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Services de santé, gestion et recherche de politique

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

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

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

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

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

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

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EDITORIAL

da Vinci Revisited: Building Momentum for Action

Everyone in healthcare should watch Morgan Gleason's "I Am the Patient and I Need to Be Heard" videos.[1] They offer compelling, straightforward examples from the perspective of a 15-year-old about how to improve care. Listen to me; talk to me. Let patients in hospital sleep. Rethink IV pumps that beep loudly and continuously in a patient's room without notifying staff that there is a problem. And more.

Thanks to the reach of social media, Morgan's story and call to action have spread across borders. Viewed thousands of times on YouTube, her videos have been tweeted and retweeted, shown at conferences and prescribed as compulsory viewing for staff in some hospitals. Word is getting out, and the videos are moving hearts and minds.

The challenge now, as always, is to translate that discussion and momentum into concrete action – let's walk the talk.

A frivolous, but timely, analogy: it's sweet that #hardtotrashtalkSweden was trending on Twitter in Canada and #hardtotrashtalkCanada was trending in Sweden during the men's gold medal hockey game,[2] with many tweeting that both countries should share a beer to celebrate a great game. But the Molson Canadian beer fridge has not, at the time of writing, been reprogrammed to accept Swedish passports. (Featured in a range of advertisements and on-site in Sochi, the fridge requires a Canadian passport to open.)

The need to drive to action is by no means new. It's been hundreds of years since Leonardo da Vinci is supposed to have said, "I have been impressed with the urgency of doing. Knowing is not enough; we must apply. Being willing is not enough; we must do."

Like modern researchers, da Vinci often used empirical and observational approaches to learning. And, as in his time, translating the resulting evidence into concrete, sustainable action that changes policy or practice is challenging.

Sharing research evidence through publication is an important first step in the process. With this idea in mind, this issue of *Healthcare Policy / Politiques de Santé* features papers that illuminate the perspectives of patients and front line primary care teams, as well as research that explores important healthcare issues, such as predicting which patients are at risk of becoming high-cost users of the health system, variations in coverage of care for survivors of paediatric brain tumours and the effect of communities of practice in local public health services. Rounding out the issue are discussion and debate pieces on the extent to which amenable mortality is a good measure of health system effectiveness, as well as on regional investment in health research.

Whatever your role in the health sector, I hope that you will find much food for thought, as well as fuel for action, in this issue of the journal.

JENNIFER ZELMER, BSC, MA, PHD
Editor-in-chief

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1. http://morgangleason.com
2. http://www.huffingtonpost.ca/2014/02/23/hard-to-trash-talk-sweden_n_4841988.html.

ÉDITORIAL

Vinci revisité : prendre l'élan à partir de l'action

Toutes les personnes qui œuvrent dans les services de santé devraient regarder les vidéos de Morgan Gleason intitulées « I Am the Patient and I Need to Be Heard »[1]. Une jeune fille de 15 ans y présente des exemples simples et convaincants de l'amélioration des services de santé. Écoutez-moi; parlez-moi. Laissez dormir les patients hospitalisés. Repensez les pompes intraveineuses qui sonnent constamment dans les chambres sans pour autant avertir le personnel d'un problème. Et encore d'autres.

Grâce à la portée des médias sociaux, l'histoire et l'appel de Morgan se sont diffusés au-delà des frontières. Visionnées des milliers de fois sur YouTube, ses vidéos ont été référées, retransmises, montrées lors de conférences et présentées au personnel de certains hôpitaux. Le message passe et les vidéos touchent le cœur et la raison.

Comme toujours, le défi est maintenant de transposer ce débat et cet élan en gestes concrets – passons à l'action.

Pour faire une analogie frivole, quoique opportune : il est amusant de voir que le mot-clé #hardtotrashtalkSweden était en vogue au Canada alors que #hardtotrashtalkCanada marquait la tendance en Suède pendant la partie de la médaille d'or en hockey masculin[2]. Plusieurs personnes écrivaient que les deux pays devraient partager une bière pour célébrer cette excellente partie. Mais, au moment d'écrire ces lignes, le réfrigérateur de Molson Canadian n'avait pas été reprogrammé pour accepter les passeports suédois. (Il fallait un passeport canadien pour activer l'ouverture de ce réfrigérateur présenté dans plusieurs annonces publicitaires et sur les lieux, à Sotchi.)

Le besoin de passer à l'action n'est pas une nouveauté. Cela fait des centaines d'années qu'on attribue à Léonard de Vinci les mots suivants : « J'ai toujours été saisi par l'urgence d'agir. Savoir ne suffit pas, il faut appliquer. Vouloir ne suffit pas, il faut agir. »

Tout comme les chercheurs modernes, de Vinci faisait souvent appel à l'observation et aux méthodes empiriques pour nourrir son apprentissage. Et, comme à son époque, la transposition des résultats en gestes concrets et durables qui transforment les politiques ou la pratique demeure tout un défi.

L'échange des données de recherche par la publication constitue une étape importance de ce processus. C'est pourquoi le présent numéro de *Politiques de Santé / Healthcare Policy* contient des articles qui présentent le point de vue des patients et des équipes de première ligne, de même que des recherches qui se penchent sur d'importants enjeux des services de santé tels que la détection des patients à risque de devenir des usagers très coûteux, les écarts dans la couverture des traitements pour les survivants d'une tumeur cérébrale infantile et l'effet des communautés de pratique sur les services locaux de santé publique. Le numéro présente également des discussions et débats sur la mortalité évitable comme indicateur de l'efficacité d'un système de santé et sur l'investissement régional dans la recherche en santé.

Quel que soit votre rôle dans le secteur de la santé, j'espère que vous trouverez dans ces pages matière à réflexion et à l'action.

JENNIFER ZELMER, BSC, MA, PHD
Rédactrice en chef

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1. http://morgangleason.com
2. http://www.huffingtonpost.ca/2014/02/23/hard-to-trash-talk-sweden_n_4841988.html.

DISCUSSION AND DEBATE

Examining the Role of Amenable Mortality as an Indicator of Health System Effectiveness

Examen du rôle de la mortalité évitable comme indicateur de l'efficacité du système de santé

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Abstract

A recent paper in this journal raised questions as to the reliability, sensitivity and validity of amenable mortality as an indicator of health system effectiveness. In this commentary, we revisit the evidence that was put forward, and suggest that there are several good reasons for assessing health system effectiveness on the basis of amenable mortality. Moreover, provided multiple years of data are used to increase the precision of measurement of amenable mortality rates in very small regions, this indicator of health system effectiveness can be considered a valuable tool for research and performance measurement.

Résumé

Un article récemment publié dans cette revue soulevait la question de la fiabilité, de la sensibilité et de la validité de la mortalité évitable comme indicateur de l'efficacité du système de santé. Nous reprenons ici les éléments présentés dans l'article et nous soutenons qu'il y a plusieurs

bonnes raisons d'évaluer l'efficacité du système de santé en fonction de la mortalité évitable. De plus, puisque des données sur plusieurs années sont employées pour préciser les mesures du taux de mortalité évitable dans de très petites régions, cet indicateur de l'efficacité du système de santé constitue un outil valable pour la recherche et pour la mesure du rendement.

In a recent paper, Lavergne and McGrail (2013) note the growing interest internationally and in Canada in the use of amenable mortality as an indicator of health system performance, and they question the reliability, sensitivity and validity of this indicator. The purpose of this indicator is to measure, for a given population, the mortality due to causes of death before age 75 that should not exist in a well-functioning health system (i.e., the causes are amenable to health system interventions). The list of such causes of death is pre-established by experts' consensus, and there are currently several such lists (see CIHI 2012). The data necessary for the calculation of this indicator are collected through national vital statistics, each death in Canada being attributed a cause by a physician.

In this commentary, we revisit the evidence put forward by Lavergne and McGrail (2013) to demonstrate that this indicator is not reliable, sensitive and valid in a sub-provincial context. Overall, with the exception that rates of amenable mortality may be unstable in small regions, we suggest that amenable mortality is a reliable and sensitive indicator of regional health system effectiveness ("effectiveness" is a more accurate term than "health system performance" in this context), and one to which, for good reasons, health system leaders are increasingly paying attention. The next section revisits the claim that amenable mortality does not reflect the effectiveness of the health system. We then revisit the claim that it has poor statistical properties (reliability and sensitivity).

Is Amenable Mortality a Good Indicator of Health System Effectiveness?

We expect a good indicator of health system effectiveness to be sensitive to outcomes under the control of the health system: we want to measure outcomes that are affected by the way the system works and not (or rather, not too much) by the myriad factors beyond the purview of the health system. Amenable mortality is a measure of the number of deaths for which an effective cure exists (a cure that works in all cases, except for the frail). Therefore, more amenable deaths in a given region would indicate a less effective system. There is discussion regarding the meaning of "cure": in the more stringent definition of Nolte and McKee (2004), cure means therapeutic or surgical intervention, whereas other authors would also include in the list effective prevention (making lung cancer an amenable cause of death) (CIHI 2012). Our comments and defence of the concept apply to both the stringent and the lenient definitions.

There are several reasons to support the use of amenable mortality as an indicator of health system effectiveness.

The first reason relates to the boundaries of health systems: a valid performance indicator of health system effectiveness should be sensitive to health system interventions. There are many factors outside the primary responsibility of the health system that affect death rates. Limiting the field of study to the causes of death most likely to be affected by health system interventions makes health system leaders more accountable for improvements in this measure of performance. In addition, if a large fraction of total mortality is not sensitive to the actions of the health system, using total mortality as the outcome measure will underestimate the true effectiveness of a health system relative to another one (see Box 1).

BOX 1. Measuring effectiveness

Assume that total mortality (M) consists of two components: H, which is sensitive to the health system, and P, which is not (M = H + P), and that P represents on average 50% of M.

Now, assume that system A is twice as effective as system B: HA = 0.5*HB.
Because P is not affected by the health system, PA = PB.

As a result, MA = 0.5*HB + PB = MB - 0.5*HB = 0.75*MB.

According to total mortality, A will appear to be 33% more effective than B, whereas based on the sensitive measure, H, it is 100% more effective.

Note that if we were to measure absolute rather than relative effectiveness, we would not run into the same problem. But it would not make much sense to say that mortality (or the part of it that is sensitive to the health system) actually *is* effectiveness. All we want to say is that it *varies with* effectiveness.

A key point here is the role that social determinants of health play in explaining variations in amenable mortality, and what this implies for the indicator's validity. Lavergne and McGrail (2013) suggest that social determinants are a main driver of variations in amenable mortality, and that these undermine the validity of the indicator. We agree with the former suggestion but disagree with the latter, because social determinants of health are part of the environment explaining effectiveness. A health system's effectiveness relates both to the activities of people working in the system as well as to the environment in which they work (and influenced by the way the healthcare system is organized or funded).

For example, pneumonia is part of the CIHI's (2012) list of amenable (called "treatable" here) causes of death. Given the state of medical art today, no one younger than 75 should die of pneumonia. Smoking is a known cause of pneumonia and, as a result, a region with a higher proportion of smokers will have to devote more resources towards preventing, detecting and treating pneumonia than a region with fewer smokers; if it fails to do so, it can be considered a less effective health system. Also, if individuals living in poverty have poorer access to primary care, pneumonia may not be detected in time and, as a result, become fatal.

Regions with higher rates of poverty (or more pockets of poverty) may exhibit higher rates of (amenable) mortality due to pneumonia. Our claim is that this indicator measures effectiveness of the health system, specifically, its inability to provide access in due time to prevent death from pneumonia, even though it does not say that health professionals in regions with higher rates of poverty (or with more pockets of poverty) do not work effectively.

Evaluating the role of social determinants of health in the effectiveness of the health system is an empirical question that is worth examining. The results of such an analysis could help health policy makers and system managers identify the most effective policy levers to reduce the causes of death that are identified as most amenable to health system interventions. In other words, a regional health system that has a population with higher levels of poverty or pockets of abject poverty, for example, may need more resources or to deliver services differently in order to be effective.

Second, separating mortality into causes that are sensitive to health system interventions and those that are not allows us to use the insensitive part as a control (baseline) in statistical analyses of the effect of characteristics in the health system: if we find a correlation between such a characteristic (say, payment of physicians) and mortality across jurisdictions, we will not know whether this is pure coincidence or suggestive of a true causal effect. Now, if we find that the correlation comes entirely from a relationship between the characteristic and the part of mortality that is sensitive to the health system but not at all (correlation = 0) from a relationship between the characteristic and the part of mortality that is not sensitive to the health system, we will have a stronger inference in favour of a causal relationship between that characteristic and the effectiveness of the health system.

Finally, if we think that what Canadians expect from the health system is a guarantee of timely access and high-quality treatment when they are sick, rather than a longer-term focus on better health (Abelson et al. 2011; see Box 2), then it makes sense to use a good proxy of that guarantee when measuring the effectiveness of the health system rather than a broader measure of average population health, such as total mortality.

BOX 2. Understanding policy makers' views of the objective of the health system

Abelson and colleagues (2011) conducted a descriptive qualitative study with key-informant interviews to understand health policy makers' views on the objectives of the health system. They conducted 17 semi-structured interviews with senior health ministry personnel from nine provinces and two territories. The stated objectives of the health system fell into two main themes:

(a) those focused on the healthcare delivery system and (b) those focused on promoting and improving the health of individuals and populations.

Healthcare delivery system objectives were mentioned more frequently than population health objectives by almost a two-to-one margin. Specifically, respondents emphasized the diagnosis and treatment of illness and disease and ensuring that healthcare is available where and when it is required as the main objectives of their jurisdiction's health system.

We agree with Lavergne and McGrail (2013) that if the component of mortality that is sensitive to health system interventions cannot be measured in a reliable way and turns out to vary exactly like total mortality across jurisdictions, it may be preferable to use total mortality as a proxy. It is important, though, to note that both conditions must hold to reject amenable mortality as a measure of effectiveness. However, if we can reliably measure amenable mortality, we should use it as an indicator of health system effectiveness because, in addition to the information that total mortality provides, it offers more detailed information on deaths considered by experts as amenable to health system interventions, and would be supported by policy makers in the health sector as an outcome measure of improvement for which they might be ready to take responsibility.

Revisiting the Claim That Amenable Mortality Is Unreliable and Insensitive

Reliability

Lavergne and McGrail (2013) use the empirical observation that in low-populated areas of British Columbia, the rate of amenable mortality varies substantially from year to year to suggest that amenable mortality is not a reliable measure. To examine this argument closely, we need to understand the relationship between the variability and reliability of an indicator.

There are three major sources of variability in a quantitative measure:

1. *Sampling error*: We measure a statistic on a given sample, but a different sample might yield a different value for the same statistic.
2. *Random variation in the phenomenon itself*: What we measure is the result of a random process.
3. *Measurement error*: Any time a phenomenon is observed, an error can be made in its coding or measurement.

In the case of mortality in general and amenable mortality in particular, sampling error can be ruled out: these measures are based on total population (within each jurisdiction), not on samples. Not much can be said about measurement error and, more importantly, systematic variations in such measurement error across regions in Canada, because this issue has not been studied. Moreover, Lavergne and McGrail (2013) do not raise this source of error.

Mortality is a random phenomenon: it follows a binomial distribution of parameters n (total population) and p (probability of death). As a result, the observed ratio in one year will differ from the observed ratio in another year, and we can even calculate the variance in the estimated value of the probability. Not surprisingly, the variance in the estimator increases when the total number of tries (n) decreases, and small population areas yield imprecise estimates of the probability to die of a cause amenable to health system interventions. However, imprecise is not the same as unreliable. What Lavergne and McGrail (2013) find is that amenable mortality cannot be estimated with good precision in very small regions; it is certainly

less precisely estimated than total mortality, because the probability that we try to estimate is smaller. As a result, we cannot rely on empirical estimates of amenable mortality (nor, for that matter, of total mortality) based on small numbers of tries. Analysts who want to evaluate the effectiveness of a health system using amenable mortality must make sure they use enough years of data to get a more precise estimate, or that they account for random variation in their conclusions on effectiveness. But, again, the same would be true with any stochastic outcome measure.

Insensitivity

Lavergne and McGrail (2013) use empirical evidence that amenable mortality is highly correlated with premature all-cause mortality across 16 health regions in British Columbia, and we confirm the strong correlation between these two measures (amenable and all-cause premature mortality rates) across 90 health regions in Canada's provinces (with a correlation coefficient of 0.96).[1] However, we disagree on the inference drawn from the empirical evidence.

First, we argue that such a strong correlation provides support for the reliability of amenable mortality: if there were systematic error in the measurement of amenable mortality due, for example, to difficulties in coding the primary cause of death on death certificates, then we would see weaker correlations across health regions between the two variables.

Second, and more importantly, because the two measures are not perfectly correlated, there is additional information that can be gained by examining variations in amenable mortality that all-causes mortality would not yield.[2] We can learn something from the fact that Vancouver does less well on amenable mortality than its all-causes mortality ratio suggests. Lavergne and McGrail (2013) read such a discrepancy as further proof that amenable mortality is not a valid measure of effectiveness: because it is well known that Vancouver has more doctors and hospitals per capita than other regions, its health system should be more effective and, as a result, if amenable mortality indicates it is less effective, this suggests that the indicator is not reliable or valid. We respectfully disagree with this conclusion: in our opinion, the high level of amenable mortality in Vancouver shows that despite its high density of physicians and hospitals, the effectiveness of the health system is not only a matter of resource availability and usability, but also the product of the needs and demands of the population. The population of Vancouver is healthier than the rest of British Columbia but at the same time, those in Vancouver who suffer from diseases that are amenable to health system interventions are perhaps sicker or have more complex needs and require more resources per case (as, for instance, in the already mentioned case of pneumonia, some patients in Vancouver may have issues in accessing primary care). Through this example, we see that amenable mortality tells us something that all-cause mortality cannot tell, but also something that the supply of health services cannot tell, either. In particular, health system managers in Vancouver would benefit from knowing the particular causes of death that drive their high level of amenable mortality.

Conclusion

Lavergne and McGrail (2013) seem to reject amenable mortality on the grounds that (a) it focuses on secondary and tertiary prevention to the detriment of primary prevention, and (b) it implies that too great an investment in primary prevention may be less effective. We fully agree that measuring preventable mortality is of interest to policy makers because it can help identify areas where attention should be paid. However, the key question is whether we should use amenable or preventable mortality as a measure of health system effectiveness: this leads us back to our question about what Canadians expect from the health system. If we think that the outcome of interest is a healthier population on average, then effectiveness should be measured as the reduction of preventable mortality; however, if we think that the outcome of interest is timely access to high-quality care when needed, then amenable mortality is a better proxy for effectiveness. Based on the results of recent research commissioned by CIHI (Abelson et al. 2011), amenable mortality seems to be a more appropriate measure of health system effectiveness, and one for which policy makers might be ready to take responsibility to support improvements in health system outcomes.

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Notes

1. We use the Canadian definition of amenable mortality (referred to as "treatable mortality") that was developed by Statistics Canada and CIHI. The correlation is slightly weaker (0.88) if we compare the potential years of life lost (PYLL) from treatable causes with the PYLL from all causes. Mortality rates and PYLL are calculated as an average across three years (2007–2009) and are publicly available (Statistics Canada 2013).
2. This is not specific to mortality: it is well known, for example, that life expectancy and GDP per capita correlate strongly across countries (this is the famous Preston curve; one needs to use a slightly fancier measure of correlation than linear correlation). However, despite the fact that both measures are generally in agreement, we still learn from discrepancies – countries that are above the curve, such as Cuba, or below the curve, such as the United States.

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DISCUSSION AND DEBATE

Strategically Investing in Health Research: The Little-Big Program Called RPP

Investissement stratégique dans la recherche en santé : un grand petit programme nommé PPR

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Abstract

The Regional Partnerships Program (RPP) was a program of the Canadian Institutes of Health Research (CIHR) and six provinces – Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador. CIHR and each province contributed 50% to support health research that was recommended for funding by peer review but fell below the CIHR budgetary cut-off for funding. The provinces would like to commend CIHR for this strategic initiative and highlight the impact that small investment like RPP has had on engaging these provinces in the health research enterprise and expanding health research and its benefits across the country.

