HEALTHCARE

POLICY Politiques de Santé

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

Volume 12 + Number 3

The Value of Qualitative Description in Health Services and Policy Research

ROGER CHAFE

Facilitative Components of Collaborative Learning: A Review of Nine Health Research Networks

LISA LEROY ET AL.

Establishing a Primary Care Performance Measurement Framework for Ontario

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

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

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

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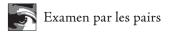
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MANAGING EDITOR

ANIA BOGACKA abogacka@longwoods.com

EDITORIAL DIRECTOR

DIANNE FOSTER-KENT dkent@longwoods.com

COPY EDITING

CENVEO PUBLISHING SERVICES

TRANSLATOR

ÉRIC BERGERON

PROOFREADER

NATHALIE LEGROS

DESIGN AND PRODUCTION

ANTONY E BICKENSON abickenson@longwoods.com

HOW TO REACH THE EDITORS AND PUBLISHER

Telephone: 416-864-9667 Fax: 416-368-4443

ADDRESSES

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

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PUBLISHER

ANTON HART ahart@longwoods.com

ASSOCIATE PUBLISHER

REBECCA HART rhart@longwoods.com

ASSOCIATE PUBLISHER

SUSAN HALE shale@longwoods.com

ASSOCIATE PUBLISHER

MATTHEW HART mhart@longwoods.com

ASSOCIATE PUBLISHER/ADMINISTRATION

BARBARA MARSHALL bmarshall@longwoods.com

ADVERTISING

For advertising rates and inquiries, please contact Matthew Hart at 416-864-9667, ext. 113 or by e-mail at mhart@longwoods.com.

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How We Will, Not Whether We Can: Improving Health and Healthcare

HEN STUDENTS LOSE HOPE, WE'RE IN TROUBLE.

I recently had the pleasure of visiting a university where I met with a group of smart, inquisitive and engaged students. Our conversation touched on many topics, but one of their questions has stayed with me. We were talking about a policy direction recently confirmed by government. The specifics don't matter — suffice it to say that it's a direction with broad public support but one that will be complex to implement, as so many meaningful health policies are.

I was asked whether I thought that it was possible for the change to be made within 5–7 years. Many were skeptical. They had been told – or in some cases personally experienced – that change does not happen that quickly in the health sector.

It's true that it doesn't always. But it can, and it should, and it must.

To illustrate, I offer five varied examples of recent progress:

- The rate of in-hospital deaths following a heart attack is falling steadily, reflecting broad-based improvements in cardiac care (CIHI n.d.);
- Since 2012, scope of practice expansions in all provinces mean that pharmacists can adapt/manage prescriptions (CPA n.d.);
- Use of electronic medical records in primary care in Canada is more than twice what it was in 2009 (CIHI 2016);
- Smoking rates are at the lowest level since measurement began (PROPEL: Centre for Population Health Impact n.d.); and
- Hospitalizations for rotavirus-related acute gastroenteritis in children have fallen significantly since a vaccination program was introduced in 2011 (Wilson et al. 2016).

So it's time to change the conversation. Instead of asking whether progress can happen, let's focus on asking how. How do we build a case, construct a coalition and sow the conditions for change? And to go further, we also need to understand the opportunities and barriers to demonstrating, evaluating, scaling and spreading approaches that deliver real and sustained value for individuals, communities and the health system.

Real change is rarely about quick fixes. In an environment as complex as the health system, transformation often requires leadership and complementary actions by a variety of stakeholders. It may involve substantial culture, policy and/or practice change.

This context is as much a challenge for researchers as it is for policy makers, healthcare leaders, clinicians and individuals. We need to understand more about how progress happens and how to speed it up so that the benefits reach everyone, not just the lucky few who happen to be connected with early adopters or policy innovators.

In this issue of Healthcare Policy/Politiques de santé, authors tackle a range of substantive issues, as well as methods such as collaborative learning, qualitative description and performance measurement that may help inform future change efforts. I hope that you will find their insights useful for accelerating improvements in health and healthcare.

> JENNIFER ZELMER, PHD Editor-in-chief

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L'amélioration de la santé et des services : voir les moyens d'y arriver, plutôt que de penser si c'est possible

UAND LES ÉTUDIANTS PERDENT ESPOIR, LES CHOSES VONT MAL.

J'ai eu le plaisir, récemment, de rencontrer un groupe d'étudiants universitaires brillants, curieux et engagés. Nous avons abordé plusieurs sujets, mais une de leurs questions m'est restée en tête. Nous parlions d'une politique de santé récemment annoncée par le gouvernement. Les détails n'ont pas d'importance, il suffit de dire que c'est une directive qui reçoit un fort appui populaire mais dont la mise en place sera complexe, comme bon nombre de politiques de santé importantes.

Les étudiants m'ont demandé si je croyais possible que le changement ait lieu au cours des cinq à sept prochaines années. Plusieurs d'entre eux se montraient sceptiques. On leur a dit – et certains l'ont sans doute vécu personnellement – que dans le secteur de la santé, les changements se produisent rarement aussi rapidement.

Il est vrai que ça n'est pas toujours le cas. Mais c'est possible, ça devrait l'être et ça doit l'être. À titre d'exemple, voici cinq dossiers récents qui illustrent le progrès :

- Le taux de décès des patients hospitalisés suite à une crise cardiaque est en baisse constante, grâce aux mesures d'amélioration systémiques des soins cardiaques (ICIS s.d.)
- Depuis 2012, le champ d'exercice des pharmaciens s'accroît dans toutes les provinces, leur permettant d'adapter et de gérer les ordonnances (CPA s.d.)
- L'utilisation des dossiers médicaux électroniques pour les soins primaires au Canada a plus que doublé depuis 2009 (ICIS 2016)
- Le tabagisme est au plus bas depuis qu'on a commencé à mesurer les taux de fumeurs (PROPEL: Centre for Population Health Impact s.d.)
- L'hospitalisation d'enfants pour cause de gastroentérite aiguë à rotavirus a connu une forte baisse depuis la mise en place d'un programme de vaccination en 2011 (Wilson et al. 2016)

Il est donc temps de changer le discours. Au lieu de nous demander si c'est possible d'accomplir un changement, demandons-nous plutôt comment on peut y parvenir. Comment faire pour étoffer les dossiers, former une coalition et réunir les conditions nécessaires au changement? Il faut de plus comprendre les facteurs favorables ou nuisibles à la démonstration, à l'évaluation, à l'adaptation et à la diffusion d'approches durables qui fonctionnent réellement, et ce, tant pour le bien des personnes et des communautés que pour le système de santé.

Les vrais changements ne sont jamais le fruit de solutions miracles. Pour un milieu aussi

complexe que le système de santé, toute transformation demande le leadership et l'action complémentaire d'une variété d'intervenants. Il est aussi parfois nécessaire de procéder à un important changement de culture, de politique ou de pratique.

Ce contexte présente bien des défis tant pour les chercheurs que pour les responsables de politiques, les gestionnaires des services de santé, les cliniciens et les individus. Nous devons mieux comprendre les rouages du progrès et les façons d'en accélérer l'étendue, afin que tous en bénéficient – pas seulement les personnes qui ont la chance de croiser sur leur chemin ceux qui adoptent rapidement les politiques novatrices.

Dans ce numéro de *Politiques de Santé/Healthcare Policy*, les auteurs s'intéressent à plusieurs enjeux d'importance de même qu'à des méthodes comme l'apprentissage collaboratif, la description qualitative ou la mesure du rendement, qui peuvent éclairer d'éventuelles initiatives de changement. J'espère que vous y trouverez des pistes pour faire avancer les changements en santé ou dans les services de santé.

JENNIFER ZELMER, PHD

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The Value of Qualitative Description in Health Services and Policy Research

Valeur de la description qualitative dans la recherche sur les politiques et services de santé



ROGER CHAFE, PHD Associate Professor, Division of Pediatrics Memorial University of Newfoundland St. John's, NL

Abstract

Health services and policy (HSP) researchers have long used qualitative research methodologies to explore health system issues. However, the appropriateness of one approach, qualitative description, for HSP research is still often overlooked. In this article, I discuss the role that qualitative description can play in HSP research, and argue for its greater acceptance as a valid form of academic scholarship.

Résumé

Les chercheurs qui s'intéressent aux politiques et services de santé (PSS) utilisent depuis longtemps des méthodologies de recherche qualitatives pour étudier les enjeux du système de santé. Toutefois, la pertinence d'une de ces démarches – la description qualitative – est souvent déconsidérée pour la recherche sur les PSS. Dans cet article, je discute du rôle potentiel de la description qualitative dans la recherche sur les PSS et je plaide pour une plus grande acceptation de la validité de cette démarche pour enrichir le fonds de connaissances.

Introduction

Qualitative researchers have made significant contributions to health services and policy (HSP) research, providing valuable insights into the ways we conceptualize health, illness,

patients' experiences, the dynamics of interprofessional teams and many aspects of care delivery. Dominant qualitative methodologies, such as grounded theory, ethnography, narrative approaches and phenomenology, are now regularly employed to pursue a variety of HSP topics. There is, however, a potentially important qualitative methodology for HSP research that is often not recognized by qualitative researchers or, at the very least, is seen as an inferior use of qualitative data. In 2000, Margarete Sandelowski highlighted the lack of stature that basic qualitative description had within the wider qualitative research community (Sandelowski 2000). While there are HSP researchers who identify using qualitative description (Granger et al. 2009; Gutierrez et al. 2013; Milne and Oberle 2005), this approach is still not widely acknowledged or known within HSP research despite previous calls for its wider adoption (Neergaard et al. 2009). This lack of appropriate recognition of qualitative description risks us missing a significant opportunity to adopt a methodological approach that is quite well suited for addressing many questions that arise for HSP researchers, and for qualitative HSP researchers to make an even greater contribution within clinical, policy and decision-making settings.

A health services research issue

While qualitative description is applicable to a wide range of HSP topics, to help clarify the approach, I will focus on its use within a recent research project. In 2011, we examined the timeliness of pain treatment at one pediatric emergency department (ED), finding that only 15% of patients received an analgesic within the recommended timeline (Porter et al. 2013). In response, the ED instituted a new pain treatment directive, which resulted in some improvements, but still left approximately 50% of patients not having their pain treated within recommended guidelines (Porter et al. 2015). We wanted to explore the barriers to further improvements in the assessment and treatment of pain which still existed within the ED (Chafe et al. 2016). Given the complexity of the care environment, and the level of understanding we hoped to acquired, we decided that some form of qualitative research which engaged nursing and physician staff within the ED was a reasonable approach to take. There were clearly other qualitative research approaches that we could have adopted, but qualitative description was likely the best approach given that our aim in this project was simply to identify possible barriers which people working in the ED felt still existed.

Sandelowski says that researchers conducting qualitative description studies "seek descriptive validity, or an accurate accounting of events that most people (including researchers and participants) observing the same event would agree is accurate, and interpretive validity, or an accurate accounting of the meanings participants attributed to those events that those participants would agree is accurate" (Sandelowski 2000). Maxwell expands on what is meant by interpretative validity, saying that interpretative accounts "are grounded in the language of the people studied and rely as much as possible on their own words and concepts." Maxwell then contrasts descriptive and interpretative validity with attempts by

qualitative researchers to give more theoretical, evaluative or generalizable accounts of a research topic. It must be reiterated that I am not arguing against qualitative projects which explore more theoretical, evaluative and generalizable interpretations, which again have been shown to provide valuable understandings. Yet limiting ourselves to an account that concerns only descriptive and interpretative validity is in keeping with what we hoped to determine in our research project – a description of the issues that people working within the ED felt were barriers to further improvements in pain management.

Qualitative description, again

It has been almost 17 years since Sandelowski first published her article calling for qualitative description to be considered as an equally valid qualitative methodology. Yet, key introductory texts to qualitative research and qualitative health research still often do not even reference qualitative description, let alone present it as an equally valid method (Creswell 2012; Green and Thorogood 2009; Morse 2012; Patton 2015). These are the same texts that many HSP researchers use in their training. Part of the reason for this continued oversight is that for many researchers the power of qualitative research lies in pushing past more simplistic descriptions of situations, and exposing or challenging the underlying conceptions that groups in society and in healthcare hold. While it is difficult to formulate a single definition, which can capture all the various aspects of qualitative research (Creswell 2012; Denzin and Lincoln 2011), it is often equated with the development of more conceptual understandings of social phenomena (Pope and Mays 1995). If a study is simply using qualitative description, accepting and reporting the concepts presented by participants as they are presented, it is not clear that qualitative description reaches this level. For those aiming at increasing our understanding of the social world, qualitative description can be seen as not much more than a journalistic account of what was seen, what people say happened and their reports about what they thought about it. In other words, for many qualitative researchers, qualitative description can seem as either uninspiring or unfinished qualitative work.

Yet, the goal of many HSP research projects is not to increase our conceptual knowledge, but to bring about change and quality improvements. For example, in our qualitative description study, we were able to report to the ED staff and management that current barriers to increasing the timeliness of pain medications identified by providers within the ED related to accurately capturing the level of pain with the current pain assessment tools, issues in treating specific complicated conditions, and inadequacy of the current initiatives to treat patients with severe pain (Chafe et al. 2016). One of the advantages of qualitative description compared to other qualitative methodologies is that there is a lower level of inference so that participants are more readily able to agree on the account being given (Sandelowski 2000). This is not to claim that the researcher is neutral or outside of the research process. Even in writing a basic description, the author selects to include certain details and exclude others (Sandelowski 2010). Yet claiming that a research participant said, for example, that she did not feel comfortable using certain medications for patients with abdominal pain can be

easily verified by referring to the interview tape or transcript in a way that more conceptual interpretations cannot. While there may be a rich evaluative discussion whether the provider should feel uncomfortable using certain medications, participants and others should be able to agree that the research participant indeed said it.

Next, to keeping the analysis at a lower level of inference such that the results given can be more readily agreed to, qualitative description keeps the analysis at a level at which those in the situation being studied should be able to readily understand. The findings of our project give an account of the barriers in the ED that were not known before, because it included perspectives from a range of people involved, but is hopefully one that nursing and physician staff working in the ED can relate to, discuss and act upon. In HSP research, rather than seeming uninspiring, qualitative description can have a powerful role in engaging a range of stakeholders at a level they relate to in order for them to better understand a situation and encourage change.

Qualitative researchers have long had concerns with the type of research project that I am describing, which is largely motivated by its practical or applied, rather than conceptual, goals. Over 20 years ago, Ritchie and Spencer (1994) proposed a framework method to address applied research questions. But they dismissively placed these types of questions into the domain of "commissioned research" to distinguish them from more proper uses of qualitative research (Bryman and Burgess 1994). Green and Thorogood make a similar distinction between "pure" and "applied" research, with applied research again concerned with the aims set by external organizations that want to use qualitative methods to solve their specific, practical problems (Green and Thorogood 2009). This distinction misses the fact that as HSP research has developed into its own domain of study, more independent researchers are formulating and pursuing these types of applied questions themselves, some even doing so while working within healthcare organizations (Chafe and Dobrow 2008). Other qualitative health researchers are more open to the applied implications of their work, but they do so still by working at the conceptual level (Morse 2012; Thorne et al. 1997). One advantage of qualitative description for certain projects is that it is able to motivate action by keeping the description closer to the everyday terms of the people involved.

Rigor

Given that it is not uncommon for HSP researchers to face questions that are mostly concerned with determining what is happening and what are people's reactions to it, qualitative description would likely be appropriate for a range of HSP studies. Better appreciating the distinctness of qualitative description as a methodology is the first step in a longer discussion around how this type of HSP research should be conducted. Being explicit that this is the approach being taken and making methodological choices in line with this direction are key starting points. Milne and Oberle emphasize appropriate interviewing skills, ensuring that participants are free to speak about a topic, and the need to probe for clarification and depth (Milne and Oberle 2005). Our project used a protocol that had included a fairly standard consent process; given

the small number of potential subjects (~30 people), we invited all physicians and nurses working in the ED to participate in the project; we developed and revised the interview and focus group guides; interviews and the focus group discussions were recorded and professionally transcribed; the analysis used both deductive and inductive coding; and institution ethics approval was granted for the entire project before it started. In other words, many of the methodological choices we made are fairly common within qualitative research projects.

Yet, this approach also possibly raises some unique methodological questions. One of the reasons we were able to usefully conduct a qualitative descriptive study is that most people in the situation we were concerned with, i.e., the activities of this specific pediatric ED, share basic beliefs about the situation: (1) beliefs about the ED and its function to treat urgent medical needs; (2) that people have certain roles within an ED, e.g., patients, parents, triage nurse, other nurses, physicians; (3) that pain is real, is often associated with an underlying medical condition and is something that is preferably avoided depending on situations; (4) that drugs which reduce pain can be administered, and that these drugs can have other impacts that may be negative and need to be considered; (5) that because of the possible potentially positive and negative impacts the drug might have in specific circumstances, there may be disagreements on whether a drug should be administered to a specific patient at a specific time, but it is usually better to reduce the pain associated with a condition earlier; and (6) that the role of developing departmental policy is that it gives direction for a consistent approach across similar situations. In our interviews with staff and patients, no indication was given that anyone challenged any of these underlying conceptions of the situation; or did we, as researchers, see the need to explore these issues in order to achieve our study aims. It is also likely that readers interested in the barriers to quicker pain management within a pediatric ED share similar views. In other words, it could be argued that there is an "agreement within the community of inquirers about the descriptive or interpretative terms used," recognizing that if these assumptions are not supported during the study another level of analysis may be needed (Maxwell 1992). It is important for the researcher in this type of qualitative research project to be reflexive and consider the impact that their background and social position may have on the findings they arrive at. Yet, if we are concerned with only providing a description of events that fits with a community's shared understanding of a situation, like trained medical staff working within the same ED, and we do not attempt to move beyond descriptive and interpretative validity in our analysis, it is not clear, in this context, whether there is an added value for the inclusion of ontological and epistemological considerations within the qualitative research process, as suggested in a number of qualitative research texts (Denzin and Lincoln 2011; Leavy 2014). The methodological implications of this possibility need to be further explored.

Conclusion

In this article, I describe qualitative description as a research methodology that is well suited for many HSP research projects. Although distinct from more conceptually focused

qualitative methodologies, it is not opposed to them, and clearly topics can benefit from being studied from various qualitative perspectives. The approach I am outlining is one likely familiar to HSP researchers using qualitative methods, even if it is not always recognized as such. It is also quite often used within healthcare organizations to engage with patients and staff around various issues. Better recognizing qualitative description will hopefully encourage researchers to explicitly adopt this methodology when it is appropriate, and to foster greater discussion of what are the most rigorous ways that it should be used within HSP.

Correspondence may be directed to: Dr. Roger Chafe, Director, Janeway Pediatric Research Unit, Associate Professor, Faculty of Medicine, Janeway Pediatric Research Unit, Room 409, Janeway Hostel, Memorial University of Newfoundland, 300 Prince Phillip Drive, St. John's, NL A1B 3V6; tel.: 709-777-2944; e-mail: roger.chafe@med.mun.ca.

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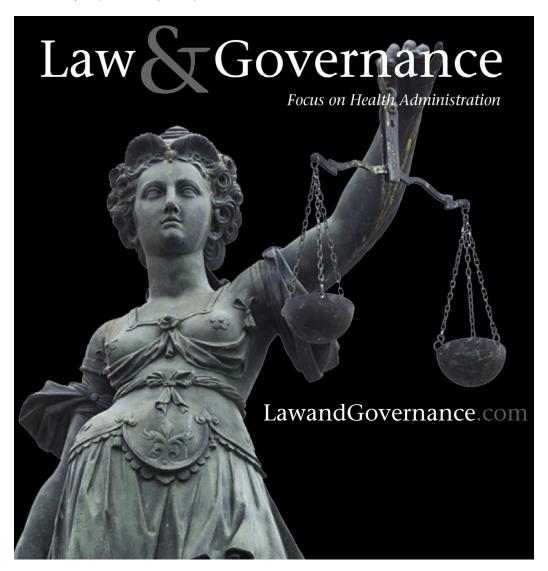
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Facilitative Components of Collaborative Learning: A Review of Nine Health Research Networks

Éléments facilitant l'apprentissage collaboratif : revue de neuf réseaux de recherche en santé



LISA LEROY, MBA, PHD US Health Division, Abt Associates Cambridge, MA

JESSICA LEVIN RITTNER, MBA, MPP US Health Division, Abt Associates Cambridge, MA

KARIN E. JOHNSON, PHD MacColl Center for Health Care Innovation, Group Health Research Institute Seattle, WA

> JESSIE GERTEIS, MPH US Health Division, Abt Associates Cambridge, MA

THERESE MILLER, DRPH
Center for Evidence & Practice Improvement
Agency for Healthcare Research and Quality
Rockville, MD

Abstract

Objective: Collaborative research networks are increasingly used as an effective mechanism for accelerating knowledge transfer into policy and practice. This paper explored the characteristics and collaborative learning approaches of nine health research networks.

Data sources/study setting: Semi-structured interviews with representatives from eight diverse US health services research networks conducted between November 2012 and January 2013 and program evaluation data from a ninth.

Study design: The qualitative analysis assessed each network's purpose, duration, funding sources, governance structure, methods used to foster collaboration, and barriers and facilitators to collaborative learning.

Data collection: The authors reviewed detailed notes from the interviews to distill salient themes. Principal findings: Face-to-face meetings, intentional facilitation and communication, shared vision, trust among members and willingness to work together were key facilitators of collaborative learning. Competing priorities for members, limited funding and lack of long-term support and geographic dispersion were the main barriers to coordination and collaboration across research network members.

Conclusion: The findings illustrate the importance of collaborative learning in research networks and the challenges to evaluating the success of research network functionality. Conducting readiness assessments and developing process and outcome evaluation metrics will advance the design and show the impact of collaborative research networks.

Résumé

Objectif : Les réseaux de recherche collaborative sont de plus en plus utilisés comme mécanisme efficace pour accélérer la transposition des connaissances dans la pratique et les politiques. Cet article explore les caractéristiques et les démarches d'apprentissage collaboratif de neuf réseaux de recherche en santé.

Sources de données/paramètres de l'étude : Des entrevues semi-dirigées ont été menées, entre novembre 2012 et janvier 2013, auprès des représentants de huit réseaux de recherche sur les services de santé aux États-Unis; et les données d'évaluation du programme d'un neuvième réseau ont été utilisées.

Conception de l'étude : L'analyse qualitative a permis d'évaluer, pour chacun des réseaux, la raison-d'être, la durée, les sources de financement, la structure de gouvernance, les méthodes pour favoriser la collaboration ainsi que les obstacles ou éléments facilitant l'apprentissage collaboratif.

Collecte de données : Les auteurs ont étudié en détail les notes des entrevues afin d'en extraire les thèmes prédominants.

Principaux résultats: Les principaux éléments facilitant l'apprentissage collaboratif sont les rencontres en personne, la facilitation et la communication intentionnelle, une vision partagée, la confiance entre les membres et la volonté de travailler ensemble. Les principaux obstacles de la coordination et de la collaboration entre les membres des réseaux de recherche sont les priorités concurrentes, le financement limité, le manque de soutien à long terme et la dispersion géographique.

Conclusion: Les résultats soulignent l'importance de l'apprentissage collaboratif dans les réseaux de recherche ainsi que les défis liés à l'évaluation de leur bon fonctionnement. Les évaluations de l'état de préparation ainsi que la mise au point de paramètres pour évaluer les processus et les résultats permettront d'améliorer la conception des réseaux de recherche collaborative ainsi que leur impact.

