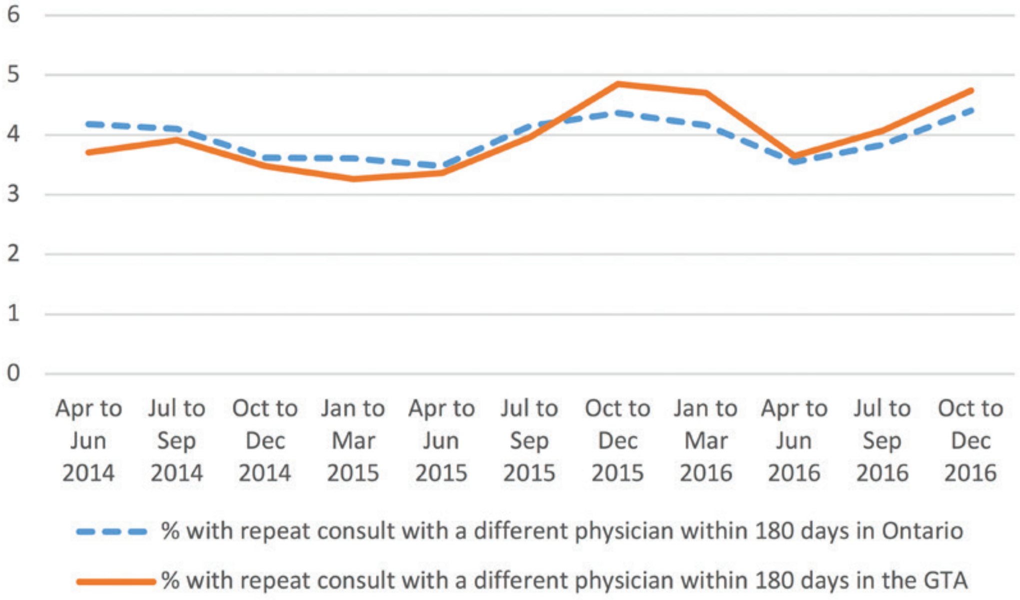
* Consults outside each period not counted. Patients can appear in both periods.

§,† Consults with different GREI physicians.

Subgroup analyses were performed for older age and GTA locale (Table 1). When looking at the 40–42 aged subgroup, there was an increase in overall number of consults, but no significant increase in the per cent of multiple consultations (4.8% vs. 5.2%, $p = 0.54$). Looking at the GTA subgroup, there was an increase in the overall number of consults and a significant increase in the per cent of multiple consultations (3.7% vs. 4.6%, $p = 0.0001$).

The number of patients who had a repeat consult 180 days after their first consult with a different physician was counted. Results were similar from April 2014 to December 2016 with minimal variability (Figure 1). The same 180-day increments were analyzed for individuals living in the GTA (Figure 1).

FIGURE 1. Repeat consultation rate (%) in 180-day increments



OFP implementation did not influence the likelihood of duplicate consultation after adjusting for age, income, rurality of residence and other factors (Table 2). However, GTA residence was a statistically significant effect modifier on this relationship (p = 0.0016). The odds ratio (OR) for duplicate consultation comparing pre- and post-OFP implementation was 1.102 (95% confidence interval = 0.926–1.312) for GTA residents and 0.942 (95% confidence interval = 0.873–1.016) for non-GTA residents. In 2016 there were a total of 10,866 consultations outside the GTA, out of 7,520,454 residents (0.14%). In comparison, there were a total of 16,848 consults in the GTA, out of 5,928,040 residents (0.28%) (Statistics Canada 2016).

Discussion

Funding IVF in Ontario allows for more equitable access to IVF services for people in Ontario. A US study showed that state-mandated insurance coverage for IVF resulted in a threefold increase in IVF utilization compared with states without insurance coverage (Jain et al. 2002). This suggests that in states without coverage, there may be a large number of people who would seek IVF if financial barriers were not present (Jain and Hornstein 2005). Compared with countries where IVF is subsidized, the US has much lower rates of IVF utilization, reflecting that cost is a barrier to access, and when this is eliminated, the actual need is demonstrated (Jain and Hornstein 2005). Similarly, when IVF funding was brought into effect in Quebec in 2010, the number of new consultations for secondary infertility treatment doubled from 14% to 29% immediately post-policy change and remained similar at 8 months at 30%. This could indicate that the availability of funding

