

HEALTHCARE

POLICY

Politiques de Santé

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

Volume 4 ♦ Number 1

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POLICY

Politiques de Santé

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

VOLUME 4 NUMBER 1 • AUGUST 2008

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.

Healthcare Policy/Politiques de Santé 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 *Healthcare Policy/Politiques de Santé* 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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Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

For deliveries to our studio: 54 Berkeley St., Suite 305, Toronto,
Ontario M5A 2W4, Canada.

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Individual subscription rates for one year are [C] \$105 for online
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[C] \$562 for print + online. For institutional subscriptions, please
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R138513668.

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mation call Barbara Marshall at 416-864-9667 or fax 416-368-
4443 or e-mail to bmarshall@longwoods.com.

Return undeliverable Canadian addresses to: Circulation
Department, Longwoods Publishing Corporation, 260 Adelaide
Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

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com.

Healthcare Policy/Politiques de Santé is published four times per
year by Longwoods Publishing Corp., 260 Adelaide St. East, No.
8, Toronto, ON M5A 1N1, Canada. The journal is published
with support from the Canadian Institutes of Health Research's
Institute of Health Services and Policy Research. Manuscripts are
reviewed by the editors and a panel of peers appointed by the edi-
tors. Information contained in this publication has been compiled
from sources believed to be reliable. While every effort has been
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sory board or any contributors. ISSN No. 1715-6572

Publications Mail Agreement No. 40069375

Printed by Harmony Printing

© August 2008

Pay for Performance in Primary Care: Proceed with Caution, Pitfalls Ahead

PAY FOR PERFORMANCE IN HEALTHCARE – THE CONCEPT THAT PAYMENT should reflect processes and outcomes of care – has generated growing interest, debate and action among policy makers, health system managers and health-care providers in Canada and internationally. With the introduction of its Quality and Outcomes Framework (QOF) for primary care in 2004, the United Kingdom raised pay for performance to a new level in both scale and scope (Roland 2004; Roland et al. 2006).

The QOF is a voluntary program that provides financial incentives for general practices to meet performance criteria in four domains: clinical (80 indicators), organizational (43 indicators), patient experience (four indicators) and additional services (eight indicators) (National Health Service 2007). General practices can earn up to 1,050 points by meeting these criteria, which were chosen and weighted based on the prevalence and illness burden of the target conditions. Each point is worth approximately £120 (\$240 CAD) to the average UK general practice (three GPs with 5,500 registered patients) (Roland 2004). GPs are allowed to exclude patients from eligibility for specific indicators on several grounds, including failure of the patient to respond to repeated invitations to attend for a health review and inappropriateness of an indicator because of terminal illness, extreme frailty or a medication allergy, adverse reaction or contraindication (Doran et al. 2006). Practice-level QOF data are published online (Majeed et al. 2007).

The QOF is the product of negotiations between the National Health Service (NHS) and the British Medical Association, assisted by academic advisers. In the words of one of those advisers, “Professional representatives were willing to negotiate the provision of care that met higher standards in return for increased resources, and the government was willing to commit additional resources if there was evidence of improved performance” (Roland 2004). Conditions favourable to the QOF initiative included a period of sustained economic growth and increasing government revenues (Roland 2004), professional commitment to evidence-based practice (Wilson et al. 2006) and the availability of computerized clinical and administrative databases that could provide routine information on primary care performance (Majeed et al.

2007). The QOF was layered on a series of quality initiatives beginning in the 1990s (Campbell et al. 2005, 2007; Galvin 2006) that were associated with substantial improvements in quality of care during the period leading up to QOF implementation (Campbell et al. 2005).

The NHS committed £1 billion (\$2.3 billion CAD) annually in new money to the QOF initiative, a 20% increase in the general practice budget (Roland 2004). General practices stood to increase their income by up to 30%, or £42,000 (\$96,000 CAD) per GP. In 2004–2005, the first year of the QOF, the average general practice achieved 958.7 points (91% of the 1,050 available), and almost half of all practices scored between 1,000 and 1,050 points (Peckham 2007). The scores were considerably higher than anticipated, and QOF incentive payments substantially exceeded the budget allocation (Doran et al. 2006). These results could reflect unchallenging performance targets, more diligent recording of performance, or quality improvements made in response to, in anticipation of or independent of the QOF incentives.

On average, practices serving socio-economically deprived populations achieve lower scores than those serving more affluent populations, although the differences are small (Guthrie et al. 2006; Sutton and McLean 2006; Wright et al. 2006; Doran et al. 2006; Ashworth et al. 2007). The QOF has been criticized for perpetuating the inverse care law (Hart 1971) – those with greatest needs get the least care – by failing to reward the extra work required to achieve quality targets in deprived areas (McLean et al. 2006).

In the absence of either a concurrent control group or comprehensive pre-QOF time series data for the QOF indicators, it has been difficult to determine the extent to which QOF has rewarded GPs for what they were already doing (new money for old rope), what they would have done anyway, what they would have done on the basis of transparent performance feedback alone and what they did in response to the financial incentives. Campbell and colleagues (2007) assessed the quality of care for asthma, coronary heart disease and type 2 diabetes among a representative sample of UK general practices at three points in time – two before the introduction of pay for performance (1998 and 2003) and one after (2005). For 30 indicators for which financial incentives were provided under QOF and 17 indicators for which financial incentives were not provided, they compared mean performance scores in 2005 to scores predicted on the basis of the trend between 1998 and 2003. The rate of improvement in quality of care for diabetes and asthma increased significantly between 2003 and 2005 after the introduction of pay for performance, while the rate for coronary heart disease continued at the same rate. For all three conditions, the rate of improvement between 2003 and 2005 did not differ significantly between incentivized clinical indicators and those for which incentives were not provided. These findings are consistent with the results of a systematic review of the empirical literature on paying for quality in healthcare and comparable interventions in other sectors, which found little evi-

dence to support the effectiveness of paying for quality (Rosenthal and Frank 2006).

In semi-structured interviews conducted just before the implementation of QOF, GPs described significant anticipatory changes in the structure and organization of their practices, including increased employment of nurses to provide nurse-led chronic disease management and triage and management of acute minor illnesses (Roland et al. 2006). They also reported recruitment of data entry clerks in response to the administrative demands of QOF, and “healthcare assistants” to undertake health promotion tasks. Most practices were in the process of refining their data collection processes to deal with QOF reporting requirements. Three years after the introduction of QOF, Campbell and colleagues (2008) conducted semi-structured interviews with 21 GPs and 20 nurses in 22 nationally representative English general practices. Although respondents believed that the QOF incentives had improved disease-specific processes of care and data capture, they described unintended effects, including the emergence of potentially competing patient-centred and QOF-oriented agendas during office visits, a decline in relational continuity between doctors and patients and resentment from nurses failing to benefit financially from QOF incentive payments that flowed to the doctors as employers and owners of the practice. Anecdotally, this last issue has also emerged in Ontario’s Family Health Teams in relation to performance-based incentives for appropriate provision of influenza vaccinations, Papanicolaou smears, mammography, childhood immunization and colorectal cancer screening. Threats to team relationships are particularly worrisome, given evidence that positive team climate is associated with improved chronic disease management, patient satisfaction, continuity of care and access to care (Campbell et al. 2001).

Several commentators (and GPs themselves) have raised concerns about the potential effects of QOF and earlier quality-related initiatives on the motivations, roles and behaviour of GPs (Charles-Jones et al. 2003; Marshall and Harrison 2005; Roland et al. 2006; Mangin and Toop 2007), based in part on theoretical work in psychology as well as empirical evidence suggesting that for complex tasks, extrinsic incentives tend to reduce intrinsic motivation and performance unless they are consonant with personal and professional interests, values and sense of self (Deci et al. 1999; Gagné and Deci 2005). In the context of QOF, the chief worry is that GPs will pursue the QOF agenda at the expense of relational continuity, coordination of care and whole-person, patient-centred care. Concern that physicians had developed an unhealthy focus on the personal financial implications of their clinical activities led Kaiser Permanente to move away from extensive use of performance-based financial incentives and to focus on regular, transparent and systematic performance feedback as the principal driver of quality improvement (Levine 2007).

Two potential mechanisms by which GPs might be tempted to “game” the QOF have been identified: classifying patients with borderline clinical measures (e.g., blood pressure) or laboratory values (e.g., blood glucose) as having a condition covered by the

criteria (Mangin and Toop 2007), and inappropriate exclusion of patients for whom GPs have missed (or are likely to miss) the QOF targets (Doran et al. 2006). The former situation (sometimes referred to as “diagnostic creep”) is particularly worrisome because it could lead to inappropriate treatment and other consequences that flow from disease “labelling” (e.g., Macdonald et al. 1984; Forrow et al. 1989). However, there is no evidence to indicate whether and to what extent this situation has arisen in the QOF or in other pay-for-performance settings. In the first year of QOF, 1% of practices excluded more than 15% of patients (in one case, 86%), raising the possibility of gaming by a small number of practices (Doran et al. 2006).

What lessons can be drawn from experience in the United Kingdom and elsewhere to guide the introduction or refinement of pay for performance in primary care?

- Depending on the context and design features, pay for performance can yield small gains at large cost, particularly when targets are set in the absence of good baseline (or, better yet, time series) data on performance, and when performance levels – rather than performance improvements – are rewarded. In a US study conducted on a large health plan, physician groups with baseline performance at or above the performance threshold improved the least but received the largest share of bonus payments (Rosenthal et al. 2005). Although in theory, pay-for-performance schemes could be budget-neutral if increased payments to high performers were balanced by reduced payments to low performers, this scenario seems implausible in any setting where providers are represented by a recognized bargaining agent, such as a national or provincial/state medical association.
- Given the above, policy makers should consider phased and carefully monitored introduction of pay-for-performance initiatives, payments that reward both performance levels and improvements over time, and focusing on a limited set of interventions (which might change over time) selected on the basis of baseline performance levels and potential health gains from improved performance.
- Sophisticated clinical information systems are a prerequisite for mounting pay-for-performance programs (and for quality improvement initiatives in general).
- Encouragement of inappropriate testing and treatment can be reduced by allowing the exclusion of patients for whom incentivized interventions are impracticable or inappropriate, recognizing that this opens the door to gaming.
- To minimize the possibility of negative unintended consequences, especially the dilution of providers’ internal motivation, primary care providers should be engaged in the design of pay-for-performance initiatives.
- Methods for avoiding, identifying and countering unwanted effects, such as provider gaming, impaired team relationships and inequities for socially disadvantaged populations and their primary care providers, need to be thought through and put in place prior to the introduction of a pay-for-performance scheme.

- Research is needed to establish the incremental effects of financial incentives beyond what can be achieved through ongoing performance feedback, quality improvement facilitators supporting practice-based quality improvement teams and participation in learning collaboratives.

For policy makers determined to go down the road of pay for performance despite the uncertainties and potential pitfalls, making haste slowly may be the best course of action.

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Rémunération au rendement : avancez prudemment, chaussée glissante

LA RÉMUNÉRATION AU RENDEMENT DANS LES SERVICES DE SANTÉ – C'EST-à-dire le concept selon lequel la rémunération devrait refléter les résultats et processus associés aux soins – donne lieu à des débats et des plans d'action et suscite de plus en plus l'intérêt des responsables de politiques, des gestionnaires du système de santé et des prestataires de services au Canada et à l'étranger. La mise en place du Quality and Outcomes Framework (QOF) pour les soins de santé primaires, en 2004, a décuplé l'échelle et l'envergure de la rémunération au rendement, au Royaume-Uni (Roland 2004; Roland et al. 2006).

Le QOF est un programme grâce auquel les cliniques de médecine générale reçoivent une incitation financière selon des critères de rendement dans quatre catégories : clinique (80 indicateurs), organisationnelle (43 indicateurs), expérience vécue par le patient (quatre indicateurs) et services supplémentaires (huit indicateurs) (National Health Service 2007). Les cliniques peuvent obtenir un total de 1050 points, selon des critères choisis et soupesés en fonction de la prévalence et du fardeau d'états de santé ciblés. Chaque point équivaut à environ 120 £ (240 \$ CA) pour une clinique de médecine générale de taille moyenne au Royaume-Uni (c'est-à-dire trois omnipraticiens traitant 5500 patients inscrits) (Roland 2004). Pour certains indicateurs précis, les omnipraticiens peuvent exclure des patients pour diverses raisons, notamment le refus du patient de répondre aux invitations répétées pour un examen de santé; la non pertinence d'un indicateur en raison d'une maladie terminale, d'une faiblesse extrême ou d'une allergie aux médicaments; les effets indésirables ou les contre-indications (Doran et al. 2006). Les données du QOF au niveau clinique sont publiées en ligne (Majeed et al. 2007).

Le QOF est le fruit de négociations entre le National Health Service (NHS) et le British Medical Association, avec l'aide d'experts-conseils du milieu universitaire. Selon un de ces experts, « les représentants du milieu professionnel étaient prêts à négocier une prestation de soins atteignant des normes plus élevées en échange d'un accroissement des ressources, alors que le gouvernement était prêt à engager des ressources supplémentaires si on pouvait garantir une amélioration du rendement » (Roland 2004). Les conditions favorables au moment de l'implantation du QOF comprenai-

ent une période de croissance économique continue, un accroissement des revenus du gouvernement (Roland 2004), un engagement professionnel envers la médecine fondée sur les données probantes (Wilson et al. 2006) et la présence de bases de données cliniques et administratives informatisées permettant d'accéder à des informations de routine sur le rendement en matière de soins de santé primaires (Majeed et al. 2007). Le QOF s'est appuyé sur une série d'initiatives visant la qualité, mises en place depuis le début des années 1990 (Campbell et al. 2005, 2007; Galvin 2006), lesquelles ont été associées à une augmentation appréciable de la qualité pendant la période précédant la mise en œuvre du QOF (Campbell et al. 2005).

Le NHS a engagé 1 G£ (2,3 G\$ CA) en argent frais chaque année dans l'initiative du QOF, une augmentation de 20 % du budget des cliniques de médecine générale (Roland 2004). Les cliniques ont vu leurs revenus augmenter de près de 30 %, soit 42 000 £ (96 000 \$ CA) par omnipraticien. En 2004–2005, la première année du QOF, une clinique moyenne obtenait 958,7 points (91 % des 1050 points possibles) et près de la moitié de toutes les cliniques ont obtenu un pointage entre 1000 et 1050 points (Peckham 2007). Le pointage était beaucoup plus élevé que prévu et les paiements du QOF pour l'incitation ont largement dépassé les budgets alloués (Doran et al. 2006). Ces résultats peuvent traduire soit des objectifs de rendement plutôt faciles à atteindre, soit une documentation plus circonspecte du rendement ou encore une amélioration de la qualité en réponse aux mesures incitatives du QOF, ou indépendamment de celles-ci.

En moyenne, les cliniques desservant des populations plus démunies au niveau socioéconomique ont obtenu de plus faibles résultats que celles desservant les populations mieux nanties, bien que l'écart entre les deux soit assez petit (Guthrie et al. 2006; Sutton et McLean 2006; Wright et al. 2006; Doran et al. 2006; Ashworth et al. 2007). Une des critiques envers le QOF a trait à sa tendance à favoriser la loi de corrélation inverse des soins (Hart 1971) – où les plus nécessiteux sont ceux qui reçoivent le moins de soins – en omettant de récompenser le travail supplémentaire nécessaire pour atteindre les objectifs de qualité dans les secteurs les plus démunis (McLean et al. 2006).

En l'absence d'un groupe de contrôle simultané ou d'une série chronologique de données complètes (antérieure au QOF) sur les indicateurs utilisés, il est difficile de déterminer si le QOF récompense les omnipraticiens pour ce qu'ils accomplissaient déjà (de l'argent frais pour une pratique déjà en place), pour ce qu'ils auraient fait de façon naturelle, pour ce qu'ils auraient simplement fait face à une rétroaction transparente sur le rendement ou alors pour ce qu'ils ont accompli en réponse aux mesures incitatives. Campbell et ses collègues (2007) ont évalué, dans un échantillon représentatif de cliniques généralistes au Royaume-Uni, la qualité des soins pour l'asthme, les maladies coronariennes et le diabète de type 2. Cette évaluation a eu lieu trois fois, soit deux fois avant la mise en place de la rémunération au rendement (1998 et 2003) et une fois après (2005). Ils ont comparé la moyenne des pointages pour le

rendement en 2005 aux résultats projetés selon la tendance observée entre 1998 et 2003, et ce, pour 30 indicateurs utilisés par le QOF et 17 indicateurs pour lesquels il n'y avait pas d'incitation financière. Le taux d'amélioration dans la qualité des soins pour le diabète et l'asthme a augmenté de façon significative entre 2003 et 2005, après la mise en place de la rémunération au rendement, tandis que le taux d'amélioration des soins pour les maladies coronariennes a maintenu le même rythme de croissance. Dans les trois cas, entre 2003 et 2005, il n'y a pas de différences significatives du taux d'amélioration entre les indicateurs cliniques touchés par les mesures incitatives et ceux qui ne le sont pas. Ces résultats concordent avec ceux d'une revue systématique de la littérature empirique portant sur les initiatives de paiements pour favoriser la qualité dans le secteur des services de santé ou portant sur des interventions comparables dans d'autres secteurs; la revue systématique fait état de peu de données appuyant le bien-fondé de l'efficacité du paiement pour la qualité (Rosenthal et Frank 2006).

Au cours d'entrevues semi-dirigées menées tout juste avant la mise en place du QOF, les omnipraticiens ont décrit d'éventuels changements significatifs dans la structure et l'organisation de leur pratique, notamment le recrutement d'infirmières pour la gestion des maladies chroniques et pour le triage et la gestion de maladies bénignes de courte durée (Roland et al. 2006). Ils ont également évoqué le recrutement d'employés pour la saisie de données afin de satisfaire aux exigences administratives du QOF et l'embauche d'assistants pour les tâches liées à la promotion de la santé. La plupart des cliniques mettaient en place des processus de saisie de données plus poussés afin de satisfaire aux exigences du QOF. Trois ans après l'implantation du QOF, Campbell et ses collègues (2008) ont mené des entrevues semi-dirigées auprès de 21 omnipraticiens et 20 infirmières dans 22 cliniques généralistes représentatives du Royaume-Uni. Bien que les répondants estiment que les mesures incitatives du QOF ont permis d'améliorer la saisie de données et les processus de soins pour des maladies précises, ils ont décrit des effets non escomptés, notamment l'émergence d'une compétition potentielle entre les programmes axés sur les patients et ceux liés au QOF pendant les consultations au cabinet; le déclin de la continuité des relations entre le médecin et le patient; le ressentiment des infirmières qui ne bénéficient pas de l'incitation financière du QOF, lequel est versé aux médecins en tant qu'employés et propriétaires des cliniques. Il convient de mentionner au passage que cette situation a été observée dans les groupes de santé familiale en Ontario dans le cadre des mesures incitatives fondées sur le rendement pour la prestation adéquate des services de vaccination antigrippale, de test de Papanicolaou, de mammographie, de vaccination des enfants et de dépistage du cancer colorectal. Les menaces pesant sur les relations d'équipe sont particulièrement préoccupantes, puisque les données démontrent qu'un climat positif au sein des équipes se traduit par une amélioration de la gestion des maladies chroniques, de la satisfaction des patients, de la continuité des soins et de l'accès aux services (Campbell et al. 2001).

Plusieurs personnes, y compris les omnipraticiens, ont exprimé leurs préoc-

cupations au sujet des effets potentiels du QOF (et autres initiatives antérieures liées à la qualité) sur la motivation, le rôle et le comportement des omnipraticiens (Charles-Jones et al. 2003; Marshall et Harrison 2005; Roland et al. 2006; Mangin et Toop 2007). Ces préoccupations se fondent en partie sur les travaux théoriques en psychologie et sur les données empiriques qui suggèrent que pour des tâches complexes, les mesures incitatives extrinsèques ont tendance à diminuer le rendement et la motivation intrinsèque, à moins qu'ils ne concordent avec les intérêts, les valeurs et le sentiment d'identité aux niveaux personnel et professionnel (Deci et al. 1999; Gagné et Deci 2005). Dans le contexte du QOF, la principale préoccupation réside dans le fait que les omnipraticiens puissent poursuivre le programme du QOF au détriment de la continuité de la relation, de la coordination des soins, et des services axés sur les patients. Préoccupé du fait que les médecins auraient pu développer un intérêt personnel malsain envers les répercussions financières de leurs activités cliniques, Kaiser Permanente a mis fin à l'utilisation massive des mesures incitatives financières fondées sur le rendement. L'organisme s'intéresse plutôt à une rétroaction sur le rendement régulière, transparente et systématique comme principal moteur de l'amélioration de la qualité (Levine 2007).

Il existe deux principaux mécanismes selon lesquels les omnipraticiens peuvent être tentés de « fausser » les données : les patients, dont les mesures cliniques (par exemple pour la pression artérielle) ou les résultats en laboratoire (par exemple le taux de glycémie) donnent des valeurs limites, peuvent être classés comme ayant un état de santé correspondant aux critères (Mangin et Toop 2007); et les patients pour lesquels les objectifs du QOF n'ont pas été atteints ou sont peu susceptibles d'être atteints risquent de faire l'objet d'une exclusion inadéquate (Doran et al. 2006). Cette dernière situation (parfois qualifiée de « dérive diagnostique ») est particulièrement préoccupante car elle peut mener à un traitement inapproprié ou à d'autres conséquences liés à la « catégorie » de la maladie (voir, par exemple, Macdonald et al. 1984; Forrow et al. 1989). Cependant, il n'existe pas de données permettant de démontrer si cette situation est présente ou non dans le cadre du QOF ou d'autres structures où est en place la rémunération au rendement. Au cours de la première année du QOF, 1 % des cliniques ont exclu plus de 15 % des patients (dans un cas, 86 %), ce qui peut laisser entrevoir la possibilité d'un faussement des données pour un petit nombre de cliniques (Doran et al. 2006).

Quelles leçons peut-on tirer de l'expérience du Royaume-Uni ou d'ailleurs pour orienter la mise en place de la rémunération au rendement pour les soins de santé primaires?

- Dépendamment du contexte et de la conception, la rémunération au rendement peut permettre d'obtenir des petits gains à fort prix, en particulier quand les objectifs sont établis sans données initiales solides (ou, mieux encore, sans séries

chronologiques) de référence portant sur le rendement, et quand sont récompensés les taux de rendement plutôt que les améliorations du rendement. Dans une étude menée aux États-Unis, les groupes de médecins pour lesquels les références de départ étaient égales ou au-dessus du seuil de rendement sont ceux qui se sont le moins améliorés mais qui ont reçu la plus grande part des primes (Rosenthal et al. 2005). Bien qu'en théorie l'effet des plans de rémunération au rendement sur les budgets puisse être nul, dans le cas où l'accroissement des paiements remis aux plus performants est équilibré par une réduction pour les moins performants, il semble difficile d'observer ce scénario dans tout contexte où les prestataires sont représentés par un agent négociateur reconnu, tel une association médicale nationale, provinciale ou d'État.

- Étant donné le point soulevé ci-dessus, les responsables de politiques devraient prévoir une mise en place surveillée (et par étapes) des initiatives de rémunération au rendement, ainsi que des paiements qui récompensent à la fois les taux de rendement et les améliorations, en mettant l'accent sur un ensemble limité d'interventions (qui peut changer avec le temps) choisies en fonction de taux de rendement de référence et des gains potentiels sanitaires obtenus grâce à l'amélioration du rendement.
- Des systèmes avancés d'information clinique sont indispensables à la mise en place de programmes de rémunération au rendement (et, en général, pour toute initiative d'amélioration de la qualité).
- En permettant l'exclusion des patients pour qui une intervention soumise aux mesures incitatives est inadéquate ou impossible, on peut diminuer le recours aux examens ou traitements inappropriés, reconnaissant ainsi le risque de « faussement » des données.
- Afin de réduire la possibilité de conséquences néfastes, particulièrement la réduction de la motivation à l'interne, les prestataires de soins primaires devraient prendre part à la conception des initiatives de rémunération au rendement.
- Avant de mettre en place des plans de rémunération au rendement, il est nécessaire de bien concevoir des méthodes permettant d'éviter, de repérer et de contrer les effets non désirés tels que le faussement des données, la détérioration des relations d'équipes ou les iniquités touchant les populations désavantagées de même que leurs prestataires de soins primaires.
- Il est nécessaire de faire de la recherche pour déterminer les effets marginaux des mesures d'incitation financières, au-delà de ce qui peut être accompli par une rétroaction continue sur le rendement, par les facilitateurs d'amélioration soutenant les équipes d'amélioration de la qualité et par la participation aux activités d'apprentissage collaboratif.

La prudence est sans doute la meilleure façon de procéder pour les responsables de politiques déterminés à mettre en place la rémunération au rendement malgré l'incertitude et la présence d'écueils potentiels.

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Access without Appropriateness: Chicken Little in Charge?

Accès ou pertinence : les alarmistes aux commandes?

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Abstract

Health policy makers in Canada have swung between the twin poles of ensuring access and controlling costs. Recently, access has dominated. Reconciling these opposing ideals, rather than alternating between them, requires adding the concept of appropriateness, and recognizing that rapid access to unneeded care may do more harm than good. Several examples are given of resources wasted (and side effects endured) through inappropriate use, and a few modest suggestions for improvement are made.

Résumé

Les responsables des politiques de santé au Canada oscillent entre, d'une part, l'accès aux services et, d'autre part, le contrôle des coûts. Récemment, c'est la question de l'accès qui a dominé; les alarmistes sont aux commandes. Pour réconcilier ces idéaux, plutôt que d'alterner entre les deux, il faut intégrer le concept de la pertinence et recon-

naître qu'un accès rapide aux soins non nécessaires peut causer plus de tort que de bien. Il existe plusieurs exemples de ressources gaspillées (et d'effets secondaires subis) à cause d'un usage inadéquat; et il y a peu de propositions visant l'amélioration.

HOW BAD IS CANADA'S HEALTHCARE SYSTEM? IF ONE WERE TO JUDGE from press coverage, it is in deep trouble – unsustainable, and forcing sick Canadians to wait for life-or-death care unless they are lucky enough to be able to travel south of the border. If one were to judge from comparative statistics, however, a different picture emerges: health outcomes are better than the average for OECD countries; costs are more or less under control, although with some worrying trends; and people receiving care seem relatively satisfied. F. Scott Fitzgerald wrote: “The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function.” Health policy analysts stress three key goals – cost, access and quality – and suggest that trade-offs among them are inevitable. It goes without saying that there is always room for improvement, and indeed, several thorough reviews of the system have reached remarkably similar conclusions about the changes that need to be made: Expand the definition of insured services beyond the historically based emphasis on hospital and physician care to include, at minimum, targeted home care services, prescription drug coverage and better mental healthcare. Reform primary healthcare. Emphasize disease prevention and health promotion. Get better data. Reorganize care to improve efficiency and patient flow.

Ignoring, for a moment, the fact that there is no such thing as a Canadian healthcare system – it being neither national nor a system – health policy makers are confronted by Fitzgerald's intelligence test. We appear, indeed, to have responded by holding two opposed ideas, cost and access, but only one at a time, swinging alternately between them. For the past few years, one idea has dominated – access – which translates as, “There are not enough...” (doctors, nurses, fill in the blank). People have to wait too long for care. Expensive drugs are not provided at public expense. Chicken Little cries triumphantly throughout the land: *The sky is falling! We need more!* Governments responded in 2004 with wait time targets for five services: cancer care, cardiac care, hip/knee replacements, cataract surgery and CT/MRI scans.

Then, the second idea intrudes: Publicly funded healthcare is unaffordable. The system is not sustainable. We need cost control. A brave few point out that our current bottlenecks result from the *success* of earlier cost control efforts: per capita inflation-adjusted Canadian health expenditures actually dropped in the mid-1990s. Funders capped hospital budgets, providing, in turn, an incentive for cost shifting. Hospitals laid off nurses; the resulting exodus from the profession soon created a nursing shortage. Physicians had to battle for operating room time; those with less internal power

(often the providers of elective surgery) found themselves on the losing side, leading to wait lists for their services. The backlash, in turn, led to the current focus on restoring resources. A cynical observer might suggest that there will soon be a similar backlash against the costs of the access agenda, particularly if the economy slides into recession.

Is our intelligence first-rate enough to reconcile these opposing ideas, rather than just alternate between them? A modest proposal suggests yes, if we allow in a third idea that too rarely enters the dialogue – appropriateness. It involves recognizing that more is not always better. Care can do harm as well as good. Rapid access to care that is not needed is not always wise.

Many years ago, Bob Evans (1984) noted that we do not want to buy healthcare, we want to buy health, but do not know what economists call the “production function” connecting them. Healthcare is not a normal consumer good. In general, markets do very well at distributing many kinds of goods, using price signals to balance supply and demand. If demand is high, price rises until enough consumers are priced out of the market to balance supply and the new, lower level of demand. If price is low, demand rises.

But healthcare adds in another wrinkle – need. And, taken seriously, this addition erodes the basic premises of markets. First, it adds another decision-maker – the expert. I decide what I want, but the healthcare professional decides what I need. Next, it destroys the mechanism of price signals. If I need care, should I get it, regardless of my ability to pay? If the answer is yes, then there is no limit to the cost that can be charged – “your money or your life” has a long history of successfully parting individuals from their cash. Conversely, if I do not need care, should I get it as long as I am willing to pay? Evans’s insight is important – why on earth would I want to? Most healthcare is not pleasant to consume; there are risks and side effects. Our focus on balancing costs and benefits leads to an understandably negative reaction from people who disagree with the conclusion that they are not “worth” the cost of treating them. Don’t we know that human life is priceless? A focus on balancing risks and benefits, in contrast, would make explicit what health professionals already know: Sometimes less is more. Treatment may do more harm than good. It is important to target interventions towards those for whom the benefits are likely to outweigh the harms.

This is usually easier said than done. Knowing whether benefits outweigh harms requires evidence. Who gathers it? One problem is that people get paid considerably more for providing a good or service than for advising that it is not necessary. Unsurprisingly, those with fiscal interests seem inclined to show that their services are beneficial (Lexchin et al. 2003). Gathering evidence takes time. Should sick people be expected to wait? If not, what should be done before the evidence is in? Evidence often shows that there is a sliding scale of benefit. How much benefit is worth buying? At what cost? People may disagree in their interpretation of the evidence. How much autonomy is appropriate, and who should decide?

In consequence, we have tended to ignore appropriateness altogether for some procedures. True, among the recommendations of the Romanow Commission (2002) was the obviously unlucky Recommendation 13: “The Health Council of Canada should take action to streamline technology assessment in Canada, increase the effectiveness, efficiency and scope of technology assessment, and enhance the use of this assessment in guiding decisions.” Clinicians are making a valiant effort to assess evidence, and have used it well in developing the wait time standards for cancer and cardiac treatment (Health Council of Canada 2007). (Not coincidentally, wait times for those conditions appear to be largely under control.) However, those for cataract surgery, hip and knee replacement, and diagnostic imaging (CT, MRI) have proven more difficult, and that appears to be where much of the Chicken Little dialogue is focused.

Why does the appropriateness dialogue have such little traction?

It is remarkably difficult to convince patients or physicians willingly to forgo therapy that they believe would be helpful “merely to save money.” In the current dialogue, efforts to target are equated with denial of needed care. Patient groups – either grassroots or provider-funded Astroturf groups, backed by the media – are quick to demand that third-party payers pay any price for the newest drug. These groups are found in most countries, making remarkably similar arguments, and few governments can resist such pressure. Decisions by Canada’s Common Drug Review (Tierney and Manns 2008) that drugs do not offer sufficient benefit to warrant listing are quickly, and vociferously, denounced by both pharmaceutical companies and patient groups. Ontario’s attempt to introduce PET scanning within the context of evaluating its effectiveness, rather than being hailed as a way of determining when this procedure is beneficial, has been denounced as limiting access.

Hang risks and benefits; the public assumption appears to be that no one should ever wait, and that more is always better. Consider the priority categories for joint replacement agreed to by the Wait Time Alliance (2005: 19), and its benchmarks:

Priority 1: A situation that has the potential to deteriorate quickly and result in an emergency admission should be operated on within 30 days.

Priority 2: A situation that involves some pain and disability but is unlikely to deteriorate quickly to the point of becoming an emergency admission should be operated on within 90 days.

Priority 3: A situation that involves minimal pain, dysfunction or disability and is unlikely to deteriorate quickly to the point of requiring emergency admission should be operated on within 6 months.

Some might suggest that situations involving minimal pain, dysfunction or disability might not warrant surgery at all, let alone within six months, and one suspects that most surgeons would agree. That, however, was not the reaction of the focus

groups: “Six months is too long to wait if you think about anyone supporting a family. How can they wait that long?” (Wait Time Alliance 2005: 20).

Shortening waiting periods for unneeded therapy that causes harm seems counter-productive. But the horror stories are almost exclusively of people denied expensive innovations that might benefit them. Somehow, the horror stories of people getting expensive innovations that proved inappropriate and even harmful do not carry the same weight. The lessons of Vioxx have not sunk in. One recent example is Bayer’s Trasyolol, a drug used to prevent blood loss during artery bypass graft surgery (Deber 2007). According to newspaper coverage, it cost roughly \$1,300 per patient, compared with \$11 and \$44 for its alternatives (Pringle 2006). It accordingly had to be better, and an estimated 246,000 US patients received it in 2006 – most for off-label uses. What did this extra money buy? Two recent non-randomized studies told us: higher death rates, and higher risks of such serious side effects as kidney problems, heart attacks and strokes (Mangano 2007). The total cost for these worst outcomes was estimated at between \$250 million and \$1 billion. (One excellent source for keeping up with the published data is websites set up by lawyers sensing a new revenue opportunity).

Things have gotten sufficiently out of hand that in 2008 the *New York Times* started running a series entitled “The Evidence Gap: High-Priced Promise,” with the tag-line, “Articles in this series will explore medical treatments used despite scant proof they work and will consider steps toward medicine based on evidence.” The first example the newspaper selected fits within one of Canada’s five wait time targets – specifically, CT scanners to produce detailed images of the heart (Berenson and Abelson 2008). The article described a US clinic asking to buy a machine that would cost them \$1 million. But the doctors can pay for the equipment by doing enough CT angiograms (at \$500 to \$1,500 per test), and over 150,000 such scans were done in the United States in a single year, for a cost of more than \$100 million. Such tests are not without risk; the dose of radiation is large enough to increase the lifetime risk of cancer. And the evidence that they benefit most patients is not there. But lobbying from patient and physician groups has ensured that US Medicare continues to pay for them.

In Ontario, nearly \$100 million has been spent to increase the supply of CTs and MRIs. More machines have been bought, and more scans have been paid for. The government pulled in providers to determine how best to proceed (Trypuc et al. 2006a,b,c). In response to greater capacity, utilization has soared. What is worrying is that the clinical benefit is often problematic. For example, a recent ICES analysis by You et al. (2008) reviewed hospital charts; the authors found that the most frequent reason for ordering a CT scan of the brain was headache, and less than 2% of those scans showed an abnormality. These tests also led to other tests in 25% of cases. How low a yield is appropriate? Scans involve radiation – regardless of the questions of wise use of resources, at what point does the clinical harm (e.g., increased cancer risk) outweigh the potential benefit?

The second story in the *New York Times* series looked at the cancer drug Avastin (Kolata and Pollack 2008). This drug has long been a poster child for the horror stories of people denied care. It costs up to \$100,000 per year per patient; its sales are over \$3.5 billion per year (\$2.3 billion in the United States). And studies show that it prolongs life by only a few months, if that. Is it worth it?

Another Canadian example, following enormous pressure, newspaper stories about dying patients, lawsuits and involvement by the Ontario Ombudsman, the Ontario Ministry of Health and Long-Term Care agreed to send patients with colorectal cancer to the United States for another expensive drug, Erbitux. According to a story in the *Globe and Mail*, Ontario paid \$32 million for 418 patients to have the infusions, alone or in combination with another drug, over a three-year period starting in 2005 (Priest 2008). Further research, reported at a 2008 meeting, suggested that it was useless for 40% of patients. The *Globe* story, however, conveyed this as yet another example of nasty government refusing to pay for something – in this case, not immediately making available (and paying for) a newly developed \$500 test to see whether the drug would work. Little mention was made of the money wasted, and side effects endured, by premature adoption of a therapy with insufficient evaluation.