Introduction

Collaborative networks and learning communities are increasingly used as effective mechanisms for accelerating knowledge transfer into policy and practice. Given the information explosion facilitated by technological advancement, organizations across diverse sectors – from business to economics to psychology – rely on networks for internal and external knowledge sharing, communication and collaboration. Collaborative networks provide a structure for individuals and organizational entities that are autonomous, geographically dispersed and heterogeneous in their operating environment and culture, to work collectively to achieve a common or compatible goal (Camarinha-Matos and Afsarmanesh 2006; Shuman and Twombly 2009). The benefits of collaborative networks are clear: they stimulate creativity and the identification of innovative approaches to solve complex problems; they align organizational objectives and activities to achieve efficient and high-quality results; they enhance sharing of individual and collective assets (e.g., lessons learned, tools, funding); and they foster trust, teamwork, reciprocity and mutuality (Camarinha-Matos and Afsarmanesh 2006; Sorgenfrei and Smolnik 2014).

The implementation and funding of collaborative health networks has flourished throughout the past two decades. The 2006 Inventory and Analysis of Clinical Research Networks identified nearly 300 clinical research networks in the US and Canada. Approximately half carried out clinical trials as their primary activity, and others supported observational research, outcomes research or best-practice modelling (Kagan et al. 2009). Furthermore, the number of research networks is increasing. Beginning in the 1990s, commentators noted a move towards "big science": large, collaborative research initiatives with annual budgets of \$5 million or more (Kagan et al. 2009). In 2013, the Patient-Centered Outcomes Research Institute invested >\$100 million to develop 29 health data networks and a coordinating centre (Fleurence et al. 2014; PCORI 2013).

For health services and clinical research, networks offer analytical advantages such as increased sample size and population diversity for enhanced statistical power, subgroup analyses and generalizability (Go et al. 2008). Networks allow researchers to answer a broader array of questions, for example, about variation in process and outcomes by region and setting (Ayanian et al. 2004). Networks facilitate collaboration on analyses that require the expertise of methodologists at other institutions.

In addition to these analytical functions, some research networks emphasize *shared learning* among participants through collaborative learning models and techniques from the business and organizational development fields. Scientific collaboration can be limited by the independent culture of scientists, disciplinary specialization and decentralization of research capabilities (Bos et al. 2007). However, through meetings, presentations and training of junior researchers, research networks promote collaboration, professional development and shared learning in both informal and formal ways. A growing trend capitalizes on the contributions of scientists with different perspectives by fostering interdisciplinary, multidisciplinary and transdisciplinary research (Adler and Stewart 2010; Chilingerian et al. 2012; Fiore 2008; Hall et al. 2012; Popp et al. 2014). The interdisciplinary aspect of research networks is the most obvious in community-based research including practice-based research networks (Israel et al. 1998; Schmittdiel et al. 2010) but is also apparent in clinical research networks (Go et al. 2008).

Despite the growth in research networks, the mechanisms and structures through which research networks promote collaborative learning have not been systematically explored. How do health research networks that seek to facilitate shared learning motivate researchers to participate? Once participation is established, how do networks promote key objectives such as exchanging information, sharing innovation and collectively focusing on a topic? The purposeful combination of study-specific support and collaborative learning functions in research networks may be one of the most effective ways to catalyze broader innovation in science because it brings together both analytic and collaborative learning functions.

The large data sets and systematic research methods available to networks support more complex analyses than a single study. The infrastructure of collaborative learning networks facilitates the exchange of ideas to promote development and dissemination of state-of-the art approaches and the training and retention of a skilled scientific workforce. Research networks with strong collaborative learning functions may be especially valuable for accelerating new and complex fields of research that rely on interdisciplinary methods, including health services research (Bowers et al. 2013).

This study originated from our efforts to design and implement a Technical Assistance Center for the Agency for Healthcare Research and Quality (AHRQ) Multiple Chronic Conditions Research Network (MCCRN). AHRQ established the MCCRN to foster collaboration among 45 research grant recipients funded between 2008 and 2010 to conduct studies on MCC. The purpose of the MCCRN was to expand and enhance the existing body of knowledge and evidence on care for people with MCC. The role of the Technical Assistance Center was to convene the 45 investigator teams and facilitate a series of in-person and virtual network activities (LeRoy et al. 2014). In addition to evaluating the MCCRN and Technical Assistance Center, we observed and documented the facilitative elements of collaboration among the MCCRN over time.

The objective of this paper is to explore the characteristics of nine health research networks; illustrate how they used collaborative approaches to develop a shared vision and structure to promote collaborative learning; and offer recommendations for enhancing collaboration in health research networks.

Methods

Study design

To learn from the experiences of health research networks and compare the facilitative components of the MCCRN with other networks, we conducted a qualitative study using telephone interviews with leaders of research networks. We wanted to understand the phenomenon of collaboration among network participants, including the best ways to facilitate shared learning when research studies are diverse and topics are in emerging fields of study (Moustakas 1994). Therefore, we gathered perspectives and experiences on collaborative learning research networks from investigators in research networks outside the MCCRN. This information was combined with findings about the MCCRN from project evaluations.

Sample selection

To identify research networks that were currently in operation and incorporated learning collaborative functions and were advancing an emerging field of health services research,

we searched and reviewed public websites and peer-reviewed and grey literature. We searched the PubMed database of the US National Library of Medicine at the National Institutes of Health, Google Scholar and ScienceDirect using the terms: "research network," "learning OR research collaborative," "health research network," "health collaborative," "interdisciplinary research" and "transdisciplinary science." Searches were limited to articles published in English on collaborative healthcare research networks administered in the US. We also asked AHRQ staff members who facilitate and coordinate research networks and network officials that we contacted to identify eligible networks. Through this process, we identified 18 potential networks. We did not conduct an exhaustive scan of research networks, rather we sought to identify a sample of networks with a collaborative learning emphasis but varied structures and focuses. We searched for mature networks whose leaders could reflect on collaborative learning and related processes. After a careful review, we limited our non-MCCRN sample to eight diverse and established health-related research networks.

Interview guide and interview procedures

We developed a short, semi-structured interview protocol with questions about network mission, funding, organizational structure and membership, and methods for collaboration and knowledge dissemination. We also asked about barriers and facilitators of coordination and collaboration among network participants, and elicited recommendations for funding, designing and sustaining future research networks. The Abt Associates Institutional Review Board determined that the study was exempt from review. Interviews were conducted between November 2012 and January 2013. Two trained researchers facilitated the interviews, along with one assigned note-taker. Respondents were network leaders, usually the steering committee chair or project officer for the sponsoring organization.

For the MCCRN, characteristics, barriers and facilitators were based on the project's final evaluation report, which summarized data on the experiences of MCCRN participants collected via online survey and one-on-one telephone interviews. We included our own observations on implementing the Technical Assistance Center, which was part of the evaluation.

Analyses

Multiple team members reviewed detailed notes from the interviews to distill salient themes. Coding was based on a priori codes from the literature, as well as themes that emerged from the data. Network websites were reviewed for additional information if information was missing. The coding team held three analytical retreats to discuss and compare codes across the nine networks and to interpret the data.

Characteristics of Collaborative Networks

In the following section, we describe the characteristics of the nine networks, including mission, funding and membership (Table 1), as well as governance structures and approaches for collaboration and dissemination (Table 2).

Network purpose and evolution

Respondents shared similar motivations for forming their networks: to advance a field of research, collect data on understudied populations and accelerate the implementation of research findings into practice. In each network, collaborative learning was an explicit part of the mission. In most cases, networks were designed to bring individuals together from a range of disciplines to answer similar research questions, pool study subjects or data sets, and share and disseminate methods and knowledge among network members and with the larger community. Inception varied across networks; for example, the Collaborative Care Research Network was born out of a Collaborative Care Conference, during which the founders identified both the need for an evidence-base on mental health-primary care integration and an organizational mechanism to support it. Two networks (PECARN and MCCRN) were established through the American Recovery and Reinvestment Act to advance patient-centred outcomes research, one with a focus on infrastructure development and another on collaboration among community-based providers and researchers. One network aimed to "create a community of people who engage in both research and clinical practice, in an attempt to accelerate research findings into the care setting." Similarly, the Medicaid Medical Directors Network originated to increase knowledge sharing among state officials, to decrease independent struggles with common issues and to implement multistate measurement and quality improvement projects. Finally, training young researchers was cited as a motivation, helping them develop their careers and encouraging them to focus on important research topics.

Funding

Six networks were funded by federal healthcare agencies, two with grants from private organizations and one from multiple-funding sources (Table 1). Of the networks that received federal funding, the Cancer Prevention and Control Research Network and HMO Research Network (HMORN) were jointly funded by multiple agencies. As previously mentioned, two networks were funded through the American Recovery and Reinvestment Act. Funding varied substantially, ranging from \$350,000 to \$1 million per year. The length of initial funding varied but as of 2013, half the networks had been functioning for more than 10 years. Respondents stated that network duration and sustainability were primarily dependent on available funding and on the level of effort and interest among members. Some networks suffered budget cuts when the financial climate worsened. These cuts reduced the ability to convene or support travel to in-person meetings, and maintain network websites and data registries. When asked if funding was adequate to achieve intended network goals, all respondents but one said that funding was insufficient and that obtaining funding was always a challenge. Respondents noted that some members sought additional funding for individual projects developed within the network. One respondent said that a few established investigators served as magnets for research network funding. Thus, while their network intended to help less-experienced investigators become project leaders, funders tended to award grants to senior investigators, hindering the professional development of younger researchers.

TABLE 1. Comparison of research network organizational characteristics, 2013

Network	Mission and/or goals	Members	Funder(s)	Coordinating centre
Cancer Prevention and Control Research Network (CPCRN)	Accelerate the adoption of evidence-based cancer prevention and control to reduce the burden of cancer	10 organizations 180 individuals	Centers for Disease Control and Prevention & National Cancer Institute	University of North Carolina Chapel Hill
Community Health Applied Research Network (CHARN)	Conduct comparative effectiveness and patient-centred outcomes research to improve patient care at federally supported community health clinics	23 organizations (including health centres) 73 individuals	Health Resources and Services Administration	Kaiser Foundation Hospitals Center for Health Research
Collaborative Care Research Network (CCRN)	Conduct practice-based primary care research that examines the impact of behavioural health on primary care and health outcomes	78 organizations III individuals	None	American Academy of Family Physicians (AAFP) National Research Network
MacArthur Research Network on Socioeconomic Status (SES) & Health	Enhance learning on socioeconomic factors that affect the health of individuals and their communities	13 organizations	MacArthur Foundation	None
Medicaid Medical Director's Learning Network	Advance the health of US Medicaid patients by increasing the sharing of knowledge between state Medicaid Medical Directors	45 states* 59 individuals	Agency for Healthcare Research and Quality	AcademyHealth
HMO Research Network (HMORN)	Improve healthcare delivery through comparative effectiveness research that connects resources and capabilities of healthcare systems	18 organizations 400 individuals	Member dues support cross-project infrastructure, in close coordination with specific projects (e.g., Cancer Research Network)	N/A; organized under a Board of Governors and several executive committees, in close coordination with the leadership of individual projects; one member organization administers the budget
Pediatric Emergency Care Applied Research Network (PECARN)	Conduct multi-institutional research on prevention and management of acute illnesses and injuries in children and youth across the continuum of emergency medicine healthcare	18 organizations 19 individuals	Health Resources and Services Administration	University of Utah
Washington University (WU) and Barnes- Jewish Hospital (BJH) Epicenter for Prevention of Healthcare Associated Infections	Develop improved systems to detect and prevent healthcare-associated infections	13 organizations 20 individuals	Centers for Disease Control and Prevention	None
Multiple Chronic Conditions Research Network (MCCRN)	Advance the field of multiple chronic conditions through comparative effectiveness research, infrastructure development, and dissemination of collective work	45 organizations 75 individuals	Agency for Healthcare Research and Quality	Abt Associates

^{*}All states are invited to participate in the Medicaid Medical Director's Learning Network; however, the number of states represented fluctuated over time. At the time of the interview, 45 states were active in the network.

TABLE 2. Research network governance structure and methods for collaboration and dissemination

	Governance structure				Methods of collaborative learning	
Network	Steering committee	Sub- committees	Annual in-person meetings	Conference calls	Workgroups	Webinars
Cancer Prevention and Control Research Network (CPCRN)	×		×	×	×	×
Community Health Applied Research Network (CHARN)	×	×	×	×	×	×
Collaborative Care Research Network (CCRN)	×	×		×		
MacArthur Research Network on Socioeconomic Status (SES) & Health			×	×	×	
Medicaid Medical Learning Network	×		×		×	×
HMO Research Network (HMORN)	×	×	×	×	×	×
Pediatric Emergency Care Applied Research Network (PECARN)	×	×	×	×	×	×
Washington University (WU) and Barnes-Jewish Hospital (BJH) Epicenter for Prevention of Healthcare Associated Infections	×	×	X	×	×	X
Multiple Chronic Conditions Research Network (MCCRN)			×	×	×	×

All networks also maintained typical communication vehicles, such as a website and LISTSERV.

Membership

Network membership comprised researchers in geographically diverse organizations and in academic medicine and research institutions, universities, hospitals and health centres. Membership size ranged from 10 member organizations to ~78, and from 13 individual participants to more than 400. Researchers and their organizations typically applied to serve as a research network "node" (site) and/or a coordinating centre through a funding agency's request for applications. In one instance, a network director invited individuals to participate in her proposed network based on their disciplines and their level of interest and engagement in topics outside their research specialty. She especially sought early career researchers and individuals with expertise in interdisciplinary research. The MCCRN included researchers who received individual AHRQ grants on MCC who were later brought together by the agency to participate in the network.

Research network participants represented various disciplines and diverse content expertise in the areas of healthcare, research, economics and policy who shared common interests. In the words of one respondent:

"Part of what makes our centre work is that there are common themes ... even though individuals have different research projects and strengths, they are all

associated with healthcare-associated infections ... having some thematic consistency and common interest makes a big difference."

According to several respondents, diverse knowledge and skills were valuable to the network and essential for cross-disciplinary collaboration.

Several respondents reported that their networks experienced yearly member turnover. For example, one network experienced a 50% turnover for the network as a whole, and a 40% turnover among principal investigators. Reasons for turnover included job changes and retirement. Also, one respondent noted that network participation is difficult for sites without academic infrastructure because they lack ongoing research support.

Network governance

In all but two networks, a steering/advisory committee oversaw implementation and day-to-day management (Table 2). Several networks did not initially have governance structures, but created steering committees as missions and membership evolved. One of these networks had minimal structure for the first three years as network members primarily engaged in sharing knowledge. As the network's vision and research matured, members wanted more structure and created a formal steering committee and governing bylaws. One respondent explained:

"Initially, it was difficult to keep the network together ... without having a group leader, which was why a steering committee was developed."

Steering committee roles and responsibilities were fairly consistent across networks: typically, the steering committee developed agendas and facilitated monthly or quarterly meetings, monitored research and collaborative activities and managed key decisions (e.g., future research projects, authorship criteria for publication). Steering committees usually comprised a chair and vice chair, a funding agency representative and a few representatives from the research sites or coordinating centre. Generally, a new steering committee was elected every few years. In addition to steering committees, five networks maintained subcommittees or workgroups for executing work effectively and efficiently. More than half of the research networks were supported by a coordinating centre that provided administrative and technical support to network participants (e.g., data assistance, organization of member collaborative activities, guidance on dissemination of research, products and tools).

Methods of collaboration and dissemination

Respondents reported that the best method for promoting collaborative learning among research network members was in-person meetings. Research networks regularly brought members together at least once a year, and most networks held two to four annual face-to-face meetings. Three networks, for convenience to members, coordinated in-person meetings with national conferences. One network exclusively used this method. Two others held both

dedicated network meetings and meetings coordinated with national conferences. Four networks held additional in-person meetings throughout the year for steering committees or special interest/working groups.

Half the networks used teleconferencing. Conference call frequency varied considerably: one network held weekly member calls, while another held quarterly, 6-hour conference calls. The other two networks held periodic calls with subgroups such as the steering committee and working groups. All networks used a website and eight also used a LISTSERV to exchange information and foster collaboration.

Facilitators and Barriers to Collaboration

Below we describe the facilitators and barriers to collaboration identified by respondents.

Facilitators of collaboration

As mentioned above, one of the main facilitators of effective collaboration was in-person time with members, funders and key stakeholders. Building trust between members arose as a key theme throughout our interviews, with respondents saying that trust served as a crucial facilitator for overcoming differences in research and disciplinary approaches. One respondent emphasized the importance of bringing members together to enhance and maintain trusting relationships:

"It's essential to create free time for individuals to get to know one another. At the beginning of the in-person meetings [we] would always have a dinner meeting. These dinner meetings helped facilitate trust and a common connection between members. Having this trust made it possible for everyone to work together more effectively as a group. This process would not have been as successful via web conference or through email."

A few respondents mentioned the importance of maintaining a "shared vision" or a common set of agreed-upon goals and objectives. Traditionally, researchers are trained to pursue their own projects independently. Given the non-collaborative tradition of research, as well as the challenge in managing multiple investigators and competing ideas, it is essential for networks to reach a consensus on the mission and focus of the work, identify strategies to integrate diverse interests and find common ground among network members. With the MCCRN, we found that surfacing methodological and substantive issues of mutual interest to participants were essential in motivating investigators to collaborate. Common problems and research challenges brought network participants together to problem-solve and consult with each other on solutions. Most respondents spoke about the difficulty and time commitment of conducting collaborative research and network involvement:

"Many sites wanted to do the work but didn't have the patience it took to engage with the network. Because the workload is about twice as much as the investigators

are actually paid to do, everyone participating really has to be passionate about the work that they are doing."

In addition, respondents thought it important that network members believed in collaboration as the best method to answer their research questions.

"Being a part of a network requires tolerance for ambiguity, a certain humility about your own discipline, an appreciation and a passion for a particular problem, and the realization that you can only solve that problem if you work together."

Furthermore, all respondents spoke of the importance of establishing strong leadership and a culture of transparency for developing common goals and equitable participation:

"Strong leadership was essential in this circumstance. Everyone went into the network with certain assumptions. The group needed guidelines – and a system to be accountable to. In the beginning, there was a constant pushing and pulling."

Barriers and challenges to collaboration

Funding and financial sustainability were identified as the greatest barriers to research collaboration. Collaboration takes time and thought, and many researchers are responsible for attracting funding that pays for their own salaries. Collaborative research across multiple institutions is expensive to organize and implement, and funding for this type of work is limited. Established research networks reported that their funding declined over time. In addition, respondents discussed the limitations of short funding periods. Building trust, a collaborative spirit, infrastructure and systems took years. Thus, short funding periods were a serious barrier, especially for research networks with ambitious goals. As an example, investigators in the MCCRN took almost two years to coalesce as a group and identify areas for collaboration. The network was funded for three years without a mechanism for extending funding. This was not long enough for participants to build sufficient momentum around collaborative efforts. When asked how many years are needed to develop an effective research network, respondents recommended a minimum of 5 to 6 years, with 7 to 10 as the ideal:

"You need to have a long-term investment because it's inefficient in the short term. Researchers need to know if the network is going to be supported for long enough to get the payoff."

To offset the challenges of sustainable funding, one network created a supplemental funding pool, which allowed the investigators to quickly apply for and obtain support for add-on collaborative or multi-member work. Although flexible funding facilitated collaborative work in this network, the mechanism was not used by the other networks.

Several respondents cited changes in travel regulations for federally funded work as a specific barrier that hindered or even prevented in-person network meetings.

Furthermore, respondents pointed to busy schedules and competing demands for time as a barrier to collaborative research. Many network investigators were practising physicians or professors balancing research network activities with other institutional demands and requirements. For example, one respondent stated that while some sites wanted to "do the work," they did not have the time or patience to engage in all network activities. Finally, as previously described, high membership turnover was common. This too added to the difficulty of establishing trust and maintaining collaboration.

Discussion

Our analysis of a set of US health research networks shows variation in their governance, focus, membership and funding. In all networks, however, the work of building collaborative structures — establishing a culture of trust, compromise and sharing — took time and thought. Each research network in the study came up with its own mechanisms and ways of creating infrastructure, but it expressed a common recognition of the need to carefully craft processes and techniques that fostered learning among the participants. All network representatives mentioned the importance of holding face-to-face meetings, finding time for regular communication and interaction, and maintaining ongoing network structures and processes in the midst of competing demands.

In addition to structural facilitators such as a meeting organizer, our results highlight the essential role of actively building trust and relationships for establishing collaborative learning processes. The importance of effective communication in developing trust and strengthening relationships is a common theme in studies of research networks (Williams et al. 2008). Effective networks do not simply throw people and ideas together, but intentionally promote and build on the dynamic and emergent relations between members. As described by Vangen and Huxham (2003), trust building is a cyclical process. Positive outcomes form the basis for trust development. With each consecutive positive outcome, trust builds incrementally, over time, in a virtuous cycle (Vangen and Huxam 2003). Scott and Hofmeyer (2007) stress the centrality of network theory and social capital in determining network outcomes. Members themselves shape the identity, function and products of their networks through their individual interests, and through shared properties including common goals; trust; compatibility of language, culture and methods; transparency; rewards (e.g., building professional relationships and reputations); and level of collaboration readiness and skill (Scott and Hofmeyer 2007; Stokols et al. 2008; Williams et al. 2008).

Despite the central role of learning network functionality, assessing the specific components that make research networks effective in promoting trust between members and achieving research goals is challenging. As our findings illustrate, one difficulty in evaluating the success of learning network functionality in networks is that objectives vary over time, especially as funding changes and individual research efforts move to completion. Techniques

for surfacing the common substantive interests of members need to be documented and tested, as they may predict participation and engagement in collaborative networks. A starting point for these techniques could be readiness assessments from areas such as health innovation improvements (Weiner et al. 2008) and community—academic partnerships (Goytia et al. 2013).

Another limitation in determining the factors that contribute to research network effectiveness is the lack of established outcome measures. The most common metric for evaluating outputs from research networks is publications. However, research collaboration will not always lead to a publication and other valuable – but difficult to measure – results from learning collaborations include intellectual and social capital, personal satisfaction, fun and pleasure, quality of results, prestige, training, communication, implementation, sustainability (Bleeker et al. 2010; Bukvova 2010; Fenton et al. 2007; Kreger et al. 2007), and training and career development for junior research staff.

Our findings may be useful for others forming and evaluating research networks. While our analysis is based on a small sample of research networks in one country, our interview results are consistent with previous research (e.g., Pless et al. 2010; Williams et al. 2008) in emphasizing the importance of collaborative learning in research networks, and mechanisms for fostering it. Further, the findings resonated with our applied experience facilitating trust-building and information-sharing through the MCCRN Technical Assistance Center. While we used asynchronous collaboration methods such as a shared website and newsletter, we found in-person meetings especially useful. In these, we used specific learning community techniques to foster group conversations and learning. Meetings were structured according to interests expressed by grantees. We found that collaborative activities increased over time, but interest and engagement in collaborative research varied across participants.

Given the technological advances and the financial costs of in-person learning communities, more networks are turning to virtual collaboration to meet their organizational goals and address geographic dispersion among network members. Over the past 10 years, business and organizational development practitioners have assessed the management and performance of virtual networks and teams. While research reveals that virtual teams outperform co-located groups, such teams are successful only when managers implement task-related processes that capitalize on specialized knowledge and expertise of virtual groups and promote cultures that prioritize diversity (Siebdrat et al. 2009). Our own experience and the reports of representatives from other networks suggest that virtual collaboration is unlikely to be successful until familiarity and trust are established through in-person experiences.

Based on our analysis, we offer several suggestions for the development of research networks. First, the time and resources to facilitate collaboration cannot be underestimated and underfunded. According to our respondents, infrastructure needs do not decline over time, but rather change over the life of the network. In turn, readiness assessment may be a valuable tool for developing network structure and activities to meet members' needs. As noted above, few evaluations of health services research networks have been published and

metrics for assessing network success are nascent. Ultimately, the benefits of collaborative networks may need 5 or 10 years to be realized, and evaluations must take this into account. Developing process and outcome evaluation metrics would greatly advance the design of research learning networks and show their impact. Last, continued sharing of research network experiences and success stories can help current and developing collaborative endeavours refine mechanisms to meet their objectives.