Résumé

Le Programme de partenariats régionaux (PPR) est une initiative des Instituts de recherche en santé du Canada (IRSC) et de six provinces – la Saskatchewan, le Manitoba, le Nouveau-Brunswick, la Nouvelle-Écosse, l'Île-du-Prince-Édouard et Terre-Neuve-et-Labrador. Dans le cadre de ce programme, les IRSC et chaque province apportent 50 % en appui à des projets de

recherche recommandés pour un financement après examen par les pairs, mais qui se situent en deçà du seuil de financement des IRSC. Les provinces félicitent les IRSC pour cette initiative stratégique et tiennent à souligner l'impact de petits investissements comme ceux du PPR, que ce soit pour leur apport aux projets de recherche des provinces ou pour l'élan qu'ils donnent à la recherche en santé et ses bénéfices partout au pays.

In 1997, Canada's Medical Research Council (MRC) established a Regional Partnerships Program (RPP) to address the distribution of medical research funds across four provinces – Saskatchewan, Manitoba, Nova Scotia, and Newfoundland and Labrador (all with medical schools) – in response to a decline in funding compared to the other provinces (British Columbia, Alberta, Ontario and Quebec) that were home to Canadian medical schools.

With the change from MRC to the Canadian Institutes of Health Research (CIHR) on the heels of the CIHR Act in 2000, RPP was expanded to include New Brunswick and Prince Edward Island, provinces in which such research was underrepresented. After 16 years and less than $70 million of investment from the federal health research granting agencies (MRC and CIHR), RPP has changed the landscape of health research. In the six RPP provinces, it has provided support for research initiatives that have had an impact on patient care, trained highly qualified health research professionals and advanced health research. Furthermore, RPP has contributed to CIHR's mandate of improved health for Canadians, more effective health services and products and a strengthened Canadian healthcare system, through exercising leadership within the Canadian research community and fostering collaboration with the provinces. Although the final funding opportunity for RPP was in spring 2013, the impact of this program and the research it has supported will continue.

In 2004–2005, CIHR commissioned an in-depth review of RPP, which documented the positive influence of investment on health research outcomes and encouraged the continuation of the program (CIHR 2007). At that time CIHR decided to continue the program for an additional two years and to consider a renewed program design within one year (CIHR 2007). However, since then CIHR has undergone a multi-year review of all funding programs and has undertaken a substantial change in the program funding design (CIHR 2014). Although partnership programming continues to be a major focus for the organization, CIHR decided to sunset this particular partnership program (CIHR 2013). This paper provides a brief commentary on the value of RPP from the perspectives of the six RPP provinces, garnered from recent conversations with individuals in each province who have been instrumental in administering the program in their jurisdictions. The program serves as a model of how small, strategic investment and collaboration with partners has had an impact on health research, its outcomes and the engagement of the health research community across the country.

What Is RPP?

RPP was established to enhance health research in provinces with medical schools, where there was a continuing decline in research funding. The program required that each of the provinces establish a local advisory committee to oversee this funding opportunity and set priorities for health research. Research grants were submitted to the federal funding agency for peer review; those that ranked within the fundable range but below the budgetary cut-off for funding were eligible to receive financial support through RPP. Funding was arranged through a partnership in which the federal granting agency provided 50% of the value of the grant or award and provincial sources were responsible for the matching funds. Since 1999[1] the investment per year for RPP has been $4.4 million from the federal granting agency, with the partners providing at least a $4.4-million match. Each province, through its advisory committee, ensured that research funding supported regional health research priorities. Each province determined which programs would be supported from the suite of those that were eligible (new and renewal operating grants, training and salary awards), and no RPP recipients were eligible to receive repeat funding on back-to-back grants.

What Has RPP Meant for the Provinces?

RPP has had obvious advantages for each grant or award recipient. Details on the number of award holders and the impact of RPP funding on research programs, personnel and future funding opportunities are available from the summative evaluation conducted in 2005 (CIHR 2007). The program has also benefited the provinces in meaningful ways, as highlighted below.

- For each of the RPP provinces, the program has resulted in the development of relationships with provincial government departments involved in health research and innovation. In bringing together key stakeholders among the provincial governments, decision-makers, funding organizations, researchers and users of research, the program has involved the provinces in the role of health research in implementing changes in healthcare and contributing to their economic base through capacity development.
- RPP has been important in providing bridge funding for new and established investigators to initiate and maintain internationally competitive research programs and continue to contribute to the health research knowledge base. The program has been instrumental in the research careers of some of Canada's top health research scholars. A number of RPP recipients have gone on to earn senior Canada Research Chairs and prestigious awards and honours in their fields, or have taken leadership roles in their academic careers (CIHR 2007, 2009). Accomplishments such as these are achieved as a result of long-term demonstration of successful research. Opportunities such as RPP have contributed by supporting research programs that might otherwise have been significantly disrupted.
- The provinces have been able to build health research capacity and contribute to their economic base through education and innovation. In each province, RPP has contrib-

uted to funding trainees, either directly or through operating grant support, thereby enhancing the health research base. Although the federal granting councils are not obligated to ensure research investment in all regions of the country, this is clearly in the spirit of the CIHR Act (Government of Canada 2000) and was a fundamental consideration in both the establishment of RPP[2] and its continuation.[3]

- The investments made through this program have resulted in substantial long-term gains and leveraged dollars beyond the initial investments (CIHR 2007). Researchers have continued to succeed in bringing external research dollars to each of the provinces, from grants fully funded by CIHR or the other granting councils, the Canada Foundation for Innovation, Genome Canada, the health charities and a variety of international funding opportunities. From the perspective of the provinces, this program has been important in leveraging funds; much of the funding was directed towards salary support for highly qualified personnel.
- The provinces, through RPP, have been able to support health research of regional importance that meets national scientific merit as judged by peer review. This has resulted in support for biomedical and clinical research as well as research in health policy, service delivery and social and population health, which are of immediate importance to healthcare practice within the province. Examples of the research supported by RPP, from each of the six provinces, can be found at the CIHR website (CIHR 2009). The impact of RPP-funded studies, like other research, may be immediately apparent and have long-term benefits. For example, a study that received national attention (Abraham 2008), and which identified the genetic basis of a lethal sudden cardiac disease in a Newfoundland population, was supported through early RPP funding. The knowledge from the basic biomedical research (Merner et al. 2008) was utilized to provide screening for a population at risk for this lethal disease. The study provided an opportunity for people who tested positive to be identified and treated. For others, identified as non-carriers, early screening has removed the burden of not knowing. The program has had a direct benefit on many families and an impact on delivery of services (Hodgkinson et al. 2009).
- As a result of RPP, a valuable collaboration has been developed across the provinces to discuss and address administrative policies in health research support. As part of the program, the chairs and funding partners of each provincial program met annually, providing an opportunity to discuss and exchange best practices and lessons learned at the administrative level.

Concluding Thoughts

MRC and CIHR are to be commended for initiating and supporting this program over the years. A formal review of RPP took place in 2004–2005, and an attempt was made to evaluate the program against its initial objectives (CIHR 2007). As such, the evaluation team was able to demonstrate substantial increases in research funding for researchers in the RPP provinces,

which mirrored the overall increase in funding to the research community in Canada following the establishment of CIHR. Although the results did not indicate that the actual research funding reached the desired per capita funding rate, RPP has helped CIHR meet its mandate by increasing the overall number of health research grants funded in the regions.

Whether the loss of RPP will have a negative impact on regional health research, in particular given the ongoing changes in funding opportunities at CIHR (2014), remains to be seen. However, RPP has demonstrated how a relatively small federal investment can make valuable and significant contributions to scientific knowledge and to training the next generation of scientists and health professionals. The program has contributed to an increased involvement of the provinces in the health research enterprise. It has provided an important example of how the health research enterprise can be enhanced through encouraging partnership and leveraging investment.

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Notes

1. Initially, MRC provided one-third of the funding and set a maximum investment of $500,000 per province. However, with the advent of CIHR, the funding ratio was changed to 1:1 and the investment was increased per province to $1 million. In addition, the provinces of New Brunswick and Prince Edward Island were included in the program, each being eligible for $200,000.
2. "This situation raises the wider issue as to whether MRC, as a Federal Government Agency, has some social responsibility to ensure that a viable health research base is maintained in the different regions of the country" (Wood 1994).
3. "The other context to recognize is the belief that the presence of medical researchers in a region has a direct and positive impact on the quality of medical services available to the population of the region. … Given this belief, it follows that some minimal level of funding for health research should be maintained" (CIHR 2007).

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RESEARCH PAPER

Communities of Practice as a Professional and Organizational Development Strategy in Local Public Health Organizations in Quebec, Canada: An Evaluation Model

La communauté de pratique à titre de stratégie de développement organisationnel et professionnel dans les centres de santé et de services sociaux au Québec, Canada : un modèle d'évaluation

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Abstract

Communities of practice (CoPs) are among the professional development strategies most widely used in such fields as management and education. Though the approach has elicited keen interest, knowledge pertaining to its conceptual underpinnings is still limited, thus hindering proper assessment of CoPs' effects and the processes generating the latter. To address this shortcoming, this paper presents a conceptual model that was developed to evaluate an initiative based on a CoP strategy: Health Promotion Laboratories are a professional development intervention that was implemented in local public health organizations in Montreal (Quebec, Canada). The model is based on latest theories on work-group effectiveness and organizational learning and can be usefully adopted by evaluators who are increasingly called upon to illuminate decision-making about CoPs. Ultimately, validation of this conceptual model will help advance knowledge and practice pertaining to CoPs as well as professional and organizational development strategies in public health.

Résumé

Les communautés de pratique (CdP) figurent parmi les stratégies de développement professionnel les plus employées dans des domaines tels que la gestion et l'éducation. Bien que cette démarche ait suscité un grand intérêt, les connaissances au sujet de ses bases conceptuelles demeurent fragmentaires, faisant ainsi obstacle à une évaluation adéquate des effets des CdP et des processus qu'elles génèrent. Pour remédier à cette lacune, cet article présente un modèle conceptuel qui a été mis au point afin d'évaluer une initiative fondée sur une stratégie de CdP : les laboratoires de promotion de la santé. Il s'agit d'une intervention visant le développement professionnel, qui a été mise en œuvre dans des centres de santé et de services sociaux à Montréal (Québec, Canada). Le modèle tire profit des dernières théories sur l'efficacité des groupes de travail et sur l'apprentissage organisationnel. Ce modèle peut servir aux évaluateurs qui s'intéressent à la prise de décision éclairée dans le contexte des CdP. En bout de ligne, la validation de ce modèle conceptuel contribuera à l'avancement des connaissances et des pratiques propres aux CdP de même qu'aux stratégies de développement professionnel et organisationnel dans le milieu de la santé publique.

A crucial issue in the public health sector is that of professional development for a workforce in a context of change – change both within public health itself and in the setting in which it operates. New approaches to intervention, emerging problems and new ways of organizing services present challenges that, more than ever, demand updating of practitioners' and managers' skills (Frenk and Gonzalez-Block 2008; Paccaud 2011).

Such a changing landscape has significant repercussions for the workforce, and questions are raised about professionals' capacity to adapt (Amodeo 2003; Scharff et al. 2008). For

many years, efforts have been made to develop means to support public health professionals within such a context (Calhoun et al. 2008; Gebbie and Turnock 2006; Scharff et al. 2008). Continuing education plays a key role in this regard.

Koo and Miner (2010) have presented an analysis of the issues in professional development in public health and provided a framework for guidance based on the latest knowledge in adult education. They point to the need for a number of elements, including access to training outside academic settings; reflexive learning grounded in the day-to-day experience of the workforce and the problems it faces, involving situations as complex as those encountered in practice; and programs focusing on results considered as meaningful and tangible by learners. A number of the points they enumerate are reflected in CoP, a professional and organizational development approach that has already been widely implemented in management and education settings (Fontaine and Millen 2004; Wenger 1998) and that could prove a promising avenue for public health.

Drawing on the CoP model, a team from Montreal's *Direction de santé publique* (DSP; Public Health Department) recently developed and introduced a professional development strategy to support local public health teams in the *Centres de santé et de services sociaux* (CSSS; Local Health and Social Services Centres) in its territory. In accordance with Quebec's most recent health system reform (2005), CSSSs pertain to the local level of the public health network. They have been assigned responsibility for their population and, accordingly, must formulate local action plans to implement the innovative models put forward in provincial and regional plans (Ministère de la santé et des services sociaux 2004). The regional authority is called upon to establish support systems for the CSSSs in their new public health responsibilities. The purpose of this paper is to describe one such initiative, Health Promotion Laboratories, and to situate them as a type of CoP focused on professional and organizational development. A further purpose is to present the conceptual model that was developed to evaluate the labs and to discuss their potential for the advancement of knowledge and practice in public health.

Health Promotion Laboratories

Health Promotion Laboratories bring together about 10 managers and professionals from different disciplines recruited from a CSSS team who are willing to meet regularly on a voluntary basis, with the goal of changing some of their practice in order to improve interventions. These labs provide participants with a concrete opportunity to engage in reflective practice and skills development as they consider issues regarding their work in their territory and the need for innovation. Planning models and concepts emerging from the new public health movement are promoted in the labs. The regional authority – in this case, the DSP – delegates one of its professionals to take on a support role throughout the two to three years of the project, during which meetings are held every two or three weeks. The CSSS also gives participants time off to prepare for and attend the meetings. Sessions are led by one of the participating managers or professionals. Having approved the initiative, the CSSS executive director commits to paying regular visits to provide support to the lab.

A seven-step operating procedure is suggested for labs: (1) identify an issue and the appropriate participants who are interested in addressing it; (2) specify the operational approach; (3) grasp the basic public health concepts; (4) broaden the issue; (5) pinpoint possibilities for action; (6) develop a partnership; and (7) propose and implement a new health promotion intervention (referred to below as "the project"). Participants are asked to share their experiences in the lab with their colleagues in the organization; they are thus expected to transfer the knowledge produced. Furthermore, the entire team from which the participants are recruited is involved in the decisions and actions that emerge from the labs and can consequently develop its skills. The DSP's involvement comprises providing support to the CSSSs to help elicit and foster reflection and discussion; guiding the process; providing support to prepare for and lead a lab; and encouraging the sharing of expertise and interaction between local and regional instances (see Tremblay et al. 2012 for a detailed description of labs).

Health Promotion Laboratories: A Community of Practice

Communities of practice (CoPs) are groups of individuals who share a concern or passion for a subject and interact with one another on an ongoing basis to expand their knowledge and develop their expertise (Wenger 1998; Wenger et al. 2002). CoPs may take different forms, depending on their size; their homogeneity or heterogeneity (whether they involve a single discipline or several); their scope, both internal (professionals from the same team) and external (clients, partners, etc.); whether they arise spontaneously or are planned; and their relationship with the organization (invisible, unacknowledged until they are institutionalized). Irrespective of their various forms, CoPs share three basic features. The first is a *field of knowledge* or a theme that determines their raison d'être. The latter is the field that brings the individuals together, guides their learning and defines the identity of the community (Wenger et al. 2002: 31). It suggests the "long-standing issues" that require sustained learning. The second feature is a *community of participants* who interact with one another and learn together, build relationships and develop a sense of belonging, mutual commitment and common identity. The third feature is a *shared practice and understanding*, a body of knowledge (theoretical, practical, anecdotal, etc.) that provides the common foundation that allows participants to pursue common goals and work and learn together.

CoPs differ from other organizational entities such as project teams, work groups and informal networks in that they focus on the co-development of skills and the construction and exchange of knowledge. In practice, the distinctions are not quite so clear-cut, and a CoP may have points in common with other organizational entities (Gabbay et al. 2003); however, the basic features listed above must appear.

As a tool for knowledge management and professional and organizational development (Li et al. 2009), the concept of CoP has been applied in the fields of management (Fontaine and Millen 2004; Millen et al. 2002), education (Butler et al. 2004) and urban planning (Soekijad et al. 2004). It has also recently been applied in the health sector (Bentley et al. 2010; Li et al. 2009). A number of authors, noting the often limited effectiveness of traditional strategies to foster improved professional practice in health (Grimshaw et al. 2001; Grol and

Grimshaw 2003), have highlighted the potential of CoPs as a means of facilitating the updating of practices and the introduction of evidence-based innovations and support for enhanced performance (Andrew et al. 2008; Fung-Kee-Fung et al. 2008; Mallinson et al. 2006; White et al. 2008). The Centers for Disease Control and Prevention (CDCP 2011) are thus sponsoring a support network for virtual CoPs, and innovative experiments have been conducted in a variety of contexts, including smoking (McDonald and Viehbeck 2007) and cancer (Bentley et al. 2010; Fung-Kee-Fung et al. 2008). Still, CoPs are not yet widely used in public health (Bentley et al. 2010; Li et al. 2009).

A number of studies provide detailed descriptions of CoPs and the factors associated with their implementation (Barrett et al. 2009; Chua 2006; McDermott 2000). Millen and colleagues (Fontaine and Millen 2004; Millen et al. 2002) assessed the effects of CoPs in 10 organizations from different sectors. Using sound methodology, they reported benefits on the professional (e.g., level of trust, abilities), group (e.g., creation of a common context) and organizational levels (e.g., innovation, business opportunities, work scheduling). In a review of experiments conducted in the health sector, Bentley and colleagues (2010) documented the positive effects on such factors as professionals' sense of belonging, interpersonal communication and the exchange of knowledge, job satisfaction and adherence to clinical guidelines. These authors stress that this body of work suffers from certain limitations in that it provides little information regarding the mechanisms that might help explain how the observed benefits accrue. In a critique of the concept and of the numerous metaphors its promoters use to guide the implementation of CoPs, Bentley and colleagues (2010: 4, 3) conclude that "the evidence is only emerging on the success of health sector CoPs" and "Whether or not CoPs are an effective form of collaboration remains an open question." Given the lack of clarity of the concept and its dimensions (Bentley et al. 2010; Li et al. 2009), as well as the scarce information on the processes at work in CoPs (Bentley et al. 2010; Verburg and Andriessen 2006), one can only conclude that further research is needed to better understand their effects, the processes generating such effects and the influence of contextual factors.

An examination of the literature reveals that the Health Promotion Laboratories initiative developed by the DSP shares several common features with the CoP model (Wenger et al. 2002). With the aim of improving professional practices, the labs bring together a community of participants who share a common foundation of knowledge and practices and who are interested in public health practice issues. Although empirical studies point to potential benefits stemming from the introduction of CoPs, the search for theoretical formulations that could help identify effect variables and, especially, their related process variables has not proven very successful, thus confirming previous conclusions (Bentley et al. 2010; Li et al. 2009; Verburg and Andriessen 2006). Work on theory development is thus necessary, and an excellent point of departure is provided by knowledge in at least two fields: theories on the effectiveness of work groups and on knowledge dissemination in organizational settings.

Towards an Evaluation Model for Communities of Practice

Professional development: Working-group effectiveness models

Although CoPs are a relatively new social entity, there are a number of models and a long and rich tradition of research that can help understand them. Indeed, concepts from open systems theory have helped shape applied organizational social psychology for decades (Katz and Khan 1978). Open systems theory has set the stage for other, more specific functional models (i.e., input–process–output). These models have inspired many conceptualizations of team effectiveness (Wittenbaum et al. 2004). Four reasons support the notion that there is sufficient kinship between CoPs and teams to benefit from team functional models.