So, what might be done? One might hope that Chicken Little will gain some perspective and celebrate what works well. Other suggestions also come to mind. The first is to focus on appropriateness. This does not mean that the call for evidence should be used to block innovation; we should innovate, but also evaluate. Ideally, new therapies would be applied within the context of trials and registries, so that evidence could be collected and subsequent use targeted towards those for whom such treatments would do more good than harm. Another suggestion is to negotiate the price to be paid for these therapies, particularly for drugs, rather than agree to pay whatever companies wish to charge. Another is to shift the dialogue from cost–benefit to risk–benefit. Finally, it might be nice to focus on outcomes, with the recognition that we may end up paying less attention to diagnostic imaging and elective hip/knee surgery and more to prevention, home care and the other reforms that keep being suggested, but have so far not been implemented.

With luck, the title of this column might become yesterday's news, with Chicken Little settled happily in her barn. It is high time that health policy stopped being guided by fictional poultry.

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The Helix in the Labyrinth: Do We Need Genetic Health Services and Policy Research?

Le labyrinthe de la spirale : la recherche sur les
politiques et les services de santé touchant à la
génétique est-elle nécessaire?



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The Helix in the Labyrinth: Do We Need Genetic Health Services and Policy Research?

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Abstract

In Canada and elsewhere, targeted health services and policy research (HSPR) has been suggested as a means to clarify the health system implications of developments in genetics and genomics. But is such research really needed? We argue that substantial investments in basic genetic and genomic research, coupled with persistent uncertainty about the health system implications of advances in these fields, justify the development of specialized HSPR in genetics and the sustained involvement of the wider HSPR community. Genetic health services and policy research will play a crucial role in informing decision-makers at all levels of the health system about whether and how to integrate developments in genetics, genomics and other complex new technologies.

Résumé

Au Canada comme ailleurs, la recherche sur les politiques et les services de santé (RPSS) a été proposée comme moyen de clarifier les répercussions, sur le système de santé, des avancements en génétique et en génomique. Mais une telle recherche est-elle vraiment nécessaire? Nous soutenons que les investissements substantiels de recherche en génétique et en génomique, jumelés à l'incertitude persistante quant aux répercussions, sur le système de santé, de l'avancement de ces disciplines, justifie l'élaboration de RPSS spécialisée touchant à la génétique ainsi qu'un engagement soutenu envers

le milieu de la recherche sur les politiques et les services de santé. La RPSS touchant à la génétique jouera un rôle important pour éclairer les décideurs de tous les niveaux du système de santé dans leurs choix concernant les avancements de la génétique, de la génomique ou d'autres technologies complexes.

AS THE CANADIAN INSTITUTES OF HEALTH RESEARCH INSTITUTE OF Genetics and Institute of Health Services and Policy Research embark on another in a series of requests for applications targeted at genetic health services and policy research, it is worth considering what is to be gained by this strategic investment. Is this a case of the squeaky wheel getting the grease, or a measured response to a pressing need? We argue that investment in genetic health services and policy research (HSPR) is needed to clarify the nature and extent of the healthcare and health system implications of developments in genetics and genomics, and to provide the evidence base to support decision-making by clinicians, healthcare administrators and system planners. At the same time, HSPR that takes genetic technologies and associated services as its focus can contribute broader insights about the healthcare and health system implications of other complex interventions. Genetic HSPR offers opportunities for all interested researchers and policy makers, and benefits from engagement by the wider HSPR community.

The Challenge

There is widespread agreement that developments in genetics pose challenges for healthcare and health systems, but consensus is lacking about which challenges are most important.

Many commentators expect the role of genetics in medicine to expand in the coming years as increasing amounts of genetic information are used to identify health risks and manage disease (Khoury 2003). For some, these developments promise a revolution in medicine and healthcare. Francis Collins and Allan Guttmacher, Director and Deputy Director, respectively, of the US National Human Genome Research Institute, epitomize this enthusiastic view. As they put it, "With this achievement [the completion of the human genome project], humankind has crossed into new territory ... there is a high likelihood that medical care will undergo a transformation as a consequence" (Collins and Guttmacher 2001). They add, "the practice of medicine has now entered an era in which the individual patient's genome will help determine the optimal approach to care, whether it is preventive, diagnostic or therapeutic. Genomics

... is poised to take center stage in clinical medicine ..." (Guttmacher and Collins 2002: 1519–20).

Yet others question the revolutionary potential of genetics, suggesting inherent limitations in our ability to predict or manage disease with the fruits of genomic science. Holtzman and Marteau (2000) argue that genetic information will not be sufficiently predictive to guide medical practice for most common and complex diseases. Even in rarer cases, where inherited susceptibilities are clearly defined by genetic tests, the gap between the ability to diagnose and the ability to treat (the "therapeutic

gap") remains. Meanwhile, Carlsten and Burke (2006) question the added value of genetics in some public health efforts, suggesting that genetic information about increased susceptibility to lung cancer might lead to greater fatalism among the more susceptible, more smoking among the less sus-

... others question the revolutionary potential of genetics, suggesting inherent limitations in our ability to predict or manage disease ...

ceptible and less emphasis on highly successful societal efforts, such as smoking bans and tobacco taxes. Attention to these high-profile areas can detract from more pressing concerns – issues such as home care or the social determinants of health – that may prove more relevant to health improvement and system sustainability. For those who express such doubts, the challenge is less the science itself and more the excess scientific and public enthusiasm – termed "genohype" (Holtzman 1999) – that surrounds this area of science and technology.

For others, the challenge of genetics for healthcare arises from the marketing practices of those who control intellectual property rights (IPR). In Canada and around the world, policy attention was galvanized by the Myriad case, in which a US biotechnology company sought to assert its intellectual property rights over genes in ways that fostered debate about the appropriate scope of IPR in genetics (Heller and Eisenberg 1998) and compromised the planning, cost control and service delivery efforts of individual jurisdictions (Gold et al. 2002). In response, policy makers struck committees and ordered commissions and reports to consider the implications of such practices (Australian Law Reform Commission 2004; OECD 2000; Ontario Ministry of Health and Long-Term Care 2002; Cornish et al. 2003). While the Myriad dispute has quieted, commentators continue to disagree over whether these policy initiatives were justified and the extent of the ongoing challenge for health systems (Caulfield et al. 2006; Gold et al. 2007).

There is little doubt that developments in genetics and genomics are improving our understanding of disease. It is also increasingly clear that these developments will lead to health improvements for specific inherited conditions. But the scope and depth of additional health improvements, and the full implications of marketing practices in genetics, remain unknown. A host of complex questions need to be addressed: How can clinicians and consumers be supported to use genetic tests appropriately? What outcomes should be measured to judge the benefits of genetic information? And how should associated changes in practice be financed, funded, regulated and delivered? As Calnan et al. (2006) have argued, the real challenge for health system planners and policy makers may in fact be persistent uncertainty about what genetic and genomic science will yield for health and health systems. Policy makers must make decisions in the face of this uncertainty, alongside both high hopes and persistent “hype” about the genomic enterprise, increasing the need for high-quality health services and policy research.

The State of the Art

The path from research discoveries in genetics and genomics to improved health services is not a straight one, fostering an expansive mandate for genetic HSPR.

The Human Genome Project and associated efforts have encouraged major public and private investments in genetic and genomic science. These investments generate important discoveries, but do not lead automatically to clinically useful products and improved service arrangements. One challenge is well known: the growing quantity of basic research discoveries is not always matched by reliable epidemiological information about genetic risks across multiple populations (Ioannidis et al. 2001). But health services and policy challenges are concurrent with, rather than subsequent to, the challenges of genetic epidemiology: technology validation occurs alongside service implementation, service organization addresses both realistic and unrealistic expectations, and stakeholders debate the ends to be pursued as they contemplate current and future possibilities. Genetic technologies are increasingly relevant for large sections of the population – notable examples include prenatal diagnosis, newborn screening and genetic testing for adult-onset conditions (e.g., hereditary cancer syndromes). Service design and implementation challenges are growing, even as the gap between what is hoped for and what is possible persists.

In this context, public policy makers have been motivated to call for HSPR in genetics with an expansive mandate. In Canada, the Institute of Genetics and the Institute of Health Services and Policy Research of the Canadian Institutes of Health Research jointly sponsor a Health Services for Genetic Diseases Initiative that, since 2003, has invested approximately \$5.2 million in such research. Like all HSPR, spe-

cialized HSPR in genetics seeks to identify optimal models of primary, secondary and tertiary care for the delivery of validated genetic technologies and services, support service organization and policy development to address public health needs through genomic technologies, and explore systems for the regulation, financing and funding of genetic health services. In addition, HSPR in genetics seeks to develop novel strategies to inform public policy and engage stakeholders (including lay and provider

populations) in deliberations regarding the goals of genetic healthcare and ways to manage often-inflated expectations. To this end, the genetic HSPR community has a sustained history of engagement with ethical, legal and social questions (known as ELSI,

... the genetic HSPR community has a sustained history of engagement with ethical, legal and social questions ...

or GE3LS). Further, the community has developed and used international networks and engaged policy makers at all levels (macro, meso and micro) (Burke et al. 2006). In recent years in Canada, several large research teams have emerged that address this broad mandate, including Apogee-Net, a knowledge network dedicated to supporting policy making in genetics (www.aetmis.gouv.qc.ca/site/en_apogee.phtml), GeneSens, evaluating health service and knowledge translation interventions in genetics (www.genesens.net) and CanGeneTest, examining the organization of genetic laboratory services, including technology assessment, regulation and public health programs (www.cangenetest.org).

The Proposal

With its broad mandate and analytic approach, insights from genetic HSPR are relevant to HSPR as a whole. Yet continued engagement with the broader HSPR community is essential if these benefits are to be realized.

Genetic HSPR has evolved with a clear focus and an expansive mandate. But does this specialized domain have anything to offer its parent discipline? And what should be the relationship between genetic HSPR and HSPR? We argue that the genetic HSPR community can ill afford to become detached from the broader HSPR community. At the same time, lessons learned from the exploration of genetic health services and health policy can inform the HSPR enterprise as a whole.

It is not necessary to suggest that genetic technologies pose unique social and

health system challenges to argue that distinctive insights can be generated from specialized HSPR in this area. Genetic HSPR is characterized by its engagement with ethical, legal and social issues; by the determination of many of its practitioners to explore genetic health technologies as complex interventions; by the need to consider the impacts of genetic technologies across all domains of healthcare; and by the vexing questions posed where inflated expectations exist alongside limited evidence. None of these characteristics of genetic HSPR is unique to this domain, but the convergence of these characteristics renders this specialization a rich source of methodological, theoretical and empirical insight.

The longstanding engagement of genetic HSPR with ethical, legal and social issues increases the sensitivity of the wider HSPR community to the broad implications of technological innovation and alerts practitioners to the influence of such factors in service and system change. In addition, like other healthcare innovations in which practices and understandings, not only outcomes, may be altered, the use of genetic science and technology in healthcare warrants attention as a complex interven-

tion (Campbell et al. 2007). The “complex intervention” framework enhances the need for the full spectrum of research methods and fosters a reflexive and theoretically sophisticated approach to design and evaluation. Further, HSPR for genetics encourages exploration

... HSPR for genetics encourages exploration across all levels of the healthcare system.

across all levels of the healthcare system. Genetics is relevant to most of healthcare, including primary care (e.g., family history, risk assessment and referral), secondary and tertiary care (e.g., risk assessment and management) and public health (e.g., newborn screening), with complex interactions across these many arenas. Finally, the expansion of genetic medicine raises fundamental evaluative, organizational and policy questions that have relevance beyond this particular instance, including coverage decisions (how can decisions about public subsidy be made quickly in the face of limited evidence?), service organization challenges (how can inter-professional learning and collaboration be fostered?) and system design dilemmas (what are the implications of private access for the utilization of public services?).

The appeal of genetics for those who practise genetic HSPR has encouraged many to become highly specialized, with substantive knowledge of genetics alongside expertise in the organization and delivery of health services and relevant evaluative and analytic methodologies. We have suggested that the gains from this specialization

may be considerable. But are there also hazards? Might the genetic HSPR community become a closed clique, with insufficient external peer review and critique to sustain rigorous knowledge production? In our view, this risk is real. For HSPR in genetics to sustain excellence, it requires ongoing cross-fertilization by experienced researchers with interests in associated areas: health system domains that might be affected by genetics (primary care reform, screening, telemedicine) or cognate specializations (e.g., imaging research). These interactions promise to enhance the nascent specialization of genetic HSPR and enrich research in the wider HSPR community.

Conclusion

It has been more than 50 years since Watson and Crick identified the structure of DNA. During that time, there have been successive waves of anticipation and dread about the implications of genetic science for medicine and society. As the double helix approaches middle age, we remain uncertain about the ultimate effects of this new knowledge. Yet, clarification will not come from examination of genetic science and technology alone. Rather, it relies on research that takes the labyrinth of healthcare and health systems as its focus. Genetic health services and policy research will play a crucial role in informing decision-makers at all levels of the health system about whether and how to integrate developments in genetics, genomics and other complex new technologies. To be of the best quality, this research must engage the wider health services and policy research community.

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Work Mistreatment and Hospital Administrative Staff: Policy Implications for Healthier Workplaces

Harcèlement professionnel et administrateurs en
milieu hospitalier : répercussions politiques pour
des milieux de travail plus sains



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Abstract

Research on work life quality in hospitals has focused on how nurses and physicians perceive or react to work conditions. We extend this focus to another major professional group – healthcare administrators – to learn more about how these employees experience the work environment. Administrators merit such attention given their key roles in sustaining the financial health of the hospital and in fulfilling management functions efficiently to support consistent, high-quality care. Specifically, we examined

mistreatment in the workplace experienced by administrative staff from a hospital in a large Canadian city. Three dimensions of mistreatment – verbal abuse, work obstruction and emotional neglect – have been associated with diminished well-being, work satisfaction and organizational commitment, along with stronger intent to leave. In this paper, we provide additional support for interpreting these three dimensions as mistreatment and report on their frequencies in our sample. We then consider implications for policy development (e.g., communication and conflict resolution skills training, mentoring programs, respect-at-work policies) to make workplaces healthier for these neglected but important healthcare professionals.

Résumé

Les recherches sur la qualité de vie au travail dans les hôpitaux ont porté sur la perception et la réaction des infirmières et des médecins face à leurs conditions de travail. Nous nous intéressons à un autre groupe professionnel important – les administrateurs des services de santé – afin de connaître l'expérience de ces employés face à leur environnement de travail. Une telle attention à l'égard des administrateurs est nécessaire étant donné le rôle important qu'ils jouent dans la viabilité financière de l'hôpital et dans l'accomplissement efficace des fonctions de gestion pour assurer des soins cohérents et de haute qualité. Plus précisément, nous avons étudié le harcèlement professionnel éprouvé par les administrateurs d'un hôpital d'une grande ville canadienne. Trois aspects du harcèlement professionnel – la violence verbale, l'entrave au travail et la négligence psychologique – sont associés à une diminution du bien-être, de la satisfaction au travail et de l'engagement organisationnel, de même qu'à une plus forte intention de quitter le milieu de travail. Dans l'article, nous proposons des moyens additionnels d'interpréter ces trois aspects du harcèlement, et nous faisons rapport de leur fréquence dans notre échantillon. Ensuite, nous abordons certaines répercussions pour l'élaboration de politiques (par exemple, la formation en communication ou en résolution de différends, les programmes de mentorat ou les politiques de respect au travail) afin de faire des milieux de travail un endroit plus sain pour ces professionnels de la santé importants, mais négligés.

IN CANADA AND ELSEWHERE, CONCERN IS MOUNTING ABOUT THE WELL-BEING of healthcare organizations and their employees (Cox and Leiter 1992; Lowe 2002). Conditions such as work overload, poor interpersonal relations and unsupportive climates are commonplace, contributing to staff burnout, low morale and voluntary turnover (Shamian and El-Jardali 2007). The last is particularly troubling in light of persistent workforce shortages and under-funding, which strain health systems already stretched to capacity. Costs of turnover are escalating in part because of high

rates of departure by health professionals, especially nurses (Gray et al. 1996) and administrators (Castle 2006). Surprisingly, the fact that turnover costs due to working conditions are largely avoidable (Abelson 1987) has not been given the attention it deserves from health system executives, policy makers and managers.

Emerging data confirm that healthcare workplaces can benefit from improved retention by strategic planning to sustain a healthy and satisfied workforce (Yassi et al. 2002). In this vein, research on work life quality offers insights into sources of unhealthy work conditions as well as levers for improvements. In Canada, several initiatives illustrate the growing interest in advancing the healthy workplace agenda across sectors, including healthcare, using evidence-informed policy. For example, the Quality Worklife–Quality Healthcare Collaborative (QWQHC), a multidisciplinary coalition of health leaders and partners, has formulated an action strategy for Canada’s healthcare providers following a comprehensive review of literatures and practices (QWQHC 2007). More broadly, the National Quality Institute, working with Health Canada, has developed pan-industry criteria for organizational policy to support employee health. Managing workplaces in accordance with such policy should yield more stable staffing levels by providing healthcare employees with the organizational resources, social support and respect they need to work productively and effectively.

In hospital contexts, most research on work life quality has focused on how nurses and physicians perceive or react to work conditions. This work has been invaluable in identifying deficits in practices that adversely affect these professionals and the care they can provide for patients. However, researchers also need to examine how other health professions experience the work environment. In particular, administrative staff merit such attention given their key role in ensuring the financial health of the hospital and fulfilling management functions efficiently to support continuous, high-quality care (Garman et al. 2006). Importantly, the costs of productivity loss from turnover of health administrators appear second only to those of physicians (Waldman et al. 2004).

In this paper, we follow up on a study (Harlos and Axelrod 2005) of mistreatment experienced by hospital administrators, which revealed that many who were verbally abused, prevented from getting their work done or neglected emotionally were planning to quit. Past research has shown that the intent to leave is the most immediate antecedent to, and best predictor of, voluntary turnover (Griffeth et al. 2000). The earlier study showed that verbal abuse, work obstruction and emotional neglect influence other work outcomes, with the result that these administrators tended not to feel good about themselves at work, unsatisfied with their jobs and detached from the hospital.

We go on to determine the frequencies of mistreatment dimensions. We also provide empirical support for interpreting these experiences as mistreatment. From this evidence base, we consider implications for policy development to make workplaces healthier for this neglected but important healthcare profession.

Workplace Mistreatment

People who believe they have been mistreated at work perceive that interpersonal interactions or organizational practices have violated a moral or legal contract for resources, opportunities or treatment (Harlos and Pinder 1999; Sheppard et al. 1992). Mistreatment makes employees feel distressed, less satisfied with their job and less committed to the organization; they are also less productive and more likely to quit (Bowling and Beehr 2006). Interpersonal mistreatment related to verbal interactions warrants investigation for at least three reasons. First, although more prevalent than violations that are physical or sexual in nature, they have received far less research attention in workplace studies. Second, consequences are serious. Even incivility or rudeness lowers individual productivity and organizational returns (Cortina et al. 2001). Third, in industrialized nations employment litigation related to verbal behaviours is on the rise. Increasingly, court decisions hold that yelling or swearing at employees, threats of firing and destructive criticism violate the employment contract. At the same time, legislated protection against such treatment is increasing. Canada, along with Sweden, Belgium and France, is taking a leadership role in this regard. In 2004, Quebec became the first North American jurisdiction to enact legislation against harassment that encompasses verbal exchanges, followed by Saskatchewan in 2007.

Because administrative work requires high levels of contact with people (England and Kilbourne 1988), we suspected that hospital administrators – just like nurses and physicians – experience mistreatment related to verbal interactions. We also wondered whether they experience mistreatment from organizational practices, as do administrators and managers in other industries (e.g., Baron and Neuman 1998; Harlos and Pinder 1999).

Overview of Our Study and Findings

We conducted a study of employees whose positions were excluded from union membership at a large urban hospital in western Canada. Because the positions represented administrative functions that deliver hospital services across management, professional and support ranks from 42 departments, we refer to these employees as administrators. Our data provide only a sketch of administrator experience, given that they are from a single hospital. Additionally, the sample is somewhat heterogeneous because we combined administrative ranks. This prevents us from drawing conclusions about the role of rank (position) in relation to mistreatment. However, the implications for policy are minor because the standard in emerging legislation and preventive policies – at least in terms of verbal mistreatment – is zero tolerance. Nevertheless, these data are a useful starting point for understanding the work realities of healthcare leaders and staff who struggle behind the scenes to ensure that services are well managed and cost-effective, and meet quality expectations. Our results provide an initial platform

for policy development that takes working conditions of this population into account.

The earlier study (Harlos and Axelrod 2005) describes the development of a scale of workplace mistreatment, including our use of in-depth research accounts to generate items. Factor analysis of the items revealed three underlying factors, or dimensions: verbal abuse, work obstruction and emotional neglect. Verbal abuse (measured by eight items) reflects spoken behaviours that denigrate people. Items include being yelled at, blamed for others' mistakes and spoken to in a harsh, cold tone of voice. Work obstruction (four items) involves encountering various blocks in getting work done. Sample items include failing to get needed resources or support and having requests for information ignored. Emotional neglect (five items) refers to a sense of abandonment engendered when employee needs for socio-emotional support and recognition are ignored. Component items include not being given constructive feedback and not being told that one is valued or appreciated. Overall, this scale contributes to the literature on healthy work environments (Kelloway and Day 2005) by introducing a reliable and valid means of measuring the kinds of interactions and practices that provoke perceptions of mistreatment.

For the purpose of this paper, we examined whether associations exist between dimensions of mistreatment and workplace (un)fairness. Respondents rated how fair each of five aspects of the workplace (supervisors, co-workers, subordinates, patients/clients/residents/visitors and the organization) was to them using a single item (e.g., "Overall, my organization treats me fairly") on a 1- to 5-point scale from "strongly disagree" to "strongly agree." This approach conforms to the standard in organizational research, which regards injustice, unfairness or mistreatment as having occurred when targets or victims so label it (Folger and Cropanzano 1998). Specifically, Pearson correlation coefficients revealed that verbal abuse was significantly associated with perceptions of unfairness concerning supervisors ($r=-.50$, $p<0.001$), co-workers ($r=-0.29$, $p\leq 0.001$) and the organization ($r=-0.30$, $p\leq 0.001$). Work obstruction was significantly associated with unfair supervisors ($r=-0.55$, $p<0.001$), co-workers ($r=-0.36$, $p<0.001$), subordinates ($r=-0.24$, $p<0.01$) and the organization ($r=-0.46$, $p<0.001$). Emotional neglect was significantly associated with unfair co-workers ($r=-0.25$, $p<0.01$) and the organization ($r=-0.28$, $p\leq 0.001$). The number of significant correlations at the organizational level implies that authorities beyond co-worker and supervisory levels were seen as sources of mistreatment. No significant relationships were seen involving unfair treatment by patients/clients/residents/visitors.

To assess how often respondents had experienced mistreatment dimensions, we analyzed frequencies (never, once, monthly, weekly, daily) as rated by respondents from the previous 12 months for each item. We report here the monthly, weekly and daily occurrences of mistreatment dimensions (see Table 1). To index verbal abuse, we determined the percentage of respondents for the three frequency categories who reported one or more items that define the dimension. This approach is consistent

with Canadian legislation, which permits single (along with repeated) behaviours to define such mistreatment. Table 1 shows that the majority of respondents (70%) experienced some measure of verbal abuse on a monthly basis. Of particular importance is the finding that about 10% reported such abuse on a daily basis. The fact that respondents represented over 40 departments suggests that verbal abuse is endemic in this hospital. Correlational results (described above) indicate that supervisors and co-workers were the main perpetrators of verbal abuse. Surprisingly, we found that even administrators in leadership positions experienced such mistreatment.

TABLE 1. Percentages of respondents reporting behaviours in last 12 months (N= 125)

Factor	Reported (%)		
	Monthly	Weekly	Daily
Verbal abuse ^a	69.6	32.0	9.6
Work obstruction ^b	56.8	29.6	10.4
Emotional neglect ^c	80.8	52.0	37.6

^a Indexed by minimum of 1 of 8 items.

^b Indexed by minimum of 1 of 4 items.

^c Indexed by minimum of 1 of 5 items.

We used a similar approach – determining the percentage of administrative personnel reporting at least one dimension item according to frequency category – to index work obstruction and emotional neglect (Table 1). Again, the daily frequencies are striking: 38% of respondents reported some measure of emotional neglect, and 10% felt obstructed in some aspect of their work every day. These results, along with correlations noted earlier, suggest an emotionally barren culture in which the needs to be recognized and to feel connected to others are routinely overlooked by co-workers and the organization. To illustrate, a patient services manager frustrated by the lack of action – despite much talk – about patient safety exclaimed, “We don’t need swimming lessons, we need life preservers. It doesn’t feel good to be ignored when you’re going down for the third time!” A security supervisor provided an example of work obstruction when he was neither consulted nor informed when a new access control system was installed in the hospital, impeding his ability to carry out his duties. The number of significant correlations between work obstruction and unfairness (reported above) suggest problems with procedures at multiple levels of administrative management. The results support the argument by Cropanzano and Byrne (2001) that organizational policies themselves can be a source of unjust treatment when they are poorly designed or rigidly implemented.

To summarize, our data provide a novel look at the work life of hospital adminis-

trators. Further studies are needed to confirm results on the nature and prevalence of work mistreatment in this population. Such research can support healthcare reform through insights that address work environment issues and strengthen health human resources (Lowe 2002). For example, West et al. (2006) reported a strong association between human resource management systems that emphasize employee engagement and reduced patient mortality following a study across 52 hospitals in England. This finding supports Deber's (2005) contention that small changes, parlayed in this instance across a region, can yield big advances in healthcare outcomes. In her commentary, Deber (2005) also recommends reform by providing the basics of satisfying employment experiences – individual respect, job security and good working conditions. Our findings reaffirm the importance of these basics and echo the need to focus on the fundamentals of management systems in hospitals.

If we accept that the basics of work life quality are important, then developing policy for a healthy workplace through improved interpersonal relations, socio-emotional support and work functioning becomes a key strategic goal. What formalized processes might reduce the prevalence of work mistreatment and lower costs (individual, organizational and societal) of unhealthy conditions in an industry that can ill afford to pay?

Implications for Health Policy: Back to Basics

The take-home message from this research stream is clear: workplace mistreatment makes it harder for hospitals to retain administrative personnel and harder for administrators who do stay to work effectively. In addition, the costs to hospitals, in terms of deficits in recruitment, training and productivity, from administrators who quit (or intend to) because they believe they have been mistreated are largely unnecessary, because the bulk of such turnover is avoidable. As Abelson (1987) points out, departure related to reasons such as “better working conditions elsewhere” or “better organization to work for elsewhere” is under an organization's control. The latter reason is relevant given that an organization can develop a reputation as an abusive place to work (Powell 1998). A hospital with such a reputation suffers the strategic disadvantage of being less able to attract skilled staff compared to a hospital known for its high-quality, healthy work environment.

In healthcare organizations, policy development for healthier workplaces can only benefit from knowledge about working conditions across the range of key professional groups, including administrators. This approach is consistent with the recommendation that policy makers include views from diverse interests for effective policies (Cropanzano and Byrne 2001). These authors also recommend that, along with learning about policy implementation, managers become critical thinkers and skilled communicators who practise fairness and foster organizational justice.

Effective interpersonal skills may be more critical for administrators than for any

other professional group in hospital service positions. Oftentimes, they report both to higher-ranking managers and clinical heads, creating potential ambiguity as well as conflict. In terms of the latter, Garman et al. (2006) observe that hospital administrators typically have strong reward power, which can pit them against other professionals when they must deny requests for resources or revoke resources already allocated. We caution that administrators promoted on the basis of technical rather than management or leadership skills will be especially challenged in navigating the complex and competing accountabilities, interests and alliances in hospital systems.

Healthcare organizations can adopt several strategies to address these issues. For example, they can prepare written guidelines and formal procedures concerning interpersonal conduct. Codifying respect-at-work policies can prevent complaints to regulatory agencies or courts, according to analyses of over 6,000 complaints fol-

lowing the introduction of Quebec's anti-harassment legislation ("Quebec Finds" 2007). Promoting respectful conduct through information sessions and campaigns, for example, signals the organization's commitment and helps all employees appreciate the importance

... Garman et al. (2006) observe that hospital administrators typically have strong reward power ...

of the issue. Hospitalwide training to teach all employees effective communication and conflict resolution reinforces the organization's support to make a demanding workplace less difficult. Periodic review of procedures and policies (Cropanzano and Byrne 2001) to minimize bottlenecks in getting work done and assess whether employee needs are being addressed will help ensure that policies serve as remedies rather than a source of complaints.

Policies that reinforce positive social relationships and recognize emotional needs of employees can counter the lonely and demoralizing work environments that some healthcare professionals experience (Harlos and Axelrod 2005; Lavoie-Tremblay et al. 2005). Psychosocial support is a key component of healthy workplaces (Kelloway and Day 2005), and its generally low levels in healthcare are a source of concern to provincial governments and regional health authorities (e.g., British Columbia 2004/2005). Mentoring programs and other sanctioned opportunities for interprofessional collaboration are initiatives that foster a sense of recognition and support.

More broadly, Kelloway and Day (2005) suggest a national strategy to address workplace health issues through assessment, intervention, education and training. In this vein, reducing the prevalence of work mistreatment poses particular challenges because it requires both that employees speak up and that organizations listen. Because employ-

ers tend not to act when employees complain, Namie (2003) recommends that policies to counter verbal abuse and bullying include enforcement processes and restorative interventions. Yet, some employees are reticent to speak up, no matter how troubling the

... improving the work environment for administrators also will improve the quality and sustainability of hospital services ...

problem or how powerful the policy. Silenced complaints prevent organizations from identifying problems and implementing solutions. For this reason, leading organizations in healthcare and elsewhere are implementing accountability or “whistle-blower” policies to

protect individuals who report wrongdoing. More broadly, research-informed models and criteria for healthy workplaces offer rich sources for policy innovations that can be customized to reflect goals and missions of specific healthcare organizations.

Conclusion

Our findings imply that improving the work environment for administrators also will improve the quality and sustainability of hospital services. To effect this change, we suggest a basic but underused approach: look, listen and learn to develop coordinated policies for respectful workplaces that provide all employees with what they need – emotionally and functionally – to feel satisfied and to succeed in their work. If we manage healthcare organizations as if administrative work truly mattered, we might be rewarded with a ready supply of skilled administrators willing to meet challenges with focus, enthusiasm and perseverance.

ACKNOWLEDGEMENTS

The authors would like to acknowledge financial support for this research from the Social Sciences and Humanities Research Council of Canada. We are grateful to Cy-Thea Sand, along with the anonymous reviewers and editors of *Healthcare Policy*, for helpful comments that improved this manuscript.

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Call to Authors

DISCUSSION AND DEBATE

The Discussion and Debate section of *Healthcare Policy* offers a forum for essays and commentaries that address: (1) important health policy or health system management issues; or (2) critical issues in health services and policy research. Submissions should be a maximum of 2,000 words exclusive of (no more than 20) references. The main points of the paper should be highlighted in an abstract (summary) of 100 words or less.

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La section « Discussion et débat » de *Politiques de Santé* offre un forum pour la publication de comptes rendus et de commentaires portant sur les sujets suivants : (1) d'importantes questions liées aux politiques de santé ou à la gestion du système de soins de santé; ou (2) des questions cruciales concernant les services de santé et la recherche sur les politiques. Les articles devraient être d'au plus 2 000 mots, sans compter les références (pas plus de 20). Les points saillants de l'article devraient être mis en évidence dans un résumé (sommaire) de 100 mots ou moins.

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Canadians with Health Problems: Their Use of Specialized Services and Their Waiting Experiences

Temps d'attente et utilisation des services spécialisés chez les Canadiens ayant des problèmes de santé



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Abstract

Improving access to healthcare has been a consistent priority for Canadians. In particular, reducing patient waiting times for health services has been a prominent policy issue. Across the country, governments are using a range of strategies to reduce patient waiting times for care, with a particular focus on reducing waits for specialized services. Although information is emerging on waits for selected procedures, there is limited

information on whether the utilization of services or waiting experiences of Canadians with health problems are different from those of the general population. Data from the Health Services Access Survey (2001–2005) were used to compare waiting experiences for specialized services between adults with health problems and healthier adults. The specialized services included specialist visits for a new illness or condition, non-emergency surgery and diagnostic tests. National-level estimates revealed that adults with health problems were more likely to self-report that they required specialized services. However, the median waiting times for these services were comparable to those of healthier adults.

Résumé

L'amélioration de l'accès aux services de santé est une priorité constante pour les Canadiens. Plus spécialement, la réduction des temps d'attente pour les services est une question dominante en matière de politiques. Partout au pays, les gouvernements mettent en place des stratégies pour réduire les temps d'attente, en particulier pour les services spécialisés. Bien que l'information sur les temps d'attente pour certaines interventions soit de plus en plus disponible, il existe peu d'information, au Canada, sur les différences d'utilisation des services ou des temps d'attente entre les personnes ayant un problème de santé et la population en général. Les données provenant de l'Enquête sur l'accès aux services de santé (2001-2005) ont été employées pour comparer les temps d'attente pour les services spécialisés entre les adultes ayant un problème de santé et les personnes en meilleure santé. Les services en question comprenaient les consultations auprès des spécialistes pour une nouvelle maladie ou un nouvel état de santé, les chirurgies non urgentes et les tests de diagnostic. Les estimations à l'échelle nationale révèlent que les adultes ayant un problème de santé sont plus susceptibles de déclarer volontairement qu'ils ont eu besoin de recourir à des services spécialisés. Cependant, la médiane des temps d'attente pour ces services était comparable à celle qu'on observe pour les adultes en meilleure santé.

IMPROVING ACCESS TO HEALTHCARE HAS BEEN A CONSISTENT PRIORITY FOR Canadians. In particular, reducing patient waiting times for health services has been a prominent policy issue. In 2004, Canada's First Ministers listed timely access to high-quality care at the top of their collective agenda, committing to achieve "meaningful reductions in wait times in priority areas such as cancer, heart, diagnostic imaging, joint replacements and sight restoration" (Ontario Canadian Intergovernmental Conference Secretariat 2005). Across the country, governments are using a range of strategies to improve access to care and reduce patient waiting times.

However, limited information exists on the waiting experiences of Canadians with health problems, such as those with chronic care needs, who are often hospitalized and are heavy users of the healthcare system. Data from two Commonwealth Fund surveys raised questions about whether Canadians with health problems tended to have different waits for a doctor's appointment than their healthier counterparts. In 2005, 36% of Canadian adults with health problems reported waiting six days or longer for a doctor's appointment, while in 2004, 26% (regardless of health status) reported waiting that long (Shoen et al. 2004, 2005; Commonwealth Fund 2004). Although the questions and survey approach were similar, the surveys were conducted in two different time frames and had relatively small sample sizes (1,410 Canadians were part of the sample in 2004, and 751 in 2005). Other Canadian data, such as wait times reported for cardiac surgery in Ontario, suggest that sicker patients have shorter waits for surgery (Cardiac Care Network of Ontario 2008). This study analyzes data from a population-based Canadian survey, with a larger sample size than that of the Commonwealth Fund, to determine whether Canadians with health problems have longer or shorter waits for specialized services. A better understanding of the profile of patients who wait longer for care may allow policy makers to design more targeted wait time reduction initiatives.

In 2001, Statistics Canada first released results from the Health Services Access Survey (HSAS), designed to capture information on patients' experiences accessing healthcare, including their experiences related to waiting for specialized services (Sanmartin et al. 2002). Using 2001–2005 results from the survey, this study assesses whether waiting experiences and waiting times for specialized services – including specialist visits for a new illness or condition, non-emergency surgery and diagnostic tests (MRI, CT or angiography) – differ between adults with health problems and healthier adults.