Correspondence may be directed to: Lisa LeRoy, MBA, PhD; US Health Division, Abt Associates, 55 Wheeler Street, Cambridge, MA 02138; tel.: 617-349-2723; e-mail: lisa_leroy@abtassoc.com.

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Assessing Continuous Quality Improvement in Public Health: Adapting Lessons from Healthcare

Évaluation de l'amélioration continue de la qualité en santé publique : adapter les leçons des services de santé



ALEX PRICE, PHD Doctoral Researcher, Dalla Lana School of Public Health University of Toronto Toronto, ON

ROBERT SCHWARTZ, PHD Professor, Dalla Lana School of Public Health University of Toronto Toronto, ON

JOANNA COHEN, PHD Professor, Johns Hopkins Bloomberg School of Public Health Baltimore, MD

HEATHER MANSON, MD, FRCPC, MHSc Assistant Professor, Dalla Lana School of Public Health University of Toronto Chief Health Promotion, Chronic Disease and Injury Prevention Public Health Ontario Toronto, ON

> FRAN SCOTT, MD, CCFP, MSc, FRCPC Associate Professor, Faculty of Health Sciences McMaster University Hamilton, ON

Abstract

Context: Evidence of the effect of continuous quality improvement (CQI) in public health and valid tools to judge that such effects are not fully formed.

Objective: The objective was to adapt and apply Shortell et al.'s (1998) four dimensions of CQI in an examination of a public health accountability and performance management initiative in Ontario, Canada.

Methods: In total, 24 semi-structured, in-depth interviews were conducted with informants from public health units and the Ministry of Health and Long-Term Care. A web survey of public health managers in the province was also carried out.

Results: A mix of facilitators and barriers was identified. Leadership and organizational cultures, conducive to CQI success were evident. However, limitations in performance measurement and managerial discretion were key barriers.

Conclusion: The four dimensions of CQI provided insight into both facilitators and barriers of CQI adoption in public health. Future research should compare the outcomes of public health CQI initiatives to the framework's stated facilitators and barriers.

Résumé

Contexte: Les données sur l'effet de l'amélioration continue de la qualité (ACQ) en santé publique et les outils valides pour estimer cet effet ne sont pas encore entièrement au point. Objectif: L'objectif était d'adapter et d'appliquer les quatre dimensions de l'ACQ de Shortell et al. (1998) dans l'examen d'une initiative de reddition et de gestion du rendement en santé publique en Ontario, Canada.

Méthode: En tout, 24 entrevues semi-dirigées en profondeur ont été menées auprès d'informateurs d'unités de santé publique et du ministère de la Santé et des Soins de longue durée. Un sondage en ligne auprès des gestionnaires de la santé publique a aussi été administré dans la province.

Résultats: Un ensemble d'éléments facilitants et d'obstacles a été identifié. Les cultures d'apprentissage et organisationnelle, propices à la réussite de l'ACQ, ont été mises en évidence. Toutefois, les limites de la mesure du rendement ainsi que le pouvoir discrétionnaire de la gestion constituent des obstacles importants.

Conclusion : Les quatre dimensions de l'ACQ présentent des pistes tant pour les éléments facilitants que pour les obstacles à l'adoption de l'ACQ en santé publique. D'autres recherches devraient être menées pour comparer les résultats des initiatives d'ACQ en santé publique par rapport aux éléments facilitants et aux obstacles énoncés dans le cadre de travail.

Introduction

This study examines the implementation of a public health accountability and performance management system featuring declared principles of continuous quality improvement (CQI) in Ontario, Canada. CQI is an approach to the management and improvement

of organizational services and processes (Dilley et al. 2012; Nicolucci et al. 2010; Radawski 1999). The approach stands in contrast to quality control and assurance by virtue of its focus on identifying opportunities to improve work processes as opposed to identifying individualized problems and maintaining a status quo (Dever 1997). CQI relies heavily on performance measurement and analysis, as well as on the involvement of leadership and front-line staff in decision-making processes (Kosseff 1992; McLaughlin 1987; Radawski 1999).

The adoption of quality improvement approaches such as CQI in public health has been a recent and popular development (Capacity Review Committee 2006; Corso et al. 2010; Dilley et al. 2012). Despite this phenomenon, there exists a limited body of empirical evidence on the impact of quality improvement approaches in public health settings (Corso et al. 2010; Dilley et al. 2012; McLees et al. 2014; Riley et al. 2012). Moreover, valid and reliable frameworks for assessing the integrity and impact of such systems in public health are still emerging. In contrast, development of CQI in healthcare settings has been much more extensive, dating back to the late 1980s (Chinnaiyan et al. 2012; Radawski 1999; Rex et al. 2002).

Adapting Healthcare Quality Improvement Knowledge for Public Health

This study uses Shortell et al.'s (1998) four dimensions of CQI as an analytical framework for assessing a public health quality improvement initiative in Ontario (Figure 1). The four dimensions of CQI represent an assessment framework derived from systematic reviews of empirical healthcare research. In addition, Shortell et al.'s earlier research on the cultures of high-performing organizations is used to augment the cultural dimension of the adapted framework (Shortell et al. 1995). For instance, developmental cultures featuring an emphasis on risk-taking, innovation and change, as well as group cultures with strong teamwork and participation, found the greatest success in supporting CQI initiatives. Hierarchical and rational cultures that stress bureaucratic norms and narrow definitions of achievement were found to act as barriers.

Within clinical health research fields, the four dimensions of CQI have received empirical validation (Bennett and Crane 2001; Forsner et al. 2008; Solomons and Spross 2011). One example includes Forsner et al.'s (2008) controlled study of evidence-based practice in Swedish psychiatric care. The investigators examined the implementation of clinical guidelines and found that in the test group, in which the four dimensions of CQI were applied, the reported guideline compliance was significantly greater (p < 0.001) than in the control group.

Many of the key factors presented in the four-dimensions framework overlap with those emphasized in the public health quality improvement literature. For instance, in their qualitative study of 51 quality improvement initiatives in various public health departments in the US, Riley et al. emphasized leadership and appropriate performance measures, which are also highlighted in the strategic and technical dimensions of CQI (Riley et al. 2012). Resource inadequacy was a key barrier in McLees et al.'s (2014) study of 74 public health agencies involved with the National Public Health Improvement Initiative in the US, as it is in the strategic dimension of Shortell et al.'s framework. The importance of training and education in quality-improvement concepts and techniques is also stressed in both the public health literature and the technical dimension (Corso et al. 2010). Knowledge transfer and exchange,

supportive organizational cultures and the influence of implementers in decision-making outlined in the structural, cultural and strategic dimensions were factors that did not appear to have extensive profiles in the public health literature.

Strategic dimension **Cultural dimension Technical dimension** Structural dimension Conditions and processes Reflects organizational Training and information Mechanisms for facilitating that offer the greatest beliefs, values and systems needed for learning through the opportunity for improvement behaviours quality-improvement efforts organization and system **Facilitators Facilitators Facilitators Facilitators** I. Training opportunities I. Leadership and 1. Foster openness, I Effective forums of 2. Data quality and availability communication collaboration, teamwork communication 2. Include all stakeholders in and learning decision-making 2. Developmental culture 3. Group culture Data used to understand processes, systems and performance Decisions made on basis of analysis and understanding of data Work processes and systems improved **Barriers Barriers Barriers Barriers** 1. Time constraints 1. Resistance to change 1. Lack of training opportunities I. Lack of mechanisms for 2. Goals and priorities of 2. Achievements not 2. Poor information systems disseminating knowledge leadership and celebrated or rewarded 2. Limited use of management diverge 3. Hierarchical culture communication mechanisms 3. Resource inadequacy 4. Rational culture 4. Work overload Inability to produce knowledge and disseminate it to inadequate prioritization but are not recognized, acknowledged or of adequate training

FIGURE 1. The four dimensions of continuous quality improvement (CQI)

celebrated

Research Context

The public health system in Ontario features several key stakeholders, including the Ministry of Health and Long-Term Care (MOHLTC), boards of health and local public health units. The Ministry provides provincial stewardship and 75% of core funding for the public health system and is also charged with upholding key legislation. Boards of health are municipal and regional public health governing bodies that are responsible for overseeing their corresponding public health units and providing them with the remaining portion of core funding. Public health units are the agencies that deliver programs and services in their respective jurisdictions.

Following the 2003 outbreak of Severe Acute Respiratory Syndrome (SARS) in Ontario, a major reform of the system was initiated by the Minister of Health (Smitherman 2004). This reform included the declarative adoption of CQI as a means of pursuing performance improvement (Capacity Review Committee 2006; Law et al. 2013; MOHLTC 2008, 2011). CQI adoption has taken the form of a system of accountability and performance management, currently undergoing implementation across 36 municipal and regional public health jurisdictions. The system is composed of (1) the Ontario Public Health Standards (OPHS),

which outline the program and service requirements for boards of health and public health units, as well as broad goals and outcomes across each area of public health; (2) accountability agreements between the Ministry and boards of health and their public health units that establish specific performance indicators and targets related to areas of the OPHS; (3) organizational standards that articulate management and governance requirements for boards of health and public health units; and (4) reporting requirements for the collection and analysis of performance measurement information (MOHLTC 2008, 2011, 2013).

Methods

A mixed-methods approach consisting of key informant interviews and a web survey was used to assess Ontario's public health accountability and performance management initiative. All data collection and analysis were conducted by the principal author with university ethics approval and editorial feedback from co-authors. This study used many elements of a case study approach, such as interview and survey methods and triangulating analysis, which have been used extensively in the field of implementation research (Long and Franklin 2004; McDermott 2004; Mischen 2006). Research conforming to case study characteristics has also been used to investigate public accountability and performance management (Christensen and Lægreid 2014; Hildebrand and McDavid 2011).

Key informant interviews were conducted in three public health units (sites A, B and C). Sample selection was conducted to reflect diverse implementation contexts characterized by both rural and urban service environments, as well as municipal and regional governance. In total, 20 semi-structured key informant interviews of ~1 hour in length were conducted. All interviews were tape-recorded and professionally transcribed in full. Public health unit informants included executive, management and specialists in various areas of public health, such as chronic and infectious disease prevention and control. These groups of individuals represent the primary implementers of the province's public health accountability and performance management intervention.

Four separate interviews with representatives of the MOHLTC were also conducted during the same period of data collection. These interviews also followed a semi-structured approach and included individuals directly involved with the development of the province's quality improvement initiative.

Interview questions for both public health unit and Ministry informants included specific and broad items relating to facilitators and barriers within the four dimensions of CQI. For example, Ministry and public health informants were asked to choose characteristics of Shortell et al.'s (1995) organizational cultures typology (i.e., teamwork, risk-taking, bureaucratic, efficiency-focused) that best reflected their work environment. Broader items included questions asking informants to independently identify what conditions or factors were critical to the success of implementing Ontario's system of accountability and performance management.

In addition to key informant interviews, a web survey of public health managers was conducted. Targeting all public health managers in each of the province's 36 health units,

recruitment involved contacting each senior executive to seek approval and access to their organizations. In total, 12 public health units agreed to participate and provided contact lists of public health managers; 97 surveys were distributed; 53 questionnaires were returned, providing a response rate of 54.6%. This sample, while only covering one-third of all public health units, represented a near-equivalent distribution of rural, mixed rural and urban, and urban jurisdictions. Survey questions, for example, asked about manager discretion, relating to stakeholder decision-making in the strategic dimension; resistance to the intervention, relating to barriers in the cultural dimension; familiarity with components of the initiative, as well as sentiment regarding performance measurement pertinent to the technical dimension; and prospective thoughts on the use (and usefulness) of collected information for performance management and quality improvement.

Directed content analysis was applied to qualitative data by using an initial coding frame informed by pre-existing empirical and theoretical literature (Hickey and Kipping 1996; Hsieh and Shannon 2005; Potter and Levine-Donnerstein 1999). Strong, anomalous themes were then coded separately. Established codes were then matched with facilitators and barriers of Shortell et al.'s (1998) four dimensions of CQI and analyzed. Quantitative data collected using keysurvey.com were recoded for descriptive and bivariate analyses using SPSS. Two-sided Fisher's exact tests $(p \le 0.05)$ assessed association because of the small survey sample (Daya 2002). Findings from the survey supplement the qualitative data, and all presented findings did not feature missing data (n = 53).

Findings

The findings in this study are presented across strategic, cultural, technical and structural dimensions and focus primarily on the facilitators and barriers in the four-dimensions framework. Overall, evidence of both facilitators and barriers in each dimensional category related to Ontario's system of public health accountability and performance management was apparent.

Strategic dimension

The strategic dimension emphasizes the importance of leadership, communication and inclusion of all stakeholders in decision-making. Analysis of interview data found statements of strong leadership expressed by each public health unit. Local-level leadership in quality improvement focused mainly on outcomes in priority populations, such as immigrants from countries with endemic infectious diseases. Ministry informants identified leadership as a key driver of implementation efforts and acknowledged its strength within public health units, who they felt shared their interest in showing high performance. A Site-B informant confirmed this leadership sentiment:

"Well, we have very strong leadership values of teamwork and participation and participatory management in most of our program areas. I think we are very strong that way." - Site-B informant

Communication relating to the initiative was evident from interview findings identifying various forums for the development and conveyance of its elements. Several public health unit informants noted that the province's new system of accountability and performance management had prompted both internal and external dialogue, which has since increased their understanding of performance objectives and quality improvement more broadly. Site-A stood out as a particularly strong example of this:

"I think that changing conversations has actually motivated people, not just here in the health unit but even as I talk to people across the province. People like the fact that we are being asked to think about these questions and like the fact that we are going to be held more accountable for actually making a difference." — Site-A informant

Similarly, a large proportion of survey respondents reported moderate or great familiarity with many components of the intervention, including accountability agreements (96%), performance targets (98%) and reporting requirements (94%).

Implementer inclusion in decision-making was mixed. Although many public health unit informants cited participation in committees and working groups related to the CQI initiative, their influence over final decisions varied. In some cases, such as human papillomavirus (HPV) vaccination, public health agents were able to negotiate "more realistic" performance targets.¹ In other instances, local informants noted that the Ministry took a hard line in making decisions despite concerns voiced by the field. For example, when a prescriptive OPHS protocol for tuberculosis follow-up was challenged because of evidence of alternative best-practice, requests to change the protocol were denied by provincial decision-makers. One Ministry informant corroborated this dynamic by stating their interest in the input provided by the field, but the decisions ultimately rested with those holding authority over legislation:

So, yes, [consultation] is to enable conversations within a forum that in a sense the majority of the practitioners and the province have agreed to talk about. It's supposedly a partnership. The province always has the upper hand. (laughing) He who controls legislation has the upper hand." – Ministry informant

Informants in each of the three public health unit interview sites raised concerns over the narrow timelines for achieving targets. One Ministry informant noted that many of the targets are set to 100%, matching with the OPHS, and that even public health units with low baselines would be expected to meet targets within the first two years of implementation.

Divergence between the Ministry and the field was expressed in terms of provincial and local health priorities. Some informants argued that targets set by the Ministry such as senior falls were not a priority in their jurisdiction or, generally, a major responsibility of public health because of small target populations and the many determinants outside of their control.

Although many public health unit informants acquiesced to the province's quality improvement initiative, each of the local public health unit interview sites placed greater emphasis on internal systems of performance management to foster meaningful performance improvement. For instance, one Site-A informant stated:

"At this point I feel more confident in our organization's capacity to demonstrate success in performance management than I do with the two indicators my team has been given within the accountability agreement system from the Ministry of Health and Long-Term Care." – Site-A informant

Despite the implied and explicitly stated opportunity cost created by misalignment in local and provincial priorities apparent in interview findings, 74% of survey respondents disagreed or strongly disagreed that an emphasis on provincial performance measurement and target achievement would interfere with the quality of program and service provision at a local public health level.

Resource inadequacy was often referenced in relation to the cost neutrality of the intervention and the current public health funding model, more broadly. While public health unit informants highlighted the quality of their agencies' human resources, some did not consider general resourcing to be adequate for achieving all targets — a phenomenon that was reflected by nearly one-third of surveyed public health managers. Issues of increased burden on public health units to show compliance with provincial targets and fulfill local priorities were, in some cases, compounded by rapidly expanding local populations that the current public health funding model does not compensate for. For example, one Site-B informant explained:

"I think that both financial and human resources, I think for most if not all boards of health [our] reach is beyond our grasp ... [our] population increases five to ten thousand a year. Basically I've been getting base budget increases for the last few years. In other words very few if any new staff to service a population even over the last four years that would be in the order of twenty to forty thousand additional people." – Site-B informant

Ministry informants acknowledged the need for greater equity in the public health funding model, although some were not convinced that public health performance improvement required additional funding, but rather greater efficiency. Other barriers such as work overload did not have a strong profile in the data, although some public health unit and Ministry informants speculated that smaller, rural health units may struggle with performance expectations related to intensive analytical tasks such as population health assessment.

Cultural dimension

Facilitators of the cultural dimension are distinguished by openness, collaboration, teamwork and learning. At the local level, all three public health unit interview sites exhibited at least

some of the characteristics of developmental and/or group culture. Site-A exhibited many characteristics of group culture, such as teamwork and participation. Organizational hierarchy appeared fairly flat, and even front-line workers were said to be involved in program decision-making, collective priority-setting and performance monitoring. One Site-A informant noted:

"Certainly I think we prided ourselves on teamwork and participatory management styles and participation of front-line staff into decision-making where that makes sense." – Site-A informant

Site-B appeared to be an equally distributed mix of developmental, group and rational cultural types – emphasizing efficiency and achievement of OPHS requirements. Group culture was apparent in reference to the interdisciplinary team-based approach to program and service provision. Leaders also regarded teamwork as an important value of their culture, as illustrated by instances of participative management in various program areas. Developmental culture emerged in the context of the health unit's internal, evidence-based approach to CQI planning, which allowed for informed innovation and risk-taking. A Site-B informant expanded by stating:

"... there has been a very strong undercurrent in my organization ... that your programming is evidence-based and you have a method for reviewing it and each time trying to learn more about how it went and improve it. It's a continuous cycle of implementation, reflection, evaluation, and review and kind of revision. So there is constant introduction of innovation as well as fine-tuning things as they go." – Site-B informant

Site-C presented a dominant developmental culture. Risk-taking and innovation were often regarded as very important aspects of the organization's culture. These aspects of developmental culture were contextualized in terms of evidence-informed decision-making, which was paradoxically argued to reduce risk at the same time. Risk-taking in the development of strategic plans and priorities and examples of innovative programming were highlighted as proof of the health unit's commitment to a developmental culture. An example of one Site-C informant reflecting on the health unit's organizational culture explained that:

"... evidence informed decision-making is a large component. It's one of the strategic priorities in our health unit and so really having that ... engaging in processes of informed innovation certainly informs decision-making and out of that what are the risks that we are taking to do things differently than other health units based on the evidence that we have found." – Site-C informant

Resistance to change, unrewarded achievement, and hierarchical and rational organizational cultures are regard as barriers to the cultural dimension. In this regard, there was limited evidence of an approach for rewarding achievement and good performance related directly to the province's CQI initiative. However, some public health unit interviewees argued that celebrating achievement of targets was important – something that their health units did internally when goals were achieved or improved upon. Site-A provided an example of this:

"I think setting targets and celebrating the reaching of the targets is the other part. Part of our plan will be not just setting goals but also celebrating the achievement of the goals ... What we look at when we set out goals for staff and within the organization, knowing that we are not going to achieve every goal every time but celebrate our achievements and keep us moving forward." – Site-A informant

Moreover, there was some uncertainty about the level of support for facilitating factors and the presence of barriers such as hierarchical cultural norms. On the issue of whether the system was primarily intended to promote learning (a key characteristic of CQI), those surveyed in the area of chronic disease prevention were significantly more uncertain than respondents from other areas (p < 0.02). Likewise, 84.3% of the survey sample agreed or strongly agreed that the initiative was primarily concerned with maintaining compliance with public health practice and performance expectations – resembling a quality assurance orientation. In addition, respondents in the area of emergency preparedness were more likely to disagree (p < 0.02) with the statement that data generated from the provincial initiative would be used to improve performance.

Technical dimension

Training opportunities and the quality and availability of data are the primary facilitators in the technical dimension. In Ontario, training in quality improvement, and CQI specifically, manifested mainly at the local level, with public health units providing instruction to staff on strategic planning. Guidance in program and service provision was evident through provincial OPHS protocols, but these materials did not relate specifically to quality improvement training. A Site-A informant reflected on this gap:

"I'm not aware of any kind of ... the how stuff that's come from the Ministry other than just ... okay your targets are now being established with an expectation we do something about them." – Site-A informant

Gaps in training and data systems can be precursors to frustration and false starts, according to Shortell et al. (1998). Guidance from the Ministry on how public health units were to achieve performance targets or improve was limited. Moreover, some guidance materials, such as the previously mentioned tuberculosis protocol, were criticized by Site-C informants for not reflecting best available evidence and local expertise:

"So we had examples where we are absolutely convinced that we should vary the standards or not conform exactly with the [tuberculosis] protocol. This is the

Ministry telling us how to practise public health where actually we know more about practising public health than they do ... It always ends up the same way because their lawyers advise them to stick to the letter of the law. I don't know. Something to do with liability. This is not the best use of our resources." – Site-C informant

Considerable concern with the quality of performance measurement information relating to the provincial initiative was raised by all parties. The choice of population health outcomes as measures of public health performance was identified as problematic because of externalities that made attributing public health outputs difficult. Some performance indicators were perceived as unreflective of public health performance by health units. For instance, the tobacco use indicator was highlighted as one such problematic measure:

"We only have one performance indicator that relates to chronic disease and that is the one about the number of youth who smoked a whole cigarette. I think it doesn't reflect in any way the work that we do but I understand the Ministry's need to show a tangible objective outcome and so we will do that and be happy with providing that information. I would say it has very minimal contribution to anyone understanding anything about what we do." — Site-B informant

Ministry informants generally agreed that information systems needed to be improved and that this task was a difficult one. However, Ministry informants also noted that where evidence was weak, best-practice information was used in place of causal linkages between OPHS requirements and outcomes. One Ministry informant explained:

"So the real work is at the linkages between requirement, to short-term outcome, to medium-term, to long-term outcome ... so wherever we made a link we found evidence to support that but where we couldn't, it was based on best practices and what was occurring in the field and the assumptions that were being made that had been integrated right at the beginning of the '98 standards all the way through." – Ministry informant

Structural dimension

The structural dimension focuses on effective forums of communication for facilitating learning throughout an organization or system. In Ontario, the CQI initiative is supported by several communication forums, such as accountability agreement working groups, committees and monthly teleconferences amongst public health specialists, leadership and the Ministry. At a local level, several public health unit informants noted active lines of communication between themselves and other public health units pertaining to collaborative projects, research and other forms of knowledge production and exchange. In contrast, some Ministry informants stated that public health units do not typically work cooperatively or

collaboratively because of jurisdictional protectionism. This divergence in perspectives was reflected in informants' testimony:

"The fact that none of them work cooperatively, the fact that there are turf wars and all that good stuff, I think is one of the challenges." – Ministry informant

"I think there is a lot of similarities between health units. We talked a lot." – Site-B informant

"We work really well with our partners so we can capitalize on limited resources and make the most of them so that again we can really accomplish the goals we set out for communities and make our communities healthier places to be. So we do a lot of collaborative work with other health units but also with our community partners as well in order to accomplish public health goals." – Site-A informant

Within the structural dimension, the lack or limited use of communication mechanisms related to the quality improvement initiative fosters an inability to produce knowledge and diffuse it within systems. Ambiguity relating to how information would be fed back to public health units and used for quality improvement was apparent and highlighted by local informants:

"I don't know. I think that remains to be seen. I'm hoping it's more to be used in a combination with evidence to make ongoing improvements to public health programs and policies." – Site-C informant

Ministry informants stated that performance information would allow for "discussion" with public health units. Some public health unit informants speculated that these discussions would include questions of what barriers to performance existed. One public health unit interviewee noted that performance information lacked the context to address why the results were the way they were. Meanwhile, several other informants argued that their public health unit would have to provide additional, unsolicited information to explain their performance achievement. One Site-B informant explained:

"So, in my earlier interview with you I described some of the vehicles that you can use and that I voluntarily send to the Ministry like our performance report, it's rare that I would get an acknowledgement, let alone do they read it. So I don't think the Ministry is all that interested in what we are doing apart from the information that we use to populate what I would call to be our financial reports." – Site-B informant

In contrast to the provincial initiative, all public health unit interview sites described specific internal processes of quality improvement such as balanced scorecards, evaluation,

reporting and strategic planning elements. Only 55% of survey respondents believed the province's system of accountability and performance management had the intent of providing learning opportunities and improving performance.