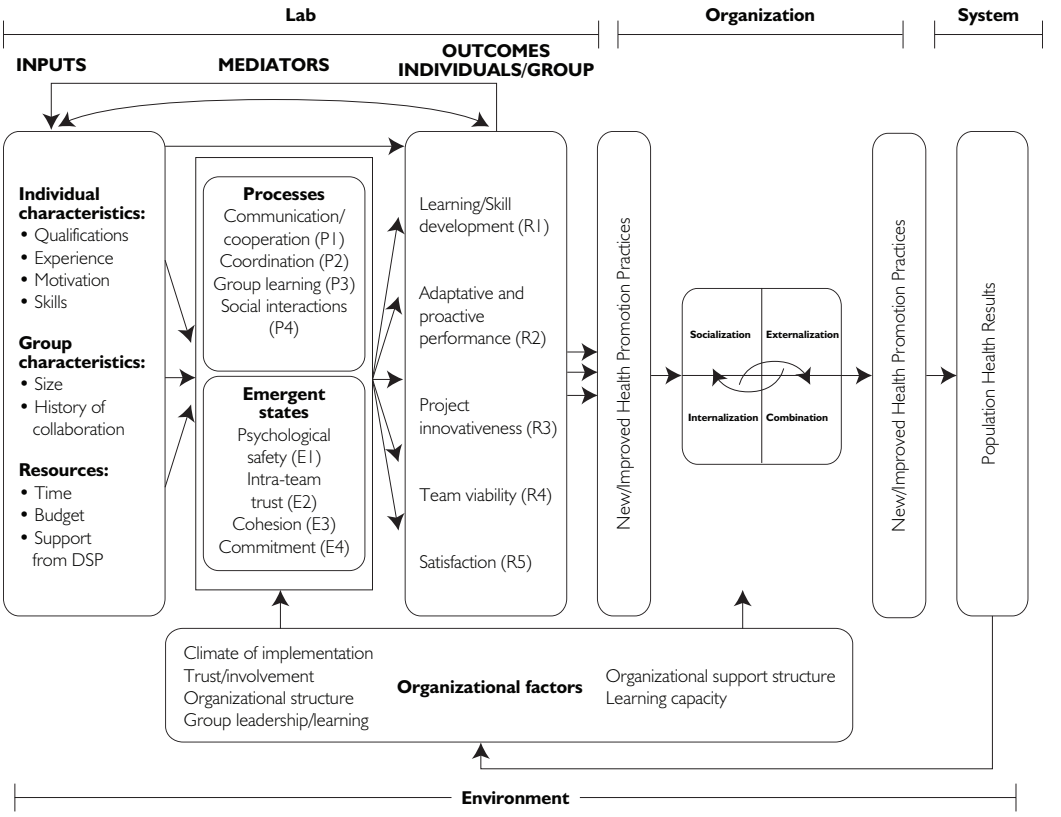
First, definitions of teams concur that CoPs are akin to teams. For example, Kozlowski and Bell (2003: 334) define teams as "composed of two or more individuals who (a) exist to perform organizationally relevant tasks, (b) share one or more common goals, (c) interact socially, (d) exhibit task interdependencies (i.e., workflow, goals, outcomes), (e) maintain and manage boundaries, and (f) are embedded in an organizational context that sets boundaries, constrains the team, and influences exchanges with other units in the broader entity." Reviews of team types suggest that CoPs can be distinguished as self-managing teams, autonomous teams (Hollenbeck et al. 2012), advisory teams (Devine 2002) or parallel teams (Cohen and Bailey 1997).

Second, CoPs are embedded in an organizational context (Kirkman et al. 2011), or more than one context when they serve as an inter-organizational coordination structure (Uitdewillgen and Waller 2011). Third, Raven (2003) describes CoPs on a continuum comprising elements common to CoPs and teams such as emergent mission, voluntary membership, dynamic leadership and loose task interdependence. Because of the kinship between these two forms of entity, team effectiveness models can shed light on CoPs' effectiveness. Fourth, studies using functional models have already produced interesting results. For example, a recent study of CoPs shows that the extent to which CoPs are aligned with organizational objectives, comprise highly task-interdependent individuals, and promote participation and self-organization is predictive of CoPs' effectiveness (Kirkman et al. 2011). Consequently, we believe a functional approach derived from team effectiveness models is likely to help the study and understanding of CoPs embedded in healthcare organizations.

Our model (see Figure 1, left side) takes footing on the structure and content of Ilgen and colleagues' (2005) input–mediators–output–input (IMOI) model of team effectiveness. The IMOI model takes its strength from two improvements over the traditional input–process–output models. First, the IMOI model uses the term "mediation" to explain the transformation of inputs into outcomes. As a transformative process, mediations take two forms: processes and emergent states. Processes refer to the members' interdependent actions that are oriented towards a common goal. Emergent states refer to attitudes, values, cognitions and motivations that emerge from the individual level and become group-level properties. Our review and thinking of CoPs' challenges lead us to consider that individual characteristics, group

characteristics and resources will be transformed by processes (e.g., communication, coordination, learning and social interactions) and emergent states (e.g., psychological safety, intra-team trust, cohesion and commitment) to produce outcomes such as competencies, performance, innovation, team viability and individual satisfaction.

FIGURE 1. CoP evaluation model



Moreover, because of the importance of feedback loops in the IMOI models, outcomes will have an impact on organizational learning and practices that will necessarily affect individual and group characteristics. We believe this aspect is particularly interesting given the ongoing and dynamic nature of CoPs. Furthermore, the ways in which outputs, such as knowledge sharing, are reinvested over time in CoPs is important because these entities need longer life cycles for their outputs to take effect (McDermott and Archibald 2010).

Organizational learning: The Nonaka model

This portion of the model (see Figure 1, right side) deals with the process by which the introduction of labs may produce effects on the organization. The possible organizational impact of CoPs rests on the hypothesis that the benefits they bring participating individuals, particularly in terms of new practices, will be spread more widely in the organization – first and primarily,

in the team to which the participating professionals belong. Individual learning is thus to be transformed into organizational learning (Cohen and Levinthal 1990; Fiol 1994).

Organizational learning can be approached from a number of perspectives offered by sociology, psychology, politics and anthropology, among other fields (Dierkes et al. 2001). Although many models have been proposed, few have been the subject of practical application or applied research (Demers 2007). Nonaka's (1994, 2006) model is one of the most often cited in the literature on the subject. It posits two types of knowledge: explicit and tacit. Explicit knowledge is formal, learned knowledge that may be codified in the form of data, manuals or specifications. Tacit knowledge is knowledge derived from experience; it is highly personal and hard to formalize. The Nonaka model sees organizational learning as a dynamic process of knowledge creation based on four processes of "conversion," or sharing, of tacit and explicit knowledge: socialization, the sharing of tacit knowledge among individuals; externalization, the articulation of tacit knowledge as explicit concepts; the combination of different units of explicit knowledge; and internalization, the transformation of new explicit knowledge into tacit knowledge. Table 1 provides examples of each of these processes. Ultimately, this sharing of knowledge gives rise to the emergence of new health promotion practices within the organization. These propositions regarding the dissemination/conversion of knowledge within an organization have recently been validated by Champagne and colleagues (2011) in their evaluation of the SEARCH/EXTRA program, a professional development initiative that bears some resemblance to the Health Promotion Laboratories project.

TABLE 1. Processes of knowledge dissemination/conversion: Definitions and examples

Process	Definition	Examples
Socialization	Sharing of tacit knowledge among individuals	Participants share their experiences in the lab with colleagues from other teams in the organization
Externalization	Articulating tacit knowledge as explicit knowledge	Lab participants present a poster during a conference for professionals and researchers in public health
Combination	Integrating different units of explicit knowledge	Participants incorporate knowledge derived from the labs into an information document for their colleagues at work
Internalization	Transforming new explicit knowledge into tacit knowledge	New labs are introduced to other teams in the organization

The different characteristics of the organizational and environmental contexts in which the labs operate are likely to influence the way they are implemented and the effects they produce. In line with Champagne's (2002: 46) conceptual framework, the implementation and effects of labs are deemed to result from the climate of implementation, the trust and involvement of the actors, the organizational structure, and group leadership and learning. Regarding the question of the dissemination of knowledge generated in labs, Cousins and colleagues (2004) reviewed the literature on factors that influence knowledge utilization from an organizational learning perspective. They suggested two broad categories of organizational

factors: organizational support structures and learning capacity. The support structures include the stock of organizational knowledge, organic structure, communication processes, incentive systems, educational activities and information systems. Learning capacity refers to organizational culture, leadership for learning, explicit learning strategies, and teams' work habits and processes. Table 2 outlines each of these factors.

TABLE 2. Organizational context: Dimensions investigated and examples of indicators

Construct	Dimensions	Examples of indicators
Climate of implementation	Management strategies	Support of the CSSS in implementation; existence of institutional documents to introduce the labs; level of support by professionals from the DSP, etc.
	Adequacy of resources allocated for implementation	Levels of resources in personnel, material and time
Trust and involvement of the actors	Shared vision and support for innovation	Clarity of expectations regarding the labs; perception of potential effects of labs; consistency of labs with other undertakings in the organization; degree of involvement of managers and professionals
Organizational structure	Complexity and organic structure	Degree of formalization (type of evaluation of professionals, etc.); extent of centralization of authority (accessibility of managers, degree of autonomy of employees, etc.)
	Organizational culture	Openness to new ideas, error management, etc.
Learning and leadership	Collective appropriation of labs	Willingness to carry on with labs, level of enthusiasm, etc.
Organizational support structure	Internal and external communications network	Relations with institutions and community; intra-organizational communication, etc.
	Stock of knowledge	Attribution of value to scientific evidence; use of research in decision-making; degree of access to new knowledge, etc.
	Decision process	Extent of participation by professionals, etc.
Learning capacity	Expertise and experience	Availability of continuing education; proportion of professionals with higher education, etc.

Discussion

This paper has presented Health Promotion Laboratories and a conceptual model that can be used to evaluate them. The program, which accords with the CoP model, has proven to be an innovative professional development strategy and to respond well to concerns that have been raised about professional development in public health. The following discussion deals

with the potential that the implementation and evaluation of the labs have for the advancement of knowledge and practice in public health.

The practice of public health requires models for action that are congruent with the complexity of the phenomena one wants to change. Thus, seeking to affect the health of a population implies consideration of the social determinants of health and of the complex interactions involving the individual, the community and other dimensions of the environment (Tremblay and Richard 2011). CoPs, such as the Health Promotion Laboratories, offer a model for action that has great potential value in view of the conditions that must be established in order to make such action possible. "In its place, models of distributed leadership based on collaboration, a shared vision and flexibility in both timing and approach are those most likely to succeed in building health-promoting organizations and healthy individuals" (Norman 2009: 870). The labs are, in fact, founded on flexible networks of interprofessional collaboration that are developed by forming multidisciplinary teams around a common theme to share their experiences. They thus constitute a unique opportunity for professionals to attain a broader and more profound vision that will equip them to deal head-on with the inherent complexity of health problems.

As dynamic, adaptive systems that evolve over time in accordance with an organizational context and a contingent social environment, CoPs are themselves complex realities. Consequently, they can be properly evaluated only with research mechanisms that are also grounded in a complex vision of this reality. Many authors have stressed the potential of dynamic systems models for evaluating the implementation and impact of public health programs, particularly initiatives based on partnership and collaboration (Norman 2009). The purpose of the conceptual model presented in this paper, a model grounded in open systems theory, is to provide a complex understanding of the labs. The strengths of the model include its conceptualization of the causal processes that lead to learning in both the team and the CSSS, its formalization of the links between the individual, the group and the organization, and the importance of its feedback loops. The evaluation model is thus an attempt to make up for one of the shortcomings identified in the literature, namely, the small number of studies that have dealt with the processes by which CoPs produce their effects.

Another feature of the model is that it is rooted in a transdisciplinary perspective, for it draws on a mix of knowledge from various disciplines. According to Morin and Le Moigne (1999), to properly consider a complex subject, a transdisciplinary vision is essential in order to avoid arbitrarily breaking up the systematic and multidimensional nature of the phenomenon under study. By building on teamwork models derived from occupational and organizational psychology and on theories of organizational learning and change drawn from sociology and management, the model proposed here provides practitioners and researchers with an interdisciplinary representation that has breadth and depth and is adapted to the subject under study.

The model presented here clearly makes up for shortcomings in the literature on CoPs, a field that is still largely atheoretical. There are many evaluation studies of CoPs now under

way in which it can be applied. For example, funded by the CIHR Partnerships for Health Systems Improvement Program, an evaluation of labs in five CSSSs in the Montreal area (Canada) is currently being conducted with the model (reference withheld to preserve the blind review process). Based on a multiple-case study design, the evaluation seeks to assess the implementation of the labs, analyze the effects on the participants and the organization, and identify the processes that generate these impacts. Included in the methodology are quantitative and qualitative strategies that will allow the testing of specific hypotheses related to specific parts of the model as well as validating the general theoretical formulation through the case study analytical approach. This study, which will use quantitative and qualitative strategies to assess specific parts of the model and validate the general theoretical formulation, will help significantly in advancing our knowledge of CoPs. It will also provide decision-makers with invaluable insights into how CoPs work, including the outcomes that can be reasonably expected and the organizational conditions required to help reach them (e.g., optimal mix of participants or supporting information systems).

Conclusion

Health Promotion Laboratories are an innovative professional development intervention that shares many features with the CoP model. Ongoing evaluation of this intervention will provide additional insight into its impact.

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RESEARCH PAPER

The Team Climate Inventory as a Measure of Primary Care Teams' Processes: Validation of the French Version

L'Inventaire du climat d'équipe comme mesure des processus d'équipes de première ligne : validation de la version française

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Abstract

Purpose: Evaluate the psychometric properties of the French version of the short 19-item Team Climate Inventory (TCI) and explore the contributions of individual and organizational characteristics to perceived team effectiveness.

Method: The TCI was completed by 471 of the 618 (76.2%) healthcare professionals and administrative staff working in a random sample of 37 primary care practices in the province of Quebec.

Results: Exploratory factor analysis confirmed the original four-factor model. Cronbach's alphas were excellent (from 0.88 to 0.93). Latent class analysis revealed three-class response structure. Respondents in practices with professional governance had a higher probability of belonging to the "High TCI" class than did practices with community governance (36.7% vs. 19.1%). Administrative staff tended to fall into the "Suboptimal TCI" class more frequently than did physicians (36.5% vs. 19.0%).

Conclusion: Results confirm the validity of our French version of the short TCI. The association between professional governance and better team climate merits further exploration.

Résumé

Objet : Évaluer les propriétés psychométriques de la version française courte de 19 items de l'Inventaire du climat d'équipe (ICE) et examiner l'apport des caractéristiques individuelles et organisationnelles dans la perception de l'efficacité des équipes.

Méthode : Parmi un échantillon aléatoire de professionnels de la santé et de personnel administratif provenant de 37 établissements de première ligne de la province de Québec, 471 personnes sur 618 (76,2 %) ont répondu à l'ICE.

Résultats : L'analyse factorielle exploratoire a permis de confirmer le modèle original portant sur quatre dimensions. Les coefficients alpha de Cronbach étaient excellents (de 0,88 à 0,93). L'analyse de structure latente révèle une structure de réponses à trois classes. Les répondants provenant d'établissements dotés d'une gouvernance professionnelle sont plus susceptibles d'appartenir à la classe « ICE élevée » que ceux provenant d'établissements dotés d'une gouvernance de type communautaire (36,7 % contre 19,1 %). Le personnel administratif est plus enclin à se retrouver dans la classe « ICE sous-optimal » que les médecins (36,5 % contre 19,0 %).

Conclusion : Les résultats confirment la validité de notre version courte de l'ICE. Il serait pertinent d'étudier plus en profondeur le lien entre la gouvernance professionnelle et un meilleur climat d'équipe.

Team-based care is one of the key features of high-performance primary care (PC) settings (McMurchy 2009; Shortell et al. 2004). It is central to the Chronic Care Model (Bodenheimer et al. 2002) and to the Medical Home (Center for Policy Studies in Family Medicine and Primary Care 2007; College of Family

Physicians of Canada 2011). Moving from small or mid-size practices with family physicians practising "alone together" (Freidson 1975) to practices requiring structural and functional integration of multidisciplinary PC staff has been a key feature of, and a challenge to, primary care reform initiatives in many countries. Canada is no exception. Team-based work is a key feature of Ontario's Family Health Teams, Quebec's Family Medicine Groups and Alberta's Primary Care Networks, among others (Hutchison et al. 2011). Being able to measure team functioning reliably is of interest not only to health services researchers, but also to clinicians and managers so that they can monitor the evolution and effectiveness of newly formed teams, diagnose where teams may need help to be more effective or measure the impact of teamwork on the quality of care delivered.

The Team Climate Inventory (TCI) (Anderson and West 1998) is among the few instruments that have been validated and used in a variety of contexts and countries (Lemieux-Charles and McGuire 2006). It is based on a rigorous conceptual framework and on extensive research into group climate and innovation (Anderson and West 1998; West and Field 1995). Anderson and West (1998) stated that for individuals to function effectively in a group, they must interact, share common goals and have sufficient task interdependence to develop shared understandings. Those authors proposed a four-factor theory of group climate for innovation: (a) *participative safety* acknowledges that trust is essential for members' involvement; (b) *support for innovation* is the expectation of and support for the introduction of new ways of doing things; (c) *vision* refers to valued outcomes and a common higher goal as motivating factors; and (d) *task orientation* refers to a shared concern for excellence. The TCI has been validated in different languages, and the four-factor structure has always been confirmed (Agrell and Gustafson 1994; Kivimäki et al. 1997; Mathisen et al. 2004; Ouwens et al. 2008; Ragazzoni et al. 2002; Strating and Nieboer 2009).

Higher performance on the TCI has been associated with improved health outcomes (Beaulieu et al. 2013; Bower et al. 2003), better access to care, improved patient satisfaction (Bower et al. 2003; Goh and Eccles 2009; Poulton and West 1999; Proudfoot et al. 2007) and improved job satisfaction and openness to innovation (Gosling et al. 2003; Lemieux-Charles and McGuire 2006; Poulton and West 1999; Proudfoot et al. 2007). Team effectiveness, as measured by the TCI, is one of the 24 priority indicators for providers in the Canadian Institute for Health Information's Pan-Canadian Primary Health Care Indicator Update Report (CIHI 2012).

Most of the work linking results of the TCI to a variety of outcomes has been done with the original 38-question version of the questionnaire (Anderson and West 1998). A shortened 14-question version has been proposed by a Finnish team (Kivimäki and Elovainio 1999), but that version is not based on a robust methodology and has yet to be associated with health outcomes. However, the authors of the original TCI have validated a shorter 19-item version (M. West, personal communication, October 1, 2008) that we translated into French and used

in a study of the association between organizational characteristics of PC practices and quality of care (Beaulieu et al. 2013). In that study, we demonstrated that this short version of the TCI was among the predictors of better quality of care. The objectives of this paper are to report on the psychometric properties of the French version of the short TCI and to explore the contributions of individual and organizational characteristics to perceived team effectiveness.

Methods

Study population

The study population is composed of 471 family physicians, healthcare professionals (mainly nurses) and administrative staff working in a random sample of 37 primary care practices recruited in the province of Quebec for an observational study of organizational predictors of quality of care (Beaulieu et al. 2013). Community primary care centres (CLSCs), traditional fee-for-service practices and Family Medicine Groups (FMGs) are the three main PC organizational models in Quebec. CLSCs are large public organizations providing an array of PC services to a geographically defined population. The teams are mainly composed of family physicians, nurses and social workers. Physicians are salaried. Traditional fee-for-service practices are composed mainly of family physicians and their administrative staff; a few hire nurses, and the premises are privately owned. FMGs typically comprise eight to 10 full-time equivalent family physicians, not necessarily in a single location. In becoming an FMG, the group receives funding for two registered nurses, an administrative assistant and a secretary, above and beyond any existing staff. FMGs can be public, with salaried physicians in CLSCs, or privately owned, with physicians being paid fees for service.

TCI questionnaire and French translation

The original TCI is a 44-item questionnaire. Items are grouped under five scales, four related to dimensions of team functioning (38 items) and a fifth containing social desirability questions (6 items) (Anderson and West 1998). The short 19-item version eliminates the social desirability scale and keeps the original four team-functioning scales. Participative safety (6 items, Cronbach 0.84) and support for innovation (5 items, Cronbach 0.81) are scored on a 5-point Likert scale, and vision (4 items, Cronbach 0.86) and task orientation (4 items, Cronbach 0.84) on a 7-point scale (M. West, personal communication, October 1, 2008). The distribution of the global score ranges between 4 and 24, higher values indicating higher levels of team functioning. The authors recommend excluding practices with response rates of 30% and less (Borrill and West 2001). We produced a French version using the following steps: A first translation into French by a professional translator not expert in the domain, followed by an analysis to resolve discrepancies; a back-translation into English by a different translator

who was unaware of the original version; a review by the researchers on the team, who had expertise in organizational research. The two English versions were also compared with regard to number of words and readability statistics. We did not perform a formal pretest.

