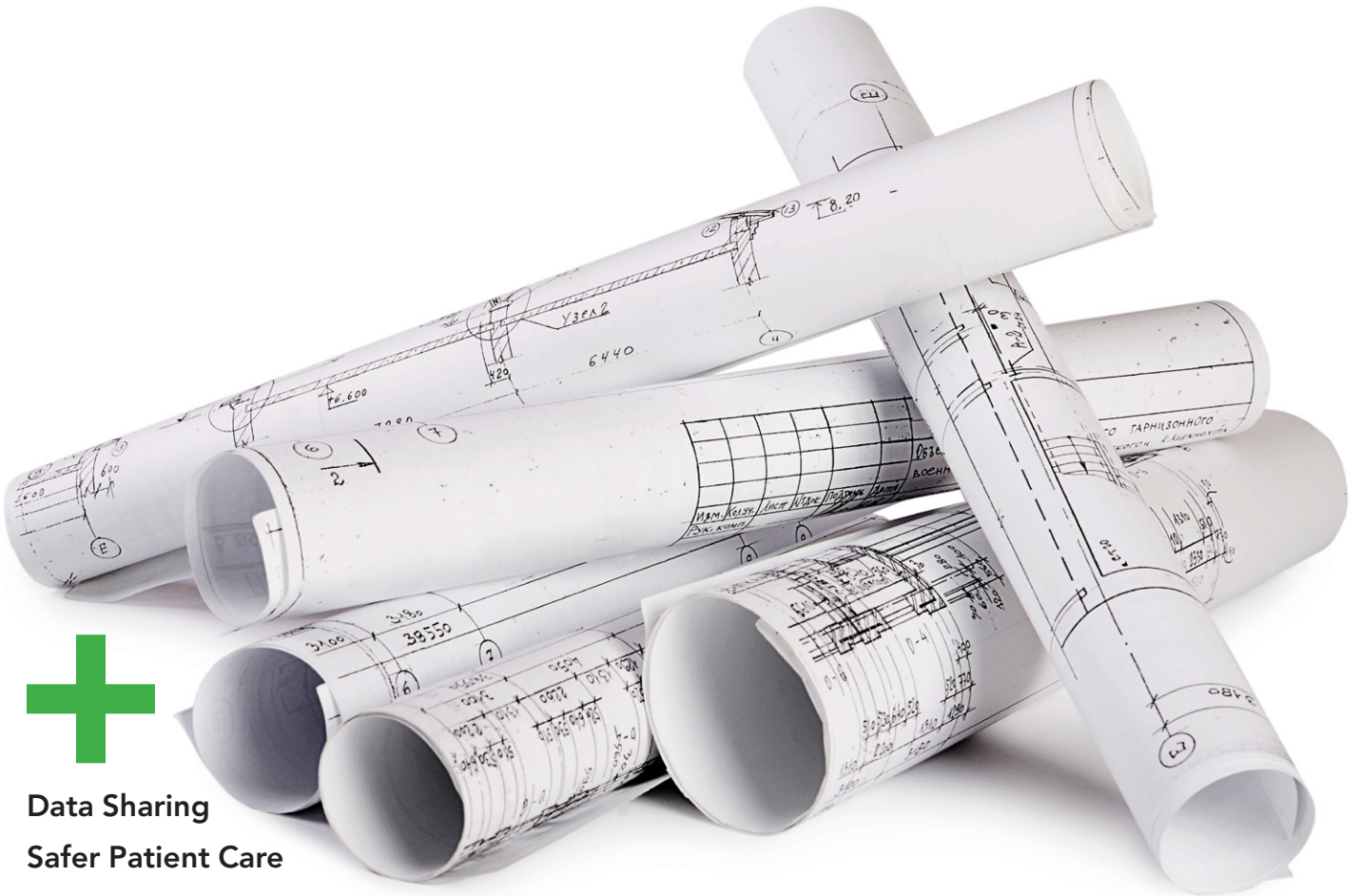
Vol.19 No.4 2017 • www.healthcarequarterly.com

Healthcare Quarterly

IMPROVING SYSTEM PERFORMANCE

PRINCIPLES FOR HEALTH SYSTEM CAPACITY PLANNING: INSIGHTS FOR HEALTHCARE LEADERS

p. 17



Data Sharing

Safer Patient Care

Innovations In Primary Care

Strategies For Challenging Behaviours

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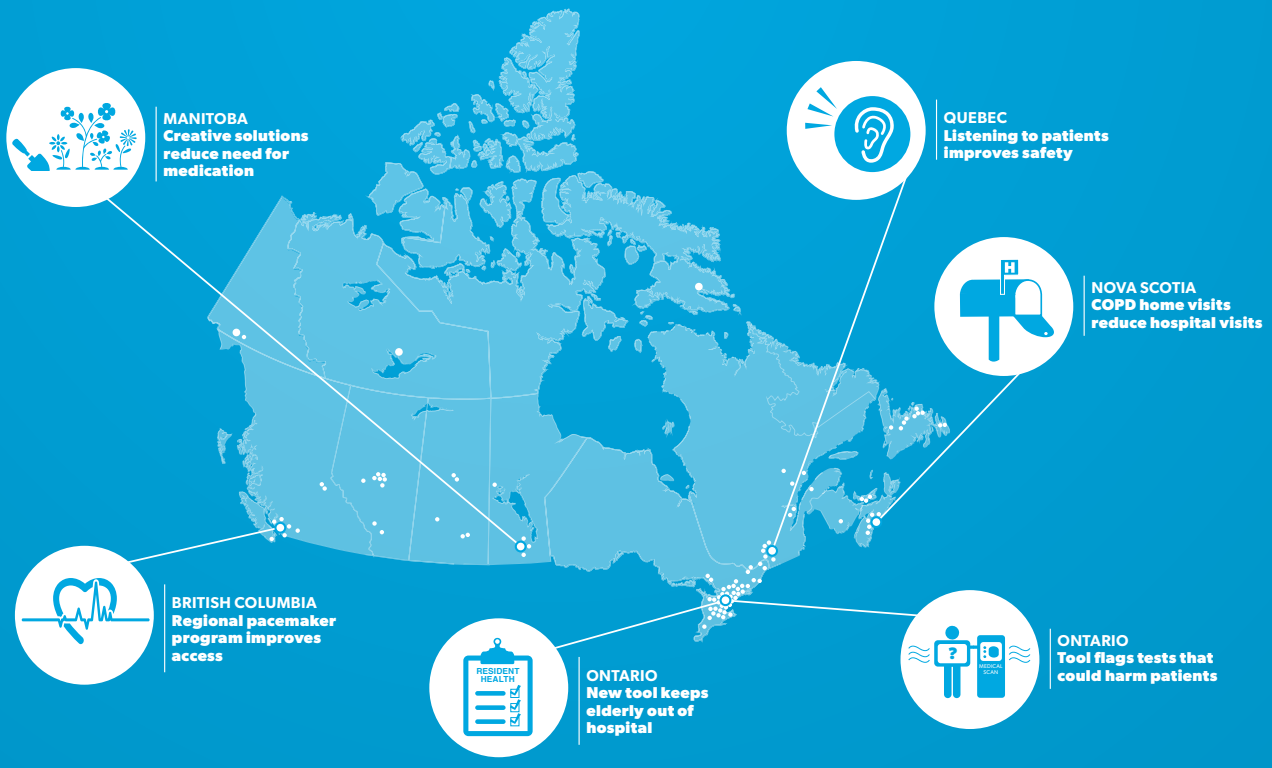

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As strange and unsettling as 2016 has been (Brexit, the U.S. federal election, scary-clown epidemic), there is solace in drawing the year to a close with another issue of *Healthcare Quarterly* brimming with articles on topics of vital concern to contemporary healthcare.

Improving System Performance

Long-term capacity planning: one would be hard pressed to find a system administrator who does not believe in it. But what of the *process* of such planning? James Shaw and his colleagues begin to unlock that mystery by discussing the planning principles that arose out of a symposium with leaders of Ontario's local health integration networks. The authors report that the resulting principles, such as the development of a long-term vision and continuous stakeholder engagement, are already being "built into" the province's health ministry's planning activities (e.g., a provincial dementia strategy).

Training the system-performance lens onto hospitals specifically, Les Vertesi considers the measurement of performance and quality in light of institutions' varying operating environments. Mining CIHI's Discharge Abstract Database, Vertesi queries reliance on the average length of stay (ALOS) marker, as well as how inpatient days associated with transfers-in are factored. His analysis clarifies the importance of both planned and unplanned patient ratios for understanding hospitals' performance and ability to meet quality improvement and financial targets.

Data Sharing

Electronic health records (EHRs) hold massive potential for care coordination. Josephine McMurray and her co-authors tackle the matter of EHR interoperability – in other words, how multiple care providers in "expanded circles of care" can access, exchange, interpret and act on the data in this aptly characterized "technical Tower of Babel." Discussing the results of a workshop on the topic held in the Waterloo–Wellington health network, the authors illuminate participants' calls for more research on several topics, including regulatory and legislative environments, as well as standardization.

Safer Patient Care

Medical device reprocessing (MDR) is a given, but improving practices requires knowing more about how to evaluate it. In their article, Bailey Lorv et al. relate the creation and impact of an MDR quality management framework at Trillium Health Partners. Their 10 key performance indicators include patient safety incidents, delayed surgical cases and decontamination time. The authors see their framework – "tool for continuous and purposeful evaluation of MDR" – as a basis on which they and others can now build.