TABLE 2. Factors associated with duplicate consultations

		N	%	OR	LCL	UCL
Age	<= 29	8,875	19.4%	Ref		
	30–34	16,344	35.7%	1.287	1.110	1.491
	35–39	15,137	33.1%	1.445	1.247	1.675
	40–43	5,436	11.9%	1.621	1.358	1.935
Income	Lowest	7,823	17.1%	Ref		
	2nd	8,676	18.9%	0.965	0.820	1.135
	Mid	9,254	20.2%	1.029	0.879	1.205
	4th	10,765	23.5%	0.937	0.802	1.095
	Highest	9,030	19.7%	1.172	1.004	1.368
	Missing	244	0.5%	1.143	0.566	2.307
Rurality	Urban	38,701	84.5%	Ref		
	Semi-urban	5,380	11.7%	1.135	0.981	1.312
	Rural	1,537	3.4%	1.147	0.886	1.486
	Missing	174	0.4%	1.187	0.525	2.686
Time period	Pre	22,594	49.3%	Ref		
	Post	23,198	50.7%	1.073	0.975	1.180

LCL – lower confidence limit
UCL – upper confidence limit

encouraged patients to seek ART (Tulandi et al. 2013). The increase in demand was so great that the Quebec provincial budget went over estimates by CA$40 million, resulting in discontinuation of the program in 2015 (Hendry 2015). In general, women who utilize ART are more likely to be older, richer, more educated and white (Tulandi et al. 2013). After the Quebec policy change, there were more patients with incomes below the Canadian median (CA$65,000) (47.4% vs. 36.7%, $p = 0.02$) and more likely to be unemployed (11.6% vs. 3.6%, $p < 0.001$). Thus, there is evidence that public funding may increase equitable distribution of ART and work towards minimizing barriers such as cost.

By introducing the OFP, the goal was to increase access to IVF for people in Ontario, rather than to promote population growth: "Ontario is committed to supporting people who are trying to start or expand a family by making IVF treatments more accessible regardless of sex, gender, sexual orientation or family status. Women under the age of 43 will be eligible for IVF funding, if a healthcare provider determines this is the most appropriate family-building option for them" (Ontario MOHLTC 2015b). Thus, an explicit goal of this funding program was to expand access to fertility care. After introduction of the OFP, we saw an increase in the number of annual consultations for infertility pre- versus post-OFP implementation (24,565 vs. 27,714, respectively). This suggests that by introducing publicly funded IVF, more people were seeking care for infertility, as patients who previously could not afford IVF could now consider it as an option. The increase in demand can affect access, as there will be increased strain on the system resulting in longer wait times and delays to accessing care. With any change in health policy, there can be unintended negative consequences. Physicians and health administrators were concerned that there would be an increase in the number of duplicate consultations with the introduction of the OFP as an attempt by individuals to obtain IVF as soon as possible, especially among older women attempting to access a funded IVF cycle before the 43-year-old age cut-off. The heterogeneous prioritization methods among fertility clinics are relevant for all patients, but particularly for those who run the risk of aging above the thresholds set for funding eligibility. Author AA reviewed all available clinic websites at the time of publication, and only one clinic publicized their prioritization strategies, which was first come, first served. Thus, for the vast majority of clinics, patients would be unsure of their likelihood of accessing a funded IVF cycle within a specific time frame.

There was a small but statistically significant increase in the rate of duplicate consultations. Although it is unlikely to be clinically relevant, the MOHLTC should consider the cost of duplicate consultations and the associated extra costs, such as repeated diagnostic tests, in the annual budget calculations.

There are many possible hypotheses why a large increase in duplicate consultations did not occur. There is a lack of published data on reasons for lack of duplicate consultations in a publicly funded healthcare program. Thus, the authors have developed proposed theories discussed here. The process by which patients were placed on a funded IVF cycle wait list may have been confusing for patients and family physicians to navigate, and it is possible that a greater increase in duplicate consults was not seen because patients were not aware that they could request multiple consultations at different clinics and that there were different criteria for prioritizing patients at different clinics. Patients may have been generally trusting in the healthcare system to have a fair process. When questioned, patients assumed funds were distributed by a centralized, standardized process and felt the allocation process was not transparent (Assal et al. 2019, manuscript submitted). It is also possible that fertility specialists declined consultations from patients who were already seen at another fertility clinic or that family physicians were not willing to send patients to multiple different doctors for the same medical problem, and thus were acting as good gatekeepers of our medical system whether they had intended to or not. We also speculate that patients may have heard from word of mouth that the wait lists at all fertility clinics were similar and that there would be no advantage to taking the time to attend multiple different clinics. This may be because of a well-distributed number of funded IVF cycle allotments at each fertility clinic, making each clinic's wait list short enough for patients to be satisfied with. A further understanding of the study findings is a future research goal.