Independent variables: Individual and organizational characteristics

Individuals' characteristics (sex, age and professional role) were collected on the TCI questionnaire. A questionnaire, validated in previous research (Lévesque et al. 2010), was completed by the physician in charge to provide information on organizational characteristics. This questionnaire was based on the conceptual framework of the main study, inspired by the work of Contandriopoulos and colleagues (2000) that defines an organization according to its *vision*, *structure*, *resources* and *organizational practices*. The organizational variables for this analysis were chosen based on the literature on teams (Lemieux-Charles and McGuire 2006) and included, among others, PC model (CLSC, FMG, etc.), governance and practice size.

Administration of the TCI

All family physicians, healthcare professionals, secretaries, receptionists and practice managers who were involved in providing comprehensive primary care to the practice population of patients were considered members of the PC teams. Such a definition was needed in CLSCs, where services are also provided to clients with specific needs (prenatal care, school care, home care) by multiple providers. TCI questionnaires were distributed to each member with a personalized letter. We sent two reminders over a six-week period. Questionnaires were anonymous.

Analysis

VALIDATION OF THE FRENCH VERSION

Although the instrument is administered at the individual level, the team climate is meant to reflect shared perspectives. To ascertain the level of inter-rater agreement we used James and colleagues' (1993) within-group inter-rater agreement multi-item $r_{wg(j)}$ indices as advised by the developers (Anderson and West 1998). Inter-rater agreement for each of the TCI subscales was satisfactory, with $r_{wg(j)}$ indices varying between 0.72 and 0.99. A value of 0.7 is the traditional cut-off point denoting high versus low agreement (LeBreton and Senter 2008).

Our plan was to perform confirmatory factor analysis (CFA) and exploratory factor analysis (EFA). However, owing to the relatively small sample size and presence of multi-collinearity, the necessary assumptions for CFA were not met. EFA was performed to test the validity of the French version of the TCI. Principal components analysis with varimax rotation of the factor loading matrix was used. To evaluate the fit of the models, we examined the Kaiser-Meyer-Olkin measure of sampling adequacy, Bartlett's test of sphericity, the diagonal elements on the anti-image correlation matrix and the communalities (Bartholomew et al. 2008).

To test reliability and internal consistency for each of the scales of the translated TCI, Cronbach's alphas were calculated for each of the four scales and for the global score and compared to those of the English version provided by the original authors (M. West, personal communication, October 1, 2008).

ASSOCIATION BETWEEN TCI SCORES AND INDIVIDUAL AND ORGANIZATIONAL CHARACTERISTICS

We used latent class analysis (LCA) (Clogg and Goodman 1984) and latent class regression (LCR) (Bandeen-Roche et al. 1997) to explore the influence of organizational and individual characteristics on the distribution of responses of the TCI scales. LCA allowed us to explore whether and how categories of respondents showed different patterns of responses and whether those patterns varied according to the instrument's items or subscales. LCA is a type of cluster analysis that posits the existence of an unobserved or latent classifier that explains relationships observed between categorical variables. It provides a parsimonious summary of the patterns of item responses in the data and can reveal features that are not apparent in an item-by-item analysis. Classical linear regression was less appropriate because of the small range of the TCI scores. LC regression, which can be viewed as multinomial logistic regression, defines the probability of belonging to a class of individuals who share a common characteristic. The decision on the optimal number of classes to retain was guided by the Bayesian Information Criterion (BIC) (Schwarz 1978). LCA was conducted on each TCI scale separately and then on the overall TCI score, using class membership for each of the individual scales as the items of analysis. Statistical analyses were performed with R 2.15.0 software and SPSS 20.0 software (IBM Corp., Armonk, NY, USA).

Ethics approval

The study was approved by the Research Ethics Committee of the University of Montreal Hospital Research Centre.

Results

The French TCI questionnaire was sent to 618 persons in the 37 participating practices and was completed by 471, for a total response rate of 76.2% (mean of 77.8% per practice; SD, 16.1%; range, 37.5%–100%). Table 1 describes practices' characteristics and Table 2, respondents' characteristics. Response rates differed according to the respondents' role in the practice, being 73.8% for physicians, 69.2% for other healthcare professionals and 83.1% for administrative staff.

TABLE 1. Participating practices' characteristics (N = 37)

Practices' characteristics	n (%) or m (SD)
Organizational model (n [%])	
• Community primary care centres (CLSCs)	9 (24.3%)
• Traditional fee-for-service	12 (32.4%)
• Family Medicine Groups (FMGs)	16 (43.2%)
Governance model (n [%])	
• Professional	25 (67.6%)
• Community	12 (32.4%)
Practice size (number of physicians) (m [SD])	7 (2.7)
Sharing of clinical activities among physicians (n [%])	
• Mostly all physicians share clinical activities (urgent care, hospital care, coverage during vacations, etc.)	30 (81.1%)
• Some or none of the physicians share clinical activities	7 (18.9%)
Presence of mechanisms for maintaining or evaluating competence at the practice (continuous professional development activities and chart audits) (n [%])	30 (81.1%)
Team climate inventory (TCI) (m [SD])	
• Participative safety (1–5)	3.8 (0.4)
• Support for innovation (1–5)	3.7 (0.4)
• Vision (1–7)	5.2 (0.5)
• Task orientation (1–7)	4.7 (0.6)
• Overall TCI score (4–24)	17.4 (1.8)
Mean response rate per practice, percent (m [SD])	77.8 (16.1)

TABLE 2. Respondents' characteristics (N = 471)

Role in the practice	Number contacted	Number responded	Response rate (%)	Respondents only	
				Age (m [SD])	Female (n [%])
Physician	260	192	73.8	48.0 (10.9)	87 (48.3%)
Other health professional	133	92	69.2	41.5 (10.1)	91 (91.9%)
Administrative staff	225	187	83.1	45.5 (10.7)	166 (94.9%)
Overall	618	471	76.2	45.6 (10.9)	344 (75.8%)

TABLE 3. Factor loadings and communalities: Principal components analysis with varimax rotation on the 19-item short version of the French Team Climate Inventory (F-TCI)

Items	Factors				Communality
	Participative safety	Support for innovation	Vision	Task orientation	
We have a "we are in it together" attitude.	0.77				0.63
People keep each other informed about work-related issues in the team.	0.66				0.61
People feel understood and accepted by one another.	0.66				0.64
There are real attempts to share information throughout the team.	0.63	0.42			0.69
There is a lot of give and take.	0.63				0.61
We keep in touch with one another as a team.	0.65				0.70
This team is always moving towards the development of new answers.		0.69			0.77
This team is open and responsive to change.		0.71			0.77
People in this team are always searching for fresh, new ways of looking at problems.		0.77			0.79
Members of the team provide and share resources to help in the application of new ideas.		0.90			0.80
Team members provide practical support for new ideas and their application.		0.75			0.74
How clear are you about what your team's objectives are?			0.76		0.72
How far are you in agreement with these objectives?			0.86		0.83
To what extent do you think other team members agree with these objectives?			0.80		0.81
To what extent do you think members of your team are committed to these objectives?		0.43	0.71		0.81
Do your team colleagues provide useful ideas and practical help to enable you to do the job to the best of your ability?				0.85	0.77
Are team members prepared to question the basis of what the team is doing?			0.42	0.55	0.73
Does the team critically appraise potential weaknesses in what it is doing in order to achieve the best possible outcome?				0.74	0.80
Do members of the team build on one another's ideas in order to achieve the highest possible standards of performance?		0.45		0.61	0.79

Note. Factor loadings <0.4 are suppressed.

Validation of the French version

EXPLORATORY FACTOR ANALYSIS

We first examined whether factorization would be appropriate. All the items were significantly correlated (Pearson's r>0.3) with at least one other item, indicating that factorization would be justified. The Kaiser-Meyer-Olkin measure for sampling adequacy was 0.95, well above the recommended threshold value of 0.6 (Tabachnick and Fidell 2007). Bartlett's test of sphericity was significant (X2 = 6464.72, df = 171; $p<0.001$). The diagonal elements on the anti-image correlation matrix were all well above 0.5, supporting the inclusion of all 19 items in the factor analysis. Finally, communalities (shown in Table 3, last column) were all superior to 0.3, confirming that each item shared common variance with the others. All 19 items of the questionnaire were thus included in the EFA.

Table 3 presents the factor loading matrix for the final solution. Eigenvalues were superior to 1 for the first three components (participative safety, support for innovation, vision) and very close to 1 (0.9) for the last (task orientation). In the final model, the first component accounted for 22% of the variance, the second and third accounted each for 19% and the fourth accounted for 14%, for a total of 74% of the total variance accounted by the model. Item loadings closely matched the instrument's scales. The four-factor model supported by theory was thus confirmed.

RELIABILITY

As shown in Table 4, Cronbach's alphas for the four components were very good (from 0.88 to 0.93) and were slightly superior to the values provided by the authors of the original version (M. West, personal communication, October 1, 2008), indicating good internal consistency for each scale. The Cronbach's alpha for all 19 items was 0.95.

TABLE 4. Cronbach's alphas of the French version of the TCI compared to the original English 19-item version

	Cronbach's α	
TCI scales	**French version**	**Original version**
Participative safety	0.88	0.84
Support for innovation	0.93	0.81
Vision	0.91	0.86
Task orientation	0.88	0.84

Association between TCI scores and individual and organizational characteristics

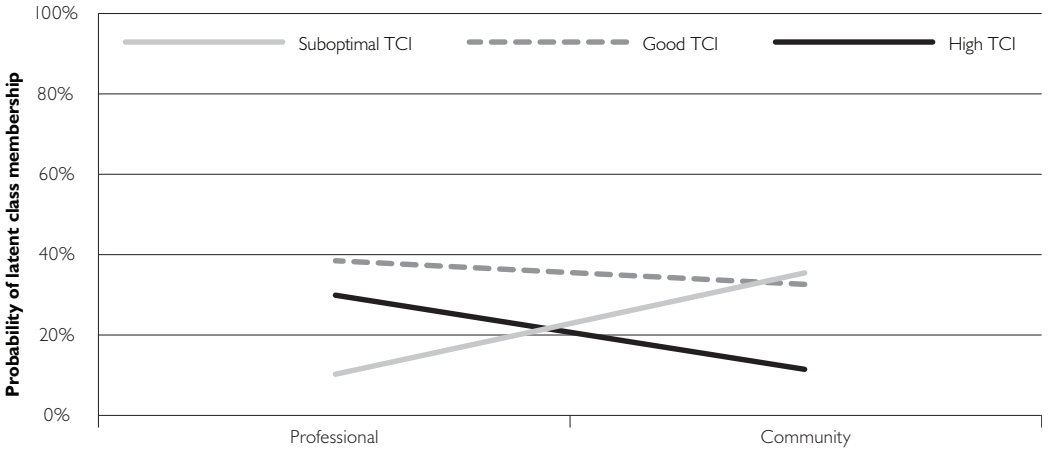
LATENT CLASS ANALYSIS

Three classes were obtained when conducting LCA on the overall TCI: Class 1 (Suboptimal TCI; 26.8% of respondents) corresponded to a rather neutral or subpar evaluation of each scale of the questionnaire; Class 2 (Good TCI; 44.6% of respondents) was indicative of an average–high team climate overall; and Class 3 (High TCI; 28.6% of respondents) indicated respondents were more likely to be in the most positive class for each individual scale. No class revealed a complex assessment of team climate that could have been very positive for some scales and clearly less so for others.

LATENT CLASS REGRESSION

Two characteristics, the governance model of the practice and the professional roles, significantly affected respondents' prior probabilities of belonging to any one of the three classes of the overall TCI defined by the LCA. Figures 1a and 1b present the results of the LCR and depict how the probability of latent class membership was affected by each of these characteristics. Respondents in practices with professional governance had a 36.7% probability of belonging in the "High TCI" class compared to respondents in practices with community governance (19.1%), and this was significantly different from the probability of belonging in the "Suboptimal TCI" class, which was greater in practices with community governance than in those with professional governance (41.8% vs. 18.8%) (Figure 1a).

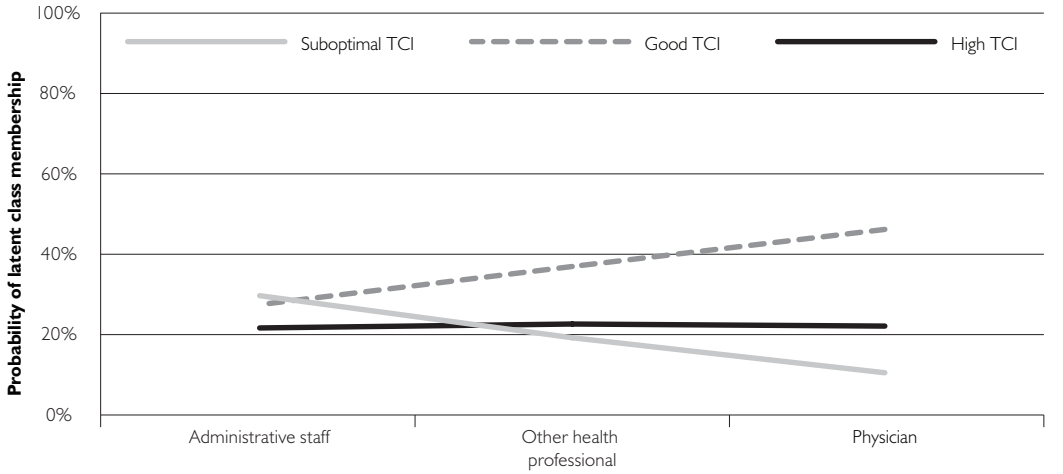
FIGURE 1A. PC practices' governance model as a predictor of latent class membership for the overall TCI



Administrative staff tended to fall more frequently into the "Suboptimal TCI" class than did physicians (36.5% vs. 19.0%), who were more likely to belong in the "Good TCI" class (51.5% vs. 34.4%) (Figure 1b). Interestingly, the probability of belonging in the "High TCI" class

was identical in all three professional groups, being in the range of 30%. The probability of belonging to the highest-scoring class was greater for respondents in practices where physicians shared their various clinical activities (unfavourable duty hours, coverage during absences, hospital coverage, etc.), but this association fell short of reaching statistical significance (p=0.053).

FIGURE 1B. Respondent's role in the practice as a predictor of latent class membership for the overall TCI



Discussion

Our results confirm the validity of our French version of the 19-item short TCI provided by the original developers and contribute to the scant body of knowledge on the relationships between individual and organizational characteristics and team processes in PC practices in Canada. In addition, the results of our observational study provide evidence on the construct validity of our short French version because the TCI score was associated with the overall technical quality of PC score (Beaulieu et al. 2013). Having access to a valid and reliable measure of team processes in both French and English is an asset for Canadian health services researchers and decision-makers.

Although the implementations of a variety of interdisciplinary teams in Canada have been studied (Oandasan et al. 2006; Primary Health Care Transition Fund 2007), we cannot draw a clear picture of the contribution of organizational factors to team processes in the practice settings that currently exist in Canada. Few studies have explored these associations using quantitative measures of team processes like the TCI. We know of only one published study conducted in a sample of 21 Family Health Teams in Ontario using the TCI (Howard et al. 2011). Team culture and access to information technology were the only factors associated with higher TCI scores. Team size, skill mix, governance model and provider type showed no relationship with the TCI.

In our study, the only individual characteristic associated with the TCI was the respondent's professional role in the practice. Family physicians were less likely to belong in the class of respondents who scored team processes lower, while administrative staff were more likely to belong in that class. This relationship has been observed by others (Goh and Eccles 2009;

Proudfoot et al. 2007), but not in the Ontario study (Howard et al. 2011). To a certain extent this finding is not surprising, but low perceived level of engagement by administrative staff should be disquieting, considering their unique contribution to team effectiveness (Crabtree et al. 1998; Schlosser 2003). However, the probability of belonging to the class reporting the highest team climate was the same for all three types of providers. Achieving a high degree of engagement in all team members is thus possible.

Professional governance was predictive of a more favourably assessed team climate. This was not reported by Howard and colleagues (2011) in the Ontario study, but the number of teams studied was small (n = 21) and only four had a community governance model. Data are scant on the impact of governance models on team climate. In the United Kingdom, Poulton and West (1999) reported that team climate was higher in fundholding practices – perhaps a more entrepreneurial culture – than in non-fundholding ones. Also in the United Kingdom, others have reported that tensions occurred in PC trusts where community nurses were engaged by the community authorities and practice nurses were engaged by the physicians (Williams and Laungani 1999).

How do the results from our study settings compare to what is expected or has been observed in terms of TCI scores? Comparisons with specific studies are not easy because the studies differ in how TCI scores are reported. According to the published user guide (Borrill and West 2001), our sample scored above average on the vision subscale and average on the three others. It has been observed that PC teams' subscale scores tend to be lower than those of other multidisciplinary teams (Goh and Eccles 2009).

We did not carry out a test–retest evaluation, which is a limitation of our study. Our main objective was not to perform a formal validity assessment of the French version, as this would have been too demanding of the study participants. Test–retest reliability was not reported in any of the validation studies in other languages (Agrell and Gustafson 1994; Kivimäki et al. 1997; Mathisen et al. 2004; Ragazzoni et al. 2002; Strating and Nieboer 2009). However, Loo and Loewen (2002) performed test–retest evaluations on the long and short English versions of the TCI and found them to be good.

Some might also question why the Cronbach's alpha on the global score is so high when the tool is described as having four dimensions. Do the subscales really discriminate between different aspects of team climate? First, it should be noted that this finding has been observed for both the long and short versions of the TCI (Agrell and Gustafson 1994; Anderson and West 1998; Kivimäki and Elovainio 1999; Loo and Loewen 2002). Anderson and West (1998: 245) reported correlations in the 0.35 to 0.62 range among subscale scores and commented that "while these correlations are not high enough to give rise to concerns over multicolinearity, they do highlight the possibility that perceptions of climate may be prone to a halo effect."

Conclusion

In addition to validating a French version of the original short TCI, our analysis showed how useful this tool may be to researchers who want to study team processes using quantitative

study designs on larger numbers of teams. We see that the TCI is not only useful as a global measure of team function but also makes possible a finer analysis of the four central processes of team functioning. More research is needed to explore the TCI subscales' sensitivity to change, as this could make the TCI an interesting outcome measure for interventions aimed at enhancing team processes.

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RESEARCH PAPER

Patients' Perceptions of Joint Replacement Care in a Changing Healthcare System: A Qualitative Study

La perception des patients sur les soins associés à l'arthroplastie dans le cadre d'un changement dans le système de santé : une étude qualitative

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Abstract

Background: Ontario has introduced strategies over the past decade to reduce wait times and length of stay and improve access to physiotherapy for orthopaedic and other patients. The aim of this study is to explore patients' experiences of joint replacement care during a significant system change in their care setting.

Methods: A secondary analysis was done on semi-structured qualitative interviews that were conducted in 2009 with 12 individuals who had undergone at least two hip or knee replacements five years apart at a specialized orthopaedic centre in Ontario, Canada. Interview transcripts were coded and then organized into themes.

Results: Although the original study aimed to capture participants' experiences with changes in anaesthetic technique between their first and second joint replacements, the participants described several unrelated differences in the care they received during this period. For example, participants had difficulty obtaining a referral to an orthopaedic surgeon from their family physician. They also noted that the hospital stay and in-hospital physiotherapy they received were shorter after the second joint replacement surgery. They identified guidance from physiotherapists as an important component of their recovery, but sometimes had difficulty arranging physiotherapy after hospital discharge following their most recent surgery.

Conclusions: The changes described between the first and second joint replacements provide the participants' perspective on the impact of policy changes on wait times, reduced lengths of hospital stay and physiotherapy access. The impact of these policy changes, often made in an attempt to improve access to care, had an unintended and detrimental effect on participants' perceptions and experiences of the quality of care provided.