Much in the patient-safety domain depends – as McMurray et al. and Lorv et al. show – not just on data gathering, but purposeful data use. Undertaking their study at Toronto's University Health Network, Hibak Mahamed et al. examined the use of incident reporting systems (IRSs) to improve patient safety. Their scrutiny of an IRS for *Clostridium difficile* infection identified four main hurdles: limited data input, lack of review-committee diversity, lack of measurable action items and variable feedback wait time. While brief, the authors' comments on how to address these concerns are enlightening.

Innovations in Primary Care

Our next article could profitably be read alongside Vertesi's observations on the escalation of unplanned hospital admissions. Lynette Krebs and her team dissect low-acuity emergency department (ED) presentations to understand the link between having a primary care physician (PCP) and ED use – and how to "divert" non-urgent patients. One of Krebs et al.'s most noteworthy findings is that while a sizeable majority (74.4%) of ED patients had a PCP, only 18.6% of them saw their PCP before presenting at the ED. It is clearly not enough to link patients to PCPs in order to steer them away from the ED; other strategies, such as increasing patients' "attachment" to their physicians, are needed.

Diagnosis and management of dementia at the primary-care level often falls short of goals and ideals. Ontario's emerging primary care collaborative memory clinics (PCCMCs), the subject of Linda Lee and her co-authors' paper, is an innovative response to that problem. Pivoting on the principle of person-centred care, this physician-led clinic type "represents an ideal chronic disease management approach in that it triages patients based on need." The impressive results include increased capacity, reduced wait times, efficient use of resources and greater patient satisfaction.

Next up, P. Tony Singh considers the impact of advanced access scheduling on a unique population: members of the Canadian Armed Forces (CAF). Aimed at improving continuity, access and patient satisfaction, the six-month pilot project he describes took place at a CAF clinic in Ottawa. Singh is forthright about the major turbulence the project encountered (in some cases created); however, once the data were analyzed, six "crucial lessons" – that surely could be extrapolated to other patient cohorts – emerged, involving planning around human resources, rostering and technology-enhanced scheduling.

Strategies for Challenging Behaviours

Caring for seniors with dementia who exhibit challenging behaviours is the goal of the Behavioural Supports Ontario (BSO) program. Of the BSO's three models of care, however, which is the most effective? Michelle Grouchy et al. attempt to find the answer. Focusing on individuals in long-term care facilities, the authors discovered that in-home BSO teams significantly "outperform" mobile teams. Their superiority is felt in critical areas such as care planning and provision, resident outcomes and lowering rates of restraint and inappropriate antipsychotic use.

From the behavioural challenges of a largely elderly population, we conclude with those affecting younger people. In 2011, *Healthcare Quarterly* published an article (http://www.longwoods.com/content/22584) documenting the behavioural gains brought about by workshops for staff and families to address the behavioural needs of children with autism. In this issue of the journal, one of that paper's authors – Shawn Reynolds – and Brea Chouinard return to the topic to assess durability. Their principal finding is that parents continued to use the skills they had learned. Parents also underscored the importance of having an impartial facilitator and capacity building. Despite the very small sample size on which Reynolds and Chouinard drew, their conclusions point the way to future research aimed at addressing the behavioural complexities of this challenging population.

– The Editors

In this issue *Vol.19 No.4 2017*

Healthcare Quarterly

Volume 19 Number 4 • 2017

How To Reach The Editors And Publisher
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ISSN No. 1710-2774 eISSN No. 1929-6347
Publications Mail Agreement No. 40069375

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Pediatric Insulin Pump Therapy: Reflecting on the First 10 Years of a Universal Funding Program in Ontario

Rayzel Shulman, Fiona A. Miller, Thérèse A. Stukel, Denis Daneman and Astrid Guttmann

Abstract

We evaluated the universal funding program for pediatric insulin pumps in Ontario by examining the dynamics underlying patterns of pump use and adverse events using population-based health administrative data available at the Institute for Clinical Evaluative Sciences (ICES), supplemented by other data. We found that (1) pump use has increased steadily since 2006 with variation across centres and disparity in use by socioeconomic status; (2) pump discontinuation is uncommon; (3) physicians value pump therapy in numerous ways that provide important insights into patterns of uptake; and (4) the safety profile of pump therapy is, in general, very good; however, individuals of lower socioeconomic status are at an increased risk of acute diabetes complications, most frequently diabetic ketoacidosis. This comprehensive mixed-methods evaluation reveals the need to understand and intervene to reduce social disparities in the use and adverse outcomes of technologies used for diabetes management.

The Issue

Technologies used for managing chronic diseases such as diabetes come with high expectations, making them more likely to be adopted; however, they often bring marginal benefits at increased costs (Anderson et al. 2008; Berwick 2003; Canadian Institute for Health Information 2011; James Lind Alliance 2016). Insulin pumps for children with type 1 diabetes exemplify such challenges, with these being broadly adopted in countries with middle-to-high incidences of type 1 diabetes despite equivocal evidence about comparative long-term effectiveness with insulin injection therapy (Nuboer et al. 2006; Phillip et al. 2007; Sulmont et al. 2011). Many longitudinal studies show an improvement in the level of hemoglobin A1c (HbA1c) – a measure of glycemic control – within the first year of starting pump therapy; however, it appears that the level of HbA1c reverts back towards the baseline thereafter (Shulman et al. 2012). In addition, the impact of pump therapy on the rate of hypoglycemia is mixed, although the rate of diabetic ketoacidosis (DKA), a preventable and life-threatening complication of type 1 diabetes, does not appear to be increased in patients using pump therapy (Shulman et al. 2012). This raises complex questions about the valuation, real-world effectiveness and adequate implementation of a new technology – a challenge for health services delivery and policy development.

The Diabetes Control and Complications Trial showed that long-term complications of diabetes could be reduced by providing intensive insulin therapy through multiple daily injections or an insulin pump (Diabetes Control and Complications Trial Research Group 1994; Nathan et al. 2005). Pump therapy allows for increased flexibility in daily life and eliminates the need for multiple daily injections; therefore, its use has increased markedly in pediatric contexts (Hofer et al. 2010; Olsen et al. 2015; Shulman et al. 2012). Accordingly, in 2006, the Ontario Ministry of Health and Long-Term Care (MOHLTC) announced funding for insulin pumps and related supplies for all children with type 1 diabetes up to the age of 19 years; this facility was provided because of public and professional interest in the pump's potential for optimizing glucose control and to address the two-tiered funding situation that had developed, despite equivocal evidence about long-term comparative effectiveness.

As part of a comprehensive mixed-methods evaluation of this policy decision, we evaluated the dynamics underlying patterns of pump use and adverse events in the following ways: (1) the value physicians place on pump therapy to understand patterns of pump use and inform decisions about funding technology for children with diabetes (Shulman et al. 2016a); (2) the characteristics and resources of pediatric diabetes centres (Shulman et al. 2016b); (3) the manner in which the program is used by centres and by individuals (Shulman et al. 2016c); and (4) the safety profile of pump therapy (Shulman et al. 2016d).

Pump Use in Children and Youth: The Ontario Context

The Network of Ontario Pediatric Diabetes Programs, under the mandate of the Northern Diabetes Health Network, was established in 2001 to improve access to specialized diabetes

care for all children in Ontario. In 2013, this mandate was assumed by the Ontario Paediatric Diabetes Network (OPDN) and coordinated by the Provincial Council for Maternal and Child Health, a program of the MOHLTC. The OPDN currently comprises 35 centres, including 30 community and 5 tertiary centres, each employing physicians, nurses, dietitians and social workers with training in diabetes care.

Our evaluation capitalizes on population-based health administrative data from the MOHLTC available for research purposes at ICES, and uses quantitative data on centre practices and qualitative data on provider expectations to illuminate core findings from the administrative data analysis. This mixed-methods approach may be useful to inform funding decisions and implementation processes for technologies used for treatment of diabetes more generally.

Pump Use

Pump use has increased in Ontario since 2006; by 2012, 38% of all children with type 1 diabetes were using pumps (Figure 1). Pump discontinuation is uncommon, suggesting that early enthusiasm does not wane and/or result in higher downstream rates of discontinuation. However, we observed a large variation in pump use across centres (Figure 2) (Shulman et al. 2016c). We were unable to identify any centre-level characteristics, such as centre type (tertiary, large or small community), that were associated with uptake. However, our qualitative study about how physicians value pump therapy provides several important insights into factors that may influence uptake. Enthusiasm may stem, in part, from the idea that novel technologies are inherently appealing to patients and their families; from physicians' own enthusiasm for pump therapy because of what it might achieve in the future; for the social benefits it confers for patients; and as a tool to motivate patients to improve their diabetes self-management (Shulman et al. 2016a).

FIGURE 1.
Pump use following the introduction of a universal funding program in Ontario in 2006

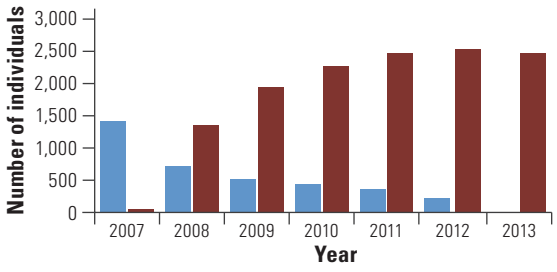
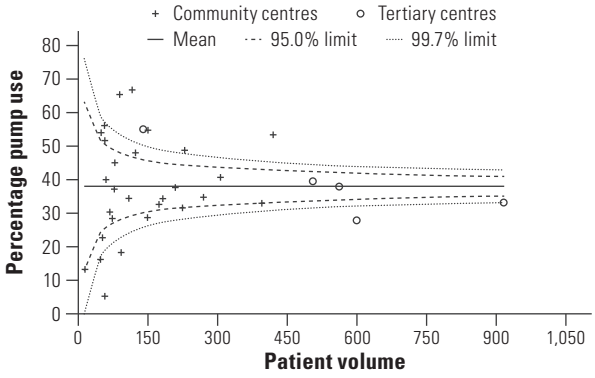


FIGURE 2.
Funnel plot showing the percentage pump use by centre volume of patients with diabetes in Ontario in 2012



Disparity in pump use

Although we report an increase in pump use, we also observed disparity in use by socioeconomic status; pump users were more likely than non-pump users with diabetes to be in the highest-income quintile (29.6 vs. 19.1%, $p < 0.0001$) (Shulman et al. 2016c). This may relate, in part, to the cost of pump therapy, as the additional cost of supplies (25% not covered by the government) may be a financial barrier for low-income families. Further, the findings of our qualitative study suggest that the degree of available ancillary support for diabetes management (family, school) influences physicians' predisposition to recommend pump therapy (Shulman et al. 2016a).