Discussion

This study shows a mix of facilitators and barriers to CQI best-practice in Ontario, according to Shortell et al.'s (1998) four-dimensions framework. Evidence of strong leadership interest and involvement in quality improvement at both local and provincial levels was clear. Strong developmental and/or group cultures were also evident at public health unit interview sites, which reflected leadership efforts to foster high performance and provided additional insight into their CQI capacity. The importance of senior and managerial leadership engagement cannot be over-emphasized, as previous reviews of public health quality improvement initiatives have shown (Dilley et al. 2012; Randolph et al. 2012). However, Ontario's quality improvement initiative also featured limitations placed on the meaningful influence of local leadership in decision-making by provincial stakeholders, which was reflected by misalignments in priorities, even though agreement on the principle of quality improvement was mutual. A part of this phenomenon may be because of the split emphasis that Ontario's system of accountability and performance management has between quality assurance and quality improvement. Assurance of legislative and service requirements promotes top-down decision-making and control, whereas a focus on improving outcomes requires local leadership and discretion. Similar misalignments were highlighted in the work of Degroff et al. (2010) who argued that many of the challenges to applying performance measurement to national public health programs in the US were due, in part, to the competing interests of quality improvement and public accountability (DeGroff et al. 2010).

In addition, the availability of indicators that accurately reflect performance continues to be one of the greatest constraining factors to CQI in public health settings, as many have already pointed out, and one that sets it apart from healthcare (Kahan and Goodstadt 1999; Scutchfield et al. 2009; Weir et al. 2009). Public health unit informants were adamant that performance targets indicated by population health outcomes, which are subject to numerous determinants outside of their control, were problematic. Given that CQI relies upon the quality of performance measurement information for informed decision-making, developing public health metrics that are more attributable to service outputs should be a priority.

Limitations

This study is limited by its small public health unit sample, which, although offers valuable insight into a nascent quality improvement process, ultimately, cannot represent the broader set of units. Also, while boards of health are acknowledged to be important stakeholders in Ontario's public health system, members were not included in this study because of unsuccessful recruitment. Furthermore, this study offers a snapshot of an initiative in a fluid environment and in its very early stages. Changes to the approach are expected, which have potential

implications on the perceptions of informants. This also means that evidence of outcomes resulting from the presence of facilitators and barriers was beyond the scope of this study.

Conclusion

This study illustrates the applicability of Shortell et al.'s (1998) four dimensions of CQI as a framework for understanding public health quality improvement. The study also represents one of the first attempts to examine the implementation of a CQI initiative across a complex public health system using an empirically derived and validated framework from the healthcare field. Insight provided by the framework relating to facilitators and barriers of CQI implementation has largely confirmed disparate public health research on the topic (Corso et al. 2010; McLees et al. 2014; Riley et al. 2012; Shortell et al. 1998). This confirmation is a promising indicator that the framework may hold value as a tool for public health decision-makers developing and implementing CQI systems. Finally, future research should test the four-dimensions framework in other public health environments and, more importantly, examine the linkages between the framework's indicated outcomes and attributable facilitators and barriers.

Note

HPV vaccination in Ontario is voluntary. Target levels had previously been set at levels comparable to those of mandatory vaccinations, such as measles, mumps and rubella (MMR).

Correspondence may be directed to: Alex Price; e-mail: alex.price@mail.utoronto.ca.

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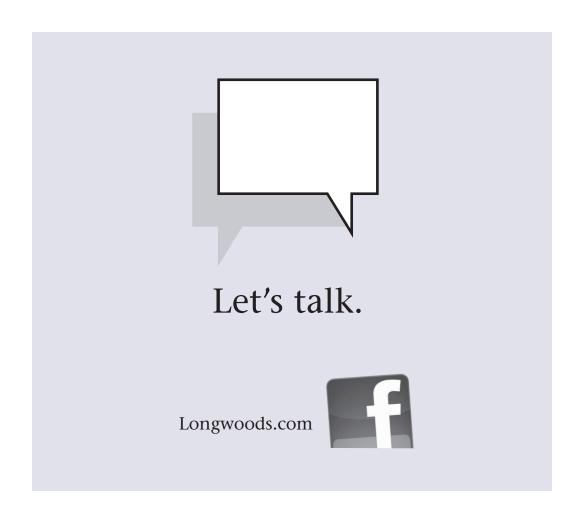
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Towards Integrating Primary Care with Cancer Care: A Regional Study of Current Gaps and Opportunities in Canada

Vers une intégration des soins de santé primaires et des soins contre le cancer : étude régionale des lacunes et des occasions actuelles au Canada



JONATHAN SUSSMAN, MD, FRCP(C), MSc Department of Oncology, McMaster University Hamilton, ON

DARYL BAINBRIDGE, PHD
Department of Oncology, McMaster University
Hamilton, ON

WILLIAM K. EVANS, MD, FRCP(C)
Department of Oncology, McMaster University
Hamilton, ON

Abstract

Background and Objectives: Better integration between cancer care systems and primary care physicians (PCPs) is a goal of most healthcare systems, but little direction exists on how this can be achieved. This study systematically examined the extent of integration between PCPs and a regional cancer program (RCP) to identify opportunities for improvement.

Method: Cross-sectional survey of all practising PCPs in the region of interest using a study-specific instrument based on a three-tier conceptualization of integration.

Results: Among the 473 PCPs who responded (63% response rate), perceived role clarity and the desire for greater involvement in patient care varied across the care trajectory. Specific gaps were identified in PCPs' understanding of the referral process and patient follow-up after treatment.

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Conclusion: Our novel survey of PCPs explicated the strategies that could improve their integration in cancer care, including mechanisms to support PCPs in the initial diagnosis of their patients and standardized post-treatment transition plans outlining care roles and responsibilities.

Résumé

Contexte et objectif: Une meilleure intégration entre les systèmes de soins contre le cancer et les médecins de première ligne (MPL) est un des objectifs de la plupart des systèmes de santé, mais il existe peu de guides d'orientation pour y arriver. Cette étude examine systématiquement l'étendue de l'intégration des MPL et des programmes régionaux contre le cancer afin de repérer les occasions propices à l'amélioration.

Méthode : Un sondage transversal, employant un instrument spécifique pour l'étude fondé sur une conceptualisation à trois volets de l'intégration, a été mené auprès de tous les MPL de la région étudiée.

Résultats: Parmi les 473 MPL qui ont répondu au sondage (taux de réponse de 63 %), la clarté du rôle perçu et le désir d'une meilleure participation dans les soins au patient varient le long de la trajectoire de soins. Des lacunes précises ont été identifiées quant à la compréhension qu'ont les MPL du processus d'aiguillage et du suivi des patients après le traitement.

Conclusion: Notre nouveau sondage auprès des MPL éclaire les stratégies qui pourraient permettre d'améliorer l'intégration entre les MPL et les soins contre le cancer, notamment des mécanismes de soutien pour les MPL dans le diagnostic initial ainsi que des plans standardisés de transition post-traitement qui définissent les rôles et responsabilités pour les soins.

Introduction

The care of cancer patients is characterized by multiple, complex and often stressful interactions involving a wide range of care practitioners and settings, along the various stages from initial diagnosis to palliative care (Kristjanson and Ashcroft 1994). Cancer patients and their families frequently report feeling overwhelmed and lost in a system that is increasingly difficult to navigate (Institute of Medicine and National Research Council of the National Academies 2005; Sullivan et al. 2004). Primary care physicians (PCPs) report being isolated from the cancer care system and, therefore, less effective in helping patients cope with their diagnosis and treatments (Aubin et al. 2012; Kasperski and Ellison 2007). Furthermore, poor integration between the cancer system and PCPs results in reluctance by some patients to be referred back to primary care following cancer treatment (Hudson et al. 2012; Mayer et al. 2012).

Although there is a need for a significant proportion of cancer care to be provided through specialized centres, it is also clear that for comprehensive care, especially during the early health-care diagnostic and post-treatment phases, community providers must be involved to help ensure that patients' supportive care and informational needs are met and their non-cancer-related

health issues are managed (Klabunde et al. 2009; Roorda et al. 2012). A large study of cancer patients in the US illustrated that reduction in PCP involvement was associated with poorer overall care and health outcomes, especially in the management of non-cancer-related health conditions (Earle and Neville 2004). Major challenges to PCPs include lack of knowledge about cancer treatments, as well as insufficient communication and role confusion between PCPs and cancer specialists in the provision of care (Aubin et al. 2012; Dworkind et al. 1999).

In Ontario, Canada, cancer care is provided by regional cancer centres, community oncologists and PCPs. Integration of PCPs with cancer specialists and centres is largely informal (CCO 2015). Cancer Care Ontario (CCO) is the government's cancer advisor, directing and monitoring the funding for cancer services in the province. CCO integrates all specialized cancer care providers including overseeing nursing and allied health, but are not explicitly linked to community providers, including PCPs. To date, most cancer care system integration initiatives have only focused on specialized providers. CCO, as well as decision-makers elsewhere in Canada and in the US, has identified better integration between cancer care programs and PCPs as a key strategic objective; however, little direction exists on how this could be best achieved across the trajectory of illness (Dohan and Schrag 2005; Hudson et al. 2012; Salz et al. 2012; Sullivan et al. 2004). The purpose of this study was to systematically examine the extent of integration of PCPs with a regional cancer program (RCP) for the care of cancer patients and to identify opportunities for integration to be improved, from the perspectives of PCPs.

Methods

Design

A cross-sectional survey of all practising PCPs in the selected healthcare-planning region was undertaken. We assessed PCPs' perceptions of/satisfaction with integration between PCPs and the RCP according to the three domains employed by CCO's Cancer System Quality Index initiative: Clinical, Functional and Vertical Integration (Table 1) (Levitt and Lupea 2009). Ethical approval to conduct the study was obtained from the McMaster University Ethics Board, Hamilton, ON.

Setting and Sample

The study sample included all identified active PCPs with office addresses within the Hamilton, Niagara, Halton and Brant Local Health Integration Network (HNHB LHIN) area in Ontario (ON), Canada. This region extends over 7,000 km² and has a population of 1.4 million (Government of Ontario 2010). Over 200,000 seniors live in the HNHB LHIN, representing the largest proportion in all ON LHINs (LHIN 2009) The HNHB LHIN age-standardized rate per 100,000 for new cancer incidences is 592 (578 in ON) and for mortality 219 (202 in ON) (CCO 2016). The PCP to population ratio is 76 per 100,000 population in the HNHB LHIN, lower than the provincial rate of 85 per 100,000 population (LHIN 2009).

TABLE 1. Domains of integration measured and study findings

Domain of integration	Definition	Indicators measured	Findings
Clinical	Extent to which patient care services are coordinated across the various functions, activities and operating units of the cancer system.	PCP knowledge of how to work up newly diagnosed patients for common cancers. Clarity of PCP role across the care trajectory. Self-reported care provision by PCPs across the care trajectory.	PCPs indicated knowing how to initiate investigations of signs and symptoms and how to identify the appropriate referral, except in the case of neuro-oncology and, to some degree, head/neck cancer. PCP role uncertainty indicated, particularly while patients are undergoing treatment. Most PCPs indicated being involved in patient care across the care trajectory, but less so in the palliative care stage.
Functional	Extent to which key support functions and activities are coordinated across operating units of the cancer system.	Communication between PCPs and the RCP. Diagnostic tests are available in a timely fashion.	Most PCPs were satisfied with the exchange of information between their practice and the RCP; however, some delays were indicated in patient information received from RCP. Few PCPs used the regional cancer centre's web portals for information. PCPs reported problems obtaining MRIs and CT scans, as well as delays in obtaining biopsy results.
Vertical	Extent to which there is regional collaboration, coordination and leadership with respect to cancer services that is recognized as a "system."	PCP understanding of referral to the RCP and system navigation. PCP perception of RCP coordination.	Many PCPs did not know the procedure for referring patients to the RCP. Strong need expressed for guidelines on when and how to connect their cancer patients to the RCP. Most PCPs agreed that a cancer system navigation program is required. PCPs felt there was generally good coordination of care between their practice and the RCP. However, many PCPs felt coordination and access to services for cancer patients following diagnosis need to be improved.

CT = computed tomography; MRI = magnetic resonance imaging; PCP = primary care physicians; RCP = regional cancer program.

This setting includes a diversity of rural and urban communities with the full range of cancer care services at a regional tertiary care cancer centre, including surgery, radiation therapy and medical oncology, as well as supportive care for patients in treatment. There is no singular model of palliative care across the region; these services are highly variable and are fragmented in some communities (Bainbridge et al. 2011).

The wide spectrum of organizational and compensational models for PCPs is represented including fee-for-service, capitation and salary-based remuneration. The research team used multiple sources to construct and verify the study sample including databases from The Ontario College of Family Physicians (membership obligatory for PCPs practising in ON), The College of Physicians and Surgeons of Ontario, The Canadian Medical Directory and a current list of HNHB LHIN PCPs obtained from a physician recruitment agency.

Instrument

The data collection survey instrument was designed to assess key aspects of integration of PCPs with the RCP. While no single accepted definition of care integration exists in general medical care or specifically for cancer care, the concepts of role clarity and communication between providers are foundational (Ahgren and Axelsson 2005; Maslin-Prothero and Bennion 2010; Suter et al. 2009) and formed the basis of the instrument developed and used in this study. We used the CCO-defined constructs of functional, clinical and vertical integration to develop questions that are meaningful to system planners working towards the stated objective of improving the integration of all care providers during the care of cancer patients across the trajectory: from initial investigation of suspected cancer, to post-treatment follow-up, to palliative care once the cancer is deemed incurable (Levitt and Lupea 2009).

An existing questionnaire specific to the measurement of PCP integration in cancer care was not found, and therefore, we reviewed a number of instruments that contained questions on PCP involvement in cancer care to ensure inclusion of important content. These sources included the multidisciplinary Cancer Services Integration Survey (Dobrow et al. 2009), the Patient Navigation in Cancer Care Family Physician Questionnaire (Doll et al. 2005), the National Family Physician Survey (Woodward and Pong 2006) and the Family Physicians and Cancer Care Manitoba Survey (Sisler et al. 2004). Our survey was based on the salient content areas of these instruments, the relevant literature and input from experts in cancer care integration. Expert opinion was sought with respect to the instruments' coherence and comprehensiveness, and pilot testing was conducted with five clinicians outside the study area. Most items were dichotomous (yes/no) to improve ease of completion, with many of these items allowing for open-text elaboration when answered negatively, to further divulge issues. Questions were grouped by stage in the cancer trajectory (peri-diagnosis, active treatment, follow-up and palliative) following the nomenclature of CCO documentation (Cancer Quality Council of Ontario 2015). A core set of indicator items was repeated for each stage of the trajectory. The instrument was organized in this fashion for ease of flow and completion, to prime respondents for thinking separately about their interaction with the cancer system/patient at each stage, and to enable comparison in indicator items across the cancer trajectory.

Data collection

A Dillman Tailored Design Method with up to four mail contacts was used to administer the mail survey, with an added telephone contact stage for non-responders (Dillman 2000). A small incentive was included with the survey (\$10 gift card). Completed surveys were returned via mail (stamped addressed envelope [SAE] provided) or toll-free fax.

Data analysis

Response data were analyzed using SAS version 9.1 (SAS Institute, Cary, NC) and SPSS version 21 (IBM Corp., Armonk, NY). Analysis was primarily descriptive, with item results presented as frequencies and proportions. Thematic analyses were completed on open-text comments and quantified (Creswell 2013). Confidence intervals for the binomial proportions were calculated using the Wald method. Cronbach's alpha as a coefficient of internal consistency between items within a trajectory stage and percentage of missing responses were calculated to provide measures of instrument validation.

Exploratory analyses were conducted using multivariate logistic regression to explore potential associative factors for high- or low-activity areas of integration and PCP involvement. Independent variables selected were years in practice, cancer education sessions attended (yes/no) and number of newly diagnosed cancer patients in the past year. Outcomes for this analysis included practitioner understanding of the process of referral to the RCP, role clarity

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and care provision across the trajectory of the patient's cancer experience and satisfaction with information provided by the RCP, considered as dichotomous variables (yes/no).

Results

Of 748 PCPs deemed eligible to participate, 473 (63%) completed a study survey. These practitioners represented a wide range of years in practice with a median duration of 25 years, and 69% having practised over 10 years in the study area (Table 2). A comparison of demographics between respondents and non-respondents revealed no significant differences (chi-square test, all p < 0.05) between these groups.

TABLE 2. Primary care physician characteristics (N = 473)

Respondent characteristics	Value
Male, <i>n</i> (%)	279 (59.0%)
Years since graduation, median (range)	25 (1–57)
Length of practice in region, n (%)	
0–4 years	72 (15.2%)
5–10 years	76 (16.1%)
II-20 years	(23.5%)
>20 years	213 (45.0%)
Solo practice, n (%)	177 (37.4%)
Practice setting, n (%)	
Private office	416 (87.9%)
Walk-in clinic	32 (6.8%)
Community health centre	20 (4.2%)
Academic teaching unit	23 (4.9%)
Other	57 (12.1%)
Primary source of income, n (%)*	
FFS	254 (53.7%)
CAP	103 (21.8%)
Mixed [§]	52 (11.0%)
Salary	18 (3.8%)
Other	47 (9.7%)
Size of practice, n (%)	
<1,000 patients	48 (10.1%)
1,000-1,999 patients	234 (49.5%)
≥2,000 patients	177 (37.4%)

CAP = capitation; FFS = fee-for-service. *Source >80% of income for family medicine. ⁵FFS and either CAP or sessional pay each ≥20% of income.

Peri-diagnosis

A substantial proportion of the PCPs reported problems accessing the RCP for newly diagnosed patients. Only 61% of PCPs reported knowing the procedure for referring patients to the RCP. About one-third (35%) of respondents said that cancer-related diagnostic tests were not available in a timely fashion, with 27% of all respondents reporting delays in obtaining MRI results. Nearly half (48%) of the respondents felt that coordination and access to services for cancer patients needed improvement, and most (81%) agreed that some kind of a cancer system navigation program was required to help their patients access necessary medical and supportive care services (Table 3).

TABLE 3. Primary care physician perceptions throughout the stages of cancer

Cancer stage	Respondents' perceptions (agree)	n (%)	95% CI
Peri-diagnosis	Cancer-related diagnostic tests NOT done in timely fashion ($N=468$)	163 (34.8)	(30.7, 39.3)
	MRIs NOT done in a timely fashion	125 (76.7)	
	CT scans NOT done in a timely fashion	107 (65.6)	
	Biopsy results NOT received in a timely fashion	82 (50.3)	
	Don't know procedure for referring patients to RCP (N = 461)	179 (38.8)	(34.5, 43.4)
	Where to call unclear	110 (61.5)	
	What tests to order prior to referral unclear	106 (59.2)	
	Who to call unclear	139 (77.7)	
	Coordination/Access to services for cancer patients needs improvement ($N = 439$)	211 (48.1)	(43.4, 52.7)
	Cancer system navigation program is required ($N=460$)	371 (80.7)	(76.8, 84.0)
	Recommend a Coordinator model*	176 (47.4)	
	Recommend an Advisor model [§]	48 (12.9)	
	Recommend a Shared model [¶]	130 (35.0)	
	Unsure or recommend other model	17 (4.6)	
Active treatment	Manage patients' common symptoms related to cancer or its treatment as problems arise ($N=452$)	348 (77.0)	(72.9, 80.6)
	Continue to manage patients' other medical issues ($N = 469$)	461 (98.3)	(96.6, 99.2)
	Provide patients with information about their cancer and cancer treatments ($N = 461$)	262 (56.8)	(52.3, 61.3)
	Involved with patients in decision-making process about cancer management ($N=458$)	257 (56.1)	(51.5, 60.6)
	Know how to contact a provider within RCP involved in patients' care ($N = 459$)	345 (75.2)	(71.0, 78.9)
	Have difficulty reaching RCP providers to discuss patient (N = 457)	83 (18.2)	(14.9, 22.0)
	Feel inadequately informed by RCP regarding significant changes in patients' health status $(N=454)$	99 (21.8)	(18.2, 25.8)
	Feel inadequately informed by RCP regarding changes in patients' medications or treatments ($N=460$)	78 (17.0)	(13.8, 20.7)
	Feel inadequately informed by RCP regarding next steps in patients' care ($N=460$)	87 (18.9)	(15.6, 22.8)

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Cancer stage	Respondents' perceptions (agree)	n (%)	95% CI
Follow-up	Encourage cancer patients to follow-up at practice upon completion of cancer treatment $(N=468)$	420 (89.7)	(86.6, 92.2)
	Easy to connect patients back to RCP if recurrence of initial cancer diagnosis is suspected $(N=434)$	397 (91.5)	(88.4, 93.8)
	Feel adequately informed by RCP regarding what is involved in follow-up of cancer patients upon being discharged from oncologist care ($N=461$)	362 (78.5)	(74.5, 82.0)
Palliative	Know who to contact to obtain palliative care services for patients ($N=461$)	350 (75.9)	(71.8, 79.6)
	Refer to publicly funded home care ($N = 473$)	233 (49.3)	(44.8, 53.8)
	Refer to palliative care physicians ($N=473$)	143 (30.2)	(26.3, 34.5)
	Refer to hospital palliative care ($N=473$)	89 (18.8)	(15.5, 22.6)
	Refer to residential hospice ($N = 473$	74 (15.6)	(12.6, 19.2)
	Refer to palliative care team/network (N = 473)	50 (10.6)	(8.1, 13.7)
	Main resource used is Myself ($N = 473$)	31 (6.6)	(4.6, 9.2)
	RCP responsive to requests for advice ($N = 374$)	300 (80.2)	(75.9, 83.9)
General	Overall, felt there is good coordination of care between practice and RCP ($N=452$)	389 (86.1)	(82.5, 89.0)
	In general, satisfied with the way information is exchanged between practice and RCP across trajectory of care (e.g., quality, timeliness, completeness, etc.) $(N=460)$	398 (86.5)	(83.1, 89.4)
	Interested in attending multidisciplinary case conferences on patients ($N=456$)	207 (45.4)	(40.9, 50.0)
	Accessed Cancer Centre's web portals as a source of information ($N = 463$)	39 (8.4)	(6.2, 11.3)
	Attended educational sessions to increase knowledge regarding cancer care ($N=469$)	304 (64.8)	(60.4, 69.0)
	Current method of remuneration adequately compensates me for the care I provide to my cancer patients ($N=454$)	244 (53.7)	(49.1, 58.3)

CI = confidence interval; CT = computed tomography; MRI = magnetic resonance imaging; PCP = primary care physicians; RCP = regional cancer program. *Coordinator model – navigation program becomes responsible for coordinating appointments and the PCP practices are informed but not responsible for care. Shared model – navigation program helps coordinate patient appointments and the PCP practices coordinate care. Advisor model – navigation program provides PCPs with advice, and physician practices coordinate care and appointments.