Résumé

Contexte : Au cours des dix dernières années, l'Ontario a mis en place des stratégies visant une réduction des temps d'attente et de la durée des séjours ainsi qu'une amélioration de l'accès aux services de physiothérapie pour les patients en orthopédie ou autres. Le but de cette étude est de sonder l'expérience des patients face aux soins associés à l'arthroplastie lors d'un important changement dans leur établissement de soins.

Méthode : Une analyse secondaire a été effectuée sur des entrevues qualitatives semi-structurées menées en 2009 auprès de 12 personnes qui avaient subi au moins deux arthroplasties du genou ou de la hanche, à cinq ans d'intervalle, dans un centre spécialisé d'orthopédie en Ontario, au Canada. Les transcriptions des entrevues ont été codées puis organisées en thèmes.

Résultats : Bien qu'au départ l'étude visait à rendre compte de l'expérience des patients face aux changements des techniques d'anesthésie entre la première et la seconde arthroplastie, les participants ont fait part de plusieurs différences indépendantes dans les soins reçus au cours de cette période. Par exemple, ils ont éprouvé des difficultés à obtenir auprès de leur médecin de famille un acheminement vers le chirurgien orthopédiste. Ils ont également souligné que le séjour à l'hôpital et les services de physiothérapie reçus à l'hôpital étaient plus courts lors de

la deuxième arthroplastie. Ils ont indiqué que l'encadrement des physiothérapeutes constituait un élément important du rétablissement, mais qu'ils avaient parfois des problèmes à obtenir un rendez-vous en physiothérapie après leur congé de l'hôpital suite à l'arthroplastie la plus récente.
Conclusion : Les changements décrits entre la première et la deuxième arthroplastie donnent un aperçu de la perception des patients quant à l'impact des changements de politique pour les temps d'attente, la réduction des séjours à l'hôpital et l'accès aux services de physiothérapie. Ces changements de politique, souvent effectués dans le but d'améliorer l'accès aux services, ont eu un impact non désiré et néfaste sur la perception des participants et sur leur expérience quant à la qualité des soins reçus.

Across Canada and internationally, most jurisdictions are striving to find ways to contain healthcare spending while also ensuring good access to high-quality care. Several evidence-based health policies have been introduced in Ontario with the goal of reducing wait times for surgery (Ontario MOHLTC 2008), reducing length of hospital stay (Kehlet and Wilmore 2008; Raphael et al. 2011) and lowering the system cost of physiotherapy (Dales 2005) for patients who require joint replacement. These provincial strategies aim to expedite patient care as a means of reducing costs to the healthcare system and providing greater access. Although patient outcomes are often cited as a driving force behind these initiatives, few studies have explored patients' experiences of these system changes, and no studies have examined patients' experiences of the impact of different strategies on a single procedure. We also question whether strategies whose primary aim is system cost reduction can be compatible with "patient-centred care" (Laine and Davidoff 1996).

Background

Wait times

Total joint replacement is a common surgical procedure that improves pain and functional limitations associated with arthritis (Canizares et al. 2009; CIHI 2009). Strategies to reduce wait times for selected procedures, including knee replacement surgery, were introduced in Ontario in 2004. Wait times for surgery are often calculated as the time between the date of surgical consultation – when the decision to proceed with joint replacement is made – until the date of surgery. Using this definition, the average wait times for hip and knee replacement in Ontario were 186 and 230 days in 2012, respectively (Ontario MOHLTC 2008). However, Rotstein and Alter (2006) have argued that wait time actually begins much earlier. They conceptualize wait time as the time of onset of illness until treatment. Failure to consider the time from which patients first seek healthcare from their primary provider and the process of referral to a specialist may mask the actual wait time experienced by patients.

Length of stay

Shortening length of stay has become a focus for organizations faced with increased demands and limited resources. This is one reason hospital stays following total joint replacement are becoming increasingly shorter (Hunt and Beverland 2009; Husted et al. 2012; Jimenez-Garcia et al. 2011; Raphael et al. 2011). Much of the current research on length of stay focuses on clinical interventions and issues that prevent or facilitate early discharge. Clinical pathways (Gregor et al. 1996), early physiotherapy (Chen et al. 2012), patient education (Jones et al. 2011) and multi-modal analgesia (Duellman et al. 2009) may facilitate faster recovery and contribute to shorter lengths of stay following total joint replacement. Longer hospital stays have been associated with patients who are older than 75 and those with multiple co-morbidities that complicate their recovery (Styron et al. 2011). Despite the implementation of a range of clinical and bed management interventions aimed at reducing length of stay, few studies have investigated the patient's experience of early discharge. Some total joint replacement patients value being discharged earlier so that they can recuperate in a familiar environment, yet these patients also report having concerns about returning to their normal activities after early discharge (Hunt et al. 2009). Patients undergoing joint replacement also have expressed a desire for more individualized discharge planning and more guidance on regaining mobility (Fielden et al. 2003; Hunt et al. 2009).

Physiotherapy funding

At the same time that length of hospital stay has been decreasing after total joint replacement, public funding of physiotherapy in Ontario has undergone government cutbacks (Dales 2005). It is well established that early physiotherapy is important for patients who have undergone total joint replacement to help achieve the desired positive outcomes (Nazzal et al. 2012). Key informants across Ontario have supported the importance of securing outpatient rehabilitation to facilitate shorter hospital stays; however, with the current limitations of physiotherapy, this goal is difficult to ensure (Fancotte et al. 2010). Some postulate that limiting physiotherapy funding may prevent patients from receiving early interventions and treatment and result in further burden on the healthcare system (Dales 2005).

These policies have evidence to support their implementation, yet there is little research on the impact that they have on the experience of care of patients who have undergone total joint replacement surgery. To address this gap, we qualitatively analyzed interview data we obtained from participants who had undergone two or more joint replacements. We asked the following research question: "How are patients' experiences influenced by policy decisions set in relation to hip and knee replacement?" These data provide insight into the participants' experiences of three distinct policies (decreased wait times, length of stay and physiotherapy funding) that influenced their care when undergoing total joint replacement.

Methods

Our team undertook a secondary analysis of an interview data set whose primary aim was to explore participants' experiences of regional anaesthesia during hip and knee replacement surgery. Secondary analysis, a long-accepted methodology for interpreting statistical data, is a relatively new approach with qualitative data sets. Following the guidelines set out by Hinds and colleagues (1997), our study met the criteria for re-usability of qualitative data in terms of (a) accessibility (we were the team who had conducted the original research); (b) quality (the original research design was publishable, the data set was complete and full summary notes were taken of all analysis meetings held regularly over 12 months); and (c) suitability (the selected patient population matched the emerging themes we identified, and we did not believe that additional interviews were needed to achieve theoretical saturation).

Ethics approval was received from our hospital's research ethics board, and each participant provided informed consent prior to taking part in the original study. All participants were recruited from one specialized orthopaedic facility associated with a tertiary hospital. Participants were included in the original study if they had undergone two or more total joint replacement procedures and had general anaesthetic for their first procedure and regional anaesthesia for their last procedure. Twelve patients took part in one interview in 2009 to explore their experiences of total joint replacement at two different times, approximately five years apart (Webster et al. 2011). During this five-year period between their surgeries, several changes were made to the organization of care delivery at this centre. Most notably, funding to support length of stay and in-patient physiotherapy was reduced and outpatient physiotherapy was de-listed, giving fewer patients access to publicly insured physiotherapy.

As described elsewhere (Webster et al. 2011), our strategy for obtaining study participants involved developing a data set of eligible patients from an electronic patient record database. From this set, our team selected a purposive sample of 12 participants who had two or more hip or knee replacements in the last 10 years, with the last surgery being within the past five years. Maximum variation sampling was employed: participants were selected by age, gender and occupation. Seven participants had hip replacements, four had knee replacements and one had both hip and knee replacements. There were six men and six women in the sample, and their ages ranged from 40s to 80s. Many participants were retired; their past professions included housekeeper, carpet layer, teacher, nurse, accountant, construction worker and parks and recreation manager. Interview questions (see Appendix) were constructed to begin with open, broad questions about the participant's experiences leading up to surgery followed by questions about each specific surgery. A series of questions were then asked to encourage the participants to reflect on any differences or similarities between the first and second total joint replacements. Finally, questions were asked to determine the patient's understanding of pain and pain management and his or her knowledge of how anaesthesia may have influenced their experiences. All questions were meant to be exploratory and relied on neutral prompts to allow differences between participants' perceptions and experiences to emerge during the course of the interview.

The interview guide was pilot tested with a participant identified by our research team. All interviews (both pilot and study interviews) were conducted by the primary investigator (FW), recorded and professionally transcribed verbatim for data analysis.

Saturation is generally described as the point at which no new information pertaining to the developing themes is being generated (Patton 2002). Achieving saturation during secondary analysis has been highlighted as more difficult. However, a subset of our team of researchers (FW, CM, SB) met over the course of several months to read and discuss each transcript in detail, and we believed that sufficient data were available upon which to identify new themes that emerged from the original data set. The coding template that was developed for the original study on patient experiences with anaesthesia included codes that captured participants' descriptions of care related to physiotherapy, wait times and in-hospital rehabilitation. In addition, a larger team met twice throughout the study period to discuss preliminary themes as they emerged. This larger group included a physiotherapist, a pain psychologist, an advanced practice nurse and a doctorate-prepared nurse-researcher.

Findings

Although the original study explored patient experiences with regional versus general anaesthesia (Webster et al. 2011), other issues emerged unsolicited during the interviews as being central to the participant's experience of hip or knee replacement. These issues reflected the participant's experiences of several inter-related policy changes that affected his or her care. We have organized these experiences into the following themes: (a) wait times, (b) reduced length of stay and (c) post-discharge physiotherapy. One major contributing factor to patients' resilience with respect to these new policies is their socio-economic status.

Wait times

Many participants described that progressive changes in their mobility and related pain were the leading factors that drove them to seek help, leading to joint replacement. Participants often described different thresholds for determining the point at which they sought specialist help, which sometimes differed from their referring physicians' opinions: "I think that winter, I realized that my pain was getting worse. I talked to … my doctor … some time in the spring of 2001. He told me that yes, it was arthritis, and it was better if I waited until 65 because they will have to do maybe some maintenance that will take me to 80 before they have to do anything. I say, 'If I wait until I am 65, I'll be in a wheelchair'" (#2).

Our participants reported that in actively seeking referral for surgery they encountered significant barriers. Most often, the barrier they identified was related to their primary care provider or physician. Specialist consultation with an orthopaedic surgeon for hip or knee replacement requires a consultation with, and referral from, a primary care provider or other physician. Many participants told us that their primary care providers told them to wait as long as possible before requesting a referral for surgery. One man shared this experience: "It got to the point where I was hobbled, I was really limping badly. The doctor assured me that

if I stayed on crutches and kept the weight off … I'll be fine. After six months I went back and he kept telling me 'stay on it, stay on it, stay on it.' After another eight months I went back and he said [the same thing]. I said to him, 'Look, what happens in six months if it's the same thing?' He says, 'Then I'll put you on the list.' And I asked him, 'How long is the waiting list?' He said, 'A year.' So I was potentially looking at another 18 months on crutches. And I got very frustrated" (#6). Several participants disagreed with their primary care provider's criteria for referral. As one participant told us, "If it isn't falling off or dripping blood on his floor, I mean, he's not going to do anything. He says, 'You're not sick enough, you're not bad enough. Can you sleep at night? Oh, you're not bad.' I mean, these were his criteria for getting serious" (#5).

Other participants also described the experience of disagreeing with their physicians who had suggested they wait for surgery: "And I kept telling my family doctor, 'Please could you send me to [the surgeon],' [and the doctor replied,] 'Oh, it's all arthritis, it's all arthritis.'… And then I said to [family doctor], 'Well, you know, [in] the length of time you're taking to tell me it will take me a year to see [surgeon], he would have seen me already.' A year has passed, two years have passed. … I would be waiting until now if I wasn't insistent on him" (#7). It is possible that some of these patients may eventually give up on seeking help for their pain. At the same time, some patients described a different experience with their surgeon: "[My doctor] says, 'Is the pain enough that it wakes you up at night?' and I said, 'Absolutely!' And he goes, 'Well, I've looked at your x-rays and with that answer,' he says, 'You need a hip replacement right away.' And within, I think, four weeks I was on the table having my hip replaced" (#6).

As in many other studies, we did find that participants expressed a degree of acceptance of chronic pain in their lives, either due to age or their health status. For example, one participant shared, "When you have arthritis you get used to a certain level of pain that you can tolerate, you know? You live with it and you just know you have to live with it, so you don't complain about a minor pain that doesn't immobilize you, let's say" (#1). This participant's idea that "you don't complain" was a stoicism expressed by most patients. Although living in chronic and sometimes debilitating pain, participants took pride in not viewing themselves as "crybabies" (#6). We hypothesize that this notion may prevent some individuals from fully advocating for themselves with their primary care providers when facing delays at the level of referral.

Reduced length of stay

At our institution, the length of in-patient stay after total joint replacement had decreased from approximately eight days to four days over the previous decade. Participants in our study tended to have a longer length of stay with their first joint replacement and a shorter stay after their second joint replacement. Without being prompted, the majority of participants raised this issue as being the central difference between their two surgeries. The length of hospital stay following the first surgery was mostly viewed as having been quite positive: "My first visit, they had me four days downstairs and then they moved me upstairs for therapy – which was

wonderful – and I was there four days. And you went to a therapy room and did your exercises every day. And you walked to the solarium for breakfast, lunch and dinner, with a menu. And we met other patients" (#10).

In contrast, many felt that their hospital stay during the second visit was less positive. As one patient described, "I wasn't really ready to go home but they sent me home anyway. Just there was no way I could even get up to get a glass of water. I didn't feel well, I didn't feel strong. They had given me [pain medication], so I wasn't in pain. But I couldn't eat, I could only eat very sparingly, and I was very, very weak" (#8). Another participant said, "There was no rehab in the hospital this time, you were just shunted out the door after four days, and so obviously that was cost-cutting" (#9).

We suspect the home environment and socio-economic status of patients affected their recovery and their ability to manage a shortened length of stay. There was a wide range of differential access to support and resources that participants described. For example, one participant who preferred a shorter length of stay spoke about the support he had at home and taking his wife to dinner for nursing him during his recovery. He said, "I had the walker, and then I had the high toilet seat … and I slept downstairs with a bathroom. … My wife slept in a chair next to me. … My wife would have to help me stand up. … So I said to my wife, 'Sweetheart, you've been such a wonderful nurse to me I'm going to take you to [restaurant] for dinner'" (#4). Other participants described how living alone affected their ability to manage following surgery: "I guess one is always glad to go home, but living alone you have to plan ahead. … I had lots of frozen dinners and things like that. … I think I was even using paper plates just to avoid doing dishes" (#1). Another participant, who was discharged on a Sunday, had difficulty obtaining one of the medications he had been prescribed: "It was a Sunday that I was discharged. Went to my pharmacy with one of the prescriptions and they said, 'Well, we don't have that. That's a very special item. You can only get that in special pharmacies.'… My wife had to drive … about 10, 15 miles away when the [pharmacy] phoned around and found it …" (#8).

Post-discharge physiotherapy

All of our participants reported being highly committed to their exercise program post-discharge. As one participant said, "So anyway, I've seen a chap who I have a lot of faith in, a physio guy, and he's given me some exercises, and so if I do them I do feel better" (#5). Another said, "When I came back at one month I say, 'Look, I do my exercises, but I want some guidance. I want to go somewhere.'… It's important because if you don't do the therapy, I, from my experience, I don't think I will have been able to recuperate" (#2). Repeatedly, participants attributed their recovery to the physiotherapy they had received.

The following quotation is typical of what we heard: "The one thing, I did have to work hard on the physio to get that stretching back. After all those surgeries I did the exercises that I was prescribed to do on my own, as well as having physio. And I think … every time I hear somebody who's going to have that kind of surgery I say, 'Do your exercises'" (#1). However,

as a result of shorter length of stay and subsequent reduction of in-patient physiotherapy, some patients encountered difficulties accessing physiotherapy, as exemplified by the following patient's remark: "My first knee surgery, I went up to the rehab unit here for a week, so I was in about two weeks. … With the hip, I think I was home in four days … and then I was told that physio would get in touch with me. … And that, of course, took a while because they have a waiting list" (#1).

Discussion

A variety of policies and strategies have been implemented in Ontario that affect wait times, length of hospital stay and provision of physiotherapy services in the community for patients undergoing total joint replacement.

The Ontario Wait Times Strategy was introduced in 2004, and one of its objectives was to reduce wait times for hip and knee replacement (Ontario MOHLTC 2008). The strategy involved setting targets and reporting wait times, increasing the number of procedures, investing in longer hours of operation and standardizing best practices to improve patient flow. In 2006, it was estimated that 40% of the wait times for joint replacement occurred between the referral and the decision to have surgery, and the remaining 60% occurred between the decision to have surgery and the actual joint replacement (Rotstein and Alter 2006).

Additionally, in 2005 the Ministry of Health and Long-term Care made changes to physiotherapy funding for patients who undergo total joint replacement. Patients under 20 years or over 64 years are publicly insured for 100 physiotherapy services per year. However, patients between 20 and 64 years of age are covered for only 50 such services each year after acute hospitalization, unless they fall under other government service plans (Ontario MOHLTC 2005).

Although each of the funding policies (i.e., wait times, length of stay and physiotherapy coverage reductions) was developed separately, patients undergoing joint replacement experience them as part of one continuum of care. There are several assumptions underlying these policies and the measurement of their impact.

First, patients are conceptualized as being a homogeneous group who will be affected similarly by changes in care delivery. In fact, our findings suggest that patients vary in their home living situations, which in turn influence their ability to manage post-operatively. Patients' ability to manage post-operatively has been viewed as an individual attribute rather than as the result of socio-economic status, over which they have little control. We speculate that those with greater socio-economic status have more access to resources, an assumption that is supported by other research in the field (Hawker et al. 2006). As a result, implementation of these policies may not be affecting all patients equally. In addition, measurements of short-term outcomes are limited in their ability to capture patients' long-term, evolving and complex needs over time.

A key finding from our research is that although policy-related changes are implemented and evaluated in isolation, these policies interact with one another and act concurrently as a major influence on the overall experience of the patient. For example, with a reduced length of

stay, patients receive less in-hospital physiotherapy, and then they also have trouble accessing it after discharge because they have to arrange and pay for it themselves if they require ongoing rehabilitation. For patients with lower socio-economic status and those with limited resources, we hypothesize that the de-listing of physiotherapy could create problems for their longer-term health status and care needs. Patients of lower socio-economic status are less likely to be able to afford supports at home such as canes, walkers and raised toilet seats. They may also be less likely to have a spouse or other family member able to take time off work to support their recovery.

Our findings also support research by Rotstein and Alter (2006) showing flaws in the conceptualization of when the wait actually begins. Even with a high-profile wait time reduction program in place, some patients described their experiences with primary care physicians who delayed referring them to an orthopaedic surgeon for consultation and surgery. As others have noted, in Ontario the primary care provider serves as the gatekeeper to specialist care (Bederman et al. 2009). As a result, primary care providers can delay referral and increase wait times. Tension also exists between what some physicians think is sufficient pain and reduced mobility to warrant surgery versus the patient's values and quality of life.

Patients also described being caught between opposing views held by two physician groups: family physicians who follow patients in the community, and specialists who provided their surgeries. The primary care physicians described by our participants expressed a desire to increase the age of the patients at time of surgery in order to reduce the number of revision surgeries that might have to be done over a lifetime. This view contradicts the specialist view that earlier surgery leads to better outcomes (Caracciolo and Giaquinto 2005; Jones et al. 2003). It also underscores a difference between some family physicians' preference – to reduce lifetime number of surgeries – and the patients' desire to maintain their quality of life. Other studies have reported that patients themselves "often decline or delay total joint arthroplasty for reasons that aren't well understood" (Jacobson et al. 2008). Our findings suggest that although the data show a decreased wait time for joint replacement since the introduction of the Wait Times Strategy, not all patients may be perceiving a reduced wait time (from symptom onset until surgery). Future research could address this important issue and provide insight into the complex factors influencing wait times, including patient and provider characteristics.