Safety profile

Increased use of the pump enabled by government funding may lead to widespread benefit; however, it may also result in inappropriate use, causing harm. Yet, despite the rapid increase in pediatric pump use in Ontario, the rate of DKA (5.28/100 person-years) (Shulman et al. 2016d) is similar to that reported in other population-based studies of pediatric pump users (6.26/100 person-years) (Danne et al. 2008). Although no causal association can be inferred, the DKA rate among those beginning pump therapy was not higher in the period after initiation compared with that two years before. Also reassuring is that the risk of DKA or death in the first two years of pump use was exceedingly low, suggesting that initial pump use education and implementation of the funding program in Ontario were effective.

Although the safety profile of pump therapy in this context is good, compared with individuals in the least deprived quintile, the risk of DKA or death for those in the most deprived quintile was significantly higher (hazard ratio = 1.58, 95% confidence interval [CI] = 1.05–2.38) as was the rate of diabetes-related acute care use (risk ratio = 1.60, 95% CI = 1.27–2.00).

Although we could not explore why this is the case, these children may have less robust family or school supports – key factors that physicians view as important to achieving favourable outcomes (Shulman et al. 2016a). Provision of 24-h support was not associated with these outcomes. Higher glycated hemoglobin, history of DKA, older age and higher nursing patient load were associated with a higher risk of DKA or death and diabetes-related admissions and emergency department visits. This suggests the need for targeted interventions and additional support for groups of youth with type 1 diabetes who are at the highest risk for adverse events.

Implications

This comprehensive evaluation reveals the need to understand and intervene to reduce social disparities in use and adverse outcomes of technologies used for treatment of diabetes. As new programs and policies for pediatric diabetes care are developed, we should anticipate how potential benefits and harms may be distributed across social gradients and aim to reduce the existing disparities. It is important to evaluate new programs and policies to determine their overall impact and the distribution of the impact across social gradients. These new technologies should be universally available to prevent creation of a two-tier treatment approach based on socioeconomic status. HQ

Acknowledgements

Rayzel Shulman received salary support from the Canadian Child Health Clinician Scientist Program for her PhD. Denis Daneman is the R.S. McLaughlin Foundation Chair in Paediatrics. Astrid Guttmann receives salary support from a Canadian Institute for Health Research Applied Chair in Reproductive and Child Health Services and Policy Research.

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A Snapshot of Advance Directives in Long-Term Care: How Often Is "Do Not" Done?

Sheril Perry and Christina Lawand

Abstract

Advance directives allow individuals and their families or legal guardians to communicate preferences for interventions and treatments in the event that these individuals are no longer able to make decisions for themselves. This study examines how often do-not-hospitalize (DNH) and do-not-resuscitate (DNR) directives were recorded for residents in 982 reporting Canadian long-term care facilities between 2009–2010 and 2011–2012 and, to the extent possible, whether these directives were followed in acute care settings. It found that three-quarters of long-term care residents had a directive not to resuscitate and that these directives appeared to be well followed across the continuum; only 1 in 2,500 residents with a DNR received resuscitation in hospital. Fewer residents – 1 in 5 – had a directive not to hospitalize, and about 1 in 14 (7%) of these residents was admitted to hospital. The data are unable to determine whether patients or their families provided consent for these hospitalizations at the time of a decision to transfer. Close to half of hospitalizations among residents with a DNH directive were from potentially preventable causes, such as injuries or infections. Although hospital transfers from long-term care decreased over the study period, hospitalizations could be further reduced with the enhancement of palliative care services in long-term care settings.

About the data

Data used for this study are based on the assessments of almost 200,000 long-term care residents in four Canadian provinces and one territory. The data were submitted by participating long-term care facilities to the Continuing Care Reporting System (CCRS) – a data holding of the Canadian Institute for Health Information (CIHI) – between 2009–2010 and 2011–2012. Information for subsequent years is unavailable, as advance directive data elements were modified as of 2012–2013.

To follow the trajectory of long-term care residents in acute care, CCRS records were linked to those of CIHI's acute care Discharge Abstract Database. Coverage for this study is limited to the following jurisdictions:

- Manitoba and Yukon: do-not-resuscitate (DNR) reporting only.
- Nova Scotia, Ontario and British Columbia: both do-not-hospitalize (DNH) and DNR reporting.

Ontario and Yukon coverage includes most long-term care facilities that receive public funding, whereas data are limited to participating facilities in other provinces, resulting in predominantly Ontario-based reporting.

How often is a DNR directive followed?

More than three-quarters of long-term care residents in the study had a directive to not resuscitate (Figure 1). A DNR directive states that no cardiopulmonary resuscitation or other life-saving methods are to be used in the event of cardiac arrest or respiratory failure. Over the study period, less than 0.05% of residents with a DNR directive – or about 1 in 2,500 – received resuscitation in an acute care hospital after being transferred there for treatment. This suggests that DNR orders are well communicated between care facilities and well understood by care providers.

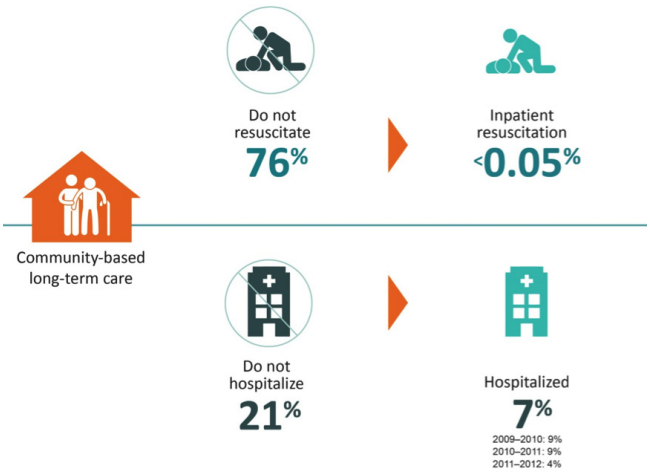
How often is a DNH directive followed?

About 1 in 5 long-term care residents (21%) had a documented DNH directive. This type of directive states that the resident is not to be hospitalized even if he or she acquires a medical condition requiring hospital care. It is important to note that a DNH directive comes into effect only if the resident is unable to provide informed consent at the time of a decision to hospitalize or if a family member or legal guardian is unavailable to consult about treatment options.

Almost 6,000 (N = 5,783) hospitalizations occurred among residents with a recorded DNH directive over the 3-year study period. This represents almost 7% (1 in 14) of long-term care residents with a DNH directive. More than half of these cases (N = 3,331) involved residents who were moderately to severely cognitively impaired (or who likely could not make decisions for themselves).

Residents with a DNH directive were about half as likely to be hospitalized as those without one. The hospitalization rate of residents without a DNH directive was 15%. However, hospitalization for both groups of residents declined by about half between 2009–2010 and 2011–2012. This coincides with a push in Ontario's long-term care sector to reduce avoidable hospitalizations.

FIGURE 1.
Percentage of long-term care residents with a DNR or DNH directive and, of those, percentage of residents for whom resuscitation or hospitalization occurred



Why are residents with a DNH directive hospitalized?

The top 10 causes of hospital stays were responsible for nearly 60% of all hospital admissions, including:

- infections such as pneumonia, urinary tract infections and sepsis (infection of the bloodstream) – 21%;
- trauma or injury, such as a broken hip sustained in a fall – 20%;
- exacerbation of chronic conditions such as heart failure and chronic obstructive pulmonary disease – 9%; and
- end-of-life or palliative care – 6%.

Nearly half (47%) of the hospitalizations for residents with a DNH directive were potentially avoidable (Walker et al. 2009). As outlined in Table 1, the proportion of hospital stays for injuries was about twice as high (19%) for residents with a DNH directive as for those without one (10%). The proportion of palliative care hospitalizations was slightly higher for residents with a DNH directive, and overall it tripled for both groups of residents over the 3-year study period – increasing from 3% of total hospitalizations among long-term care residents in 2009–2010 to 9% in 2011–2012.

TABLE 1.
Comparison of hospitalization cases among residents with and without a DNH directive

	Residents with a DNH directive	Residents without a DNH directive
Total hospitalization episodes	5,783	44,114
Potentially avoidable hospitalizations*, *n* (%)	2,676 (46.3)	19,946 (45.2)
Injury case, *n* (%)	1,110 (19.2)	4,672 (10.6)
Palliative care§, *n* (%)	350 (6.1)	2,084 (4.7)
Death in hospital, *n* (%)	1,230 (21.3)	9,570 (21.7)

*See Walker et al. (2009).

§CMG code 810 – Palliative Care.

Categories are not mutually exclusive, and a single stay may fit into several categories.

Source: Discharge Abstract Database, 2009–2010 to 2011–2012, Canadian Institute for Health Information.

Both groups of hospitalized residents were equally likely to die in hospital, with about 1 in 5 not surviving his or her hospital stay.