Active treatment

Most (77%) of the PCPs reported managing the common symptoms of their patients related to cancer or its treatment as problems arose. However, only about half (56%) reported that they are involved with their cancer patients in the decision-making process about their cancer management. Most (75%) PCPs reported that they knew how to contact a provider within the RCP to go over questions or concerns involving a patient. However, 22% of PCPs reported not being adequately informed by RCP providers about significant changes in patients' health status (Table 3).

Follow-up

Most (90%) PCPs reported encouraging their cancer patients to follow-up at their practice upon completion of treatment, and that it is easy to reconnect patients to the RCP if a recurrence is

suspected. Fewer PCPs (79%) felt adequately informed by the RCP regarding what was required in the follow-up of their cancer patients upon being discharged from the oncologist's care (Table 3).

Palliative

Many (76%) PCPs knew who to contact to obtain palliative care services for their cancer patients, and most (80%) stated that the RCP was responsive to their requests for advice pertaining to this stage of care. The main resource PCPs reported using for their palliative care cancer patients was publicly funded homecare. Very few (7%) PCPs indicated being solely responsible for palliative care (Table 3).

PCPs' role across care trajectory

The majority of PCPs understood their role and felt it was valued at various stages of the cancer trajectory. This was most evident around the diagnostic, follow-up and palliative care phases and less so during active treatment (Table 4). Of note, PCPs advocated for more involvement in follow-up and palliative phases of care.

TABLE 4. Primary care physician role in cancer-related care

Cancer stage	PCP respondent role statement (agree)	n (%)	95% CI
Peri-diagnosis	PCP role clear ($N = 463$)	336 (72.6)	(68.3, 76.4)
	PCP role valued (N = 418)	314 (75.1)	(70.8, 79.0)
Active treatment	PCP role clear (N = 464)	300 (64.7)	(60.2, 68.9)
	PCP role valued (N = 420)	280 (66.6)	(62.0, 71.0)
	PCP involved in patient care ($N = 466$)	380 (81.5)	(77.8, 84.8)
	PCP wishes more involvement in patient care ($N = 443$)	118 (26.6)	(22.7, 30.9)
Follow-up	PCP role clear (N = 461)	312 (67.7)	(63.3, 71.8)
	PCP role valued (N = 425)	325 (76.5)	(72.2, 80.3)
	PCP involved in patient care (N = 468)	420 (89.7)	(86.6, 92.2)
	PCP wishes more involvement in patient care ($N = 459$)	219 (47.7)	(43.2, 52.3)
Palliative	PCP assumes responsibility for patient care ($N=460$)	350 (76.1)	(72.0, 79.8)
	PCP wishes more involvement in patient care ($N = 446$)	207 (46.4)	(41.8, 51.1)

CI = confidence interval; PCP = primary care physician.

Major barriers to PCPs' involvement in cancer care for their patients that emerged from the open-text comments included limited access to patient information and/or the cancer treatment plan, lack of professional interaction with the RCP and direction as to the appropriate role of the PCP and limitations in their own knowledge and skill in oncology.

Care coordination, informational exchange, education and remuneration

Overall, most physicians (86%) reported that there is good coordination of care between their practice and RCP (Table 3). Despite some problems with communication, most PCPs (87%)

reported being satisfied with exchange of information between their practice and the RCP (Table 3). Just under half (45%) of the respondents expressed an interest in attending multidisciplinary case conferences (MCCs) on their cancer patients. If RCP referral guidelines were developed, most PCPs said that they preferred to receive these as a one-page summary sheet with key contact information, rather than in pamphlet form or on the Internet. Few (8%) reported having accessed the RCP web portals for information on treatments or referral processes.

Slightly over half (54%) of PCPs reported that they received adequate remuneration for the care provided to their cancer patients. The most frequently reported reason for dissatisfaction with compensation was that payment inadequately covers the time and effort spent with cancer patients and/or their families. PCPs on capitation payment arrangements also identified that their patients being seen by oncology associates at the RCP negated the fees the PCP would normally receive.

Factors associated with reported integration

Multivariate logistic regression was applied to explore the associations of PCP responses pertaining to their involvement and understanding of the processes in patient cancer care, RCP perceptions and other key factors of integration (Table 5). Physicians who had attended cancer education sessions (Table 3), had more years in practice or had seen more newly diagnosed cancer patients in the past year, tended to report better role clarity, being more involved in patient care across the disease trajectory and were more likely to understand referral procedures to the RCP. Cut points of effect for years in practice and number of cancer patients were not apparent.

TABLE 5. Multivariate regression of factors associated with system knowledge and role clarity at selected critical stages (N = 473)

Factor	Associated variables	OR (95% CI)	p-value*
PCP knows procedure for referring patients to RCP	Attends cancer education sessions	1.53 (1.01, 2.32)	0.047
	Years since graduation	1.03 (1.01, 1.05)	0.001
	Number of new cancer patients seen	1.88 (1.43, 2.46)	<0.0001
PCP role clear at follow-up	Attends cancer education sessions	1.52 (1.00, 2.32)	0.052
	Number of new cancer patients seen	1.33 (1.01, 1.74)	0.042
	Years since graduation	1.02 (1.00, 1.04)	0.019
PCP assumes responsibility for palliative care	Attends cancer education sessions	2.28 (1.40, 3.73)	0.001
	Number of new cancer patients seen	2.10 (1.52, 2.91)	<0.0001

 $CI = confidence interval; OR = odds \ ratio; PCP = primary \ care \ physician; RCP = regional \ cancer \ program. \ *p-values < 0.05 \ are \ significant.$

Item response psychometrics

Missing responses were relatively low (4.6%) for the 45 dichotomous scaled items. Binomial frequency distributions indicated a variable range of responses for items, most ranging between 20% and 80%, with few floor or ceiling effects noted, with the exception of items about management of patients' other medical issues during active treatment and ease of

connecting patients back to RCP in case of recurrence, which most PCPs answered in the affirmative. Acceptable internal consistency was found within the items relating to each of the clinical–functional domains of integration, but less so for vertical integration.

Discussion

Although patterns-of-care research has shown that there is evidence of ongoing contact between PCPs and cancer patients across the care trajectory, there is little known about the nature of the encounters, to what extent providers work together and the types and extent of gaps in care (ICES 2006; Klabunde et al. 2009; Roorda et al. 2012). This study represents one of the first efforts to quantify these gaps, specifically in the context of PCP and RCP provider integration from the diagnosis stage to palliative care. Table 1 maps key response items to the three domains of integration (i.e., clinical, functional and vertical) and the main findings for each.

Studies have shown that clinical guidelines and navigational pathways in general are considered useful by PCPs in caring for cancer patients (Mayer et al. 2012; Papagrigoriadis and Koreli 2001; Zitzelsberger and Graham 2004). Our finding that many of these physicians do not understand the referral process to the RCP, and perhaps lack adequate guidelines, is important for planners to consider if PCPs are to remain involved in patient care at this initial transition. We found that basic information about where and whom to call and what diagnostic testing to have in place is not well understood. Emerging approaches to streamlining the patient transition into an RCP require mechanisms to ensure that PCPs are clear about referral processes. At the time of the study, tools to support the referral process had been developed for specialists, but were not systematically disseminated to PCPs. Web-based technologies seemingly have the potential to address PCP knowledge gaps in connecting patients to the RCP, but at this point, fewer than 10% of respondents report using RCP web resources. Systematic dissemination of referral guidelines in hardcopy, with reference to the RCP web portal, would likely have good uptake, particularly, given that respondents indicated overwhelmingly a need for a simple chart or card outlining referral procedures and key contact information for the RCP.

There is emerging evidence that targeted informational support to PCPs using a simple procedure that includes a faxed note of their patient's progress during the initial transition period best meets the information needs of these providers (Mansell et al. 2011; Ray et al. 1998). In an Australian study, it was observed that this basic procedure lead to significant improvements in physician confidence in the management of patients, with communications with the RCPs, and satisfaction in shared care (Jefford et al. 2008). The shared care finding is notable when considering that in the current study, over a third of respondents felt that their role was not valued across the trajectory of care, and many desired ongoing contact with the appropriate teams in the RCPs. Interventions to better support PCPs with specific information about the care of their patients and how to connect with the RCP would be expected to help improve this situation, leading to better care integration.

During active treatment, virtually all respondents indicated that they continued to be involved in the care of their patients' non-cancer medical problems and most indicated that they managed some of the side effects of treatment as well. This finding is reassuring in light of an Institute of Medicine review that suggested that PCPs' overall involvement in cancer care may be diminishing (Institute of Medicine and National Research Council of the National Academies 2005). Potential gaps remain in the provision of fully integrated care, in that almost half of the respondents reported not providing informational support to their patients about cancer and its treatment, and a similar proportion indicated having no involvement in their patients' cancer therapy decisions. Because PCPs are the preferred informational support across the trajectory of care for many cancer patients, methods to improve information sharing specific to the needs of these providers are essential for the realization of this patient preference (Whelan et al. 2003).

Although most PCPs knew who to contact during active treatment about issues specific to shared patients, over a fifth felt inadequately informed about changes in the condition or treatment trajectory of these patients. This would clearly impair PCPs' ability to provide appropriate care. Studies showing the benefit of standardized written communications between PCPs and cancer specialists would inform what interventions would be most helpful to address this gap. Finally, the interest expressed by some respondents in attending MCCs on their patients is important for system planners to consider the expansion of MCCs as part of quality improvement initiatives. Our findings suggest that it may be feasible to attempt to broaden the mandate of MCC attendance, perhaps using videoconferencing technologies, to facilitate attendance by PCPs. MCC participation by PCPs is possible using the RCP teleconference platform currently used by cancer specialists. PCP involvement in these MCCs would potentially support improvements in provider role clarity and patient care planning.

At the follow-up phase of cancer care, respondents indicated ongoing care provision for non-cancer-related problems, but there remained gaps in the provision of survivorship care. Only two-thirds of PCPs indicated that their role during this phase was clear, and a substantial proportion did not feel that their role was valued. These obstacles must be overcome to ensure that PCPs are well positioned to support and execute survivorship plans for the ever-increasing number of cancer survivors.

Palliative care for cancer patients remains problematic with well-described, chronic shortages of community-based services and continued high utilization of acute care services, especially emergency departments (Carstairs 2010; Henson et al. 2015; Hui et al. 2010). Most PCPs in our study indicated knowing how to arrange basic palliative care services, yet some perceived that the RCP was not responsive to their requests for advice on how to manage this care in their patients. Once again, guidelines were felt to be useful to support PCPs, especially in helping them navigate the resources available in the community for this phase of care.

In an exploratory multivariable analysis, we found that PCPs indicated higher rates of important integration parameters such as familiarity with processes of referral, role clarity and feelings of being valued, with both increasing years of practice and attendance at educational

events that include explicit patient care and process best practices. These findings support the need for outreach and education by RCPs, especially for PCPs early in their careers. We also observed that regardless of the model, many respondents felt the compensation for care of cancer patients to be inadequate. This finding concurs with the finding of the work from other research groups studying models of care integration that have determined the importance of financial incentives as a key element of success in care integration and patient outcomes – a key consideration for health system planners (Shortell et al. 2000; Wagner 2004). However, greater remuneration on its own can have a negative impact on the internal motivation of providers and does not guarantee greater PCP integration or better-quality care (Gosden et al. 2001; Scott et al. 2011).

A limitation of this study using self-reported data is the potential for respondent bias. Some PCPs may have exaggerated their involvement in cancer patient care or their understanding of the transition processes, whereas non-respondents may be even more detached from cancer care and the RCP. Our findings almost certainly present a better scenario than the overall reality in PCP–RCP integration. Similarly, associations found between self-reported practice factors and involvement in care provision could be because of PCPs who perceive themselves as highly involved in cancer care, inflating the number of new cancer patients seen or the related education sections attended. We neither assessed integration from the perspective of the RCP, other cancer care providers or patients nor corroborated the PCPs' perspectives with administrative information, such as time to RCP intake, PCP service provision, etc. Input from non-physicians, service administrators and patients is also important in designing interventions to improve cancer system integration. This study did not directly assess the cost implications of poor integration and whether improvements would lead to changes in healthcare costs. Finally, our study-specific instrument requires further validation in different cancer care systems to test its reliability and validity.

There are two important preliminary observations to make when considering the overall results of this study. The first is that it is feasible to conduct this type of research with PCPs using a proven methodology for mailed surveys (i.e., clear study purpose, small incentive, SAE/fax return, targeted follow-up) (Vangeest et al. 2007) as shown by our response rate of 63%. The second observation is that the various aspects of care provision and integration between RCP and PCPs differ across the trajectory of care and that interventions are important to support gaps, especially in the peri-diagnostic and post-treatment surveillance phases of care. It is also evident that communication between community and RCP providers requires improvement, and that interventions need to incorporate clear guidelines about roles and responsibilities for patient care.

By identifying the specific aspects of caring for patients from the perspectives of a large and representative sample of PCPs within a regional planning structure, this study represents an important first step towards informing the design of system interventions to improve PCP satisfaction with/perception of integration with the RCP. The following strategies have been explicated: (1) Tools to support initial work-up at the cancer centre, such as diagnostic

assessment and RCP navigation; (2) Mechanisms to facilitate PCP involvement in MCCs; (3) Other mechanisms that enable real-time communication between PCPs and the RCP during therapy; (4) Standardized post-treatment transition plans that include explicit statements about roles and responsibilities in care; and (5) Clear avenues for PCPs to connect directly with specialists at the RCP. These actions that are aimed at increasing PCP involvement need to regard the comfort levels of these providers and uphold patient care continuity. This study serves as a partial baseline for evaluating regional and provincial initiatives that are designed to improve system functioning and the patient care experience through enhancing RCP and PCP integration.

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Correspondence may be directed to: Jonathan Sussman, MD, FRCP(C), MSc, Department of Oncology, McMaster University, Juravinski Cancer Centre, 699 Concession St. Rm 4-204, Hamilton, ON L8V 5C2; tel: 905-387-9711 ext. 64509; e-mail: sussman@hhsc.ca.

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Establishing a Primary Care Performance Measurement Framework for Ontario

Mise en place d'un cadre pour la mesure du rendement des soins primaires en Ontario



WISSAM HAJ-ALI, BSCN, MPH, CPH

Health Quality Ontario

Institute of Health Policy Management and Evaluation, University of Toronto

Toronto, ON

BRIAN HUTCHISON, BA, MD, MSc, CCFP, FCFP
Departments of Family Medicine and Health Research Methods, Evidence and Impact
Centre for Health Economics and Policy Analysis
McMaster University
Hamilton, ON

On behalf of the Primary Care Performance Measurement Steering Committee

Abstract

A systematic approach to Primary Care Performance Measurement is needed to provide useful information on a regular basis to inform planning, management and quality improvement at both the practice and system levels. Based on an environmental scan, a summit of primary care stakeholders and a stakeholder survey and supported by Measures and Technical Working Groups, the Ontario Primary Care Performance Measurement Steering Committee, representing 20 stakeholder organizations, identified system- and practice-level measurement priorities and related specific performance measures across nine domains of primary care performance. This initiative addressed measures' selection and technical specification. It did not include data collection. Lessons learned in Ontario can assist other jurisdictions developing frameworks for monitoring and reporting on primary care performance. Cross-country alignment could lead to a coordinated approach to measure and target areas for primary care performance improvement in Canada.

Résumé

Une approche systématique pour la mesure du rendement des soins primaires est nécessaire afin d'obtenir, sur une base régulière, de l'information utile à la planification, à la gestion et à l'amélioration de la qualité, et ce, tant au niveau de la pratique que du système. En se fondant sur une analyse du contexte, sur un sommet réunissant les intervenants de première ligne ainsi que sur un sondage auprès des intervenants, et comptant sur l'appui des groupes de travail technique et sur les mesures, le Comité directeur pour la mesure du rendement des soins primaires en Ontario, qui représente 20 organisations clés, a identifié les priorités de mesures aux niveaux du système et de la pratique ainsi que des mesures connexes dans neuf domaines du rendement des soins primaires. Cette initiative porte sur la sélection et la spécificité technique des mesures. Elle ne comporte pas de collecte de données. Les leçons retenues en Ontario peuvent aider d'autres juridictions à développer des cadres de travail pour le suivi et la production de rapports sur le rendement des soins primaires. Un alignement à travers le pays pourrait mener à une approche coordonnée pour mesurer et viser les secteurs pour l'amélioration du rendement des soins primaires au Canada.

Introduction

A strong primary care system is the backbone of a high-performing health system. For over a decade, Ontario has focused on strengthening primary care delivery. However, the province lacks a coordinated and comprehensive approach to collect, analyze and report data on the performance of primary care at either the practice or system level. At both levels, the paucity of regular feedback on key aspects of performance hinders efforts to identify opportunities for improvement and track the effect of improvement initiatives. At the system level, the meagre information available on primary care performance makes it difficult to monitor and evaluate the effectiveness of policy changes and investments.

In recent years, clinicians, managers and policy makers have increasingly recognized the need for systematic, ongoing feedback on primary care performance. The limited comparative data available on primary care performance at the provincial level – mainly from the Commonwealth Fund International Health Policy Surveys of primary care physicians and the public – indicate that Ontario's primary care performance compares favourably with other provinces, but lags behind international peers, particularly in timely access to care and primary care infrastructure (e.g., primary care teams, electronic medical record [EMR] systems and processes for performance measurement and improvement) (Aggarwal and Hutchison 2012; CIHI 2015, 2016; Hutchison 2013, 2014; Hutchison and Glazier 2013; Hutchison et al. 2011; Marchildon and Hutchison 2016; Osborn et al. 2014, 2015; Strumpf et al. 2012). Individual primary care practices and organizations have had little access to information on their performance, usually restricted to data they collect and analyze themselves. However, most lack the capacity to generate their own performance data.

A number of primary care measurement frameworks have been developed in Canada in recent years, for example, those of Accreditation Canada (n.d.), CIHI (2012), Haggerty and Martin (2005), Haggerty et al. (2007), Hogg et al. (2008), Levesque et al. (2011), Watson et al. (2004). Pan-Canadian and provincial/territorial results for a 16-measure subset of CIHI's 51 primary healthcare indicators have recently been reported (CIHI 2016). Most of the proposed frameworks have been applied on a limited basis, often in a research context. None has been used to report on a province-wide basis on primary care performance at either the organization or system level.

The identification of the need for an overarching framework for strengthening primary care in Ontario can be traced to the 2010 McMaster Health Forum, Supporting Quality Improvement in Primary Health Care in Ontario (Lavis 2010). The Forum participants recommended that a planning group, including representatives of the funder and regulator of health services in Ontario (the Ministry of Health and Long-Term Care [MOHLTC]), and professional associations related to primary care (Ontario Medical Association, Registered Nurses' Association of Ontario, Association of Ontario Health Centres, Ontario College of Family Physicians) develop a strategy for strengthening primary healthcare in Ontario.

In response, the MOHLTC established and chaired the Primary Healthcare Planning Group. The group had a mandate to: (a) draft and build consensus on a strategy for strengthening primary care in Ontario; and (b) plan a meeting where a broad-based group of stakeholders would discuss and finalize the strategy (Ontario MOHLTC 2011). In its final report, the Primary Healthcare Planning Group recommended that "a Working Group be established under the auspices of Health Quality Ontario (HQO) to design a performance measurement framework including indicators to examine how the primary care system is performing against its goals and objectives at the practice, local, regional and provincial levels".

Beginning in 2012, organizations representing patients and family caregivers, primary care providers, data holders, researchers, managers and policy makers from across Ontario have worked collaboratively to develop a structured approach to measuring primary care performance that can inform decision-making at the practice and system levels. These efforts became the Primary Care Performance Measurement (PCPM) initiative. The initiative was intended as a practical, context-specific exercise to develop an approach to performance measurement that would meet the needs of key primary care stakeholders in Ontario: patients, caregivers, providers, managers, policy makers and the public. It was not designed to develop, refine or validate a conceptual framework for understanding and measuring primary care performance or to establish a generalizable set of performance measures. In this paper, we describe and reflect on the process that Ontario used to develop such an approach to PCPM.

Methods

Establishing the PCPM framework

On November 21, 2012, HQO and the Canadian Institute for Health Information (CIHI), in collaboration with their partners (the MOHLTC, Cancer Care Ontario [CCO], the Institute

for Clinical Evaluative Sciences [ICES], eHealth Ontario and Local Health Integration Networks [LHIN]), co-sponsored an Ontario PCPM Summit in Toronto. The Summit was an invitational meeting of senior leaders from key primary care data partners and information users in Ontario. Its purpose was to start laying the foundation for PCPM in Ontario.

To support the Summit, HQO conducted an environmental scan, which examined the current state of PCPM in Ontario, across Canada and internationally. The scan provided a snapshot of existing and recently completed projects that addressed the measurement of performance in primary care settings. The scan included:

- A comprehensive literature review, with an electronic search of MEDLINE®, CINAHL, EBSCO Information Services and Google Scholar databases, using the keywords: "performance measurement," "performance standards," "conceptual framework," "outcome and process assessment," "quality indicators," "evaluation of primary care" and "design and performance measurement."
- A review of grey literature.
- Contacts with organizations throughout Ontario and Canada that HQO knew were doing relevant research or developing performance measurement frameworks for primary care.

The environmental scan identified 19 performance measurement frameworks, initiatives and data sources, and summarized them in a matrix (CIHI 2013; HQO 2013a). HQO used these findings to identify primary care domains that could form the basis for an overarching framework and to select potential measurement priorities (aspects of primary care performance that are valuable to measure at the practice and system level) for each domain. Our goal was not to identify the most comprehensive or rigorous of the existing frameworks, but to select a framework around which potential performance measures could best be organized and presented for consideration by participating stakeholders. Accordingly, we selected HQO's Nine Attributes of a High Performing Health Care System Framework as the most appropriate framework for examining primary care performance in Ontario, in part because the framework was already being used in HQO's public reporting on health system performance and was therefore familiar to many stakeholders. In addition, in its 2011 report, the Primary Healthcare Planning Group recommended it (together with the Triple Aim) as the basis for a primary care measurement framework for Ontario.

The Nine Attributes align with the Triple Aim Framework of the Institute for Health Care Improvement (IHI) and six of the attributes correspond to the Six Aims for Improvement of a Health Care System proposed by the Institute of Medicine (IOM) in its ground-breaking report, Crossing the Quality Chasm: A New Health System for the 21st Century (IHI n.d.; IOM 2001) (Table 1). Because we wished to focus on primary care performance (i.e., outcomes of care and processes linked to outcomes, rather than the structure and organization of primary care), we initially excluded the HQO domain of appropriate resources. However, stakeholders were insistent that it be included on the grounds that primary care performance is contingent on the availability of needed resources.

TABLE 1. HQO's Nine Attributes, IOM's Six Aims for Improvement and IHI's Triple Aim

	Triple Aim (IHI)			
Nine Attributes (HQO)/Six Aims for Improvement (IOM)	Population health (better health)	Patient experience (better care)	Per capita health cost (better value)	
Access*/timeliness§	×	×	×	
Integration*		×	×	
Efficiency*§			X	
Effectiveness*§	×	×	X	
Focus on population health*	×	×		
Safety* [§]		×	X	
Patient-centredness*/person-centredness§		×		
Appropriate resources*			X	
Equity*§	×	×		

HQO = Health Quality Ontario; IHI = Institute for Health Care Improvement; IOM = Institute of Medicine. *HQO. *IOM. Source: Adapted from Kates et al. (2012).