Conclusions

One limitation of our study is that the issue of changes in policies related to care was not a primary objective of the original study. Nevertheless, it was a significant finding that the majority of participants spontaneously raised these healthcare change-related issues. Future research needs to look at more effectively measuring the impact of these changes on the individual patient. Policy makers need to examine the variability in patients' experience related to their characteristics and context, as patients are not a homogeneous group. In addition, recall bias and disease severity could influence the findings of this study, given the time

elapsed between each participant's two surgeries. Participants took part in one interview and were asked to recall their experiences of two separate joint replacements that occurred in the prior ten years. However, surgery is a significant event in most people's lives, and many can remember the events preceding and afterward clearly. The patient perspectives provided were quantified (e.g., length of stay for each surgery) and have good face validity with known healthcare system changes for total joint replacement patients during the study period.

In summary, as policy changes that affect patient care continue to be introduced, a broad range of outcome measures must be sought that take into consideration patients' experiences. Our findings point to the need to examine how new policies that are developed in isolation can have an unexpected synergistic effect. Differences in patients' resources and surgical outcomes need to be considered and included in any evaluation of outcomes. Additionally, the calculation of wait times may need to be adjusted to reflect the actual wait time experienced by patients.

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RESEARCH PAPER

Predicting Patients with High Risk of Becoming High-Cost Healthcare Users in Ontario (Canada)

Détecter les patients qui présentent un haut risque de devenir des usagers très coûteux pour les services de santé en Ontario (Canada)

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Abstract

Literature and original analysis of healthcare costs have shown that a small proportion of patients consume the majority of healthcare resources. A proactive approach is to target interventions towards those patients who are at risk of becoming high-cost users (HCUs). This approach requires identifying high-risk patients accurately before substantial avoidable costs have been incurred and health status has deteriorated further. We developed a predictive

model to identify patients at risk of becoming HCUs in Ontario. HCUs were defined as the top 5% of patients incurring the highest costs. Information was collected on various demographic and utilization characteristics. The modelling technique used was logistic regression. If the top 5% of patients at risk of becoming HCUs are followed, the sensitivity is 42.2% and specificity is 97%. Alternatives for implementation of the model include collaboration between different levels of healthcare services for personalized healthcare interventions and interventions addressing needs of patient cohorts with high-cost conditions.

Résumé

La littérature et l'analyse des coûts des services de santé démontrent qu'une petite portion de patients mobilise la majorité des ressources des services de santé. Une démarche proactive consiste à privilégier les interventions visant des patients qui présentent des risques de devenir des utilisateurs très coûteux (UTC). Cette démarche demande un recensement précis des patients à haut risque avant que des coûts substantiels ne soient engagés et que leur état de santé ne se soit détérioré davantage. Nous avons mis au point un modèle de prévision pour recenser les patients susceptibles de devenir des UTC en Ontario. Les UTC correspondent aux premiers 5 % d'utilisateurs qui génèrent les coûts les plus élevés. L'information a été recueillie selon diverses caractéristiques démographiques et modes d'utilisation. La régression logistique a été employée comme technique de modélisation. Si on effectue le suivi des premiers 5 % de patients à risque de devenir des UTC, le résultat de la sensibilité est de 42,2 % et celui de la spécificité s'élève à 97 %. Les choix pour l'application du modèle comprennent la collaboration entre divers niveaux de services de santé pour offrir des interventions personnalisées, ou encore la mise en place d'interventions qui répondent aux besoins de groupes de patients présentant des états de santé dont les coûts sont élevés.

Literature from different jurisdictions has shown that a relatively small proportion of patients consume the majority of healthcare resources. In Ontario, for example, 5% of healthcare users consumed 61% of hospital and home care spending (Rais et al. 2013). A study of physician services utilization in British Columbia found that 5% of healthcare users consumed 30% of spending on physician services (Reid et al. 2003). In Manitoba, 5% of prescription drug users accounted for 41% of prescription expenditures (Kozyrskyj et al. 2005). In Australia, high-cost users (HCUs) accounted for 38% of both in-patient costs and in-patient days (Calver et al. 2006). US data from the Arizona Health Care Cost Containment System showed that 10% of patients accounted for two-thirds of healthcare costs (Moturu et al. 2010). Another study in the United States looking at healthcare expenditures from 1928 through 1996 found that the top 5% of HCUs accounted for more than half of health spending in both 1987 and 1996, while the top 10% accounted for about 70% of all healthcare spending (Berk and Monheit 2001). Yet another US study found that

5% of the population accounted for 49% of total healthcare spending (Center for Healthcare Research and Transformation 2010).

Given the impact of these HCUs of healthcare, interventions directed at them may improve overall patient outcomes and quality of life, and reduce healthcare spending. A report from The Commonwealth Fund (2012) supports this view, emphasizing the need to address high-cost healthcare users as the first step towards achieving "rapid improvements in the value of services provided." Gawande (2011) also argued that focusing on a few areas or individuals would have a significant impact on patient outcomes and system costs.

A proactive approach to addressing the problem of HCUs is to target interventions towards patients who are at risk of becoming HCUs. This approach is aimed at preventing at-risk patients from becoming HCUs in the first place. Such an approach requires some mechanism to identify or predict high-risk patients accurately before substantial preventable or avoidable costs have been incurred and health status has deteriorated further (Billings et al. 2006). One such mechanism is a statistical predictive model.

A number of publications have proposed various methods to predict future HCUs, each advocating a different model, predictor variables and type of data. Billings and colleagues (2006) presented a case-finding tool for patients at risk of readmission to hospital and developed an algorithm to identify high-risk patients in the United Kingdom. The key factors predicting subsequent admission included age, sex, ethnicity, number of previous admissions and clinical condition. In the United States, Fleishman and Cohen (2010) found that medical condition information improved prediction of high expenditures beyond that obtainable using gender and age. Ash and colleagues (2001) also found that risk models based on Diagnostic Cost Groups (DCG) were at least as powerful as prior cost for identifying HCUs. In Ontario, Walraven and colleagues (2010) derived and validated an index to predict early death or unplanned readmission after discharge from hospital. Variables independently associated with this outcome (from which authors derived the mnemonic "LACE") included length of stay ("L"), acuity of the admission ("A"), co-morbidity of the patient (measured with the Charlson co-morbidity index score, "C"); and emergency department use (measured as the number of visits in the six months before admission, "E").

Building upon previous research, we developed a predictive model to identify patients at risk of becoming high-cost healthcare users in Ontario. The methods and results of this predictive modelling are presented here. Potential ways to utilize this information in practice and the next steps are also discussed.

Methodology

The purpose of the model presented in this paper is to predict who will or will not become a high-cost healthcare user in the next year, given various patient-level characteristics in the current year and two previous years. The model predicts HCU status in fiscal year (FY) 2010/11 among patients (users of the healthcare system) from FY 2009/10, using patient characteristics from FY 2007/08 through FY 2009/10. The model was validated by applying it to

predict HCU status in FY 2009/10 using patient characteristics from FY 2006/07 through FY 2008/09 (out-of-sample prediction power). Data for the analysis were obtained from the Ontario Ministry of Health and Long-Term Care (MOHLTC).

The cohort of patients incorporated in the model included all Ontario residents serviced by the Ontario healthcare system during FY 2009/10 in one of the following care types (database in parentheses):

- Physician services – OHIP (Claims History Database)
- Acute in-patient care – AIP (Discharge Abstract Database)
- Day surgery – DS (National Ambulatory Care Reporting System)
- Emergency room – ER (National Ambulatory Care Reporting System)
- Dialysis – (National Ambulatory Care Reporting System)
- Oncology – (National Ambulatory Care Reporting System)
- Outpatient clinic – (National Ambulatory Care Reporting System)
- Rehabilitation – Rehab (National Rehabilitation System)
- In-patient mental health – MH (Ontario Mental Health Reporting System)
- Complex continuing care – CCC (Continuing Care Reporting System)
- Long-term care – LTC (Continuing Care Reporting System)
- Home care – HC (Home Care Database)

Data from various administrative sources were linked using encrypted health insurance numbers. In Ontario, which has a single-payer government health system (OHIP), all patients have unique health insurance numbers that are recorded in all sectors whenever a patient receives a health service.

Patients were excluded if they died during FY 2009/10 (as they could not become high users the next year) or were under five years of age in FY 2009/10 (as the history of disease and health utilization progression is required to build a good predictive model). The validation patient cohort was built similarly based on FY 2008/09 data.

HCUs of healthcare in FY 2010/11 (for the modelling cohort) or in FY 2009/10 (for the validation cohort) were defined as the top 5% cost-incurring healthcare users. In order to identify HCU status, we summed costs across care types for each user. Patient costs for AIP, ER, DS, Rehab, CCC, MH and HC were derived from actual unit cost[1] (actual cost per weighted case) times weighted volume of services (number of weighted cases). Cost for OHIP claims was represented by fees approved. Patient cost for LTC was estimated using average cost per patient per day times patient length of stay. Costs for outpatient oncology, outpatient dialysis and outpatient clinic were not included owing to data quality issues with case mix and cost data in these sectors, and the Ministry's general recommendation not to use these data in funding formulas in Ontario. Users (patients) were sorted in descending order of total expenditures, and the top 5% of users were classified as high-cost healthcare users. A binary variable was created and added to the data to identify patients as either high users or not.

Information was collected on factors (covariates) that may have an influence on the outcome (becoming a high user). These included demographic variables (e.g., age, sex, Rurality Index of Ontario [RIO] Score by the Ontario Medical Association[2]); clinical variables (e.g., ICD-10 based chapters created from ICD-10 and ICD-9 diagnoses[3]), with further separation of certain chronic conditions such as diabetes, congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD)[4]; socio-economic status (SES) variables (e.g., material and social deprivation indices[5]); and utilization variables for all care types from current year and previous two years, enabling us to account for disease progression (e.g., number of visits, number of hospitalizations).

Continuous variables, if necessary, were transformed to categorical variables (e.g., age into age groups). Continuous variables for healthcare utilization were categorized based on percentiles (zero category was created first, then median was calculated for the remaining positive values, and two remaining categories were created: less than median, and equal or more than median). Where applicable, missing values were imputed via the multiple imputation technique (using SAS PROC MI, SAS Institute). The final data set had missing values for only three variables in our model: Rurality Index of Ontario (1.51% of patients with missing values) and social and material deprivation (3.72% of patients with missing values). The pattern of the missing data allowed us to assume that the values were missing completely at random (MCAR). As a next step, a number of variables were reduced using the variable clustering technique (SAS PROC VARCLUS, SAS Institute).

A logistic regression model predicting the next year's HCU status was built and executed in SAS 9.1.3 on the FY 2009/10 patient cohort. Performance of the model was evaluated using C-statistic for predictive ability of the model. Significance of the parameter estimates (p-values) and odds ratios were evaluated as well.

Validation of the model on the FY 2008/09 cohort was done to evaluate the out-of-sample prediction power. Good predictive models should show strong performance in the new (out-of-sample, scored) data, since in-sample performance could be unduly optimistic if the model over-fitted the data (in this case, out-of-sample performance could be very poor). Moreover, this is the intended application of predictive models: to apply the model to the new data with unknown outcomes in order to predict them. Receiver-operating characteristic (ROC) curve and calibration (goodness-of-fit) curves were constructed based on the validation sample. Out-of-sample model performance was evaluated using sensitivity, specificity, positive and negative predictive values, and accuracy on the validation sample (calculated for scenarios if following up on the top 1%, 5%, 10% or 15% of patients with the highest risk of becoming HCUs). Cut-off probability levels for different potential follow-up cohorts (if following up 1% of highest risk users, 5%, 10% or 15%) were selected, and the outcome variable was set at 1 if the predicted probability equaled or exceeded that cut-off. Multiple cut-offs for follow-up are presented (following up 1%, 5%, 10%, 15%) to enable dialogue on the degree of sensitivity that could be achieved if different resources are utilized (assuming that implementation of follow-up interventions requires additional resources).

Formal ethics review was not required because de-identified Ministry administrative data were used.

Results

Patient characteristics of the model cohort and the validation cohort are presented in Table 1. The population of patients in the FY 2009/10 model cohort was 10,300,856. The number of variables in the initial model was 97. Sixty-four variables were transformed. The number of variables removed because of clustering was 28, leaving 69 variables in the final model. See Table 1 at www.longwoods.com/content/23710.

The model achieved a very strong C-statistic: .865.[6] Odds ratios for all predictor variables used and their 95% confidence intervals are reported in Table 2. Among the patients that the model predicted to be high-cost healthcare users in 2010, 46.2% were not HCUs in 2009. See Table 2 at www.longwoods.com/content/23710.

Odds ratios analysis reveals that age is a strong predictor of becoming a high-cost healthcare user, and there is a clear pattern of substantially increasing risk as age increases. Similarly, as the material and social deprivation indices increase, the risk of becoming a high-cost user increases. Interestingly, social deprivation seems to increase risk more than material deprivation. Males have an increased risk compared to females. There is also a clear pattern of increased risk as the degree of rurality increases (as measured by the Rurality Index of Ontario Score). Current and past (1 year ago and 2 years ago) healthcare utilization across different care types are among the strongest predictors of becoming high-cost healthcare users. Of particular note are long-stay, long-term care utilization, more than one hospitalization in in-patient mental health, chronic continuing care, acute in-patient care, high number of outpatient dialysis and oncology visits, and high number of services in home care. The most influential diagnoses (controlling for all other variables in the model) are mental and behavioural disorders; congestive heart failure, chronic obstructive pulmonary disease and diabetes; diagnoses in pregnancy, childbirth and the puerperium ICD chapter; and congenital malformations, deformations and chromosomal abnormalities.

Based on out-of-sample validation, both the ROC curve (Figure 1) and the calibration (goodness-of-fit) curves (Figure 2) show very good out-of-sample model performance. Table 3 presents sensitivity, specificity, positive and negative predictive values, and accuracy for different cut-off points for the validation (out-of-sample) cohort. If the top 5% patients at risk of becoming HCUs are followed, the achieved sensitivity and specificity is 42.2% and 97%, respectively. These values suggest very reasonable predictive power, indicating that the model picks up 42.2% of all high-cost healthcare users and correctly identifies 97% of those who are not high users. Accuracy of 94.2% is also very reasonable (percentage of true positive and true negative out of all patients).

FIGURE 1. Receiver operating characteristic (ROC) plot of model performance on scored 2008 data

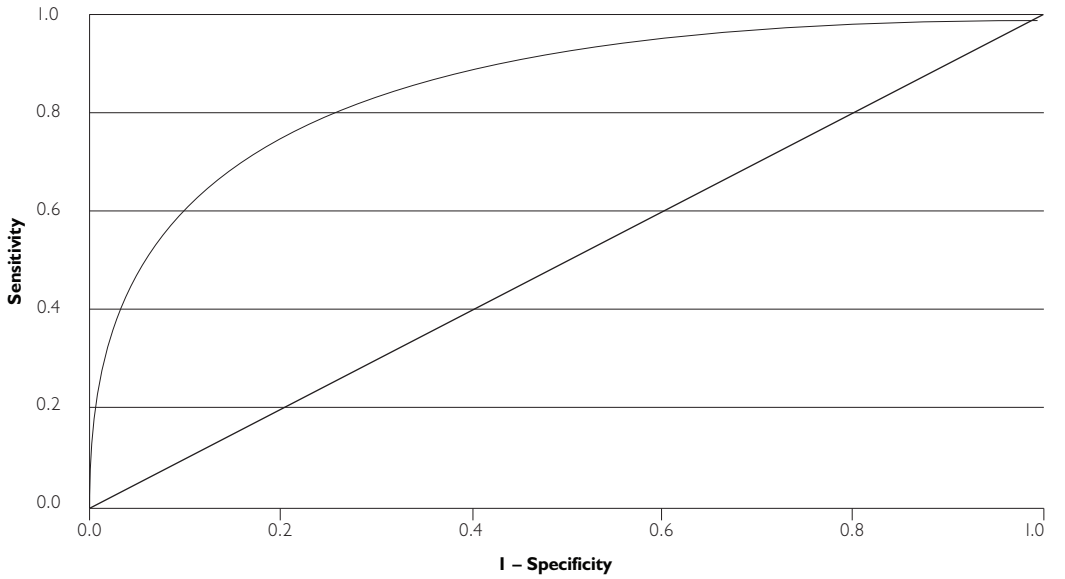

FIGURE 2. Goodness of fit (calibration) curve on scored 2008 data

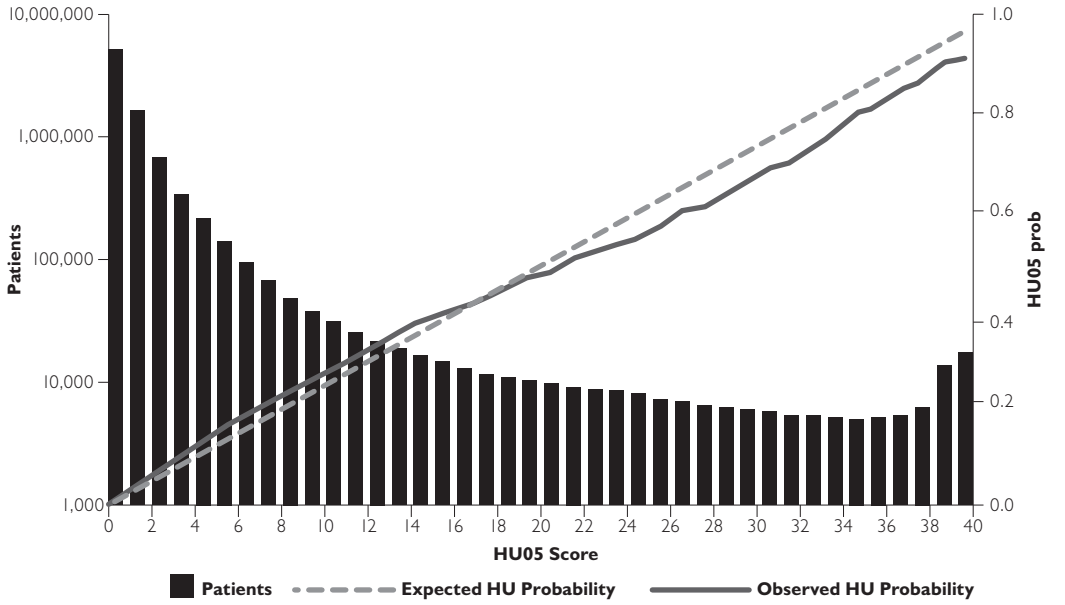

Table 3 also presents sensitivity, specificity and so on for other follow-up cut-off points (such as 1%, 10% and 15%). This analysis is still based on the 5% HCU model (i.e., predicting the risk of becoming a top 5% high-cost healthcare user). However, the cut-off point for follow-up of patients could be selected at any level (following up 1%, or even 10% of patients with the highest risk of becoming top 5% healthcare users), depending on availability of healthcare funding for follow-up, thus increasing or decreasing the sensitivity, or the number of captured future top 5% high-cost healthcare users.

TABLE 3. Predictive (out-of-sample) performance of the model

Metric	Selection of patients based on predicted probabilities – the top:				Formula	Notes
	1%	5%	10%	15%		
Sensitivity	15.8%	42.2%	57.1%	66.4%	TP/(TP + FN)	picks up % of all high users
Specificity	99.8%	97.0%	92.5%	87.7%	TN/(FP + TN)	correctly identifies % of those who are not high users
Positive Predictive Value	79.9%	42.6%	28.8%	22.4%	TP/(TP + FP)	good at confirming high users
Negative Predictive Value	95.7%	96.9%	97.6%	98.0%	TN/(FN + TN)	reassuring that a patient will not become a high user
Accuracy	95.5%	94.2%	90.7%	86.7%	(TP + TN)/(P + N)	% of true positive and true negative out of all patients

Notes: TP – true positive, FN – false negative, TN – true negative, FP – false positive, P – positive, N – negative

Conclusion

This is the first attempt in Ontario to develop and validate a tool for predicting patients at risk of becoming high-cost healthcare users. Presented results suggest that the performance of the model is very good, and the model has been validated for an out-of-sample validation cohort. Special attention could be paid to the factors, listed in the Results section, that are the strongest predictors of becoming HCUs.