Who is most likely to be hospitalized with a DNH directive?

The factors that were associated with transfers to acute care hospitals for residents with a DNH directive were similar to those of other studies on the hospital transfer of long-term care residents (Biola et al. 2010). Individuals who were relatively young (younger than 90), more independent and more stable in health were more likely to be admitted to hospital.

Conclusions and discussion

There is an opportunity to raise awareness with residents and families about advance care planning. Research shows that

a decision to transfer a resident to hospital despite the person's advance wishes is often made by family members (Biola et al. 2010). The stress of a hospital transfer and potential risk of infection can often outweigh the perceived benefits of treatment (Konetzka et al. 2008; Ouslander and Maslow 2012). Sometimes, serious infections such as pneumonia can be treated in long-term care facilities, often with better outcomes for these patients (Fried et al. 1997; Thompson et al. 1997). That being said, it is up to residents and their families to decide on the best course of action.

Although a lot of progress has been made, potentially avoidable hospitalizations can be further reduced in long-term care settings. Initiatives to improve the quality of long-term care and avoid unnecessary hospitalizations, such as Ontario's Residents First initiative (Health Quality Ontario, n.d.), appear to be bearing fruit; hospitalizations among all long-term care residents dropped significantly – by about 50% – over the 3 years of this study period.

Results also suggest that palliative care services can be enhanced in long-term care. Palliative care is one of the few areas that did not experience a decline in hospital transfers over the study period. Although many jurisdictions in Canada have initiatives under way to improve end-of-life services out of hospital, few nursing homes have formal palliative care programs (Quality Hospice Palliative Care Coalition of Ontario 2010; Williams et al. 2010).

These findings and others, as well as more information on data and methods, are described in detail in a recent CIHI publication, *A snapshot of advance directives in long-term care: How often is do not done?* This report is available free of charge at: <https://secure.cihi.ca/free_products/advance_directive_often_do_not_done_en.pdf>. HQ

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Open Innovation Prizes and Challenges: Learnings from the ImagineNation Series

Jennifer Zelmer, Fraser Ratchford and Justin Noble

Introduction

Innovation – defined by the Council of Canadian Academies (2009) as "new or better ways of doing valued things" – is central to the future of healthcare. Although it is relatively easy to identify goals that matter to citizens, clinicians and health systems, the best means to achieve these goals at scale is often less clear, and there may be significant lags between new discoveries or identification of best practices and their widespread adoption (Advisory Panel on Healthcare Innovation 2015; World Health Organization 2005).

The public interest in closing these gaps is high, but accelerating the process is not straightforward. Recent Canadian reviews point to a variety of potential solutions. For example, the Ontario Health Innovation Council advocated for a dedicated innovation office, brokers to connect innovators with resources, investment in local technologies, changes to procurement, creation of incentives and removal of barriers and optimization of pathways to adoption and diffusion of innovations (Ontario Health Innovation Council 2014). Likewise, the Advisory Panel on Healthcare Innovation (2015) made a series of proposals for accelerating progress on a pan-Canadian basis. The findings of these and other reviews strongly suggest the need for innovative thinking and approaches, not just with respect to healthcare delivery and policy, but also with regards to policy and programs that foster innovation in the health sector.

In this context, Canada Health Infoway launched the *ImagineNation Challenges* in 2011. Like the prize that Charles Lindbergh claimed for the first non-stop flight between New York and Paris or the space industry's XPRIZE, these challenges are based on an open innovation model. Unlike granting or procurement processes that pick who will be supported and may specify the means that will be used, this approach specifies the "what," not the "who" or the "how." Challenge hosts identify a desired outcome and reward innovators who best meet it. In doing so, they can lower participation barriers and engage a broader range of innovators and change agents.

This paper provides an overview of the *ImagineNation Challenges* experience to date, as well as key lessons learned about what does and does not work to foster participation and progress towards identified goals. We also offer some suggested starting points for those interested in using this approach in other contexts.

ImagineNation Challenges: An Overview

The *ImagineNation Challenges* seek to inspire, provoke and promote innovation in health and healthcare to improve the quality of care and the patient experience for Canadians by leveraging widely distributed knowledge, skills and resources to accelerate value from emerging digital solutions. Desired outcomes – such as growth in the use of e-visits or improvement in quality of care through clinical information exchange – are identified up front. Individuals or teams register to participate via a website (<http://www.imaginenationchallenge.ca/>) and then track their outcomes, share their experiences and receive support through a community of innovators. Teams that are most successful in delivering on the desired outcomes receive recognition, monetary awards and other prizes.

Since 2011, there have been 10 *ImagineNation Challenges* (Table 1), plus several student/faculty and solution design challenges undertaken separately. They have involved 435 team or individual submissions, 211 volunteer judges, 18 supporting organizations and $2.3m in awards. Collectively, teams' digital health solutions were used almost 75 million times in the course of the challenges, 3.5 million times for consumer-focused solutions and 71.4 million times for solutions designed to be used by clinical teams (Table 1).

Take the 2012–2013 Outcomes Challenge as an example. A diverse range of teams – from one focused on online access to lab results across British Columbia to another expanding systematic reporting of cancer pathology results in Ontario – took part. In some cases, individual organizations participated; in others, teams brought together multiple healthcare providers. For instance, first place in the e-booking category went to a group of regulated health professionals in 14 clinics in British Columbia, including registered massage therapists, chiropractors and their office staff. Second place went to a group of 49 clinics in Quebec. Their focus was to address challenges commonly encountered by patients who need to book last-minute appointments with physicians and by healthcare practitioners and administrators who deal with last-minute appointment cancellations.

TABLE 1.
Evolution of the *ImagineNation Challenges*

Challenge	Purpose	Outcome
Ideas	Asked Canadians for bold new ideas to transform healthcare using digital health – how would they enhance access to services, improve quality of care delivery or make the system more efficient?	More than 1,000 people participated over the 13-week challenge period: submitting ideas, serving as judges or voting for their favourite suggestions. Videos of award recipients (<https://www.youtube.com/watch?v=74Cg_74czlA>) showcase the ideas that were brought forward, some of which participants or others went on to develop further.
Outcomes	Challenged Canadian healthcare professionals to accelerate the use and growth of digital health solutions in their practices or organizations in four areas: e-booking, patient access to health information, clinical synoptic reporting and medication reconciliation.	43 teams from across Canada with a range of solutions took part, from online access to lab test results in BC to tools to systematically report cancer pathology results in Ontario. Together, they logged more than three million uses of their solutions (mostly by individual consumers), along with an almost 95% increase in users.
Patient, career and business impact	Gathered information on how public investments in digital health have made an impact for patients, on the careers of health professionals, and in helping organizations grow, evolve or better meet the needs of their clients.	Elicited over 100 patient (<http://imaginenationchallenge.ca/from-burnaby-to-halifax-canadians-share-stories-about-health-its-impact-2/>), career (<http://imaginenationchallenge.ca/digital-health-investments-benefiting-business-careers-2/>) and business (<http://imaginenationchallenge.ca/digital-health-investments-benefiting-business-careers-2/>) success stories regarding the use of digital health, which were shared broadly.
Accelerate	Encouraged clinical innovation and consumer health demonstration projects that had received Infoway investment through other programs and successfully met agreed milestones to exceed the original targets and continue to engage new users for their digital health solution.	Award recipients, the Ottawa Hospital, the Nova Scotia Department of Health and Health PEI, all recorded double-digit growth in the use of their solutions over a six-month period.
Public health social media	Sought to inspire public health organizations in Canada to use social media initiatives in creative and innovative ways to improve public health.	29 teams participated in a quest to harness the power of social media to address public health issues and concerns. Together, they achieved over 30 million social media impressions during the course of the challenge.
e-Connect	Challenged healthcare providers to connect digitally with their patients and each other through e-visits, e-requests for prescription renewals and refills, e-requests for services and e-reports on services. The focus was on improving both use and quality of the solutions.	41 teams participated and together they reached more than 71 million uses of their digital health solutions (mostly related to solutions for clinical teams).
Data impact I and II	Invited teams to answer important health and healthcare questions with existing data.	51 submissions from 34 teams furnished new, usable evidence for policy makers, significantly compressing the time it usually takes to undertake such research.

Begun as an experiment, the ImagineNation Challenge series is now a core component of Infoway's innovation program. The challenges have engaged stakeholders at a grassroots level in advancing health and healthcare using digital solutions, including individual Canadians, students, healthcare providers and companies of all sizes. In addition to identifying early adopters and accelerating their progress towards specific outcomes, the goal is to foster a community of innovators for peer support and knowledge exchange, during and beyond the challenge timeframe. One of the ways that this is accomplished is to involve a wide range of national supporting organizations with mutual goals such as safety, quality and improved patient experience. They help to shape challenge questions, recruit participants and judges, share information about challenge teams and outcomes and contribute in other ways. In addition, challenges offer a range of opportunities, such as:

- identifying, celebrating and accelerating early adopters of digital solutions that have strong patient/clinical benefits through a novel open innovation approach;
- fostering a community of innovators for peer support and knowledge exchange, during and beyond the challenge timeframe;
- informing broad-based adoption and investments through case studies, adoption metrics/benchmarks, benefits evaluation and peer support; and
- cost-effective, lower-risk, outcome-oriented investments that encourage participation from a wide range of stakeholders.