Methods

Data

The HSAS is a population-based, cross-sectional survey with data available for 2001, 2003 and 2005 (Sanmartin et al. 2002, 2004; Statistics Canada 2006). The survey was incorporated into the Canadian Community Health Survey (CCHS) in 2005 (Statistics Canada 2006). Respondents to the HSAS are a subsample of the CCHS, which covers Canadians who are 15 years of age or older and living in private dwellings in the 10 provinces. The data collected in the HSAS are obtained through a complex sample design involving stratification, clustering and multistage sampling. Detailed information on the sampling strategy has been discussed elsewhere (Sanmartin et al. 2002, 2004; Statistics Canada 2006). The survey includes self-reported information on service needs, difficulties accessing services and wait times for services. Key definitions appear in Table 1.

TABLE 1. Key definitions of specialized services

Specialized service	Definition	Wait time measured
Specialist visit	Visit with a medical specialist to obtain a diagnosis for a new illness or condition; does not include specialist visits for ongoing care for a previously diagnosed condition	Time elapsed between point at which individuals and their doctor decided that they should see a specialist and the day of the visit
Non-emergency surgery	Booked or planned surgery provided on an outpatient or inpatient basis; does not refer to surgery provided through an admission to the hospital emergency room as a result of, e.g., an accident or life-threatening situation	Time elapsed between point at which individuals and their surgeon decided to go ahead with the surgery and the day of surgery
Diagnostic test	MRI, CT scan or angiography requested by a physician to determine or confirm a diagnosis; does not include X-rays, blood tests, etc.	Time elapsed between point at which individuals and their doctor decided to go ahead with the test and the day of the test

Source: Statistics Canada, Health Statistics Division. 2006. *Access to Health Care Services in Canada: January to December 2005*. Ottawa: Minister of Industry.

Study population

The study included respondents who were 18 years of age or older. Using available information from the HSAS, “adults with health problems” were defined using criteria similar to those used by the Commonwealth Fund survey (Shoen et al. 2004, 2005). Table 2 describes the definition applied in this study and its comparison with that used by the Commonwealth Fund. For this study, “healthier adults” were defined as those who did not meet any of the criteria established by the study definition. In 2005 the total sample of healthier adults was 24,121, while the sample for adults with health problems was 9,978.

Analysis

Weighted distributions and frequencies were used to describe baseline characteristics of the study population and assess wait times for specialist visits for a new illness or condition, non-emergency surgery and selected diagnostic tests. Data from the HSAS were weighted to account for the sampling and non-response in the survey and to reflect the demographics of the Canadian population. Wait times were compiled only for those who received a specialized health service within the preceding 12 months. Records with item non-responses were excluded from all calculations. To account properly for the complex survey design, variance estimates and 95% confidence intervals for all estimates were calculated using bootstrap survey weights. Median waiting

times were age- and sex-adjusted using a direct method of standardization based on the July 1, 2001 Canadian population (excluding the territories). Statistical analyses were computed using SAS statistical software (version 9.1 SAS Institute Inc.).

TABLE 2. Definition of adults with health problems

Study definition	Commonwealth Fund definition [†]
Poor or fair self-rated health	Poor or fair self-rated health
Had at least one chronic illness and contacted a healthcare provider* 10 times or more in the past 12 months	Had a serious or chronic illness, injury or disability requiring intensive medical care in the past two years
Was an overnight hospital patient for four or more days in the past 12 months**	Had major surgery or was hospitalized for something other than a normal pregnancy in the past two years

* "Healthcare provider" includes family physician/general practitioner, eye specialist, dentist/orthodontist, chiropractor and/or other medical doctor. The 10 visits could be distributed among any of the providers listed.

** The criterion for a heavy user of medical care (four or more overnight hospital days) was based on similar definitions used by investigators in the following study: Statistics Canada. 1999. "Health Care Services – Recent Trends." *Health Reports* 11(3): 91–112; catalogue no. 82-003-XPB. † Shoen et al. 2005.

Results

Baseline characteristics

In 2005, adults with health problems represented 26.6% of the study population, or approximately 6.5 million Canadians 18 years of age or older. This percentage is greater than the proportion in 2003, but similar to that reported in 2001. Compared to healthier adults, there was a greater proportion of females among adults with health problems. In 2005, 58.1% of adults with health problems and 48.3% of healthier adults were female. Furthermore, there was a greater proportion of older adults among those with health problems. The same year, those aged 65 years or older represented 25.2% of adults with health problems and 12.8% of healthier adults.

Access to specialized services

Adults with health problems were more likely to report that they required specialized health services than their healthier counterparts. In 2005, 23.1% of adults with health problems required a specialist visit for a new illness or condition, compared with 8.1% of healthier adults (Figure 1). Adults with health problems were also more likely to require diagnostic tests (21.7% versus 5.0%) and non-emergency surgery (13.8% versus 4.4%). Similar results were found in 2001 and 2003 (data not shown).

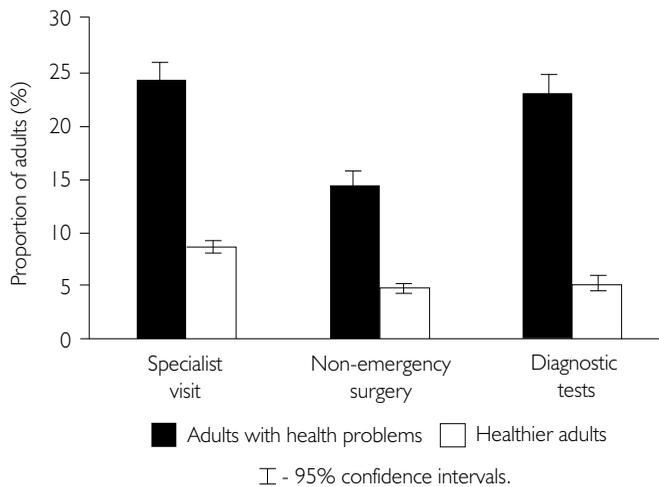
Although adults with health problems were more likely to require specialized services, the proportion of those accessing these services was similar to that of their healthier counterparts. For those both with and without health problems, nine out of 10 who said they required specialized care went on to access the service.

Some adults who received specialized health services reported difficulties in obtaining access due to a variety of reasons, including problems getting an appointment or waiting too long for an appointment. Both adults with health problems and their healthier counterparts were more likely to report difficulties in accessing a specialist visit than in accessing the other categories of specialized services. There was no significant difference between the two groups in the proportion reporting difficulties accessing specialized services.

Median waiting times for specialized services

Despite the variation in the proportion of adults with health problems and healthier adults who required specialized services, the median waiting time for such care was similar between the two groups. In 2005, the age–sex standardized median waiting time for specialist visits and non-emergency surgery was approximately one month for both groups. Adjusted waiting times for diagnostic tests were shorter, with adults in both groups waiting approximately three weeks in 2005 (Figure 2). Between 2001 and 2005, the median waiting time for most specialized services remained fairly consistent for both adult groups.

FIGURE 1. Proportion of adults requiring specialized services, Canada, 2005

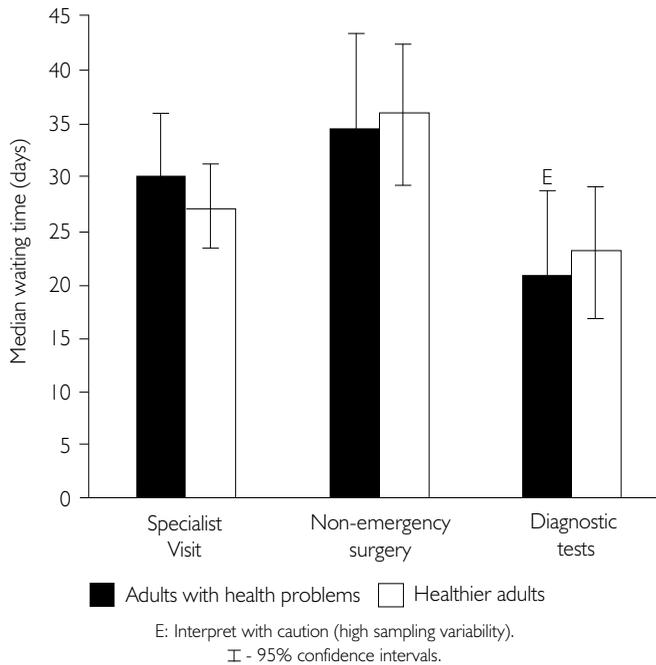


Limitations

Owing to the cross-sectional design of the HSAS, it was not possible to establish a time relationship between health status and median wait times for specialized services. Specifically, the nature of the survey did not permit identification and tracking

of a group of adults with health problems who subsequently required specialized care, establishing service use and determining waiting periods for the cohort over time. Results of the HSAS are based on self-reported information that have not been clinically validated and may be subject to recall bias (Sanmartin et al. 2002, 2004; Statistics Canada 2006). To reduce potential recall bias, survey questions repeatedly referred to services used in the past 12 months. Waiting time estimates were retrospective and included only those who completed their waiting periods and received care. Provincial-level wait time estimates were not reported for each group because sample sizes were not large enough to generate reliable estimates. The data do not reflect the waiting times of those still waiting at the time of the survey. The results are not generalizable to population groups not represented by the survey, including residents of the three territories, those living on Indian reserves or Crown lands, residents of institutions, full-time members of the Canadian Forces and residents of certain remote regions.

FIGURE 2. Age- and sex-standardized median waiting times for specialized services, Canada, 2005



Conclusions

Although findings from the Commonwealth Fund surveys suggest that Canadian adults with health problems may be more likely to wait longer for some health services than healthier adults, findings from this study with a nationally representative sample indicate that this relationship may not hold for specialized services. Although

Canadian adults with health problems may be more likely to require specialized health services, there were no substantial differences between the two groups regarding their access to care, such as their reported difficulties in obtaining access to specialized services. Furthermore, median waiting times for these services were similar in both adult groups and over time.

While we need to be cautious regarding the limitations of self-reported data, the large-sample HSAS data represent the most comprehensive information available on a pan-Canadian basis regarding access to a full range of non-emergency surgery, specialist visits and diagnostic tests. This study sheds light on the waiting experiences for specialized health services between adults with health problems and their healthier counterparts. Future research using longitudinal data is needed to clarify the relationship between health status and wait times for specialized services in Canada.

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From Big to Small: A Process for Developing Policy-Relevant Research Summaries

De « volumineux » à « concis » : procédé
pour produire des résumés de recherche
pertinents aux responsables de politiques



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Abstract

Government departments and not-for-profit agencies expend significant resources commissioning and conducting research, only to find their resulting lengthy reports shelved and unused. In this case study, we describe a project that developed short, policy-relevant research summaries of topics prioritized by the Ontario Women's Health Council, an advisory body to the province's Minister of Health and Long-Term Care. These products were created based on an understanding of policy makers' needs and work contexts and were designed to help users find, understand and utilize research evidence to inform their clinical, programmatic and policy decision-making.

Résumé

Les ministères et les organismes sans but lucratif affectent une quantité appréciable de ressources dans la commande et l'exécution de recherches, mais les longs rapports qui en découlent sont très souvent oubliés sur les tablettes et inutilisés. Nous décrivons un projet visant à produire de courts résumés de recherche pertinents aux politiques et portant sur des sujets jugés prioritaires par le Conseil ontarien des services de santé pour les femmes, un organisme du ministère de la Santé et des Soins de longue durée de l'Ontario. Ces résumés ont été créés en fonction des besoins des responsables de politiques et de leur contexte de travail. Les résumés sont conçus pour aider à trouver, à comprendre et à utiliser les données de recherche afin d'éclairer les décisions cliniques, politiques ou touchant aux programmes.

GOVERNMENT AND NOT-FOR-PROFIT AGENCIES ROUTINELY COMMISSION OR conduct research projects to develop new knowledge to guide decision-making in a range of areas specific to their constituencies and mandates. The products of these initiatives include documents produced in-house, as well as research and evaluation reports contracted to consultants and academic researchers. The resulting repositories of static information are often largely inaccessible – both to those within the organization, who may not know of the reports or be able to find them, and especially to those in the broader field, who could benefit from the knowledge languishing on shelves. For those working in healthcare and health policy, the challenges in accessing, synthesizing and using evidence are well known (Lavis et al. 2003): published journal articles, reviews, government and statistical reports and practice guidelines that highlight the latest and best research for specific types of health-related decisions remain largely unusable by policy audiences and contribute little to informing practice and policy.

The goal of getting research into practice requires, first, understanding the needs and work contexts of end users, that is, those who will ultimately use the synthesized

research knowledge for decision-making; and then, developing knowledge products and tools to help users find, understand and utilize evidence in their daily decisions. A commitment to applying user-based design as proposed by knowledge translation (KT) scholars and practitioners (e.g., Jacobson et al. 2003) is required to advance this field and tap into the currently inaccessible and unused knowledge resident in many organizational settings.

The Ontario Women's Health Council (OWHC) was an advisory body to the Ontario Ministry of Health and Long-Term Care (MOHLTC) until its mandate was completed in spring 2007. For a number of years, the OWHC Secretariat, staffed by MOHLTC policy personnel, created and solicited new knowledge on topics in women's health directly relevant to clinical and policy decision-makers in Ontario and beyond. As a result, OWHC had over 50 research, project and program reports covering a broad range of topics. One of the final tasks of the OWHC was to identify a process to make the findings of these reports, not all of which were published, more available and accessible to a broader audience of decision-makers.

The objective of our project was to apply emerging knowledge translation strategies (Graham et al. 2006; Dobbins et al. 2007; Grol and Grimshaw 1999; Lavis et al. 2003) to develop policy-oriented research summaries (Lomas 2005) of high-priority content created by or for the OWHC.

The OWHC-KT Project

The overall process for developing and launching the research summaries included the steps and stages described below and presented in Figure 1.

Step 1: Identify the topics and set priorities

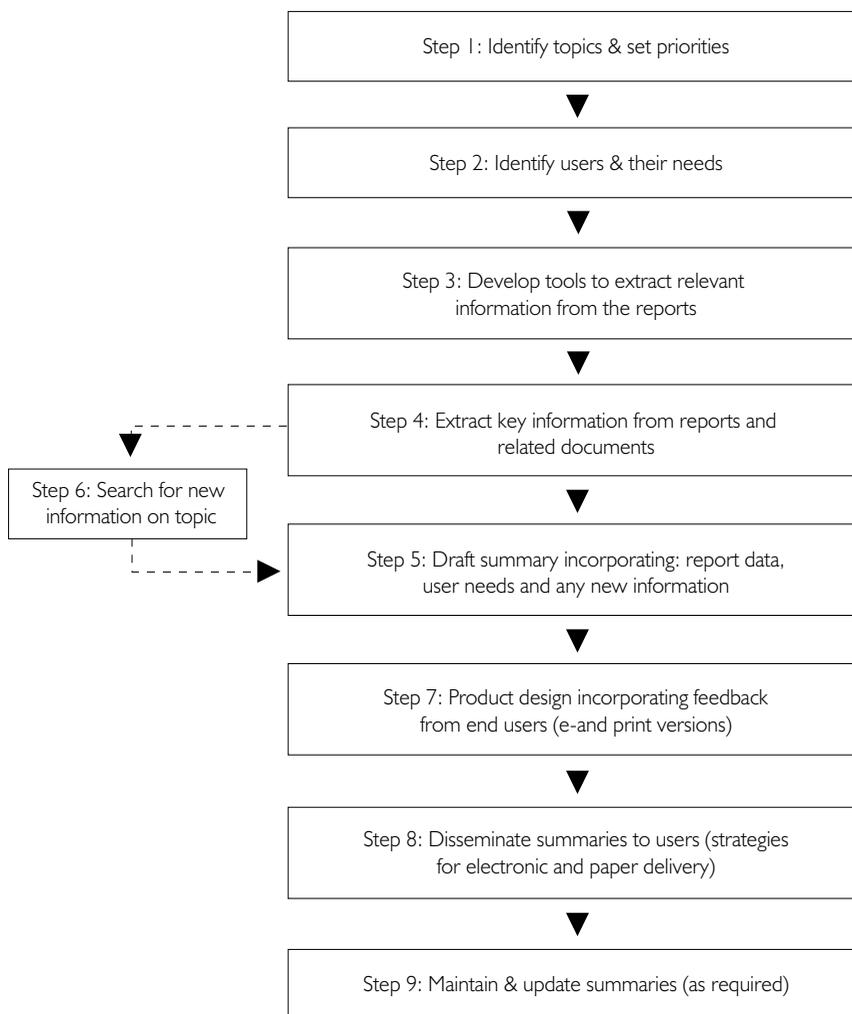
Because it was not feasible to summarize all topics¹ and the more than 50 related reports, a system of topic identification and priority setting was implemented to determine those that would be included in the knowledge synthesis and product development. A table of topics and related documentation was prepared, along with a process for surveying current and former Council members, including a data collection tool¹ that asked members to rate the importance of each topic. The survey was completed by 79% of members, and the results were collated to determine the main topics for knowledge synthesis and product development.

Of the topics selected, two were deemed to be process-related (i.e., they provided valuable "lessons learned" regarding implementation of specific activities of the Council), while seven provided specific research findings of interest to policy audiences.

Step 2: Identify the end users and their needs

The target group was determined by the OWHC to be policy personnel (at the manager and analyst levels) in the MOHLTC and related provincial ministries. Their needs for research syntheses were determined using a triangulated approach, including (1) a review of KT literature specific to evidence-informed decision-making by policy actors (e.g., Lomas 2005; Innvaer et al. 2002; Lavis et al. 2003; Dobbins et al. 2007), (2) consultation with experts in this area and (3) most importantly, informal discussions, formal interviews and focus groups with representatives from the user groups.

FIGURE 1. Overview of the OWHC-KT process



FOCUS GROUPS – CONTENT TOPICS

OWHC secretariat staff identified key users in the Ministry of Health and Long-Term Care and the Ministry of Children and Youth Services, and project staff organized focus groups with them. The sessions covered five main areas: research use, type of content required, value-added aspects to incorporate in the summaries, length and format of the summaries, and dissemination strategies.² In total, seven policy analysts and managers from various branches within these ministries attended one or more of three focus groups – two initial groups held to determine user needs regarding these topics, and one to solicit feedback on draft products.

INTERVIEWS – PROCESS LEARNINGS

For the two identified process-related topics, key informants (two per topic) with particular knowledge about the issues involved were interviewed and their insights incorporated in the summaries (see below). All interview and focus group participants served as our product testing group.

Step 3: Develop tools

Developing the draft summaries was a multi-stage process including data extraction, gathering more recent, “value-added” information on the topics, producing an initial draft, getting end-user feedback in a focus group and finalizing the summaries for production.

Step 4: Extract the key information

Two stages of data extraction were completed. First, we reviewed all reports specific to a content area and created a new document summarizing the main findings and the authors’ recommendations (these were usually found in the Executive Summary and/or Conclusion sections; if not, we reviewed all report sections). For the process-related topics, the key informant interview transcripts were reviewed and key points extracted and summarized.

Step 5: Prepare the draft summary

The second stage of data extraction involved distilling the information collected in Step 4 down to key, implementable and policy-oriented messages. Useful tips on how to formulate these messages and the draft summaries are outlined in Figure 2.

Step 6: Search for “value-added” information

Depending on the topic and the time elapsed since project completion, a section highlighting new information was sometimes required. This situation typically arose when more recent research had been done, or when related policy or program decisions on the topic had been made in other jurisdictions. Methods to assess and meet this need included conducting comprehensive literature searches, asking research or policy experts in the field (including the original authors of the research reports) and consulting recent policy decisions.

FIGURE 2. Structuring the research summary content

- Use lay rather than technical language; avoid jargon and acronyms.
- Put as much information as possible in bulleted points rather than narrative paragraphs.
- When possible, avoid reporting statistics (e.g., *p*-values, *t*-test results, etc.) that may be meaningless to those without a research background; rather, use percentages or simple descriptive statistics such as means, standard deviations and odds ratios (framed in clear language – i.e., “those in the intervention group were almost twice as likely as those in the comparison group to...”).
- When preparing more than one summary, keep the look and feel consistent.
- Include a section on “how to cite” the document, and identify the summary authors.
- Include the author of the original report and the author’s contact information. (Prior to doing this, the report author should be given the opportunity to review the material and formally grant permission to include his or her name and contact information.)
- Include information on how to access the full report(s) and any other materials that were used or cited to prepare the summary.

Six of the nine summaries included a section with additional information (the two “process” summaries did not, nor did the most recently completed research report). Additional information included citations of specific new research studies, recent guidelines from other organizations, experiences with implementing a policy in other jurisdictions and discussion of existing controversies that could influence decision-making.

FIGURE 3. Maintaining and updating research summaries

- Determine the time frame for reviewing topics for update. This can be yearly, although the intensity of work in the topic area may dictate more or less frequent reviews.
- Decide whether updates will consist of augmentation of the existing summary with new information only (e.g., “add-on”), significant revision to several sections (e.g., “update”) or complete overhaul of the topic – essentially, starting from scratch. The decision will depend on the topic, but having an *a priori* protocol outlining which factors lead to which decision is helpful. Such factors include:
 - the amount of new information;
 - the type of new information (i.e., does it support or contradict the previous conclusions?);
 - new controversies or other contextual factors that may require a different treatment of the issue.
- Determine who will make decisions regarding whether updating is required and who will conduct the topic reviews. Ideally, some of those who were on the original review and summary team will be part of the updating process.
- Develop a protocol for how to search for new information (sources, tools, etc.) and how much time will be spent doing this.
- Decide what will happen in cases where searches for new information yield nothing of note (i.e., nothing that changes the conclusions of the original summary). For example, will the same summary be re-released with a note indicating when it was last checked for new relevant information?

Step 7: Incorporate user feedback into the product design

Initial feedback was sought by sending an electronic version of the draft summary to the product testing group early in the development cycle. Next, a focus group was held with four participants who had attended one of the two initial groups; the purpose was to request specific feedback on the appearance, structure/format and content of the summaries.

Step 8: Disseminate the final product

The final summaries were produced by a graphic designer using professional graphics software. Print and electronic versions (in portable document format) were prepared with careful attention to such details as length, layout, colour-matching with the OWHC logo and so on.

FIGURE 4. The policy perspective

by Nancy Lewis, Manager, and Sarah Caldwell, Analyst, MOHLTC

Overall, the process of creating the documents was positive and informative. It illustrated how KT can be done effectively and products created that can be disseminated and used by others. The process illustrated an effective way of carrying out a prioritization exercise and provided an opportunity to take time to reflect on, and capture, lessons learned. It was also impressive to see how coherent and digestible products could be generated out of a mass of completed research projects, many of which had often overwhelming methodological detail and, within a body of reports on a content area, sometimes conflicting results and/or interpretations.

A few valuable lessons were learned along the way. For example, a project of this magnitude needs to be well planned and requires a commitment of financial and human resources from the project team and the agency funding the project. In this case, resource constraints and lack of sustainability (by virtue of the OWHC's termination) meant that an ambitious interactive Web platform originally proposed by the project team had to be abandoned. It also proved impossible in some cases to reconstruct the (undocumented) path from research into policy with the resources available, with the result that the documents were often silent on policy implications, even though this was originally intended to be one of the key "value-added" results of the undertaking. In addition, more time should have been devoted at the front end to planning for the later parts of the process – analysis, "thinking through", garnering feedback – in order to strengthen these elements of the project. Finally, the unique circumstances of the OWHC's situation meant that products could not be sustained and revised in the long term, lessening their continued utility.

Nevertheless, the process of creating these summaries was valuable, and should be recommended to decision-makers who wish to create policy-relevant summaries for various audiences.

Results of the OWHC-KT Project

In total, nine research summaries were prepared: seven specific to content areas and two that described "lessons learned" about process issues related to policy implementation. In addition, the OWHC requested that a step-by-step handbook be developed describing this process.³

Several methods were used to disseminate the summaries, which were printed in colour and were two to four pages long. Following the initial release of the summaries at a farewell reception for the OWHC, electronic versions were posted on the Council's website (www.womenshealthcouncil.on.ca/English/Knowledge-Translation-Tools.html). They were also sent to an identified end-user group including CEOs and planning directors of Local Health Integration Networks and Community Health Centres.

Given the nature of the project as the OWHC's "swan song," no specific summary maintenance plan was developed (Step 9 in Figure 1). However, in general, decisions regarding maintaining and updating research summaries can have significant resource implications and should be considered as early as possible in the development process. If

... decisions regarding maintaining and updating research summaries can have significant resource implications and should be considered as early as possible in the development process.

the project intends to maintain and update summaries, the issues outlined in Figure 3 should be considered.

Similarly, no specific evaluation activities were planned to assess the impact of the summaries. However, informal feedback suggests that those who received them found the summaries

visually appealing and useful in their content, size and format. Future projects of this type would provide valuable information by building in an evaluation and follow-up component. Figure 4 offers a brief critique of the project process from the perspective of two end users.

Summary

Pineault et al. (2006) have proposed the concept of a "research collective" – a group comprising decision-makers and researchers actively involved in creating syntheses as research is still underway or just completed. While such an approach provides an ideal context in which to create useable summaries, or at least to engage both sides in meaningful and ongoing dialogue (Pineault et al. 2007; Innvaer et al. 2002), it is not always feasible nor possible in cases where the research is already complete. In these cases, the process described in Figure 1 may prove useful.

Several features of this project were unique in the context of existing models of knowledge translation (e.g., Graham et al. 2006). First, the project team was charged with summarizing and synthesizing multiple studies, conducted by multiple research teams, which were related only in that the OWHC funded them. The synthesis work itself was what Graham et al. (2006) termed "third-generation knowledge" or synthesized products and tools. Second, the project team included the same policy personnel who were (a) involved in funding the research and (b) representative of the end-user group (provincial bureaucrats in health and social services portfolios). Third, and related to the two points above, the research being summarized was highly user-interactive (in the KT sense) because, being funded by OWHC, it reflected direct user involvement in deciding the initial research priorities. Finally, the process actively pro-

vided opportunities for researchers and end users to work collaboratively to determine the content and style of the final products (Innvaer et al. 2002).

We therefore propose that this case study exemplifies a blended user-interaction approach for research dissemination that fits well within the “knowledge creation” core of the framework proposed by Graham et al. (2006). As such, this type of activity is one part of a larger KT process that includes a number of steps in an “action cycle”: problem identification; knowledge selection and adaptation to the local context; assessment of barriers and tailoring of specific interventions to be implemented in that context; monitoring and evaluation; and sustainability.

This project therefore highlights techniques that might be useful to address a very specific aspect of the full spectrum of knowledge-to-action activities that can occur between researchers and decision-makers (Lomas 2005). We suggest, based on our experiences with this process, that the summaries themselves might best be viewed as

an adjunctive strategy to be accompanied by an interactive KT plan, including, for example, ongoing consultations, education sessions or transmission to end users by a knowledge broker who could review, translate and discuss key findings and work to identify strategies for local implementation

... the simple act of bringing the research team together with potential end users increased awareness of the evidence ...

(Lavis et al. 2003). A key result of the consultation phases of our project was that the simple act of bringing the research team together with potential end users increased awareness of the evidence and, perhaps, the probability that the summaries would be consulted if these users were faced with a related decision or situation. The extent to which these same summaries would be viewed as useful by other types of decision-makers – within the policy context (e.g., politicians) and beyond (e.g., healthcare providers, patients) – is not known and requires further research.

ACKNOWLEDGEMENTS

This project was funded by the Ontario Women’s Health Council, Ontario Ministry of Health and Long-Term Care. We thank Nancy Sicchia for her graphic design work.

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NOTES

¹ A list of topics and the data collection tool are available from the first author.

² The interview guide and summary of focus group results are available from the first author.

³ The handbook is available from the first author.

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Coping with Structural Change: How a Regional Health Authority Is Helping Local Public Health Managers Take on New Responsibilities

S'adapter à un changement structurel : une région régionale des services de santé aide les gestionnaires de la santé publique locaux à assumer de nouvelles responsabilités

by CANADIAN HEALTH SERVICES RESEARCH FOUNDATION

Abstract

The Montérégie Health and Social Services Agency in Quebec takes a population-centred approach to service delivery. For the newly appointed public health managers in particular, the new structure has meant gaining competencies in new areas, from socio-demographic analysis to partnership development. This innovative initiative was recently featured in *Promising Practices in Research Use*, a series produced by the Canadian Health Services Research Foundation highlighting organizations that have invested their time, energy and resources to improve their ability to use research in the delivery of health services. Tell the Foundation your own stories and visit the *Promising Practices* inventory at http://www.chsrf.ca/promising/index_e.php.

Résumé

L'Agence de la santé et des services sociaux de la Montérégie adopte une approche de prestation de services axée sur la population. La nouvelle structure a permis notamment aux gestionnaires de la santé publique nouvellement affectés dans les centres d'acquérir des aptitudes dans de nouveaux secteurs, allant de l'analyse sociodémographique au développement de partenariats. Cette initiative novatrice a fait l'objet d'un article dans *Pratiques prometteuses dans l'utilisation de la recherche*, une série mensuelle produite par la Fondation canadienne de la recherche sur les services de santé, qui présente des organismes ayant investi temps, argent et ressources afin d'améliorer leurs capacités à utiliser la recherche dans la prestation des services de santé. Vous pouvez nous suggérer des idées d'article et consulter la liste des numéros de *Pratiques prometteuses dans l'utilisation de la recherche* au http://www.chsrf.ca/pratiques/index_f.php.

CANADA'S HEALTHCARE WORKPLACE IS CHANGING, AND EMPLOYEES NEED new skills to assume fresh responsibilities. Nowhere is this more evident than in Quebec, where community health centres, residential and long-term care centres, hospitals and related institutions have come together into full-service local health and social services centres. It's a population-centred approach to service delivery and it requires employees to have competencies in new areas, from socio-demographic analysis to partnership development.

For public health managers in particular, the new structure brings both opportunities and challenges. "On one hand, we're excited about the population-centred approach, which is the orientation of public health," says Jocelyne Sauvé, director of public health at the Montérégie Health and Social Services Agency, and a fellow in the Canadian Health Services Research Foundation's Executive Training for Research Application (EXTRA) program. On the other hand, Dr. Sauvé worries about a loss of visibility for public health on decision-makers' radar. "Before the amalgamation, public health accounted for 20 percent or more of the budget for most centres," says Dr. Sauvé. "Now, it accounts for less than five percent of the combined budget if a hospital is part of the new organization, and less than 10 percent if there's no hospital involved."

The amalgamated structure has also meant greater responsibilities for the centres' newly appointed public health managers. Their role is to carve out a niche for public health and, at the same time, integrate it with the other services making up each centre's service continuum. They are responsible for managing the local public health action plan and serve as resource persons for their centres in regard to the population-centred approach.

The goal of Dr. Sauvé's EXTRA project was to help public health managers deal

with these additional responsibilities by building their skills in areas that would help them navigate in the new organizational context. Her focus on skills and competencies was a result of an initial literature review on how public health services fared when restructuring amalgamated them under the same governance structure as treatment services.

“Some studies have found that when preventive services ‘compete’ with treatment services in the same organizational structure, the treatment side ‘wins,’” says Dr. Sauvé. “However, other research has found that the governance structures are less important than the qualities and skills of the public health managers involved.”

The first step was to identify the key competencies required by local public health managers. A literature review came up with many technical/professional skills and behavioural competencies, and a group of public health managers assembled and prioritized a list of 32. These were further validated and cross-referenced against such factors as the relative importance of each skill to meeting managers’ responsibilities. The result was a ranked list of 14 skills and competencies.

Meanwhile, another stream of research in Dr. Sauvé’s literature review focused on how best to transfer knowledge and develop priority competencies. This research informed the development of a learning plan tailored to the needs of the managers and organizations involved. “We pulled a number of things together,” says Dr. Sauvé, “including the varied professional backgrounds of the managers, the available opportunities and advice from the literature on which learning approaches, such as seminars or face-to-face interaction, favoured the acquisition of which skills.”

A collective learning exercise was then launched, focusing on four competencies: effective public health interventions; population-centred approaches and responsibilities; population health and well-being surveillance; and strategic influence. Positive movement was recorded in all these areas, and significant changes were noted in a number of them. For example, participants rated their skills significantly higher after the learning exercise in all four target competencies. In addition, they felt significantly better equipped to fulfill two of their specific responsibilities.

The approach is now being used at the provincial level. “Though we have some areas to work on, we are pleased that the results have been so positive,” says Dr. Sauvé. “I think it comes down to the time we took to find and consider the evidence from the literature, and use it in a rigorous way to develop with managers and their organizations a learning approach and focus that met their needs.”

Emergency Department and Walk-in Clinic Use in Models of Primary Care Practice with Different After-Hours Accessibility in Ontario

Utilisation des services d'urgence et des cliniques
sans rendez-vous dans des modèles de soins
de santé primaires comportant différents
services d'accessibilité après les heures normales,
en Ontario



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Abstract

Introduction: New models of primary healthcare delivery recently implemented in Ontario are designed to improve after-hours accessibility. This study examined whether the six-month prevalence of emergency department and walk-in clinic use differed among patients of eight Family Health Network (FHN), 16 Family Health Group (FHG) and 12 fee-for-service (FFS) physicians in one city.

Methods: Patients over one year of age who had visited their family doctor in the previous 12 months (n=9,373) were randomly selected from computerized records. A mailed survey asked about urgent health problems in the previous six months and use of health services for those problems. A generalized estimating equation approach was used to compare the proportions of patients using the emergency department and walk-in clinic in the FHN versus other practice types, adjusting for clustering of patients within practices. Multiple imputation was used to impute data for non-respondents and missing items on the surveys.

Results: The response rate was 62.3% (5,884/9,373). Six-month prevalence of emergency department use was 11.4% (199/1,753) among the FHN practices, 15.7% (347/2,236) among the FHG practices (odds ratio [OR] = 1.47; 95% confidence interval [CI] = 1.21–1.80) and 14.3% (252/1,779) among the FFS practices (OR=1.33; 95% CI=1.12–1.59). Six-month prevalence of walk-in clinic use was 1.7% (30/1,723) among the FHN practices versus 1.9% (41/2,236) in the FHG practices (OR=1.07; 95% CI=0.68–1.68) and 3.4% (59/1,779) among the FFS practices (OR=2.08; 95% CI=1.41–3.08). The statistical significance of results was unchanged using multiple imputation.

Conclusions: Patients' use of the emergency department and walk-in clinics differs across primary care practice models with different after-hours accessibility arrangements and incentives.

Résumé

Introduction : Les nouveaux modèles de prestation de soins de santé primaires établis récemment en Ontario ont été conçus pour améliorer l'accessibilité après les heures normales de travail. Cette étude visait à savoir s'il y a des différences dans la prévalence, sur une période de six mois, de l'utilisation des services d'urgence et des cliniques sans rendez-vous, et ce, entre les patients de huit réseaux Santé familiale (RSF), de 16 groupes Santé familiale (GSF) et de 12 médecins fonctionnant selon le paiement à l'acte, dans une ville.

Méthodologie : Des patients âgés d'un an ou plus qui ont visité leur médecin de famille au cours des 12 derniers mois (n=9 373) ont été choisis de façon aléatoire à l'aide des dossiers informatisés. Ils ont reçu par la poste un sondage les questionnant sur leurs problèmes urgents de santé, ainsi que sur l'utilisation des services de santé à cet égard, au cours des six derniers mois. La méthode de l'équation d'estimation généralisée a été employée pour comparer la proportion de patients utilisant les services d'urgence et les cliniques sans rendez-vous dans les RSF, par rapport aux autres types de pratique, en ajustant la répartition en grappes au sein des pratiques. L'imputation multiple a servi à extrapoler les données des non-répondants et des items laissés en blanc dans le sondage.