The Steering Committee for the Summit established the following criteria (weighted equally) to shortlist a set of measurement priorities for the Summit participants to consider:

- 1. The information is valuable to have on a regular basis for one or more purposes (e.g., service planning, management or quality improvement) at the practice and/or system (community, regional or provincial) levels.
- 2. There is a potential for comparisons of performance across practices, organizations, communities, regions, provinces/territories and/or countries.
- 3. The aspect of primary care performance is linked in evidence to one or more components of the IHI's Triple Aim:
 - Improving the patient experience of care (better care).
 - Improving population health (better health).
 - Reducing/controlling the per-capita cost of healthcare (better value).

To facilitate the Summit participants' discussions and priority setting, the Steering Committee prepared and distributed to participants a worksheet of 60 potential measurement priorities and other background materials before the meeting. The committee encouraged participants to share the information and consult widely within their organizations and with their stakeholders.

In total, 61 senior leaders attended the Summit. Following facilitated discussion, they voted for their highest performance measurement priorities, keeping in mind the following question: What aspects of primary care performance would be the most valuable to measure on a regular basis to inform decision-making at the practice and system (community, regional, provincial) levels? The votes were tabulated to generate separate ranked lists of practice- and system-level measurement priorities. The Summit proceedings can be found on CIHI's and HQO's websites (CIHI 2013; HQO 2013b).

Following the Summit, the Steering Committee was broadened to include additional organizations representing primary care providers, hospitals, home and community care providers, patients and family caregivers. In Spring 2013, the organizations represented on the Steering Committee circulated a stakeholder survey to engage their members and solicit their views on the aspects of primary care performance that would be the most valuable to measure. Over 850 people responded. Informed by the Summit and survey results, the Steering Committee finalized the overarching PCPM framework (Figure 1).

Developing specific measures for the PCPM framework

HQO, the Steering Committee, a Measures Working Group and a Technical Working Group collaborated to develop specific measures for the framework (Figure 2). The responsibilities of the three groups were:

- Steering Committee: Identify a set of measurement priorities for the PCPM framework based on the Summit and survey results.
- Measures Working Group: Select preferred measures for each measurement priority building on and guided by the criteria that were used during the Summit.
- Technical Working Group: Advise on technical specifications and infrastructure requirements for data extraction, analysis and reporting.

The Measures Working Group included primary care providers (n = 7), health system decision-makers (n = 5), patients and family caregivers (n = 3), patient relations professionals (n = 2), primary care researcher/clinicians (n = 2) and quality improvement specialists (n = 2). The Technical Working Group comprised primary care researcher/clinicians (n = 3) and data specialists from 10 organizations (n = 15).

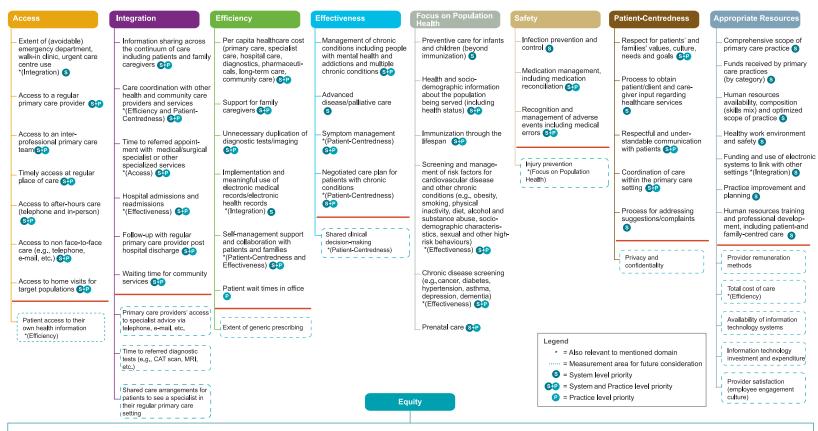
Results

Recommended measures

In its Phase One Report, the Steering Committee selected specific measures for the measurement priorities in eight domains of the PCPM framework: access, integration, efficiency, effectiveness, focus on population health, safety, patient-centredness and appropriate resources (HQO 2014). Equity – the ninth domain – was identified as a cross-cutting domain that would be assessed based on a recommended set of 14 economic, demographic and social variables applied to the performance measures in the other domains.

At the system level, 48 (27%) of the 179 recommended measures are currently available at the LHIN level and 90 measures (50%) are available at the provincial level. Available system-level measures are derived from multiple sources, including the MOHLTC's Health Care Experience Survey (HCES), the Canadian Community Health Survey, the Commonwealth Fund International Health Policy Surveys and administrative data sets held by the ICES and CCO. The currency and frequency of reporting vary among the sources.

FIGURE 1. The Primary Care Performance Management framework (Ontario Primary Care Performance Measurement Steering Committee 2014)



Equity is a cross-cutting domain and will be assessed in relation to a variety of economic and social variables such as income, education, gender, disability, social support, mental health status, urban/rural location, age, sexual orientation/identity, language, immigration, ethno-cultural identity and Aboriginal status.

Focus on population health Patient-**A**ppropriate Integration **E**fficiency Access Effectiveness Safety centredness resources Steering Committee review of proposed measures **Technical Working Group key activities** Advise on technical specifications and infrastructure requirements (data extraction, analysis, reporting) Measures Working Group key activities Select specific measures for each domain and measurement priority based on five considerations: 1. Potential to compare with practice, regional, national or international primary care performance 2. Evidence that the measure addresses one or more aspects of Institute for Healthcare Improvement Triple Aim (improving patient experience of care, improving population health, reducing/controlling per capita cost of healthcare) 3. Validity/reliability 4. Alignment with existing performance measurement initiatives in Ontario 5. Current availability of data (secondary consideration) Health Quality Ontario Primary Care Team key activities

FIGURE 2. Process to develop specific measures for the Primary Care Performance Measurement framework

Only 15 (13%) of the 112 practice-level measures in the PCPM framework will be available in the near future to all primary care clinicians, mainly through the ICES-HQO Primary Care Practice Reports and CCO. Table 2 summarizes practice- and system-level measures by availability.

The recommended measures draw on multiple data sources. Administrative data held by the ICES, MOHLTC (Health Analytics Branch) and CCO could provide 23 practice-level measures (21%) and 32 system-level measures (18%). Electronic medical record data could generate 24 practice-level measures (21%) and 13 system-level measures (7%). A practice-level patient experience survey could provide 65 practice-level measures (58%). Population survey data could produce 68 system-level measures (38%). Provider reported that data could provide 47 system-level measures (26%). Finally, primary care organization-reported data could be the basis for 19 system-level measures (11%).

The technical details for each recommended measure, including measure name, description, definition and existing or potential data source, can be found in the Technical Appendices of the Steering Committee's Phase One Report.

Recommendations for implementation

To support the implementation of the PCPM framework, the Steering Committee made a series of recommendations that are outlined in Box 1.

TABLE 2. Summary of specific measures by availability

Domain	Number of measures						
Practice and system levels*	Currently reported	Currently reported but modified wording recommended	Not currently available but could be reported using existing infrastructure [§]	Not currently available but included in survey tool under development; infrastructure required for data collection, analysis and reporting [®]	Measures not currently available; new infrastructure required for data collection, analysis and reporting [†]	Total	
Access	8	3	I	0	12	24	
Patient- centredness	2	2	12	9	12	37	
Integration	15	2	3	I	11	32	
Effectiveness	15	I	16	I	43	76	
Focus on population health	24	4	4	1	14	47	
Efficiency	7	1	8	0	7	23	
Safety	3	3	3	0	14	23	
Appropriate resources	14	I	0	0	14	29	
Total	88	17	47	12	127	291	
Equity	Cross-cutting domain – Analysis will be based on 14 population characteristics: age, gender/sex, urban/rural location, ethno-cultural identity, disability, social support, income, education, sexual orientation/identity, language, immigration, aboriginal status, employment status and mental health status						

^{*}Refers to province-wide (vs. local) availability. ⁵For example, Health Quality Ontario-Institute for Clinical Evaluative Sciences Primary Care Practice Report, Health Care Experience Survey; [¶]Health Quality Ontario Primary Care Patient Experience Survey.

BOX 1. Recommendations of the Steering Committee to support the transition to better primary care performance measurement

- · Accelerate efforts to strengthen vendor requirements to incorporate standardized high-value data elements; facilitate standardized data capture, data transfer and exchange; and simplify processes for extracting and analyzing data.
- Develop the necessary infrastructure to make the measures available throughout the province at both the practice and system levels, including: (1) a practice-level patient experience survey and a mechanism for pooling EMR data to provide regular feedback to practices over time and allow for comparison with peers; (2) a mechanism for collecting data from primary care providers and organizations; and (3) a mechanism for combining primary care performance measures from
- Develop aggregate measures of primary care performance that reflect performance at a broad domain level (e.g., effectiveness), for a more limited area of practice (e.g., management of chronic conditions) or based on a framework such as the IHI's Triple Aim.
- · Identify organizational responsibility for producing coherent, user-friendly reports using performance measurement data.
- Include the PCPM framework measures in new survey tools or updates of existing ones.
- · Equip primary care providers, organizations, health system managers and policy makers with an understanding of performance measurement, quality improvement methods and leading practices.
- Update and revise the PCPM framework, as required, to align with emerging evidence, changing policy priorities, new data sources and evolving information needs, using structures and processes that are inclusive of stakeholders, including patients, caregivers and the public.
- Commission an arm's-length formative evaluation of the implementation of the PCPM framework to detect and address implementation challenges and to identify and build on implementation successes.

[†]For example, electronic medical record-based measures.

As a next step, the Steering Committee committed to selecting two priority subsets of measures and recommended approaches for data collection to support immediate measurement at both the system and practice levels.

Discussion

Lessons learned

Other jurisdictions developing systems for monitoring and reporting on primary care performance can benefit from the lessons learned in Ontario related to stakeholder and patient engagement and resources requirements. Stakeholder engagement has been a key success factor in this initiative. Stakeholder ownership of the recommendations is an important driver of uptake, implementation, sustainability and, ultimately, quality improvements. The collaboration among stakeholders representing patients, providers, data holders, researchers, managers, policy makers and funders from across Ontario has supported alignment and a high degree of consensus on the specific measures that constitute the framework.

Tapping into the experience and expertise of patients and family caregivers through their participation on the Steering Committee and in the Measures Working Group greatly enhanced the meaningfulness and potential value of the recommended PCPM measures. We learned early in the process that the perspectives of primary care providers, managers and policy makers are not always consistent with those of patients and their families. A key to success was the comfort and ability of the patient and family caregiver participants to express themselves freely during the measures selection process. The effect of the partnership with patient and family caregivers is evident from the number of selected measures that are patient-reported – 66 at the system level and 64 at the practice level out of the 199 measures in the framework. In addition, new measures were created and survey-based measures were substantially reworded to reflect the concerns, needs and values of patients and caregivers. Based on this experience, we strongly recommend extensive participation by patients and family caregivers throughout initiatives of this type.

Engagement and consensus-building among a broad range of stakeholders are time-consuming and resource-intensive. The Steering Committee guiding the work met over 20 times, for an average of 4 hours per meeting. The Measures and Technical Working Groups met eight times, each for an average of 4 hours per meeting. Representation included 22 people on the Steering Committee, 21 people on the Measures Working Group and 18 people of the Technical Working Group. The HQO team supporting the work included four dedicated staff and a Senior Advisor who invested, on average, 60% of their time throughout the course of two years with supervision from a senior leadership team. This level of commitment was only possible because the partners in this initiative shared a conviction that a systematic approach to performance measurement and feedback is an essential underpinning for practice- and system-level healthcare improvement.

Not all of the organizations represented on the Steering Committee had collaborated before. However, after working together over a period of two-and-a-half years, the Steering Committee achieved a high level of trust and mutual respect.

The Steering Committee was the final decision-maker in the process with the HQO providing secretariat support. This arrangement helped to build stakeholders' sense of ownership and commitment to implementation of the recommendations.

How could the measures be used?

The recommended PCPM measures were identified through a rigorous and inclusive stakeholder engagement process that was designed to identify performance measures that are valuable for decision-making. Alignment of the PCPM initiative with existing performance measurement and quality-improvement initiatives in Ontario was considered during the framework's development and was facilitated by representation on the Steering Committee and Working Groups of organizations that are leading many of those initiatives.

The recommended set of measures provides a menu of primary care performance measures for use at the system and practice levels. Clinicians, primary care organizations, system managers, policy makers, funders, researchers and organizations representing patients and the public can draw on this bank of recommended measures to meet their diverse needs. The measures can help primary care practices to identify opportunities for improvement and clinicians to evaluate and explore aspects of their performance as part of reflective learning activities. Health system managers, policy makers and funders could use the measures to monitor system performance and the effect of policy initiatives and health system investments. Planners and decision-makers could use the measures to conduct population needs-based planning. Evaluators could use the measures to assess the implementation and effects of innovative primary care programs. Researchers could select outcome measures for use in clinical, health services and policy research in primary care. The measures could help patient-advocacy and civil-society organizations gauge the responsiveness of primary care to the needs and expectations of patients, family caregivers and the public. For some measures, data will be available from existing reports or data sources. In other cases, users would need to collect data themselves.

Data gaps

Our process identified major gaps in data availability at both the practice and system levels. At the system level, important gaps exist for mental health, health promotion, maternal health, family and caregiver experience, comprehensiveness of care and healthcare provider experience. In the short term, data availability could be enhanced by adding additional high-priority measures to the HCES and expanding the number of measures derived from administrative databases held at ICES. At the practice level, key data gaps include mental health and safety. Standardized EMR specifications that facilitate the extraction, pooling, analysis and reporting of EMR data are critically required to improve the availability of high-value practice-level measures.

Relationship to other frameworks

The Ontario PCPM framework differs from other conceptual and measurement frameworks for primary care in a number of respects. Most other frameworks aim to be generic,

whereas ours is intended to be specific to the current and short-term-future context of Ontario. Our framework makes a distinction between measures that are applicable at the practice/organizational level and those that are relevant to performance measurement at the system level. Our process was driven by stakeholder perceptions of what would be useful to measure, whereas most other frameworks have been expert-driven. The Ontario framework is populated by a large number and wide diversity of specific measures, reflecting the multiple perspectives represented in the development process. Because this initiative was focused on performance, our framework and specific measures emphasize outcomes of care, processes of care linked in evidence and logic to health outcomes and patients' experience rather than structural and organizational characteristics that figure more prominently in other frameworks.

An initiative is underway in Alberta to develop common quality and outcome measures for the province's Primary Care Networks (PCNs) (Oddie and Krajnak n.d., Scott Oddie personal communication, February 26, 2014). The participants include 25 executive directors, evaluators and provider leads from 13 PCNs and representatives from Alberta Health, Alberta Health Services, Health Quality Council of Alberta, CIHI and academic institutions. Their proposed minimum data set for PCNs includes measures related to access, health promotion, early detection and disease prevention, chronic disease management, patient experience, interdisciplinary teams, cost of services and safety, all of which are included in the PCPM set of measures.

Conclusion

Systematic, regular and relevant performance measurement is essential to identify opportunities for – and the impact of – improvement efforts. A process that is inclusive of key stakeholders can help to ensure the development of a framework that meets the needs of stakeholders and maximizes their commitment to its application to support improvements in policy and practice.

Given the context-specific and stakeholder-driven nature of this initiative, our framework and specific performance measures cannot be generalized to other times and places. However, our methods are transferable and the suite of measures that were selected and technically specified may be a useful source of potential measures for use in other settings. Our process was time- and resource-intensive, in part because of the size and complexity of Ontario's healthcare system, and may need to be streamlined in settings where fewer resources are available. If properly aligned, similar processes in other provinces can build a coordinated and sustainable approach to measure primary care performance in Canada. Given the primitive state of routine PCPM in Canada, particular attention needs to be given to the identification of data gaps and the development of processes for collecting and analyzing data to fill those gaps.

Correspondence may be directed to: Wissam Haj-Ali, Health Quality Ontario, 130 Bloor Street West, 10th floor, Toronto, ON M5S 1N5; e-mail: wissam.haj.ali@mail.utoronto.ca.

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Location, Location: Characteristics and Services of Long-Stay Home Care Recipients in Retirement Homes Compared to Others in Private Homes and Long-Term Care Homes

Tout est une question d'emplacement : caractéristiques et services pour les bénéficiaires de soins à domicile de longue durée dans les maisons de retraite en comparaison aux autres résidences privées et aux foyers de soins de longue durée



JEFFREY W. POSS, PHD Associate Adjunct Professor, School of Public Health and Health Systems University of Waterloo Waterloo, ON

CHI-LING JOANNA SINN, BSC
PhD Candidate, Aging, Health, and Well-Being
School of Public Health and Health Systems, University of Waterloo
Waterloo, ON

GALINA GRINCHENKO, MECON Manager, Decision Support Hamilton Niagara Haldimand Brant Community Care Access Centre Hamilton, ON

JANE BLUMS, BA, BSCN, MA

Director of Decision Support

Hamilton Niagara Haldimand Brant Community Care Access Centre

Hamilton, ON

Location, Location

TOM PEIRCE, MBA Vice President Quality, Performance & Chief Innovation Officer

Hamilton Niagara Haldimand Brant Community Care Access Centre Hamilton, ON

JOHN HIRDES, PHD, FCAHS
Professor, School of Public Health and Health Systems
University of Waterloo
Waterloo, ON

Abstract

We examine recipients of publicly funded ongoing care in a single Ontario jurisdiction who reside in three different settings: long-stay home care patients in private homes and apartments, other patients in retirement homes and residents of long-term care homes, using interRAI assessment instruments. Among home care patients, those in retirement homes have higher proportions of dementia and moderate cognitive impairment, less supportive informal care systems as well as more personal care and nursing services above those provided by the public home care system, more frequent but shorter home support visits and lower than expected public home care expenditures. These lower expenditures may be because of efficiency of care delivery or by retirement homes providing some services otherwise provided by the public home care system. Although persons in each setting are mostly older adults with high degrees of frailty and medical complexity, long-term care home residents show distinctly higher needs. We estimate that 40% of retirement home residents are long-stay home care patients, and they comprise about one in six of this Community Care Access Centre's long-stay patients.

Résumé

Nous avons examinés, dans une seule circonscription en Ontario et au moyen des instruments d'évaluation d'interRAI, le cas des bénéficiaires de soins continus financés par les deniers publics qui résident dans trois types d'établissements : les bénéficiaires de soins à domicile de longue durée en appartements et résidences privées, les patients en maisons de retraite et les résidents en foyers de soins de longue durée. Parmi les patients qui reçoivent des soins à domicile, on observe chez les résidents en maisons de retraite une proportion plus élevée de démence et de troubles cognitifs modérés, moins de soutien sous forme de soins informels, moins de soins personnels et des services infirmiers supérieurs à ceux fournis par le système public de soins à domicile, des visites à domicile plus fréquentes mais plus courtes ainsi que des dépenses publiques pour les soins à domicile moins élevées que prévu. Ces dépenses moins élevées peuvent être dues à l'efficience de la prestation des soins ou au fait que les maisons de retraite fournissent certains services qui sont habituellement fournis par le système public de soins à domicile. Bien que les personnes dans chacun de ces établissements soient principalement des aînés qui présentent un haut degré de fragilité et de complexité médicale, les résidents dans les foyers de soins de longue durée présentent un bien plus grand besoin de soins. Nous estimons qu'environ 40 % des résidents en maisons

de retraite sont des patients en hébergement de longue durée et représentent environ un sixième des patients de longue durée liés à ce Centre d'accès aux soins communautaires.

Introduction

In Ontario, Canada, Retirement Homes (RH) have been regulated since 2010, and are defined in legislation as a "residential complex or the part of a residential complex," "occupied primarily by persons who are 65 years of age or older," whose residents are "not related to the operator of the home," and have "at least two care services available, directly or indirectly" (Government of Ontario 2010). In 2014, there were more than 700 licensed RHs in Ontario, mostly privately funded and for-profit (RHRA 2015a), and while capacity has grown in recent years, demand has outpaced growth (CMHC 2015).

RHs may provide a range of services to their residents among the minimum of two required for licensure, including meals; assistance with bathing, personal hygiene, dressing or walking; administering medications; continence care; or making a doctor, nurse or pharmacist available (ORCA 2015). They range in size from a minimum of six to 250 units or larger, with semiprivate or ward accommodations up to multi-bedroom suites that vary widely in rent (CMHC 2015). RHs represent an option for older persons looking to relocate from a private house or apartment to a setting where services are available to meet present or anticipated needs or preferences, and to live near others with similar interests. Needs of potential residents are assessed before a tenancy agreement to ensure suitable care is available (ORCA 2015).

As a place of residence, RHs may be placed somewhere between private homes or apartments (PH) and nursing homes, called long-term care homes (LTCH) in Ontario. The need for personal care or other health-related services is not a requirement to move into RH, and some persons choosing to move there are entirely independent and self-reliant. For more information on RHs in Ontario, including a searchable database of facilities, see http://www.rhra.ca/en/register/.

Home care is part of publicly funded health services in Ontario, with delivery organized into and administered from 14 geographic areas called Community Care Access Centres (CCAC). They provide home health services for various populations including child and school, short-term acute and rehabilitation, palliative and persons requiring support to remain in their own homes (Government of Ontario 2015). Eligibility is based on need, and co-payment is not required for services. Persons in RH are considered equally for eligibility along with those in other community settings.

More than 55,000 persons reside in RHs in Ontario (RHRA 2015a), but it is unknown how many of them receive ongoing home care services through their local CCAC. Ontario has about 77,600 LTCH spaces (OANHSS 2015) and 359,000 seniors receive supportive services annually through their CCAC in community settings, including RH (OACCAC 2016).

Operationally, the Hamilton Niagara Haldimand Brant (HNHB) CCAC is the largest CCAC in Ontario, and has among the most persons over the age of 65. It serves a diverse urban and rural area of 7,000 km² with a population of 1.4 million people.

This study seeks to understand the subset of RH residents served by the HNHB CCAC, and how they compare with others served in PH settings. This comparison also includes LTCH residents in the HNHB catchment area to profile the continuum of housing options for older persons receiving care.

Detailed clinical measures are drawn from the RAI family of assessments that are developed by interRAI, an international collaborative of researchers.

The RAI-Home Care (RAI-HC) is a standardized comprehensive clinical assessment system designed for home care, with demonstrated reliability and validity (Carpenter et al. 2004; Landi et al. 2000; Morris et al. 1997). It has been mandated in Ontario since 2002 for use among all adult, non-palliative home care patients expected to be on service 60 days or longer. It is normally done at program entry, and then every 6 to 12 months, or sooner in the case of a significant change in health status. Assessors are care coordinators with healthcare backgrounds employed by the CCAC, trained in the administration of the RAI-HC and the use of its information.

The RAI-Minimum Data Set 2.0 (RAI-MDS 2.0) assessment is a standardized comprehensive clinical assessment designed for LTCH facility care, with demonstrated reliability and validity (Hawes et al. 1997; Mor 2004; Poss et al. 2008a, 2008b). Its use in LTCH in Ontario began in 2005 and was adopted by all LTCHs by 2010. It is administered within the first 14 days of a resident's stay, and then every three months thereafter, or sooner in the case of a significant change.

Both the RAI-HC and the RAI-MDS 2.0 produce scales and other measures reported here, including the Cognitive Performance Scale (Morris et al. 1994), Activities of Daily Living Hierarchy Scale (Morris et al. 1999), Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale (Hirdes et al. 2003), Depression Rating Scale (Burrows et al. 2000) and Resource Utilization Groups Version III for Home Care (RUG-III/HC) case mix grouping algorithm (Poss et al. 2008a, 2008b).