Although much of the focus is on the goals of each particular challenge, the intent is also to achieve broader impact through leveraging challenge outcomes. For instance, challenges have

strengthened Infoway's relationships with supporting organizations and with innovators across Canada. In both cases, this has led to further collaboration and engagement. Likewise, data on use of solutions provided by challenge teams have been used as input to business cases, change management resources and adoption benchmarks for subsequent larger-scale investment. Team experiences have also been shared in a variety of ways and led to subsequent formal evaluations and research. This information helps to inform broad-based adoption and investments through case studies, adoption metrics/benchmarks, benefits evaluation and peer learning. In addition, challenge teams have used their awards to progress their ideas and solutions further. For instance, Niagara Public Health received the Canada's Choice award in the Ideas Challenge and used the prize funds to turn their idea into a mobile app. Infoway too has launched additional investments based on challenge results, both to scale/spread local solutions and to incent broad adoption of proven types of solutions.

Lessons Learned

As for any innovation, dynamic evolution has been key to the *ImagineNation Challenges*. This experience has demonstrated that open innovation can be a cost-effective, lower-risk approach to engaging a wide range of stakeholders in advancing desired outcomes. That said, results depend on effective challenge design and implementation. Examples of factors that we have found promote success in the use of this model include:

- *Partnerships and outreach:* Innovators abound in the health sector, but it is often challenging to reach all those who may be able to contribute to a particular goal. Active involvement of a range of supporting organizations, many of whom leveraged their communications channels to reach key stakeholders, was key. Individual personal outreach also helped to secure participation.
- *Active management:* Open innovation takes work; successful challenges do not just happen. Good design; effective communication; infrastructure such as a robust online challenge platform; and active engagement of participants, supporting organizations and judges have proven essential.
- *Fun:* Even grown-ups like to play. Monetary awards matter and help to spark interest in a challenge, but many teams are more motivated by friendly competition and the intrinsic benefits of reaching meaningful goals.
- *Nudging:* A small amount of external encouragement from something like a challenge – and a crisp and sustained focus on tracking progress towards a specific goal – helps to drive innovation.
- *Recognition:* Many teams say that the challenges help validate the importance of their work and provide a chance to celebrate successes. Leaders from within and outside participating organizations are also keen to recognize successful teams.

At the same time, we have also learned much about what does not work, such as:

- *Complexity:* Challenge questions and rules must be streamlined as much as possible. It is easiest for teams to focus and succeed when there is a single clear outcome to pursue.
- *Mismatch with issue being addressed:* Open innovation works best when there are multiple potential individuals or groups with the skills and capacity to address the goals identified. It needs to be part of a broader portfolio of strategies to support innovation, including addressing underlying enablers and barriers to progress (e.g., capacity-building or policy change).
- *Not enough time, or too much:* Early recruitment is important. After a certain point, many potential participants feel that they do not have the ability to earn awards or that there is not enough time to qualify. At the same time, judging periods that are too long tend to result in compressed judging just before the deadline when there may be less opportunity for judges to ask questions if needed.
- *Incenting speed:* The vast majority of challenge submissions come in the last 48 hours prior to the deadline. In the first Data Impact Challenge, we changed the rules so that half of a team's points came from the speed of their submission and half came from its quality. While this had the desired result of encouraging earlier entries, it affected participation in the challenge.
- *New challenge too soon:* Many individuals, organizations and judges have participated in more than one ImagineNation challenge. A break between opportunities increases participation.

Conclusion

In a sense, open innovation challenges represent a return to a historical model for incenting innovation, dating back to at least Napoleon's time. In today's digital world, though, there are new ways of connecting teams with each other and with the resources that they need to be successful, of sharing their experiences, of tracking their progress and of celebrating their successes. As the experience of the *ImagineNation Challenges* illustrates, there are many potential benefits to be had through open innovation, but optimizing results depends on effective challenge design and execution as part of a broader portfolio of strategies to accelerate progress. HQ

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Resources for Getting Started with Open Innovation

The following resources provide useful starting points for those seeking more information about open innovation:

- The US Government's *Getting Started with Challenge and Prize Competitions* page: <www.digitalgov.gov/2014/03/31/get-started-with-challenge-and-prize-competitions/>.
- Nesta's *Innovation Policy Toolkit*: <www.nesta.org.uk/innovation-policy-toolkit>.
- McKinsey's *Using Prizes to Spur Innovation* report: <http://www.mckinsey.com/business-functions/strategy-and-corporate-finance/our-insights/using-prizes-to-spur-innovation>.
- Deloitte's report on *The Craft of Incentive Prize Design*: <http://dupress.com/articles/the-craft-of-incentive-prize-design/>.
- *ImagineNation Challenge* outcomes, rules, judges, awards and more: <www.imaginenationchallenge.ca> (English) or <http://defiimagination.ca/> (French).

Principles for Health System Capacity Planning: Insights for Healthcare Leaders

James Shaw, Ivy Wong, Bailey Griffin, Michael Robertson and R. Sacha Bhatia

Abstract

Jurisdictions across Canada and around the world face the challenge of planning high-performing and sustainable health systems in response to growing healthcare demands. In this paper, we report on the process of developing principles for health system capacity planning by the Ministry of Health and Long-Term Care in Ontario. Integrating the results of a literature review on health system planning and a symposium with representatives from local health integration networks, we describe the following six principles in detail: (1) develop an aspirational vision, (2) establish clear leadership, (3) commit to stakeholder engagement, (4) engage patients and the public, (5) build analytics infrastructure and (6) revise policy when necessary.

The majority of industrialized countries in the world have clear policy commitments to providing healthcare to their populations in ways that are effective, equitable and accessible for all (Ettelt et al. 2009). However, efforts to achieve these goals are challenged by many international trends, including the aging population and the growing number of people living with chronic diseases, including dementia (Pefoyo et al. 2015). Most healthcare systems are not structured to adequately support this increasingly complex patient population, leading to increased use of acute care facilities and growing health system costs – which threatens long-term system sustainability. The challenges of this changing demographic situation highlight the need for comprehensive health system planning, focusing on restructuring healthcare activities to better promote chronic disease management for these patients in the community.

Despite the widespread recognition that comprehensive, long-term planning is necessary to achieve these important changes (Ettelt et al. 2012; Fazekas et al. 2010), policy makers face clear barriers to following through with the capacity planning process. The political cycle of democratically chosen governments is often short-term, spanning four years for most provincial and territorial governments in Canada. As such, political leaders of health systems at the Ministerial level are necessarily concerned with shorter time frames than the 10- or 20-year perspectives that are required for meaningful long-term planning (Ettelt et al. 2009). However, building the infrastructure to properly support self-management of chronic conditions in the community relies on long-term shifts in the allocation of resources over time.

Although planning for healthcare has been conceptualized in different ways, the concept of health system capacity planning is generally considered to include a framework that guides the distribution of human resources and capital in order to achieve particular system-level goals over time (Ettelt et al. 2009, 2012). Fazekas et al. (2010) provided a detailed assessment of capacity planning activities in health systems around the world, identifying three overarching criteria by which healthcare capacity planning might be assessed. The first is "vision," referring to the links between clearly stated health system goals and governance strategies over both shorter- and longer-term horizons. The second is "governance," referring to the role of system-level policy levers and the organized involvement of health system stakeholders throughout the planning process. The final criterion is "intelligence," referring to the availability and analysis of relevant data to inform capacity planning. These three criteria provide a frame of reference for our discussion of the process carried out in Ontario to establish principles for health system capacity planning that can bring about a health system oriented towards managing chronic conditions in the community, while acknowledging the challenges posed by the short-term political cycle.

In this paper, we describe the development of core principles for a health system capacity planning process currently under way in Ontario and comment on the role of health

system leaders in that process. We examine the importance of central success factors, including collaboration and dialogue, throughout the capacity planning process, and comment on the important role of patient engagement in anchoring healthcare planning in the actual experiences of patient care.

Background and Methods

In Ontario, the Ministry of Health and Long-Term Care (MOHLTC) is making a significant effort to link short-term priority setting with long-term capacity planning. The Ontario Liberal Party has formed the government for four consecutive terms, as a majority government from 2003–2007 and 2007–2011, then as a minority government from 2011–2014 and again as a majority since June 2014. Building progressively upon (short-term) priority setting in their Action Plan for Health Care each year from 2012–2015, including a focus on improving primary care access and reducing wait times in acute care, the MOHLTC is now incorporating a stronger focus on the broader system changes needed to shift the emphasis towards the effective management of chronic conditions in the community.

In order to set the course for a long-term capacity planning process in Ontario, the MOHLTC hosted a one-day symposium with leaders of Ontario's regional healthcare commissioning agencies, the local health integration networks (LHINs). The symposium was facilitated by the Women's College Hospital Institute for Health System Solutions and Virtual Care (WIHV), which was engaged by the MOHLTC to co-develop the symposium and the resulting principles for capacity planning. However, the MOHLTC maintained decision-making authority over the contents and topics addressed during the symposium. Representatives from all 14 LHINs in Ontario were present, along with representatives from other noted health system agencies. The purpose of the symposium was to identify current practices and opportunities to "kick-off" a collaborative capacity planning exercise taking place over the subsequent two years. This symposium offered the opportunity for the MOHLTC to provide context for the capacity planning process, gather feedback and engage in a moderated and focused discussion among LHIN leaders about principles and priorities for capacity planning and appropriate next steps.

Prior to the symposium, LHIN representatives were invited to complete a survey regarding current practices and perspectives related to capacity planning in Ontario – this was seen as an essential first step in engaging them as stakeholders. The survey was brief, and addressed: (a) LHIN activities and vision related to capacity planning in Ontario, (b) which stakeholders were being included in the LHIN planning processes and how and (c) the data being used to inform local capacity planning. A total of 8 out of a possible 14 responses were received, and select survey data were presented graphically at the symposium to help structure the discussion.