Résultats : Le taux de réponse était de 62,3 % (5 884/9 373). La prévalence, sur une

période de six mois, de l'utilisation des services d'urgence était de 11,4 % (199/1 753) au sein des RSF, de 15,7 % (347/2 236) au sein des GSF (rapport de cotes [RC] = 1,47; 95 % intervalle de confiance [IC] = 1,21–1,80) et de 14,3 % (252/1 779) pour la pratique du paiement à l'acte (RC=1,33; 95 % IC=1,12–1,59). La prévalence, sur une période de six mois, de l'utilisation des cliniques sans rendez-vous était de 1,7 % (30/1 723) au sein des RSF par rapport à 1,9 % (41/2 236) au sein des GSF (RC=1,07; 95 % IC=0,68–1,68) et 3,4 % (59/1 779) pour la pratique du paiement à l'acte (RC=2,08; 95 % IC=1,41–3,08). La signification statistique des résultats demeurait la même après l'application de l'imputation multiple.

Conclusions : Il existe des différences d'utilisation des services d'urgence et des cliniques sans rendez-vous au sein des modèles de soins de santé primaires organisés selon diverses mesures incitatives ou d'accessibilité après les heures normales.

P RIMARY CARE IN ONTARIO, AND ELSEWHERE IN CANADA, HAS BEEN UNDERgoing funding and organizational changes since the late 1990s. While provision of after-hours services to patients has not been formally required, a full spectrum of after-hours arrangements exists. Family Health Networks (FHNs) and Family Health Groups (FHGs) are among the new models introduced in Ontario since 2001. In these models, physicians are encouraged to form groups or networks but continue to practise independently, while sharing after-hours clinic and on-call responsibilities to a defined patient group. There is evidence from studies in the United States that improved continuity of primary care reduces emergency department use (Christakis et al. 2001; Gill et al. 2000) and hospitalization (Gill and Mainous 1998; Mainour and Gill 1998). Between 15% and 25% of Canadians use emergency department services at least once in a year (Brown and Goel 1994; Chan et al. 2001), and up to 30% of these visits are for non-urgent problems (Burnett and Grover 1996; Vertesi 2004). One Canadian study reported that fewer than half of patients with an urgent health problem reported using out-of-hours services of their family practice, and 20% used the practice's on-call service (Grad et al. 1998).

Difficulty (perceived or actual) in accessing family physicians for immediate care both during and out of regular hours is a major cause of emergency department use (Boushy and Dubinsky 1999; Burnett and Grover 1996). Emergency department costs for minor acute illnesses are much higher than in primary care settings (Campbell et al. 2005), and use of the emergency department may result in lack of continuity of care, duplication of tests and procedures, absence of proper follow-up and poor communication with the family physician (Dunnion and Kelly 2005; Jansen and Grant 2003).

In the Canadian healthcare setting, walk-in clinics provide primary care services to

patients without an appointment or prior relationship. Approximately one-quarter of patients with a family physician in Canada use a walk-in clinic in a six-month period (Bell and Szafran 1992). Patients often use these services during the business hours of their regular physician out of convenience, and frequently do not attempt to contact their family physician (Miller et al. 1989; Szafran and Bell 2000). Although some walk-in clinics provide care for a population of regular patients (Barnsley et al. 2002), they have been described as providing discontinuous care (Belle Brown et al. 2002), neglecting preventive and mental health (Barnsley et al. 2002) and increasing duplication of services or repeat visits to the family physician for the same episode (Bell and Szafran 1992; Campbell et al. 2005; Jones 2000).

Description of primary care in Ontario

In the province of Ontario, the FHN initiative began in March 2001, and in 2003 the FHG model was introduced. FHNs are required to roster their patients through a formal enrolment process and are paid by a blended funding model of capitation for a basket of services with quota-based incentives for preventive services. Health services outside the basket are reimbursed through a combination of fee-for-service and premium payments for prenatal and intrapartum care, specific mental health conditions, hospital care, palliative and home care and office procedures. FHGs are fee-for-service funded, with additional bonuses for achieving targets for specific services. There is no limit to fee-for-service billings, and they are encouraged but not required to roster patients. Physicians in FHNs receive an access bonus that is reduced by the cost of services provided to their rostered patients by non-FHN primary care physicians. FHG physicians receive fee premiums for services provided to rostered patients after hours and regular fees for services provided to non-rostered patients. Both models also provide back-up to a nurse-staffed 24/7 telephone health advisory service for rostered patients, and are contractually required to provide a minimum number of weekly after-hours clinics.

The other main practice model is fee-for-service (FFS). Patients are not rostered, and there are no maximums on services billed or the number of patients seen. There are no contractual obligations to provide after-hours or telephone coverage, although some FFS physicians choose to provide these services.

A potential benefit of new models of primary care may be reduced use of other services, such as emergency departments and walk-in clinics (Christakis et al. 2001; Gill and Mainous 1998; Gill et al. 2000; Mainous and Gill 1998). The purpose of this study was to compare the patient-reported prevalence of emergency department and walk-in clinic use during the previous six months by patients receiving care in Family Health Networks, Family Health Groups and fee-for-service practices.

Methods

The study was conducted in Thunder Bay, Ontario, a city with a population of approximately 115,000 and one acute care hospital with a full-service emergency department. The hospital provides primary, secondary and tertiary care to Thunder Bay and acts as a referral centre for secondary and tertiary care for the region of Northwestern Ontario, consisting of 18 other communities spread over a large geographic area with a population of approximately 300,000.

Family physicians were deemed ineligible for the study if they provided only limited services (i.e., specialized clinics such as sexual health, sports medicine or walk-in clinic only [n=17] or practised in the emergency department only [n=22]). At the time of the study, services for urgent medical problems in the city included family physician services, after-hours clinics for family practice patients whose physicians were in an FHN or FHG, five walk-in clinics available to anyone and the city's full-service 24-hour hospital emergency department.

Recruitment of physicians and patients took place from December 2004 to February 2005.

Recruitment of physicians

One FHN, three FHGs and 12 FFS physicians were recruited. All eight physicians in the city's one FHN participated and were considered the index group. In order to make the three physician groups as similar as possible, physicians in the FHG and FFS groups were approached based on matching, as closely as possible, gender and year of graduation from medical school to the eight FHN physicians (37.5% female, median year of graduation 1986). Of the 23 eligible physicians from the three FHGs in the city, 18 were approached and 16 agreed to participate (37.5% female, median year of graduation 1985). Fifteen eligible FFS physicians were approached, and 12 agreed to participate (16.7% female, median year of graduation 1989). All physicians in the participating FHN practised in one building; however, not all FHG physicians were co-located. FHG and FFS physicians were dispersed across seven buildings. FHN and FHG physicians did not work in additional community walk-in clinics (WICs); four FFS physicians reported working in a WIC in addition to their own clinic.

Sampling frames and questionnaire

In this study, the patient roster was used as the sampling frame in the FHN practices because it was considered to be comprehensive and to represent the true patients of the physician. For the FHG and FFS practices, it was necessary to use electronic billing data from patient visits to create a sampling frame. The sampling frames for all models were restricted to patients seen in the past year to minimize the number of

surveys mailed to patients who were no longer with the practice. The lists were further restricted to patients over the age of one year and living in a community within a 25-km radius of the Thunder Bay hospital emergency department, as indicated by their home postal code.

The questionnaire asked about occurrence of an urgent health problem in the past six months and the healthcare services that were used, including the emergency department and walk-in clinics. If no response to the questionnaire was received within four weeks, a second modified letter and another questionnaire were mailed. The questionnaire was based on adaptations of questions used in a previous study of emergency department use in Canada (Grad et al. 1998) and previously validated surveys for socio-demographic and self-reported health questions (Ware and Sherbourne 1992; Statistics Canada 1999). The Hamilton Health Sciences and the Thunder Bay Regional Health Sciences Centre research ethics boards approved the study.

Sample size and statistical analyses

The primary outcome was the proportion of respondents that reported a visit to the emergency department in the previous six months in the FHN versus FHG and FFS practices. The secondary outcome was the proportion of patients that reported using a walk-in clinic in the past six months. The sample size was based on ability to detect a 3% absolute difference in proportions with a baseline of 10% emergency department use in a six-month period, with 80% power and a type 1 error of 5% (two-tailed). To account for clustering of the outcome within physicians, the sample size was inflated by a factor of 1.15, based on an intraclass correlation coefficient of .001 from a quality assurance project conducted in Hamilton (Department of Family Medicine, McMaster University, unpublished data).

Between-group comparisons of the proportion of patients that self-reported using the emergency department or a walk-in clinic in the past six months were made with the generalized estimating equation (GEE) approach assuming an exchangeable correlation structure (Liang and Zeger 1986; Zeger et al. 1986). The QIC (quasi-likelihood under the independence model criterion) statistic was used to confirm that the exchangeable correlation structure assumption was suitable (Pan 2001). Goodness-of-fit of the models for emergency department and walk-in clinic use was also tested (Horton et al. 1999). A non-significant p-value for the chi-square test indicates a suitable model fit. Separate multiple variable models with stepwise forward logistic regression (using $\alpha=0.05$ for inclusion and $\alpha=0.10$ for exclusion) were computed with emergency visit and walk-in clinic as the outcomes to examine the presence of potential socio-demographic and health status confounders. The variables that remained significantly associated with emergency department (ED) use were age, annual household income and self-rated health (excellent, very good, good, fair, poor).

The only variable significantly associated with walk-in clinic use was age. These variables were included as covariates in the final models that adjusted for covariates.

To address the possibility that non-response may have biased the results, data on the outcomes and covariates were imputed for all surveyed patients, including non-respondents and respondents with incomplete surveys. Data on age and sex were available for all patients sampled, and these were used to impute the other covariates in the model: household income and self-reported health, and the outcome variables: use of the emergency department or a walk-in clinic. The multiple imputation approach was used to create 10 complete imputed data sets (Rubin 1987). The Genmod procedure was used to calculate the GEE parameter estimates for the 10 imputed data sets; the MIAnalyze procedure in SAS, which takes account of the reduced variance from imputation, was then used to calculate the overall combined GEE estimates.

Analyses were done with SAS version 9.1 (Cary, NC, USA). The criterion of statistical significance was set at $\alpha=0.05$ (two-sided).

Results

Response rate

Questionnaires were mailed to 9,612 patients from 36 practices. Two hundred fifteen patients were subsequently deemed ineligible because they had left the practice or were deceased. The overall response rate was 62.3% (5,884/9,373). The mean response rate was 65.4% (minimum to maximum: 54.1% to 75.4%) among the FHN practices, 59.8% (minimum to maximum: 39.5% to 66.5%) among the FHG practices and 63.6% (minimum to maximum: 52.5% to 71.9%) among the FFS practices. Only 1.1% (66/5,884) of respondents did not consider themselves a patient of the physician whose list we sampled, and 31 respondents did not answer the question. These patients were removed from the analysis.

Patient characteristics

The mean age of respondents was 43.8 years (standard deviation [SD] = 22.2) compared to 36.3 years (SD=20.3) among non-respondents ($p<0.001$). Over half (60.3%; 3,549/5,884) of respondents were female, compared to 57.5% (2,021/3,513) of non-respondents ($p=0.008$). Table 1 shows the demographic characteristics of respondents in the three models.

Sixty-five respondents did not answer the question about the occurrence of an urgent health problem. Of those who responded, the prevalence of a self-reported urgent health problem in the past six months was 20.6% (346/1,772) among the FHN respondents, 25.5% (569/2,236) among FHG respondents and 23.0% (409/1,779) among FFS respondents.

Emergency Department and Walk-in Clinic Use in Models of Primary Care Practice

TABLE 1. Demographic characteristics and self-reported health of questionnaire respondents in the three practice models

	FHN* (n=1,772) n (%)	FHG† (n=2,236) n (%)	FFS‡ (n=1,779) n (%)
Female	1,062 (59.9)	1,412 (63.1)	1,012 (56.9)
Age: mean years, standard deviation	42.2, 22.7	44.1, 21.4	44.7, 22.0
Highest education (among respondents aged 20 and older) (n=4,580)			
Current student	36 (2.7)	50 (2.8)	35 (2.4)
Some or completed elementary school	105 (7.8)	153 (8.5)	117 (8.2)
Some or completed high school	558 (41.2)	666 (36.8)	591 (41.3)
Some or completed college or some university	456 (33.7)	612 (33.8)	459 (32.1)
Completed university (any degree)	198 (14.6)	328 (18.1)	230 (16.1)
English main language spoken at home (n=5,787)	1,718 (97.0)	2,135 (95.5)	1,715 (96.4)
Household income in 2004 (n=5,069)			
<\$14,999	124 (7.9)	183 (9.5)	145 (9.3)
\$15,000–\$29,999	207 (13.2)	250 (12.9)	217 (13.9)
\$30,000–\$44,999	238 (15.2)	271 (14.0)	240 (15.3)
\$45,000–\$59,999	241 (15.4)	288 (14.9)	209 (13.4)
\$60,000–\$79,999	247 (15.8)	340 (17.6)	290 (18.5)
\$80,000–99,999	219 (14.0)	266 (13.7)	223 (14.2)
\$100,000 or higher	292 (18.6)	338 (17.5)	241 (15.4)
Own the current home (n=5,718)	1,572 (89.8)	1,935 (87.5)	1,529 (87.0)
Working at a paying job (among adults aged 18 to 64 years) (n=3,667)	800 (74.1)	1,093 (74.7)	826 (73.5)
Self-reported health status (n=5,724)			
Excellent	426 (24.3)	410 (18.5)	345 (19.6)
Very good	636 (36.3)	824 (37.2)	673 (38.3)
Good	502 (28.6)	677 (30.6)	502 (28.6)
Fair	148 (8.4)	237 (10.7)	185 (10.5)
Poor	41 (2.3)	65 (2.9)	53 (3.0)

* Family Health Network.

† Family Health Group.

‡ Fee-for-service.

Emergency department and walk-in clinic use

The self-reported six-month prevalence of emergency department use was 11.4% (199/1,753) among the FHN respondents, 15.7% (347/2,236) among FHG respondents and 14.3% (252/1,779) among FFS respondents. The proportion of respondents who reported visiting a walk-in clinic was 1.7% (30/1,723) among FHN respondents, 1.9% (41/2,236) among FHG respondents and 3.4% (59/1,779) among FFS respondents.

With the FHN patients as the reference category, the adjusted odds ratio (OR) for emergency department use for the FHG patients was 1.5 (95% confidence interval

[CI] = 1.2–1.8) and for the FFS patients was 1.3 (95% CI=1.1–1.6) (Table 2). The adjusted OR for walk-in clinic use for the FHG patients was 1.07 (95% CI=0.7–1.7); for the FFS patients the OR was 2.1 (95% CI=1.4–3.1) (Table 3). The adjusted ORs for emergency department use, with missing data imputed for the comparison of FHG and FFS versus the FHN model, were 1.3 (95% CI=1.03–1.5, $p=0.02$) and 1.3 (95% CI=1.06–1.5, $p=0.008$), respectively. For walk-in clinic use, the ORs were 1.2 (95% CI=0.8–1.8, $p=0.42$) and 2.0 (95% CI=1.4–2.9, $p=0.001$), respectively.

TABLE 2. Odds ratios for unadjusted and adjusted emergency department use

	Odds Ratio (95% confidence interval) Excluding missing data*			
	Unadjusted	p-value	Adjusted [†]	p-value
FHN [†]	—			
FHG [‡]	1.45 (1.22–1.74)	<0.001	1.47 (1.21–1.80)	<0.001
FFS [§]	1.31 (1.10–1.55)	0.003	1.33 (1.12–1.59)	0.001
Age (years)	—	—	0.99 (0.987–0.995)	<0.001
Self-reported health status	—	—	0.92 (0.88–0.97)	<0.001
Household income	—	—	1.28 (1.05–1.17)	<0.001

* Odds ratios (OR) for adjusted model coefficients using multiple imputation of missing data – OR FHN versus FHG=1.26 (95% confidence interval 1.03–1.54), OR FHN versus FFS=1.27 (95% confidence interval 1.06–1.51).

† Family Health Network.

‡ Family Health Group.

§ Fee-for-service.

|| Self-reported health status ranges from 1=excellent, through 5=poor.

¶ Goodness-of-fit chi-square = 13.9 (df=9), $p=0.12$.

TABLE 3. Odds ratios for unadjusted and adjusted walk-in clinic use

	Odds Ratio (95% confidence interval) Excluding missing data*			
	Unadjusted	p-value	Adjusted	p-value
FHN [†]	—		—	
FHG [‡]	1.03 (0.65–1.64)	0.89	1.07 (0.68–1.68)	0.78
FFS [§]	1.31 (1.10–1.55)	0.0007	2.08 (1.41–3.08)	<0.001
Age (years)	—	—	0.987 (0.979–0.995)	0.0016

* Odds ratios (OR) for adjusted model coefficients using multiple imputation of missing data – OR FHN versus FHG=1.19 (95% confidence interval 0.77–1.83), OR FHN versus FFS=2.03 (95% confidence interval 1.42–2.92).

† Family Health Network.

‡ Family Health Group.

§ Fee-for-service.

|| Goodness-of-fit chi-square = 5.7 (df=9), $p=0.77$.

The intraclass correlation coefficient (ICC) among physicians for ED use was 0.004 and for WIC use was 0.002. The ICC among the eight distinct clinics in which physicians were located was 0.003 for ED use and 0.0002 for WIC use.

Discussion and Conclusions

The results of this study suggest that characteristics of the family practice are associated with patients' use of the emergency department for self-defined urgent health problems. Patients whose physicians were in an FHG or FFS practice were 45% and 31% more likely than patients in the FHN model to visit the emergency department in a six-month period, and patients in an FFS practice were twice as likely as FHN patients to use a walk-in clinic.

Previous studies have shown associations between improved primary care access and reduced emergency department use. Studies in the United States have shown reductions in emergency department use after improved access to and addition of after-hours primary care (Piehl et al. 2000; Lowe et al. 2005). In the United Kingdom

... characteristics of the family practice are associated with patients' use of the emergency department for self-defined urgent health problems.

and the Netherlands, general practitioner (GP) cooperatives involving large numbers of GPs and patients have been formed to reduce the burden of after-hours care on GPs and the emergency department (van Uden et al. 2003; Pickin et al. 2004; van Uden and Crebolder 2004). A control-

led before-and-after study comparing emergency department use before and after the introduction of a general practice cooperative with after-hours clinics in the United Kingdom found no difference in emergency department use rates (Pickin et al. 2004). However, studies in the Netherlands have shown reductions in emergency department use after introduction of GP cooperatives (van Uden et al. 2003, 2005; van Uden and Crebolder 2004).

The FHN model features a package of services and incentives, including the after-hours clinics, 24/7 physician back-up to telephone triage for rostered patients and the financial negation if rostered patients visit another family physician, which together may affect use of services outside the practice. Although both FHN and FHG models provide after-hours services and 24/7 physician back-up to the telephone triage for rostered patients, emergency department use was different in the two models. In addition, significantly more patients in the FFS model reported a visit to a walk-in

clinic compared to patients in the FHN model, but the difference between the FHN and FHG patients was not statistically significant. It is possible that physicians in the FHN advertised and educated patients regarding the after-hours clinics and the 24/7 physician back-up to a greater extent than FHG physicians to attempt to limit patients' use of walk-in clinics and avoid negation of the access bonus in that model. Emergency department use may also have been similarly affected.

Reduction of unnecessary emergency department use and visits for minor complaints has been of interest in many jurisdictions; however, there are concerns about

Reduction of unnecessary emergency department use and visits for minor complaints has been of interest in many jurisdictions ...

the safety and effectiveness of these efforts. A Canadian study has reported that even among emergency department attendees triaged as non-urgent, 7% were subsequently admitted to hospital (Vertesi 2004). On the other hand, a study in which patients with complaints that could be deferred to

next-day care were randomized to immediate emergency department care or next-day care in a primary care clinic found no adverse effects on patient safety in the deferred group (Washington et al. 2002). There are reasons to pursue the safe diversion of non-urgent patients from the emergency department to primary care, relating to continuity of care, duplication of services and costs. For example, one study in Canada has shown that patients who attended the emergency department for a minor acute illness were 6.5 times more likely to use healthcare for the same complaint again within three days and 4.9 times more likely to use healthcare for the same problem 3–14 days later, and that costs of treating minor ailments in primary care are lower than in the emergency department (Campbell et al. 2005). On the other hand, in smaller communities where family physicians often staff the ED (Haggerty et al. 2007), patients may experience continuity through use of the ED.

Younger age, lower income and poorer self-reported health status were significantly associated with emergency department use in the multiple-variable model. Previous studies have also found that young children (Chan et al. 2001), those with lower socio-economic status (Mustard et al. 1998; Menec et al. 2005; Li et al. 2006; Hong et al. 2007) and poorer self-reported health (Zuckerman and Shen 2004) are more likely to use the emergency department. Inclusion of these variables in the model for emergency department use and age in the walk-in clinic use model changed the results very little, suggesting they were not confounders. Since the conversion to the new prac-

tice models in Ontario was very recent at the time of this study, most patients would already have had a family physician and would not have chosen their practice model. Consequently, we would not expect different types of patients in the different models.

There were several limitations in this study. We were unable, using a self-report questionnaire, to determine the severity of the urgent health problem or appropriateness of the emergency department visit. If patients in the FHN model experienced a lower severity of urgent health problem compared to patients in the other models, this factor may have biased the results. An additional limitation may arise from the different lists used to create the sampling frames in the different models. The patient sampling frame was based on rostered patients in the FHN model and billing data in the other models. FHN physicians may see patients who are not rostered on a fee-for-service basis. Although there are financial incentives in the model to roster, and premiums for care of patients with chronic disease and selected mental health conditions, it is possible that the FHN group was healthier than the patients sampled in the other models because of selection of patients into the roster for capitated payment. There may be differences between physicians who choose to enter reformed practice models, and this study did not have sufficient sample size to address the potential influence of these characteristics on the effects found.

The response rate obtained in this study was typical of mailed health-related survey response rates (Rimm et al. 1999). Analysis with multiple imputation to create complete data sets did not change the conclusions for emergency department or walk-in clinic use, but the effect sizes for the comparisons between groups on emergency department use were reduced slightly.

This study was conducted in one medium-sized Ontario city with a single emergency department. Further research should compare patterns of healthcare utilization in larger urban settings with greater choice of hospital emergency departments. It would also be useful to determine which aspects of reforms may be beneficial and cost-saving if patient encounters with more costly healthcare services are reduced.

This study found that patients whose family physicians practised in a model based on capitation, with a contractual agreement to provide some after-hours services and to roster patients, used the emergency department less often than patients whose physicians practised in other models. This study contributes to knowledge about the effects of Canadian reforms in primary care.

ACKNOWLEDGEMENTS

Funding for this research was provided by the Ontario Ministry of Health and Long-Term Care Primary Health Care Transition Fund. The views expressed in this report are the views of the authors and do not necessarily reflect those of the Ministry.

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Evaluating Interventions Aimed at Promoting Information Utilization in Organizations and Systems

Évaluation des interventions visant à promouvoir l'utilisation de l'information dans les systèmes et les organisations



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Abstract

This paper presents a theoretical and practical framework for evaluating interventions aimed at promoting information utilization in organizational decision-making. The

framework integrates three distinct yet complementary theoretical perspectives on information utilization in politico-administrative systems: (1) the literature on evaluation utilization, (2) current thinking on knowledge transfer (KT) in the health policy field and (3) approaches derived from the analysis of lobbying in political science. Our analysis calls into question the relevance of effect analysis in evaluating organizational or policy-level KT initiatives, but also suggests dimensions that should be explored when evaluating KT initiatives. We conclude that there are probably trade-offs to be made between the effectiveness of KT and the scientific robustness and validity of the information transmitted.

Résumé

Cet article présente un cadre théorique et pratique pour l'évaluation des interventions qui visent à promouvoir l'utilisation de l'information dans la prise de décision organisationnelle. Le cadre intègre trois perspectives théoriques distinctes, mais complémentaires, sur l'utilisation de l'information dans les systèmes politico-administratifs : (1) la littérature portant sur l'utilisation de l'information, (2) la réflexion actuelle sur le transfert de connaissances (TC) dans le domaine des politiques de santé et (3) les approches découlant de l'analyse du lobbying en science politique. L'analyse remet en question la pertinence de l'analyse des effets dans l'évaluation des initiatives de TC au niveau organisationnel ou politique, mais elle propose également des aspects dont devrait tenir compte une évaluation des initiatives de TC. Pour conclure, nous ajoutons qu'il est sans doute nécessaire de trouver un compromis entre, d'une part, l'efficacité du TC et, d'autre part, la validité et la rigueur scientifique des informations transmises.

THE RELATIONSHIP BETWEEN POLICY MAKING AND SCIENTIFIC KNOWLEDGE has long been the subject of debate. Recent years have seen a resurgence of this debate in healthcare, expressed as a growing preoccupation with ensuring that scientific knowledge is taken into account in the development and implementation of health policy. Nevertheless, efforts to integrate knowledge into organizational decision-making and policy development also present a particular challenge for evaluation – specifically, identifying operational and conceptual tools that can be used to assess a particular intervention aimed at integrating knowledge into organizational or political decision-making.

Ferlie and Shortell (2001: 283) identify four levels as targets for system change: “the individual, the group or team, the overall organization, and the larger system or environment in which individual organizations are embedded.” At the individual and group levels, there are well-developed strands of work designed as evidence-based

practice, quality improvement and implementation research (e.g., Doumit et al. 2007; Bonetti et al. 2005; Eccles et al. 2003, 2005; Grimshaw et al. 2006; Rycroft-Malone et al. 2002; Kitson et al. 1998; MacIntosh-Murray and Choo 2005). This literature focuses on the development and evaluation of interventions to ensure that professional practice aligns with best practices and evidence. Most of this work rests on statistical analysis, since it can rely on repeated quantitative measures of a well-defined output (the more or less easily measured change in clinicians' repeated clinical decisions), although qualitative approaches are also used (MacIntosh-Murray and Choo 2005), and psychological and social factors are taken into account.

... our concern is the incorporation of evidence, not into individual or group practice, but rather into governance and management.

Rather than cover the same ground, this paper targets broad organizational (management) and systemwide (governance) decision-making levels. In other words, our concern is the incorporation of evidence, not into individual or group practice, but rather into governance and management. At this level, these concerns have been explored from different angles. In the field of evaluation, there is a vast literature on evaluation utilization that has not only modified our ideas on utilization, but also contributed to the development of evaluation methods that promote utilization. Current thinking on knowledge transfer (KT) in the health policy field (e.g., CHSRF 2003, 2005; Lavis et al. 2003; Lomas 2005; Denis and Lomas 2003) has also identified approaches that promote knowledge utilization. Finally, a third approach, derived from the analysis of lobbying in political science, examines information utilization within the larger process of policy development. Each of these approaches sheds its own light on the phenomenon, but these literatures are relatively independent; to our knowledge, there have been few efforts at theoretical and conceptual integration. All three approaches focus on knowledge transfer interventions in a much murkier context than those targeted by implementation research, since the former target KT that can, at best, hope to influence a few one-shot decisions to an imprecise degree in an indeterminate time frame (Weiss 1977; Knott and Wildavsky 1980; Patton et al. 1977). This limitation prevents the use of statistical methods (unless one relies on self-declaration of perceived use, which we feel is inappropriate; see Knott and Wildavsky 1980). Moreover, the nature of the evidence itself will usually be much softer than the randomized controlled trials behind evidence-based practice.

The objective of this paper is to develop a framework that will enable the evalua-

tion of interventions aimed at promoting information utilization in organizational and systemic decision-making. We propose a conceptual model of information utilization whose originality is based on the integration and articulation of the three theoretical perspectives on information utilization in politico-administrative systems described above. The integrative framework we propose is organized around three main themes.

... every decision is based on information, whether internalized or externalized.

be original in that it demonstrates, at the levels we focus on, the weakness of the causal link between any given knowledge-dissemination intervention and actual knowledge utilization, calling into question the relevance of effect analysis in evaluating many KT initiatives. On the other hand, our model demonstrates the importance of the intervention process. Finally, we discuss the conceptual model's implications for the types of evaluation possible and the dimensions of utilization that should be considered when evaluating information utilization.

First, we analyze the concept of information by comparing different types of information utilization. Second, we examine information as it is perceived in the political arena. Third, we look at the process of information transmission.

We consider this model to

Types of Information

We posit that every decision is based on information, whether internalized or externalized. It is equally credible to suggest that not all information is of the same type, nor of equal value. One possible typology would distinguish information according to its scientific credibility or strength (Rycroft-Malone et al. 2002; Kitson et al. 1998). However, as we will argue, no convincing evidence exists that shows a link between scientific validity and utilization. As Knott and Wildavsky (1980: 545) point out, "excellent analysis is often ignored. Information is one, but only one, input into the bargaining process that yields policy decisions." We thus rely rather on Peterson's (1995) typology of the kinds of information used in health policy development.

Peterson's model implicitly conceives the decision-making process as teleological and instrumental, in that decision-makers strive to maximize the positive and minimize the negative consequences of their decisions. Thus, for the decision-maker, the decision process implies an attempt to foresee the consequences of decisions, generally in a context of high uncertainty and ambiguity. According to Peterson, decision-makers are sensitive to two types of consequences or sources of uncertainty. On one side are

“programmatic” consequences, related to the objectives or impacts of the policy or decision (Will the proposed means make it possible to achieve the objectives? What are the secondary impacts of the decision?). On the other side are the “political” consequences, those related to the impacts of the decision on the balance of political power, in the narrow sense of the term (Will this decision raise or reduce satisfaction levels among the electorate? Does it change the power relationships among political adversaries?).

For each of these two types of uncertainty, decision-makers will use three sources or types of information. First, there is the decision-maker’s own experience, which includes interaction with his or her immediate circle, exposure to content circulated by the media, daily activities and past decision-making. The second is what Peterson calls *distributional information*, which comes from different organized groups or actors potentially affected or concerned by the decision. Finally, the third source of information – termed “analytical” – aims to be neutral and free of bias or subjectivity by basing itself on scientific methods. From this model we can create a matrix of six cells in which each of the three types of information is used to respond to each of the two types of uncertainty. We believe it is useful to consider how this typology might be combined with classic categories in the field of evaluation: conceptual, instrumental and symbolic utilization (Table 1).

TABLE 1. Matrix of information utilization in decision-making

	Everyday experience	Distributional information	Analytical information
Programmatic uncertainty	Conceptual utilization		Instrumental utilization
Political uncertainty			Symbolic utilization

Ever since its earliest days as an academic specialty, the field of evaluation has explored the meaning and definitions of utilizing the information and knowledge that arise from an evaluation project (Weiss 1988). On observing that evaluation results seemed to be less utilized than might have been expected, evaluators questioned what would be adequate means of promoting evaluation utilization. This debate led to a broader reflection on evaluation utilization and resulted in the identification of different types of utilization (Champagne et al. 2004; Beyer and Trice 1982). The best-known categories – instrumental, symbolic and conceptual – have been taken up in the literature on knowledge transfer. The less familiar category – process utilization – is seldom used in KT literature but appears relevant to our focus here.

Instrumental utilization refers to the use of programmatic analytical information to make, influence or change a decision, policy or program (Patton 1988). *Symbolic utili-*

zation occurs when analytical information produced by evaluations or other scientific sources also serves to legitimize predetermined positions. *Conceptual utilization* refers

Instrumental utilization refers to the use of programmatic analytical information to make, influence or change a decision, policy or program (Patton 1988).

to the cognitive process of enlightenment, through which analytical information received by decision-makers is gradually integrated and assimilated, becoming part of their everyday experience base (Weiss 1977). *Process utilization* refers to the use of evaluation strategies in

themselves as a tool to enhance the use of information (something we address in the next section of this paper).

Finally, as mentioned earlier, *distributional information* is characterized by the fact that it emanates from groups personally concerned by the information they are transmitting. It should be stressed that it is not the validity of the information in itself, but the presumed neutrality of the source that distinguishes analytical information from distributional information. Because the typology based on utilization of evaluation results does not address any competition that may exist among sources of information, it follows that this typology would not mention distributional information.

Information in the Political Arena

Another way of approaching utilization of scientific information in policy development is to conceive of it as arising at the junction of two fields with distinct properties. On one side is the field of science, the main source of information in this case, and on the other side is the politico-organizational arena, considered broadly, that is likely to put this information into practice. We will return later to the hypothesis that the information used may in fact be co-produced by the intersection of the fields, but first we believe it is useful to examine the specificities of each and the logic underlying their behaviours.

The meeting of the political and scientific arenas

Hannah Arendt defended the idea that the scientific and political arenas were based on fundamentally different principles. Whereas science functions using the ideal of truth, even if only for heuristic ends, in politics there are only opinions. "What is annoying is that factual truth, like all other truth, demands to be recognized and refuses to be discussed, whereas discussion is the essence itself of political life"

(Arendt 1972: 307, authors' translation). A fundamental difference between truth and opinion is that truth, by its nature, is unique and unquestionable, while the nature of opinion is to be free and in perpetual evolution.

Yet another difference, which for Arendt is more fundamental, is that the forms of communication that deal with truth are never, in themselves, about action: they do not aim to bring about truth, but rather to describe it. In contrast, discourse dealing with opinion is, by nature, action-oriented and aimed at changing the course of events. According to Arendt, it is not possible to move from one discursive universe to the other without changing the nature of the content itself. "If the person speaking factual truth wishes to play a political role, and thus be persuasive, he will almost always take considerable detours to explain why his own truth best serves the interests of any group" (Arendt 1972: 318, authors' translation). When presented summarily, this proposition may seem radical, but it simply formalizes observations around which there is consensus in the field of political analysis.

This process poses a challenge for health specialists: groups pushing their own interests will stand up and oppose even the most unambiguous scientific findings. ... From this perspective, health science constantly wrestles with self-interested politics. Even robust findings are only as good as the policy coalition that assembles around them. (Morone 2005: 13)

Setting the agenda

One obvious characteristic of information, on the other hand, is the conditional nature of the criteria for relevance. No information is relevant or interesting in itself. Information is relevant only in relation to a given context (Knott and Wildavsky 1980), whether this is conceptualized as a research question or as an administrative reform. Thus, administratively and politically, only information related to a subject on the agenda is relevant, regardless of any consideration of its value or scientific interest. In this context, often the most important factor in moving a dossier along, and likewise for promoting utilization of scientific knowledge, is for it to be on the agenda. To get a dossier on the agenda, it is obviously not only possible, but even desirable, to use as arguments specific information drawn from the scientific arena. Nevertheless, the nature of this information by no means determines the success in getting the dossier on the agenda. There are certain facts, extremely well documented and scientifically considered to be true, that have no impact in the political arena (e.g., that pollution due to automobiles is a major factor in urban morbidity and mortality). Conversely, other scientific facts become central and formative in the political arena, as demonstrated by the issue of tobacco control.

The Process of Information Transmission

Knowledge transfer and co-production

The view presented above on the interaction between the political and scientific fields is not always taken into account in decision-making circles and among granting agencies. The dominant view is what we will call here the school of knowledge transfer.

If the vision derived from Arendt's works is eminently political and structuralist, the KT perspective is functionalist and founded on an iterative empirical approach, rather than on any specific theoretical basis. According to this approach, the issue of the utilization of scientific knowledge in policy development and implementation is first and foremost an issue of communication between a source and a receiver (Ko et al. 2005). At the risk of overly simplifying, this means transmitting to the right person, at the right time, the right information presented in the right way. Given all the proper conditions, and if the information supplied is scientifically valid, sound and reliable, then utilization will occur and the ultimate outcome will be better policies. We will not present this model in detail, as it is likely already familiar to the reader. On the other hand, there is room for some interesting cross-analysis between the politico-structuralist and the KT schools.

One of the significant contributions of the KT movement has been the suggestion that the most relevant information, and therefore the most useful and usable, is a product of neither the politico-administrative nor the scientific arena, but rather a co-production made possible by the interaction of individuals in both. Involving the decision-maker at various stages of the knowledge production process creates a two-way interaction that promotes a co-building of knowledge based on teamwork and partnership (Lavis et al. 2003). This interaction would support the utilization of research or evaluation results (Gibbons et al. 1994; Denis and Lomas 2003; Lavis et al. 2003) and tallies with what is known about process utilization.

