HEALTHCARE

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

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Dummheit

ROBERT G. EVANS

Towards Reconciliation of Several Dualities in Physician Leadership ANURAG SAXENA, KEITH WALKER AND GERRY KRAINES

Barriers and Facilitators to Family Planning Access in Canada JENNIFER HULME ET AL.

Use of Compassionate Supply of Antiretroviral Drugs to Avoid Treatment Interruptions or Delayed Treatment Initiation among HIV-Positive Patients Living in Ontario: A Retrospective Review DEBORAH YOONG ET AL.

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

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

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

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

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

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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Healthcare Transformation and the Need for Courageous Leadership

or Yes Minister's Sir Humphrey Appleby, "courageous" was the most ■ damning way of describing a proposed course of action ("controversial" only means that you will lose votes; "courageous" means you will lose the election, he explains to Bernard Woolley in an early episode of the show). Telling Jim Hacker that a plan was courageous was a sure way to get it dropped, whether or not the proposal was in the public interest.

The rooms and corridors in which Canadian health policy is formed are a long way from the setting of the humorous television show, but tests of courage, small and large, abound. I recently had the privilege of participating in a Canadian College of Health Leaders/Institute for Health Policy, Management, and Evaluation panel on leadership for healthcare integration. Panelists held leadership roles in different parts of the health system and were at different points in their careers, but all agreed that individual and collective courage on the part of leaders was essential for achieving meaningful health sector transformation.

This insight is neither unique to the panel nor to healthcare. For example, Warren Bennis and Robert Thomas (2002) compared the leadership styles of Generation X and Y with those of their grandparents' generation. They found that successful leaders of both eras were able to adapt to unforeseen circumstances and overcome obstacles, an ability that was put to the test early in their careers through an intense "crucible" experience involving adversity that tested their values and perseverance. These turning points forced individuals young and old to decide who they are and what they are capable of.

It takes courage to venture into the unknown. And it takes courage to work towards ambitious goals for healthcare transformation, building coalitions for change and persevering in spite of challenges that arise. Good research can help to bolster courage. For example, better information can make it possible to reach a little further or with more confidence. It can focus attention, clarify context, decrease unknowns, spread knowledge of best practices and blind alleys and suggest effective approaches to change.

The articles in this issue of Healthcare Policy/Politiques de santé tackle challenging policy questions and leadership challenges. Their focus ranges from issues highlighted by recent measles outbreaks to questions about access to family planning services, quality of physiotherapy for injured workers and use of antiretroviral medications by individuals who are HIV-positive. In all cases, the issues involved are complex. There is no one contributing factor. Neither is there a single, quick, simple solution. It is these complexities which the authors address, shining light on the issues involved and bringing new knowledge to inform policy options.

Courage is also an appropriate theme for this issue because in it we provide tribute to Pat Martens. Pat was a leading health services and population health researcher, a compelling communicator and a generous contributor to our community, including serving as an editor for Healthcare Policy/Politiques de santé. She asked important and challenging research questions, forged new frontiers by engaging a broad range of partners in creating and using knowledge and continued to devote her time to protecting the health of others even after she was diagnosed with mesothelioma. Speaking personally, I am very grateful to have known and learned from Pat. I, along with so many others, miss her greatly.

> JENNIFER ZELMER, PHD Editor-in-chief

Reference

Bennis, W.G. and R.J. Thomas. 2002. Geeks and Geezers: How Era, Values and Defining Moments Shape Leaders. Boston, MA: Harvard Business Review Press.

Besoin d'un leadership de courage pour la transformation des services de santé

our le personnage de Sir Humphrey Appleby, dans la série Yes Minister, le mot « courageux » était une des pires façons de décrire un plan d'action (« controversé » signifie qu'on va perdre des votes; « courageux » signifie qu'on va perdre l'élection, explique-t-il à Bernard Woolley dans un des épisodes). Dire à Jim Hacker qu'un plan était courageux équivalait à abandonner l'idée, qu'elle soit ou non d'intérêt public.

Les chambres et les corridors où s'élaborent les politiques de santé au Canada sont bien loin des décors de la série humoristique, mais les leçons de courage y abondent. J'ai récemment eu le privilège de participer à un panel sur le leadership pour l'intégration des soins de santé, organisé de concert par le Collège canadien des leaders en santé et l'Institut de politique, gestion et évaluation en santé. Les panélistes occupaient des postes de leaders dans divers secteurs du système de santé et en étaient à différentes étapes de leur carrière, mais tous et toutes étaient d'accord pour dire que le courage des leaders, qu'il soit individuel ou collectif, est essentiel pour mener à bien les transformations dans le milieu de la santé.

Cette idée n'est pas exclusive au panel ou aux services de santé. Par exemple, Warren Bennis et Robert Thomas (2002) ont comparé le style de leadership des générations X et Y avec celui des générations de leurs grands-parents. Ils ont découvert que les leaders des deux périodes étaient capables de s'adapter aux circonstances imprévues et de surmonter les obstacles, une aptitude vérifiée tôt dans leur carrière par une vive expérience mêlée d'adversité, où les valeurs et la persévérance sont mises à l'épreuve. Ce point tournant force les personnes, jeunes et vieilles, à consolider leur identité et à reconnaître leurs aptitudes.

Il faut du courage pour s'aventurer dans l'inconnu. Et il faut du courage pour s'attaquer à des objectifs ambitieux visant la transformation des services de santé, pour former des coalitions en vue du changement, pour persévérer malgré les défis qui se présentent. La recherche peut aider à donner du courage. Par exemple, une bonne information peut permettre d'aller un peu plus loin en toute confiance. Elle permet de circonscrire l'attention, de clarifier le contexte, de réduire l'inconnu, de répandre les connaissances des pratiques exemplaires ou des avenues sans issues et de proposer des démarches efficaces pour le changement.

Les articles du présent numéro de Politiques de Santé/Healthcare Policy s'attaquent à d'ambitieuses questions politiques et à des défis de leadership. Ils portent sur plusieurs sujets, allant d'enjeux révélés par la récente éclosion de rougeole aux questions d'accès pour les services de planification familiale, à la qualité des services de physiothérapie pour les travailleurs

et à l'utilisation des médicaments antirétroviraux par les séropositifs. Dans tous ces cas, les questions sont complexes. Il n'y a pas qu'un seul facteur en jeu. Pas plus qu'il n'y a qu'une seule solution simple et rapide. C'est sur cette complexité que les auteurs se penchent, tentant d'éclaircir les enjeux et d'apporter de nouvelles connaissances pour appuyer les politiques.

Le courage est aussi un thème approprié pour ce numéro, où l'on rend un dernier hommage à Pat Martens. Pat était une chercheuse de pointe qui vouait son travail aux services de santé et à la santé de la population. C'était une communicatrice chevronnée qui apportait beaucoup à la communauté, notamment à titre de rédactrice pour Politiques de Santé/ Healthcare Policy. Elle a su poser d'importantes question de recherche, elle a repoussé les limites en réunissant une vaste gamme de partenaires pour créer et utiliser les connaissances et elle a continué de consacrer son temps à la protection de la santé des autres, et ce, même après qu'on lui ait diagnostiqué un mésothéliome. Personnellement, je me sens privilégiée de l'avoir connue et d'avoir appris auprès d'elle. Pat me manque beaucoup, comme elle manque à plusieurs autres personnes.

> JENNIFER ZELMER, PHD Rédactrice en chef

Référence

Bennis, W.G. et R.J. Thomas. 2002. Geeks and Geezers: How Era, Values and Defining Moments Shape Leaders. Boston, MA: Harvard Business Review Press.

Researcher Patricia Martens Turned Dry Data into Stories*

Ann Silversides

about health research manifested itself in different ways throughout her life. She believed strongly in the power of such data to point to ways of improving health and reducing inequality.

A gifted and enthusiastic teacher, skilled academic and widely admired administrator, she served as the director of the Manitoba Centre for Health Policy (MCHP) from 2004 to 2014.

When she was diagnosed with mesothelioma, an aggressive form of cancer usually caused by exposure to asbestos, she recognized the opportunity to speak up and support the campaign to have Canada join other developed countries in banning asbestos. She sent a letter urging Prime Minister Stephen Harper to acknowledge that all forms of asbestos are hazardous to human health, though she only received a polite form letter in reply, her husband, Gary Martens, recalls.

Ever the curious researcher, she told local media soon after her diagnosis, "I want to try to understand this cancer-care journey, so this gives me an opportunity to put on my scientific hat and say, 'How could we do this a little better?"

Focusing on her work kept her from dwelling on what she called the "yucky things" about her disease.

Patricia Martens died at the age of 62 on Jan. 10. "It is surely a tragic irony that someone who was such a proponent for public health would die from this illness," said David Henry, a Toronto academic, research scientist and friend of Dr. Martens.

Dr. Martens's first career was as a high school chemistry and mathematics teacher in Winnipeg. In 1978, however, she moved with her husband, Gary Martens, to work a farm in rural Manitoba. She returned to university when both her children were in school.

Consequently, she entered the research world late – she was 47 in 1999 when she was awarded her PhD in health sciences at the University of Manitoba. Though her academic career was relatively short, by the time of her death, Dr. Martens had presented at more than

^{*}Reprinted with permission from Ann Silversides, independent journalist, and The Globe and Mail. Available at: www.theglobeandmail.com/life/health-and-fitness/health/researcher-patricia-martens-turned-dry-data-into-stories/article22974112/

400 conferences and published more than 300 articles, reports, book chapters and abstracts. She became a fellow of the Royal Society of Canada and of the Canadian Academy of Health Sciences.

Dr. Martens was also admitted to the Order of Canada in 2013, received the R.D. Defries Award (the highest award from the Canadian Public Health Association) and was named the 2014 Justice Emmett Hall Laureate for contributions to health research.

Dr. Martens was famous in health policy circles for her lively and humorous presentations, often involving the use of unusual props.

She would distribute licorice sticks, for example, to help non-statisticians grasp the significance of the Lorenz curve, a graphical representation of income-related inequality. The more the curve sags, the greater the inequality. Dr. Martens would have audience members bend their licorice to mirror the curve on the slide of a graph she projected - a curve that revealed, in one instance, that rates of suicide (and suicide attempts) in Manitoba were much higher for people in the 20-per-cent-lowest-income category. This curve, she noted, suggested the need for targeted interventions. In contrast, an almost-straight line on another graph revealed that among people over 55, dementia affects all income groups in Manitoba almost equally, suggesting the need for universal interventions.

Dr. Martens also liked to show snapshots of a variety of deer-crossing road signs, to prompt reflection on whether deer actually look different in different provinces and countries, and to stress the importance of investigation and context.

Most memorable, however, was her trademark "squish and shift" gesture, in which she clasped her hands and raised her arms to form a triangle. She used this gesture to help audiences understand the significance of changing the position and shape of a bell curve representing the distribution of a particular health or social indicator in a population.

If the whole curve could be shifted in a positive direction (she would maintain the triangle proportions but shift her arms to the side) the overall population health gains could be significant, but the gap between the least and most healthy (the tails of the curve) would remain the same. Next, she would demonstrate the "squish" (she would bring her elbows closer together) to explain the importance of a targeted effort to reduce inequality by improving the condition of those who were least healthy.

"She was not as staid as some of her academic peers," her husband, a retired University of Manitoba lecturer, wryly observes. (He abandoned full-time farming in 1996 and began commuting to Winnipeg with his wife.)

"Pat could take dry data, tables and graphs and make an engaging and compelling story," says Brian Postl, dean of health sciences at the University of Manitoba. "And she was so credible - anyone working with large data sets recognizes this."

She was a giant in her field as well as being remarkably selfless and generous, Dr. Henry added. He credits her with providing invaluable advice and guidance to him when he arrived from Australia in 2007 to become president of the Toronto-based Institute for Clinical Evaluative Sciences, a health research centre similar to the one Dr. Martens headed in Manitoba.

Yet asked what challenges Dr. Martens faced in her life, her husband said she would sometimes lament that women had trouble in high-level leadership roles. "She sometimes thought she was not taken seriously enough."

Dr. Martens was born in Calgary on Jan. 25, 1952, the middle child of three. Her father, Howard, was an insurance salesman whose job saw the family move cities every five years or so. Her mother, Hazel, was a homemaker while raising the children and later worked in libraries.

Dr. Martens met Gary Martens when both of them were studying chemistry at the University of Manitoba. They married in 1974. She went on to become a teacher at St. Mary's Academy, a private girls' school in Winnipeg, while her husband took a job at a soil lab. But he yearned to be near the family farm, where he had grown up with his Mennonite parents. "Pat had always lived in cities and it took a year to convince her to move," he said.

The couple bought and also rented farmland near Kleefeld, about 60 kilometres south of Winnipeg, and they worked as much as 640 acres.

Dr. Martens settled in quickly. She created her own community with other young mothers, became active in the local Mennonite church, assumed the role of farm bookkeeper, kept a large garden and took meals out to the field.

The couple had two large trucks, and Gary remembers them driving loads of oats to Winnipeg in tandem – he in one truck with their five-year-old son, John, and Pat in the other with Rebecca, their infant daughter.

Before returning to university, Dr. Martens became active with La Leche League, which promotes breastfeeding. For her master's degree, she studied the barriers that helped explain the low (40 per cent) breastfeeding rate among Sagkeeng First Nations women. For her PhD thesis, she designed an intervention – her key innovation was the training of peer counsellors – that resulted in an increase (to 70 per cent) of breastfeeding rates among the women. Rates of low birth weight and premature births also dropped.

As director of the MCHP, Dr. Martens launched new programs of collaborative research. For example, she convened a Need to Know team, composed of two planners from each regional health authority in Manitoba, MCHP academics and staff from the province's health ministry. They developed reports on subjects such as healthcare utilization and mental health. (The team won a Canadian Institutes of Health Research Knowledge Translation Award for regional impact.)

Dr. Martens's personality was key to the success of her initiatives, maintains Monique Vielfaure Mackenzie, executive director of Regional Health Authorities of Manitoba. "She had a knack for making whoever she spoke with feel like the only person in the room. You just felt comfortable with her. She was never intimidating, despite all her accomplishments."

Researcher Patricia Martens Turned Dry Data into Stories

Dr. Martens died at her farm home, almost two years after she received her diagnosis of mesothelioma. She had continued to work and participate, as much as possible, in the activities of the MCHP until weeks before her death.

Dr. Martens once told a local reporter she was "a bit of scattered research scientist who also loves to be a farm lady and work in a church and do the local community stuff."

Patricia Martens leaves her husband, Gary; children, John and Rebecca; grandchildren, Charlotte and Alexander; and extended family.

Dummheit

Stupidité

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"Mit der Dummheit kämpfen Götter selbst vergebens." – Friedrich Schiller (Against stupidity, the gods themselves struggle in vain.)

Abstract

Immunizing against influenza is tricky; against measles is not. Influenza comes in many constantly evolving strains, but one measles shot in childhood confers lifelong immunity. Unlike the flu, measles was wiped out. Its return represents an outbreak not of disease, but of stupidity. The matrix of stupidity is, however, reinforced by strong strands of malice, as when Andrew Wakefield's fraudulent 1998 paper linked the MMR vaccine to autism. The fraud was unmasked and the vaccine—autism link disproven, but the evil influence continues.

Measles offers an illustration of Virchow's insights that medicine is a social science and that politics is medicine writ large. It is this "inconvenient truth" that is being suppressed by muzzling the Chief Public Health Officer (CPHO) and attacking public health for addressing "social determinants."

Résumé

L'immunisation contre la grippe peut être compliquée, mais contre la rougeole, ça ne l'est pas. Les souches de la grippe sont en continuel changement, alors qu'une injection contre la rougeole pendant l'enfance protège pour la vie. Contrairement à la grippe, la rougeole avait été éradiquée. Son retour représente une éclosion, non pas de maladie, mais de stupidité. Le creuset de la stupidité est toutefois renforcé par une forte malveillance. L'article frauduleux d'Andrew Wakefield établissait, en 1998, un lien entre le vaccin ROR et l'autisme. La fraude fut démasquée et le lien entre le vaccin et l'autisme totalement réfuté, mais les mauvaises influences poursuivent leur chemin.