The symposium included presentations to the group from individuals who had led capacity planning initiatives previously, both within and outside of healthcare. The presentations emphasized what they understood to be central success factors for the planning process. Specific presentation topics included:

- An overview of the development of the Places to Grow Act, a policy specifying processes of urban planning across Ontario in the coming decades.
- LHIN perspectives and discussion outlining current capacity planning processes at the LHIN level and potential opportunities for collaboration with the MOHLTC.
- Organizational perspectives outlining the capacity planning processes being undertaken in some hospital and long-term care contexts.
- Community perspectives outlining capacity planning needs in the home and primary care contexts.

Efforts to achieve these inter-related goals are now widely viewed as essential to driving meaningful health system improvement …

Analysis

The analysis of the symposium discussion and development of principles to guide the health system capacity planning process in Ontario was based on the Institute for Healthcare Improvement's "Triple Aim" (Berwick et al. 2008). The Triple Aim was developed by Don Berwick and colleagues to represent decades of insight into high-performing health systems (Berwick et al. 2008). As an overall *mandate* for health systems that hope to fulfill their obligations to the populations they serve, the Triple Aim puts forward three inter-related goals that drive excellence in healthcare. These goals are: (1) improve the health of the population, (2) improve the experience of patients who encounter the health system and (3) control costs associated with routine health service delivery. Efforts to achieve these inter-related goals are now widely viewed as essential to driving meaningful health system improvement and were selected to form the overall goals for the health system planning process in Ontario (Dentzer 2013).

Guided by the Triple Aim, the recorded notes and discussion from the symposium were distilled into important themes using thematic analysis strategies by a team of analysts at WIHV (Braun and Clarke 2006). These important themes were then discussed by a group of representatives from the MOHLTC and WIHV to identify six core principles that could be used to guide the capacity planning process for healthcare. These principles were compared against the criteria developed by Fazekas et al. (2010) to ensure that the capacity planning process articulated: (a) a strong vision, (b) a clear governance and stakeholder engagement strategy and (c) the comprehensive use of available data and investment in new data sources where possible (Fazekas et al. 2010).

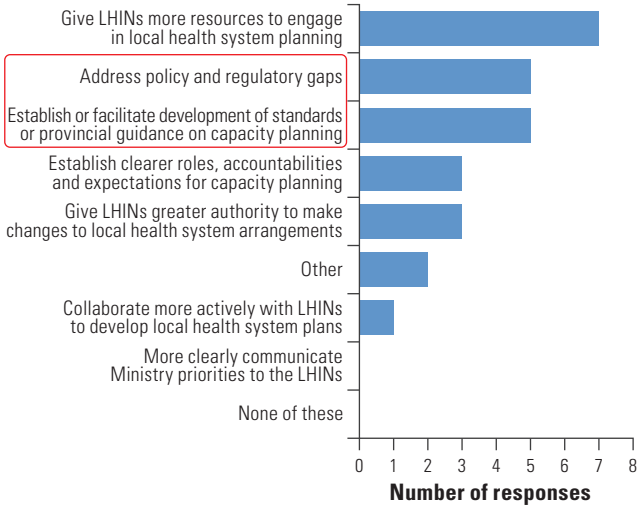
Results

The results of the thematic analysis in the form of principles to guide capacity planning in Ontario are described in order below. Additional literature is also addressed where appropriate to provide context for understanding the principles.

Principle 1: Develop a long-term, aspirational vision

The first element of developing a long-term capacity plan was to articulate an aspirational vision for the health system that will garner support for the planning process from Ontario health system stakeholders and the public. This point is well supported in international literature addressing the importance of a clear direction in efforts to achieve healthcare transformation (Carter et al. 2010; Schang et al. 2014). Key stakeholders participating in the symposium believed this vision should come from the MOHLTC and be focused on high-level, long-term goals. Although the most frequent response to the question, "How can the MOHLTC support LHINs in capacity planning?" was to provide additional resources locally (addressed in Principle 3), both addressing policy and regulatory gaps and the development of provincial standards and guidance were also common responses (Figure 1). These points were discussed during the symposium, and participants agreed that a strong vision-setting role for the MOHLTC was essential. The consensus suggested that this vision will create the foundation on which the rest of the capacity planning activities will be built.

FIGURE 1.
How the MOHLTC can support LHINs in capacity planning



In Ontario, at the time of the symposium, the MOHLTC had already committed to a vision in Ontario's Action Plan for Health Care that places patients at the centre of the health system (MOHLTC 2015). This vision focuses on the experiences and needs of patients by building upon four central pillars: (1) improving access to care by the right providers at the right times, (2) connecting services more comprehensively across the continuum of care, (3) systematically sharing more information with the public to enable informed decision-making about their health and (4) protecting the universal public healthcare system by emphasizing sustainability. These goals will help to form the foundation for articulating a more specific vision for capacity planning in Ontario.

One crucial adjunct to the development of a strong vision for health services is the creation of a suite of metrics and targets that healthcare stakeholders can recognize as representing the capacity planning vision (Ettelt et al. 2009; Schang et al. 2014). Although distinct effort must be made by policy makers to use these data to inform decision-making (Schang et al. 2014), the existence of such metrics represents tangible outcomes that stakeholders can integrate into their own organizational activities. Some metrics might reflect aspirational goals (i.e., to be achieved over longer time frames), but the establishment of both short- and long-term metrics plays a crucial role in fostering clarity of focus and understanding of health system changes over time (Larsson et al. 2012).

Principle 2: Clear and visible leadership

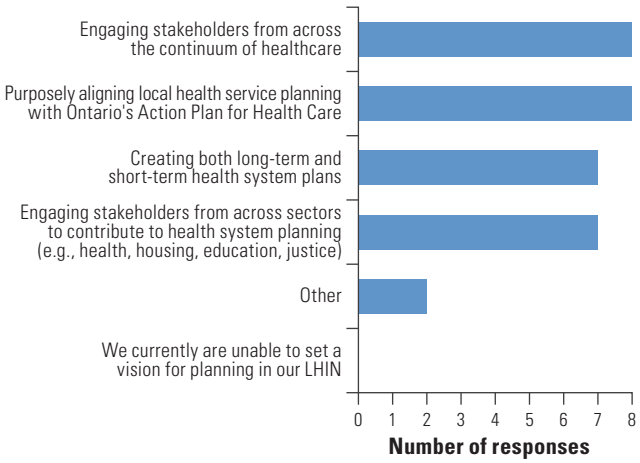
The stakeholders agreed that successful capacity planning relies on vocal and supportive leadership from both elected politicians and other senior government leaders, and identifying these leaders is the second element of the process. Research and commentary on capacity planning and healthcare transformation suggest that both political will and a strong public commitment provide substantial support to capacity planning (Eidelman 2010; Greer et al. 2008). The expression of support from political and other government leaders helps to demonstrate the importance of planning to stakeholders, encouraging their active participation. Furthermore, patients and the public will look to elected representatives to demonstrate commitment and provide the appropriate messaging related to planning the health system of the future. Ensuring that both elected officials and civil servants are committed to championing the capacity plan will maximize its chances for success.

Principle 3: Continuous and committed stakeholder engagement

Developing a capacity plan that is comprehensive, meaningful to healthcare providers and the public and maps the way to achieving the vision set by provincial/territorial bodies will require a substantial investment of time and resources on the part of both government and key stakeholders. As the plan develops, stakeholders will want to know what issues are being addressed and how they can provide further input specific to their needs. In articulating these principles, WIHV and the MOHLTC

decided to distinguish between stakeholders who *work* with or in the health system and stakeholders who *use* the services of the health system (i.e., patients and caregivers). This was primarily to emphasize the unique importance of patients in providing guidance for health system capacity planning as distinct from other health system stakeholders; patient engagement is described specifically in Principle 4. Symposium participants agreed that a process for systematically engaging key stakeholders throughout the development of the long-term capacity plan is essential to its success. This point was also reflected in the findings of the pre-symposium survey, where all respondents reported the importance of local stakeholder engagement to their own capacity planning processes (Figure 2).

FIGURE 2.
Vision and capacity planning by LHINs



A variety of processes related to ongoing stakeholder engagement for policy development have been described in the literature (Lavis et al. 2009). One important theme across these initiatives that was emphasized by LHIN leaders during the MOHLTC-LHIN symposium was the need for dedicated resources to ensure that stakeholder engagement occurs in systematic and comprehensive ways. These activities might include social media campaigns, town-hall-style meetings, invitations for public input via a dedicated email address and meetings with individuals or groups. The central point was that the effort to engage stakeholders should be well-enough resourced to achieve meaningful engagement as opposed to piecemeal strategies for input.

Principle 4: Commitment to engaging patients and the public

The crucial role of patients as the central stakeholders in health system capacity planning cannot be over-emphasized, as Ontario has already made clear in the Action Plan for Health Care. Planning for the future of healthcare is about what will best meet the needs of patients and the public, and so their input is essential to a successful planning process. The recent report of the Canadian Advisory Panel on Healthcare Innovation (2015) explained that a large gap exists in Canada "between the rhetoric of patient-centred care and the experience of many patients and families" (Canadian Advisory Panel on Healthcare Innovation 2015: 3). A strong capacity plan that intends to build a patient-centred health system for the future thus must systematically engage patients and the public in the design of health services, making them central to the capacity planning process.

Although a variety of groups must buy into the capacity planning process to ensure its success (as described in Principle 3), *the plan itself must be built around patients and the public*. This means clear mechanisms should be established to incorporate sustained contributions by patients from the very beginning of the plan's development. Carman et al.'s (2013) seminal discussion on patient engagement illustrates the potential contributions of patient and family involvement across the entire health system, including in policy making. Shifting towards true "partnership and shared leadership" in health system planning (Carman et al. 2013), the province can encourage patients to participate fully in the committees and working groups that contribute to the capacity planning process. This will help to ensure the centrality of patients and the public to the capacity plan for the future health system in Ontario.