Likewise, the KT school proposes that for analytical information to be legitimized, it should be subject to deliberation. Such deliberation is justified on the basis that although scientific information may be reliable, it is also uncertain, dynamic, complex, disputable and rarely complete (CHSRF 2005). These characteristics would allow scientific information to be complemented by non-scientific data (expertise, viewpoints and realities of other actors) and for knowledge to be adapted to the context in which it would be used (Pirkis et al. 2006; Lavis et al. 2005; CHSRF 2005; Abelson et al. 2003). Still, for best results, the deliberation process should include balanced representation of scientists, users and groups involved (CHSRF 2005; Pirkis et al. 2006).

Lobbying

One possible approach to bringing the KT and the politico-structuralist schools closer

together is by means of conclusions drawn from political science on the influence of lobbying on policy development.

We begin by presenting briefly one of the first analytical views of lobbying proposed by Milbrath in 1960 (Milbrath 1960, 1963; Koepl 2001; Terry 2001). This model is of interest to our discussion insofar as it considers lobbying as essentially a process of communicating information (de Figueiredo 2002). This concept of lobbying allows us, in practice, to apply the model more broadly to understand how information and its communication are integrated into decision-making in a political context.

Anyone wishing to influence the decision of a governmental official, then, must be concerned not only with getting the information to him but also with the problem of presenting it so that the decision maker will be receptive. The only effective communications are those which get through the perceptual screen. In fact there is no other way to influence governmental decisions short of remaking the personalities of decision makers or replacing them with other persons. The lobbying process, then, is essentially a communication process, and the task of the lobbyist is to figure out how he can handle communications most effectively in order to get through to decision makers. (Milbrath 1960: 35)

This description of the nature of lobbying postulates that for information to be used, what is most important is not how valid or how sound it is, but rather its capacity to be communicated to the decision-maker. This is one point of compatibility between the politico-structuralist and KT schools. For Arendt (1972), the political and scientific arenas are too interdependent on many levels to be separated from each other. It is therefore both inevitable and desirable that there be cross-fertilization between the two. However, she insists it is analytically fundamental to understand that their logics differ, as do the nature and position accorded to information (Boaz and Pawson 2005). In the political arena, there are only, on the one hand, producers of performative discourse who are thereby political by nature, and on the other hand, information that, simply by existing in that arena, cannot be neutral. We could therefore say that to intervene in the political arena is to accept its rules and to accept being a lobbyist among others, in line with Milbrath (1960). Moreover, Quebec law provides a definition of lobbying that encompasses, at least potentially, the activities of knowledge transfer:

Any oral or written communication with a public office holder in an attempt to influence or that may reasonably be considered by the initiator of the communication as capable of influencing a decision ... (Quebec 2006)

It is worth noting here that Milbrath's proposed description of lobbying is not incompatible with the position of the KT school. In fact, we can conceive of a political system that works according to the Milbrath model and within which researchers would constitute a particular type of producer and disseminator of analytical information, along the lines of Peterson's model. In this process, the determinant of information utilization would still not be its scientific validity, but rather the effectiveness of the information-dissemination strategies. If Milbrath's model does not entirely reconcile the politico-structuralist vision with that of KT, it is nevertheless compatible with both and at least permits a common conceptualization of the phenomenon that would allow us to build hypotheses to check the robustness of each model against empirical practice.

Lobbying and power

At a second level, the communication process that is characteristic of lobbying is not simply aimed at transmitting neutral information. One of its central functions is to enable the communication of power relationships or, in other words, to sensitize decision-makers to the possible or probable consequences of their decisions. In the vocabulary of Clark and Wilson (1961), we could say that lobbying consists of convincing an individual that his or her action (or decision) is associated with positive or negative incentives. Thus, even if lobbying is limited to a communication process, this process is integrated into broader power relationships that must be considered in the analysis.

We therefore believe that there is an important distinction to be made in the lobbyist's level of control – or more generally, that of the organization being represented – over the consequences that are emphasized. On the one hand, a "performative" discourse around consequences is sometimes possible, in the sense that given a certain decision, the group affected can to some extent control the unfolding or the nature of the consequences. On the other hand, groups often must be satisfied with a "fatalistic" discourse on the consequences, recognizing that they do not control them but can only describe a logical sequence that is outside their control. A simple but clear illustration of this distinction can be found in the two sentences: "If you continue, I will push you and you will fall," and "If you balance on the edge, you will ultimately fall." In both cases, the speaker is trying to modify the behaviour of another person – an action that corresponds to the classic definition of the exercise of power (Crozier and Friedberg 1977) – by communicating to the other information on the consequences of his actions. However, while in the first formulation the speaker asserts his ability to control the consequences, in the second he presents the same consequences as being outside his control.

From this perspective, the results of relevant scientific studies, if brought to the decision-maker's attention, are identical in nature to lobbying efforts based on a fatal-

istic sensitization to consequences. Similarly, if we refer back to Peterson's typology, all scientific knowledge transfer, however neutral, involves communicating specific analytical information to the decision-maker and therefore implies a desire to influ-

ence the decision-making process by changing the weight attributed to a particular type of consequence. While the objective may be as well-intentioned and programmatic as possible, the process is nevertheless identical in nature to that of lobbying, with the effectiveness of the message dependent

Lobbyists are an important source of information for decision-makers, while decision-makers hold the decisional power coveted by lobbyists.

upon implementing strategies that will influence the decision-maker. The effectiveness of lobbying depends upon sensitizing the decision-maker to a specific and partisan group of consequences, while endowing these particular consequences with more importance than they actually have (Slovic 1966; Kahneman et al. 1982; Brunsson 1982), all within an integrated set of communication strategies.

In terms of desirability, the KT school is particularly compatible with lobbying theories and analyses. Actually, a fundamental characteristic of the lobbyist–decision-maker relationship is that of mutual benefit. Lobbyists are an important source of information for decision-makers, while decision-makers hold the decisional power coveted by lobbyists. Decision-makers benefit from lobbyists' ability to supply them rapidly and freely with important information. In exchange, the lobbyists, who are in a position to develop relationships of trust with decision-makers and to be regarded as dependable and predictable, gain an invaluable channel of communication. Many empirical studies have documented this symbiotic relationship and the structuring of exchanges it implies in terms of information circulation (Berry 1997; Heinz et al. 1993; Birnbaum 1993; Jordan 1991; Ainsworth and Sened 1993; Sousa 1998).

Similarly, the KT movement emphasizes that the development of interpersonal relationships among researchers and actors within decision-making circles offers advantages to both parties. On the one hand, it makes it possible to take into account the needs of the potential users of research and evaluation results and the specificities of their decisional contexts that could influence their choices and decisions (Cousins 2006). On the other hand, it allows researchers to deepen the utilization context and to prepare the way for development (Hanney 2003). Finally, collaborative research helps stimulate utilization of evaluation results via the proximity created between knowledge producers and users (Cousins 2006; Pirkis et al. 2006; Hanney 2003).

An effective communication process

The literature on lobbying has always stressed that the effectiveness of communication with the decision-maker is much more important in influencing the decision than is the validity of the information being communicated. This fundamental lesson – which is the A-B-C of lobbying – is interesting in that it corresponds exactly to the advice currently offered to researchers by the KT movement for increasing knowledge utilization. One version of this trend is to entrust to specialists – knowledge brokers (CHSRF 2003; Clark and Kelly 2005) – the role of interface between information producers and decision-makers. The structural position and role of these brokers makes them indisputably lobbyists according to the majority of current definitions, as well as under most laws governing the practice of lobbying (Quebec 2006). However, this specific view of KT is not very compatible with the notion of co-production of knowledge.

A second version of KT seeks to maximize the effectiveness of the communication process by offering advice and formulas to producers of scientific information on how to improve communication (Lavis et al. 2003; Dickinson 2004; CHSRF 2002). This perspective thus implicitly recognizes, as suggested by the analysis of lobbying, that the determinant of utilization is not necessarily the nature of the message but rather the process of communication. Thus, identifying a target for the message (Lavis et al. 2003), adapting the message to the selected decisional environment (Dickinson 2004) and formulating it in such a way as to reduce the cultural gap between the parties (Gülich 2003) are all integral components of the tool set that will make it possible, in Milbrath's terms, to pass through the decision-maker's perceptual filter. Likewise, the main messages of a study should be specified and presented synthetically and concisely (Lavis et al. 2003), and the message content should include relevance, interests, needs, objectives, concerns, contextual information and consequences of implementing the knowledge (CHSRF 2002, 2005; Dickinson 2004; Entwistle et al. 1998). The message should therefore be established and formulated in line with the needs of the decision-maker, something every good lobbyist has always known.

In addition, both the KT school and the literature on lobbying consider that certain personal traits of the lobbyist, or of the actor disseminating the knowledge, will influence the effectiveness of the communication process. The logical link is that these personal traits will affect the perceived legitimacy of the carrier and thereby also the perceived legitimacy of the current information, which ultimately will influence any eventual utilization. Thus, a long-term relationship with the decision-maker, a reputation for reliability, a certain level of celebrity and a recognized mastery of the issue are examples of traits currently considered to be generally positively associated with effectiveness (Heinz et al. 1993).

Implications for Applied Evaluation of Organizational KT

The starting point for the development of the framework presented here was our being invited to evaluate an innovative experiment in knowledge building and dissemination: the Research Collective on the Organization of Primary Care Services in Quebec (Pineault et al. 2006, 2007). Our first thought was to elaborate and measure a set indicators of effects and impacts. However, we soon found ourselves theoretically stranded by the logical complexity and uncertainty of the link between KT activities and their intended effects. We then decided to conduct a logic analysis of the Research Collective. Logic analysis is a way to analyze the theory of the intervention by comparing the program theory or the implemented intervention with scientific knowledge (Contandriopoulos et al. 2000; Brousselle et al. 2006, 2007). At that point, we started working on the integration of three fields that approach information utilization from different perspectives and use different concepts to understand the complexity of a phenomenon. Our unambiguous conclusion was that because of this complexity, there could definitely be cases where scientific information of good quality is transmitted according to the rules without any subsequent utilization. Information utilization depends not only on the transmission process, but also, and primarily, on the contextual dynamics of the political arena, over which the researcher has no control. In addition, it appears that neither the content, the nature nor the scientific quality of the information will have anything but a marginal impact on its utilization. Thus, there is only a weak causal link between information transmission and its utilization in the decision-making process.

This conclusion calls directly into question the relevance of effect analysis. Most effect analyses of KT at the macro level rely on questionnaire sampling of users' perceived use (e.g., Landry et al. 2003; Amara et al. 2004). This practice allows for large samples and quantitative data. However, the divergence between self-report and actual use can be significant. By way of illustration, consider physicians' opinion that their prescribing behaviour is unaffected by the pharmaceutical industry's marketing, notwithstanding abundant evidence to the contrary (Morgan et al. 2006; Steinman et al. 2001). In fact, our framework suggests there is only a very tenuous and questionable link between perceived and actual utilization of information, leading us to set perceived use aside as an unreliable and invalid indicator of utilization.

While our framework prompted us to reject effect analysis as a method to evaluate KT of the kind we dealt with, we nevertheless retained the idea of developing a practical and valid evaluation framework, in the firm conviction that it is possible to evaluate an intervention's potential for utilization. Integration of the three approaches presented here demonstrates that there are different dimensions supporting informa-

tion utilization. We believe it is possible to evaluate information utilization by assessing dimensions that have an impact on the actual utilization of information, according to the theoretical model developed above.

Turning again to the evaluation of the utilization potential of specific information-transmission initiatives: if optimal conditions are brought together, we can conclude that the potential for information utilization is strong, but given the complexity involved, we cannot draw the conclusion that there is any real utilization. Evaluation helps in understanding whether the conditions were favourable for information utilization and whether the process was optimal or could have been planned differently to improve the potential for utilization. Paradoxically, we could legitimately suggest that potential is in no way a guarantee of real utilization. We could easily imagine an initiative with strong utilization potential but no actual utilization at all and, conversely, an initiative with weak utilization potential that, for whatever reason, results in an important utilization of information.

At the practical level, we evaluated the Research Collective's KT activities by analyzing the characteristics of the context, the traits of the information carrier, the characteristics of the process of information transfer and the externalities related to the utilization. For each of these dimensions, we identified specific characteristics and synthesized the theoretical effects that each of the strands of literature studied here predicted. Sometimes the predicted effects are convergent in all the literature and sometimes they are not, prompting some discussion. However, this approach allowed us to establish, with a strong theoretical basis, the potential information utilization of the Research Collective. The detailed evaluation is currently submitted for publication elsewhere (Brousselle et al. 2008).

Conclusion

The logic analysis we carried out here extends beyond the specific case of the Research Collective and leads to significant consequences: first, for understanding the role of research, and of the researcher, in the decision-making process; and second, for developing an evaluation project on information utilization.

Concerning the role of research and of researchers themselves in the decision-making process, we conclude, first, that information emanating from the research community is probably used only to limit the programmatic uncertainty faced by the decision-maker. However, this is not the only level of uncertainty, and the decision-maker will probably also take political factors into account. Then, in the political and organizational arenas, information coming out of research will always compete with other sources of information (regular, distributional and from other analytical sources). Scientific information will probably not be considered significant *a priori*. This conclusion has consequences at different levels.

First, scientific criteria for information quality (validity criteria) are concepts belonging to the scientific field, and their ability to be exported to the field of political decision-making is questionable. Thus, if it is important that there be mechanisms to maximize the chances that information communicated by the research community meets scientific standards of validity, these mechanisms belong to the field of science. Moreover, and we believe this is an important conclusion, it is questionable whether these criteria have an impact on information utilization.

Second, three major dimensions seem to influence utilization: the context of the political arena, the traits of the information carrier and the characteristics of the information transmission process. The only element over which the researcher has a certain amount of control is the transmission process. Our analysis demonstrates its importance for information utilization. Convergences among the literature on lobbying and knowledge transfer support the relevance and validity of these factors. Still, even if it is possible to ensure that the information transmission process is carefully thought out to maximize utilization, there are no guarantees the information will be used. The quality of the process is in some way a necessary, but not sufficient, condition for information utilization.

Third, the convergence between political theory and knowledge transfer means that increasing the consideration of scientific information in decision-making requires changing the knowledge dissemination process to make it similar to more general lobbying efforts. Our line of argument shows, in fact, that the nature of knowledge transfer is related to a specific type of lobbying. Thus, if there are good reasons to believe that incorporating knowledge more fully into decision-making is desirable, then researchers should be able to orient their actions more broadly in such a way as to influence the decision-making process – which inevitably draws the researcher out of the scientific arena and more deeply into the dynamics of the political arena, where opinions must be asserted.

Finally, it is important to note the potential for tension between conditions that support effective communication processes in the political arena and demands for validity in the scientific arena. Thus, concessions may be required on the scientific validity front for the sake of political effectiveness. In this context, researchers may need to find a compromise between effective information transmission and adherence to scientific criteria. However, we cannot postulate *a priori* that compromises in scientific validity have a negative impact on the quality of the decision or of the political process.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the input of Jean-Louis Denis and the support of the investigators of the Research Collective on the Organization of Primary Care Services in Quebec, Raynald Pineault, Danièle Roberge, Pierre Tousignant, Danielle Larouche, Dominique Lesage and others.

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Delivering Primary Care to Homeless Persons: A Policy Analysis Approach to Evaluating the Options

Prestation de soins de santé primaires pour les sans-abri : évaluation des options à l'aide d'une analyse des politiques



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Abstract

Homeless persons are numerous, carry a significant burden of illness and face challenges in accessing care. A search of the literature revealed insufficient empirical sources to permit the use of standard systematic review methodology to determine the most effective way to deliver point-of-first-contact healthcare to homeless people. Instead, we used a policy analysis approach. We found that the dominant model of primary care in Canada performs poorly when assessed on 13 evaluation criteria. While there is variable performance on individual measures, the three alternative models – targeted standard facility/clinic site, fixed outreach site and mobile outreach service – all perform well. Our findings suggest that some factor other than performance on the specified measures, such as costs, feasibility, geographical fit or local preferences, should be used to choose a specific model. Our analysis clearly indicates that the status quo model of primary care is inadequate to meet the needs of homeless people.

Résumé

Les sans-abri sont nombreux, ils doivent surmonter de durs problèmes de santé et font face à des défis d'accessibilité quant aux soins de santé. Nos recherches dans la littérature n'ont pas permis d'amasser suffisamment de sources empiriques pour mener une revue systématique méthodologiquement acceptable afin de déterminer les façons les plus efficaces d'offrir des points d'accès de première ligne pour les sans-abri. Nous avons donc employé une méthode d'analyse des politiques. Nous avons découvert que, selon les 13 critères d'évaluation utilisés, le modèle actuel des soins de santé primaires au Canada présente un faible rendement. Bien que le rendement varie pour ce qui

est des mesures individuelles, les trois autres modèles – établissements ou cliniques normales ciblées, points de contact fixes et points de contact mobiles – présentent un bon rendement. Les résultats laissent croire que des facteurs autres que le rendement des mesures particulières, tels que le coût, la faisabilité, la commodité géographique ou les préférences locales, devraient être employés afin de choisir un modèle particulier. Notre analyse indique clairement que le statu quo pour le modèle de soins primaires est inadéquat quant aux besoins des sans-abri.

THE 1999 CANADIAN NATIONAL HOMELESSNESS INITIATIVE (NOW THE Homeless Partnering Strategy; HRSDC 2008) defined as homeless “any person, family or household that has no fixed address or security of tenure.” How many people fall within this definition is unknown, particularly since “rough sleepers” (persons on the streets) and “couch surfers” (individuals chronically staying with others) are almost impossible to enumerate. However, the 2001 Census found that 14,145 persons were using shelters at any given time in Canada; by the 2006 Census, that number had risen to 19,630 (Statistics Canada 2002, 2008). Males, aged 35 to 64 years, were the most common subgroup within this population, followed by males, aged 15 to 34 years (Statistics Canada 2002). Data from Toronto and Ottawa revealed that families constitute a significant portion of shelter users, occupying 42% and 35% of shelter beds in each city, respectively (Hwang 2001). Aboriginal people are over-represented in the homeless population; in Toronto, they accounted for 2% of the total population in 1999 but 25% of the homeless population (Begin et al. 1999).

It is difficult to describe with precision the health problems of homeless persons, in part because of the heterogeneity of this population across geographical regions (Lindsey 1995). A number of studies have attempted to document the health conditions encountered by homeless populations in specific facilities or regions (Nuttbrock et al. 2003; Blewett et al. 1999; Spanowicz et al. 1998; Plescia et al. 1997). It is apparent that certain conditions, such as trauma, respiratory infections, dermatological conditions, mental illness and substance abuse, are strongly associated with homelessness. Almost all other forms of chronic illness – such as diabetes, osteoarthritis and high blood pressure – that are common in both housed and homeless populations are made worse by homelessness because of inability to receive regular care or to self-manage the condition appropriately. Moreover, diseases such as HIV/AIDS or tuberculosis, which require aggressive treatment, undoubtedly carry a much less favourable prognosis for homeless persons than for the general population. One indicator of the severity of these morbidities is the much higher rate of premature death among homeless persons compared to the housed population (Roy et al. 1998; Hwang 2000).

Despite this substantial burden of illness, homeless persons face a variety of barriers to receiving appropriate healthcare. A significant obstacle to accessing care in Canada is the absence of a valid entitlement document, i.e., a provincial health card (Hwang et al. 2000). Homeless people may be unable to afford supplies or medications that are not covered under provincial healthcare plans (OMR 1996). Physicians' offices are seldom located in areas where homeless people tend to congregate and are usually open only during regular office hours, posing significant transportation and scheduling challenges (Gelberg et al. 2002; Kurtz et al. 2005). Homeless people may encounter psychological barriers, such as fear of care refusal (Bunce 2000) or feelings of stigmatization by healthcare providers (Gelberg et al. 2004). Finally, homeless individuals may delay seeking medical care because other needs, such as securing food and shelter, are more critical to their daily survival.

Homeless persons are numerous, carry a significant burden of illness and face challenges in accessing care. This paper asks the question: What is the most effective way to deliver point-of-first-contact or primary healthcare to homeless persons? A search of the literature revealed insufficient empirical sources to answer the question using standard systematic review methodology. Instead, as discussed below, we used a policy analysis approach.

Data Retrieval

A structured literature search was conducted for English-language publications from 1990 to 2006 in the following databases: Medline, Embase, Cinahl and the Cochrane Library, Social Services Abstracts, Social Sciences Citation Index, Social Sciences Index, Sociological Abstracts, CBCA, Canadian Newsstand, JStor, Readers' Guide and PAIS International. Throughout the study period a "My NCBI Alert" was used to deliver new search results from Medline (PubMed) on a weekly basis, and periodic update searches were conducted in the other databases.

Search strategies for each database were developed using natural-language keywords and controlled vocabulary terms specific to each database. Three related searches covered the following topics: primary healthcare services for homeless persons; impact of primary healthcare services for homeless persons; and health problems of homeless persons.

Additional sources were identified through a manual search of bibliographies and references, and the World Wide Web was searched using Google (advanced search mode) to identify grey literature, organizations involved in providing services to the homeless and examples of programs providing primary care services to homeless persons. All references were recorded in a database created using Reference Manager 11.

Analysis

The search revealed that the literature, though extensive, was largely descriptive. There was insufficient empirical data to conduct a systematic review (Bravata et al. 2005) of primary care delivery methods. There were also too few robust evaluations of primary care programs for homeless persons to permit a narrative synthesis (Dixon-Woods et al. 2004). However, the existing literature did lend itself to a policy analysis approach. Such an approach examines the relevance of specific research findings to a policy issue, weighs the evidence and constructs a logical case about the utility of specific policy options for addressing the issue in light of predetermined policy objectives (Aday and Begley 1993). The key steps in policy analysis are articulating a broad policy goal; dividing that goal into measurable objectives; selecting evaluation criteria by which the attainment of objectives will be assessed; and judging how various policy options are most likely to perform when measured by these predetermined evaluation criteria. In the absence of definitive empirical evidence about the various policy options, this judgment process necessarily represents the informed opinion of the policy analysis team.

Results

The a priori policy goal is to ensure use of the most effective way to provide point-of-first-contact healthcare to homeless persons. Measurable objectives that support this goal may be taken from the seven defining attributes of appropriate primary healthcare recently identified by the Canadian Institute for Health Information through a comprehensive consultation process (CIHI 2006). These attributes correspond closely to the seven desirable system-level service delivery attributes identified by the Working Group on Homeless Health Outcomes for the United States Department of Health and Human Services (US Bureau of PHC 1996). The objectives are:

1. Ensuring access to primary healthcare through a regular primary healthcare provider.
2. Enhancing the population orientation of primary healthcare – for example, health promotion strategies that engage and mobilize the community.
3. Providing comprehensive whole-person care that addresses physical, social and psychological dimensions.
4. Enhancing an integrated approach to 24/7 access.
5. Strengthening the quality of primary healthcare.
6. Building patient-centred care, that is, taking into account the patient's desire for information and decision-making in an empathetic and open manner.
7. Promoting continuity through integration and coordination.

To ensure that the evaluation criteria for each of these objectives are specific to the needs of homeless persons, it is necessary to consult the literature describing the barriers that this disadvantaged population faces in obtaining primary care. That is, evaluation criteria are the adaptations to the delivery and structure of care necessary to counter the barriers. Such adaptations were summarized at the 1998 National Symposium on Homeless Research in the United States (McMurray-Avila et al. 1998) and may be inferred from the many discussions of barriers to care faced by homeless persons (Bunce 2000; Gelberg et al. 2004; McMurray-Avila et al. 1998; OWHC 2002). The criteria deemed most relevant are listed in Table 1.

TABLE 1. Evaluation criteria for homeless primary care

Goal	Objectives	Evaluation criteria
To enhance the health of homeless persons through the provision of optimal primary care	Ensuring access to primary healthcare through a regular primary healthcare provider	<ul style="list-style-type: none"> Entitlement documents not required for care or for ancillary services Service available at venues likely to suit homeless persons
	Enhancing the population orientation of primary healthcare	<ul style="list-style-type: none"> Collaboration with public health authorities on harm reduction strategies
	Providing comprehensive whole-person care	<ul style="list-style-type: none"> Multidisciplinary team care Established referral routes for specialty services Social work assistance available for benefit entitlement, housing
	Enhancing an integrated approach to 24/7 access	<ul style="list-style-type: none"> Service available at times likely to suit homeless persons Evidence of reduced emergency room use
	Strengthening the quality of primary healthcare	<ul style="list-style-type: none"> Special expertise in areas germane to the clinical conditions of homeless persons, e.g., substance abuse, sexually transmitted diseases
	Building patient-centred care	<ul style="list-style-type: none"> User involvement in service planning and operation
	Promoting continuity through integration and coordination	<ul style="list-style-type: none"> Appropriate access to electronic medical records by multiple providers Mechanisms to contact patients Hospital liaison for planning discharge

What are the options for delivering primary care to homeless persons? The literature suggests four broad options, distinguished largely by the location at which care is delivered, but also by associated organizational features: the status quo based on

independent family doctors' offices and three models directed specifically at homeless clients – standard facility/clinic site, fixed outreach site and mobile outreach service. Although the voluminous literature on homelessness and health includes many brief descriptions of local interventions, no single paper provides a sufficiently generic experience upon which broad generalizations can be based. However, from the diverse papers available on each specific model of care, it is possible to extract common characteristics, which can then be reassembled into an archetypal description of that model. The selection of sources is purposive but, for this essentially illustrative intent, need not be either systematic or exhaustive. The resulting description can be moved beyond a synthetic “typical” composite to capture the model's full potential by the addition of innovative but successful features found in only a few sites. The idealized composite picture that emerges may then serve as a paradigm of that model of care when assessing potential effectiveness. A brief description of each model follows.

Primary care status quo

Many types of practices can be found in Canada, but physician-centred solo and small group practices are the norm. In the 2001 National Family Physician Workforce Survey, 73% of family doctors reported that private offices were their main practice setting. Solo practice is more common in inner cities, with 46% of family doctors in these areas reporting solo practice, compared to 19% in isolated or remote areas. Between 1989 and 2000, the number of physicians reporting that they operate “office-only” practices – meaning they did not make house calls, provide hospital or nursing home care, work in emergency departments or provide obstetrical services – rose from 14% to 24%. Most family doctors in Canada are paid on a fee-for-service basis by submitting bills to provincial or territorial health insurance plans for each service provided. Alternative payment structures accounted for 11% of total clinical payments in 2000–2001 but are increasing (CIHI 2003). In 2001, 94% of Canadians aged 15 and over received care from a family physician, commonly during regular office hours. However, almost one in five of those who sought “first contact” services in 2001 had difficulty accessing care at some point in that year (CIHI 2003). The 2004 National Physician Survey found that only 20% of practices were open to new patients, and a Decima poll reported that five million Canadians over 18 years of age were unable to find a family doctor in the 12 months preceding the survey (CFPC 2004).

A recently described typology of Canadian primary care models summarized the status quo under the term *professional contact model*. This model aims to facilitate a care-seeking person's ability to make first contact with the healthcare system. Individuals usually travel to the physician's office, a single location where the physician may practise alone or in a group. Such physicians are rarely associated with other health professionals and are commonly paid on a fee-for-service basis. With the profes-

sional contact model, there is no tool beyond patient loyalty to ensure long-term continuity of care, and there is no formal mechanism to ensure integration with other health services. The model facilitates accessibility and responsiveness to patients but performs poorly in terms of effectiveness, productivity, equity and quality (CHSRF et al. 2003).

Standard facility or clinic site

Descriptions are available in the literature of standard facilities or clinic sites exclusively dedicated to serving homeless persons in Miami (Fournier et al. 1993), New York (Morrow et al. 1992) and Los Angeles (Gelberg et al. 1996); some additional details on the operation of such initiatives were drawn from other published sources. Such clinics may originate as a charitable and volunteer initiative, but generally are affiliated with an institution such as a hospital or community health centre. Academic links providing training for nursing and medical students are common. Care is delivered by multidisciplinary teams, with non-clinical services available from social workers or legal staff. Close connections are maintained with social service agencies and public health units to which clients can be referred. A hospital affiliation facilitates referrals to specialists, but some specialty care may be available on site.

Clinics are often found near shelters, and in some cases outreach visits to these sites may take place. Typically, clinics have both daytime and evening hours of operation. The emphasis is on immediate care for acute illnesses, with the hope that persons requiring more complex care can be successfully integrated into the general health system. Screening and health education are common elements of care (Edwards et al. 1998; Macnee et al. 1996). Care is provided without charge, as are a limited range of medications and laboratory tests. More sophisticated testing may be available from affiliated organizations. A significant number of patient encounters are repeat visits. A broad array of clinical services available in a timely manner may reduce emergency room use.

Fixed outreach model

A composite picture of fixed outreach programs can be constructed from descriptions of initiatives in New York (Plescia et al. 1997), Boston (Kline and Saperstein 1992), New Orleans (Steele and O'Keefe 2001), California (Fiore 1995) and Ohio (DiMarco 2000), with additional details extracted from other sources. "Outreach" in this model refers to care that is provided in non-traditional settings frequented by, or convenient to, homeless persons, in the absence of which such individuals would be unlikely to access services (Morse et al. 1996). The care may be delivered at schools (Berti et al. 2001; Nabors et al. 2004), in community drop-in centres (Cunnane et al. 1995; Reuler 1991) or in transitional housing settings (Rog et al. 1995), but the most common location is at homeless shelters. Regularly scheduled sessions are held at these

venues and are staffed predominantly by nurses but with physicians, social workers and counsellors on the team as well. Care is delivered without charge, and often some medications are also available free of charge to patients. Mechanisms may be in place to expedite registration for benefit programs for those patients who are eligible.

Services include acute care for minor and chronic conditions, preventive care and education, and referral to other providers or agencies. Outreach clinics usually have good linkages with many other health and social agencies, including public health units to which patients can be referred; referrals to community clinics and specialty care at nearby hospitals are common. There may be formal administrative and funding ties between the outreach clinic and established healthcare facilities in the region. Brief clinical records are commonly kept, providing the basis for activity reports that focus on types and volume of services but only rarely on outcomes (Tischler et al. 2002; Bradford et al. 2005; Cunningham et al. 2005). Increasingly, these records are kept in electronic format (Blewett et al. 1999). In a large number of cases patients are seen on only one occasion, but a small number of patients become regular users of these sites. By becoming frequent users with attendant documentation, such individuals assist the clinics accomplish what is often their main goal in addition to the provision of immediate care: helping individuals reintegrate into mainstream care programs by eventually transferring care to more traditional care venues.

Mobile outreach service model

Program descriptions from New York (Redlener and Redlener 1994) and Georgia (Tollett and Thomas 1995; Testani-Dufour et al. 1996), supplemented with details from other programs, provide sufficient information to construct a composite picture of the mobile outreach service model. Mobile services operate from vehicles of various descriptions at sites convenient to homeless persons, such as at shelters or on the streets. Often the units visit their sites on a regular schedule so that clients can anticipate their arrival. The target population may be specialized, such as youth (Auerswald et al. 2006) or persons with mental illness (Farrell et al. 2005; Morris and Warnock 2001), or it may focus on anyone without a home. Visits may be scheduled or offered on a walk-in basis, and there is no cost to the user. The services provided may be determined by a preliminary needs assessment and modified on the basis of subsequent client input. Space may limit the range and volume of services available, but common services include diagnosis, including the performance of basic laboratory tests; the treatment of acute and chronic conditions, for which a limited range of medications may be dispensed; screening and prevention activities; educational interventions; and referrals to other community agencies or specialized care. These services are provided by a team weighted towards nurses but including a variable physician pres-

ence and other providers, such as social workers. Point-of-contact electronic records may be linked to a central database, and hand-held devices may be used to enter new encounter data (Buck et al. 2005; Bunschoten 1994). Success may be measured by such programs on the basis of tabulations of the numbers of client encounters, repeat visits or referrals, or by surveying clients and providers. Sponsors may include independent charitable organizations or healthcare institutions such as hospitals; extensive collaboration with other agencies is common. Costs relative to other delivery methods are seldom reported because they are challenging to assess and may depend on location or funding source (Wray et al. 1999).

Based on the data presented above, it is now possible, as shown in Table 2, to apply the evaluation criteria to the four options. The status quo performs poorly by all but one of the 13 evaluation criteria. While there is variable performance on individual measures, the remaining three models all perform well. This finding implies that some factor other than performance on the specified measures should be used to choose a specific model. Such factors might include comparative costs, feasibility for staffing, geographic distribution of the population served or local preferences.

Conclusion

Primary care in Canada has witnessed the appearance of a number of new models of payment and organization over the last two decades. Some of these may be better suited to meeting the needs of homeless persons than others, but the literature as yet contains no evidence to support this assertion. Indeed, the lack of published research on Canadian programs for the care of homeless persons was a striking finding in this project. To better understand this deficit, a snowballing technique was used to identify 42 primary care programs targeting homeless individuals across Canada. All were approached to take part in key-informant interviews, and 18 agreed. None was able to provide published or unpublished program descriptions or evaluations. There was a consensus among informants that the programs lacked the evaluation skills to create such documents and that any costs associated with creating documents would reduce already inadequate clinical care budgets.

It is easy to assume that a health system such as Canada's, which provides universal first-dollar coverage, meets the health needs of homeless persons. But the concept of "horizontal equity" that underlies the system – equal needs receive equal resources – fails to appreciate the different and far greater needs present in vulnerable groups. These populations require a system that incorporates "vertical equity," that is, the capacity to meet unequal needs with unequal resources. The disproportionate burden of illness borne by the homeless population constitutes a dramatic inequality of health need, yet in comparison to specialized services designed to meet these needs, the cur-

rent model of primary care in Canada is inadequate. To ignore this inadequacy by failing to provide specialized care is to permit the operation of what has been termed the “inverse care law,” which states that “the availability of good medical care tends to vary inversely with the need for it in the population served” (Hart 1971: 405). If, as has been proposed, a measure of any health system’s merit is the way in which it treats its most vulnerable citizens (Brownell et al. 2001), Canada’s primary care system must urgently address the health needs of the homeless population.

TABLE 2. Evaluation of four models

Evaluation criteria	Status quo model	Standard facility/ clinic site	Fixed outreach site	Mobile outreach service
Entitlement documents not required for healthcare or for ancillary services	poor	excellent	excellent	excellent
Service available at venues likely to suit homeless persons	poor	well	excellent	excellent
Collaboration with public health authorities on harm reduction strategies	poor	well	adequate	adequate
Multidisciplinary team care	poor	excellent	excellent	excellent
Established referral routes for specialty services	excellent	excellent	excellent	adequate
Social work assistance available for benefit entitlement, housing	poor	excellent	excellent	well
Service available at times likely to suit homeless persons	poor	well	adequate	excellent
Evidence of reduced emergency room use	poor	adequate	unknown	unknown
Special expertise in areas germane to the clinical conditions of homeless persons, e.g., substance abuse, sexually transmitted diseases	poor	excellent	excellent	well
User involvement in service planning and operation	poor	poor	poor	adequate
Appropriate access to electronic medical records by multiple providers	poor	well	adequate	well
Mechanisms to contact patients	poor	well	fair	fair
Hospital liaison for planning discharge	poor	unknown	poor	poor

Assessment scale: poor–fair–adequate–well–excellent.

ACKNOWLEDGEMENTS

This study was made possible by an operating grant from the Canadian Institutes of Health Research.

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Healthcare Policy/Politiques de Santé, and has played a key role
in the journal's inception and development.