La rougeole est un excellent exemple de l'idée de Virchow voulant que la médecine soit une science sociale et que la politique soit une médecine pratiquée à grande échelle. C'est cette « vérité dérangeante » qu'on supprime en bâillonnant de l'administrateur en chef de la santé publique (ACSP) et en accusant la santé publique de s'intéresser au « déterminants sociaux »

de la santé.

are having a bad flu season in British Columbia. Now a team of researchers headed by Dr. Danuta Skowronski at the BC Centre for Disease Control has confirmed medical suspicion that this year's flu vaccine is working very poorly, if at all. Many of us are getting our shots, and then getting the flu as well. Predictably, "this season's dismal results are prompting many Canadians to question why we even need an influenza-immunization program" (Weeks 2015a).

Such questions completely miss the point of this year's experience. Flu rates are unusually high because in most years, they are significantly lower. When the dominant influenza strain is one against which the offered vaccine is more effective, the vaccination program works. Developing the right vaccine for a constantly moving virus target is always a challenge, but most years the effectiveness rate is about 60%.

The BC study raises some genuine scientific questions. Recent advances are "allowing researchers to develop ... a much deeper understanding of the true benefits and limits of the current flu vaccine" (Weeks 2015a). Such an understanding could provide a basis for more effective, and perhaps more cost-effective, anti-flu campaigns in the future. Science advances.

But ignorance does not. Most of those who refuse the flu shot have based their opposition not on a sophisticated assessment of the benefits and limits of current vaccines for different demographic groups, but on some form of scientific nihilism – bizarre personal beliefs as to how the world works. Their opposition long predates this year's rather disappointing results, or the just-released study from the BC Centre for Disease Control. The leadership of the BC Nurses' Union, for example, which championed its members' right to refuse immunization while continuing to work in hospitals and long-term care institutions, was acting not on professional principle, drawing on up-to-date scientific knowledge, but on plain old dummheit. They were, in effect, asserting a right to bring in the flu virus and put vulnerable patients at risk. Some nurses, as well as other health professionals, were appalled.

Arguments about compulsory medication and constitutional rights are equally beside the point. There is a sign in the Vancouver airport that reads, more or less, "You are under no obligation to submit your person or property to inspection. You can always choose not to board the aircraft." A passenger's right to privacy does not trump the security interests of other passengers and the crew. One might have thought it obvious that institutionalized patients had a similar right not to be unnecessarily exposed to dangerous infections. (Security of the person, eh?) Apparently not. (Hand sanitizers, for voluntary use, are no doubt worthy in intent. But they have the air of a TSG – tiny symbolic gesture.)

One should not overestimate the extent of anti-flu shot sentiment. I suspect that most of the population – us – are quite capable of understanding that the flu virus is a complex beast, and that vaccines have to be developed before the flu season on the basis of advance bets as to what this year's threats will be and what will offer the best defence. Sometimes, as this year,

the bug wins. But more often it does not. And most of us, particularly those old enough to remember the really debilitating flus of 40 years ago, will get our shots next year. A real influenza is no mere heavy cold. It can be fatal, particularly among the elderly, and it is seriously miserable, with prolonged after-effects, even among the young and healthy.

But the political and ideological climate surrounding immunization, and the instant media amplification of protest, make it hard to imagine any cool, laboratory-based, scientific rethink of immunization policy. There is always more to learn, particularly when things do not work out as planned. But for now, get the shot.

And get it because, as again everyone understands, you are doing it for me as well as for you. "Herd immunity" – which occurs when the proportion of the population immunized is sufficient that the infective agent cannot spread – protects those who were too thoughtless or too stupid to protect themselves. It also protects those who, for sound medical reasons, cannot safely be vaccinated. Immunization is a classic example of what economists call a "positive externality" in which your behaviour confers benefits on me, and vice versa. Conversely, your failure to get the shot is a form of "free riding" in which you are relying on me to take steps that will benefit you. It is a standard demonstration in intermediate economic theory that commodities with positive externalities will be underprovided in a free-market society of purely selfish individuals. A little concern for others – or, if that fails, public regulation, subsidy, or both – can make everyone better off.

At time of writing (early February 2015), the issue of inadequate immunization suddenly exploded in the media discourse. A recent high-profile outbreak of measles in Disneyland Park in California – "the Happiest Place on Earth" – has presumably stimulated much of the excitement. This occurrence may be fortuitous in drawing extraordinary attention to a larger underlying problem: the recent decline in rates of immunization against a wide range of oncecommon childhood diseases.

Measles vaccination is a major public health success story. Prior to the development of a safe and effective vaccine in 1963, measles cases in the United States were averaging about 400,000 per year ("Of Vaccines and Vacuous Starlets" 2015). Within less than a decade, that number had fallen to under 100 annually. The disease was effectively wiped out, and remained so until 2012. Over the last two years, however, the number of reported cases began to rise sharply. In 2014 there were 644; in the first month of 2015 there were 100 more.

Of course, that is in the "Excited States," where all manner of weirdness is endemic. Fortunately, that could not happen in calm and sensible Canada, right? Alas.

A year ago, for example, there was a measles outbreak in the Fraser Valley, British Columbia, traced to the Mount Cheam Christian School (Maki 2014). The school's spiritual guide apparently discourages vaccination because childhood illness is "God's will." (One might ask how many of the children's mothers were advised to give birth squatting under a bush while prayers were intoned?)

The fundamentalist Christian dimension is not incidental: "The cases in Chilliwack have

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some resemblance to November's measles outbreak in southern Alberta A student at the Coaldale Christian School who had been to the Netherlands contracted measles and set off the chain reaction" (Maki 2014).

Picard (2015) notes that "there were significant outbreaks of measles in five Canadian provinces last year. They were much worse than the Disneyland outbreak."

There is no mystery behind these outbreaks, or the rapidly rising overall rates of infection. Unlike influenza, the measles virus is not a moving target with multiple varieties, constantly evolving. There is no challenge in determining from year to year which of a number of strains the vaccine should address. And vaccination in childhood confers lifelong immunity; there is no need to reach the whole population each year. So rising measles rates are a simple and natural consequence of parents' failure to have their children immunized. We are witnessing a new epidemic – of *dummheit*.

Measles is the bellwether for a range of childhood diseases that, while typically relatively benign (been there, done that), can in some cases turn very nasty indeed. Falling immunization rates are not a trivial issue, and the extensive media coverage is a good sign. But "Why here? Why now?" And what to do about the situation?

Picard (2015) has a vigorous response to the last question: make vaccination mandatory, or at least difficult for parents to avoid. After all,

[0]nly about 2 per cent of parents are intractably against vaccinations – an oddball group of conspiracy theorists and religious zealots. ... Do we have an inalienable right to catch and spread infectious diseases? Of course not. ... Better a little coercion than a dead child.

Renzetti (2014) is equally forthright:

... we need more of a good old kick in the pants [for the anti-vaxxers]. If we penalize people for other behaviour that's harmful to the public good – smoking in bars, not using car seats – then why would we not fine them for refusing to vaccinate their children? Under the law, you are not allowed to physically abuse your children – why should you be allowed to willfully expose them and others to easily prevented harm?

The Economist reinforces Renzetti's dismissive description of anti-vaxxers as encouraged and promoted by "[a] gaggle of B-list celebrities such as Jenny McCarthy ..., a former Playboy model and anti-vaccination megaphone" The article includes an emotive photograph of Ms. McCarthy, mouth open wide, captioned: "Playmate, actress, epidemiologist" ("Of Vaccines" 2015).

But Schiller gives us a warning. Just because we are dealing with obvious and self-evident dummheit does not mean that the problem can be resolved by earnest efforts at better educa-

tion and communication. As suggested by the measles outbreaks in the Christian schools in Alberta and British Columbia, opposition to vaccination can be part of religious belief, notably impervious to fact or argument. But the "rapidly growing group of skeptics, parents with a hodgepodge of doubts and fears, real or imagined" (Picard 2015) appears to have become a cult in themselves, independent of any formal religion. The sudden and rapid rise in measles cases in the United States reflects this rapid growth, and the new social media, providing closed communities for pathological internal hypercommunication, lend themselves to cult formation and promotion.

Cultists also tend to be quite skillful in evading public authority. As Picard (2015) notes:

The United States actually has some of the strictest mandatory childhood vaccination rules in the world. But many states also have "religious" and "personal belief" exemptions that allow parents to opt out.

The persistence and spread of dummheit has a further aspect – malice. Like the toughness of a composite material – consider fibreglass – cult beliefs depend on strands of malice binding together and strengthening a matrix of ignorance and gullibility. Cult leaders are often well aware that they are promulgating nonsense, and that it pays. Here the notorious Andrew Wakefield enters the story.

Andrew Wakefield is a British former physician and medical researcher who in 1998 published a paper in *The Lancet* making the now-discredited claim that there is a link between the measles-mumps-rubella (MMR) vaccine and the development of autism ("Wakefield's Article Linking MMR Vaccine and Autism Was Fraudulent" 2011).

The word "fraudulent" is of central significance. It means that Wakefield's work is not simply a focus of scientific disagreement or controversy, but represents deliberate malfeasance – a conscious attempt to mislead (the lawyers' *mens rea*). Secondly, it opens an obvious door to an action for libel. British law is particularly supportive of libel actions, and a successful suit can be very lucrative for the plaintiff. (Liberace famously remarked about the personal hurt he suffered from being libelled: "I cried – all the way to the bank.") But there is one sure defence: proof that the alleged libel is in fact true.

Wakefield has yet to succeed at law; his latest effort was a defamation suit filed in January 2012 in Travis County, Texas. The defendants, like Wakefield himself, were all British nationals or organizations, but he may have hoped for a more sympathetic hearing (he requested a jury trial) in the American South. If so, the stratagem failed. In August 2012, District Court Judge Amy Meachum dismissed his suit and ordered him to pay the defendants' costs as well as his own (Dyer 2012). Her ruling was upheld on appeal.

But this is only a recent episode in a long and sordid tale that has unfolded since 1998. Wakefield's results, as reported in *The Lancet*, have never been reproduced. A 2004 investigation by *Sunday Times* reporter Brian Deer identified "undisclosed payments" to Wakefield indicating financial conflicts of interest on Wakefield's part. A 2010 inquiry by the British

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General Medical Council into allegations of misconduct found him guilty on three dozen charges, including dishonesty and irresponsibility in his published research. *The Lancet* immediately retracted his 1998 publication ("Retraction" 2010), noting that some of its claims had been proven false. *The Lancet's* editor-in-chief, Richard Horton, said he felt the journal had been "deceived" (Bosley 2010). Wakefield was subsequently struck off the medical register and is barred from practising medicine in the United Kingdom.

The "undisclosed payments" (Deer 2004) were fees paid to Wakefield, amounting to nearly half a million pounds, under a contract with a firm of solicitors trying to build a case against the manufacturer of the MMR vaccine. This relationship, unknown to his co-authors, had begun two years before the publication of the fraudulent *Lancet* article. Brian Deer's disclosure of these payments led Wakefield to drop then-pending libel actions against Deer and the *Sunday Times*; the judge awarded costs to the defendants.

Wakefield subsequently moved to the United States, where he draws his not-inconsequential income from various forms of anti-vaccine publicity, despite his loss of medical qualification. Critiques and ridicule of his work could fill a small library.

By contrast, in 2011 Deer was named the UK's specialist journalist of the year in the British Press Awards. The judges said that his investigation of Wakefield was a "tremendous righting of a wrong" ("Brian Deer Wins a Second British Press Award" 2011).

It is an amazing story. It is well said (and variously credited, from Napoleon Bonaparte to Robert A. Heinlein) that one should never attribute to malice that which is adequately explained by incompetence. But in this case, the attribution is clear. As the editors of the *BMJ* asked:

Who perpetrated this fraud? There is no doubt that it was Wakefield. Is it possible that he was wrong, but not dishonest: that he was so incompetent that he was unable to fairly describe the project, or to report even one of the 12 children's cases accurately? No. A great deal of thought and effort must have gone into drafting the paper to achieve the results he wanted ... ("Wakefield's Article" 2011)

The journals have been cleansed and the legal record set straight. But the evil that men do lives after them, and the taint remains. There is still in the popular culture a certain strand of unease and suspicion about childhood vaccination. In the United States, of course, there is also a significant portion of the American population that simply does not have access to adequate healthcare, but this has always been true. The anti-vaxxers of conviction are those who drank, but not deeply, at the Pierian Spring. Wakefield was and is foremost in poisoning the shallower waters.

The American data on measles cases are particularly disturbing, because Wakefield's original paper is nearly 20 years old. The damage is only now starting to show up. How long is the lag time; how high will the rates climb before they start to drop again? And will they drop? Although Wakefield's papers have been withdrawn and he has been "struck off," he continues

to work his evil, and his message has clearly metastasized as it has gained a cult following. As this is being written, a Canadian survey reports that 20% of respondents believe that there is a link between autism and the measles vaccine, and another 20% simply "do not know" (Weeks 2015b).

One thing is crystal clear. The resurgence of measles, and of other childhood diseases, is not a challenge to "bench science" or to medicine in the narrow sense. That work was all done, and done well, a generation ago. The vaccines are in hand, and their safety and effectiveness long established. The clinical problem was solved. We are now facing what might be called a form of "social disease." The measles resurgence exemplifies the insights of Rudolf Virchow (1821–1902), the great German pathologist and father of social medicine, who wrote: "Medicine is a social science, and politics is nothing more than medicine on a grand scale."

Virchow went much farther than worrying about anti-vaxxers:

In his view, medicine and public health practices, applied politically, could transform society; politics and social systems could have profoundly positive or negative effects on public health; and both the physician and the politician had a moral obligation to heal society.

Virchow believed that all epidemics were social in origin. ... The improvement of social conditions, he wrote, would achieve the desired result "far more rapidly and more successfully."

Virchow, like Florence Nightingale, was skeptical of the germ theory because of its potential to de-emphasize the social factors that caused disease and to encourage a superficial approach to prevention and cure. (Contagion: Historical Views of Disease and Epidemics 2015)

As though on cue, here we have Peter Shawn Taylor, editor-at-large of *Maclean's* magazine, offering his take on public health in the *Globe and Mail*:

Across the country, public health departments at all levels of government have wandered much too far from their original mandates. Instead of focusing on the prevention of communicable diseases, they've been indulging in overt ideological crusades, inventing obscure new problems and claiming jurisdiction in areas well past the limits of their competency. ...

It is not the job of public health to have an opinion on taxes, economic policy, free trade or corporate control. Neither should it be their business to interfere in the freely-made choices of adults.

Public health ought to stick to their needles, and leave the economy alone. (Taylor 2014)

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Taylor's comments reflect a degree of scientific nihilism as glaring in its own way as that of the anti-vaxxers. A large and growing body of research has built on and confirmed Virchow's insights, and this broad base is familiar to and well understood by all of today's students and practitioners of public health. And like Virchow before them, they have taken up the moral obligation to try to heal society.

Those efforts have not always enjoyed universal support, now or in Virchow's time:

The Health Department of a great commercial district, which encounters no obstacles and meets with no opposition, may safely be declared unworthy of public confidence; for no sanitary measure, however simple, can be enforced without compelling individuals to yield something of pecuniary interest or of personal convenience to the general welfare. (Metropolitan Board of Health of the State of New York 1868)

Taylor's polemic, an attack on pretty much the entire public health community of Canada, seems in fact to be part of just such an "overt ideological crusade" to protect any pecuniary interests or personal convenience that might be threatened by the intellectual heirs of Rudolf Virchow. Many "inconvenient truths" emerge from study of the social determinants of health.

Specifically, Taylor defends, and indeed celebrates, the measures taken by the Harper government to downgrade the position of the Chief Public Health Officer (CPHO) of Canada and place it under direct political control. These changes have been universally condemned by the Canadian public health community.

Picard expresses well what is at stake in the leashing and muzzling of the CPHO, in his commentary on the de facto suppression of that officer's most recent report:

Over a decade of service, the first CPHO, Dr. David Butler-Jones, tackled issues like the social determinants of health, Canada's poor record on child health, the resurging threat of infectious disease, the sex and gender inequalities in health outcomes and the impacts of aging, to name a few.

The latest report follows that tradition. Its theme is the future of public health, but the real gem hidden in there is a chapter on public health impacts of climate change.

When a report of this import falls silently and invisibly, the sound you're hearing is Canadians suffering harm. (Picard 2014)

The neutering of the CPHO is of a piece with the Harper government's sidelining of the Chief Electoral Officer, the termination of the mandatory Census long form, the destruction of long-term studies of environmental change, and the general muzzling of the scientific community wherever the federal arm can reach. Don't like the message? Kill the messenger.