Principle 5: Build data and analytics infrastructure to support intelligent capacity planning

Previous research suggests that the availability of high-quality data and appropriate analytical capacity are essential requirements for successful capacity planning, enabling the continuous monitoring and evaluation of health system resources and demands (Fazekas et al. 2010; Schang et al. 2014). MOHLTC-LHIN symposium participants agreed that these data and analysis infrastructure should be developed as a province-wide resource, as opposed to relying on multiple independent data systems and analysis processes that might exist in parallel. Although Ontario does have significant capacity regarding the availability of high-quality health system data through the Institute for Clinical Evaluative Sciences, and substantial analytic capacity at the MOHLTC and elsewhere, leveraging existing resources and further investing in more robust and real-time data will ensure capacity planning responds accurately to population health needs (Ettelt et al. 2012).

A consolidated, province-wide health system performance data reporting system would enable provincial/territorial healthcare leaders and other key stakeholders to fully leverage the value of data to inform ongoing health system planning. Such a system would enable the collection of health system

performance data with a very short time lag, offering as close to "real time" performance information as possible (Hollingworth et al. 2015). The availability of such data on a provincial/territorial scale would allow a more accurate determination of how population health needs and system performance vary across the province, enabling a more targeted and informed approach to system planning. However, such a consolidated data and reporting system is not without its challenges; policy mandates presented by the *Personal Health Information Protection Act* in Ontario, for example, pose potential barriers to the comprehensive integration of data as recommended here (Grossman et al. 2010). Further review of policies that might intersect with the development of a comprehensive data and analysis system is a necessary part of this step. Despite the challenges associated with comprehensive and integrated healthcare performance data systems, their development represents an important step towards intelligent planning for the health system of the future.

Healthcare leaders throughout the system thus can play active parts in both initiating and sustaining capacity planning …

Principle 6: Review and revise existing policy related to long-term capacity planning

One central goal of long-term capacity planning is the more complete integration of health and social services in ways that meet patients' often complex needs (Ettelt et al. 2012). Health system fragmentation continues to result in the inappropriate use of healthcare resources, often adversely affecting patient outcomes (Schaink et al. 2012). Participants of the MOHLTC-LHIN symposium agreed that identifying and altering legislative and policy barriers to more complete integration are important steps to the success of capacity planning.

A variety of policy topics relate to the development of a long-term capacity plan, which points out the need for stronger health system integration. These policy topics include health human resources, the structure of the home care sector and integrated funding models, all topics currently being reviewed in Ontario and elsewhere in Canada. Building the review of these and other relevant policy issues into the capacity planning process enables a comprehensive consideration of policy barriers and enablers to meaningful system change.

Conclusions

We have reviewed the six central principles that arose from the early phases of capacity planning in Ontario. Healthcare leaders across Canada and elsewhere can consider whether and how their organizations or practices reflect these principles and the roles they might play in advancing a strong capacity plan. Building collaborative relationships with central planners at the provincial/territorial levels enables stronger engagement in the early phases of the planning process (Lavis et al. 2009), and can foster more meaningful stakeholder engagement throughout. Healthcare leaders throughout the system thus can play active parts in both initiating and sustaining capacity planning, collaborating with government agencies and applying these principles in locally relevant ways.

The results of this capacity planning exercise are already being built into the planning activities of the MOHLTC. First, the MOHLTC is utilizing these principles in their short-term efforts to develop a provincial dementia strategy and enhance the provincial emergency room/alternate level of care strategy. Second, these principles will be used to guide further engagement of LHINs in order to produce more collaborative system planning across the province. Finally, these principles will support the Patients First health reforms currently under way in Ontario, guiding the processes of stakeholder engagement and strategic planning that will help to restructure the primary and community care sectors.

Furthermore, we want to emphasize the central importance of meaningful patient engagement to the capacity planning process. In order to move beyond the rhetoric of patient and public involvement in healthcare policy making (Canadian Advisory Panel on Health Care Innovation 2015), comprehensive approaches to building patient input and participation into capacity planning are essential.

In conclusion, Ontario is embarking on an important journey to build a strong, patient-focused, data-driven health system. This process starts with the development of a long-term capacity plan that sets a clear aspirational vision for the future and charts a clear course to achieve that vision. By following the six principles described in this paper, we believe that Ontario will have a greater chance of achieving that vision. HQ

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Comparing the Health of Canadian Hospitals: Paying Attention to the Mix of Planned and Unplanned Admissions

Les Vertesi

Abstract

Canadian hospitals are being placed under increasing scrutiny for both performance and safety in some cases with a threat of financial consequences for failure. However, there are no accepted standards for comparing the relative context in which hospitals must operate; the unstated assumption being that all are starting from the same place and have equal opportunities for success. A "healthy hospital" should be able to meet the needs of its community with a mix of both planned (scheduled) and unplanned (emergency) services. The proportion of admissions that are planned has been falling in most Canadian hospitals and unplanned admissions have been rising, creating an unhealthy state with added costs. Canadian Institute for Health Information's databases give us a way to monitor these changes, but it is not routinely done. Making this information more available would help to identify hospitals most in need of support.

Introduction

Hospital performance and quality continue to attract attention as Canadian healthcare comes under increasing scrutiny from international comparisons (The Commonwealth Fund 2014). Quality Councils mandated to help improve quality are well established in most provinces, and some ministries have signalled their seriousness by tying performance measures to hospital funding (BC Health 2014). Inherent in all of this is an assumption that hospitals are all starting more or less from the same place and have equal opportunities to improve if only they would adopt management principles such as "LEAN" (Lean Enterprise Institute 2016) and follow "best practices" in clinical services. The absence of metrics on hospital environment allows this to persist even though common sense would suggest they are not all starting from the same place.

The Canadian Institute for Health Information (CIHI) maintains a long list of indicators for hospital performance (CIHI 2016a), each designed to track specific areas of interest. At a high level, the average length of stay (ALOS) is still one of the most closely monitored perhaps because it is the most directly linked to expenditures. Strong performers are expected to have a low ALOS, whereas longer stays are grounds for scrutiny or sometimes penalties. Similar tracking exists for waiting lists, complications and a host of other comparisons, many that are tracked internationally by the Organisation for Economic Co-operation and Development (OECD) (OECD 2016). Yet no matter how rigorous the methodology, real progress on quality remains elusive.

This article suggests a higher-level approach that introduces the notion of "hospital health" as a metaphor for the ability to meet reasonable expectations for quality within an available budget. It begins with the observation that all hospitals must find a balance between the planned and unplanned services they provide to their community. Planned admissions may also be called "booked cases" or "electives," terms that can be misleading because they imply lower importance.

In fact, a large number of planned admissions are for cancer, cardiac illness and chronic pain, all the issues that were raised at the time of the Canadian waitlist crisis that led to the interprovincial agreements in 2003. Unplanned services on the other hand can be easily tracked as those resulting from unscheduled visits to an emergency department (ED). The terms "planned" and "unplanned" are preferred because they suggest that the ability to plan is a separate matter from both urgency and the degree of need.

Hospitals must of course deal with both types of admissions, but it should be evident that whenever possible, a planned admission is always preferable to an unplanned one (Rowe 2012) from both a cost and a patient care point of view (Table 1). The extent therefore to which a hospital is successful at maintaining a desirable balance between these two is not only a measure of the public's access to hospital services, it is also a marker for institutional health.

TABLE 1.
Comparing planned and unplanned admissions

Unplanned admissions	Planned admissions
Haphazard arrival times, including weekends and holidays	Predictable arrivals
Patient has waited longer and is therefore usually more ill, which implies longer stay	Known problem allows pre-arranged care plan to be in place
Different physicians and sometimes wrong hospital, absent care plans add to LOS	Fewer physicians involved decreases communication and risk of errors
Chaotic arrival patterns + longer LOS add to cost and congestion and make accountability difficult	Physicians can be more easily held accountable for LOS and costs

Methods

The Discharge Abstract Database (DAD) (CIHI 2016b) created and maintained by the CIHI already provides the necessary tools. Unplanned entries can be identified using the Entry field for ED admissions. Non-ED admissions can be further divided into either new admissions or inter-hospital transfers using other fields. The point is that a true count of "planned" admissions must exclude those transferred from other acute hospitals, as they are not really new admissions.

Using the inpatient DAD with the methodology described above and with maternities and neonates excluded, three separate streams for entry into hospitals can be identified, each with very different ALOS characteristics (Table 2). These three methods of access to hospital beds have been noted by others (Lucas et al. 2014), but there has been little published research into their significance. Emergency is the dominant method of access in Canada and carries a longer ALOS than planned admissions. Transfers-in are the fewest in number but have the longest ALOS, whereas planned admissions have the shortest ALOS. The Planned Days Ratio (PDR) is a measure that expresses the balance between planned and unplanned services as the proportion of total inpatient days consumed by planned admissions.

TABLE 2.
Three basic modes of hospital entry

Route of admission	Count	Total days	ALOS (days)	% of patients	% of days
ED	1,183,020	10,290,973	8.70	62.9	67.0
Direct (planned admissions)	474,711	2,519,866	5.31	25.3	16.4
Direct (transfers from other acute hospitals)	221,996	2,551,616	11.49	11.8	16.6
Total acute admissions*	**1,879,727**	**15,362,455**	**8.17**	**100.0**	**100.0**

ALOS = average length of stay; ED = emergency department.

*All acute admissions to Canadian hospitals during financial year 2014/2015, excluding maternity and neonates. ED group includes (~2%) from unexpected day procedure admissions (P & C in CIHI database). Excludes territories and Quebec.