Longwoods Publishing gratefully acknowledges the
financial support of the following organizations:



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Fondation canadienne de la recherche sur les services de santé



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ONLINE EXCLUSIVES

**Physician Experiences Providing Primary Care to People with Disabilities****Expérience des médecins offrant des soins de santé primaires aux personnes présentant une incapacité**

MARY ANN MCCOLL, DONNA FORSTER, S.E.D. SHORTT, DUNCAN HUNTER, JOHN DORLAND, MARSHALL GODWIN AND WALTER ROSSER

Abstract

The 2003 Statistics Canada Health Services Access Survey found that 12% of Canadians polled did not have a family doctor, and 18% reported access problems such as long waiting times and difficulty contacting the doctor. Research has repeatedly shown that where a problem with access exists in the general population, it is considerably more severe in subsets of the population that are most disadvantaged. Statistics at both the national and local levels confirm that although people with disabilities have greater need for health services, including both institutional and community services, they also experience significant disadvantages in attempting to access service. The question explored in this study is how physicians' perceptions of disabled patients and behaviour towards them might affect access to primary care for adults with disabilities. The study used a qualitative interpretive approach to uncover physicians' perspectives on working with people with disabilities. Semi-structured interviews were conducted with a sample of 34 physicians in Eastern Ontario. Physicians were asked:

- How are disabled patients similar to/different from non-disabled patients?
- How are you as a physician different with disabled patients?

Physicians' perceptions, as revealed by their responses to these questions, were interpreted in terms of four types of barriers to access to primary care for disabled adults: physical, attitudinal, expertise-related and systemic. These barriers were examined for their impact on finding a doctor, getting an appointment, getting into the office and receiving a reasonable standard of care.

Résumé

L'Enquête sur l'accès aux services de santé (Statistique Canada 2003) montre que 12 % des Canadiens interrogés n'avait pas de médecin de famille et que 18 % d'entre eux

ont signalé des problèmes d'accès tels que les temps d'attente et la difficulté à entrer en contact avec le médecin. Les recherches ont maintes fois démontré qu'il y avait un problème d'accès pour la population en général. Ce problème est d'autant plus sévère pour les secteurs de la population les plus désavantagés. Les statistiques nationales et locales confirment que bien que les personnes présentant une incapacité ont davantage besoin de services de santé, que ce soit des services institutionnels ou communautaires, ce sont également celles qui souffrent le plus de désavantages dans l'accès aux services. La présente étude pose la question à savoir si les différences dans la perception des médecins envers les patients présentant une incapacité et si leur comportement face à ces patients mènent à des iniquités d'accès aux soins primaires pour les adultes ayant une incapacité. La méthode qualitative/interprétative a été employée pour connaître le point de vue des médecins sur leur travail avec des personnes présentant une incapacité. Des entrevues semi-structurées ont été menées auprès d'un échantillon de 34 médecins de l'Est ontarien. On leur a demandé :

- En quoi les patients présentant une incapacité sont-ils semblables ou différents des autres patients?
- En tant que médecin, agissez-vous différemment envers les patients présentant une incapacité?

La perception des médecins, tel que le montre leurs réponses, a été interprétée en quatre types d'obstacles à l'accès aux soins primaires pour adultes présentant une incapacité : physique, psychologique, lié à l'expérience et systémique. On a étudié ces obstacles selon leur impact dans la recherche d'un médecin, dans la prise d'un rendez-vous, dans l'accès au cabinet du médecin et dans l'obtention normale de soins acceptables.

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ONLINE EXCLUSIVES

**Variations in Lifetime Healthcare Costs across a Population****Variation des coûts de services de santé au cours de la vie pour une population donnée**

EVELYN L. FORGET, LESLIE L. ROOS, RAISA B. DEBER AND RANDY WALLD

Abstract

The mean costs of providing healthcare increase with age, but within every age/sex cohort there is substantial variation. Moreover, this variation does not disappear over the users' lifetime. This study applies Markov modelling to administrative data to examine the variability of healthcare costs currently covered under the *Canada Health Act* across a population and over the lifespan. Policy initiatives that ignore individual variability across the lifespan yield inequitable results. For example, age-specific policies that exempt seniors from costs charged to the rest of the population will transfer healthcare resources to healthy low-cost seniors from younger individuals with higher needs.

Résumé

Le coût moyen de prestations de services de santé accroît avec l'âge, mais au sein de toute cohorte âge/sexe il existe des variations substantielles. Or, ces variations ne s'estompent pas au cours de la vie des utilisateurs. La présente étude applique le modèle de Markov aux données administratives pour étudier la variabilité des coûts de services de santé présentement couverts par la *Loi canadienne sur la santé* pour une population donnée au cours de la vie de l'utilisateur. Les initiatives politiques qui ne tiennent pas compte des variabilités individuelles au cours de la vie mènent à des résultats inéquitables. Par exemple, les politiques fondées sur l'âge qui accordent aux aînés une exemption de coûts par rapport au reste de la population conduiront à un transfert des ressources en faveur d'aînés sains et peu coûteux au détriment de jeunes personnes dont les besoins sont importants.

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ONLINE EXCLUSIVES

**Health System Organization and Governance in Canada and Australia: A Comparison of Historical Developments, Recent Policy Changes and Future Implications****Organisation et gouvernance des systèmes de santé au Canada et en Australie : comparaison du parcours historique, des changements politiques récents et des répercussions à venir**

DONALD J. PHILIPPON AND JEFFREY BRAITHWAITE

Abstract

The Canadian and Australian health systems have evolved in very similar ways. Recent policy changes in each country, however, suggest a growing divergence with respect to governance. This paper traces the origins and key milestones in the evolution of governance models, with a selective focus on two provinces in Canada (Saskatchewan and Alberta) and the state of New South Wales in Australia. While divergent models seem to be manifesting, many similar underlying features remain. We assess these developments and comment on the current patterns of organization and governance, both to provide insights on future directions and to suggest what the two countries might learn from each other.

Résumé

Les systèmes de santé au Canada et en Australie ont évolué de façon similaire. Toutefois, les récents changements de politiques dans les deux pays portent à croire qu'il y a une divergence grandissante quant à la gouvernance. L'article relate les origines et les principales étapes des modèles de gouvernance respectifs des deux pays, plus précisément ceux de deux provinces canadiennes (la Saskatchewan et l'Alberta) et ceux de l'État de la Nouvelle-Galles du Sud, en Australie. Bien que les modèles semblent divergents, il existe entre eux plusieurs caractéristiques similaires. Nous évaluons leur progression et commentons les modèles d'organisation et de gouvernance actuels, à la fois pour donner un aperçu des orientations à venir et pour dégager ce que ces pays peuvent apprendre l'un de l'autre.

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Review of applications will commence on October 1, 2008 and continue until the position is filled.

Physician Experiences Providing Primary Care to People with Disabilities

Expérience des médecins offrant des soins de santé primaires aux personnes présentant une incapacité



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Abstract

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Résumé

L'Enquête sur l'accès aux services de santé (Statistique Canada 2003) montre que 12 % des Canadiens interrogés n'avait pas de médecin de famille et que 18 % d'entre eux ont signalé des problèmes d'accès tels que les temps d'attente et la difficulté à entrer en contact avec le médecin. Les recherches ont maintes fois démontré qu'il y avait un problème d'accès pour la population en général. Ce problème est d'autant plus sévère pour les secteurs de la population les plus désavantagés. Les statistiques nationales et locales confirment que bien que les personnes présentant une incapacité ont davantage besoin de services de santé, que ce soit des services institutionnels ou communautaires, ce sont également celles qui souffrent le plus de désavantages dans l'accès aux services. La présente étude pose la question à savoir si les différences dans la perception des médecins envers les patients présentant une incapacité et si leur comportement face à ces patients mènent à des iniquités d'accès aux soins primaires pour les adultes ayant une incapacité. La méthode qualitative/interprétative a été employée pour connaître le point de vue des médecins sur leur travail avec des personnes présentant une incapacité. Des entrevues semi-structurées ont été menées auprès d'un échantillon de 34 médecins de l'Est ontarien. On leur a demandé :

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THE HEALTH SERVICES ACCESS SURVEY (STATISTICS CANADA 2004) clearly shows that Canadians experience problems with access to primary care. According to the survey, 12% of Canadians polled did not have a family physician, and 18% reported problems with access, such as long waiting times or difficulty reaching the doctor. Problems that delay access to primary care can result in higher downstream costs of health services. Sanmartin and Ross (2006) found that the lack of a family doctor was one of the most significant determinants of failure to receive necessary care. Research has repeatedly shown that where a problem with access exists in the general population, it is considerably more severe in subsets of the

population that are most disadvantaged (Brownell et al. 2001). Sanmartin and Ross (2006) confirmed that the presence of a disability (operationalized as activity limitation) increased the odds of failing to receive necessary routine care by more than 50%.

“Access,” a term that typically refers to human resources shortages or problems in geographic distribution of providers, has become one of the most pressing issues for health policy; however, for people with disabilities, access is a much broader and more important issue (Neri and Kroll 2003). It includes:

1. the physical configuration of the practice – e.g., stairs, doorways, examining tables;
2. the attitudes of providers and staff towards people with disabilities;
3. expertise about the natural course and typical complications associated with disability;
4. systemic factors that act as disincentives or obstacles to access or equity (McColl 2006).

For people with disabilities, access issues can actually prevent their receiving service, not simply delay or inconvenience it.

One of the key determinants of access to health services for people with disabilities is provider perspectives and understanding of disability. Even unrecognized perceptions can influence physicians’ judgments and interventions, and have profound effects on the treatment process (Duckworth 1988). Sanchez and colleagues (2000) observed that attitudes of providers towards people with disabilities remained a significant deterrent to good-quality care. Furthermore, the issue of physician attitudes towards disability was complicated by a perception that attitudes were already all that they should be (Sanchez et al. 2000). Unfortunately, negative attitudes among physicians mirror those of society in general, creating obstacles for people with disabilities (Antonak and Livneh 2000).

Negative attitudes towards disability can assume a number of different forms. The simplest is the view that a person’s disability is a negative trait (Tervo et al. 2002) or an abnormality (Office for Disability Issues 2004). Equally unhelpful is to view the disability as an illness. Jorgensen (2005) found that physicians looked at disability as illness, whereas the disabled patient considered the disability a condition of life. While illness and disability may (and often do) co-exist, the two call for quite different responses from clinicians (Paris 1993). Whereas illness elicits an acute, curative response, this approach is not applicable to a condition that is a part of everyday life for the patient. It inappropriately perpetuates the “sick” role and is ultimately disempowering for people who are often struggling with conditions that are already challenging (McColl and Bickenbach 1998).

There is an interesting paradox in physicians' perceptions of disability. Veltman et al. (2001) reported that one-fifth of doctors did not take adequate account of the disability, while another fifth tended to attribute everything to the disability, and therefore did not explore new complaints as thoroughly as was warranted. Misunderstandings and discordant expectations between physicians and disabled patients exist regarding patients' overall health, potential for recovery and even life expectancy (Iezzoni et al. 2003).

There are four points at which patients experience barriers to access in primary care: finding a doctor, getting an appointment, entering and using the facilities in the practice, and receiving a reasonable standard of care. The purpose of this study was to describe the issues and challenges confronting family physicians in providing excellent care to their patients with disabilities, and to assess the impact of those issues on access to primary care for people with disabilities. The four types of barriers (physical, attitudinal, expertise-related and systemic) and the four access points (signing up, getting an appointment, being examined, obtaining quality care) can be grouped into a matrix that offers a framework for subsequent discussions of our results (see Table 1).

TABLE 1. Matrix of barriers and access points

Areas of access	Types of barriers			
	1. Physical	2. Attitudinal	3. Expertise-related	4. Systemic
a) to a doctor		X		X
b) to an appointment		X		X
c) to the office	X	X		
d) to a high standard of care	X	X	X	

X = Cells where our findings provide evidence of the presence of barriers for people with disabilities.

Methods

Design

The goal of this study was addressed using a qualitative interpretive approach to uncover physicians' perspectives on working with people with disabilities. The study was part of a larger quantitative study looking at the effect of payment type on quality and access to primary care for people with disabilities. The semi-structured interview administered to a subsample of physician participants permitted exploration of issues arising at the level of the individual physician in providing primary care to his or her patients with disabilities.

Sample

Physicians in Eastern Ontario were invited to participate in this study if they:

- had been in the same practice for at least one year;
- provided ongoing comprehensive care to patients (practices that were limited to a specific component of care, e.g., psychotherapy, were excluded);
- were located in a community setting;
- had patients with one of a list of severe physical or cognitive disabilities (spinal cord injury, acquired brain injury, intellectual disability, cerebral palsy, rheumatoid arthritis, post-polio, other mobility-related disability).

Of 241 practices in the region, 503 physicians were initially identified. On the basis of the criteria above, 125 were deemed ineligible. Of the remaining 378, 305 declined or did not respond to the letter of invitation, mostly owing to issues of time or space. The remaining 73 physicians participated in the larger study of which this was a part, and 34 participated in this qualitative study. Practices with more than one participating physician were encouraged to select one person to participate in the interview so as not to overweight the responses by one organization.

The 34 physicians who volunteered to participate in the qualitative study were evenly distributed across three payment types – 11 each for salaried and capitation practices and 12 from fee-for-service (FFS) practices. Twenty-three (67.6%) of the physicians interviewed were female, and 21 (61.8%) were from rural areas. Twenty-four physicians (70.6%) worked full time. Most of the FFS and capitation physicians interviewed worked full time at one practice, whereas only three of 11 salaried physicians worked full time at one location.

Data collection

Qualitative interviews were conducted to solicit information about how family physicians work with and perceive their interactions with patients with disabilities (see Figure 1). The interview was semi-structured and permitted exploration of issues arising at the level of individual physicians in their relationships with disabled patients. The 15- to 30-minute interview usually took place in the physician's office or exam room. These interviews were taped and transcribed. The interviews were analyzed using NVivo software. Interview data were initially coded according to three core questions:

1. How are disabled patients different from non-disabled patients?
2. How are disabled patients similar to non-disabled patients?
3. How is the physician different with disabled patients?

Data were partitioned into three subsets according to these questions and then open-coded line by line for content. Codes were subsequently categorized into themes, and themes were developed when at least three interviewees raised the issue. This process generated a finite set of themes associated with each of the core questions.

FIGURE 1. Interview schedule for qualitative data on physicians' perceptions

1. In this study we are particularly interested in adults with physical or cognitive disabilities in your practice who are between 18 and 65 years of age.
(Please write down the names or initials of patients with the following diagnoses, so that you may refer to them in responding to subsequent questions: spinal cord injury; acquired brain injury; multiple sclerosis; cerebral palsy; post-polio syndrome; intellectual disability; rheumatoid arthritis; other disabling condition.)
2. How do their health complaints compare with your average non-disabled patients of the same age?
(Probe: How are they the same / different from their non-disabled contemporaries?)
3. How do you think your experience with these patients differs from that with your other non-disabled patients of the same age?
(Probe: Do they have a longer set of issues, types of services, number of visits per year, referral needs, amount of time per office visit, staff accommodations, etc.?)
4. Are there any special considerations that they require?
(Probe: These considerations may be things that you do provide, or things that you are not able to provide.)
5. Are there any primary care services that you are unable to provide to your patients with disabilities?
6. What else, if anything, do you need in order to be able to provide what you consider excellent care to your patients with disabilities?

Ethical considerations

The research protocol and consent form were submitted to and approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board in December 2003.

Results

This section summarizes the comments made by physicians about their experiences with disabled patients in their practice. The discussion is augmented with verbatim quotations taken from the transcripts.

Question #1: How are disabled patients different from non-disabled patients?

In response to inquiries about how disabled patients differed from other patients in the physician's practice, interviewees offered a number of very consistent observations.

MORE TIME REQUIRED

It was consistently reported that disabled patients needed more of the physician's time than non-disabled counterparts. The explanation for this included physical, communication and cognitive aspects of disability. In terms of physical factors, disabled patients were often slower in their movements, taking more time to dress and undress themselves, requiring more time for the physician to position and examine them, and taking longer to enter and leave the office. Physicians noted a need to physically rearrange office space before and after an office visit from a patient with physical disabilities.

Communication with disabled patients was also noted to be more time intensive for several reasons. Depending on the disability, patients might experience dysarthria, causing them to communicate more slowly, or they might use technological aids, slowing the process. Family physicians noted that they tended to question the patient with a disability in a different way – they asked more probing questions and gave more attention to circumstances of the complaint and whether doctor and patient had understood each other accurately. When family members or caregivers attended appointments, three-way conversations were more time-consuming. Patients with a cognitive disability required either more detailed or simplified instructions and explanations. Some also required written material to support verbal directives.

PREMATURE AGING

Some physicians noted that their disabled patients seemed to age prematurely. That is, at mid-life they seemed to have problems more usually associated with old age. Patients with developmental disabilities in mid-life were observed to experience dementia and other medical conditions typically associated with an older age cohort:

“She is just in her early 60s, maybe late 50s even, but the complaints are, I think, more similar to someone who might be in her 70s or 80s, and she looks older as well. In the sense of just getting around, she seems frailer than people of her age.”

SPECIFIC HEALTH ISSUES

Physicians noted a number of common health problems that people with disabilities typically encounter. These pertained mostly to those patients with mobility impairments. Physicians noted specific health concerns, including pain, bladder, bowel and skin problems. Limited sensation was also noted as the source of a number of presenting problems common among disabled patients.

VULNERABILITY

Family physicians were aware that their disabled patients were potentially more vulnerable. From a medical point of view, their health was considered more vulnerable to secondary complications, such as unattended minor infections that progress quickly to major infections. Physicians also noted that medical issues among people with disabilities were often influenced by financial issues and economic vulnerability. Disabled patients were perceived to be at increased risk of physical and sexual abuse:

“Many of our clients are not only disabled, they are also in a lower socio-economic group, so sometimes there’s the third component, which is sort of their interface with society and the variety of organizations and bureaucracy they have to contend with. ... These people are very vulnerable, very vulnerable in many ways. They’re vulnerable medically, they’re vulnerable to abuse, they’re vulnerable in their living situation.”

COMPLEXITY

In general, physicians perceived that their disabled patients had more problems than their non-disabled patients, and that their problems were often not amenable to the tools available to the family physician:

“They tend to have more problems, and those problems are often not usually solvable problems. Often their disabilities are fixed or they’re slowly progressive; there’s really very little you can do other than help to deal with that process – whereas if you had a diabetic, you could help to reverse that, stop it.”

Several interviewees felt they needed more training to assess and treat these patients properly. They were unsure how to properly position or examine a patient who lacked sensation, or who experienced spasticity or paralysis. Physicians indicated that they had not been trained in handling procedures relative to specific disabilities and were uncertain about them.

Several physicians also observed that their disabled patients had a greater need for medication than their non-disabled patients, and that finding the right medications for them was difficult. Concerns included difficulty finding medications that addressed chronic pain, interactions between medications, and conditions that did not respond as expected to treatment. There was further concern about treatment interactions for multiple problems and about the development of antibiotic resistance over time. It was also noted that disabled patients often required more office visits because they had multiple issues or problems, greater need for follow-up regarding these issues, and increased complications related to their specific disabilities.

COORDINATION

Interviewees observed that their disabled patients often required services that could not be provided in the physician's office, and they therefore referred them to a number of other community services and professionals. In addition, most disabled patients had specialists and were followed by community agencies where they received professional and non-professional services. Family physicians viewed themselves as the central coordinator for all these services. Not only did they refer and facilitate access to these services, they also provided follow-up and interacted with external care providers:

"Then there's a huge function of kind of being the receptacle for different reports coming in, and following and finding out what's going on. You have to be kind of like a traffic cop, directing them to the appropriate resources, is the way I look at it."

IMPORTANCE OF RELATIONSHIPS AND LIVING SITUATION

Physicians demonstrated an awareness of the importance of family and living situation for their disabled patients, to a greater extent than for their non-disabled patients. Depending on the patient's level of disability, physicians expressed an increased need to assess and be aware of who was providing care or support in the immediate living environment. Physicians were aware of the need for family members and caregivers to be involved in discussions regarding care of their disabled patients. They were sensitive to the financial and time commitments required of family caregivers. With regard to patients living in group homes, community support staff often provided a level of assurance of health supervision. These individuals could be a valuable source of information about health issues and often facilitated attendance at appointments.

SOCIAL ISSUES

In general, family physicians noted that their disabled patients needed physician assistance to complete forms for access to services and benefits for which they might be eligible. Family physicians also noted that their disabled patients experienced a variety of psychosocial problems and, although they were related to community care and relationships, these required the attention, time and concern of the family physician:

"So they come with a different kind, a set of different problems than somebody fully mobile does. ... They may be having difficulty getting certain things done through the system, so for instance they might need me to fill out forms. They may require some paperwork from some government ministry that needs to be filled out so that they can get a motorized scooter or get paid for some grab bars in their bathroom."

Physician Experiences Providing Primary Care to People with Disabilities

LEARNING FROM PATIENTS

Family physicians noted that their disabled patients offered them an educational opportunity. Disabled patients taught them about specific medical issues, such as management of complex or repeated urinary tract infections, but also about assumptions made regarding health and wellness. Several physicians commented on the rewards of caring for patients with disabilities:

“They add a lot to the practice too, they teach me a lot. We all assume that we have four limbs, but one chap, he is a paraplegic because of a car accident, he teaches me stuff that I need to know.”

ADAPTATION

Physicians noted that their disabled patients were often able to adapt and cope better than their non-disabled counterparts. Physicians felt that their disabled patients were on the whole happier with their lives and less likely to complain than their non-disabled patients:

“And they seem to be happy with their lot, curiously, more than many of us. We should follow their example.”

Question #2: How are disabled patients similar to non-disabled patients?

Physician interviewees also reported a number of ways in which their disabled patients were no different from other patients.

BASIC PRIMARY CARE

Physicians felt that disabled patients experienced the same range of general health problems as their non-disabled patients. Family physicians were equally aware of the need for health monitoring and other regular health services among their disabled and non-disabled patients. They also noted that their disabled patients had the same need for prevention and screening as their non-disabled patients.

THERAPEUTIC RELATIONSHIP

Family physicians noted that there was the same need among disabled as non-disabled patients to form a therapeutic relationship that was unique and workable for each patient. Regardless of disability, there was a general need to think about a patient's personality and how best to work with him or her. For one interviewee, treating a patient

with a mental disability as if he were not disabled seemed to be the key to the therapeutic relationship:

“They’re the same because they’re human beings. We’re all the same at some point. There are the same issues in terms of how you forge that therapeutic relationship ... figuring out the key to each relationship and how to help people and how to understand how they are looking at and dealing with their own situations.”

EXPECTATION FOR RECOVERY

Physicians noted that their disabled patients were as likely as their non-disabled counterparts to expect a full recovery from illnesses or new conditions that brought them to the doctor. They expected to be treated as aggressively as anyone else, and to be given every chance to have optimum health despite their disability. In some ways, recovery from minor concerns is doubly important for individuals with pre-existing disabilities, so that new complaints do not further compromise independence and quality of life.

DIFFICULTY OBTAINING NECESSARY SERVICES

Physicians noted that all their patients had difficulty accessing a variety of services in the community, such as nutrition counselling, physiotherapy and occupational therapy. Systemwide shortages made access to needed services difficult for both disabled and non-disabled patients. Physicians felt that long waits were experienced by all patients and that there was a general lack of access to needed programs. Disabled patients had no advantage in terms of accessing services in short supply.

Question #3: How are you different with disabled patients?

Data were coded to uncover how interviewees felt they behaved differently towards their disabled and non-disabled patients.

EXTRA TIME ALLOWED

Just as interviewees noted that disabled patients typically take more time than non-disabled, some also noted that they allow more time. They routinely book double appointments for their disabled patients in order to ensure that their care is properly reviewed and that assessments can be done in a thorough and comprehensive manner. One salaried physician noted that salaried practice offered the economic luxury of discretion about the allocation of time.

“Sometimes we do have to book some extra time because we say, okay, I’ve got to get this person in and really review things and make sure we’re on track. ... [R]ightly or wrongly, there are often annual or periodic assessments booked for an hour rather than the usual half an hour.”

HOME VISITS

When asked, family physicians noted that they accommodated their disabled patients through making home visits. These visits ranged from occasional to regular to frequent occurrences as part of care provision. Reasons given for home visits included the patient’s lack of mobility, lack of transportation and difficulty getting into the office. Where allied health staff were available, home visits were often conducted by other members of the healthcare team, such as nurses or social workers:

“Well, certainly from the physical logistics of the office, which you are probably aware, there are some patients that I can’t see in the office because they are in a wheelchair. So those ones I have to make special dispensation for and I just visit them at home.”

TELEPHONE CONSULTS

Although telephone prescriptions and consultations are not how practices typically function, physicians reported that they made exceptions for their disabled patients. In recognition of the patient’s difficulty coming in to the office, and also in recognition of their own inability to schedule a home visit on short notice, physicians volunteered that they would use the telephone as a means of conducting a patient interview. In addition, several interviewees stated that they would call in prescriptions over the phone to save a disabled patient a trip to the office. They noted that they were much more likely to do this for patients with mobility issues as compared to intellectual disabilities. Some physicians also provided counselling over the phone.

MORE COUNSELLING/FOCUS ON COPING

Family physicians commented that they provided regular, and in some cases frequent, counselling to their disabled patients. Although they admitted that they lacked expertise in counselling specific patients, such as those with intellectual disabilities, they considered it an essential part of the care provided. Individuals with mental disabilities were perceived as requiring a great deal of counselling and support, as well as assistance with social relationships. Counselling sessions often included family members

and caregiving staff, and sometimes involved other professionals where available, such as the nurse practitioner or social worker.

INSISTANCE ON ATTENDANT

Not all reported differences in physicians' treatment of disabled and non-disabled patients made primary care more accessible for those who are disabled. Many of our physician interviewees volunteered that they required their disabled patients to bring someone with them who could help with access if required. For patients with physical disabilities, the required assistance typically related to dressing and positioning. For patients with cognitive disabilities, it related to both the provision and the receipt of information.

LESS LIKELIHOOD OF EXAMINATION

Physicians noted that they were less likely to examine disabled patients for a variety of reasons. Patients with mobility issues were difficult to transfer onto an examining table. Dressing and undressing sometimes took a considerable amount of time and required a skilled assistant. Physicians' offices often lacked equipment, such as transfer lifts or adjustable examining tables that facilitate moving patients. Physicians commented that they sometimes did partial examinations when a thorough examination exceeded the bounds of ability or efficiency. They admitted that many of their disabled patients had not had a complete physical examination for as long as they could remember. Further, they acknowledged that they were more likely to accept a verbal report from a disabled patient, and to proceed to treat without examination, than they were for a non-disabled patient:

"If it's difficult to do a physical examination because you have to transfer them, and you have to get someone to help you to do that, you are going to be more reluctant to do it. So you might do it less frequently than you would like to or than you ordinarily would."

LOSS OF FOCUS ON PREVENTION

For a variety of reasons, many of our interviewees noted that their disabled patients did not get the same consideration in regard to preventive healthcare as their non-disabled contemporaries did. For example, physicians noted that it was difficult to check blood pressure on patients whose arms were contracted. Some patients were not weighed because they couldn't get on the scale. Family physicians noted that they

sometimes lost track of regular preventive care issues with their disabled patients because of the volume of other health concerns. Long-term health and maintenance of regularly scheduled care was not a priority. Physicians also noted that their patients were concerned about the number of medical appointments they had and did not wish to come in for regular preventive care:

“And in all honesty, you may forget about some of the long term, health maintenance things, such as preventative manoeuvres, because you are focusing a bit more on the day-to-day management of their disability.”

LESS ATTENTION TO SEXUAL OR REPRODUCTIVE ISSUES

Patients' level of comprehension was identified as an issue that influenced the likelihood of some preventive care, particularly those tests related to reproductive or sexual issues. Patients with intellectual disabilities were less likely to be provided with Pap smears and breast, pelvic or prostate exams because physicians felt they would not understand the rationale behind these. Referring specifically to mammograms and Pap smears, physicians reported that they sometimes waived these tests in patients with intellectual disabilities for fear that the patient would not understand the need for the test or would not tolerate it. In addition, physicians' sensitivity about sexual abuse influenced their physical examination. One interviewee noted that doctors needed to be more aware of personal safety issues and about explanations for specific types of examinations, such as Pap smears.

Another issue was the assumption that disabled patients were not sexually active and therefore did not need to be treated the same as non-disabled persons of their age and gender. For example, disabled women might not be offered birth control or fertility counselling because of issues associated with their disability:

“There were some issues about birth control and things which of course are issues for any woman in her 30s. The concern was over why she needed it.”

Discussion

Our results showed that physicians noted numerous important differences between their disabled and non-disabled patients, and they were remarkably consistent in their views. They stated unequivocally that disabled patients took more time and were more complex. Furthermore, they noted very astutely that caring for a disabled patient required them to provide more social care rather than strictly medical care. Our interviewees employed a number of creative strategies for overcoming issues of access and

hardship for their disabled patients, yet they admitted that basic primary care, like physical examinations and preventive health measures, suffered because of logistical difficulties and constraints on physicians' time.

In several cases, physicians acknowledged that their offices did not permit wheelchair access, nor did they have special facilities to accommodate sensory or cognitive disabilities. Interviewees admitted that they were unaware of the correct manner of providing physical assistance to disabled patients, and in some cases were unwilling to do so. Given the time required to transfer, position and undress such patients, this meant that family doctors were less likely to examine a disabled patient and more likely to accept the patient's verbal report of a problem. There were varying views on this issue of providing assistance during the appointment, with some family doctors saying they simply provide the needed assistance themselves, and others saying they cannot be expected to do so. Several of our interviewees offered that they had no training in how to relate to or assist someone with a disability. They not only had personal discomfort with the issue, but also perceived potential professional liability if an incident, such as a fall, occurred.

Attitudinal barriers potentially affect access at all four access points shown in Table 1. Although our small sample provided no evidence of it, there are suggestions elsewhere in the literature that disabled patients may be systematically excluded from family practices because of the burden they are perceived to impose on the physician's time (Batavia and DeJong 2001; DeJong 1997; McColl 2006). In our study, attitudinal barriers appeared only with regard to accommodating the special needs of disabled patients in the practice. Several physicians noted that they required their disabled patients to bring an attendant to assist with functions such as transferring, dressing and undressing, communication and follow-through. This requirement potentially diminishes the second type of access (to an appointment) because of the necessity to schedule appointments when the attendant or assistant can be available. While it may enhance the third and fourth types of access (access to the office and equipment, and access to a high standard of primary care), it may impede confidentiality and full disclosure because of the lack of privacy between patient and doctor.

Expertise-related barriers have their primary impact on the standard of care delivered. As several authors have pointed out, the inability to diagnose disabling conditions accurately and to anticipate further disabling consequences is a significant deterrent to high-quality primary care (Glazier 2004; Bernatsky et al. 2006). While our interviewees were clearly experts in primary care, many noted the need for more information about disability. They observed that the average practice would contain only a few patients with disabilities, and that it was difficult for doctors to develop an understanding of the issues on that basis. Particularly since disability can stem from a variety of diagnoses, and can be highly variable in its presentation from person to person, it is difficult for family physicians to achieve any sort of critical mass in a typical practice to permit them to acquire the necessary expertise. They admitted that they

had relatively little exposure to adult disability in medical school or residency training, and were more familiar with the concept of disability in their elderly patients (Claxton 1994). Recently, consensus guidelines have been published for primary care of adults with developmental disabilities (Sullivan et al. 2006). These make a compelling case for the need for special attention to disability-related issues, but they also serve as an acute reminder of the complexity and resource-intensive nature of providing excellent primary care to people with disabilities.

Systemic barriers include shortages and maldistribution of physician human resources, both of which can lead to difficulties finding a doctor and long wait times due to large caseloads. Recent data from the College of Family Physicians of Canada (2005) show that only 20% of family practices are open to new patients. Systemic barriers are experienced by all patients; however, barriers are potentially exacerbated for disabled adults, who physicians virtually unanimously report take more time. For physicians in volume-driven practices, whether fee for service or capitation, taking more time is inconsistent with the financial incentive system. Patients who require more time than the standard 10- to 15-minute appointment become an economic liability (Chisholm and Stewart 1998; Barros 2003). Furthermore, there are often no supports to assist physicians with complex patients in solo or small practices, such as other health professionals or even administrative staff, to fulfill some of the functions that are not strictly medical. Because of the additional time needed to treat disabled patients, the current rates of remuneration may make these patients financially disadvantageous for the physician.

Disability groups have argued that physicians should not need to be given incentives in order to provide the same standard of care to disabled patients that they provide to non-disabled. If we consider primary care a service to which all are entitled, there should be no need to explicitly reward provision to disabled people. This approach would represent horizontal equity – assuming that disabled people are equal to other citizens, they should be provided with equal access to resources. The alternative position, vertical equity, would recognize that where healthcare is concerned, disabled people are not like other patients (McCull et al. 2006; Mercer et al. 2003). They are high users of care and experience considerable unmet needs within the healthcare system (McCull 2005; McCull and Shortt 2006). Furthermore, they are acknowledged by physicians to require on average a greater investment of medical human resources. The way to achieve equity, therefore, is through resource allocation commensurate with patients' needs. This issue is one of the most difficult in service provision to people with disabilities: whether to adopt a universalist, human-rights approach and treat disabled people like everyone else, or whether to recognize the special needs of disabled people and treat them as a minority group whose needs are explicitly ensured. The rhetoric on disability policy reflects both these positions with equal force.

To date, the issues of people with disabilities have received little attention in most

jurisdictions in the process of primary care reform. Adults with disabilities are high users of primary care. They make three times as many visits to the family doctor as their non-disabled contemporaries, and yet they report three times as many unmet needs (McColl et al. 2005; McColl and Shortt 2006). The costs of providing service to this population may be higher than average, but the costs of ignoring them will surely be higher still. The recent emphasis on multidisciplinary provision and chronic disease management in primary healthcare may well address some of these problems. However, Canada lags behind other developed countries in implementing chronic disease management and multidisciplinary care. Morgan et al. (2007) refer to this as an “inconvenient truth.” While it may be inconvenient for many Canadians, like all access problems, it has potentially greater consequences for people with disabilities.

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RESEARCH PAPER

Variations in Lifetime Healthcare Costs across a Population

Variation des coûts de services de santé au
cours de la vie pour une population donnée



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Abstract

The mean costs of providing healthcare increase with age, but within every age/sex cohort there is substantial variation. Moreover, this variation does not disappear over the users' lifetime. This study applies Markov modelling to administrative data to examine the variability of healthcare costs currently covered under the *Canada Health Act* across a population and over the lifespan. Policy initiatives that ignore individual variability across the lifespan yield inequitable results. For example, age-specific policies that exempt seniors from costs charged to the rest of the population will transfer healthcare resources to healthy low-cost seniors from younger individuals with higher needs.

Résumé

Le coût moyen de prestations de services de santé accroît avec l'âge, mais au sein de toute cohorte âge/sexe il existe des variations substantielles. Or, ces variations ne s'estompent pas au cours de la vie des utilisateurs. La présente étude applique le modèle de Markov aux données administratives pour étudier la variabilité des coûts de services de santé présentement couverts par la *Loi canadienne sur la santé* pour une population donnée au cours de la vie de l'utilisateur. Les initiatives politiques qui ne tiennent pas compte des variabilités individuelles au cours de la vie mènent à des résultats inéquitables. Par exemple, les politiques fondées sur l'âge qui accordent aux aînés une exemption de coûts par rapport au reste de la population conduiront à un transfert des ressources en faveur d'aînés sains et peu coûteux au détriment de jeunes personnes dont les besoins sont importants.

THROUGHOUT THE DEVELOPED WORLD, AGING POPULATIONS HAVE BEEN identified as a threat to the sustainability of healthcare. Many have argued that researchers must refine their estimates of age-related costs in order to facilitate the social and public policy changes necessary before private finances and government budgets are overwhelmed by demographic changes (Alemayehu and Warner 2004; Knickman and Snell 2002). Most research has estimated age and sex-standardized utilization and costs, benchmarks that are clearly necessary for general planning and projection purposes. In order to ensure that resources are in place to serve an aging population, we must know how much it costs, on average, to provide healthcare to men and women as they age. Less attention has been paid to the variability of individual costs over time, which is the focus of this paper.