When information is ignored or suppressed, dummheit can flourish. But whatever else he may be, Stephen Harper is no dummy.

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Towards Reconciliation of Several Dualities in Physician Leadership

Pour la réconciliation de plusieurs dualités dans le leadership en médecine



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Abstract

Leadership has a renewed focus in healthcare, and physicians are being increasingly involved in a range of leadership roles. The aim of this paper is to discuss several dualities that exert tensions at the systems and individual levels. Although oppositional, the common dualities of physician leadership are not mutually exclusive but represent a complex, dynamic and interdependent relationship, often coexisting with each other and exerting tensions in multiple dimensions. The authors contend that a dialectic understanding - instead of either/or or finding a middle ground - of the opposite poles of these dualities allows for generating meaningful leadership perspectives and choices.

Résumé

Le leadership est au centre de l'attention dans les services de santé et les médecins s'impliquent de plus en plus dans une vaste gamme de rôles liés au leadership. L'objectif de cet article est d'aborder diverses dualités qui exercent des tensions aux niveaux des systèmes et des personnes. Bien qu'elles soient opposées, les dualités habituelles du leadership des médecins ne s'excluent pas l'une l'autre, mais représentent plutôt une relation d'interdépendance complexe et dynamique; elles coïncident souvent l'une avec l'autre et exercent des tensions sous plusieurs dimensions. Les auteurs affirment qu'une compréhension dialectique des pôles qui s'opposent dans ces dualités – plutôt que de choisir un des deux ou de trouver le juste milieu – permet d'obtenir un point de vue appréciable sur le leadership ainsi que sur les choix présents.

lacksquare urrently, leadership is a key focus in healthcare organizations based on a clear articulation of the need for improvement in healthcare leadership. Driven by the necessity for better access, higher quality of care, enhanced efficiency, coordination of care, higher patient experience and overall better outcomes for patients and populations, the healthcare delivery systems are moving towards integrated care delivery models, the latter defined as, "networks of organizations that provide or arrange to provide a coordinated continuum of services to a defined population and who are willing to be held clinically and fiscally accountable for the outcomes and the health status of the population being served." Commitment, alignment and integration of physicians in the integrated healthcare delivery models are considered essential for success, as physicians are participants in the delivery of care and contributors to the evolution of clinical services; however, it is a complex and challenging endeavour. It requires simultaneous efforts at coupling physicians and healthcare systems at several fronts including economic, structural (formal roles in organizational leadership structures and clinical governance), process-related (e.g., involvement of physicians in quality improvement initiatives) and policy levels. There is general agreement that leadership by physicians is linked to improved physician engagement and organizational effectiveness.

This paper draws on the research and practical experiences of the authors to highlight several dualities that affect leadership by physicians. These dualities are often oppositional and none have an absolute claim on truth and sometimes may run the risk of one being regarded as more important than the other – referred to as the "inevitable hierarchization" (Baxter and Hughes 2004). Some of these dualities exert palpable tensions at systems level, while others are more acute at the individual level. The authors contend that a dialectic understanding of the opposite poles of dualities and the tension between these allows for generating a meaningful perspective and making appropriate choices for effective leadership. These dualities are discussed below.

Dualities That Need to Be Reconciled Predominantly at the Systems Level

Leadership versus management

Efforts to discern distinctions between management and leadership often resolve in overlapping purposes and roles; the former usually referring to ensuring constancy (stability) and the latter to change (pursuit of vision) (Kotter 1990). The recent trend to designate virtually all formal authority positions in healthcare structures as leaders may reflect a hesitancy to use the words managers or management. The denigration of management (Rowling 2011: 1–2) and resulting tendency to call everyone a leader, while expecting stability and consistency with expectations of adherence/compliance, may be problematic for both functions and render both less meaningful – management becomes less effective and leadership becomes merely an espoused value.

Every manager can and must exhibit leadership behaviours, but designating every formal hierarchical position in healthcare structures a leadership position is neither enough to elicit leadership behaviour from individuals nor required for organizational success. Healthcare relies heavily on efficient management and there is nothing wrong in labelling a position "managerial" or "administrative," if the tasks and role expectations are in the managerial domain. An operational aspect of management that needs to be reconciled is the contentious issue of budgetary responsibility, especially in settings where a dyad leadership (joint responsibility between physician leaders and leaders with other backgrounds — nursing, technical, business, etc.) model is in place. If there is no signing authority for the budget, it may lead to perceptions of a weakened leadership (or managerial) role, although some physician leaders may be satisfied with a focus on clinical delivery outcomes.

Affirming versus enabling leadership

Leadership by physicians needs to expand in some areas and retreat from other areas. There is a vital need for increased involvement of physicians in: (a) policy – especially in the areas of quality and clinical innovation, payment policy and medical education and training (Laugesen and Rice 2003); and (b) strategic and higher-order operational decisions in healthcare systems, as it affects commitment and the decision quality (Parayitam et al. 2007). This requires that strong, value-based and assertive physician leaders become key partners with other healthcare leaders (Zismer and Brueggemann 2010).

On the other hand, in many interprofessional team care settings, physicians do not need to assume positional leadership roles; in such settings, there is a requirement for physicians to become trusted team players (Whitehead 2007). Although the principles and practices for interprofessional healthcare teams have been articulated, including the need for collaborative/shared leadership, the actual enactment of collaborative leadership remains challenging. This is because the teams are situated in traditional hierarchical healthcare structures and medicolegal systems that promote physicians' positional power (Lingard et al. 2012a), and the existing models of interprofessional collaboration have not yet mastered the notion of

collective competence (Lingard et al. 2012b); the latter referring to a team's ability to make collective sense of workplace events, develop and use the collective knowledge base and develop a sense of interdependency (Boreham 2004).

Assuming responsibility versus maintaining legitimacy

Despite calls for increasing leadership by physicians (Mountford and Webb 2009), in some quarters of the physician community, there is a perception that physicians are already leaders by virtue of their professional and somewhat elitist status. This perception coupled with the awareness of "professional egocentricity" (NPSF 2010) together with a disdain for these imputations may result in some reluctance to step into leadership roles. However, when formal leadership is not perceived as synonymous with transactional leadership (a one-sided and autocratic role of the leader), this reticence may be overcome. Being aware of alternate leadership perspectives, such as servant leadership (leadership based on the idea of the leader acting as a servant, with the duty to serve the followers), and transformative leadership based on changing individuals by helping them reach higher levels of motivation and morality approaches may relieve the trepidation to further perpetuate fearsome stereotypes of leadership.

A second factor may contribute to hesitancy for some physicians who wish to aspire to pursue leadership careers for virtuous or even practical reasons. Their journey may be looked down upon by their peers and disparaged as a move away from the role virtues associated with the unfettered practice of medicine towards the dark side (Glabman 2006). Sometimes the frank lack of support or reliance structures for these roles (Sherrill 2005) raises sufficient warrant to dismiss opportunities. Taken together, these factors are not conducive to increased and effective uptake of leadership roles by physicians. Physicians who are not personally interested in formal leadership positions might better help their colleagues who wish to pursue leadership roles by framing their colleagues' choices as opportunities to influence healthcare at a systems level.

Dualities That Need to Be Reconciled Predominantly at the Personal Level

Influence versus accountability

It is useful to consider that physicians practicing clinical medicine co-exist in a professional community that is inherently governed "politically" – in essence, self-governed. The hospital, on the other hand, functions as a managerial, accountability hierarchy, so that all employees have managers who are accountable for what they do, and ensuring they adhere to policy. It is in the interface between these two symbiotic "organisms" that the tension emerges: a politically governed body of "state authorized," professional decision-makers (physicians) – who by virtue of their knowledge work have attributes of autonomy and "expert" power asymmetry (Pearce 2004) – and an accountability hierarchy (the healthcare institution in which

physicians have been granted privileges to practice). Engaging physicians is critical to achieve organizational goals and is one of the expected "tasks" of physician leaders. Physician leaders simply do not have the same types of "positional authority" over physician clinicians that hospital managers have over their subordinate employees. For this reason, physician leaders must earn" personal and political authority to generate commitment among their physician "peers" to work efficiently and to high standards, and "apply" that personal and political capital when necessary through personal persuasion and mobilizing peer pressure. This is best done using appropriate influence practices rooted in positive psychology (study of what makes individuals and communities thrive) and appreciative inquiry (systematic inquiry on what works when a system is at its best and using "positive questions" to shape the future) and by avoiding coercion (Silversin and Kornacki 2000). In some instances - when persuasion, peer pressure and collaborative negotiation have failed to bring about the appropriate behaviours - there is also an appropriate place to "resort" to more well-chosen formal tools such as peer-review, privileges and credentialing to ensure accountability by staff physicians (Pronovost and Marsteller 2011).

Promoting effectiveness versus nurturing colleagues

For effective leadership, the centrality of the relationship with "followers" has long been known and recently reiterated in the healthcare settings (Grint and Holt 2011). The leader's task involves balancing the "demands of efficiency and the need to nurture human spirit" as "the employees today are less likely to put up with a workplace that emphasizes efficiency at the expense of meeting human needs" (Helgesen 1990: 234-35) - this was true in 1990 and is true today, especially with the new workforce generation. This is not easy because leaders need to push people out of comfort zones and manage their emotions on the journey forward (Heifetz and Laurie 2001).

The phenomenon of "conundrum of accountability" for the physician leaders arises with colliding conflicts between the fiduciary and strategic demands owed by physician leaders to their organization and the promises, and the psychological contracts, interests and expectations of their constituents (Merry 1991). These dual affiliations and often opposing demands may make a physician leader ineffective; consequently, the organizations suffer by having a physician who neither provides effective leadership nor is fully engaged in direct patient care. The physician leader, therefore, must have the self-awareness and self-confidence to recognize that the greater good is, at times, superordinate to the autonomy of the individual physician clinician (Kraines 2010).

Clinical practice versus administrative work

Physician leaders need to balance their clinical practice with time devoted to leadership work because of two reasons. First, clinical practice is an integral component of "physician identity" that imparts a unique perspective for mindsets and psychological health. Second, it is generally believed that continued involvement in clinical work is necessary for maintaining credibility with physicians (Holmboe et al. 2003). Physician leaders who continue to engage in clinical practice need to pay particular attention to the "advocacy" role because of their "visibility" and consequent role modelling as well as the work they need to do at the systems level. Although physicians are aware of the need for advocacy at both individual patient and system levels, the actual balance of the "agency" (acting in the interests of the individual patient) and "activism" (changing social conditions that impact the populations) in practice settings requires additional work.

The administrative roles for most physician leaders are situated in clinical and academic domains and to some degree in public and political domains. Further, physician leaders in academic health centres are expected to deliver on clinical as well as academic missions. This requires physician leaders to work across multiple inter- and intra-organizational boundaries, including the fault line between universities and hospitals/regional health authorities. This cross-boundary work across the fault lines is challenging due to differences in the clinical and academic settings in organizational cultures, organizational processes around decision-making and accountability mechanisms.

Balancing clinical and administrative work requires not only personal time management but also an ability to utilize appropriate mindsets (often referred to as wearing my other hat), e.g., "agency" with "activism," short-term gains with long-term goals and, in the educational settings, remaining patient-centred and learner-focused.

Discussion - Reconciling Dualities

A reconciliation of several common dualities in physician leadership is conducive to increasingly meaningful and effective leadership by physicians. Although oppositional, the common dualities of physician leadership are not mutually exclusive but represent a complex, dynamic and interdependent relationship. Further, it is not necessary to find a middle common ground between these dualities. A dialectic emphasizing that both "poles" are important — "the coexistence of diametrically opposed elements" (Levine 1971), accepting that both are true at the same time, in a both/and manner, adds a third approach to reconcile these dualities (Coser 1971: 184).

For the purpose of this article, dialectic thinking refers to the ability to arrive at a reasonable approach to resolve contradictions. Developing a "dialectic" thinking requires deep self-awareness and awareness of other perspectives to create and maintain a balance between these two dynamics (Basseches 2005). This internal reconciliation allows the leaders to frame and facilitate interpersonal and organizational discussions in a dialectic language. This sets the stage for reconciliation of dualities and at the very least is a respectful acknowledgement of "different truths," even if no agreement is reached; this by itself is a powerful step in establishing trust with and among groups – the very basis of effective leadership. Reconciliation of the dualities may sometimes involve ensuring that the decisions and actions are consistent with upholding both "truths" through a wider perspective, which accommodates both "realities."

Alternatively, reflections and deliberations of the different "truths" may lead to emergence of new realities. A couple of examples illustrate this reconciliation.

Both strategic and operational decisions in organizations (e.g., creating integrated delivery models or achieving financial and quality targets) almost always require working across intra- and often inter-organizational boundaries. It is well-known that human interactions are influenced and often determined by the identity of individuals and groups - the manner in which the individuals classify themselves and others into social categories (Hogg and Terry 2000). It is further complicated by the observations that individuals have multiple simultaneous identities and their relative importance varies with time and context. A general approach to solving system-wide issues is by creating a superordinate identity (Gaertner et al. 1999) – essentially a larger tent under which multiple groups and individuals can come together to work towards a common goal. Although this approach has merit, it is not always successful (physician engagement is still a work in progress), as the groups sometimes perceive this as a loss of identity of the subgroup to which they belong. This requires that while a superordinate identity is being created, careful attention is paid to preserving and protecting group identities and that the larger collective work is not perceived as "subsumation" of individuals and groups. Specific recommendations for cross-boundary work - creating intergroup safety, fostering intergroup respect, bridging groups to develop trust, developing intergroup community, integrating group differences to generate interdependence and bringing groups together in emergent directions (Ernst and Chrobot-Mason 2011: 81-220) - allow for implementation of decisions to achieve organizational goals through a dialectic approach.

Patient advocacy - the "agency" component referred to above - by physicians offers an opportunity to apply dialectic thinking. Instead of advocating for an individual patient at all costs (thesis), as the resources are finite (antithesis), the concept of distributive justice – socially just allocation of goods in a society - allows for a meaningful allocation of resources for realistic outcomes, i.e., the best we can do for the patients given the resources we have so that other "individual" patients who are later in the queue can be appropriately cared for (synthesis). The recommendations in the relatively recent Choosing Wisely Canada initiative – endorsed by many national societies – allow for an evidence-based appropriate use of resources for diagnosis and management (Levinson and Huynh 2014). Physician leaders can become role models in their individual clinical practice and exhibit leadership by ensuring adoption of this framework throughout the organization, increasing the likelihood of attaining financial and quality-of-care goals.

Conclusion

Physician leaders are constantly balancing and adjusting to the ever-moving landscape of medical knowledge and have the additional task of successfully managing and leading in healthcare organizations. Adopting a dialectic approach to leadership dualities at both the individual and systems level enhances leadership by physicians. At the individual level, the leaders need to develop and apply a dialectic mindset and commit to life-long leadership development. At the

systems level, the dialectic approach would involve: (a) valuing managerial roles and reflecting these in organizational designations, (b) actively including physician leaders at strategic and operational levels in healthcare organizations, (c) incorporating collective competence principles in organizational development for both interprofessional teams for patient care and for leadership teams, (d) screening for appropriate mindsets in the selection of leaders and managers, (e) ensuring protected time for physician leaders' clinical practice, (f) managing the physician community for leadership "cultivation" and (g) educating senior leaders in healthcare settings and on what makes physician leadership unique.

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Quality of Physiotherapy Services for Injured Workers Compensated by Workers' Compensation in Quebec: A Focus Group Study of Physiotherapy Professionals

Qualité des services de physiothérapie chez les travailleurs qui reçoivent une indemnisation de la Commission de la santé et de la sécurité du travail au Québec : groupe de discussion réunissant des professionnels de la physiothérapie



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Abstract

Musculoskeletal disorders are among the leading causes of work-related physical disability in the province of Quebec in Canada. The authors conducted a focus group study with physiotherapists and physical rehabilitation therapists working with patients whose treatments are compensated by the Quebec Workers' Compensation Board with the goal of exploring quality of care and ethical issues. Three main themes were identified: (1) systemic factors, (2) complexity in treatment decisions and (3) inequality of care. Although physiotherapy professionals strive to give these patients the best possible care, patients might not always be provided with optimal or equal treatment. When compared with other patients, there appear to be differences with respect to access to care and types of services offered to injured workers, raising equity concerns. Factors that shape and constrain quality of physiotherapy services for injured workers need to be addressed to improve care for these patients.