Subgroup analyses of women aged 40–42 demonstrated that women in this age group were already at a higher likelihood of receiving multiple consultations. The introduction of the OFP did not affect the rate of duplicate consultations in this group, although this study may have been underpowered to detect a difference in this age group. One would expect that this group of women would be the most likely to seek out duplicate consultations, as they are more likely to age out of eligibility for a funded IVF cycle. The lack of statistical significance may reflect short enough wait times for patients desiring an OFP-funded IVF cycle at fertility clinics, making it not worthwhile to take the time to seek out multiple fertility consultations, or the fact that the wait lists were too long at all clinics for some of these women to be eligible for a funded IVF cycle at any clinic before aging out of the system. Although the wait time was in months to years, this is typical in the Canadian healthcare system. For example, 2018 data from the MOHLTC indicate that the average wait time for a hip replacement in Ontario is 253 days (MOHLTC 2018b). Thus, the wait time for IVF may have been more readily acceptable to patients.

The OFP had a greater impact on the rate of duplicate consultations in the GTA compared with outside the GTA. This is likely because of the higher concentration of fertility clinics in this region making it more accessible to seek out multiple consultations: currently within the GTA, there are 34 fertility clinics, 14 of which provide IVF (MOHLTC 2018a). Outside the GTA, there are currently 16 fertility clinics, four of which provide IVF (MOHLTC 2018b); these four clinics are in London, Burlington, Ottawa and Kingston. There are no fertility clinics offering funded IVF in Northern Ontario, and thus, patients from Northern Ontario typically travel far to access these services in the GTA, demonstrating the inequitable access to IVF services based on geographical location. Thus, people living in the GTA have a greater opportunity to obtain consultations at different clinics. In this study, the greater proportion of consultations seen in the GTA (0.28%) compared with that outside the GTA (0.14%) further demonstrates the inequality of care.

The strengths of this study include taking advantage of a natural experiment caused by a policy change and observing the effects in the population. The use of population-based data allows for complete data and no loss to follow-up. The methods used in this study are subject to certain limitations. People already being followed by a fertility clinic and then seeking a new consultation would not be captured as a duplicate if the initial consultation was prior to October 2014. In addition, if a different diagnostic or billing code was utilized, it would not be captured in this analysis. However, the decision to limit the analysis to consultation billing codes only for infertility was chosen to increase specificity and avoid including women who were not being seen for IVF and could be viewed as a strength of this study. Similarly, there may be fertility physicians who were missed, and thus, their consultation data would be missing. Furthermore, this analysis was limited to female consultations, as the majority of patients seeking IVF are female. However, same-sex male couples seeking fertility consultations for IVF using a donor egg and a gestational carrier would be missed, as these consults are paid for privately by the couple, as well as female-to-male transgender individuals for whom the health card status was designated as male, although this is a small proportion of patients seeking IVF services and likely would not affect overall findings of the study.

Having a centralized system to process IVF funding for patients seems substantively fair, and we hypothesized that it would result in cost savings by eliminating duplicate consultations. However, the data do not support this theory, as the increase in duplicate consultations was not clinically relevant, nor did it result in substantial increased costs to OHIP. Since the data were obtained for this study, wait lists have begun to shorten at individual fertility clinics, averaging one year in Ontario, and more clinics have been moving to a first come, first served model, making the differentiators between clinics less relevant over time (personal communication, OFP Team 2019). This study prompted the researchers to next examine the patients' perspectives on what factors should be considered important in deciding who should receive publicly funded fertility treatments to help guide the MOHLTC and fertility physicians on how to best allocate the limited funded IVF cycles in Ontario in the future.

Conclusion

The OFP introduced publicly funded IVF to a limited number of Ontarians per year with a goal of increasing access to fertility treatments for Ontarians. There is a lack of transparency and standardization of allocation of fertility funding across the province of Ontario. After introduction of the OFP, an increase in overall number of infertility consultations was observed together with a modest increase in OHIP duplicate consultation costs, which was lower than expected in response to the introduction of the OFP. The lack of duplicate consultations outside the GTA may reflect the lack of fertility clinics in these regions, highlighting the need for fertility clinics outside the GTA to provide equitable access to Ontarians.

The results of this study are relevant to healthcare policy makers. When developing similar programs introducing public funding for non—OHIP-covered services, an increase in total number of physician consultations to access the service should be expected. However, the cost of duplicate consultations would not be as high as anticipated, as demonstrated in this study.

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