Methods

Long-stay home care population (private homes and retirement homes) Four administrative databases maintained by HNHB CCAC were used. These four databases are provided in de-identified, linkable form to the University of Waterloo as part of a contractual agreement that imbeds researchers and graduate students within HNHB CCAC.

- All RAI-HC assessment records done in the home care patient's residence were considered for calendar year 2014 (n = 29,659).
- Assessments were linked to a patient's address table. Home address records classified as "private dwelling" or "retirement home" and active on the day of assessment were identified. During CCAC data entry, the patient's address field is validated against known retirement home addresses at the time of patient intake (n = 27,723).
- 3. A referrals database of patients on active home care service informing referral start and end dates was then linked. Cases discharged within 30 days of the RAI-HC assessment were excluded, as there was insufficient time to observe a stable pattern of services (n = 24,242).

- 4. Billed services were used in the final linkage. Services were aggregated for the 30-day period starting on the day of the RAI-HC assessment. Cases receiving no service within 30 days of the RAI-HC assessment were excluded. The 30-day period represents sufficient time to understand patterns of service in relation to the patient's characteristics measured by the RAI-HC assessment. Cases (n = 109) averaging more than 8 hours of personal support per day were excluded, as they represent short-term intensive support not typical of long-term service (n = 22,377).
 - If a patient had more than one assessment, the most recent one was selected (n = 17,945).

There were 1,453 persons with assessments in either PH or RH that were excluded from the final sample because they were on service for fewer than 30 days. These cases differed slightly, in that they represented both more low-risk cases whose care might have been referred to agencies outside the CCAC and more high-risk cases who were more likely to be discharged because of death, hospitalization or LTCH placement.

Expected costs for the 30-day period were case mix adjusted using the 23 classifications of the RUG-III/HC grouping algorithm with the addition of co-residing with an informal caregiver as a final split for each group, doubling the number of classifications. This change was helpful, given there are no adjustments in RUG-III/HC for informal care availability that is known to drive home care intensity (Van Houtven and Norton 2004), and it differs greatly between PH and RH.

Long-term care home population

LTCHs submit RAI-MDS 2.0 assessment data directly to the Canadian Institute for Health Information (CIHI). As part of a data-sharing agreement with interRAI, a research extract is provided by CIHI to interRAI Canada at the University of Waterloo. Assessments in this analysis were done in the quarterly period between January 1 and March 31, 2014. If a resident had more than one assessment, the most recent assessment was used. This cross-sectional data set is representative of persons living in LTCHs in HNHB's catchment area at the time the community population was observed.

The goal was to achieve a representational view of the populations in these three settings. The RAI-HC is conducted every 6 to 12 months, so the full year of assessments was included. RAI-MDS 2.0 assessments are done every three months, and this dictated the sampling frame. Placing LTCH at the beginning of the calendar year minimized the likelihood of an individual being included in both, as patients are much more likely to transition from community to LTCH than the reverse.

Statistical testing of differences between cohorts used chi-square for nominal/ordinal and *t*-test for continuous measures. SAS 9.4 was used.

Ethics clearance was received from the University of Waterloo's Office of Research Ethics (ORE# 20862).

Results

Table 1 presents selected characteristics from the RAI-HC and RAI-MDS 2.0 assessments, for home care patients in PH and RH, as well as for residents of LTCHs. It is necessary to keep in mind that the results represent all LTCH residents, while values for PH and RH are for the subset residing in those settings who have sought and are receiving help from CCAC home care services. In other words,

the community samples reflect groups of mostly older persons with sufficiently high needs requiring ongoing and regular personal care, nursing or therapy services. As a result, these findings cannot be directly compared with studies that describe entire populations of older persons in PH or RH.

Compared to PH, individuals in RH are almost nine years older on average, and are more likely to be female and widowed. This is consistent with the understanding that women are more likely to be widowed and living on their own in later life (Statistics Canada 2011), and that RH is a preferred location for persons living on their own and seeking on-site services such as meals or housekeeping. Age is also influenced by the absence of younger persons in RH, compared to PH. LTCH residents are more similar in age to RH residents, if somewhat younger. About 17% of persons in the RH cohort are married, but half record a person other than their spouse as the primary informal caregiver. In these cases, it may be that the spouse does not live with them, possibly because they are in a LTCH, or they are too frail to be an active caregiver.

For many characteristics associated with care needs, we see a pattern of lowest proportions in PH, somewhat higher in RH, and very markedly higher in LTCH. These characteristics include dementia diagnosis, cognitive and physical impairment, wheelchair use, bladder incontinence, wandering and aggressive behaviour. This pattern is consistent with long-stay home care serving individuals who can be supported with scheduled visits, whereas LTCH residents require the availability of 24-hour care.

Stroke and heart failure are more similar among settings, but psychiatric diagnoses, particularly depression and anxiety, are much more common among LTCH residents.

Over 45% of RH residents have a Cognitive Performance Scale value of 2 that is approximately equivalent to 19 on the Mini-Mental State Exam and is consistent with mild to moderate dementia, suggesting much greater cognitive impairment than seen in the PH cohort. Higher levels of cognitive impairment are much rarer among both PH and RH cohorts.

The Changes in Health, End-Stage disease and Signs and Symptoms (CHESS) scale is associated with health instability and mortality. Similar proportions of persons living in PH and RH have notable health instability, whereas LTCH residents have lower levels of health instability. Another study (Hirdes et al. 2014) reported similar lower levels of health instability in LTCH compared with persons receiving home care in seven Canadian provinces and territories.

The pattern of daily pain seems to be inversely associated with significant cognitive impairment, perhaps where pain becomes more difficult to ascertain with increasing cognitive impairment. However, it is remarkable that the reported prevalence between community and LTCH-residing persons is approximately five times greater in PH and RH.

RH residents have significantly lower rates of depressive symptoms than persons in PH. This finding is surprising, especially because depressive symptoms are known to be associated with dementia (Snowden et al. 2014), something that explains the much higher rate in LTCH, but not in RH. An alternative explanation is offered by the significantly greater age in RH, where older age has been found to be protective of depressive symptoms (Szczerbińska et al. 2012). Age-stratified versions of Tables 1 and 2 are presented in Appendix 1 (available at: http://www.longwoods.com/content/25025). This hypothesis is supported by the disappearance of significant differences in depressive symptoms between PH and RH, and lower rates observed among individuals over the age of 80 in either setting.

TABLE 1. Selected characteristics of home care patients in private homes and retirement homes, and residents of long-term care homes

	PH	RH	LTCH	p-value PH vs. RH	p-value RH vs. LTCH
N	15,115	2,830	10,939	_	-
Median days on service (at time of assessment)	280	366	549	_	_
Mean age, years	76.6	85.4	83.6	<0.0001	<0.0001
Age under 65 years, %	18.8%	4.5%	5.9%	<0.0001	0.0025
Age 85 years and older, %	33.4%	63.0%	56.1%	<0.0001	<0.0001
Female, %	62.9%	69.7%	70.9%	<0.0001	0.1745
Married, %	41.5%	17.4%	24.5%	<0.0001	<0.0001
Widowed, %	38.0%	67.4%	56.7%	<0.0001	<0.0001
Diagnoses, %	'			,	
Dementia	17.0%	30.4%	63.6%	<0.0001	<0.0001
Stroke	17.4%	20.6%	21.6%	<0.0001	0.3065
Heart failure	12.5%	15.0%	11.4%	0.0002	<0.0001
Any psychiatric diagnosis	20.3%	23.7%	39.0%	<0.0001	<0.0001
Cognitive performance scale, %	<u>'</u>				
0 (intact)	43.2%	21.8%	10.7%	<0.0001	<0.0001
I	16.2%	17.6%	9.9%		
2	28.3%	45.4%	16.2%		
3–6	12.4%	15.1%	63.2%		
Activities of daily living hierarchy, %					1
0 (independent)	52.7%	40.6%	3.0%	< 0.000 I	<0.0001
I-2	28.7%	40.3%	16.1%		
3–6	18.6%	19.1%	80.9%		
Wheelchair primary means of locomotion indoors, %	12.0%	15.1%	57.6%	<0.0001	<0.0001
Fall in last 90 days, %*	39.7%	44.2%	36.8%	< 0.0001	<0.0001
CHESS§ 2+, %	44.2%	42.9%	20.2%	0.1975	<0.0001
Daily pain, %	63.8%	53.9%	12.6%	<0.0001	<0.0001
Bladder incontinence daily, %	25.7%	37.8%	66.5%	<0.0001	<0.0001
Depression rating scale 3+, %	16.0%	13.0%	38.2%	< 0.000 I	<0.0001
Wandering, easily altered, %	1.3%	3.0%	10.7%	<0.0001	<0.0001
Wandering, not easily altered, %	0.5%	0.6%	8.4%		

	PH	RH	LTCH	p-value PH vs. RH	p-value RH vs. LTCH
Any aggressive behaviour, easily altered, %	4.5%	6.7%	20.4%	<0.0001	< 0.0001
Any aggressive behaviour, not easily altered, %	2.6%	3.4%	30.0%		
9 or more meds in last 7 days, %	55.0%	66.3%	64.8%	<0.0001	0.1466
Antipsychotics, %	9.1%	14.8%	32.0%	<0.0001	< 0.0001
Anxiolytics, %	17.4%	19.8%	14.8%	0.0027	<0.0001
Antidepressants, %	28.6%	33.7%	52.2%	<0.0001	<0.0001
Any of these 3 medications, %	40.6%	48.5%	67.4%	<0.0001	<0.0001

CHESS = changes in health, end-stage, signs and symptoms; LTCH = long-term care home; PH = private home; RH = retirement home. *In long-term care: fall in last 180 days. §Scores of 2 or more represent notable health instability.

Medications show distinctive patterns by setting. Antipsychotic prevalence follows patterns of both psychiatric diagnoses and dementia. Anxiolytic use is highest among RH residents. Antidepressants show increasing prevalence from PH to RH to LTCH.

Table 2 summarizes additional characteristics found only in the RAI-HC assessment. Patterns of caregiver relationship and co-residing with a caregiver differ greatly between PH and RH, which can be explained by differences in marital status and life stage that influence a move to RH. Nearly 60% of the PH cohort has a caregiver living with them, compared to 13% in RH. This difference, along with availability of bundled or other services by RH operators, explains the large differences in informal care time. In turn, informal care time is positively associated with caregiver distress (unable to continue, or feelings of distress, anger or depression).

The belief that the person would be better off in a living environment other than where they currently reside shows markedly higher proportions among the RH cohort, driven by cases in which the informal caregiver holds this belief but the care recipient does not, or both believe it. The type of other living environment is not known, but the difference may be partially explained by a greater proportion of the RH cohort waiting for a bed in LTCH, along with a possible sense of loss of having left their former place of residence behind. Analyses not shown indicate that persons waiting for a bed in LTCH, regardless of setting, have higher needs.

RH settings rarely note any issues with home environment concerns, compared with PHs, which is expected given institutional standards and provincial licensing and inspection. Remote alerting may be a standard component of some RH facilities, making this security feature more than twice as prevalent compared to PHs.

The proportion of persons rating their health as poor is lower in the RH cohort, on its face surprising, given the higher levels of cognitive and physical impairment. Rates of feeling lonely are fairly similar, although fewer RH residents go outside of their building regularly, something that could be related to the availability of services on-site (e.g., hair salon, chapel).

TABLE 2. Additional characteristics and services for long-stay home care patients in private homes and retirement homes

Informal caregiver co-resides, is spouse, %	35.8%	8.5%	
		0.3%	<0.0001
Informal caregiver co-resides, other than spouse, $\%$	24.0%	4.7%	
Informal caregiver, but does not co-reside, %	38.1%	84.4%	
No informal caregiver, %	2.1%	2.4%	
Mean informal care hours/week	21.3	8.3	<0.0001
Caregiver distress, %*	26.8%	12.1%	<0.0001
Better off in another living environment, %			
Client or caregiver believes	18.7%	31.1%	<0.0001
Client alone believes	2.2%	2.6%	
Caregiver alone believes	9.4%	15.2%	
Both believe	7.1%	13.3%	
Waiting for long-term care home placement, %	3.0%	8.0%	<0.0001
No environmental issues (accessibility, safety, etc.), %	72.3%	94.9%	<0.0001
Medic alert/electronic security alert, %	14.3%	34.4%	<0.0001
Poor self-rated health, %	22.6%	12.8%	<0.0001
Indicates that he/she feels lonely, %	11.0%	12.4%	0.048
No days out of house/building in a typical week, %	17.0%	25.4%	<0.0001
Exercise therapy in last 7 days, %	15.5%	20.9%	<0.0001
Received help by others (paid or informal) in last 7 days, %		1	
Meal preparation	84.7%	99.3%	<0.0001
Ordinary housework	93.3%	99.2%	<0.0001
Medication management	51.9%	84.6%	<0.0001
Received by a paid service/program in last 7 days, %			
Homemaking (any source)	20.1%	62.1%	<0.0001
Personal support (any source)	57.8%	79.6%	<0.0001
Personal support (home care through CCAC)	55.3%	70.7%	<0.0001
Nurse (any source)	25.2%	32.1%	<0.0001
Nurse (home care through CCAC)	24.4%	13.9%	<0.0001
Daily nurse monitoring	5.2%	22.2%	<0.0001

	PH	RH	p-value PH vs. RH		
Help by CCAC in 30 days after assessment					
Any PS, %	70.5%	85.7%	<0.0001		
Mean hours per week of PS (among those receiving)	5.6	4.9	<0.0001		
Mean number of visits of PS (among those receiving)	21.3	37.7	<0.0001		
Mean length of time per PS visit (among those receiving), minutes	72.1	36.4	<0.0001		
Any nursing, %	33.7%	20.3%	<0.0001		
Any physical therapy, %	26.0%	28.7%	0.0022		
Any occupational therapy, %	34.7%	26.8%	<0.0001		

CCAC = Community Care Access Centres; LTCH = long-term care home; PH = private home; PS = personal support; RH = retirement home. *Caregiver unable to continue, or expresses feelings of distress, anger or depression.

Many of the PH cohort and virtually the entire RH cohort receive regular help with meals and ordinary housework, from paid or unpaid sources. However, a more marked difference is seen for medication management where daily medication administration, normally by a registered practical nurse, may be common practice in RHs.

Formal services in the past seven-day period can be understood from CCAC service/billing records representing CCAC services only and from the RAI-HC assessment that reflects services from all sources. CCAC services do not include homemaking in either setting, and where received, it would be fee-for-service or bundled in the case of RH accommodation. Homemaking is much more commonly received among those in the RH cohort, in part because of its availability and options for bundling, but also related to those in RH not having access and support from a co-residing informal caregiver. Across all sources (CCAC and other), the proportion of persons receiving personal support or nursing is higher in RH than in PH. Of greater interest is the comparison of service patterns received from CCAC alone versus all sources. Among the PH cohort, these proportions are very close for personal support and nursing (55% from CCAC compared to 58% from any source and 24% from CCAC compared to 25% from any source, respectively). This closeness suggests that individuals living in PH rarely receive additional nursing or personal support by a source other than the CCAC. In contrast, there is a larger difference observed in these numbers for RH: personal support 71% to 80%, and nursing 14% to 32%. These differences suggest that more persons in RH, particularly for nursing, are receiving paid services not provided through the CCAC.

Among persons receiving services through the CCAC, RH residents are more likely to receive personal support. Patterns of personal support delivery show RH receiving more visits that are of shorter duration. This finding is consistent with the ability of a single personal support provider to organize care for multiple clients into more frequent but shorter visits in RH, while travel times between PHs makes this less viable. CCAC-provided nursing is less

common in the RH cohort, as is occupational therapy, the latter possibly related to fewer environmental issues. Receipt of physical therapy is slightly more common in RH.

Table 3 shows the observed and expected costs. RH shows significantly lower costs (9%) than expected, driven by significantly lower costs than expected for personal support and nursing.

TABLE 3. Thirty-day service costs

Costs in 30-day period after RAI-Home Care assessment	Private home	Retirement home
All service costs, observed	\$808.59	\$780.72
All service costs, expected§	\$794.01	\$858.53
Observed exceeds expected	\$14.58*	(\$77.81)*
Personal support cost, observed	\$488.45	\$526.28
Personal support cost, expected [§]	\$479.87	\$572.10
Observed exceeds expected	\$8.58 n.s.	(\$45.82)**
Nursing cost, observed	\$171.60	\$102.55
Nursing cost, expected [§]	\$165.42	\$135.55
Observed exceeds expected	\$6.18 n.s.	(\$33.00)**

Expected from RUG-III/home care classification, with additional co-resides with an informal caregiver split for each classification. Paired t-tests: n.s. = not significant: * significant < 0.05; ** significant < 0.000 I

Discussion

A retirement home in Ontario may have a different label elsewhere, such as an assisted living facility in the US, which creates challenges for researchers, policy makers and consumers. Even in Canada there is no standard level of governance or regulation of similar facilities. For example, while the *Retirement Homes Act* (2010) and the *Community Care and Assisted Living Act* (2004) set the health, safety and staffing requirements for licensure in Ontario and British Columbia, respectively, similar facilities in Manitoba are neither licensed nor regulated by the government. Although locally adapted models of care and housing will undoubtedly result in distinctive settings and populations, more consistent use of terminology will benefit ease of comparison across research studies and public reports.

This study shows that long-stay home care patients living in RH are a distinct population. Compared to those in PH, RH individuals tend to be older and are more likely to have greater cognitive and physical impairment, have fallen recently, experience incontinence and show aggressive or wandering behaviour. Their support network also differs. Home care patients in RH are much less likely to live with their informal caregiver and thus receive less informal help overall. In contrast, RH individuals have significantly lighter care needs compared to LTCH residents.

Caution is advised in comparing these descriptive findings and inferring their relationship (for example, falls or antipsychotic use) to quality of care provided. To make comparisons, much more sophisticated adjustment for what are clearly different levels of risk would be required.

The area served by the HNHB CCAC has an estimated 114,000 persons aged 75 and

older (Statistics Canada 2015). Of these, our analyses count 9,243 (8.1%) as LTCH residents, 9,750 (8.6%) as long-stay home care patients in PH and 2,503 (2.2%) as long-stay home care patients in RH. A small number of individuals may have been counted in both long-stay home care and LTCH. An estimated 6,100 (CMHC 2015) to 7,200 (RHRA 2015b) individuals live in HNHB RHs, suggesting that long-stay home care reaches ~40% of RH residents. Conversely, RH residents constitute about one in every six long-stay home care patients of the CCAC. The relationship between RH settings and the CCAC is a significant one.

A major finding was the higher number but shorter duration of CCAC personal support visits in RH. This finding may be related to efficiency in the organization and delivery of the care. The congregate nature of RH enables one or more workers to provide services at a single location that possibly explains some of the lower-than-expected service costs in RH. Another contributor may be the provision of some services by the RH operator as part of purchased or bundled services. The drivers and health outcomes that may be linked to this type of service pattern are compelling questions for future study.

This cross-sectional examination cannot show the transitions related to RH and long-stay home care services, for example, the proportions in RH who moved there as existing CCAC patients, those whose transition coincided with needs resulting in CCAC services, or those whose needs increased after some time in RH. It is likely that a change in social supports, for example, becoming widowed, may play a role in the decision to move to RH (Erickson et al. 2006).

Each of the three locations of care captures a range of individuals, something that is obscured by the collective treatment of these cohorts. Some degree of overlap is likely, more so between the PH and RH cohorts. Undoubtedly, there are some in LTCH who could safely reside in PH or RH, and some in PH or RH who stretch the limits of appropriate care and will soon be transitioning to a different setting. This speculation is supported by a third of RH residents and their caregivers who rated the person as better off in another living environment and where a higher proportion are waiting for long-term care placement. Person—environment theory offers a framework for exploring transitions between locations of care (Kahana et al. 2003). Central to the theory is that discrepancy between personal needs or preferences and environmental characteristics (e.g., physical help, safety) is a precursor to environmental dissatisfaction, poor well-being and chronic stress. Where a community-dwelling person is older, has functional and/or medical needs and depends on informal support, the person—environment fit is a useful construct. Decisions to relocate may be constrained by many things not measured here, including patient/family wishes, availability of options and cost.

With rents in Ontario for RH averaging \$3,236 per month (CMHC 2014), the decision to move there may be financially open only for some. Persons with mild-to-moderate dementia are residing in RH, often with low levels of informal support, suggesting that RH may serve to either postpone or avoid admission to LTCH, but only for those economically able to do so. This would be consistent with evidence that lower socioeconomic status is predictive of LTCH entry (Mustard et al. 1999).

The role of long-stay home care in retirement homes, compared with those in private residences, has not been reported before. Measures of clinical characteristics and services attempt to capture the experience of these persons requiring care; future work may extend the picture to consider unmet needs and quality of life.

Correspondence may be directed to: Jeffrey Poss; e-mail: jwposs@uwaterloo.ca.

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ONLINE EXCLUSIVE



Estimating the Cost of Cancer Care in British Columbia and Ontario: A Canadian Inter-Provincial Comparison

CLAIRE DE OLIVEIRA, REKA PATAKY, KAREN E. BREMNER, JAGADISH RANGREJ, KELVIN K.W. CHAN, WINSON Y. CHEUNG, JEFFREY S. HOCH, STUART PEACOCK AND MURRAY D. KRAHN

Abstract

Background: Costing studies are useful to measure the economic burden of cancer. Comparing costs between healthcare systems can inform evaluation, development or modification of cancer care policies.

Objectives: To estimate and compare cancer costs in British Columbia and Ontario from the payers' perspectives.

Methods: Using linked cancer registry and administrative data, and standardized costing methodology and analyses, we estimated costs for 21 cancer sites by phase of care to determine potential differences between provinces.

Results: Overall, costs were higher in Ontario. Costs were highest in the initial post-diagnosis and pre-death phases and lowest in the pre-diagnosis and continuing phases, and generally higher for brain cancer and multiple myeloma and lower for melanoma. Hospitalization was the major cost category. Costs for physician services and diagnostic tests differed the most between provinces.

Conclusions: The standardization of data and costing methodology is challenging, but it enables interprovincial and international comparative costing analyses.

Résumé

Contexte : Les études de coûts sont utiles pour mesurer le fardeau économique du cancer. La comparaison des coûts entre systèmes de santé peut éclairer l'évaluation, l'élaboration ou la modification des politiques pour les soins contre le cancer.

Objectif : Estimer et comparer les coûts pour les soins contre le cancer en Colombie-Britannique et en Ontario du point de vue des payeurs.

Méthode: Au moyen d'un registre sur le cancer et de données administratives liées, et au moyen d'analyses et d'une méthodologie des coûts normalisés, nous avons estimé le coût de 21 sièges du cancer selon les étapes de soins afin de dégager les différences entre les provinces. Résultats: Dans l'ensemble, les coûts sont plus élevés en Ontario. Les coûts étaient plus élevés pour les étapes initiales de post-diagnostic et de pré-mortalité et ils étaient plus bas pour les étapes de pré-diagnostic et de continuité, et généralement plus élevés pour le cancer du cerveau et le myélome multiple, mais moindre pour le mélanome. L'hospitalisation constitue la principale catégorie de coût. Les coûts pour les services de médecins et les tests diagnostics sont ceux qui varient le plus entre les provinces.

Conclusion : La standardisation des données et des méthodologies pour les coûts présente un défi, mais elle permet d'effectuer des analyses comparatives des coûts interprovinciales et internationales.