Résumé

Les troubles musculosquelettiques figurent parmi les principales causes d'incapacités physiques attribuables au travail dans la province de Québec, au Canada. Les auteurs ont dirigé un groupe de discussion réunissant des physiothérapeutes et des thérapeutes en réadaptation physique dont les clients reçoivent une indemnisation de la Commission de la santé et de la sécurité du travail, et ce, afin d'étudier la qualité des services et de se pencher sur des questions d'ordre éthique. Les auteurs ont identifié trois principaux thèmes : (1) les facteurs systémiques, (2) la complexité des décisions pour le traitement et (3) l'inégalité des soins. Bien que les professionnels de la physiothérapie s'efforcent de donner aux patients les meilleurs soins possibles, ces derniers ne semblent pas toujours recevoir des traitements optimaux ou égaux. Comparés à d'autres patients, il semble y avoir des différences quant à l'accès aux soins et au type de services offerts, ce qui soulève des préoccupations quant à l'équité des services. Pour améliorer les soins qui leur sont offerts, il faudra se pencher davantage sur les facteurs qui influencent la qualité des services de physiothérapie pour les travailleurs victimes d'un accident de travail.

Introduction

In Quebec, a province of Canada, musculoskeletal disorders are among the leading causes of work-related physical disability and are very costly in terms of treatment, lost productivity and diminished quality of life (Lebeau and Duguay 2011). These disorders constitute almost 37% of occupational injuries compensated by the Quebec Workers' Compensation Board, the Commission de la santé et de la sécurité du travail (CSST) (IRSST 2013). The CSST is a cause-based medico-legal system (Lippel and Lötters 2013) aiming at compensating injured workers after an injury sustained at work. Like other workers' compensation boards in Canada, as well as their counterparts in most Anglo-Saxon countries, the CSST considers the eligibility of injured workers' claims based on the cause of the injury, meaning that the

injury must have happened at work and during work paid time to be eligible for compensation (Association des commissions des accidents du travail du Canada 2014). Laws regulate the functioning of the compensation process, and the CSST has the mandate of enforcing these laws with respect to compensation for medical care and for physical, social and vocational rehabilitation.

In the Quebec system, when a work injury is declared, the physician evaluates the patient, determines the diagnosis and confirms that the injury has been sustained and caused by work. If the physician's evaluation demonstrates that the injury was caused by their work, this information is sent to the CSST to support the injured workers' claim for compensation. Once the claim is accepted, the injured worker is entitled to receive different compensations such as replacement wages and medical benefits, as well as rehabilitation treatments such as physiotherapy. Indeed, as physiotherapists (PTs) are specialists in the musculoskeletal system, they are often implicated in the evaluation and treatment of persons with musculoskeletal injuries, including work-related back or neck pain and soft-tissue strains (Johnston et al. 2012). When physical work-related injuries are diagnosed by the physician, he or she often refers injured workers to physiotherapy clinics for treatment. The CSST then mandates the PTs involved in treating injured workers to improve their functional abilities and to prepare them for a safe return to work (RTW) (commission de la santé et de la sécurité du travail 2010). However, as the CSST system is a medico-legal system, even if the primary healthcare professional involved in the care of an injured worker is a physiotherapist, the treating physician is still recognized as the principal healthcare manager of the worker's case. The physician usually sets the parameters for the process of care and the RTW, and is the person responsible for transmitting this information to the CSST board. The physician is the only healthcare professional who makes decisions relating to supplementary imaging or investigations, change in RTW plans and ending treatment. Most of the time, the treating PTs will be responsible for informing physicians of the progress of the patient and options for RTW. Preferably, the RTW decisions would be made by the physician in conjunction with the treating physiotherapist, the CSST case manager, other involved healthcare professionals, the employer and the worker (Briand et al. 2008).

It is also important to note that even if Quebec has a public system of healthcare, most workers covered by the CSST and requiring physiotherapy treatment are seen in private, for-profit clinics, rather than in public physiotherapy departments located in hospitals or rehabilitation centres (Fédération des cliniques privée de physiothérapie du Québec 2010). In the private sector, the CSST reimburses the clinic owner for treatments provided to patients covered by workers' compensation on a fee-for-service basis. This high proportion of patients treated in private clinics rather than in public institutions might be attributable to the low accessibility of physiotherapy care in public settings throughout the province (i.e., the presence of long wait lists for accessing physiotherapy) (Camiré 2010; Commission de la santé et de la sécurité du travail 2010; Conseil du patronat du Québec 2010; Healy 2007).

In recent years, the CSST has implemented a strategic plan in order to increase accessibility, satisfaction and quality of care (QoC) for injured workers, while attempting to reduce rehabilitation costs. In its 2010–2014 strategic plan, the CSST defines ways of improving QoC by describing three essential aspects: better access to care services for all injured workers, more effective case management of workers presenting with serious injury or risk of chronicity, and simplification of the bureaucratic and administrative procedures associated with the CSST system (e.g., by improving technological support) (CSST 2010). In the United Kingdom, the Institute of Medicine has identified six central dimensions through which QoC is expressed: safety, effectiveness, patient-centredness, timeliness, efficiency and equity (The Health Foundation 2013). QoC is central to achieving the main goals of the healthcare system and specifically of physiotherapy: improving the health (and functioning) of patients, and enhancing patient satisfaction (Andersen 2008). However, there remains uncertainty regarding whether patients covered by the CSST receive high-quality physiotherapy services (i.e., safe care, appropriate care for their condition, timely access to care, integrated and patientcentred care, and equitable provision of care) and, if not, what barriers to high QoC exist (Laliberté and Hudon 2013; Laliberté and Hudon 2014).

Some organizational factors (related to the clinic's rules and/or the process and programs of care) have been recognized as having an impact on the QoC for patients covered by workers' compensation boards in Canada (MacEachen et al. 2010), and in also many different countries (Kilgour et al. 2014). For example, in Quebec, the fees used to compensate physiotherapy care are much lower than what PTs usually receive when offering care to privately insured patients (i.e., \$36 for patients covered by CSST compared to the average of \$59.90 in Quebec private physiotherapy clinics) (Fédération des cliniques privée de physiothérapie du Québec 2010). This gap in remuneration could be seen as a disincentive for PTs to treat patients covered by workers' compensation boards. Additionally, PTs providing care to patients covered by the CSST are part of a complex system including the patient and his family, the CSST case managers and advisors, the physician in charge of the patient, the employer, the patient's supervisor and colleagues, and other healthcare practitioners involved in the case. Some administrative constraints (e.g., paperwork, payment scheme) also have been shown to increase the organizational pressure on healthcare professionals and can impede the quality of treatments for patients (Kilgour et al. 2014). Research from Canadian and Australian researchers indicates that systemic features of some workers' compensation systems pose potential barriers to the provision of high QoC for compensated patients treated in physiotherapy (Kilgour et al. 2014; MacEachen et al. 2010).

In addition, ethical considerations have recently been raised in the Quebec media regarding the excessively high frequency of physiotherapy sessions (that are not clinically justified) for patients whose treatments are compensated by the CSST (Desjardins October 1st, 2009; Nouvelles TVA October 7th, 2010). To our knowledge, these ethically questionable practices by physiotherapy clinics have not been thoroughly investigated. The lower reimbursement rates paid by the CSST might also encourage discriminative practices between workers'

compensation patients and privately insured patients inside these clinics (Kosny et al. 2011). For example, some clinics simply refuse to treat patients covered by a workers' compensation board because it involves more work for lower fees for the clinic and the treating physiotherapy professionals. This engenders a decrease in accessibility to quality care for patients and encourages discrimination towards this group of patients. One other important ethical challenge faced by PTs is that there is no well-defined or established end point to physiotherapy services (Poulis 2007). For patients with similar conditions, some PTs treat until the patient returns to a prior baseline level, some continue to treat until the patient reaches a functional threshold according to the demands of his or her employment, while others treat until the patient recovers completely and is within normal ranges of strength, motion, mobility or other relevant dimensions. In some cases, the judgement regarding when to end therapy may not be aligned with the recommendations from third-party payers such as workers' compensation boards who sometimes urge PTs to push for a faster RTW, potentially placing the treating therapist in a dilemma if this pressure goes against professional judgement (Poulis 2007).

Although many studies explore issues of QoC from the perspective of workers (Beardwood et al. 2005; Kirsh and McKee 2003; Lippel 2007; MacEachen et al. 2010), very few articles have explored this topic from the point of view of PTs (MacEachen et al. 2010; Pincus et al. 2010), and a recent systematic review on the subject concluded that further research was needed on the experiences of distinct healthcare professionals such as PTs (Kilgour et al. 2014). Exploring PTs' perspectives could help better understand these issues, identify potential obstacles to quality care, and support efforts to improve care for these persons. Given these gaps in knowledge, we conducted a focus group study to obtain a better portrait of QoC in physiotherapy services in the province of Quebec by examining two specific dimensions: the organizational and ethical issues encountered by physiotherapy professionals including PTs and physical rehabilitation therapists (PRTs) (who have a college-level training in contrast to PTs who have a master's-level training) working with CSST patients. The aim of this article is thus to highlight and raise awareness of some QoC issues associated with physiotherapy services for injured workers that are funded by the CSST.

Methods

We selected a focus group approach, as this method allows participants to discuss and brainstorm in a group setting about a particular subject. Focus groups are useful for examining workplace cultures (here the CSST physiotherapy treatment setting) and may facilitate discussion of "taboo" topics (Kitzinger 1994; Krueger and Casey 2009; Mays and Pope 1996). In this study, the interactions during the two focus groups promoted exchange of ideas around physiotherapy services funded by the CSST. These focus groups were organized as part of a larger research program funded by the Canadian Institutes of Health Research (CIHR) and investigating organizational issues and ethical challenges in physiotherapy care paid for by workers' compensation boards in Canada. The two focus groups conducted in this study

represent a first step in exploring organizational and ethical issues that might impact QoC for injured workers supported by the CSST. These results will inform the conduct of a larger study exploring PTs' perceptions of care for injured workers in Canada.

Participants

We recruited PTs and PRTs using purposive and snowball sampling methods, from May to September 2013 (Biernacki and Waldorf 1981; Marshall 1996). First, an invitation e-mail was sent to physiotherapy professionals who were identified through investigator contacts. Then, to recruit more participants in diversified settings, identified participants were asked to suggest other potential participants who might be interested to participate in the focus groups and who might have different experiences, views or opinions related to the phenomenon of interest (snowball sampling). Overall, purposive sampling was used to ensure a diversity of participants, from different clinics and with different experiences as clinicians. To participate, PTs and PRTs had to have at least two years of experience working with CSST patients. Six PTs took part in the first focus group (five females and one male). One participant exclusively held a management position in a public sector physiotherapy department and two participants were working half time as clinicians and half time as managers of private clinics (both were also the owners of their respective clinics). The other three participants worked full time as clinicians, two in the private sector and one in the public sector. There were seven PRTs in the second focus group (five females and two males), working as full-time clinicians in private clinics.

Focus groups

A member of the research team (A.H.) facilitated both focus groups while other researchers observed the sessions and took detailed notes. The main research question guiding the focus groups was: "How do physiotherapy professionals perceive organizational and ethical issues associated with the treatment of injured workers whose care is paid for by the CSST and how might these issues influence QoC for patients?" Different strategies were used to make sure that all participants could voice their own perspectives and experiences during the focus groups (Parker and Tritter 2006). First, a "round table" format was used to allow each participant in turn to share some of their concerns and identify issues they thought were the most important to discuss. An open group discussion followed with the facilitator only intervening to ensure that each participant had the chance to speak on the subject. Periodically, the facilitator proposed new questions to keep the discussion going among the participants. If needed, the facilitator asked the participants to clarify any ideas that were unclear or seemed incomplete. All questions posed by the facilitator were open-ended to encourage the participants to express themselves on each topic. Sufficient time was devoted to each topic so that all the participants had the time to share, discuss and even argue about it. Attention was given to preserve a respectful and productive dynamic and interaction between participants. Three observers were present during the focus groups and provided feedback to the facilitator during the break that occurred halfway through each focus group to help the facilitator

address points that were unclear or had not been discussed in sufficient depth. At the end of the session, participants were asked to express anything they had not had the chance to share during the meeting. Both focus groups lasted 143 minutes with a 15-minute break and were audio-recorded. Recordings were transcribed in their original language (French). Translated verbatim quotations are included in the results section to illustrate aspects of the analysis in relation to the core themes. Quotes presented in this paper were translated from French by a native English-speaking member of the research team.

Analysis

A member of the team (A.H.) performed descriptive and thematic analyses of the focus groups based on the transcripts and supplemented by field notes. Other members of the team reviewed the emerging analysis at several points during its development. Initial inductive coding responded to questions such as "What is going on here?" and "What is this about?" Examples of codes include communication, frustration and end of treatment. The second level of analysis sought to aggregate initial codes through identification of patterns and linkages within each focus group and to compare them with notes taken by the observers. Categories developed for focus group one and two were then compared with each other with the goal of identifying what was common or different between the focus groups. While comparing categories between the transcripts, core themes relating to system organization, ethics and QoC were developed.

Ethical Considerations

This project was reviewed and approved by the Research Ethics Board of the Center for Interdisciplinary Rehabilitation Research of Greater Montreal (CRIR). All participants signed a consent form prior to participating. Personal names and names of clinics or hospitals were removed from the transcripts and participants were assigned pseudonyms.

Results

We identified three core themes related to physiotherapy treatment of CSST patients: (1) systemic factors, (2) complexity in treatment decisions and (3) inequality of care. While there was a high degree of agreement between the two professional groups who participated in the study, some points of divergence were also noted. In particular, several topics which were discussed at length by PTs were not raised by PRT participants. For example, PTs talked about difficulties related to outcome measures used with CSST patients, and that standard measures were often inadequate for this context with several participants suggesting that additional tools were needed, such as psychosocial and fear of movement questionnaires. PTs also expressed dissatisfaction with the financial arrangements between CSST and physiotherapy clinics, suggesting that the rate of reimbursement was insufficient.

Systemic factors

The first theme, systemic factors, mostly relates to organizational problems encountered by physiotherapy professionals when caring for injured workers in Quebec. Participants in the focus groups returned frequently to the topic of communication among clinicians and between clinicians and administrators involved in the care of CSST patients. Communication challenges were identified as being the result of structural features of the current system. For example, participants reported that collaboration with the physicians in charge of their patients was hindered, as it was difficult to reach the physicians by telephone and most communication was by written notes (e.g., faxed letters). These communication challenges were seen as having a negative impact on the QoC provided to patients, as they contributed to a lack of coordination in treatment planning and implementation, thus affecting the timeliness and coordination of the intervention. Participants in both focus groups also expressed the view that communication was sometimes impeded when CSST case managers (responsible for payments and follow-up) lacked basic scientific knowledge to understand the therapists' treatment requests or recommendations. Participants described how communication challenges sometimes result in patients receiving mixed messages. The lack of an integrated team approach and multiple communication barriers were viewed as obstacles to treatment planning and as having deleterious effects on patient care. Several participants suggested that interdisciplinary meetings might help clinicians better follow the patient's progression and lead to enhanced care coordination.

Participants also identified variability in the policies established by different CSST jurisdictions in adjoining regions as a source of further confusion. They felt that lack of uniformity in policies made the system more complicated for patients and for therapists alike. For example, some regulations about patients' absences from treatment differed for patients from Montreal or Laval (city just north of Montreal).

Participants described the long hours needed to complete routine CSST paperwork. Considerable time is also spent writing letters to physicians and phoning the employer or the CSST agent to inform them of the patient's progress. A participant stated: "Since there is a third party payer, I, as a clinician, it makes more paperwork to fill out, there is a progress note that has to be done regularly ... thus it makes more paperwork to do." (PT-2). Participants acknowledged that this documentation was implemented for the CSST to monitor the progress of the rehabilitation process. However, they felt that the paperwork system was very inefficient, and doubted that their reports were correctly understood, or always read by CSST case managers. As a result, they expressed that the effort expended on these administrative tasks was excessive and took time away from direct patient care, which they already felt was in short supply: "In my 2.4 patients per hour, I can't see how I can compose letters to the physician; I hardly have time to finish with my patients." (PRT-2).