The performance of this model (in terms of sensitivity, for example) in comparison to other published predictive models could be of interest. Unfortunately, the authors were not able to identify published studies with reported performance for models predicting high-cost healthcare users. Nevertheless, we scanned the literature to observe the performance of other predictive models with relevant outcomes that could be an indirect proxy for future high cost, such as hospital admissions in the next year. The literature scan showed that our model has similar or better performance. For example, SPARRA (Scottish Patients At Risk of Readmission and Admission) (Government of Scotland 2012), a model that predicts next-year hospital admissions, reports 10.5% sensitivity at the 50% risk threshold (which corresponds to the top 1.6% patients follow-up), and the best performing model, IPAEOPGP (using in-patient, accident and emergency, and outpatient data, and general practitioners' electronic medical records data) (Billings et al. 2013), which also predicted next-year admissions, achieved 9.2% sensitivity for the top 1% patients follow-up. In comparison,

our model demonstrated 15.8% sensitivity for the top 1% patients follow-up. The same SPARRA model reports approximately 27% sensitivity at the 30% risk threshold (corresponding to the top 5.5% patients follow-up), and the IPAEOPGP model reports 28.5% sensitivity for the top 5% patients follow-up. In comparison, our model's sensitivity is 42.2% for the top 5% patients follow-up. While these numbers are not precisely comparable – because the models predict different outcomes, and these outcomes have different event rates (prevalence) – they provide overall reference points for our predictive model's performance. It should be noted that our model reports performance in the validation cohort (out-of-sample model performance). Table 4 summarizes the information on the performance of the models discussed, based on sensitivity and positive predictive value metrics.

TABLE 4. Comparison of model performance

Selection of patients based on predicted probabilities	Performance metric	Model***		
		SPARRA	IPAEOPGP	Current
Top 1%*	Sensitivity	10.5%	9.2%	15.8%
	Positive Predictive Value	59.8%	47.5%	79.9%
Top 5%**	Sensitivity	27.0%	28.5%	42.2%
	Positive Predictive Value	44.1%	29.4%	42.6%

* For SPARRA model it is top 1.6%

** For SPARRA model it is top 5.5%

*** Models compared: SPARRA: SPARRA model (Scottish Patients At Risk of Readmission and Admission), predicting next-year hospital admissions (Government of Scotland 2012); IPAEOPGP: IPAEOPGP model (using in-patient, accident and emergency, and outpatient data, and general practitioners' electronic medical records data, predicting next-year hospital admissions) (Billings et al. 2013)

Current: Our model, predicting high-cost healthcare users

Please note that these numbers are not precisely comparable because the models predict different outcomes and have different event rates (prevalence); however, the figures provide overall reference points for our predictive model's performance.

This paper has presented a model that predicts the top 5% high-cost healthcare users. Models also predicting the top 1% and top 10% HCUs were also explored using reported methodology, and these models showed very strong performance. The final decision as to the most useful cut-off point will depend on the specifics of policy decision-making with regard to practical implementation, and of course on the availability of scarce healthcare dollars for the follow-up.

Limitations of the current model include a very large number of predictor variables and the heavy data requirements to run the model. The number of variables could potentially be further reduced in the future. Missing values do not present a significant obstacle, as only three variables have missing values for a very small proportion of patients. Another limitation that we encountered was an inability to access available patient classification systems (such as Adjusted Clinical Groups [ACG] or Diagnostic Cost Groups [DCG]). Usage of such systems

could further improve model performance. In order to overcome this obstacle, we used a proxy in our model: all patient ICD-10 and ICD-9 diagnoses were grouped into ICD-10 chapters, with further separation of certain chronic diseases, such as CHF, COPD and diabetes. Odds ratios showed that these groups were very strong predictors of future HCU status.

Some elements of our model are being used by the Ontario Ministry of Health and Long-Term Care to support Health Links, a new model of care at the clinical level where all providers in a community – including primary, hospital and community care – are involved in coordinating plans at the patient level. The Ministry's Health Analytics Branch develops community profiles of populations and high users where the Health Links model is being established.

Further practical implementation of the model could occur in a number of ways. One potential approach is to provide the health card numbers of high-risk patients to primary care providers so that they can implement appropriate prevention strategies, potentially mitigating or avoiding HCU status in the future. For example, the Government of Scotland (2010) has described a model in which lists of patients at greatest risk of emergency admission to hospital over the next year are distributed to healthcare providers to enable "delivery of Proactive, Planned and Co-ordinated care for people with complex or frequently changing care needs."

In Ontario, there are several challenges to this approach, including concerns over privacy in regard to sharing data with providers. The Ministry's approach with Health Links[7] has been to provide aggregate information about HCUs so that providers can identify the patient populations that have historically consumed the most resources. This model could be used to identify patient populations at high risk of becoming high users, so that Health Links could develop interventions that address specific needs of those patient groups. An example might be CHF-centred clinics for congestive heart failure patients (Wijeysundera et al. 2012). Another potential approach would require converting this data-intensive model into a simpler one, with fewer variables, and creating a paper- or desktop computer-based tool that can be used by providers themselves in their offices to score patients and identify those at high risk of becoming high users.[8] In any scenario, physicians would be informed of at-risk patients to provide timely interventions to mitigate or reduce the number of HCUs, thus improving patient outcomes and saving finite resources. Ontario's Action Plan for Health Care (MOHLTC n.d.) calls for "better patient care through better value from our health care dollars," and the current study could become one of the tools facilitating implementation of the directions identified in the Plan.

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Notes

1. Actual costs in Ontario are established for each hospital using Ontario Cost Distribution Methodology (OCDM), Ontario Ministry of Health and Long-Term Care.
2. Rurality Index of Ontario methodology is described in the following document: http://www.health.gov.on.ca/english/providers/program/uap/docs/up_rio_methodology.pdf.
3. Diagnosis codes for patients were collected from all care types (all healthcare encounters) for the whole year. All diagnoses listed on a patient record were used, not just the principal diagnosis.
4. Owing to lack of access to population classification systems (such as ACG, etc.; see detailed discussion in the Conclusion section on model limitations), we used ICD-10 and ICD-9 diagnoses grouped into ICD-10 chapters with further separation of certain chronic conditions (such as CHF, COPD, diabetes). Dummy variables were entered in the model specifying whether a patient has or does not have a disease (ICD-10 or ICD-9 code) in the corresponding ICD-10 chapter (ICD-9 chapters were mapped onto ICD-10 chapters).
5. Material deprivation primarily portrays variations associated with education, employment and income. Social deprivation indicates the state of being separated, divorced or widowed, living alone, or being a member of a single-parent family (Pampalon et al. 2009).
6. C-statistic is the probability that predicting the outcome is better than chance. It is used to compare the goodness of fit of logistic regression models. Values for this measure range from 0.5 to 1. A value of 0.5 indicates that the model is no better than chance at making a prediction of membership in a group; a value of 1 indicates that the model perfectly identifies those within a group and those not. Models are typically considered reasonable when the C-statistic is higher than 0.7 and strong when C exceeds 0.8 (Hosmer and Lemeshow 2000).
7. Ontario's Health Links initiative aims to facilitate coordination of care at a local level for high-needs patients. One of the goals of the initiative is to provide better care for the 1% to 5% of people who, research has indicated, are high users of healthcare. It also aims to reduce costs, particularly expensive hospital visits, based on the assumption that many of these patients' hospital emergency ward visits, admissions and readmissions can be prevented with better coordinated care (Silversides and Laupacis 2013).
8. The authors are currently working on developing such a model.

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RESEARCH PAPER

Provincial Disparities of Growth Hormone Coverage for Young Adult Survivors of Paediatric Brain Tumours across Canada

Disparités provinciales dans la couverture pour l'hormone de croissance chez les jeunes adultes ayant survécu à une tumeur cérébrale infantile au Canada

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Abstract

Background: Young adult survivors of paediatric brain tumours (PBTs) who have been treated with radiation therapy will likely be severely growth hormone–deficient when retested at the achievement of final height. Growth hormone replacement therapy (GHRT) is administered to treat growth hormone deficiency (GHD). Public drug coverage for GHRT falls under the responsibility of provincial governments across Canada. This study sought to determine the extent of public drug coverage and cost in each Canadian province for GHRT to treat GHD during adulthood for young adult survivors of PBTs.

Methods: Data were collected from provincial government resources and drug formularies from 2012–2013 on the extent of coverage for GHRT based on a clinical case scenario representative of a young adult survivor of a PBT with childhood-onset radiation-induced GHD, the ingredient cost for GHRT and the applicable provincial public drug plan cost-sharing policies. A model was then created to simulate out-of-pocket costs incurred by a young adult male and a young adult female survivor of a PBT for one year of GHRT in each province with applicable cost-sharing arrangements and levels of low annual individual total income that best represent the majority of young adult survivors of PBTs. Out-of-pocket costs were expressed as a percentage of annual income. Comparisons were made between provinces descriptively, and variation among provinces was summarized statistically.

Results: Alberta, Manitoba, Ontario, Quebec, New Brunswick, and Newfoundland and Labrador provide coverage for GHD during adulthood on a case-by-case basis, while British Columbia, Saskatchewan, Nova Scotia and Prince Edward Island provide no coverage. The percentage of annual income to fund GHRT across the provinces without public coverage ranged from 14.4% to 25.5% for males and 21.5% to 38.3% for females, and with public coverage was 0.0% to 4.1% for males and 0.0% to 5.0% for females.

Interpretation: There are considerable out-of-pocket costs and variation in coverage provided by provincial public drug plans to fund GHRT for young adult survivors of PBTs with GHD. The implementation of a national drug formulary could potentially prevent undue financial hardship and remove disparities resulting from variations in provincial drug plans.

Résumé

Contexte : Les jeunes adultes ayant survécu à une tumeur cérébrale infantile (TCI) après un traitement par radiothérapie demeurent très susceptibles de manifester une déficience en hormone de croissance lors d'un examen effectué à la fin de la croissance. L'hormonothérapie de remplacement (HTR) est employée pour traiter la déficience en hormone de croissance (DHC). Au Canada, la couverture publique de l'HTR est du ressort des gouvernements provinciaux. Cette étude visait à déterminer, pour chacune des provinces canadiennes, l'étendue et les coûts pour la couverture de l'HTR comme traitement de la DHC chez les jeunes adultes qui ont survécu à une TCI.

Méthodes : Les données – recueillies entre 2012 et 2013 à l'aide des listes de médicaments et auprès de sources gouvernementales provinciales – portaient sur l'étendue de la couverture

pour l'HTR en fonction d'un scénario de cas clinique représentatif d'un jeune adulte ayant survécu à une TCI et présentant une DHC attribuable à la radiothérapie. Les données portaient également sur le coût des ingrédients pour l'HTR et sur les politiques de partage des coûts dans le cadre du régime provincial d'assurance médicaments. Un modèle a été conçu afin de simuler les coûts déboursés par un jeune homme et une jeune femme adultes ayant survécu à une TCI, et ce, pour une année de traitement par HTR dans chacune des provinces, en tenant compte des ententes de partage des coûts et des niveaux minimums de revenu annuel représentatifs de la majorité desdits jeunes adultes. Les coûts déboursés étaient exprimés en pourcentage du revenu annuel. Des comparaisons descriptives ont été effectuées entre les provinces. L'écart entre les provinces a été calculé statistiquement.

Résultats : L'Alberta, le Manitoba, l'Ontario, le Québec, le Nouveau-Brunswick ainsi que Terre-Neuve-et-Labrador offrent une couverture pour traiter la DHC chez les adultes, au cas par cas. La Colombie-Britannique, la Saskatchewan, la Nouvelle-Écosse et l'Île-du-Prince-Édouard n'offrent pas une telle couverture. Le pourcentage du revenu annuel pour financer l'HTR dans les provinces sans couverture varie de 14,4 à 25,5 % pour les hommes et de 21,5 à 38,3 % pour les femmes. Dans les provinces qui offrent la couverture, ce pourcentage varie de 0,0 à 4,1 % pour les hommes et de 0,0 à 5,0 % pour les femmes.

Interprétation : Les coûts à débourser et l'écart de la couverture offerte dans le cadre des régimes provinciaux d'assurance médicaments varient considérablement pour ce qui est du financement de l'HTR pour les jeunes adultes ayant survécu à une TCI et présentant une DHC. La mise en place d'une liste nationale de médicaments pourrait éventuellement aider à prévenir un fardeau financier excessif et à éliminer les disparités qui découlent de l'écart entre les régimes provinciaux d'assurance médicaments.

Approximately 850 children (0–14 years) are diagnosed with cancer every year in Canada, and 20% of these diagnoses account for cancers of the central nervous system (Canadian Cancer Society 2008). The five-year survival rate for children diagnosed with a brain tumour is over 70%, and the majority will become long-term survivors because of improvements in diagnostic procedures and treatment (Canadian Cancer Society 2008; Ries et al. 2004). Although cured of the cancer, survivors of a paediatric brain tumour (PBT) are at significant risk of developing medical, neurocognitive and psycho-social health complications as a result of their therapy and underlying disease (Turner et al. 2009).

Growth hormone deficiency (GHD) is a frequent complication observed after radiation therapy for the treatment of a PBT (Chemaitilly and Sklar 2010). Approximately 80% of individuals treated with higher doses (>30 Gray units [Gy]) of radiation therapy develop GHD within five years of treatment (Chemaitilly and Sklar 2010; Sklar and Constine 1995). GHD is associated with negative metabolic and physiological consequences, increased cardiovascular risk and reduced quality of life (Alexopoulou et al. 2010). The majority of survivors

of PBTs treated with radiation therapy will be severely growth hormone–deficient when retested at the completion of final height and would benefit from growth hormone replacement therapy (GHRT) (Darzy and Shalet 2006; Gleeson et al. 2004; Stanhope 2004).

The goal of GHRT is not isolated to optimizing achievement of final height. Young adult patients with childhood-onset GHD whose GHRT is discontinued after reaching final height exhibit negative metabolic and physiological disease outcomes, which include reduced lean mass and muscle strength as well as an abnormal lipid profile and body composition (Ho 2007; Hulthén et al. 2001; Koranyi et al. 2001). Studies have shown that these manifestations of GHD are reversible through GHRT, and therapy has been attributed to improvements in body composition, metabolic and cardiovascular parameters, muscle strength, bone-mineral density and quality of life (Alexopoulou et al. 2010; Carroll et al. 1998).

Growth hormone secretion will slow down over time in patients with radiation-induced GHD (Gleeson et al. 2004; Toogood et al. 1995). Therefore, PBT survivors diagnosed with radiation-induced childhood-onset GHD are likely to develop severe GHD during adulthood (Gleeson et al. 2004). Endocrinology consensus guidelines recommend that GHRT should not be discontinued in young adults with persistent GHD after reaching final height, in order to achieve full somatic development (Ho 2007).

Although studies have validated numerous benefits attributed to GHRT, it should be noted that such therapy has potential risks. Side effects have been observed in 5% to 20% of patients shortly after the initiation of GHRT (Alexopoulou et al. 2010; Molitch et al. 2006; Nilsson et al. 2007). The recommendation of GHRT to treat GHD in adults is justified in patients who test severely growth hormone–deficient after the achievement of final height, which comprises the majority of young adult survivors of PBTs treated with radiation therapy (Alexopoulou et al. 2010; Darzy and Shalet 2006; Gleeson et al. 2004; Stanhope 2004).

There is no national standard for coverage of outpatient medications in Canada, including GHRT, because outpatient medications are not covered under the Canada Health Act (Madore 2005). The Canada Health Act requires provincial governments to provide universal coverage for medically necessary hospital and physician services but not outpatient medications, a situation that has led to provincial governments' developing independent public drug plans that often reflect population demographics and provincial political, fiscal, legal and ethical views (Daw and Morgan 2012; Madore 2005; Rabinovitch 2004; Ungar and Witkos 2005). This situation has led to documented variations in the drugs that are covered under provincial programs, the patients who are covered and the levels of public subsidy. Such variations in coverage policy cause disparities in out-of-pocket costs and health outcomes for patients requiring essential medications (Coombes et al. 2004; Daw and Morgan 2012; Demers et al. 2008; Law et al. 2012; Ungar and Witkos 2005). Provincial governments determine their own terms and conditions regarding coverage of outpatient medications, including coverage of expensive therapies to treat rare childhood disorders or diseases such as childhood-onset radiation-induced GHD (Ungar and Witkos 2005). This variance creates opportunities for inequitable access to medications and undue financial hardship.

GHRT is expensive and unaffordable for many without the assistance of public drug coverage. The cost, on average, of one year of GHRT to treat GHD during adulthood was estimated in adults to be £3,424 (CAD$5,574) (Bryant et al. 2002). It is estimated that each year 42 young adult survivors of PBTs in Canada will be growth hormone–deficient upon retesting after the achievement of final height and would benefit from GHRT (Appendix A). Consequently, public drug coverage of GHRT to treat GHD during adulthood would have a noticeable economic impact on the Canadian healthcare system. However, the cost of untreated GHD has a higher economic burden on society owing to lost production and high medical consumption in comparison to the average population (Ehrnborg et al. 2000; Hakkaart-van Roijen et al. 1998; Hernberg-Ståhl et al. 2001; Jonsson and Nilsson 2000; Sanmarti et al. 1999). Studies have shown there is a decrease in healthcare consumption in adults receiving GHRT who previously had untreated GHD, a finding that can be attributed in part to the increase in quality of life resulting from GHRT (Hernberg-Ståhl et al. 2001; Saller et al. 2006; Svensson et al. 2004).

Although public coverage is granted for GHRT during childhood in Canada, the extent of public coverage across the provinces is unknown for survivors of PBTs who continue to present with GHD into adulthood and require GHRT (Ungar and Witkos 2005). Furthermore, there are currently no studies in Canada that assess the financial burden young adult survivors of PBTs with GHD incur to obtain GHRT. Survivors are at significant risk for multiple long-term health problems (late effects), many of which are preventable or manageable through early intervention, and inevitably will result in increased healthcare consumption if left unaddressed (Landier et al. 2004; Turner et al. 2009). Additionally, survivors of PBTs have a considerable impact on healthcare resources, and thus it is crucial to understand the extent of the associated costs within this population in order to help alleviate the burden on the Canadian healthcare system. The first objective of this study was to determine the extent of public drug coverage in each province across Canada for GHRT to treat GHD during adulthood in young adult survivors of PBTs. The second objective was to illustrate out-of-pocket costs incurred by a young adult male and a young adult female survivor of a PBT for one year of GHRT in each province across Canada.

Methods

Evaluation of provincial drug plans and extent of somatropin coverage

We initially collected data from provincial government resources and drug formularies from 2012–2013 (Government of Alberta 2012; Government of British Columbia 2013; Manitoba Health 2012; Minister of Health and Wellness 2013; Newfoundland and Labrador Department of Health and Community Services 2013; New Brunswick Department of Health 2012; Nova Scotia Department of Health 2013; Ontario Ministry of Health and Long-term Care 2013; Régie de l'assurance maladie Québec 2013; Saskatchewan Ministry of Health 2012). Subsequently, we determined the extent of coverage and ingredient costs

for somatropin, the generic name for recombinant human growth hormone administered in GHRT. We contacted provincial ministry of health representatives in order to verify somatropin coverage based on a clinical case scenario. The clinical case scenario consisted of a young adult survivor of a PBT with persistent GHD who was diagnosed with childhood-onset radiation-induced GHD. This patient has achieved final height, is recommended to continue GHRT by an endocrinologist and relies exclusively on public coverage to obtain GHRT.

Afterwards, we collected information that included cost-sharing arrangements inclusive of premiums, deductibles, co-payments and maximum annual contribution by beneficiary, as well as applicable maximum markup on covered prescription medication, maximum professional fees including dispensing fees, and plan restrictions to determine which applicable provincial drug plans met the eligibility criteria for adult survivors of PBTs with GHD (CAPDM 2012; CIHI 2012; Patented Medicine Prices Review Board 2012).