Knowing something about individual variability of costs over a lifetime, and the variation of costs among members of particular age–sex cohorts, will allow us to estimate the distributional impact of proposed policy changes. For example, if costs are

strongly related to age and vary little within particular age cohorts, then age-specific policies that exempt seniors from some healthcare costs that younger Canadians pay out of pocket or through third-party insurers are reasonable. If, on the other hand, costs vary dramatically within particular age–sex cohorts, such policies will subsidize many low-cost seniors at the expense of younger people with greater needs. This paper uses Markov modelling to estimate the level of individual variability, both at any point in time and over a lifetime.

Although opinions vary about the extent of the challenge, mean healthcare costs clearly increase with age (Hogan and Hogan 2002; Barer et al. 2004; Hogan and Lise 2004). This correlation seems to imply a relatively predictable lifetime pattern of costs; a typical individual might anticipate many years of increasingly costly disability before dying an expensive death at an advanced age. However, in any one year, healthcare expenditures are not normally distributed but are highly skewed within all age–sex categories (Monheit 2003; Forget et al. 2002, 2005). If individual variations largely even out over a lifetime, most individuals would experience some years in which their costs exceeded the mean for others of their age and sex and other years in which their own costs are lower than expected. Alternatively, most individuals might remain low-cost users of the healthcare system, even at very advanced ages. The policy implications clearly depend on the distribution of expenditures, both in any single year and over a lifetime.

Studies in the United States have highlighted the age-dependent nature of healthcare costs. While the precise figures depend on which costs are included in the calculation, one study found that mean per capita costs climb slowly through adulthood, then more rapidly after age 50 (Meerding et al. 1998). Within the US Medicare population, those over 85 cost three times as much as those between 65 and 74, and twice as much as those between 75 and 84 (Fuchs 1999). Nearly half of lifetime expenditure is incurred during the senior years, and for those who survive to age 85, more than one-third of their lifetime expenditures will accrue in their remaining years (Alemayehu and Warner 2004). However, these findings are partly a reflection of how care is organized and delivered; nursing home costs are a significant portion of the larger healthcare consumption of the oldest (Liang et al. 1996; Alemayehu and Warner 2004). Similar trends have been documented elsewhere in the OECD (Maguire 1987; Reinhardt et al. 2002).

Costs incurred in the period before death account for a disproportionate share of healthcare resources (Roos et al. 1987; Scitovsky 1988). However, people who die at older ages cost significantly more in the last six months of life than do those dying at younger ages (Roos et al. 1987). Mean costs for women tend to exceed those of men at any age (Mustard et al. 1998; Forget et al. 2005; Alemayehu and Warner 2004). Nearly all age-specific gender differences can be explained by sex-specific conditions, such as costs associated with childbirth (Mustard et al. 1998).

Analysis of the variability of healthcare costs reveals that most expenditure is

incurred by a very small proportion of the population (Forget et al. 2002, 2005; Deber et al. 2004; Monheit 2003). This significant variation exists even in age-specific expenditures. Manitoba data for hospital and physician expenditures show that, for example, 90% of men aged 20 to 24 and 70% of women aged 65 to 74 spend less than the mean per capita expenditure for their age–sex group (Forget et al. 2002; Deber et al. 2004). Not all of the high-cost users are elderly, nor are most of the elderly high-cost users. This study examines the distribution of lifetime healthcare costs across a population, taking into account the significant variability of costs in all age–sex cohorts.

Analyzing health costs over a lifetime

Most investigations of healthcare costs over a lifetime are based on cross-sectional studies of age-specific expenditures (Waldo et al. 1989; Mustard et al. 1998; Forget et al. 2005). These studies do not reflect the lifetime costs of particular individuals as they age; instead, they compare various birth cohorts at a point in time. Such studies cannot capture the implications for lifetime costs of systematic differences in life expectancies, morbidity patterns, socio-economic status and service use across a population. In particular, while they can examine the variation in healthcare costs for a particular age–sex cohort, they cannot build an individual's health history into the model and show how present costs depend not only on age and sex, but also on past utilization. Longitudinal studies, by contrast, follow a particular cohort as its members age, thus building history into the model (Lubitz and Riley 1993; Lubitz et al. 1995; Spillman and Lubitz 2000). But these studies attribute all changes over time to aging and are unable to control for changes in medical technology, relative prices and disease incidence.

Other approaches may be able to blend the advantages of both cross-sectional and longitudinal studies. A period life table model takes the experience of a “typical” individual for each year and then simulates costs (Alemayehu and Warner 2004). This approach has the advantage of holding everything but the age of an individual constant as a pattern of lifetime costs is constructed, but does not readily incorporate variation within age–sex groups. The present study uses a variation of the life table model. It employs a Markov model, which simulates expenditure patterns across a population as that population ages. As in the period life table model, costs, medical technology and disease incidence are held constant while the model examines the distribution of lifetime costs across a population.

Method

We developed a Markov model of healthcare expenditures in which the probabilities of moving between various cost states (and death) depended on age, sex and past utilization. We constructed 10 different transition matrices for males and 10 for females:

<1 year of age, 1–4 years of age, 5–14, 15–19, 20–24, 25–34, 35–44, 45–54, 65–74 and ≥ 75 . We used per capita healthcare expenditures and the morbidity and mortality experience of a population, differentiated by age and sex, for two years (2002–2003) to generate profiles of healthcare expenditures from birth to death. This procedure estimates the effects of aging on individual costs, holding constant the state of medical technology, disease incidence and relative healthcare prices as our cohort ages.

Per capita healthcare expenditure

Manitoba was chosen as the study site because the Manitoba Population Health Research Data Repository captures standardized data based on almost every physician and hospital contact in the province. This information (including patient identification numbers, physician claims, diagnoses, costs and hospitalization and institutionalization data) is maintained and controlled by the provincial department of health. All records deposited in the repository have been processed by Manitoba Health and Healthy Living to remove patient identifiers such as name and address, while preserving the capacity to link records together to form individual histories of healthcare use. The database includes direct information on physician billings, excluding some patient visits outside the province, salaries for trainees and some physicians' paid salaries for specific services (Roos et al. 1993).

The costs of inpatient hospital care and day surgery procedures have been estimated by applying the Manitoba average cost per weighted case to each discharge. This method takes into account the typical resource use associated with particular types of cases. Because Canadian hospitals receive block funding from the province, no direct hospital price data are associated with individual patients. Total cost of care for an inpatient or day surgery patient includes all physician services received during the hospital stay. Some costs, such as those associated with blood products and emergency wards, are omitted from the study because we cannot track these costs to individual patients. Other costs, such as those associated with capital expenditure and public health, are omitted because these costs are not patient specific. We capture and allocate to individual patients approximately 64% of the total amount that the province claims to spend on hospital funding. Some small percentage of costs omitted will have been spent to provide care for non-Manitoba residents, but the great bulk of the omitted costs are associated with capital costs and trainee salaries, particularly in the teaching hospitals.

This study looks only at physician visits and hospital stays, the core services fully insured and publicly provided under the *Canada Health Act*. Hospital and physician costs together accounted for 43.4% of total health expenditure and 57.7% of public expenditure in Canada in 2003 (CIHI 2005). In 2005, the comparable figures were 42.7% and 57.3%.

The database also includes data on all pharmaceutical use outside institutions, as well as information on care in the home and nursing home settings. We have chosen to omit these costs from the present study because while most provinces, including Manitoba, cover some or all of these costs for some or all patients, specific insurance arrangements vary among provinces and have changed significantly over time. While the *Canada Health Act* makes the provinces responsible for physician and hospital care, no such requirement exists for other services. This analysis focuses on publicly funded healthcare costs that are mandated by the *Canada Health Act*. Results can therefore be generalized to all provinces.

While we have chosen to omit long-term residential care from this analysis of public healthcare spending for the purposes of policy analysis, this decision does have significant implications for the costs simulated by the model. A significant portion of seniors (75+) reside in personal care homes, particularly during the last year of life. Once in a personal care home, however, these people tend to use fewer hospital resources than they otherwise might. Therefore, high users may show a transition into the medium-user group when they enter a personal care home because long-term facility costs are not counted in the analysis. A significant portion of full lifetime healthcare costs is, therefore, omitted from our model, which focuses only on those publicly funded costs mandated by the *Canada Health Act*. Some caution, therefore, should be used in interpreting these results. We omitted these costs because they are not currently mandated by the *Canada Health Act*, and we wanted to use our results to examine the distributional impact of proposed policies. Policy analysis requires that one starts from the status quo. In other words, our analysis is conducted from the perspective of the public payer mandated to provide the services covered by the *Canada Health Act*. To examine the full social cost of an aging population, we would have to include not only residential care, but all age-dependent social policies that might affect use of medical services and hospitals.

To calculate annual per capita costs, we summed physician and hospital costs for each individual for each of 2002 and 2003. We next ranked each individual by per capita costs for each year, from lowest to highest, and arranged these into deciles. Costs were divided into three categories on the basis of natural breaks in the distribution of expenditures. We defined as low costs the lowest-spending 70% of the population, moderate costs the next 20% and high costs the remaining 10% of the population. The mean annual per capita costs for each of these categories were \$96, \$600 and \$6,635, respectively, all measured in 2002 dollars. Distinguishing between low, moderate and high costs in this way is also useful for policy simulation, in which “catastrophic” costs are often associated with the costliest 10% of the population (cf. Forget et al. 2002).

To calculate predicted lifetime costs, we defined the cost categories on the basis of the experience of the entire population. This means that the per capita costs assigned to low, moderate and high users do not vary by age and sex in our model. Instead, the

probabilities that individuals will incur low, moderate or high costs (or die) will change with age and sex to reflect the actual experience of the population. In order to determine whether patterns of population costs are stable over time, we then examined the distribution of annual per capita costs between 1997 and 2003. The same pattern of a high-cost 10%, a moderate-cost 20% and a low-cost 70% persisted. When the distributions were compared in constant dollars, mean per capita costs for each of the three categories did not differ significantly by year.

Transition probabilities

We constructed 10 different transition matrices for males and 10 for females based on the probability by age and sex that an individual in each cost category would stay in the same category in the next year, move to one of the other two cost categories or die. The categories were based on previous analyses of per capita expenditure by age group: <1 year of age, 1–4, 5–14, 15–19, 20–24, 25–34, 35–44, 45–54, 65–74 and ≥75. Age categories beyond 75 were not further subdivided because the relatively small number of surviving men might introduce instability into the estimates.

Each live birth in Manitoba in 2002 was assigned to low-, moderate- or high-cost categories in the first instance, based on costs for infants less than one year of age in Manitoba in 2002. Moderate costs were incurred by 74.45% of females and 68.75% of males, while 21.99% of females and 28.41% of males incurred high costs. Only 3.56% of female infants and 2.84% of male infants fell into the low-cost category. We then calculated the probability that a low-cost female infant in 2002 would move to a low-, moderate- or high-cost category in 2003 or die before the year was complete, and repeated the process for moderate- and high-cost females, and low-, moderate- and high-cost male infants.

Table 1 illustrates the transition probabilities for male and female infants less than one year of age in 2002. Those infants who incurred moderate costs in 2002 were the least likely to die during the year and the most likely to transition to a low-cost category in 2003. This finding is as one might expect, since most infants have a number of routine contacts with the healthcare system during their first year. Moderate-cost infants received the medical services that normal infants are expected to receive during their first year of life. Those infants who incurred high costs in 2002 were more likely to incur moderate or high costs in subsequent years. Again, this finding is as expected, because the high-cost infants include those with birth anomalies and those born too early or too small.

Infants may incur low costs during their birth year for two different reasons. If an infant dies during the year, total costs incurred during that year may be quite low, depending on when the death occurred. In this case, the low cost is a statistical anomaly resulting from the way we gather costs. But an infant may also incur low healthcare

costs during her first year of life because she does not receive the routine healthcare she ought to receive. Such infants would include children whose family circumstances put them at increased risk for injury or illness, with subsequent higher healthcare costs. Our data show that the low-cost infants who survived the year were more likely than their counterparts who incurred moderate costs to be in a high-cost category during their second year of life. Female low-cost infants were even more likely than high-cost infants to incur high costs during their second year.

TABLE 1. Transition probabilities for male and female infants (< 1 year) in 2002–2003

2002 category	2003 category			
	Low	Moderate	High	Dead
MALES				
Low	0.6599	0.2183	0.1015	0.0203
Moderate	0.6980	0.2418	0.0596	0.0006
High	0.5341	0.3121	0.1310	0.0228
FEMALES				
Low	0.7087	0.1739	0.1087	0.0087
Moderate	0.7470	0.2068	0.0453	0.0008
High	0.5862	0.2885	0.1056	0.0197

Transition probabilities vary by age and sex, and are based on the costs incurred by an individual in the previous year. This approach builds “memory” into the model, in that young men incurring high costs in 2002 were much more likely to return to a low- or moderate-cost category in 2003 than were elderly women who incurred high costs in 2002 (81% versus 53%) (Table 2). And yet, young men who incurred high costs in 2002 were still much more likely to incur high costs in 2003 than were men of the same age having low costs in 2002 (18% versus 2.5%). Even though we have used only one-year transitions, the model recognizes the persistence in healthcare expenditure and reflects the way that past use of the healthcare system is mediated by age and sex. It builds in the higher probability that high-cost individuals will remain higher cost in subsequent years, but recognizes that this situation is particularly true for older people than for younger. Linear interpolation was used to smooth the transition probabilities among age categories, so there is no threshold effect as individuals age.

Many attempts to model lifetime costs have been criticized for not distinguishing between survivors and decedents. Without this distinction, estimates of lifetime costs

tend to be biased upwards because mean age-dependent costs for the elderly are inflated by the high costs incurred by those at the end of life. Our modelling strategy recognizes that individuals in any cost category and at any age may die. The transition probabilities are based on the experiences of an actual population in particular years, adjusting for the increased probability of death with age and for individuals incurring high costs.

TABLE 2. Transition probabilities for young males (20–24) and elderly females (65–74) in 2002–2003

2002 category	2003 category			
	Low	Moderate	High	Dead
MALES (20–24)				
Low	0.9229	0.0511	0.0253	0.0007
Moderate	0.6483	0.2619	0.0890	0.0009
High	0.6463	0.1673	0.1792	0.0071
FEMALES (65–74)				
Low	0.6512	0.2494	0.0937	0.0057
Moderate	0.2314	0.5602	0.2056	0.0027
High	0.1685	0.3660	0.4012	0.0643

The stability of the matrices was tested by calculating single-year transition matrices for men and women for 1997–1998, 1998–1999, 1999–2000 and 2002–2003. Individual transition probabilities for particular age–sex cost categories varied slightly; for example, the probability that low-cost 20- to 24-year-old males would remain low cost the following year did vary at the third decimal point. However, using constant dollars, the distribution of predicted lifetime costs did not vary significantly over the period. From this finding we concluded that the transition probabilities were relatively stable, at least over the short run. Over longer periods of time, probabilities will change to reflect changes in medical technology, as well as the morbidity and mortality experience of the population. Having transition probabilities for only a few years, we did not attempt a second-order Markov model, which would have required assumptions about the distribution from which the annual transition probabilities were drawn.

Simulation

We constructed a Markov model based on age-dependent probabilities for males and for females. As noted above, per capita costs assigned to low, moderate and high

users do not vary by age and sex in our model, but the probabilities that individuals will be in each category (including death, an absorbing state) change with age and sex to reflect the actual experience of the population. We used TreeAge Pro Software to simulate the model. Figure 1 represents the costing tree for males, which is identical to that for females except that the initial distribution of the birth cohort varies to reflect the higher proportion of male infants who are high cost.

FIGURE 1. A costing tree for males

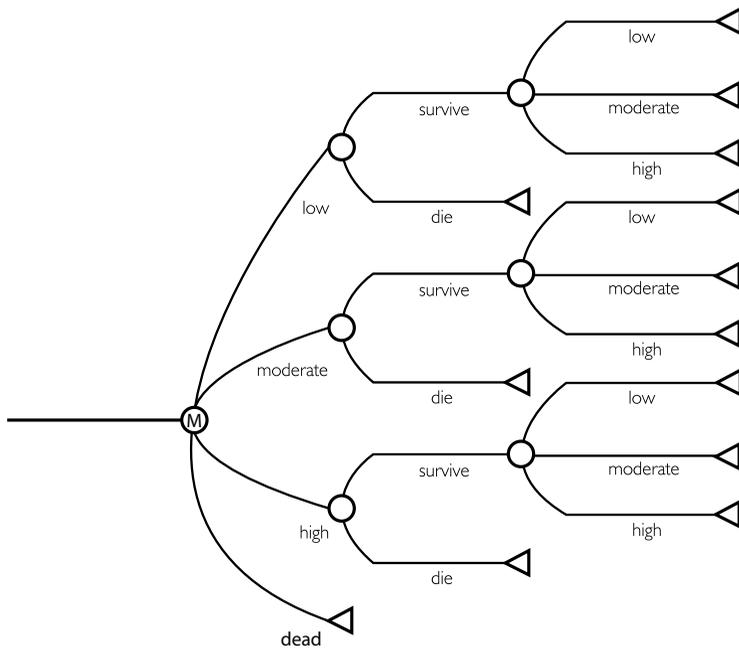


Figure 1 represents a Markov model, which is based on the concept of a decision tree. A cohort enters the model at the left. At each node, the model assigns an individual to a particular branch based on the age- and sex-dependent transition probabilities calculated from the data. When an individual "dies," the model calculates lifetime costs and life-years. As long as an individual survives, the model reassigns him to a particular branch, with the probability of entering a high-cost category rising with age and dependent on past utilization.

Figure 1 represents a Markov model. We can simulate costs by running a cohort through this model, and allowing the model to assign actual outcomes based on the transition probabilities drawn from our data.

For example, the first member of the cohort enters the model from the left. Based on our data, the model will assign this individual to the moderate-cost category in his first year with a probability of 0.6875, to a high-cost category with a probability of 0.2841 and to a low-cost category with a probability of 0.0284. For each of these possibilities, the infant may survive his first year or he may die before his first birthday. His fate will be chosen by the model based on the transition probabilities we have

calculated from the data. If he dies, the model calculates his total lifetime cost and his total number of years of life. If he survives his first year, the model will assign him to a cost category in his second year based on transition probabilities. Again, he may die or he may survive. If he dies, the model calculates his lifetime cost and his total years of life. If he survives, the model will assign him to a cost category in his third year of life. As the individual exits the right-hand side of the model alive, he is sent back to repeat the costing cycle for another year. As he ages, the transition probabilities adjust to increase his probability of being assigned to a high-cost category. For each individual in the cohort, the model will create a unique synthetic life based on the transition probabilities calculated from the actual data. Each individual in our cohort is a fiction created by the model, but together they represent the distribution of costs and outcomes that our data contain.

Two methods of Monte Carlo simulation were used. First, a cohort estimation technique permitted both calculation of mean lifetime costs for men and women and estimation of the proportion of lifetime costs incurred in high-, moderate- or low-cost years. It also allowed calculation of both life expectancy and the number of high-, moderate- and low-cost years a typical male or female can expect. Individuals in a birth cohort were assigned to an initial cost category based on population probabilities; the experience of the entire birth cohort was modelled until all died. Second, microsimulation trials were used to estimate the model. We allowed 100,000 men and 100,000 women to move through the model from birth to death and calculated the distribution of lifetime costs across the population.

Results

Lifetime costs for a typical individual

Women incur a mean cost of \$89,741 over a lifetime in hospital and physician costs, 40% more than the \$64,091 incurred by men (Figures 2 and 3). Consistent with other studies, mean per capita costs decline through childhood. Not surprisingly, women show higher per capita costs than do men during peak childbearing years. The typical female can expect to live almost six years longer than the typical male. Although a similar proportion of lifetime costs occur in high-cost years for men and women, the typical woman can expect more high-cost years. She will incur 81.6% of her lifetime costs in her 11 high-cost years, while he will incur 80.5% of his lifetime costs in his 7.8 high-cost years. The typical female will incur 20 moderate-cost years compared to 12 for the typical male. Only 47 of her years will be low cost, compared to his 52.6. The life expectancies generated by this model – 78 for women and 72.4 for men – are consistent with Canadian mean life expectancies at birth for the 1980–1982 cohort (Statistics Canada 2005). Life expectancies in Canada, and in Manitoba, have increased since then.

Variations in Lifetime Healthcare Costs across a Population

FIGURE 2. Mean annual per capita costs by age (females, 2002–2003)

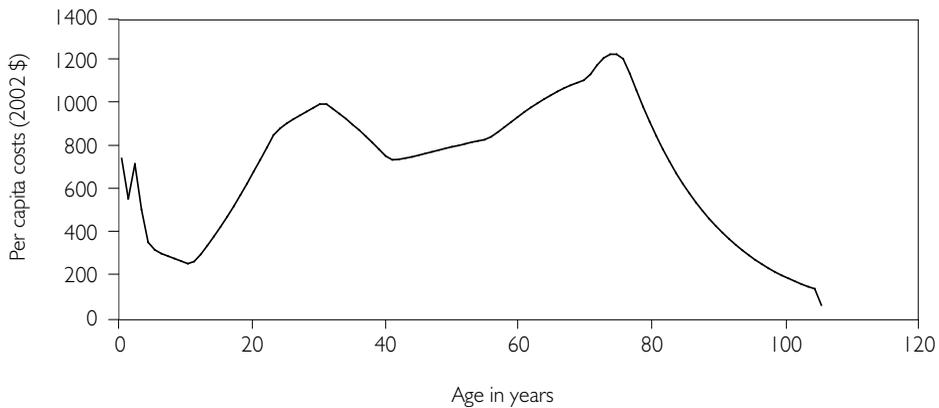
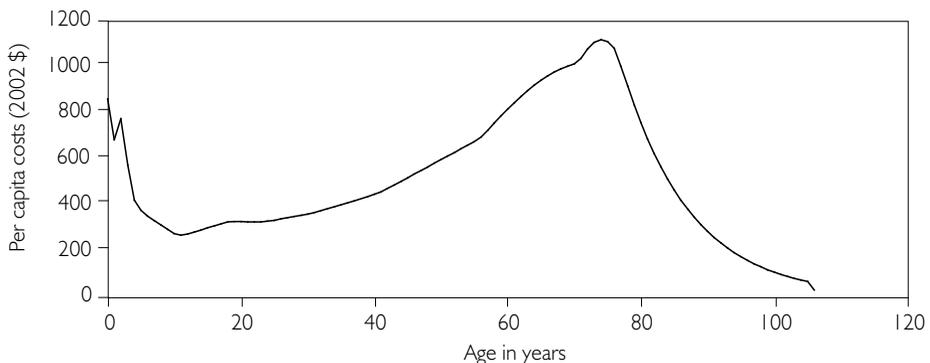


FIGURE 3. Mean annual per capita costs by age (males, 2002–2003)

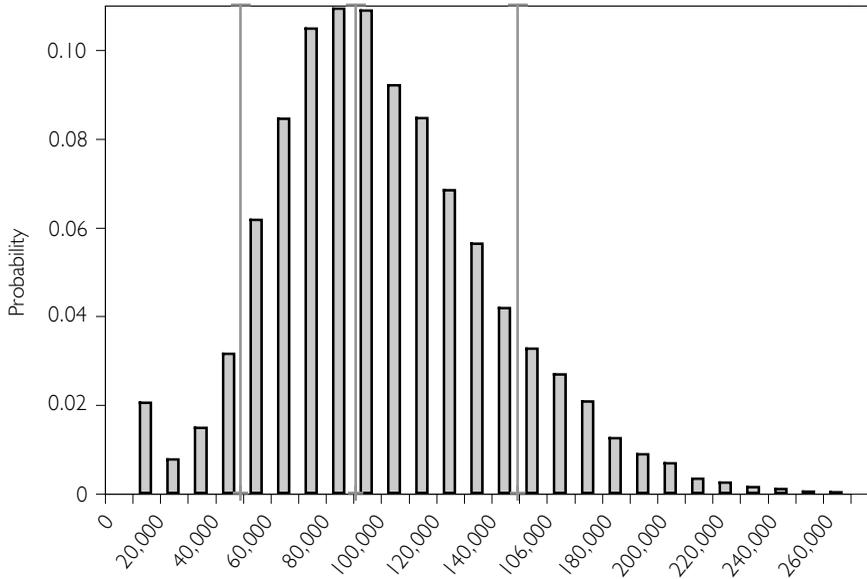


Distribution of lifetime costs across a population

In order to calculate the distribution of lifetime costs, we estimated the Markov models using Monte Carlo microsimulation trials (Figures 4 and 5). As might be expected, lifetime costs are somewhat less skewed than are per capita costs in any single year. However, the distribution is far from normal; costs are not tightly grouped around the mean. For women, mean lifetime costs are \$89,722, with a standard deviation of \$38,776. Median costs for women were \$86,125. Ten per cent of women incur lifetime costs of less than \$43,843. For men, the mean is \$64,052 with a standard deviation of \$35,331. Median costs for men were \$59,819, while 10% of men incurred lifetime costs of less than \$22,450.

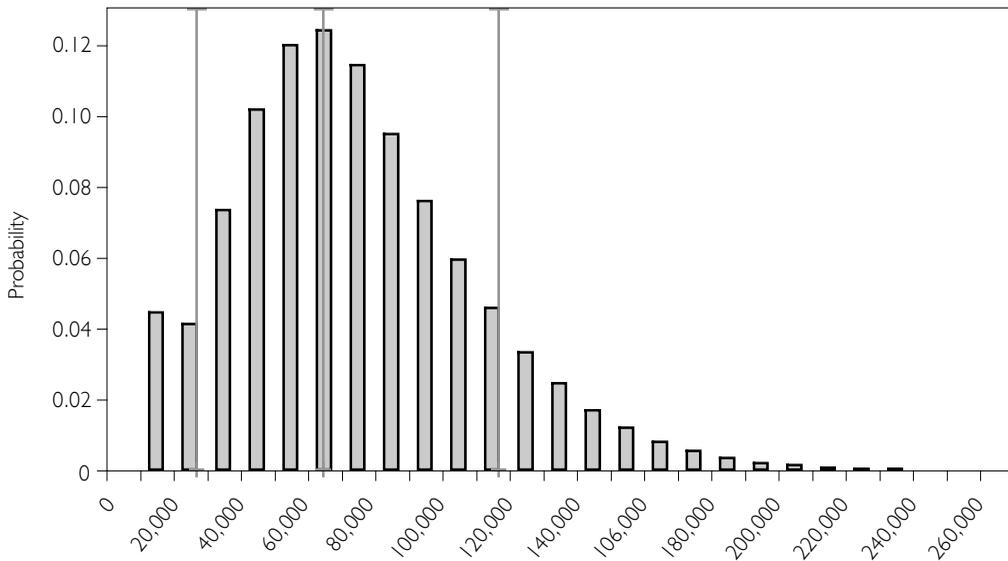
Based on the Monte Carlo trials, the typical woman can expect 11 high-cost years, but the standard deviation is 5.33. Fully 10% can expect more than 18 high-cost years; 2.5% can expect more than 23. A typical man can expect 7.8 high-cost years, with a standard deviation of 4.9 years. Ten per cent of men can expect more than 14 high-cost years, and 2.5% can expect more than 19 high-cost years.

FIGURE 4. The distribution of lifetime costs (females, 2002–2003)



Each vertical bar in Figure 5 represents the probability that a female will incur lifetime costs of the magnitude on the horizontal axis, measured in 2002 dollars. The three vertical lines represent the 10th, 50th and 90th percentiles. About 10% of women have a lifetime cost of less than \$43,843 and 50% have a lifetime cost of less than \$86,125.

FIGURE 5. The distribution of lifetime costs (males, 2002–2003)

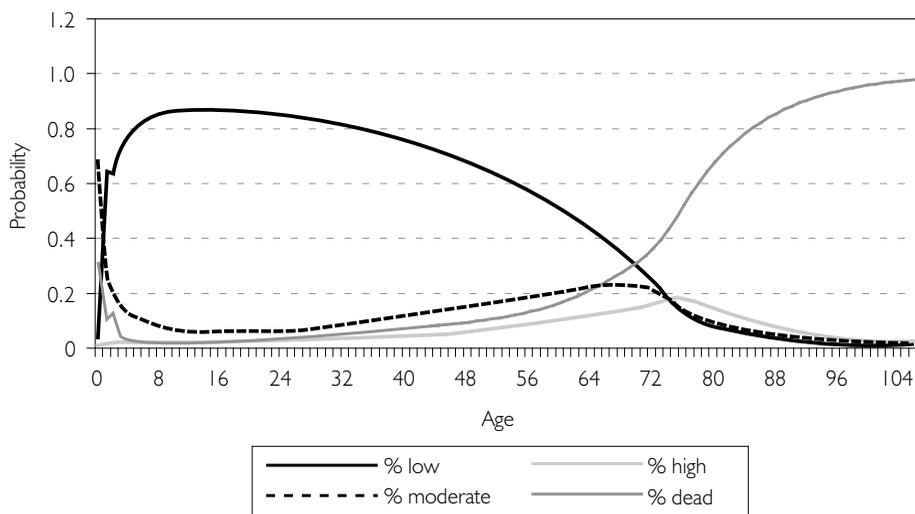


Each vertical bar in Figure 4 represents the probability that a male will incur lifetime costs of the magnitude on the horizontal axis, measured in 2002 dollars. The three vertical lines represent the 10th, 50th and 90th percentiles. About 10% of men have a lifetime cost of less than \$22,450 and 50% have a lifetime cost of less than \$59,819.

The probability of incurring high costs by age and sex

Our analysis uses transition probabilities and focuses on the distribution of age- and sex-dependent costs. Although we cannot determine when, in any individual's life, high-cost periods will occur, the pattern of probabilities that govern individual costs can be examined. Because the probability of falling into a particular cost category in any year depends on an individual's previous healthcare costs as well as age and sex, Monte Carlo estimation allows recovery of the pattern of lifetime probabilities from simulation. The probabilities of incurring low, moderate and high costs by age and sex are shown in Figures 6 and 7.

FIGURE 6. Probability of incurring low, moderate and high costs by age (males, 2002–2003)



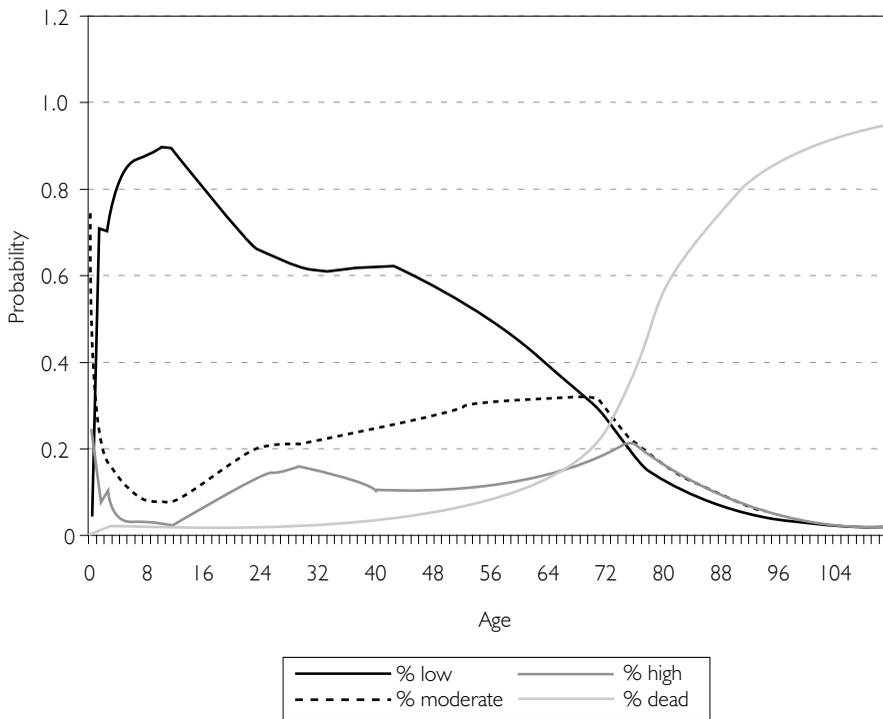
At any age, men are more likely to be low-cost healthcare consumers than to be moderate- or high-cost users. Although mean per capita healthcare costs clearly increase with age and the typical male will incur 7.8 high-cost years in his lifetime, an individual male at any age has a greater probability of incurring low costs than of incurring higher costs. Indeed, by the time the probability of incurring high costs exceeds those of incurring low costs (at age 76), a male is more likely to be dead than still alive and incurring any costs.

The story differs for women. Women, like men, have a greater probability of being low-cost users than high-cost users all their lives. In part because of childbirth, they are more likely to be moderate-cost users throughout much of their adulthood than are men; by age 71, the probability of being a moderate-cost user exceeds that of being

a low-cost user. However, as was the case for men, at the age when the probability of incurring high costs exceeds that of incurring low costs, women are more likely to be dead than still alive incurring costs. While the typical female will incur 11 high-cost years in her lifetime, and while mean per capita costs for women increase with age, an individual woman younger than 71 still has a greater probability of incurring low costs than she has of incurring higher costs in any given year.

Beyond the age of 75, both male and female survivors are about equally likely to incur high, moderate or low costs.

FIGURE 7. Probability of incurring low, moderate and high costs by age (females, 2002–2003)



Discussion

Healthcare costs will be affected as a larger cohort moves through the age spectrum, followed by a smaller cohort. This pattern implies that mean per capita healthcare costs are relevant for social planners. A greater number of individuals facing a greater probability of incurring high healthcare costs will indeed cost more in the aggregate; this factor must be taken into account when healthcare budgets are determined. Efforts to improve the efficiency of healthcare delivery make sense on grounds of both efficiency and distribution.

The relationship between individual aging and anticipated healthcare costs, however, is not a simple one. Each individual faces a greater probability of incurring higher healthcare costs as he or she ages, but the greatest likelihood is that, even in advanced age, most individuals will incur relatively low costs. However, this finding results in part from our decision not to include pharmaceuticals and costs for personal care homes, which are not mandated by the *Canada Health Act*. These costs are covered for some people, at least in part, in all provinces, but the Act does not require them to be covered, and different provinces have adopted different schemes. Effectively, our results show that publicly funded services are not likely to be unsustainable because of demographic changes; rather, unsustainability stems from the fact that large portions of age-related spending fall outside the *Canada Health Act*. Those areas – pharmaceuticals and personal care homes – are where we will see the greatest pressure for public–private partnerships and for creative financing options in coming years.

Age-specific social policies

The path-dependence of probabilities, as shown in Figures 6 and 7, implies that older individuals who move into high-cost categories are more likely to stay there than are younger individuals. Nevertheless, for any individual, the relationship between healthcare costs and aging is far from clear and predictable. This fact presents a number of implications for social policy. The simplest, and least satisfactory, set of policies designed to deal with an aging population confounds individual aging and population aging by designing a set of age-specific health benefits. Age-specific policies, such as exempting individuals over age 65 from some healthcare costs that others bear out of pocket or through third-party insurance, are likely to subsidize many low-cost seniors at the expense of younger individuals with higher costs. For example, most Canadian provinces have chosen in the past few years to cease paying for such services as eye examinations for those between the ages of 18 and 64 while retaining coverage for those over age 65. Healthcare benefits based only on age, as in the case of US Medicare, similarly fail to take into account the wide variety of individual experience within any age–sex group. A policy based on age alone, rather than individual healthcare costs, will lead to a substantial transfer to healthy seniors from the younger individuals falling into the high-needs category.

However, relying upon private insurance to cover some of the costs currently paid under the *Canada Health Act* for younger people, while retaining public coverage for seniors, would not appear to be a satisfactory answer. High-risk individuals face notorious difficulty in accessing private health insurance at reasonable costs. Risk-adjustment software that predicts healthcare expenditures for every individual in a defined population on the basis of past utilization is available and is commonly used by private

health insurance companies to set premiums. As we have seen, healthcare costs tend to persist over time for all individuals, and this persistence increases with age. Those individuals likely to be most in need of healthcare insurance are, therefore, the least likely to be able to access private insurance at reasonable premiums, the most likely to exceed lifetime limits and the most likely to be disadvantaged by the widespread uninsurability of existing conditions. Limiting public coverage for certain services under the *Canada Health Act* on the basis of age will not lead to equitable outcomes.