Participants also expressed that they are not in total control of their patients' rehabilitation care process and that many obstacles can delay their recovery or change the course of treatment. In fact, the patients and their therapists are often waiting for results (e.g.,

radiology or electromyography tests) or specific approval from physicians or employers, which can slow the progression of treatment and cause delays: "Me, I find that they are mostly waiting, the CSST patients. They wait for their appointment for injection, they wait to see the physician, they wait to speak to a case manager ... thus they are not super independent I find. Maybe it's the system that makes it so." (PT-4). This situation can lead to significant delays in the process of care for patients. In summary, the examination of systemic factors revealed organizational barriers (e.g., communication challenges between care providers themselves and with the CSST, lack of uniformity in regional policies, administrative burden and delays for specific requests) that can limit the provision of integrated care services and affect the QoC for patients in terms of efficiency, timeliness and patient-centred dimensions of QoC.

Complexity in treatment decisions

The second theme, complexity in treatment decisions, encompasses participants' reflections and frustrations regarding complexity in treatment decisions when treating patients covered by CSST. Participants from both focus groups reflected on differences between treating CSST patients and patients covered by other forms of insurance (e.g., private insurance, automobile insurance). They felt that CSST patients had higher expectations about their recovery and wanted to get back to 100% of their previous capacity before returning to work, even if this was not always feasible. Dealing with these high and sometimes unrealistic expectations was considered challenging by participants. A participant made the following comparison: "This, I find is a difference as I said with the private clientele. The private clientele ... they want to return [to work] even if I know that they are not at 100%, whereas [CSST patients] they expect, say, to be 100% in order to return to their work." (PT-4). Participants also expressed that CSST patients experience more psychosocial problems and were often categorized as "complex patients." The fact that the injury happened at work, insecurities related to recovering their abilities, pressure from the employer or the fact that patients sometimes do not like their job may render the treatment context considerably more complex than the physical injury itself. As participants treat a "person" and not only a "physical injury," they have to take these other factors into consideration when treating their patients. Some felt that their professional training did not adequately prepare them to help patients who experience psychosocial problems. Moreover, participants felt that their patients do not have easy access to specialized psychosocial health professionals when they would benefit from this support. One participant described that for CSST patients: "their entire social and psychological environment is very affected and I feel that the majority of patients are missing the resources at this level..." (PRT-4). Participants in both focus groups expressed the view that there are insufficient resources (e.g., psychologists or social workers) available within the system to help patients progress further during their physiotherapy rehabilitation: "... It is not the majority of clinics that have a mental health approach as well. And maybe that is missing." (PT-2). Participants suggested that this gap could impede the QoC provided to patients and delay recovery.

Ambiguities associated with decision-making about the course of treatment were also discussed by the participants. Issues around when to end physiotherapy care were a particular concern for many participants, particularly for patients with soft-tissue injuries and chronic pain. Several questions were repeated by participants, including who should make the decision to end treatment (e.g., physicians or PTs), when should treatment be ended (e.g., when patient has reached a plateau) and how the next steps to help the patient should be determined (e.g., surgery, intensive interdisciplinary programs). These ambiguities in patient progression and treatment planning created uncertainty for participants. In sum, participants felt that the injured workers often have high and sometimes unrealistic expectations, and many experience significant psychosocial issues. The participants do not always feel well-equipped to help patients with regards to these dimensions of their care, and experience ambiguity about the course of the rehabilitation process in some cases, which could affect the QoC by potentially impeding the effectiveness of treatment.

Inequality of care

The third theme, inequality of care, addresses ethical issues relating to inequality in the provision of care for CSST patients treated in physiotherapy. According to participants, some clinic policies and practices related to CSST patients contribute to unequal care. As mentioned earlier in this text, reimbursement rates for a physiotherapy session are fixed at \$36 by the CSST, while a non-CSST patient typically pays much more in the same clinic (average of \$60) (Fédération des privée de physiothérapie du Québec 2010). Therefore, for financial reasons, some private clinic owners reduce the duration of treatments to CSST patients (e.g., 20 minutes instead of 30 minutes per treatment). Another strategy used to compensate the loss of income associated with the fixed session rate imposed by the CSST is to place these patients under the care of PRTs instead of PTs because these professionals have a lower salary (PRTs have a college degree compared with PTs who now have a postgraduate master's degree). A participant reported that "[at] the clinic where I work, the calculation that they have made, is to have PRTs and they only see patients who are reimbursed by third party payers; they see three patients per hour; me, I see two patients per hour." (PT-2). Additionally, in the current CSST system, the same reimbursement rate applies (\$36) whether the patient is seen for an evaluation (generally lasting one hour and charged as a higher rate than a followup session) or for a follow-up treatment session (usually lasting 30 minutes). This \$36 is quite low compared with the fees charged by the clinics to patients for a whole hour evaluation time. Consequently, some owners prefer to split the evaluation in two for financial reasons. Thus, unlike non-CSST patients who receive a first evaluation in a one-hour session, in some clinics, CSST patients are evaluated in two separate sessions of 30 minutes. However, participants felt that this practice can impede the establishment of a good therapeutic relation and lead to a less effective evaluation of the patients' condition. Finally, participants also mentioned that in some clinics, CSST patients who are off work are only given appointments in the middle of the day because early morning and evening times are reserved for "active" workers.

In sum, many clinic-specific rules relating to physiotherapy care of CSST patients do not seem to encourage the best care possible and differ from the care offered to other patients in the same clinics. One participant summarized the situation: "What the [CSST] patient needs is not exactly what he receives. It's red tape politics you know." (PT-3). Participants also expressed many negative emotions during the focus groups. Terms like "frustration," "discouragement" and "exhaustion" were used numerous times. Participants expressed these sentiments usually in relation to their sense of unjust practices and policies towards CSST patients. These concerns are reflected by a participant who described this feeling: "...listen, at times I would like to switch and be a lawyer to defend the cases of the CSST. Ah I'd be happy!" (PRT-3). The theme of inequality of care encompasses a range of ways in which CSST patients' care is structured or provided differently than for other patients. Participants expressed that many clinic and CSST policies seem unjust and unfavourable in regards to CSST patients. Participants clearly expressed that these features lead to ethical tensions, and are associated with negative emotions and feelings of frustration. Inequality for CSST patients' treatments might diminish the QoC they received and could also lead to stigmatization of this clientele and create ethical distress for professionals.

Discussion

Many important issues were identified in this study that provide an insight into physiotherapy services reimbursed by the CSST. Even though this study focused on the Quebec workers' compensation system, these findings offer an important point of comparison for other Canadian provinces or other nations.

The study findings present some similarities with qualitative results from a systematic review of international studies on healthcare providers involved in the care of injured workers (Kilgour et al. 2014). These similarities relate to numerous factors such as the frustration of healthcare professionals when they experience a disconnect between their recommendations and what the insurer approves, challenges in communication with some claims managers, lower fees paid by workers' compensation boards to healthcare professionals, administrative burden and increased workload when dealing with the workers' compensation system and healthcare professionals' lack of knowledge of the system that creates uncertainty about their role in it.

Many organizational or systemic factors were found as potentially impeding diverse dimensions of QoC. For example, the findings suggest that the communication modalities established between the different stakeholders in the care of CSST patients (such as three-week reports) are far from optimal, reducing the timeliness and efficiency of care for potential beneficiaries. Effective communication, both among caregivers and between caregivers and patients, is critical for high-quality care (Institute of Medicine and Committee on Quality of Health Care in America 2001). From the perspective of the PTs and PRTs, documentation and forms used in the CSST system are inefficient and do not serve the purpose well of

promoting clear communication. Concern about excessive time spent on administrative paperwork and the effects of poor communication between different stakeholders are also reported by professionals involved in the care of injured workers in other settings (Kosny et al. 2011). For example, Wickizer and colleagues report that workers' compensation systems impose significant administrative burdens on physicians in the US in the form of billing requirements, referral approval procedures and utilization management processes (Wickizer et al. 2001). These physicians also described how aspects of the system were unresponsive to the needs of injured workers (Wickizer et al. 2001). In another study, MacEachen et al. (2010) examined the experiences of different healthcare professionals (chiropractors, occupational health physicians, PTs) in Ontario, Canada, regarding workers' compensation system. They identified QoC issues such as ineffective procedures for communication and a lack of collaboration between healthcare providers, leading to a "toxic dose of system problems" (MacEachen et al. 2010).

Participants in our study also emphasized the importance of psychosocial factors in the treatment of CSST patients. However, the current system does not facilitate the integration of other professionals to work in an interdisciplinary fashion in the patients' rehabilitation, despite the fact that consideration of psychosocial factors is an important determinant in injured workers' RTW processes (Franche and Krause 2002). Participants in this study also expressed their lack of training and the difficulties they experienced in addressing psychosocial issues with their patients. This situation could contribute to a reduction in effectiveness of interventions for patients when relevant psychosocial factors remain unaddressed and unmet during the rehabilitation process, thereby reducing QoC (Soklaridis et al. 2010).

Studies about RTW after work-related injuries also emphasize the importance of integrating the employer in the process (Durand and Loisel 2001; Franche et al. 2005; Loisel and Anema 2013). However, participants rarely described the employer as a member of the rehabilitation team, and linkage with the workplace does not seem to be supported in the current system. In Quebec, the PTs never speak nor communicate with the injured worker's employer to respect confidentiality. This renders the potential adjustments for RTW plans much harder to orchestrate for the healthcare providers such as physicians and PTs. Quebec differs from other Canadian provinces on this matter. PTs in British Colombia and Ontario now communicate by phone or by letter with the employer, with their patient consent, to facilitate the RTW process. The impact of this lack of contact between healthcare providers and employers in Quebec should be investigated in greater depth in future studies.

Finally, the negative emotions expressed by participants with regards to the significant differences between the care provided to CSST patients compared with "other patients" illustrate the impact of lack of equity in the provision of care on clinicians. PT professionals are well-aware that the system and their clinic rules contribute to inequities, a situation which sometimes leads to feelings of ethical distress for them. Equitable care is compromised when quality varies based on the source of payment of treatments. These differences include,

amongst others, structure and duration of evaluations, the likelihood of being treated by PRTs (rather than PTs) and the duration of individual treatment sessions.

In terms of policy change, many aspects of the results could orient future exploration of the impact of the CSST system on the QoC of injured workers, both for internal policies of private clinics and for CSST policies. First, private physiotherapy clinics should consider the impacts on patients' QoC of internal policies they have implemented. Depending on the PTs and their internal clinic policies, the length and frequency of treatment for patients covered by the CSST can vary greatly. For example, for financial reasons (i.e., as the fees-for-service paid by the CSST to physiotherapy clinics are lower than those paid by patients out-of-pocket or through their private insurance companies), some clinics choose to treat patients covered by the CSST for 20-minute sessions, instead of the provincial average of 30 minutes offered to non-CSST patients. Decreased treatment time or restrictions in scheduling are practices that could encourage stigmatization of patients and increase inequity in care. These internal policies also led to the expression of negative emotions in participants having to deal on a regular basis with these disparities. The FPPPQ, a federation of private physiotherapy clinics in Quebec, could serve as a facilitator to help clinics implement internal policies that would have positive impacts on the QoC for CSST patients. Second, policy revisions of the structure and mechanisms of communication between stakeholders involved in the rehabilitation process should also be examined by the CSST. It would be valuable, for example, for the CSST to develop a new pilot project aimed at enhancing communication between physiotherapy professionals, the physician and employers to facilitate the RTW process. Moreover, some CSST policies could be developed to support a more coordinated decision framework between physicians, PTs and patients throughout the rehabilitation process. Finally, the availability of external and prompt psychosocial resources, such as psychologists or social workers, during the rehabilitation phase could also facilitate the RTW and healing process for patients, as well as supporting PTs in their management of these patients. However, before suggesting specific changes to actual policy, a larger study exploring these issues with physiotherapy professionals and other stakeholders is warranted.

Limitations

This exploratory study aimed to illuminate key QoC organizational and ethical issues encountered by PTs and PRTs treating injured workers compensated by the CSST. The results reflect how these issues were perceived and experienced by the 13 participants who took part in two focus group sessions, and may not reflect all issues related to QoC in the physiotherapy domain for CSST patients. Another limitation is that all participants worked in an urban region (greater Montreal) and the results may be less applicable to care in rural regions (Lamarche et al. 2011). Finally, the participants are themselves interested by the CSST system, and their insights might not reflect the variety of perspectives among PTs and PRTs

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who treat injured workers. We propose that future studies on this topic use a larger sample of physiotherapy professionals in different regions of Quebec and other Canadian provinces. Other measures of QoC using quantitative methods could also be used to investigate other dimensions of this phenomenon.

Conclusion

This exploratory study suggests that CSST patients might not always be provided with optimal treatments owing to systemic barriers to adequate care. Because CSST patients often have complex needs requiring interdisciplinary care, the establishment of treatment plans can be challenging. This task can be complicated further by the lack of coordination and effective communication between the many stakeholders involved. Even if PTs and PRTs strive to give CSST patients the best possible care, when compared with other patients, there appears to be differences with respect to the type and quality of services offered, raising concerns about equity of care. These differences might partially be related to the model of financial reimbursement. Renewed and productive dialogue between the CSST and PTs is required to improve the different dimensions of patient care and to establish a greater sense of partnership. Work-related musculoskeletal physical disabilities are a significant burden for society, through treatment costs and loss of work productivity. They can also have a devastating impact on the quality of life of injured workers. Addressing systemic issues that limit QoC is a pressing need.

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Barriers and Facilitators to Family Planning Access in Canada

Obstacles et facilité d'accès à la planification familiale au Canada



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Abstract

Background: Contraceptives are underutilized in Canada, and nearly one in three Canadian women will have an abortion in her lifetime. To help delineate a national family planning research agenda, the authors interviewed healthcare providers and organizational stakeholders to explore their perspective on barriers to contraception across regions of Canada. Methods: Semi-structured interviews were conducted based on validated frameworks for assessing family planning access and quality. The authors purposefully selected 14 key stakeholders from government agencies, professional organizations and non-governmental organizations for in-person interviews. Fifty-eight healthcare providers and representatives of stakeholder organizations in reproductive health who self-selected through an online survey were also interviewed. Transcripts were analyzed for repeated and saturated themes. Results: Cost was the most important barrier to contraception. Sexual health education was reported as inconsistent, even within provinces. Regional differences were highlighted, including limited access to family physicians in rural Canada and throughout Quebec. Physician bias and outdated practices were cited as significant barriers to quality. New immigrants, youth, young adults and women in small rural, Northern and Aboriginal communities were all identified as particularly vulnerable. Informants identified multiple opportunities for health policy and system restructuring, including subsidized contraception, and enhancing public and healthcare provider education. Sexual health clinics were viewed as a highly successful model. Task-sharing and expanded scope of practice of nurses, nurse practitioners and pharmacists, alongside telephone and virtual healthcare consultations, were suggested to create multiple points of entry into the system.

Conclusion: Results underscore the need for a national strategic approach to family planning health policy and health services delivery in Canada.

Résumé

Contexte : Les contraceptifs sont sous-utilisés au Canada; près d'une Canadienne sur trois subira un avortement au cours de sa vie. Pour aider à définir un programme national de recherche sur la planification familiale, les auteurs ont interviewé des fournisseurs de services de santé et des responsables d'organismes afin de connaître leurs points de vue sur les obstacles à la contraception dans différentes régions du Canada.

Méthode : Des entrevues semi-dirigées ont été menées, selon des cadres de travail validés, afin d'évaluer la qualité et l'accès à la planification familiale. Les auteurs ont volontairement choisi, pour des entrevues directes, 14 intervenants clés provenant d'agences gouvernementales, d'organisations professionnelles et d'organisations non gouvernementales. Les auteurs ont également interrogé 58 fournisseurs de services de santé et représentants d'organisations (qui se sont portés volontaires lors d'un sondage en ligne) œuvrant dans le milieu de la médecine de la procréation. Les transcriptions ont été analysées pour en dégager les thèmes récurrents et saturés.