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Estimating the Cost of Cancer Care in British Columbia and Ontario: A Canadian Inter-Provincial Comparison

Estimation du coût des soins contre le cancer en Colombie-Britannique et en Ontario : une comparaison interprovinciale au Canada



CLAIRE DE OLIVEIRA, MA, PHD

Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre for Addiction and Mental Health Institute of Health Policy, Management and Evaluation, University of Toronto Toronto, ON

REKA PATAKY, BSc, MSc

Canadian Centre for Applied Research in Cancer Control, British Columbia Cancer Agency Vancouver, BC

KAREN E. BREMNER, BSC

University Health Network, Toronto Health Economics and Technology Assessment Collaborative Toronto, ON

JAGADISH RANGREJ, MSc, MMATH

Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre Toronto, ON

KELVIN K.W. CHAN, MD, MSc, FRCPC

Canadian Centre for Applied Research in Cancer Control, Cancer Care Ontario
Department of Medicine, University of Toronto
Sunnybrook Health Sciences Centre
Toronto, ON

WINSON Y. CHEUNG, MD, MPH, FRCPC Department of Oncology, University of Calgary Calgary AB

Claire de Oliveira et al.

JEFFREY S. HOCH, MA, PHD

Center for Healthcare Policy and Research, Public Health Sciences, University of California Davis St. Michael's Hospital Institute of Health Policy, Management and Evaluation, University of Toronto Toronto, ON

STUART PEACOCK, MSc, DPHIL

Canadian Centre for Applied Research in Cancer Control, British Columbia Cancer Agency School of Population and Public Health, University of British Columbia Faculty of Health Sciences, Simon Fraser University Vancouver, BC

MURRAY D. KRAHN, MD, MSc, FRCPC

Toronto Health Economics and Technology Assessment Collaborative
Faculty of Pharmacy and Institute of Health Policy, Management and Evaluation, University of Toronto
University Health Network
Toronto, ON

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Introduction

Cancer-related healthcare costs are rising in Canada (CIHI 2011). The most recent estimate of the total cost of cancer care in Canada is \$4.4 billion for 2008 (PHAC 2014). Given limited financial resources, funders of cancer care struggle to provide patients with the best therapies. Descriptive costing studies reflect the burden to healthcare systems and help translate the effects of health conditions into dollars. Furthermore, comparative studies between healthcare systems can inform evaluation, development or modification of policies and programs related to cancer screening, treatment and delivery of care (Lipscomb et al. 2013). For example, a study comparing resource use for end-of-life care in patients with lung cancer in Ontario and Surveillance, Epidemiology and End Results (SEER) regions in the US found that hospital and emergency room services were used more extensively among Ontario patients, while chemotherapy use was significantly higher among SEER-Medicare patients (Warren et al. 2011). Ontario palliative care was more likely to be administered in the hospital, whereas more home and hospice care was used by SEER-Medicare patients. Such findings could have important policy implications for both countries regarding current end-of-life care patterns, and may identify opportunities for changing practice patterns or programs.

Differences in healthcare delivery, costs and populations across Canada suggest that comparative interprovincial studies could improve cancer care; however, no previous work has undertaken comparative cost analyses between Canadian provinces. Thus far, work has been done in individual provinces, such as British Columbia (BC) (Pataky et al. 2016), Alberta (Fassbender et al. 2009) and Ontario (Krahn et al. 2010; Mittmann et al. 2012, 2014), examining utilization and costs for individual cancer sites and/or single phases of care. One study has estimated costs for various cancer sites in Ontario, but only for the first year after diagnosis (de Oliveira et al. 2013a).

The objectives of this study were to estimate and compare the direct costs for the 21 most common cancer sites, from diagnosis to death, in two large Canadian provinces with similar data holdings, BC and Ontario, from payers' perspectives (the respective Ministries of Health), and to examine potential differences in costs and their drivers. The resulting estimates, based on high-quality evidence, will aid decision-makers on issues, such as efficiency/system

performance and resource allocation. Despite challenges associated with harmonizing costing methodology and analyses between Canadian provinces, such standardization will enable comparisons at provincial, national and international levels.

Methods

Patients

We selected all patients diagnosed with cancer who were 19 years and older from January 1, 1997, to December 31, 2007, from each provincial cancer registry (BCCA 2010; Hall et al. 2006) based on available data. We included patients with a primary cancer assigned a single, valid International Classification of Diseases for Oncology topography code with a valid histology code (brain, female breast, cervix, colorectal, corpus uteri, esophagus, gastric, head and neck, leukemia, liver, lung, lymphoma, melanoma, multiple myeloma, ovary, pancreas, prostate, renal, testis, thyroid, urinary bladder and a category combining all other tumour sites) (Appendix 1; available at: http://www.longwoods.com/content/25024). We excluded patients with a date of cancer diagnosis that coincided with date of death, not residing in the province of diagnosis, or who did not have a valid provincial health insurance number.

Data

Data for chemotherapy and radiation therapy (RT) were obtained from the BC Cancer Agency (BCCA) and Cancer Care Ontario. Data on other health services were obtained through Population Data BC in BC, and the Institute for Clinical Evaluative Sciences (ICES) in Ontario (Table 2 in Appendix 1). These data were linked to the respective cancer registry data using patient-unique provincial health plan numbers. Population Data BC and ICES follow practices to protect the privacy and confidentiality of individuals and information. The study was approved by the BC Cancer Agency; the Institutional Review Board at Sunnybrook Health Sciences Centre, Toronto, Canada; and the University of Toronto Research Ethics Boards.

Valuing health resources

Measuring healthcare costs generally requires two components: utilization of data (i.e., quantity of resources) and unit cost data (i.e., cost of resources). This information was collected for chemotherapy, RT, in-patient hospitalizations, same-day surgery/procedures, physician services, diagnostic tests, out-patient prescription drugs and home and community care. Total cost estimates for in-patient hospitalizations and same-day surgery/procedures were obtained by multiplying the resource intensity weight (measure of resource utilization intensity) by the cost per weighted case (unit cost) (Baladi 1996; CIHI 1995; Pink and Bolley 1994; Wodchis et al. 2011). Cost estimates for other resources were available in the data or obtained from other sources (Earle et al. 1999; Wodchis et al. 2011). These costing methods follow the guidelines of the Canadian Agency for Drugs and Technologies in Health (CADTH 2006) and are based on previous cancer costing work in Ontario (de Oliveira et al. 2013a; Krahn et al. 2010). Healthcare costs included the costs of cancer care and the costs of caring for other health problems.

Harmonization

Because of privacy legislation, data were analyzed separately in each province; this limited our ability to undertake aggregate analyses. Nonetheless, we tried to define and measure all pertinent variables in the same manner. Some challenges are described below.

Date of diagnosis

The cancer registries defined diagnosis date differently. BC legally mandates the reporting of cancer (active registration); diagnosis is based on the date of cytological or histological diagnosis. Ontario has passive registration where ascertainment of diagnosis date relies on various administrative records. Date of diagnosis is the earliest date of hospital admission with a cancer diagnostic code, biopsy, visit to a cancer centre or death (if cause of death is cancer). To address this difference, the diagnosis date for BC patients diagnosed in the hospital was recoded as the date of hospital admission.

Cost of chemotherapy

In Ontario, all chemotherapy is delivered at provincial cancer centres. The provincially funded New Drug Funding Program and the Ontario Drug Benefit (ODB) Program also provide chemotherapy drugs; this required a careful survey of the data to capture chemotherapy accurately. BCCA's Provincial Systemic Therapy Program funds chemotherapy; drug costs are available from program data. Appointment records for chemotherapy delivery outside BCCA regional cancer centres were not available; hence, a mean chemotherapy delivery cost was assigned to unique patient-days from the Systemic Therapy Program dispensing records.

Cost of RT

Ontario uses the National Hospital Productivity Improvement Program codes to measure RT resource intensity, whereas BC does not; this made direct utilization comparison cumbersome. Furthermore, RT costs could not be obtained from the BC data; thus, we applied the Ontario cost per fraction estimate (Earle et al. 1999) to BC utilization data.

Cost of physician services

Canadian physicians are paid in several ways – fee-for-service, salary, capitation, alternate funding arrangements and combinations of these. The Ontario Health Insurance Plan (OHIP) claims database includes fee-for-service payments and shadow billings (that is, a way to track services provided by physicians who are not paid fee-for-service). However, the BC Medical Services Plan (MSP) data only include fee-for-service billings (BC MOH 2012b). BC oncologists are paid through alternative funding arrangements with the BCCA, so we used the BCCA appointment records and unit costs from the MSP fee schedule to assign costs to oncologist visits. We also assigned "treatment planning" costs to radiation oncologist visits, derived from the OHIP fee schedule, based on the complexity of the RT delivered.

Cost of diagnostic tests

The cost of diagnostic tests, including the professional and technical components, was obtained from the MSP and OHIP databases for BC and Ontario, respectively, with a few exceptions. For example, the costs of histology and specialized cancer-specific diagnostic tests were not included in the MSP (they are covered by other provincial budgets). We were unable to capture all costs through alternative data sources; thus, we underestimated the true cost in BC.

Cost of out-patient prescription drugs

In Canada, out-patient prescription drugs are covered under public and private insurance plans, or paid out-of-pocket. In BC, PharmaNet provides data on *all* out-patient prescription drugs, including those covered by BC PharmaCare (publicly paid plan) (BC MOH 2012c). This plan was age-based until 2002 and then became income-based (Morgan et al. 2006). In Ontario, only data on out-patient drugs paid by the publicly paid ODB program, which covers individuals aged 65 years and older and special cases (MOHLTC 2014), were available, which limited our ability to account for all drug-related costs. Thus, to ensure comparability between provinces, we included publicly paid prescription drugs in BC only. The samples of patients covered under the publicly paid plans in each province were quite similar.

Cost of home and community care

Home and community care is organized under different names in each province. In particular, in BC, complex continuing care is not defined in the same manner as in Ontario (and thus could not be compared individually), but is provided under home and community care (in Ontario, this is defined as other institution-based care for people who have long-term illnesses or disabilities typically requiring skilled, technology-based care not available at home or in long-term care facilities) (BC MOH 2012a). To overcome differences in the structure of home and community care data, and ensure the inclusion of comparable services, we aggregated all home and community care, including complex continuing care, long-term care, home nursing and home support, into one category within each province. Data on home and community care were missing for two health authorities in BC in later years of observation, so these values were imputed.

Cost of other care

Finally, few facilities in BC reported data on emergency department visits and/or other ambulatory care to the National Ambulatory Care Reporting System during the analysis period; given the availability of limited data (which would not enable an accurate comparison), we excluded this type of care from our analysis.

Estimating healthcare costs over time: phase of care approach

We used a phase-based approach (Baker et al. 1991; Brown et al. 1999; Yabroff et al. 2008) to estimate the costs incurred before and after diagnosis, and to deal with patients who

entered and exited or were censored from the study cohort at different times. All patients had a pre-diagnosis phase, defined as the three months before the date of diagnosis. This phase typically includes diagnostic testing to establish the cancer diagnosis (Christensen et al. 2012; Hornbrook et al. 2013). We divided the time between diagnosis and death into the following three phases based on clinical relevance and join point analysis (Baker et al. 1991; Kim et al. 2000; Yabroff et al. 2008): (1) initial care, which includes the primary course of therapy and any adjuvant therapy, defined as the six months after diagnosis (including date of diagnosis); (2) continuing care, which encompasses surveillance and active follow-up treatment for cancer recurrence and/or new primary cancer, with costs expressed as annual estimates; and (3) terminal care, which captures intensive services, often palliative in nature, defined as the 12 months before death. Patients who died had their time first assigned to the terminal phase; their remaining time, and all time of patients who survived, was then assigned to the initial phase and then the continuing phase (Brown et al. 1999; Yabroff et al. 2008). Patients with cancer who died of any cause during the analysis period were included.

We estimated mean costs for each cancer by phase of care and respective 95% confidence intervals. We also examined costs by resource (as defined above) for the four most common cancers (breast, colorectal, lung and prostate) for the initial and terminal phases to understand the cost drivers, and to enable detailed interprovincial comparisons of cost components. (Costs by resource for all cancers are available upon request.) Costs were adjusted to 2009 Canadian dollars (Statistics Canada 2014).

Results

Patients' characteristics

Table 1 describes patients' characteristics in Ontario (N=402,399) and BC (N=150,971). The proportions of patients by cancer site were approximately the same in both provinces, except for prostate, lung, breast, colorectal, thyroid (in line with previous findings; Thyroid Cancer Canada 2014) and lymphoma. Patients' mean age was 65 years; approximately 52% were male. Slightly more patients were in the two lower-income quintiles in BC; the opposite held for Ontario. In both provinces, 85% of patients lived in urban settings and about 1% lived in long-term care facilities at time of diagnosis.

Mean costs by phase of care

Mean total costs across phases were generally higher in Ontario than in BC, with greater variation in costs across cancers for Ontario. For most cancer sites and phases of care, confidence intervals for costs for each province did not overlap, suggesting significant differences. Nonetheless, the ranking of costs by cancer was generally the same at the tail ends of the distributions in both provinces. For the pre-diagnosis phase, costs varied from \$733 to \$3,833 in BC and \$1,016 to around \$4,660 in Ontario (Table 2, available at: http://www.longwoods.com/content/25024). In both provinces, costs were highest for brain and bladder, and lowest for renal and thyroid cancers. All patients contributed to this phase.

TABLE 1. Patients' characteristics

Characteristic	British Columbia, N (%)	Ontario, N (%)
Total	150,971	402,399
Cancer site		
Prostate	27,828 (18.4)	68,940 (17.1)
Breast	23,965 (15.9)	68,709 (17.1)
Colorectal	19,033 (12.6)	58,659 (14.6)
Lung	18,383 (12.2)	42,046 (10.4)
Melanoma	5,953 (3.9)	17,059 (4.2)
Bladder	3,561 (2.4)	12,580 (3.1)
Head and neck	4,307 (2.9)	12,462 (3.1)
Corpus uteri	4,126 (2.7)	12,352 (3.1)
Thyroid	2,058 (1.4)	11,448 (2.8)
Lymphoma	7,487 (5.0)	10,467 (2.6)
Renal	3,155 (2.1)	10,204 (2.5)
Gastric	2,757 (1.8)	8,107 (2.0)
Leukemia	3,781 (2.5)	8,052 (2.0)
Ovary	2,246 (1.5)	7,167 (1.8)
Pancreas	3,044 (2.0)	6,358 (1.6)
Brain	2,115 (1.4)	5,462 (1.4)
Cervix	1,571 (1.0)	4,819 (1.2)
Esophagus	1,667 (1.1)	4,349 (1.1)
Myeloma	1,812 (1.2)	4,315 (1.1)
Testis	1,044 (0.7)	3,054 (0.8)
Liver	1,310 (0.9)	2,640 (0.7)
Other tumours	9,768 (6.5)	23,150 (5.8)
Age at diagnosis	,	
Mean (SD)	65.0 (14.00)	63.5 (13.95)
Median (IQR)	66 (56-75)	65 (54-74)
Sex	<u>'</u>	
Female	71,599 (47.4)	196,017 (48.7)
Male	79,372 (52.6)	206,382 (51.3)

Characteristic	British Columbia, N (%)	Ontario, N (%)
Neighbourhood income quintile		
Missing	1,563 (1.0)	1,683 (0.4)
I – Low	32,199 (21.3)	75,662 (18.8)
2 – Medium–low	29,648 (19.6)	81,882 (20.3)
3 – Medium	28,877 (19.1)	79,363 (19.7)
4 – Medium-high	28,917 (19.2)	79,577 (19.8)
5 – High	29,767 (19.7)	84,232 (20.9)
Urban/rural residence		
Missing	130 (0.1)	0 (0.0)
Urban	127,934 (84.7)	342,751 (85.2)
Rural	22,907 (15.2)	59,648 (14.8)
Residence in long-term care facility	1,953 (1.3)	3,871 (1.0)

IQR = interquartile range; SD = standard deviation.

Costs increased greatly in the initial phase of care (Table 2). These varied from just over \$3,000 to \$32,376 in BC and from \$5,250 to \$43,409 in Ontario. Costs were highest for cancers with poor survival rates, such as brain, esophageal, pancreatic and gastric cancers, and lowest for those with high survival rates, such as melanoma, thyroid and prostate cancers. Approximately 82% of patients contributed to this phase.

Costs in the continuing phase varied from \$1,978 and \$2,858 to around \$16,992 and \$19,340 for BC and Ontario, respectively (Table 2). Mean total continuing care costs were highest for multiple myeloma and lowest for melanoma, thyroid, cervical and testicular cancers. Approximately 77% of patients were included in this phase.

Mean costs were highest for the terminal phase of care and varied from about \$33,632 to \$75,950 in BC and \$39,645 to \$89,544 in Ontario (Table 2). Costs were higher for brain cancer and lower for melanoma. The high costs for testicular cancer, \$75,911 and \$74,558 in BC and Ontario, respectively, were mainly driven by a small group of older males. Approximately 45% of our patient sample died before the end of our observation period and thus contributed to this phase.

Mean costs for the initial and terminal phases by resource for the four common cancers. In both the initial and terminal phases, in-patient hospitalizations represented the highest costs for all cancers (Figure 1). In the initial phase, we found small interprovincial differences in the costs for some resources, such as same day-surgery and RT. For example, lung cancer costs with same-day surgery were virtually identical in BC (\$601) and Ontario (\$635). We found large cost differences for chemotherapy, especially for prostate cancer, largely owing to the inclusion of hormone therapy under systemic therapy in BC (\$1,024 in BC versus \$18 in Ontario),

physician services and diagnostic tests. Cost estimates for physician services were systematically higher in BC than in Ontario for all cancer sites, while the opposite held for diagnostic tests.

In the terminal phase, we found small interprovincial differences in the costs for same-day surgery, RT and, in some cancers, home and community care and in-patient hospitalizations (Figure 2). For example, for same-day surgery, the cost difference between provinces was less than \$30 for any given cancer. The cost differences for out-patient prescription drugs, diagnostic tests and physician services were large. In particular, we found the same cost pattern for the latter two resources similar to that in the initial phase of care.

FIGURE 1. Mean costs (2009 Canadian dollars) for the initial phase of care by resource for the four most common cancers in BC and ON

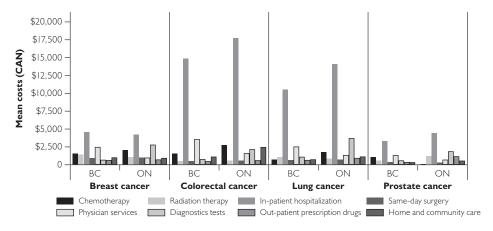
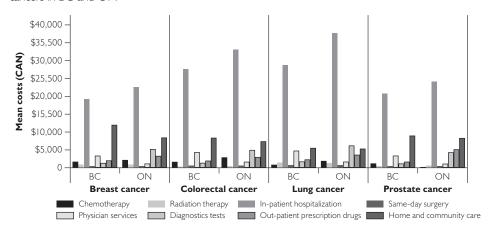


FIGURE 2. Mean costs (2009 Canadian dollars) for the terminal phase by resource for the four most common cancers in BC and ON



Discussion

In both provinces, and across cancers, costs were highest in the terminal phase, followed by the initial phase. On average, costs were highest among cancers with poor survival rates, such as brain cancer, and lowest for melanoma, with better survival. Our ranking of costs is in line with other work from

Ontario (de Oliveira et al. 2013a; Krahn et al. 2010) and the US (Yabroff et al. 2008). Previous research also found that (net) costs in the initial and terminal phases of care in the SEER-Medicare population were highest for brain cancer and lowest for melanoma (Yabroff et al. 2008).

Cancer-related treatment protocols are expected to be similar across Canada; yet, costs were generally higher in Ontario than in BC. Most cost differences are likely due to difficulties in harmonizing costing methods, missing data and the need to impute data. Some interprovincial cost differences were specific to a resource category. For most cancers, hospitalization costs were higher in Ontario owing to unit cost estimates (i.e., higher cost per weighted case values). Lower costs for diagnostic tests in BC were owing to the fact that some tests are not included in the MSP. Over our analysis period, there were many changes in Ontario with the introduction of alternative payment plans that affected the way physicians reported services rendered to patients. These may not be fully captured in the administrative data. Thus, we speculate that lower costs for physician services in Ontario may be because of an underestimation of service use through shadow billings, for example. Furthermore, differences between provinces are likely a reflection of differences in the organization and coverage of services provided, such as home and community care, and the generosity of coverage of out-patient prescription drugs under each public healthcare plan.

The findings from this study may help decision-makers on issues around health system efficiency and system performance. In particular, these results can provide insight on issues such as resource allocation (within and across cancer sites) and planning of future provincial healthcare budgets. In addition, this work may provide some understanding of system efficiency/performance, namely, on how provinces can learn from one another regarding successful cost-containment strategies and improvements around quality of care.

Undertaking cross-national or within-country costing studies can be challenging because administrative data, medical records and cancer registries were not designed for this type of research (Lipscomb et al. 2013). Differences in the organization of healthcare systems (coverage policies, payment of physicians and submission of claims) can make cost comparisons quite complex (Lipscomb et al. 2013). Even within Canada, comparison of cancer-specific care, such as chemotherapy and RT, requires care because data are not recorded in a standard manner across provinces, and cost estimates are rarely available in the data. Comparison of hospitalization costs presents fewer challenges, as standard data are reported in the same database across Canada, except for Quebec. However, despite the standard data structure, differences in coding versions (CIHI 2009) and cost per weighted case estimates over time can introduce bias between jurisdictions. This is particularly important, as hospitalizations represent a large portion of the total cost. Attention may also be required to appropriately capture costs for physician services (fee-for-service versus alternative payment plans) and diagnostic tests (physician and technician billings versus global budgets), and ensure that resource categories include the same type of care (for example, home and community care). Yet, the standardization of the costing methods among provinces will enable researchers to obtain accurate cost estimates at the national level and can aid in making international comparisons. This is one of the first

studies to undertake this type of comparative analysis; while some limitations exist, this work has provided relevant insights. Future work should focus on developing and furthering the harmonization of costing methods between provinces.

Our study used rich administrative healthcare data and included large population-based samples of adults over the age of 18 years in BC and Ontario. We included cancers, such as multiple myeloma and those typically diagnosed among younger adults, such as thyroid and testicular cancers, which have not been examined previously, particularly in studies from the US examining Medicare data (patients aged 65 years and older) (Yabroff et al. 2008). We used detailed costing methods and considered the majority of resources paid for by the BC and Ontario Ministries of Health under comprehensive universal healthcare insurance plans. Furthermore, our study is the first to estimate phase-specific costs for all major cancers in BC and Ontario.

There were some limitations. We were not able to compare costs for emergency department visits due to the lack of data in BC. Some cost estimations required making assumptions and extrapolations; in some cases, we were unable to account for all relevant costs. Although the number and type of individuals covered by the ODB and PharmaCare were quite similar, the drugs covered under the two plans may differ. Furthermore, interprovincial differences in chemotherapy and out-patient drug costs suggest hormone therapy (for example, for prostate cancer) may have been classified differently. We could not present costs by cancer stage because stage information was not available in either province for our analysis period. Previous research has found that costs are higher at advanced stages in which survival is generally short (Yabroff et al. 2008). We did not examine the relative importance of age on average costs. Other work suggests that costs of cancer care are higher for younger patients (de Oliveira et al. 2013b). We estimated all healthcare costs incurred by patients, not net cancer costs (i.e., the difference between patients with and without cancer). Future work will use a matched case—control methodology (Brown et al. 1995, 2002; Taplin et al. 1995) to estimate net costs across phases of care.

Conclusion

Cancer exerts an enormous health and economic burden, which will likely rise in coming decades in Canada. Our findings highlight important cost differences between phases of care, cancer sites and resources within and between provinces. Comparative cost studies present many challenges but enable analyses within and between countries, and can produce comparable estimates for research, policy and decision-making.

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Correspondence may be directed to: Claire de Oliveira, Independent Scientist/Health Economist, Centre for Addiction and Mental Health, Institute for Mental Health Policy Research, 33 Russell Street, Room T414, Toronto, ON M5S 2S1; tel.: 416-535-8501 ext. 36098; e-mail: claire.deoliveira@camh.ca.

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