Healthcare savings accounts

The large number of healthy low-cost seniors, however, should not lead to complacency about other proposals. In recent years, one proposal that gained a lot of attention in Canada before fading from the policy scene was the suggestion that universal health insurance for physician and hospital services should be replaced by healthcare savings accounts, in which each individual's allowance or entitlement would be paid by the government to the individual, based on some proportion of mean age and sex-dependent healthcare costs (Forget et al. 2002; Deber et al. 2004). The individual would then be responsible for paying all physician and hospital costs from that allowance or, should healthcare costs exceed the allowance, out of pocket. Allowing individuals to save surpluses in low-cost years to pay for catastrophic costs in high-cost years was imagined to make the system sustainable. Figures 4 and 5 emphasize the significant variation in lifetime healthcare costs around the age- and sex-dependent mean.

If costs were tightly distributed about the mean, then determining the optimal annual allocation to a healthcare savings account would be relatively simple; this allocation could pay costs over a lifetime if surpluses were retained to pay for excess costs in high-cost years. But lifetime costs vary tremendously, suggesting a significant cohort of individuals who incur high costs over much of their lives. Their catastrophic costs will continue to be a policy issue that health savings accounts cannot address. Dealing with catastrophic costs through other mechanisms (such as government-provided health insurance for the costliest 10% of individuals in any particular year), coupled with a program of healthcare savings accounts for non-catastrophic costs, would do little to contain government expenditure in the aggregate. The vast bulk of healthcare costs are incurred by those few individuals incurring catastrophic costs.

Healthcare savings accounts in the United States have attempted to handle this problem by allowing individuals to pay the premiums for catastrophic health insurance from these sorts of accounts. To the extent that individuals with a history of high-cost episodes remain insurable at reasonable cost, the purchase of catastrophic insurance will reduce the threat to persistently high-cost individuals. However, co-payments and annual (and lifetime) limits, the difficulty of insuring against costs incurred

through existing conditions, and risk-based premiums lessen the protection that catastrophic insurance provides to high-cost individuals.

Cautions for policy makers

Mean healthcare costs are clearly age dependent; an aging population will imply increasing aggregate costs. Policy responses to this inevitability, however, often confound mean age-dependent costs for a population with the actual risk faced by a particular individual. The “typical” individual clearly faces a lifetime of gradually and then rapidly increasing costs as he or she ages. Any particular individual, however, is not “typical”; up to 75 years of age, each individual has a significantly greater probability of incurring low healthcare costs than moderate or high healthcare costs.

This study shows that per capita healthcare costs for individuals of a particular age and sex vary, not only at a point in time but over a lifetime as well. Policy initiatives based on population means that ignore the reality of individual variation, both at any point in time and over a lifetime, can only increase inequity and inefficiency.

ACKNOWLEDGEMENTS

We are grateful for financial support from the Canadian Institutes for Health Research (MOP-127833). The results and conclusions are those of the authors; we are indebted to Health Information Services, Manitoba Health and Healthy Living, for providing data (MB Health No. 2002/2005 – 18). No official endorsement by Manitoba Health and Healthy Living is intended or implied.

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Variations in Lifetime Healthcare Costs across a Population

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Health System Organization and Governance in Canada and Australia: A Comparison of Historical Developments, Recent Policy Changes and Future Implications

Organisation et gouvernance des systèmes de santé au Canada et en Australie : comparaison du parcours historique, des changements politiques récents et des répercussions à venir



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Abstract

The Canadian and Australian health systems have evolved in very similar ways. Recent policy changes in each country, however, suggest a growing divergence with respect to governance. This paper traces the origins and key milestones in the evolution of governance models, with a selective focus on two provinces in Canada (Saskatchewan and Alberta) and the state of New South Wales in Australia. While divergent models seem to be manifesting, many similar underlying features remain. We assess these developments and comment on the current patterns of organization and governance, both to provide insights on future directions and to suggest what the two countries might learn from each other.

Résumé

Les systèmes de santé au Canada et en Australie ont évolué de façon similaire. Toutefois, les récents changements de politiques dans les deux pays portent à croire qu'il y a une divergence grandissante quant à la gouvernance. L'article relate les origines et les principales étapes des modèles de gouvernance respectifs des deux pays, plus précisément ceux de deux provinces canadiennes (la Saskatchewan et l'Alberta) et ceux de l'État de la Nouvelle-Galles du Sud, en Australie. Bien que les modèles semblent divergents, il existe entre eux plusieurs caractéristiques similaires. Nous évaluons leur progression et commentons les modèles d'organisation et de gouvernance actuels, à la fois pour donner un aperçu des orientations à venir et pour dégager ce que ces pays peuvent apprendre l'un de l'autre.

THE OBJECTIVES OF THIS PAPER ARE TO REVIEW SOME OF THE KEY MILESTONES in the evolution of health system organization and governance in Canada and Australia, to identify recent policy developments affecting the governance models and to provide insights into future directions and what the two countries can learn from each other. Two Canadian provinces, Saskatchewan and Alberta, and one state in Australia, New South Wales, were selected for detailed comparisons. These provinces and state were chosen largely because of the key role they have played in developing new organizational models in their respective countries, and thus help illustrate the pattern of development.

Canada and Australia are both federated systems with a similar division of powers between the central and provincial or state governments on matters pertaining to health. The *British North America Act* of 1867 and the *Commonwealth of Australia Constitution Act* of 1900, both Acts of the British Parliament, placed the major responsibility for the delivery of health services at the provincial or state government

level. In each country, the governance models are in effect creatures of provincial and state laws. The founders of the Canadian federation deliberately created a highly centralized system of government, with residual powers being vested at the federal level. This was not the intention in Australia, where by implication, residual powers were left to the states (Gray 1991). Accordingly, one would expect more centralized characteristics for health governance in Canada, but quite the opposite has occurred. As will be discussed later, a constitutional amendment and the five-year Australian Health Agreements have consolidated increased Commonwealth powers, while in Canada, provinces continue to dominate, with new models emerging for national initiatives.

Both countries have mixed public–private health systems in a pluralist, multi-stakeholder structure with power shared between the two levels of government. Centrally, there is the federal government (Canada) and the Commonwealth government (Australia). At the next level, there are states, provinces or territories: 10 provinces and three territories for Canada, and six states and two territories for Australia. The local or municipal government level plays a much smaller role in both systems.

Evolution of Health Systems

Origins of the systems

In Canada, at the outset, provinces relied heavily on the organization of municipalities to provide local services. The earliest forms of public governance in the Canadian health system grew out of creations at the municipal government level. Both countries had a strong tradition of religious or charitable organizations providing hospital services that preceded public institutions. The province of Saskatchewan, formed in 1905, had 297 functioning municipalities by 1916. In trying to meet the needs of their residents, municipalities began Municipal Doctor Programs, and by 1944 there were at least 101 such programs (Houston 2002). Similar programs, although on a more limited scale, also developed in the neighbouring provinces of Alberta and Manitoba (Gray 1991).

However, from the beginning, the limitations of having single municipalities provide certain services were recognized. Hospital construction was a case in point. In 1916, both Saskatchewan and Alberta passed their first municipal hospital legislation. Interestingly, these actions had been triggered in part by developments in the border community of Lloydminster, where the editor of the local newspaper, D.G. Tuckwell, a new arrival from Australia, promoted the idea of a union hospital. The legislation allowed two or more municipalities geographically adjacent to each other to form a union hospital board (Roemer 1955). Amendments to legislation over the next two decades not only provided a legislative base for these hospital plans, but also empowered municipal councils to levy a personal tax for hospital services. Taylor (1978) notes, “this appears to be the first instance in which statutory authority was granted for the levying of a personal tax for health services in Saskatchewan and, indeed, in

Canada.” Union hospital boards assumed responsibility for raising funds through taxation and the issuance of debentures to construct hospitals.

In the absence of a universal publicly funded system at that time, these hospital boards also assumed responsibilities for operating costs. The model of governance with board members chosen from the communities they served became the dominant mode of hospital governance throughout Canada. This model was also applied in other health sectors. In 1928, legislation in Saskatchewan allowed for the organization of public health districts consisting of at least eight municipalities (Roemer 1955). Commenting on the emergence of local governance models, Roemer (1955) states:

It is no accident that so much joint action by municipalities to finance health services was undertaken. Here was a need that came close to the hearts and, indeed, the pocketbooks of rural people. Faced with life and death issues, rural municipalities recognized their inability singly to meet health needs and undertook various agreements regarding both preventive and curative services, designed to protect the health of their families that cut across municipal lines.

The early Australian governance developments were very different. Municipal or local governments played only a small role in providing healthcare. After colonial settlements in the late 18th century, hospitals slowly emerged in the 19th, financed chiefly by subscription fees. Doctors, like their counterparts in England and Canada, offered services as entrepreneurs, largely to the wealthy. Charity hospitals were initiated and run by religious institutions, with a charter to treat the sick poor. Governance was contested between doctors on the one hand, who became honorary practitioners at hospitals in order to control admissions and treat their patients, and the religious or charitable organizations, often in the form of Friendly Societies, who administered the hospitals. Green and Cromwell (1984) note that the Friendly Societies obtained their revenue from subscriptions made by employed men, with coverage for members who might be temporarily unemployed, became ill or suffered a death in the family. Persons of wealth were treated at home by doctors on the basis of capacity to pay (McCoppin 1974; Inglis 1980; Horsburgh 1976).

In these early years, doctors were accorded the right to admit their private, fee-paying patients to public or charitable hospitals, who then charged patients for their accommodation (Crichton 1998). Hospital boards and doctors both benefited from a system that split responsibility and allowed private and public patients access to public facilities. Hospital boards of various forms emerged in Australian states, eventually reporting to health departments or hospital commissions. The Commonwealth slowly became involved through its taxation capacity in co-funding increasingly expensive acute care.

In the 19th and first half of the 20th century, however, the involvement of the Commonwealth government in health matters was very limited. This situation began

to change with the establishment of a federal health department in 1921, which had a mandate to provide health services in cooperation with the states. A 1946 constitutional amendment gave the Commonwealth wide concurrent powers in health policy. The Commonwealth soon became the dominant player on matters pertaining to physicians and pharmaceutical policy. Hospital matters, including arrangements with medical staff, and non-general practice community services remained in state hands. At about the same time in Canada, the Royal Commission on Dominion–Provincial Relations (Rowell–Sirois Commission) recommended that health services remain a provincial responsibility (Gray 1991).

Looking at the health delivery systems within the provinces and states, very different patterns are evident from the earliest days. In Canada, provinces focused their efforts on removing financial barriers for citizens to access care and on creating sub-provincial organizations to deliver services while generally not becoming directly involved in service provision. In Australia, however, the tradition was quite different, with states taking more direct involvement in providing services. States assumed a high level of responsibility for hospital services. In fact, Tasmania “nationalized” its hospitals in 1918, and Queensland took the same step in 1936. Thus, early governance models in Australia were characterized by an increasing degree of state government involvement in management. New South Wales and Victoria had a system of public hospitals run by independent boards until 1921, but more than half of the capital and operating expenses were covered by the state. In the other states, governments provided an ever-larger subsidy and consequently assumed an enhanced role, directly or through indirect influence, in management (Gray 1991).

Health boards and public financing

The effects of worldwide economic depression, coupled with a devastating drought in the 1930s, caused some major rethinking of the early governance models in Saskatchewan, where municipal-based models had been pioneered. Several provincial initiatives were introduced to assist municipal plans, but the main financial responsibility continued at the local level. Disparities in wealth among municipalities led to wide variation in the availability of health services, pointing to the need for a provincial program that provided financial stability while promoting greater equity in access to services and more quality control (Roemer 1955).

Emerging from the economic and social environment of the 1930s, a new political party, the Cooperative Commonwealth Federation (CCF), elected its first members in the 1934 Saskatchewan election and formed the government in 1944. From the outset, the CCF, led by T.C. Douglas, took up the cause of introducing publicly funded health insurance. On assuming government, Douglas took on the dual role of premier and minister of health. He rapidly implemented a hospital plan, first introducing a plan

for individuals receiving social assistance in 1945, and then a universal, provincewide Hospital Services Plan in 1947 (Taylor 1978). Premier Douglas's decision to go it alone, before agreement was reached at the federal–provincial level on funding, was a major gamble for an economically challenged province. But as Taylor (1978) indicates: “A social idea had been translated into an operating reality; the first universal hospital insurance program in North America had been launched. For Saskatchewan there was no turning back.”

The adoption of a universal hospital plan in Saskatchewan was quickly followed by similar plans in other provinces (Alberta, 1950; British Columbia, 1952). Newfoundland, which had entered Confederation only in 1949, brought with it a hospital services plan covering almost half its population. By the end of 1950, four provinces had hospital plans, although only those in Saskatchewan and British Columbia covered the entire population (Taylor 1978). The long-standing discussions with the federal government, which had collapsed in 1945, were reopened and finally concluded in 1958 with the passage of federal legislation providing a cost-sharing program for hospital plans. By 1961, all provinces had hospital plans in place.

Initially, the introduction of the Saskatchewan Hospital Services Plan (SHSP) did not affect the governance model, but two key developments would prove to have far-reaching effects over the years. First, the provincial government became the chief source of income for all hospitals, with the role of hospital boards largely confined to cost-sharing on capital costs. Second, in 1947 legislation empowered the minister of health to define a union hospital district, a step towards overall planning of hospital services (Roemer 1955). Notably, in the lead-up to the SHSP, Dr. Henry Sigerest, from Johns Hopkins University, Baltimore, Maryland, was commissioned to provide a series of explicit objectives and priorities on health issues for the new CCF government (Taylor 1978). His 1944 report recommended the establishment of health districts comprising many municipalities. These administrative units, or regions, were to provide the framework for preventive as well as curative services through district hospitals and rural health centres. Provincewide health insurance was recommended to underpin financing of medical care.

With hospital financing secured in Saskatchewan and new provincial grants to assist with construction, a period of increased development of hospital services emerged (Taylor 1978). Similar patterns were observed in other provinces, leading to questions about governance models based strictly on representation from participating municipalities. A mix of board structures began to emerge in all provinces from the 1950s through 1980. Boards for community hospitals generally preserved their linkages to municipalities; however, larger regional facilities and the major tertiary centres tended to evolve with provincially appointed boards.

While the costs of hospital services were brought under publicly funded plans across Canada by 1961, physician services remained privately funded for several more

years. Again, Saskatchewan led the way with the introduction of a prepaid, publicly administered medicare plan in 1962. However, this initiative triggered a bitter, provincewide doctor's strike lasting for 23 days. The historic Saskatoon Agreement that ended the strike paved the way for the pattern of physician involvement in publicly funded plans that later emerged across Canada. Essentially, the payment mechanisms for physicians recognized their contractual autonomy from government (Marchildon 2006). The concept of physicians providing services as independent practitioners has continued to the present time in all provinces.

Funding for early hospitals in Australia was an inchoate mix of charitable contributions, fees for services and tax-supported subsidies. In the early years of the 20th century, the Labor party began to argue for the nationalization of hospitals and free care for all (Gray 1991). By the 1920s and 1930s, community hospitals developed along American lines. Private wards were included in public hospitals, and physicians were able to charge fees to non-public patients. In the 1940s, plans were being hatched for a national health service; the ultimate goal was a free and universal system.

While the system of philanthropic funding that had operated since the earliest days was increasingly challenged, there was major resistance to the idea of a government-sponsored system from the medical profession and the Friendly Societies. Despite the resistance, both New South Wales and Tasmania took bold steps. In New South Wales, Health Minister Fred Flowers championed the universal rights of all to healthcare in preference to the institutionalized dependence on charity (Gray 1991; Crichton 1998). He organized a wide variety of institutional and community-based services financed from state revenues (Crichton 1998). Tasmania took the boldest step of all when it eliminated the charitable basis for the provision of hospital services and took control of hospital boards in 1918, making medical need the predominant basis for access to care (Gray 1991).

Resistance to government-sponsored, universal systems of health insurance continued, but after the Second World War, constitutional amendments gave the Commonwealth powers to introduce a subsidized, contributory scheme. Existing insurance organizations were used in what was essentially a privately organized insurance scheme, known as the Page plan, after the sponsoring Commonwealth minister for health who initiated it. This plan maintained a tiered system without pretense of universality. Eventually, in 1974, following the election of a Labor government, Medibank, a universal health insurance scheme, was instituted (Scotton and Macdonald 1993). Medibank made treatment in public hospitals free at the point of delivery. Doctors treating public patients became either salaried or sessional staff, and the costs were shared between the Commonwealth, states and territories, and patients (the latter paying 15% of the scheduled fee).

However, with a change of government in 1976 to a more right-of-centre party, the Liberal–Country Party, Medibank underwent various modifications until Labor

was re-elected in 1983. Medicare, an updated and reformed version of Medibank, was then enacted into legislation. Doctors protested, especially in New South Wales. They perceived this program, along with other political actions of governments to manage their economic power, as a scheme to erode their autonomy, rights and incomes. A series of doctors' strikes ensued. Eventually the government agreed to a package of measures that were designed to maintain or enhance medical income levels. The underlying ideological battle had been about a subsidized market system underwritten by government versus a government-controlled system incorporating universal coverage. Australia's approach was a compromise between what doctors were prepared to accept, particularly in terms of their income levels, and what government was prepared to accept, particularly in respect of financial commitments. Underneath it all, the issue of importance was who controlled what, and how.

Health boards and regionalization

By the late 1980s, existing governance models in Canada came under increased scrutiny. Kouri (2002) notes that while models of regionalization vary markedly across Canadian provinces, four specific objectives were behind the transition to a regional mode: (1) the integration of services along a wider continuum of care, (2) a greater focus on upstream strategies such as health promotion and prevention, (3) more meaningful public participation and (4) more appropriate governance. A fiscal imperative underpinned many of those objectives. Marchildon (2006) notes that structural reform through regionalization in Saskatchewan was pursued as a means to find savings through major service rationalization, integration and coordination. Similarly in Alberta, Philippon and Wasylshyn (1996) observe that major cost reductions accompanied the introduction of regionalization in that province.

Most provinces commissioned major studies to look at their health systems. A common theme emerging from these studies was the need to look at some economies of scales through consolidation. By the mid-1980s, each province had systems of hospital boards, public health boards, mental health boards and long-term care boards. In 1990 there were more than 900 hospitals in Canada, usually located on a single site and each with its own board of directors (Decter 2000). The Premier's Commission on Future Health Care for Albertans (1989) (known as the Rainbow Report) recommended that the more than 200 existing governance structures be consolidated into nine autonomous administrative areas accountable through Health Authorities (Premier's Commission 1989). The Future Directions Report in Saskatchewan (Saskatchewan Commission 1990) recommended creating 15 comprehensive Health Service Divisions to replace over 400 local boards. The Alberta report was met with strong negative reaction from rural areas and existing boards, who argued that such a move would erode local decision-making. The Alberta government's initial response

recognized the need to move cautiously on this recommendation.

In the early to mid-1990s, initiatives to create regional structures began to accelerate. Quebec had introduced elements of a regional structure in the early 1970s with regional councils, but these had limited responsibilities (Pineault et al. 1993). In 1992, following the recommendations of the Rochon Commission, the regional councils were replaced with regional boards (Pineault et al. 1993). New Brunswick eliminated 51 separate hospital boards in 1992, replacing them with eight regional boards (PEI System Evaluation Project 1997) for hospital and nursing home services. The first comprehensive health boards were established in Prince Edward Island in 1993 with five regional boards vested with very broad responsibilities for health and community services (PEI System Evaluation Project 1997). Saskatchewan implemented a regional system with 33 district boards in 1993, and Alberta did likewise in 1994 with 17 regional boards. The Saskatchewan and Alberta systems provided the most comprehensive range of services of any of the provinces with regional boards (except for PEI). Even these boards did not cover the entire spectrum of health services as payments to physicians, drug plans and specialized cancer and mental healthcare were not included.

In both Saskatchewan and Alberta, the number of regions or districts initially established was much higher than their respective commission reports had recommended. This difference clearly reflected what was seen to be politically feasible as a first step, and public outcry continued about the erosion of local input and citizen engagement. The furor was understandable, as over 200 boards were replaced in Alberta and over 400 in Saskatchewan by the new structures. While in both provinces the initial district/regional boards were solely appointed by the minister, there were commitments to look at different models in the future.

By the late 1990s, all provinces except Ontario moved to create regional health boards. These initiatives were intended to devolve authority from provincial health ministries to regional bodies that would have some measure of discretion in the allocation of health resources. In fact, these boards became operative when provincial governments were implementing tough cost-cutting measures (Maioni 2004).

In Australia, the predominant governance structure of a single board for each hospital started to come under serious question in the 1970s. There were also major variations across states and territories in respect of responsibilities, legislative powers, rights, obligations and composition of boards (Jamieson 1980). In the 1980s, the idea of regionalization via new, publicly funded Area Health Service models covering acute, preventive and mental health services for a defined population gained prominence. By the early 1980s there were 1,065 hospitals in Australia, of which about two-thirds were publicly funded and one-third privately operated (AIHW 2004). Many inquiries took place at various points, usually out of concern over how healthcare was organized and funded. New South Wales led the way in regionalization through the creation of 23 Area Health Service regions in 1986, with each region having an appointed board.

In the next decade there was a strong shift in other states and territories away from stand-alone (or “atomized”) boards, as Dwyer and Leggat (2002) call them, to various forms of regional systems.

Dwyer and Leggat note that across Australia’s states and territories, different forms of regionalization emerged and there was intermittent chopping and changing, possibly in a search for the ideal structure to match a particular health jurisdiction’s needs. Regional health authorities were abandoned in Queensland after eight years with consolidation at the state level; similar state consolidation occurred in Western Australia and Tasmania. Victoria never embraced a full regional system but developed a series of service networks in the mid-1990s, which were further restructured in 2000 into metropolitan health services (Government of Victoria 2000). South Australia’s major Generational Health Review (Government of South Australia 2003) recommended moving towards a regional system in Adelaide (rural areas had regionalized in 1995). The boundaries of New South Wales’ Area Health Services were restructured on two major occasions. Overall, restructuring in Australia has tended to be associated with changes in ministers, governments or directors-general of health departments. Often a regionalized structure was viewed as a political reaction rather than a carefully planned strategy (Stoelwinder and Viney 2000; Dwyer and Leggat 2002). An added complexity was that general practitioners were organized into regional divisions starting in the 1990s. These GP Divisions are funded and administered at the Commonwealth level separately from regionalized acute services in the states and territories, thus adding further challenges in achieving a streamlined, coordinated, integrated regional health system.

Recent Policy Changes Affecting Governance of the Health Systems

Ongoing structural change

One of the objectives of regionalization, both in Canada and in Australia, was to achieve greater efficiency in the use of health resources and thereby reduce cost escalation. With some minor exceptions in the initial years, however, healthcare costs have continued to climb at rates substantially greater than that of inflation. This factor, along with ongoing issues centred on defining the correct regional boundaries, led many Canadian provinces and Australian states into various rounds of consolidation. In Saskatchewan the 32 districts introduced in 1993 were reduced to 12 regions in 2002. Similarly, in Alberta, the 17 regions introduced in 1994 were reduced to nine in 2003. In Australia, New South Wales changed the boundaries of its Area Health Services: in 1986, 23 Area Health Services were established; by 1988 this number was reduced to 17, and by 2004 it was reduced to eight.

A sudden turnabout in health policy in Canada occurred in 2005 when Prince Edward Island, the smallest province, dissolved all regional boards. While the decision was an abrupt change, it needs to be placed in context. In effect, there were six governance entities, including the Department of Health and Social Services itself, administering a health system that included only seven hospitals for a total population of 140,000. Government took over the administration of health and social services with all staff becoming government employees. The plan eliminates all regional boards but does retain advisory boards for the five community hospitals (D. Riley, Deputy Minister, PEI Department of Health, August 30, 2005, personal communication). In 2008, New Brunswick also began to retreat from a regional structure by consolidating eight Regional Health Authorities down to two and creating a New Brunswick Health Council. Health Minister Murphy argued this change would remove barriers to patient care that have existed between regions, direct more the health care budget into patient care, reduce administrative costs and increase the performance of the system (Murphy 2008). But the most dramatic directional change came from Alberta in May 2008 when Health Minister Ron Liepert announced the elimination of all existing Health Boards replacing them with a new Alberta Health Services Board. As part of the transition, the new board assumes responsibility for each of the existing nine regions and will assume the functions of the Alberta Cancer Board, the Mental Health Board and the Alberta Alcohol and Drug Abuse Commission. The new board appointed by the minister is responsible for health services delivery for the entire province (Alberta Health and Wellness 2008). The future of any form of a regional structure in the delivery of health services is uncertain. The arguments for dismantling the regional boards in Alberta, like in New Brunswick, centre around the need to remove barriers for patients created by regional structures, the need for improved system performance and the intention to reduce administrative costs.

The most significant policy development in Australia relative to regional-level governance in recent years has been the decision in New South Wales to disestablish Area Health Service boards. In July 2004, in the policy document *Planning Better Health Reforms* (NSW Health 2004a), the minister for health announced an increased focus on providing a more efficient health system. To that end, the 17 Area Health Services were amalgamated into eight area administrations (along with an ambulance service, cancer institute, justice health service and specialized children's health service), and these are directly accountable to the Department of Health (NSW Health 2004a). Under the new system, the eight regional chief executives are directly accountable to the director-general. In announcing this change, the minister argued that one of the key principles of the reforms was to provide clinicians, health consumers and local communities with a greater say in the planning and delivery of health services at both the state and local levels. The restructuring plan also included establishing Area Health Advisory Councils (AHACs) in each of the eight areas and

the creation of a new Health Care Advisory Council to serve as the peak clinical and community advisory body to the minister (NSW Health 2004b).

Public participation

Many commentators note that one of the objectives of regionalization in Canada was to achieve enhanced public participation in decision-making to reflect regional health needs (OHA 2002; Kouri 2002; Marchildon 2006). This emphasis on public participation does not appear to have received the same attention in the evolution of health systems in Australia.

The issue of elected versus appointed board members has been a matter of much deliberation in Canada, but not to the same extent in Australia. While initially boards in Canada could reasonably state that they represented the interests of their communities, this claim became questionable with regional boards serving larger populations and geographical areas. Moreover, the intent to have regional boards make decisions on how best to use available resources raises questions about the desirability of having individuals on boards who are seen to represent the interests of specific communities. Lomas (1997) notes that each devolved authority in Canada has had to come to its own resolution of the inherent conflict among its provincial government's expectations, provider interests and citizens' needs and wants. These diverse interests have led boards variously down the paths of community empowerment, system rationalization and expenditure reductions. Noting the inherent conflict among these considerations, Lomas argues that most boards have given priority to system rationalization.

Saskatchewan and Alberta both introduced their regional systems with fully appointed boards in 1992 and 1994, respectively, with the promise to consider other models for the creation of boards in the future. Both then moved to a system of partially appointed and elected boards. This occurred in Saskatchewan in 1995, with two-thirds of board members being elected; this system remained in effect until 2002. In Alberta, a similar approach was introduced in 2002 but was discontinued in 2003. Both provinces moved back to fully appointed boards when they reduced the number of regions. Quebec replaced elected boards with appointed boards in 2002 and a CEO directly appointed by the minister and accountable to both the minister and the board (Levine 2004). As noted above, Prince Edward Island has eliminated regional boards and consolidated decision-making at the provincial government level.

The experience in Saskatchewan, with its partially elected boards in the period 1995 to 2002, provides some interesting observations. Most noteworthy is that community interest, as expressed both by candidates and voter turnout, was low. In fact, voter turnout declined from 35% in 1995 (Lomas 1997) to 10% in 1999 (Lewis et al. 2001). Lewis and colleagues surveyed district board members in 1997. Most (83%) felt devolution had resulted in increased local control and better-quality decisions.

Many respondents (76%) felt boards were legally responsible for things over which they had insufficient control. The majority (62%) felt that they were too restricted by rules laid down by the provincial government.

By comparison, the issue of public participation in governance and decision-making in health systems has received much less attention in Australia. Given the tradition of more state involvement in the operation of the health system, public expectations are considerably different. The elimination of boards in New South Wales in 2004 received little public attention, for example. It is not clear why this might be the case, but perhaps Australians are more apathetic than Canadians about reform of public institutions and structures.

Lessons Learned and Implications for the Future

Canadian experience

Canada has now had over a decade of experience with regionalization and some noteworthy patterns are discernible with respect to governance models.

First, there are some very mixed messages on the future of regionalization in Canada. Lewis and Kouri (2004) argued that the future of a regionalized system seems relatively secure in most provinces. Even Ontario, the largest province and the one jurisdiction that has resisted a full model of regionalization now appears to be going down a similar path with the implementation of Local Health Integration Networks (LHINs). The *Local Health System Integration Act* 2006 established LHINs as not-for-profit corporations that are responsible for planning, integrating and funding local health services in 14 different geographic areas in the province (Gamble and Woolcott 2006). However, relatively recent policy changes in Prince Edward Island, New Brunswick and Alberta cast serious doubt on the future of regionalization. Regionalization is a two-sided concept in that it can refer to governance and service delivery. At this point in the Canadian evolution, the concerns seem to focus primarily around the competition among regions arising from different governing structures. The focus is now shifting to a patient first approach by eliminating barriers to access that may have been created by regional structures and to ensure maximum health benefits from resources invested.

Second, in all provinces, even those with regional structures, the constitutional responsibility for healthcare has left the primary accountability for the performance of the health system at the provincial level. As Davis (2004) notes “governments can devolve authority for the delivery of healthcare, but they cannot devolve responsibility.” This has led to increased attention to new accountability expectations from regional boards, including performance agreements of various types. The recent changes in Prince Edward Island, New Brunswick and Alberta are placing more of the accountability at the provincial level.

Third, there has been an ongoing tension in provinces with regional systems between accountability to the provincial government and to the communities served. The pendulum has swung towards the province with various forms of performance agreements being mandated. Consolidating the number of regions and concurrently limiting the scope of action of regional health authorities have all served to increase provincial control over the health system. The recent changes in Prince Edward Island, New Brunswick and Alberta clearly place more control at the provincial level but in each case Governments have made commitments to put advisory structures in place to ensure community input.

Fourth, the accountability to the provincial government has been further reinforced by the elimination of elected boards in favour of boards appointed by the health minister in all provinces with regional systems. Furthermore, in most provinces there are explicit requirements in legislation affecting the hiring of CEOs and the expectations on CEOs that have resulted in increasing accountability of CEOs to the provincial government. Ostry (2006) concludes that in the process of regionalization and re-regionalization in Canada there has been a reduction in accountability between the federal government and the provinces, an erosion of local decision-making and an increased level of provincial control.

At the national level, the federal government has continued to play a significant role in funding the system with major financial injections through the 2003 First Ministers' Accord on Health Care Renewal and the 2004 First Ministers' Ten Year plan. However, this increased level of federal funding has not significantly enhanced the role of the federal government in effecting health system change. While attempts have been made to achieve more coordination and consistency among the provinces in areas like waiting times, pharmaceutical policy and home care, federal leadership continues to be at the high policy and directional level, with few levers to effect real change. The emerging model to advance new initiatives in key priority areas has been for the federal/provincial/territorial governments to create new national structures (e.g., Canada Info way, Canadian Blood Services, Canadian Institute for Health Information, Canadian Patient Safety Institute and the Health Council of Canada [2005]).

Australian experience

The experience in Australia illustrates an increased centralization of decision-making at the state level, with increasing degrees of intervention by the Commonwealth government. While several states introduced forms of regionalization, in reality it is in the State of New South Wales where there has been a long-term, sustained effort to deliver services through regional structures with regionally based governance. However, in 2004, after nearly two decades of experience with different iterations of this model in New South Wales, regional boards were abolished.

The more prominent feature on the Australian scene, compared with Canada, is the involvement of the Commonwealth government. The direct responsibility for family physicians, private specialist physician funding, overall physician policy, pharmaceuticals and aged care taken by the Commonwealth, and the increasingly robust nature of the five-year Health Agreements with the states, have influenced healthcare decision-making considerably.

Future implications

As of 2006, Canada and Australia have different patterns of governance for health services delivery, but there are very evident centralizing tendencies in both systems. While this paper has focused largely on the evolution at the provincial/state levels, active debate continues in both countries over the role of the central (federal/Commonwealth) governments. In Australia, the federal–state divide has long been a source of vigorous discussion. This debate has become much more prominent in Australia with the recent work of Podger (2006a,b), who recommends that the Commonwealth government assume greater financial responsibility for the system as both funder and purchaser. In Canada, the federal–provincial/territorial debate has focused instead on the need for more coordination, common standards and consistent healthcare access policies.

The overall picture at the provincial/state level is of a mounting tendency towards centralization. This trend is pronounced in Australia, where regional boards no longer exist in several states. The central question in Australia at this time is whether this centralizing tendency will now go beyond the individual states and territories to the Commonwealth government itself. It is a logically plausible, but politically turbulent, possibility for the Commonwealth to assume much more responsibility for the whole health system (Podger 2006a,b); but there is disagreement (Braithwaite 2006). In Canada, boards continue to operate, but as noted there are increased signs of a shift in the pendulum of power from boards back to the provincial governments. The reality is that both health systems have moved gradually to increased accountability and centralized control.

Australian detractors have lamented, as have their Canadian counterparts, that local decision-making has been eroded as a consequence. This situation has developed for a number of reasons, including the centralization tendencies in regionalization processes, the dominance of ministerial appointees rather than community members on boards and the surrendering of local hospital-based/health program decision-making to larger regional interests.

Striving for better governance in both countries will require greater attention to principles and evidence to guide future decision-making. Much rhetoric has been mobilized in prior eras, and the underlying motives for change have not always been

transparent. Continuous fiddling with structural arrangements or regional boundaries is not necessarily destined to advance efficiency or quality of care. It often creates disruption and anxiety (Braithwaite et al. 2006; Fulop et al. 2002). The available evidence suggests that mergers can lead to disaffected stakeholders and that cost-effectiveness is not realized automatically (Dwyer and Leggat 2002). While increased efficiency is the goal, it is not clear that incremental benefits are being realized. Large organizations, especially complex ones like health services, can become unwieldy. Without using a more evidence-based approach to change, decision-makers run the risk of inducing more uncertainty for providers and the public, as well as destabilizing the health system and further demoralizing healthcare workers.

There are difficulties in coming to definitive conclusions on the results of regionalization. While much has been written in Canada, there is still little conclusive evidence on regionalization's effects. Leatt and Nickoloff (2001) note that "little has been done in most jurisdictions to evaluate the success of regionalization." In reviewing the Saskatchewan situation, Marchildon (2005) observes that an assessment of the impact of regionalization on shifting expenditures for acute care is difficult to make and that a multifaceted research agenda is needed. Lawson and Evans (1992) evaluated the trends in regionalization in New South Wales. They argue that the establishment of Area Health Services had been successful, and better coordination, more focused responsibilities and improved efforts to rationalize duplication were the major benefits. While there are many assertions that the Canadian experience points to better continuity of care, less duplication of services and greater ability to organize integrated health strategies, evidence to support these assertions is still to be obtained. Marchildon (2006) observes that no comprehensive, systematic study of the impact of regionalization has yet been carried out.

While both the Canadian and Australian health systems have undergone significant structural reforms over the past two decades, many challenges continue in terms of rising costs, quality of care, appropriate access and the morale of the healthcare workforce. Increasingly, these issues are being acknowledged to demand far more than a structural or governance solution. Braithwaite (2006) argues that greater attention needs to be paid to the cultural frame of reference, which can help to explain and change behaviours and practices. The argument is that we must go beyond the structural preoccupation typical of reformers and begin to look more profoundly at the needs of patients and clinicians.

Perhaps we are observing an international trend underpinned by some core realities. At the heart of governance in healthcare are the leadership and management of an extremely complex undertaking. Health systems embody a rich mix of clinicians, support staff, managers, policy makers and politicians dealing with life-and-death issues in a context of rising costs and increasing technology. All these forces influence what is the core of the system: the patient-clinician interaction. Put this all together and you

have governance problems that are likely to be more intricate and sensitive than you will find in any other sector or human undertaking.

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