Résultats: Le coût est le principal obstacle à la contraception. L'éducation en matière de santé sexuelle est incohérente, même au sein d'une province. Des différences régionales ont été soulignées, notamment l'accès limité aux médecins de famille dans le Canada rural et partout au Québec. Le biais des médecins et des pratiques désuètes ont été indiqués comme d'importants obstacles à la qualité. Les nouveaux immigrants, les jeunes, les jeunes adultes et les femmes dans les petites communautés rurales, du nord et autochtones sont tous des groupes identifiés comme étant particulièrement vulnérables. Les personnes interrogées ont indiqué plusieurs points propices à une restructuration politique et systémique, notamment sur la question des subventions à la contraception et de l'éducation auprès de la population et des fournisseurs de services de santé. Les cliniques de santé sexuelle sont considérées comme un bon modèle de succès. Le partage des tâches et un champ de pratique élargi pour les infirmières, les infirmières praticiennes et les pharmaciens, de même que des consultations téléphoniques et virtuelles, sont proposés comme moyens de créer plusieurs points d'entrée dans le système. Conclusion: Les résultats font voir le besoin d'une approche stratégique nationale pour la prestation de services et pour les politiques de planification familiale au Canada.

Background

As the average age at first birth in Canada nears 30, young Canadians are now passing nearly half their reproductive life span before bearing children (Statistics Canada 2011). Access to the knowledge, services and methods for reliable contraception is an important concern. Women aged 20–29 years continue to represent over half of all those undergoing abortion, and nearly one in three Canadian women will have an abortion at some time in her life (CIHI 2012). Health and social disparities add additional risks to pregnancies and births resulting from unintended conceptions (Frost et al. 2008).

Contraceptives are underutilized: among heterosexual sexually active Canadians not intending to conceive, 15% use no contraception at all, and withdrawal remains the third most used contraceptive method in Canada (Black et al. 2009; Stubbs and Schamp 2008; WHO 2006). Vulnerable populations, including youth and those of low socioeconomic status, are disproportionately affected by unintended pregnancy and abortion, raising concerns about their access to quality contraceptive education and healthcare (Fisher and Black 2007; Saewys et al. 2008). Quality in family planning services has been described as "the way individuals and clients are treated by the system providing services" (Bruce 1990; Jain 1989), and includes access to services. Bertrand and colleagues further developed the concept of access to include the distance clients must travel, the costs, the attitudes of providers and unnecessary administrative barriers (Bertrand et al. 1995). Little is known about access and quality of contraceptive services in Canada and what barriers vulnerable populations experience to meet their contraceptive needs. Members of our network of family planning researchers, the

Contraception Access Research Team/Groupe de recherche sur l'accessibilité à la contraception (CART-GRAC), undertook a national consultation with leaders of professional organizations, organizations representing disadvantaged women's groups and healthcare providers working in the area of women's health. We aimed to identify gaps and opportunities for equitable access to knowledge, services and methods of family planning in Canada. Findings will contribute to the foundation of a national family planning research agenda to inform evidence-based health policy and health services planning.

Methods

This qualitative study (Neergaard et al. 2009) was nested within a national consultation on access and quality of family planning services. CART-GRAC's national bilingual on-line survey on contraceptive access, developed based on theoretical frameworks of Bertrand et al. and Bruce and Jain (Bertrand et al. 1995; Bruce 1990; Jain 1989), is reported elsewhere (Norman and Dunn 2012). This study elicited the views of government agencies, professional organizations, non-governmental organizations and professionals from disciplines involved in sexual healthcare delivery on the most important barriers for access to and quality of contraceptive services, and to suggest solutions.

Study setting

Face-to-face interviews were conducted in Ottawa, Quebec and Toronto between August and November 2011. Telephone interviews were conducted between January and May 2012.

Study participants

Our goal was to obtain a purposeful national sample of respondents that reflected a variety of professional viewpoints across Canada, and incorporate the perspectives of disadvantaged populations, and providers working in the area of sexual health. We recruited key stakeholders from government agencies, professional organizations (medicine, nursing and pharmacy), advocacy and not-for-profit groups for in-person interviews with our research team.

Additionally, we recruited the respondents to CART-GRAC's national bilingual on-line survey, which was initially distributed through established organizations across Canada representing women's health issues, groups providing healthcare to vulnerable populations and key provincial and national agencies with a focus on family planning issues. These organizations in turn distributed the survey through their professional networks (Patton 1990). If respondents consented to be contacted for a semi-structured telephone interview, they were contacted by phone to participate in this study.

Data collection

The interview guide was based on two foundational frameworks on access and quality of family planning services (Table 1) (Bertrand et al. 1995; Bruce 1990; Jain 1989). Questions elicited participants' perspectives on key barriers and solutions to improving access to and quality of family planning under each domain of the framework.

TABLE 1. Theoretical frameworks for access and quality in international family planning

Key domains of access:	Key domains of quality:
(Bertrand et al. 1995)	(Bruce 1990; Jain 1989)
Cognitive: awareness of services, public knowledge Administrative: health system delivery barriers, schedules and wait times, medical barriers – including attitudes of providers and unnecessary eligibility requirements Economic: cost of services Geographic: distance clients must travel to reach services Psychosocial: sociocultural barriers, stigma, fear of pelvic examinations and confidentiality	Choice of contraceptive methods Information given to clients Technical competence Interpersonal relations Continuity and follow-up Appropriate constellation of services

Members of the research team (W.N., E.G., J.S., S.D.) conducted face-to-face interviews with 12 purposefully selected stakeholders, with an additional two interviews conducted by telephone (the interviews took between 20 and 45 minutes). The two modalities are considered equally valid, comparable data collection methods (Patton 1990). Interviewers used handwritten notation to record interview responses.

Two members of the research team (J.H., Research Assistant) conducted semi-structured interviews by telephone in either English or French with the online survey respondents who volunteered to be interviewed. Fifteen interviews were professionally transcribed, and the remainder were transcribed and translated by J.H. due to resource limitations.

One reviewer (J.H.) organized and coded the transcripts through multiple readings to identify meaningful patterns, while also noting discordant views (Guest et al. 2011). TamsAnalyzer® software was used to organize thematic analysis. Predominant themes were periodically reviewed with the research team for input and classification.

Ethics approval was obtained from The University of British Columbia Children's and Women's Hospital Behavioural Research Ethics Board (H11-02495). Verbal informed consent was obtained from each participant. Pseudonyms were used during transcription to ensure anonymity.

Results

In addition to 14 chosen key stakeholders, 17 of the 17 managers and organization leaders and 41 of the 53 healthcare providers who had indicated in the online survey their interest in being interviewed participated, for a total of 72 interviews. Informant demographics are outlined in Table 2.

Barriers and Facilitators to Family Planning Access in Canada

TABLE 2. Informant demographics

	Language of	correspondence
	English (N = 53)	French (N = 19)
Professional category		·
Nurses, midwives and nurse practitioners providing reproductive health services	14	6
Family physicians/paediatricians providing reproductive health services	6	2
Physicians performing medical and/or surgical abortion	3	I
Other (sexual health counsellors, social workers, psychologists, support workers)	2	
Health Service Administrators, abortion and reproductive health services (often also practicing clinicians)	6	2
Managers, public health agencies (regional and national)	6	
University-based clinician researchers	4	
University-based medical/health professional educators	3	
Directors, organizations representing women and vulnerable populations	2	5
Leaders, Provincial and National reproductive health organizations	3	I
Leaders, Health professional organizations	4	2
Province/territory		•
Yukon	I	2
Northwest Territories	ı	
British Colombia	13	
Alberta	2	
Saskatchewan	1	
Manitoba	3	
Ontario (including Ottawa-based national organizations)	22	
Quebec	3	15
New Brunswick	2	2
Nova Scotia	5	

Predominant concepts and themes are summarized in Table 3, and outlined in the following text.

TABLE 3. Barriers to comprehensive family planning access and proposed solutions

Barriers	Solutions
Cost Cost of contraception is one of the primary barriers to access nation-wide Provincial and private insurance plans often limit access to the full range of contraception options High up-front cost of the intrauterine system (IUS) Prohibitive cost of travel, accommodation, abortion procedures	Universally subsidize contraception through public financing and mandated, regulated insurance Specifically find ways to subsidize the IUS/IUD Expand travel assistance programs and establish provincial reciprocal agreements for abortion procedures and IUD insertions Look to Quebec for financing models
Nowledge among the general public Weak and highly variable sexual health education across the country, with regional variability between and within provinces Efficacy and the long-term effects of hormonal contraception and the IUD are poorly understood	Prioritize early sexual education in schools as the cornerstone for boosting public knowledge Tailor accurate online and social media resources to youth, Aboriginal Canadians, new immigrants and people with disabilities Pilot confidential phone line and text messaging services for Native communities and other groups for reproductive health
Healthcare provider competence Inappropriate prescribing patterns and outdated contraindications to birth control methods Reproductive health limited in medical and nursing curricula Limited scope of practice for FPs, nurses and midwives. Shortage of providers inserting IUDs.	questions • Standardize interprofessional pre- and postgraduate education in evidence-based family planning, including surgical and medical abortion • Require continuing education programs for allied health professionals and community actors similar to the Quebec Institute of Public Health online contraceptive training program
Healthcare provider attitudes Bias against specific groups, like adolescents, or against prescribing any form of contraception Refusing referral for abortion, resulting in delays, notably in the Yukon, Prince Edward Island and New Brunswick, which require physician referrals Lack of unbiased and confidential providers for contraception and abortion care available in northern and small communities	Create multiple points of entry into the system through: • Specialized reproductive health services, including drop-in sexual health and youth clinics, open during evenings and weekends. Include rural areas and Aboriginal communities. Consider mobile clinics. Expand the range of family planning providers through task sharing and expanded scope of practice of allied health professions
Health system access Limited access to regular primary care providers nation-wide, especially in small to medium-sized towns and throughout Quebec Fee-for-service compensation and rushed patient scheduling limits the quality of comprehensive family planning counselling	Advocate for expanded scope of practice recognized by governing bodies of allied health professionals Measure the impact of existing task-sharing agreements in Alberta Quebec, Ontario and British Columbia Expand the study to include the impact of select methods available over the counter
Vulnerable populations Rural, remote and Aboriginal communities lack confidential and unbiased care Youth and young adults transitioning out of the formal education system cannot confidentially use their parents' insurance New immigrants and the working poor lack coverage if they are not on income assistance	Telephone and virtual healthcare consultations Utilize telephone consultations among nurses, pharmacists and midwives to obtain authorization for contraception in rural areas Pilot task-sharing options and Internet medical consultation for rural medical abortion

Barriers to access

COST BARRIERS

The cost of contraceptive methods was the most important barrier to family planning cited by informants. Women who are least able to afford contraception are also least likely to be insured. Participants shared stories of sacrifice and unwanted pregnancies owing to the cost of contraceptives, especially among adolescents, young adults no longer eligible for youth clinics,

immigrants and the working poor. "But it's in between ones, the working poor, who just - they just can't afford that." (Nurse Practitioner, Ontario). This often results in these groups "abandoning birth control en route" (Nurse, Quebec).

Traditionally, sexual health clinics have tried to reduce the cost barrier by offering subsidized low-cost contraceptives. However, "The cost of contraceptive medications, even at a cheaper, compassionate rate, are continually going up and up and up" (Manager, Health Unit, Ontario), and organizations reported spending a growing portion of their budgets to subsidize contraception. The Society of Obstetricians and Gynecology of Canada compassionate care program is limited because "Physicians either don't know about it, or they find the [paperwork] rather onerous." (Sexual Health Nurse, Ontario). Respondents were also concerned that insurance plans excluded certain contraceptive methods. Quebec's pharmacare plan and many private insurance schemes exclude the copper intrauterine device (IUD) on the basis that it is not a drug. Other third-party schemes only cover the intrauterine system (IUS) for heavy menstrual bleeding, but not for contraception. Informants specifically highlighted that the prohibitive up-front cost of the IUD/IUS should be addressed.

"We have to make the IUD and long-term methods more accessible to the public, because if you don't have a family doctor, at least you have five years to find one." (Nurse, Quebec)

The cost of travel and accommodation and the cost of therapeutic abortion itself in private abortion clinics were reported as major barriers for Canadian women living outside of urban areas. Reciprocal agreements between provinces to cover the costs of therapeutic abortion are lacking. The exception was among respondents in Quebec, who reported fewer cost barriers, and far fewer barriers as a whole to abortion care.

INCONSISTENT SEXUAL HEALTH EDUCATION AMONG THE GENERAL PUBLIC Informants cited schools as the cornerstone for public family planning knowledge, but noted inconsistent sexual education as a common problem in schools. Those working with strong school sexual education programs saw this as a major strength, whereas weak school programs were seen as contributing to major knowledge gaps. School curricula were often characterized as: "not standardized, taught by some teachers that don't want to talk about it, a very small number of hours, and not a very good program" (Public Health Nurse, British Columbia). Regional variability between and within provinces was highlighted. New Brunswick informants, for example, identified sexual health knowledge as lacking among Anglophone women compared to Francophones, acknowledging better quality sexual education in the Frenchlanguage school system.

INCORRECT AND OUTDATED KNOWLEDGE OF CONTRACEPTION AMONG HEALTHCARE PROVIDERS

Antiquated beliefs or biases towards certain contraceptive methods were widespread among healthcare workers, according to many informants. They cited a tendency to prescribe oral contraceptive pills over other methods, even when women were having difficulty taking a daily pill on time.

"I had a patient the other day whose physician refused her Depo-Provera because she was a teenager. ... because I spoke to her after she had her baby, and I said, 'What birth control would you like?' and she says, 'Well, I'd like the needle, but they told me I wasn't a good candidate.' She ... received poor information from her healthcare provider. And she ended up pregnant, consequently." (Nurse Practitioner, Manitoba)

Outdated contraindications to birth control methods included women being encouraged to "take a rest" from hormonal contraception, providing three or six months of contraception prescriptions to encourage frequent reassessments and denying hormonal contraception to all women over 35 regardless of risk factors. There was also a pervasive misperception that IUDs cannot be used in nulliparous women.

Informants in Prairie Provinces expressed concern that reproductive health was no longer a mandatory part of medical and nursing curricula, with a resulting narrow scope of practice that often excludes IUD insertions. Quebec informants, for example, indicated that gynae-cologists were the only practitioners inserting IUDs in some parts of the province, and sexual health centres in Manitoba receive referrals from family physicians for IUD insertions.

NEGATIVE PHYSICIAN ATTITUDES AND CONFLICTS WITH PERSONAL BELIEF Respondents described a number of experiences with physicians who refused to prescribe contraception, either by targeting specific groups such as adolescents, or refusing to provide contraception altogether, which was described as particularly affecting women living in rural areas who "...are unable to be picky about who can work in these communities" (Manager, Northern Health Services).

"We have a physician in our county who will not prescribe birth control because he doesn't believe in it. So for religious reasons ... [he] puts his women patients in a spot. We have a doctor shortage in our county. They can't change doctors, and the College of Physicians and Surgeons tell him it's okay. He doesn't have to prescribe it. If he doesn't believe in it, he doesn't have to." (Family Physician, Saskatchewan)

In Prince Edward Island, New Brunswick and the Yukon, where women require referrals for abortion services, as well as rural and Northern communities, informants described difficulty in finding a physician who will refer, with resulting delays in abortion care.

"She went to the walk-in clinic and the doctor there said – he said, Oh, well, you might as well keep the baby. Do you know how hard it is to get pregnant?' and she was crushed, terrified, upset, didn't know what to do. Because she went for help and this man told her that - 'You're lucky to be pregnant. Why would you want to get rid of it?" (Family Physician, New Brunswick)

System barriers to health service delivery

Many Canadians do not have a regular primary care provider, and "where else are you going to go for contraception?" (Family Physician, Saskatchewan). Informants at all levels in Quebec cited difficulty accessing a family physician as the major barrier to contraception. This deficit was echoed in the Prairie and Maritime Provinces, where young adult women have even greater difficulty finding a primary care provider.

Fee-for-service compensation and rushed patient scheduling were faulted for a lack of appropriate family planning counselling from physicians, underpinning the bias against methods (other than oral contraceptive pill) that require time to explain, or against IUD insertion, which may not be well-compensated. Physicians were perceived as "dealing with contraception like you deal with the common cold, take these pills every day and you'll be fine, without the targeted counselling required" (Nurse, British Columbia).

"This is ridiculous that we've got doctors working as businessmen, you know, and that ... kids need - youth especially - sometimes need a 45-minute visit to go over birth control so that they'll use it effectively. And a 45-minute visit is not realistic in a family clinic that's fee-for-service." (Nurse Practitioner, British Columbia)

Special needs of vulnerable populations

A number of populations were identified as particularly vulnerable to barriers related to confidentiality, quality of care, healthcare provider bias, geography and cost.