Simulation of out-of-pocket cost for one year of GHRT to treat adult GHD

After determining the extent of somatropin coverage, the ingredient cost for somatropin and the applicable provincial public drug plan cost-sharing policies, we created a model to simulate out-of-pocket costs incurred in each province to fund approximately one year (360 days) of GHRT for both a young male and a young female adult survivor of a PBT with GHD. Provincial catastrophic drug plans were applied in all provinces where public drug coverage was provided for somatropin to treat GHD in young adult survivors of PBTs. Catastrophic drug plans protect individuals from medication expenses that can result in undue financial hardship by setting limits for the maximum financial contribution an individual must make before the provincial government absorbs costs for all medication expenses (Fraser and Shillington 2005; Health Council of Canada 2005; Phillips 2009). Catastrophic drug plans apply for drugs approved for coverage according to the provincial drug formulary or through evaluation by the provincial government, and drugs not approved for coverage will not contribute towards the individual's maximum financial contribution. This model was based on an extension of work done by Ungar and Witkos (2005), which investigated the general extent of public drug coverage of asthma medication for children across Canada (Ungar and Witkos 2005).

The model consisted of simulating out-of-pocket costs for levels of low annual individual total income, premiums, deductibles, co-payments, maximum markup and maximum professional fees representative of each province. Young adult survivors of PBTs treated with radiation therapy are at high risk for neurocognitive impairment, an outcome that inevitably creates difficulty in securing and maintaining employment (Pang et al. 2008; Reimers et al. 2003). Thus, levels of low annual income were chosen that would represent the majority of young adult survivors of PBTs. Though median incomes for such populations vary slightly across provinces, we used an annual income of CAD$25,000 to simulate the upper threshold, and an annual income of CAD$15,000 to simulate the lower threshold. These thresholds were based on the national median individual income of 2010 (Statistics Canada 2010), and

took into consideration provincial drug plans that offer reduced cost-sharing arrangements for people with low income who do not receive social assistance. The average provincial dispensing fee was taken for provinces from 2012 that did not have regulations on maximum dispensing fees (Telus Health 2012).

A regimen of GHRT was established based on endocrinology consensus guidelines and consisted of non-weight-based recommended dosages of 0.2 mg/day and 0.3 mg/day for young adult men and women, respectively (Ho 2007). To simplify comparisons among the provinces, the medication price established for this regimen was based on the use of Humatrope® 12-mg cartridges (Eli Lilly Canada). In the event that provincial drug formularies did not provide the ingredient cost for this formulation of Humatrope®, a manufacturer wholesale price of CAD$560.04 was used as the ingredient cost, and applicable markup and provincial cost-sharing policies were applied to this price.

The model makes the assumption that the individual does not have private insurance and relies exclusively on public coverage for prescription medications; the individual does not qualify for provincial drug programs designated for individuals on social assistance; and the medication regimen will not require a change in dosage.

Out-of-pocket costs, which included all costs borne by the patient to obtain somatropin, were calculated for each province and were expressed as a percentage of total annual income. Descriptive statistics were used to demonstrate differences in out-of-pocket costs incurred among provinces. The coefficient of variation, which is the standard deviation expressed as a percentage of the mean, was calculated to assess the interprovincial variation for out-of-pocket costs resulting from cost-sharing arrangements in provinces where public drug coverage was provided for somatropin based on our clinical case scenario.

Results

Somatropin coverage under provincial drug plans for adult GHD in young adult survivors of PBTs

We obtained coverage decisions from all 10 provinces (Tables 1 and 2). Maximum allowable wholesale markup, pharmacy markup and professional fees for each province can be found in Appendix B.

Six provinces – Alberta, Manitoba, Ontario, Quebec, New Brunswick, and Newfoundland and Labrador – provide coverage for GHD during adulthood on a case-by-case basis, while the remaining four provinces – British Columbia, Saskatchewan, Nova Scotia and Prince Edward Island – provide no coverage. Newfoundland and Labrador and New Brunswick provide coverage for somatropin on a case-by-case basis based on satisfaction of specific qualifying criteria under the Select Needs Plan and Plan T – Human Growth

Hormone, respectively. Individuals qualify on the Select Needs Plan based on a diagnosis of GHD and recommendation of GHRT from an endocrinologist. Plan T – Human Growth Hormone is designated specifically for children under the age of 18 with GHD or hypopituitarism. However, after the age of 18, a patient can be considered for coverage under special circumstances if that patient was previously receiving coverage during childhood following a review by the expert advisory committee.

Alberta outlines specific criteria (growth hormone values <3 μg/L during hypoglycaemia based on the results of a diagnostic insulin tolerance test) for coverage of adult GHD, which must be satisfied in order for coverage of somatropin to be granted under special authorization (Government of Alberta 2012).

British Columbia does not provide coverage to treat adult GHD, and coverage remains specific to children 20 years and under, excluding children with Turner's syndrome, Prader–Willi syndrome or Noonan's syndrome.

Manitoba, Ontario and Quebec would provide coverage strictly on a case-by-case basis contingent on approval from the expert advisory committee and dependent on the review of all relevant medical information submitted by the patient's endocrinologist.

Saskatchewan does consider coverage for adult GHD under exceptional drug status, but based on the clinical case scenario submitted coverage would not be granted. The provincial drug committee determined that the clinical scenario provided insufficient information for it to make a valid recommendation, and an authentic case would have to be submitted to determine with confidence whether public coverage could be recommended for this indication.

Nova Scotia considers somatropin under exceptional drug status with the satisfaction of preset criteria. Patients with persistent GHD during adulthood in Nova Scotia do not satisfy the preset criteria, which are exclusively for children, and they were not eligible for public coverage after the achievement of final height.

Prince Edward Island has specific criteria for coverage of somatropin, and eligibility is exclusive to children with GHD or Turner's syndrome under the Growth Hormone Program. Coverage would not be granted for adults with GHD.

No provinces explicitly acknowledged in their coverage criteria survivors of PBTs who developed childhood-onset GHD due to radiation therapy with persistent GHD in adulthood.

Provinces differed in the level of subsidy provided for patients, even when somatropin was covered under their prescription drug plan. These variations were attributed to differences in premiums, deductibles and co-payments under provincial drug plans. The only province that provided a full subsidy, and thus resulted in the patient's not bearing any out-of-pocket cost, was Newfoundland and Labrador under the Select Needs Plan.

TABLE 1. Elements of provincial prescription drug plans providing coverage for GHRT to treat GHD during adulthood for a young adult survivor of a PBT applied in the cost analysis model for 2012–2013

Programname	Beneficiary subgroup	Premium	Deductible	Co-payment	Catastrophic drug plan
Alberta					
Non-group prescription drug coverage	Net annual household income <$20,970	$44.45/monthly	None	30% of prescription charge to a maximum of $25	Maximum coverage of $25,000 and amount exceeded will be determined on a case-by-case basis
	Net annual household income >$20,970	$63.50/monthly	None	30% of prescription charge to a maximum of $25	
Manitoba					
Pharmacare Program	Adjusted family income ≤$15,000	None	2.73% of adjusted family income	None	100% of costs will be covered once deductible has been met
	Adjusted family income $24,001–$25,000	None	4.08% of adjusted family income	None	
Ontario					
Trillium Drug Program	Net income $15,000	None	$444 year deductible paid quarterly	None	Once deductible has been met, beneficiaries pay $2 per prescription
	Net income $25,000	None	$714 year deductible paid quarterly	None	
Quebec					
Le régime général	Net income $15,000–$25,000	None	$16.25 per month	32% of the cost minus the deductible	Coverage will be provided once beneficiary contributes $992 per annum or $82.66 per month
New Brunswick					
Plan T – Human Growth Hormone	N/A	$50	None	20% of prescription charge to a maximum of $20	Coverage will be provided after beneficiary contributes $500 per annum
Newfoundland & Labrador					
Select Needs Plan	N/A	None	None	None	100% of costs will be covered

Out-of-pocket cost model simulation to treat adult GHD in young adult survivors of PBTs across Canada

Table 2 illustrates the out-of-pocket costs associated with funding 360 days of somatropin to treat adult GHD in both male and female young adult survivors of PBTs for each province after public coverage, if applicable.

TABLE 2. Out-of-pocket costs to fund GHRT for a young adult male and a young adult female survivor of a PBT across Canada for 2012–2013

Province	Ingredient cost	Public coverage	Annual income	Total cost males	Total cost females	% of Annual income males	% of Annual income females
BC	$598.04	No	$15,000.00	$3,588.24	$5,382.36	23.9	35.9
			$25,000.00			14.4	21.5
AB	$702.04	Yes	$15,000.00	$416.70	$625.05	2.8	4.2
			$25,000.00	$531.00	$796.50	2.1	3.2
SK	$637.89	No	$15,000.00	$3,827.34	$5,741.01	25.5	38.3
			$25,000.00			15.3	23.0
MB	$571.36	Yes	$15,000.00	$409.50	$409.50	2.7	2.7
			$25,000.00	$1,020.00	$1,020.00	4.1	4.1
ON	$560.04	Yes	$15,000.00	$230.00	$454.00	1.5	3.0
			$25,000.00	$365.00	$724.00	1.5	2.9
QC	$563.07	Yes	$15,000.00	$495.96	$743.94	3.3	5.0
			$25,000.00			2.0	3.0
NB	$583.04	Yes	$15,000.00	$170.00	$230.00	1.1	1.5
			$25,000.00			0.7	0.9
NS	$630.94	No	$15,000.00	$3,785.67	$5,678.50	25.2	37.9
			$25,000.00			15.1	22.7
PEI	$628.04	No	$15,000.00	$3,768.24	$5,652.36	25.1	37.7
			$25,000.00			15.1	22.6
NL	$618.54	Yes	$15,000.00	$0.00	$0.00	0.0	0.0
			$25,000.00				

Out-of-pocket costs to fund GHRT for a young adult male and a young adult female survivor of a PBT with GHD for 360 days in each province across Canada. Ingredient cost was based on Humatrope® 12-mg cartridges and includes maximum markup and professional fees. Levels of low annual income are based on the national median total income of 2010 and prescription drug plan eligibility requirements. Cost is reported for nine and six prescription refills of Humatrope® 12-mg cartridges for females and males, respectively. All costs listed in Canadian dollars.

There was a higher out-of-pocket cost to treat adult GHD in females compared to males in all provinces that did not provide coverage. This finding was also observed in provinces that provided coverage, except in Manitoba and Newfoundland and Labrador, where coverage was equal. The difference in out-of-pocket costs between females and males was much higher in provinces that did not provide coverage compared to provinces that did provide coverage. Out-of-pocket costs were, on average, 1.0% higher for females than males in provinces that provide unequal coverage, and 10.0% higher in provinces that did not provide coverage. High variation was observed in provinces that provided public drug coverage for somatropin, a finding that can be attributed to interprovincial differences in cost-sharing policies. The coefficient of variation was 65% for both males and females at an annual income of CAD$15,000, while the coefficient of variation at an annual income of CAD$25,000 was 82% for males and 66% for females.

Of the provinces that did not provide coverage, Saskatchewan (15.3%–25.5% and 23.0%–38.3% for males and females, respectively) incurred the highest out-of-pocket cost based on annual income, while British Columbia (14.4%–23.9% and 21.5%–35.9% for males and females, respectively) incurred the lowest. The difference in financial burden of prescription cost between the provinces was not considerable, and variations in cost are due to differences in policies set forth by the provinces on applicable markups and professional fees (Table 2).

Of the provinces that did provide coverage, Manitoba incurred the highest out-of-pocket cost based on annual income for men, and Quebec incurred the highest out-of-pocket cost for women (2.7%–4.1% and 3.0%–5.0% for men and women, respectively), while Newfoundland and Labrador incurred the lowest (0% for both men and women). These differences in out-of-pocket costs among the provinces were due to variations in reimbursement policies of provincial drug plans (Table 2).

Interpretation

This study illustrates the disparities that exist across Canada in the coverage of somatropin to treat persistent GHD in young adult survivors of PBTs with childhood-onset radiation-induced GHD. This variation is marked by differences in provincial public drug coverage and reimbursement policies. The out-of-pocket costs associated with funding somatropin without coverage are catastrophic, owing to the fact that catastrophic drug plans protect individuals from undue financial hardship only for drugs that are approved for coverage by the provincial government. Females incurred a larger financial burden than males in the majority of provinces. Variation in coverage among public drug plans across Canada put young adult survivors of PBTs with GHD at high risk for cost-related drug non-adherence and undue financial hardship. These findings demonstrate that survivors of PBTs do not have equal access to care and are likely to suffer undue financial hardship in the process of obtaining required medications.

Of particular concern, no province explicitly acknowledged survivors of PBTs in their criteria for coverage. This discrepancy is most likely explained by the low incidence of PBTs and is likely overlooked owing to challenges in creating coverage policies for low-prevalence needs

(Miltenburg et al. 1996). Provinces may feel that based on administrative practicality, it would be more feasible to address cases on an ad hoc basis rather than develop a specific policy. The discrepancy could also be attributed to the utilitarian approach of provincial budget allocation that, unfortunately, results in the medical needs of vulnerable populations having less priority, in the effort to provide optimal health coverage to as much of the population as possible (Ungar and Witkos 2005). This approach also results in precedent avoidance by the provincial governments, and hence in a way protects governments from the implications of funding expensive treatments in specific populations.

Variation was observed among both out-of-pocket costs and coverage for somatropin among provinces. Remarkably, variations in out-of-pocket costs existed even for provinces that did grant coverage for somatropin. These out-of-pocket costs were expenses that must be borne by patients in order to become eligible for coverage under provincial drug plans. The high variation (coefficient of variation ≥60%) observed in provinces that provided public drug coverage for somatropin can be attributed to differences in cost-sharing arrangements among public drug plans and have been outlined in previous studies as the cause for inequitable access to medications (Coombes et al. 2004; Daw and Morgan 2012; Demers et al. 2008; Law et al. 2012; Ungar and Witkos 2005). However, approximately 25% of this variation can be explained by Newfoundland and Labrador, where no out-of-pocket cost was absorbed by the patient to obtain public drug coverage for somatropin. Nonetheless, the variation is still concerning even after removing Newfoundland and Labrador, and indicates that current cost-sharing arrangements contribute to inequitable access to medications. On average each year, young adult survivors of PBTs with GHD would incur CAD$348.72 or $508.03, at an annual income of $15,000 and $25,000, respectively, in out-of-pocket costs in provinces that provided public drug coverage for somatropin. These amounts are higher than in Belgium, where adults with GHD are eligible for public drug coverage and incur only between approximately €100 and €150 (CAD$150 to $227.05) in out-of-pocket costs to obtain public drug coverage for somatropin (Alexopoulou et al. 2010). Out-of-pocket costs were substantially higher in females than males in provinces that did not provide coverage. This finding is due to the higher dose of somatropin that is required for females compared to males to achieve equivalent effects, and hence results in higher cost (Burman et al. 1997; Johannsson et al. 1996).

Studies have shown that healthcare costs, both direct and indirect, are higher in adults with untreated GHD compared to the general population. A significant reduction in healthcare consumption can be observed after initiating GHRT in adults with untreated GHD (Ehrnborg et al. 2000; Hakkaart-van Roijen et al. 1998; Hernberg-Ståhl et al. 2001; Jonsson et al. 2000; Saller et al. 2006; Sanmarti et al. 1999; Svensson et al. 2004). Current Canadian pharmaceutical policy is creating barriers in reducing healthcare consumption/costs for young adult survivors of PBTs, an outcome that is likely to result in increased economic burden on the healthcare system through the increased healthcare consumption required to address the manifestations of GHD. This economic burden is in addition to the multiple healthcare resources required to address the numerous late effects for which survivors of PBTs are at risk (Turner et al. 2009).

Limitations

The findings of this study ought to be interpreted in light of its limitations. The model assumes that somatropin is the only prescription medication the patient is taking. This assumption is not representative of most young adult survivors of PBTs who, given their high risk for late effects, will be taking multiple prescription medications (Gleeson and Shalet 2004; Turner et al. 2009). However, the cost of somatropin greatly exceeds the costs of other required medications for young adult survivors of PBTs.

This model assumes that the non-weight-based recommended dosages will be adequate in treating GHD in young adults. In reality, dosage is tailored to the individual and determined by clinical and biochemical response (Ho 2007). Thus, the regimen in the model may not reflect the actual dosage required for every young adult survivor of a PBT with GHD. However, variations from the recommended dosage and actual required dosage are not significant enough to alter conclusions reached by this model.

In addition, there is a possibility that young adult survivors of PBTs may be eligible for coverage of somatropin from health insurance through employment or through a policy in their parents' plans. However, studies have shown that survivors experience significant difficulty in both acquiring and keeping health insurance (Holmes et al. 1986; Hudson et al. 2003). Often private insurance plans have strict criteria, lifetime maximums and expensive premiums that create difficulty in survivors' either obtaining or keeping private insurance.

Conclusions

Survivors of PBTs are at high risk of medical, neurocognitive and psycho-social late effects. These factors result in an economic burden that inevitably will require support from publicly funded programs to be addressed (Turner et al. 2009). Primary concerns of PBT survivors and their families include losing health insurance, being underinsured and facing the stress of paying for required medical therapies (Turner et al. 2009; "Uninsured" 2000). This study validates the reality of that concern and shows that lack of public coverage puts survivors of PBTs at high risk for cost-related drug non-adherence. This outcome is very likely to result in increased use of healthcare resources and economic burden on society to address the manifestations of GHD, in addition to the healthcare resources required to address their multiple late effects (Law et al. 2012; Turner et al. 2009).

Variations in provincial policies cause undue financial hardship and inequitable access to medications. Policy makers need to adopt a consistent pan-Canadian approach to drug coverage to encompass not only the medical needs of survivors of PBTs, but of all vulnerable populations. This study, like others, supports the need for federal legislation to implement a national drug formulary that has equal cost-sharing arrangements for every Canadian (Coombes et al. 2004; Daw and Morgan 2012; Demers et al. 2008; Romanow 2002; Ungar and Witkos 2005). This recommendation is an achievable strategy to provide equitable access to medications for all Canadians, and has the potential to prevent financial hardship due simply to residence in a particular province.

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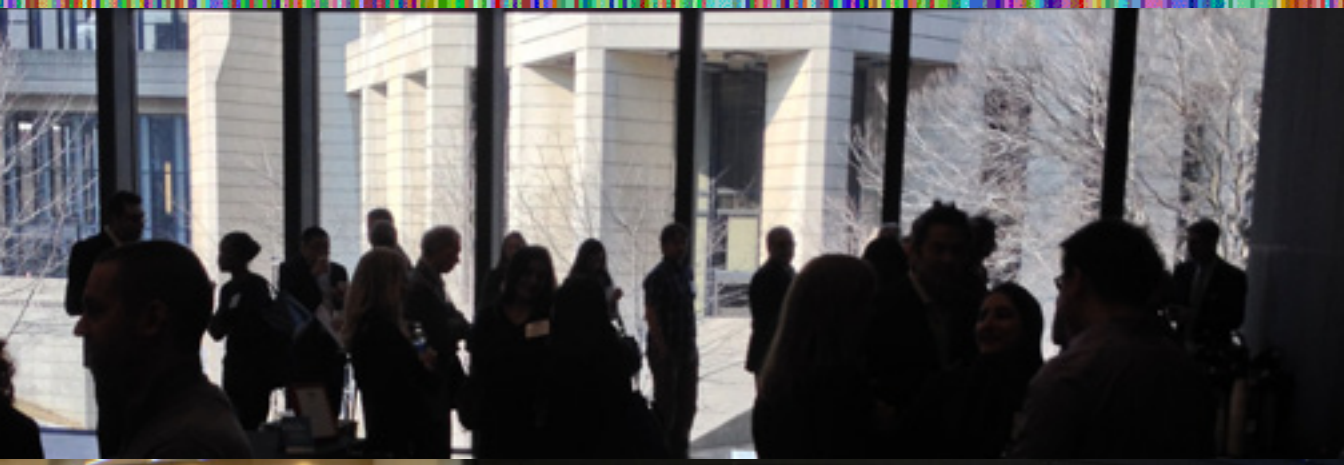

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