Rural, Northern and Aboriginal communities face a unique set of challenges related to provider attitudes. These patients have very limited choice in healthcare providers and are not assured confidentiality in settings where they may know everyone working at the clinic.

"In the north, the access – cost is not the issue. It's access, it's confidentiality ... these are the issues in the north." (Manager, Northern Health Services)

Many informants offered anecdotes of women hitchhiking hours to find a provider willing to refer them for abortion, or to seek non-judgmental contraception care. Stories emerged of women's families discovering they were pregnant before they had even returned from the clinic, or blocking the passage of the plane destined to a referral centre for therapeutic abortion.

In addition to significant geographical barriers and the lack of service providers, informants who work closely with Aboriginal populations suggested much of the messaging about family planning remains culturally irrelevant, focused on "preventing births" rather than "planning the family." Informants also highlighted the lack of tailored, culturally relevant outreach to new immigrants.

Across Canada, informants reported that young adults who transition out of the formal education system are left without sexual health education or access to the sexual health services typically associated with educational institutions. Young adults who no longer qualify for "youth services" are especially vulnerable. Some government and health institutions respond to this by trying to alter the definition of "youth" to 25 or 30 years of age to serve these clients.

"So what we see a lot of is the late teens, early twenties, who are working, often parttime jobs, often minimum wage, maybe they're going to school part-time desperately trying to not be pregnant at the same time, and really that 20 dollars a month is a struggle for them to be on birth control. And there's no subsidy for these youth." (Nurse Practitioner, British Columbia)

Findings related to recommendations for health system improvements

Participants identified a number of concepts and strategies for addressing gaps in access and quality.

FREE OR SUBSIDIZED CONTRACEPTION

Almost *every* informant, from healthcare workers to decision-makers, emphasized that the full range of contraceptive methods should be made freely available, or at a highly subsidized cost through public financing or through mandated, regulated insurance. Several participants specifically cited Quebec as a potential model, where youth under 18 years and youth aged 19–25 who are still students living with their parents can access free contraception, and there is a universal provincial drug insurance plan with a small monthly deductible.

"In my opinion, all contraception should be at extremely low cost, like one dollar for birth control pills or IUDs. Indeed, in my office last week, I had a young woman who wants to have an IUD, and she cannot afford it. She does not have 200 dollars for an IUD. And so she is using withdrawal method. I was appalled that this is happening now I've been in medicine for 40 years, and things have not improved ... very much in those 40 years. So in my opinion, the government or somebody should subsidize all contraception to make it as cheap as possible so it's easy to access for all women." (Family Physician, British Columbia)

Barriers and Facilitators to Family Planning Access in Canada

MULTIPLE POINTS OF ENTRY INTO THE SYSTEM

To overcome barriers faced by vulnerable populations, including regional disparities, the lack of accessible, quality healthcare providers, and the provider attitudes that restrict access, respondents suggested multiple means of accessing reproductive care.

SPECIALIZED REPRODUCTIVE HEALTH SERVICES.

"Having clinics whose sole purpose is ... women's reproductive care is one way of ensuring that it's a safe place for women to come and be able to ask anything and be provided with unbiased information." (Sexual Health Educator, British Columbia)

Respondents, from stakeholder organizations to service providers, endorsed specialized sexual health clinics as an appropriate strategy because they answer to the "who, when, how" of accessing timely services and knowledgeable practitioners and assure confidentiality and non-biased providers. Informants working with Aboriginal populations and youth specifically cited drop-in family planning clinics open on weekends as a "best practice," and imperative for young people outside of the formal education system or who no longer qualify for youth clinics. Suggested program models include Options for Sexual Health clinics in British Columbia, Planned Parenthood information services and clinics in other parts of Canada and maintenance of the "Cliniques de Planning" in Quebec.

EXPAND THE RANGE OF FAMILY PLANNING PROVIDERS THROUGH TASK SHARING AND EXPANDED SCOPE OF PRACTICE OF ALLIED HEALTH PROFESSIONS.

Respondents advocated for broadening the scope of practice of nurse practitioners, registered nurses and pharmacists to help bypass access barriers to reproductive health services. "There's no reason I see why nurse practitioners couldn't do medical abortions – we already do IUD insertions and we manage miscarriages within our scope of practice" (Nurse Practitioner, British Columbia). A number of key stakeholders and healthcare providers specified that contraceptives should be provided over the counter, citing recent, positive experience with behind-the-counter emergency contraception. Stakeholders from national and provincial medical, nursing and pharmacy professional organizations generally expressed openness to collaborating with each other for expanded scope of practice among allied health professionals. One model cited is the Collaborative Agreement on Hormonal Contraception in Quebec, which allows a certified nurse or pharmacist to initiate hormonal contraception (OIIQ 2012). Nurses stressed the imperative to expand the duration and responsibility of nurses in family planning, given how many women are still unable to find a family physician.

UTILIZE TELEPHONE AND VIRTUAL HEALTHCARE CONSULTATIONS.

Informants suggested telephone consultations among allied healthcare professionals to obtain authorization for contraception, such as the 24-hour telephone consultation services like HealthLink in Alberta and British Columbia or Info-Santé in Quebec. A few respondents also suggested piloting Skype and telephone consultations to expand access to medical abortion care. Confidential hotlines and text messaging services may also help Aboriginal and rural contraceptive users access confidential care.

IMPROVE PUBLIC AND HEALTHCARE PROVIDER EDUCATION

School-based sexual health programs were cited as the "low hanging fruit" to improve family planning knowledge and empower the public. To complement school-based programs, informants suggested that we tailor appealing online and social media resources to youth and specific groups such as Aboriginal Canadians, new immigrants and people with disabilities. "The deaf really use internet, but women need information in their [French] language. This would cost so little and make such a difference." (Director, non-governmental organization).

Respondents called for expanded undergraduate and continuing education family planning training programs for physicians, nurses and midwives, including updated information on abortion. The National Institute of Public Health of Quebec online family planning training program for nurses and the Ontario College of Family Physicians Advanced IUD Insertion Training Program were both cited as potential models.

Discussion

There is remarkable congruency between the family planning barriers, inequities and solutions proposed by healthcare professionals, managers, advocacy organizations and leaders of key provincial and national stakeholder organizations. The access issues raised in this study lend themselves to a number of health services and policy solutions.

Almost every informant cited cost as the central barrier to contraception access in Canada. Health policies to provide subsidized contraception could eliminate this barrier. Such policies have been shown to be cost-beneficial in a number of jurisdictions including the US (Frost and Frohwirth 2010) and Great Britain (Frost et al. 2008; Hughes and McGuire 1996; Paton 2002) by reducing the costs of unintended pregnancy. Our results suggest that Canadian family planning providers would strongly support subsidized family planning. Quebec informants cited few financial barriers, where provincial drug insurance covers the full cost of contraception to women in high-risk groups, and otherwise subsidizes about 80% of the cost of medications, including the IUS, which costs 82.66\$ (RAMQ 2014). This is thought to explain higher uptake of IUDs in Quebec (7% vs. 4.3% elsewhere in Canada) (Black et al. 2009).

This study also highlights a call from healthcare professionals to create multiple points of entry for users to access contraception in Canada. The problematic issues of lack of professionalism and healthcare provider bias, and the special needs of rural, remote and vulnerable populations, could be addressed through multiple modalities, including expanding the number

of providers through task sharing among health disciplines such as nursing, medicine and pharmacy for prescribing of contraceptives, specialized reproductive health clinics, enhanced health professional and public education, confidential telephone hotlines and culturally relevant social media. There is a major role for public health and government in planning and delivering these services.

It is an opportune time for policy makers to promote task sharing. Evaluations of the Canadian healthcare system indicate that allied healthcare professionals are underutilized (Fyke 2001; Romanow 2002). At the same time, professional associations seem increasingly open to negotiating scope of practice and task-sharing agreements. Evidence to support this shift is quickly accruing: the Quebec Collaborative Agreement on Hormonal Contraception has greatly facilitated contraceptive access in the province (Guilbert et al., 2011, 2013a, 2013b); the uptake of emergency contraception doubled in British Columbia after regulatory change allowed direct access from pharmacists (Soon et al. 2005); pharmacists in many provinces now provide the influenza vaccine (Pearson 2007); BC pharmacists are receptive to independent prescription of hormonal contraception (Norman et al. 2013; Wong et al. 2014); and the Registered Nurses' Association of Ontario currently advocates for authorization of registered nurse prescribing (Di Costanzo et al. 2012). Over-the-counter contraception is well-aligned with the American College of Obstetricians and Gynecologist's position since 2012 (ACOG 2012). There is also strong international evidence for the safety of mid-level providers to provide medical abortion and IUD insertion (Farr et al. 1998; Jejeebhoy et al. 2011; Warriner et al. 2006).

Our study has limitations. Our convenience national sample did not allow for in-depth explorations of local policy issues. We interviewed decision-makers, managers and healthcare provider volunteers who work closely with women and couples, but who may not reflect the direct perspective of contraceptive users or the majority of contraceptive providers.

These results underscore the urgent need for a national strategic approach to family planning health policy and health services delivery in Canada. Healthcare providers, and leaders among national professional and advocacy organizations sampled, clearly indicated a need for equitable access to affordable contraceptive methods, knowledge and services in Canada, particularly among marginalized and vulnerable populations. This formative research will inform future directions for health services and policy research and equity-enhancing strategies within Canada's evolving healthcare system.

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Drugs to Avoid Treatment Interruptions or
Delayed Treatment Initiation among HIV-Positive
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Recours à la distribution compassionnelle de médicaments antirétroviraux afin d'éviter les interruptions de traitement ou les délais dans le début de traitement chez les patients séropositifs qui vivent en Ontario : revue rétrospective



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Use of Compassionate Supply of Antiretroviral Drugs to Avoid Treatment Interruptions or Delayed Treatment Initiation among HIV-Positive Patients Living in Ontario: A Retrospective Review

Abstract

Background: Without a national pharmacare plan in Canada, HIV-infected patients across the nation differ in their ability to obtain essential HIV therapy. Despite the fact there are public insurance programs in Ontario, patients are unable to access medication. The authors described how frequently patients in their urban clinic could not access medications and why they required a compassionate supply of HIV drugs, with the goals of minimizing treatment delays and avoiding interruptions.

Methods: The authors conducted a retrospective review and collected information about demographic characteristics, current drug insurance and the challenges encountered. Results: Over one year, the authors provided 2,886 days of free HIV drugs to 42 patients who were predominantly citizens or permanent residents of Canada (88%). The most common obstacles were associated with the Trillium Drug Program and the total value of all drugs supplied was \$134,860.

Interpretation: This study suggests that Ontario's catastrophic drug insurance plan leaves some patients with significant gaps in drug coverage.

Résumé

Contexte : En l'absence d'une assurance médicaments nationale au Canada, il existe des différences, chez les patients séropositifs, dans la possibilité d'obtenir un traitement contre le VIH. Les auteurs décrivent à quelle fréquence et pour quelles raisons les patients de leur clinique urbaine n'ont pu accéder au médicament et, par conséquent, ont dû bénéficier d'une distribution compassionnelle de médicaments contre le VIH afin de minimiser les délais ou d'éviter l'interruption du traitement, et ce, malgré la présence de programmes d'assurance publiques en Ontario.

Méthode : Les auteurs ont effectué une revue rétrospective et ont recueilli des renseignements démographiques en plus d'informations sur l'assurance médicaments en place et sur les défis rencontrés.

Résultats : Pendant une année, les auteurs ont fourni gratuitement l'équivalent de 2 886 jours de médicaments contre le VIH à 42 patients qui étaient très majoritairement citoyens canadiens ou résidents permanents au pays (88 %). L'obstacle le plus fréquent était associé au Programme de médicaments Trillium. La valeur totale de l'ensemble des médicaments fournis était de 134 860 \$.

Interprétation: Cette étude laisse entendre que le régime d'assurance des médicaments onéreux ontarien donne lieu à d'importantes lacunes pour ce qui est de la couverture de médicaments chez certains patients.

Introduction

Current antiretroviral therapy regimens for people living with HIV have undeniable benefits but are also very costly. Antiretroviral therapy prolongs survival, reduces morbidity and decreases the risk of vertical and sexual HIV transmission to uninfected individuals (Connor et al. 1994; Cohen et al. 2011; Cooper et al. 2002; Hogg et al.1999; Palella et al. 1998). The success of antiretroviral therapy, however, is highly dependent on adherence, where non-adherence is associated with increased or rebound viremia, the development of drug resistance and consequent HIV-associated morbidity and mortality (Bangsberg et al. 2001, 2007; Hogg et al. 2006; Fielden et al. 2008; Lima et al. 2009). As transmission of HIV is strongly correlated with HIV plasma concentration, treatment interruption also increases the risk of transmission from HIV-infected persons to uninfected sexual partners and from HIV-infected pregnant women to their children (Garcia et al. 1999; Quinn et al. 2000). The major determinants of non-adherence include regimen complexity, drug toxicity and financial burden to access the medications (Kranzer and Ford 2011; Nachega et al. 2014; Osterberg and Blaschke 2005; Vermeire et al. 2001). Research published in 2012 found that about 1 in 10 Canadians reported cost-related non-adherence, with proportions ranging from 3.6 to 35.6% depending on having drug insurance and total household income (Law et al. 2012). In an Australian study, HIV-infected patients who had suboptimal adherence owing to financial stress reported that they had delayed purchasing their medication or discontinued them altogether (McAllister et al. 2013). Thus, prescribing effective yet simple and tolerable regimens for which patients incur little or no out-of-pocket expense is likely to improve outcomes.

Antiretroviral therapy is life-long, and a preferred first-line regimen currently costs about \$1,400 each month (MOHLTC 2014). Canadian jurisdictions vary considerably in the formulary listings and degree of public coverage for prescription medications used outside of a hospital setting (Demers et al. 2008). Antiretroviral drugs are no exception. They are provided free of all charges to all registered residents in British Columbia and Alberta through their specialized programs, while in most other jurisdictions, patients pay a co-payment or deductible (see Table 1 at www.longwoods.com/content/24148). In Ontario, all individuals who are 65 years old or older with a limited income or who are receiving social assistance can access many medications, including antiretrovirals drugs, through the Ontario Drug Benefit program for a nominal co-payment. Aboriginal Canadians can obtain HIV medications free of charge through Health Canada's Non-Insured Health Benefits program, while patients who are refugee claimants have free medication insurance through the Interim Federal Health Program. Patients who have legal status in Canada and have been living in Ontario for at least three months but do not qualify for any of these programs can enroll into the Trillium Drug Program (TDP), the catastrophic drug insurance plan that aims to protect Ontarians with high drug expenses (relative to their earnings) from financial hardship. The TDP requires payment of an annual deductible that varies relative to household income, followed by a co-payment once the deductible is reached. For example, the deductible for a single-person

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household with a net income of \$25,000 is \$714 per year, while the deductible for a household of four persons with a net income of \$60,000 is \$2,139 per year. As the deductible is paid in instalments, once the quarterly deductible is met, patients then have a \$2.00 co-payment for every prescription until the next quarter.

Despite the availability of these programs, some patients in Ontario still encounter obstacles that typically fall into three categories. First, some patients are unable to manage the financial requirements and arrangements of the plan. This includes individuals who are eligible for the TDP but cannot consistently afford the program's deductibles as well as patients who have both private insurance and Trillium coverage but are unable to regularly pay the out-of-pocket co-insurance portion (such as 20% of an 80% coverage insurance plan) with each prescription and await reimbursement from the public plan. Second, some patients are in a coverage "gap" between insurance plans. For example, a patient whose refugee claim has been approved may find herself without coverage because she no longer qualifies for federal insurance and her application for a provincial plan is pending. Third, some patients are in Canada without legal status and thus do not qualify for public insurance. The potential consequence of these challenges are treatment delays or interruptions, which in HIV management results in uncontrolled viral replication, increased risks of HIV transmission, the development of drug resistance and disease progression (SMART study group 2006). Anecdotally, to avoid delays or HIV treatment interruptions, many physicians and pharmacists attempt to provide essential antiretroviral therapy to such patients who require treatment but face challenges in accessing the medications. These medications are typically donated on a compassionate basis by pharmaceutical manufacturers. Our objectives were to evaluate the gaps in drug coverage at our clinic by describing the frequency with which clinicians provided free supplies of antiretroviral medications, characterizing individuals who received these supplies and the reasons they needed compassionate supply and estimating the dollar value of the medications dispensed.

Methods

We retrospectively reviewed medications given to patients free of charge between June 2011 and May 2012 at the Positive Care Clinic of St. Michael's Hospital in Toronto, Ontario, which at the time provided tertiary outpatient care to approximately 1,200 HIV-positive patients. We collected data pertaining to individuals' demographic characteristics, the duration of their HIV diagnosis, their most recent CD4 count and viral load, their current prescription drug coverage plan, the obstacle encountered that led them to require assistance and the intended plan to re-establish drug access. When available, we recorded whether patients experienced a cost-related interruption in therapy and the duration of the gap.

We classified the type and quantity of antiretroviral medications provided according to the regimen and formulation in the compassionate supply. We defined a "regimen of choice" as continuation of the same drugs for patients who were currently receiving antiretroviral therapy. We defined a "formulation of choice" as a continuation of the same formulation. For example, a patient who was receiving a combination tablet containing efavirenz, tenofovir and emtricitabine and was subsequently given each medication as separate tablets would be classified as having received the regimen of choice but not the formulation of choice. For patients who did not receive the regimen of choice, we classified the new regimen as "preferred," "alternative" or acceptable," using the most current U.S. Department of Health and Human Services guidelines (January 2011; October 2011; March 2012). A patient who was antiretroviral-naïve and given a regimen from the preferred category was also defined as having received a "regimen of choice." The number of days without antiretroviral medications that were averted was calculated based on the number of days of drug supply dispensed. Finally, we calculated the cost of the supplied antiretroviral medications using Ontario Drug Benefit formulary prices, excluding mark-ups and professionals' fees (MOHLTC 2014). The study was approved by the Research Ethics Board of St. Michael's Hospital and was not externally funded.

Results

Over one year, we gave antiretroviral medications free of charge to 42 HIV-positive patients at 95 visits, representing about 4% of the total patients followed and 4% (95/2,279) of the clinic volume seen during that period. The median number of visits per person was two (interquartile range: 1–3). The median age of patients receiving medications was 40 years, most were men and 23 (55%) were immigrants from an endemic country (Table 2). Of the patients who received a compassionate supply of antiretroviral therapy, only five (12%) were not a Canadian citizen or landed immigrant. This group included people who were refugee claimants appealing a negative decision, individuals in Canada under a student visa and people in Canada without documented status. Among the 35 patients who were currently receiving antiretroviral therapy, 26 (74%) had an undetectable viral load at their first visit. Of the seven patients who were antiretroviral-naïve at the first visit, five (71%) had a CD4 count less than 200 cells/ mm³ and two were HIV-positive pregnant women.

Among the 35 patients who had taken antiretroviral medications before receiving a compassionate supply, the most common prior coverage was through the Ontario public drug program; 13 (37%) were insured by the TDP and five (14%) were insured through public assistance. The clinic gave medications to seven patients (21%) who had received medication benefits through the Interim Federal Health Program, six (17%) who had private insurance and four (11%) who had started antiretroviral therapy during a hospitalization and had no medication insurance at discharge. While we did not systematically evaluate cost-related nonadherence, three patients recalled missing approximately one week, six months and one year of antiretroviral medications for this reason, with two patients specifically stating they were unable to afford the deductible of the public plan.

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TABLE 2. Demographic characteristics of 42 patients who received a compassionate supply of antiretroviral drugs*

Characteristic	N (%)
Age-years, median (IQR) [†]	40 (32–47)
Male	29 (69)
Ethnicity	
White	9 (21)
Black	25 (60)
Other [‡]	8 (19)
Canadian citizen or landed immigrant	37 (88)
HIV risk factor	
Men who have sex with men	18 (62)
Immigrant from endemic country	23 (55)
Injection drug use	0 (0)
Duration of HIV infection diagnosis – years, median (IQR)	3.4 (0.8–6.4)
Taking antiretroviral medication at the first visit	35 (83)
Duration of antiretroviral therapy – years, median (IQR)	1.4 (0.7–3.5)
CD4 count – cells/mm³, median (IQR)	
Most recent	430 (234–594)
Nadir	235 (82–322)
Viral load – copies/mL, median (IQR)	
Most recent	Undetectable (undetectable to 46)
Highest viral load documented	38,786 (2,026–129,094)
Not taking antiretroviral medication at the first visit	7 (17)
Most recent CD4 count – cells/mm³, median (IQR)	132 (31–377)
Most recent viral load – copies/mL, median (IQR)	53,266 (1,353–107,196)

^{*}Numbers in table are N (%) unless otherwise indicated.

‡Other ethnicity includes South and South East Asian, Latin and Arab or West Asian.

We analyzed the reasons for problems in drug coverage by visit (Table 3). Over 95 visits, the most common problem with drug insurance coverage (at 29 visits [31%]) was that patients were waiting for their application to the TDP to be approved or had been asked for additional paperwork. Among all obstacles, 63 (66%) were associated with the TDP and were primarily

[†]IQR denotes interquartile range.

due to pending activation, status change requiring enrolment into Trillium, inability to make a payment towards the annual deductible or incomplete renewal paperwork to maintain enrolment. Other obstacles that patients encountered with TDP included an incorrect activation date and in five occurrences (5%), the inability to afford the co-insurance upfront and await reimbursement.

TABLE 3. Obstacles encountered with drug insurance plans that prevented patients from accessing HIV medications, by visit

	Problem related to the Trillium Drug Program		
	No (n = 32)	Yes (n = 63)	
Obstacle	N (%)	N (%)	
Awaiting activation or additional paperwork required for Trillium	0 (0)	29 (31)	
Status change requiring enrolment into new program	8 (8)	10 (11)	
Renewal of Interim Federal Health Insurance denied	15 (16)	0 (0)	
Unable to meet deductible set by Trillium	0 (0)	10 (11)	
No insurance and unable to pay out of pocket	8 (8)	0 (0)	
Program enrolment expired	0 (0)	5 (5)	
Limits on private insurance requiring enrolment into new program	0 (0)	3 (3)	
Other*	l (l)	6 (6)	

^{***}Other* obstacles included the inability to pay a co-insurance upfront and wait for reimbursement from the public plan, an incorrect request for a delayed start date to the Trillium Drug Program and the inability to pay for a private plan's premium.

We generally provided 30 days of medications to allow sufficient time for the coverage issue to be resolved, although 23 patients (55%) required at least one additional visit to establish or re-establish coverage. Based on availability, we gave medications that resulted in a regimen of choice at 78 visits (82%) and at 32 (41%) of these visits, we gave formulations of choice (Table 4). We did not provide any antiretroviral medications that produced "unacceptable" regimens, although at 58 visits (61%), we gave medications that resulted in regimens with an increased pill burden and at five visits (5%), the resultant combination led to an increased pill burden and frequency of administration compared with the regimen received before the gap in coverage or what would have been desired had there not been a financial obstacle in initiating therapy.

Overall, we gave out 202 antiretroviral drugs and the total number of medications dispensed averted 2,886 cost-related non-adherence days. The most common product dispensed was combination tenofovir/emtricitabine, which was given 64 times (32%) and was valued at \$54,126, followed by efavirenz, which was given 48 times (24%) and valued at \$25,329. The median value of medications given per individual was \$1,995 (inter-quartile range: \$1,341 to \$4,024), and the maximum amount for any single individual was \$16,958. The total value of all medications given was \$134,860.

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TABLE 4. Characteristics of compassionate antiretroviral regimens supplied over 95 visits

Regimen characteristic	N (%)
Regimen of choice	78 (82)
Formulation of choice	32 (43)
Change in daily pill burden and frequency	
No change	32 (34)
Increased pill burden	58 (61)
Increased pill burden and frequency of administration	5 (5)
Not regimen of choice	17 (18)
"Preferred" regimen*	0 (0)
"Alternate" regimen*	13 (14)
"Acceptable" regimen*	4 (4)
May be acceptable but "use with caution" or "not acceptable"	0 (0)

^{*&}quot;Preferred," "Alternate" and "Acceptable" regimens are as those defined by the Department of Health and Human Service guidelines that were current at the time of the study (January 2011; October 2011; March 2012): those with "optimal and durable efficacy, favorable tolerability and toxicity profile, and ease of use," "effective and tolerable but have potential disadvantages compared with preferred regimens" and less satisfactory than preferred or alternative regimens, respectively.

Interpretation

Our results suggest that HIV-positive individuals residing in Ontario may be experiencing challenges in accessing and affording their antiretroviral medications. Over one year, to avoid treatment delays or treatment interruptions, we gave out close to eight years worth of antiretroviral medications valued at \$134,860 to 42 patients, an average of 69 non-adherence days averted per person. We believe this is likely an underestimate of the number of patients facing financial challenges, as we only included individuals who informed us that they were experiencing a financial problem accessing their medications. We did not systematically categorize other patients and did not include patients who might receive supply from the hospital pharmacy, visit the Toronto People With AIDS Foundation (which runs a large medication access program), share medications with others, buy medications informally from non-pharmacy or non-Canadian sources, not return for a clinic visit and be lost to follow-up, discontinue taking their therapy or defer initiating antiretroviral therapy. We think it is unlikely that patients who could otherwise afford the cost of drugs used compassionate antiretroviral drug supplies to avoid out-of-pocket payments, as each patient received a comprehensive assessment of the financial obstacle from the multidisciplinary team, including a social worker.

About two-thirds of the problems encountered were associated with the TDP, Ontario's catastrophic drug insurance plan. Each jurisdiction in Canada develops and administers its own independent medication insurance program, with varying eligibility criteria and

cost-sharing requirements. Following the 2004 federal-provincial health accord that had a goal of ensuring "no Canadian suffers undue financial hardship in accessing needed drug therapies" (Health Canada 2004), most provinces and territories have arranged to provide comprehensive drug coverage with minimal or no out-of-pocket spending for social assistance recipients and many have since adopted an income-based catastrophic coverage model for their general, non-senior population (Daw and Morgan 2012). Our results, however, suggest that the cost-sharing arrangement required of many HIV-positive patients in Ontario may have an impact on the affordability of antiretroviral medications for a significant number of people. We found that the TDP deductible, which is approximately 4% of the previous year's household net income, often presents a challenge; this may be particularly true for patients who are intermittently employed and have a variable income throughout the year. This financial hardship may compel some people to make difficult decisions such as remaining unemployed and thus qualifying for social assistance. Other patients, like two in our study, might discontinue treatment until they can afford to restart.

In addition to financial barriers, administrative difficulties with the TDP seem to represent burdens for some individuals. Initial enrolment into the program involves navigating, completing and mailing of a paper application by the patient along with mandatory accompanying documentation, including proof of income. This process typically takes four to six weeks; however, delays include incomplete forms, the time it takes for the Ministry to receive the application, the volume of applications to be reviewed and the availability of completed tax returns or other acceptable documents confirming income and private insurance benefits. Without an efficient and automated system, we found some patients were left in a coverage gap, particularly when there was an unexpected change in qualifying for their current insurance program, causing them to apply to the TDP and wait for their paperwork to be approved. Other patients who were already enrolled in Trillium occasionally found their plan was suspended and not renewed due to the requirement for new additional documents or signatures. During this interim of pending activation or renewal, only the few patients who could afford to pay the full cost of HIV medications can access their medications. The majority must delay initiation or experience a treatment interruption.

Refugee claimants appealing a negative decision were another vulnerable group requiring compassionate medication supplies. While they are legally allowed to remain in Canada, at the time of our study, they no longer qualified for health insurance, including medication coverage. On January 1, 2014, however, the Ontario Temporary Health Program was launched to address coverage gaps from the downscaling of the Interim Federal Health Program and to provide essential health and medication coverage to people whose refugee claims were denied. This program would have provided drug coverage to only two of our patients.

Financial constraints contribute to medication non-adherence in HIV (Boyer et al. 2009; Johnston et al. 2012; McAllister et al. 2013) and non-HIV (Kennedy and Morgan 2006; Law et al. 2012; Tamblyn et al. 2014) populations, and non-adherence has been shown to

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affect outcomes (Nachega et al. 2010; Piette et al. 2004). A systematic review found that cost-sharing, such as co-payments or deductibles, by vulnerable populations in high-income countries led to reductions in prescription drug use and associated increases in use of other health services, including hospitalizations (Lexchin and Grootendorst 2004). It has been shown that removing financial barriers for patients who survive a myocardial infarction can improve health outcomes without increasing overall health costs (Choudhry et al. 2011). Specific to HIV care, unlike many chronic diseases where drugs remain effective even after a period of disruption, treatment interruption in HIV management can lead to emergence of drug resistance, loss of treatment options and increased costs (Krentz et al. 2013). Provision of free antiretroviral medications has been shown to lead to more rapid treatment initiation (Solomon et al. 2013), and an economic evaluation from South Australia demonstrated that removing co-payment fees for antiretroviral medications can be cost-effective (Heymer et al. 2012). Disparities in drug coverage might explain, at least in part, why HIV-positive residents in British Columbia who have free access to antiretroviral drugs were more likely to be taking HIV therapy than in Ontario (Hogg et al. 2012).

A national pharmacare plan would address gaps in coverage and disparities between provinces as well as other health policy objectives (Morgan et al. 2013; Stanbrook et al. 2011). In the absence of such a program, policy makers might consider prioritizing universal access to medications that have an impact on public health. Antiretroviral use is associated with a marked reduction in HIV transmission, and widespread use has been proposed to reduce regional HIV incidence (Fang et al. 2004; Hogg et al. 2012; Montaner et al. 2014). As with the national approach taken to the prevention and control of tuberculosis, policy arguments can be made for eliminating financial barriers to the treatment of HIV. Such universal antiretroviral coverage is likely feasible, as it is already available in some provinces (including British Columbia, which has one of the highest HIV prevalence rate in Canada).

Ontario policy makers might pay particular attention to the administrative and financial barriers faced by patients and consider restructuring the TDP. Specific reforms to address these barriers might include enabling immediate electronic or telephone enrolment to access antiretroviral drugs and making eligibility not dependent on submission of documents or obtaining signatures (which can be particularly challenging when spouses live overseas). As well, TDP could easily accommodate changes in information that may affect deductibles, such as change in status to a single-person household without requiring a signature from an ex-spouse. Finally, consideration should be given to eliminating or lowering deductibles. Deductibles or co-payments could be fixed or based on drug costs alone, eliminating the need to confirm income or other private insurance benefits.

Strengths and limitations

Our study has several strengths. We included all patients who consulted us for assistance with antiretroviral drugs, not a sample of the population. We also collected detailed information on the financial obstacles that patients faced. Our study also has several limitations. First, while

we conducted our study within a large tertiary care urban HIV clinic, the number of people in our study was still small and we are unable to make inferences about specific populations. Second, we did not systematically record socioeconomic characteristics of our patients and, therefore, cannot make conclusions about income level and the need for compassionate care, for example. The majority of our patients requiring free medications, however, did not qualify for social assistance due to income level. Third, our study was conducted at a single site and may not be generalizable to other sites or representative of the population of people living with HIV in Ontario. Fourth, we were unable to assess the impact of patients' financial burdens on clinical outcomes, given the short time horizon of our study, although outcomes may have been difficult to assess, as leaving our patients without coverage and not intervening, when alternatives were available, would have been unethical.

Conclusion

To achieve the UNAIDS 90-90-90 goals and Diagnostics Access Initiative where 90% of all people living with HIV know their HIV status, 90% of all people with diagnosed HIV infection receive antiretroviral therapy and 90% of all people receiving HIV treatment are virally suppressed, decision-makers need to examine barriers to HIV drug access. We have shown that there are HIV-positive patients living in Ontario who qualify for provincial drug insurance but experience challenges in obtaining their medications. Future research should address the scale of this problem and the impact on clinical and public health outcomes. Clinicians need to be alert to such possible challenges and should directly question patients about their individual situation about antiretroviral drug access to identify opportunities to intervene and minimize non-adherence. Medication adherence is important for achieving the significant clinical health benefits of antiretroviral medications, and studies have shown that financial burdens can influence adherence. Out-of-pocket medication spending is a barrier to adherence that is directly amenable to policy intervention. Restructuring Ontario's Trillium's enrolment process and financial requirements may at least ease some barriers to obtaining essential medicines. Our results suggest that reform of Ontario's catastrophic drug insurance system would minimize a substantial number of obstacles in accessing antiretroviral drugs, thereby likely influencing medication adherence, possibly improving the health of people living with HIV and potentially having an impact on reducing HIV incidence.

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