As it has become common practice for hospitals located in the same community to work together by providing different but complementary services, the PDR is most reliable when applied to groups of hospitals working together in the same geographic community, for example, those in the same health authority. The term "hospital" as used in this article should therefore be understood to refer to groups of hospitals when working in that context.

The first thing to notice is that because each of these three streams differs substantially in ALOS, the combined ALOS of a hospital (or group of hospitals) is more reflective of the proportion of cases in their mix than to any real efficiency. If the mix is not known or is not explicitly stated, then ALOS as a measure of performance becomes next to meaningless. Second, although the inpatient days associated with the transfers-in group are real, the patient counts are not, as the DAD treats transfers as if they were new patients instead of simple exchanges between cooperative institutions. This point becomes important when considering the definitions being used for the ratios of interest.

Results and Discussion

In spite of attempts over many years, hospitals have been unable to control the rising number of emergency admissions (Huntley et al. 2013), nor can they limit their transfers from other hospitals without creating added problems. This leaves the planned admissions as the only realistic short-term activity that can be trimmed when budgets are tight. This is especially true within the global budget paradigm that still dominates hospital funding in Canada

in which the practice has no negative financial consequences. It does, however, upset the optimal balance as measured by the PDR.

The question is what should that balance be? Notionally, a 50–50 balance might seem right, but there is no consensus on what constitutes an optimal balance for a "healthy" hospital. As all jurisdictions struggle with rising costs within fixed budgets, one can expect the PDR to continue to fall in most communities. This is made worse by a general inattention to its relevance and, consequently, its absence in routine reports on health indicators, which might otherwise provide the feedback needed to allow an intervention. The only way to inform on this and start that awareness is by making comparisons both within Canada and, where possible, with other countries.

The Canadian Data

An analysis by the author from data prepared by CIHI for the latest complete fiscal year (2014/2015) is shown in Table 3. The table shows substantial variation in the Planned Days Ratio (PDR), reflecting the different realities faced by the hospitals in each province. The same table also shows the corresponding Unplanned Patient Ratio (UPR), defined as the count of ED admissions divided by the total number of new admissions (excluding transfers, as these are not really new patients). The provincial variation in these ratios is significant, but the variability in PDR at the individual Health Authority level (not shown) is much greater, ranging from a low of 9% in one British Columbia (BC) region to a high of 28% in central Toronto.

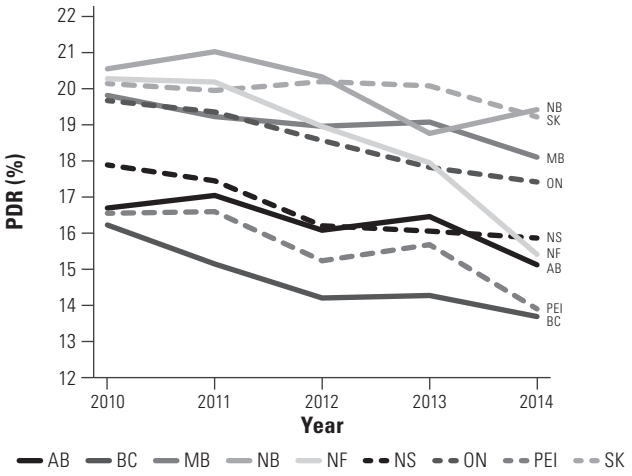
TABLE 3.
Provincial comparisons*

Canadian province	PDR	PDR as % of Canadian average	UPR
Newfoundland & Labrador (NL)	15.4%	94%	63.7%
Prince Edward Island (PEI)	13.9%	85%	67.5%
Nova Scotia (NS)	15.9%	97%	53.1%
New Brunswick (NB)	19.4%	118%	62.0%
Ontario (ONT)	17.4%	106%	63.7%
Manitoba (MB)	18.1%	110%	56.9%
Saskatchewan (SK)	19.2%	117%	57.7%
Alberta (AB)	15.1%	92%	58.9%
British Columbia (BC)	13.7%	83%	69.7%
All provinces	**16.4%**	**100%**	**62.9%**

PDR = planned days ratio; UPR = unplanned patient ratio.
*Calculated PDR and UPR are for financial year 2014/2015.

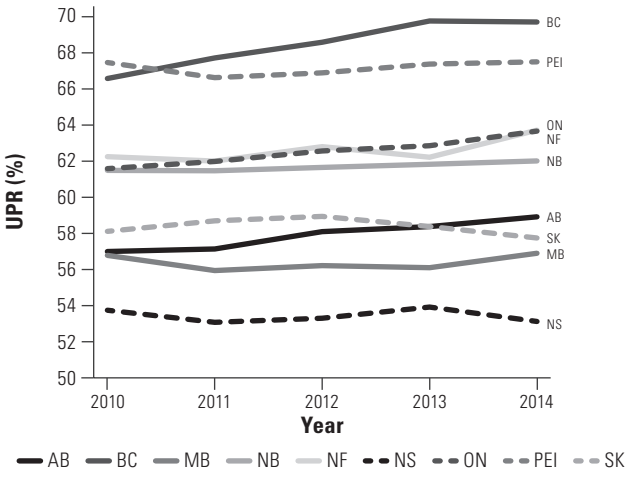
The tables above provide a one-year snapshot, but an analysis over five consecutive years also gives a sense of the direction in which things are going. Figure 1 and Figure 2 , respectively, graph the changes in PDR and UPR in each province during the past five complete years (FY 2010/2011 to 2014/2015) in the CIHI database. Most provinces show a progressive drop in PDR over this interval and a rise in UPR over the same time

FIGURE 1.
Planned admissions (as a percentage of total days)



PDR = planned days ratio.

FIGURE 2.
Unplanned admissions (as a percentage of all patients admitted)



UPR = unplanned patient ratio.

It should be no surprise that the two outlier provinces with the lowest and fastest dropping PDR also show the highest rises in UPR. The two patient streams are after all not independent of each other. Patients who are unable to access a planned hospital bed will eventually get sicker and will end up adding to the burden of admissions through emergency. Apart from the increased morbidity this causes, Table 1 shows how this

adds to the cycle of longer ALOS and rising costs (Deraas et al. 2013). It is the combination of increased ALOS, overcapacity and the added drain on the very resources needed to fix the problem that justifies the metaphor of "poor health."

Comparisons with Other Countries

The CIHI data sets make comparisons within Canada relatively easy, but the task is more difficult on an international level. The OECD does provide comparisons between countries on the usual basic statistics like ALOS, beds per population and life expectancy (OECD 2015), but there is very little available on planned versus unplanned admissions. Countries tend to compile their own statistics in different ways, making it difficult to ensure that comparable definitions are being used. Germany, however, does publish enough detail on a government website (Destatis 2016) to provide a valid comparison between Canada and at least one other large democratic country with a social safety net that spends a similar proportion of its GDP on health.

Table 4 compares Canadian hospital admissions with those of Germany for the 2012 (latest available) calendar year, with respect to the measures of interest. The first thing to notice is that the total number of hospital admissions in Germany on a per population basis is almost 2.5 times that in Canada with a lower ALOS. The PDR in Germany (41.1%) is almost triple the Canadian average (17.4%) and planned admissions there outnumber unplanned ones. Hospital funding in Germany is based not on global funding but on a DRG (Diagnosis-Related Group) methodology, a form of activity-based funding that supports an acute bed ratio of 5.3% per 1,000 population (vs. 1.7% in Canada) with an almost identical cost envelope ($4,693 vs. $4,304 in Canada) based on OECD data.

There are many differences in the two systems that make direct comparison difficult, and a detailed analysis of that subject would be outside the scope of this article. However, the size of the differences in both PDR and UPR is difficult to ignore, especially when health expenditures per population are almost identical. More comparisons with other countries are needed to see the extent to which Canada is truly an outlier, and this should be the subject of future research.

Interpretation and Summary

All hospitals need to find a balance between the planned and unplanned services they provide to their community. The extent to which a hospital is able to achieve such a balance is a valuable index not only of public access to care but also the state of its institutional health. Because unplanned services imply unpredictable arrival patterns, longer hospital stays and higher costs, hospitals with an excess of unplanned admissions will also be struggling financially and be less able to meet expectations of quality improvements. As global budgeting permits planned services to fall without consequences and as this is still the dominant method of financing hospitals in Canada, the matter should be of more concern than has been seen to date.

Both the PDR and UPR can be easily calculated from the DAD for one's own facility by any hospital or health authority. Although there is no consensus on what constitutes a minimum safe level for PDR, the combination of a dropping PDR with a rising UPR should be a signal of trouble. The connection with Canada's waitlist problems should be self-evident, as planned admissions are the ones who make up the waiting list.

TABLE 4.

Comparison of hospital admissions in Canada and Germany*

	Canada (financial year 2012/2013)			Germany (2012)		
Data	**Patient count**	**Percentage**	**ALOS (days)**	**Patient count**	**Percentage**	**ALOS (days)**
Unplanned (emergency) admissions	1,127,216	62	8.56	7,464,171	43	7.84
Planned (direct) admissions	474,551	26	5.36	9,245,824	53	4.92
Transfers in from other hospitals	214,336	12	11.41	634,857	4	10.46
All admissions combined	**1,816,103**	**100**	**8.06**	**17,344,852**	**100**	**6.38**
Calculations						
Population (millions)			26.2			80.4
Admissions per 1,000 population			6.9			21.6
Calculated PDR			17.4%			41.1%
Calculated UPR			70.4%			44.7%

ALOS = average length of stay; PDR = planned days ratio; UPR = unplanned patient ratio.

*All data exclude maternities and newborn admissions. Canadian data exclude Quebec and territories.

Source for German data: https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Gesundheit/Gesundheit.html.

Source for population data: Statistics Canada website (http://www.statcan.gc.ca/eng/start) and Organisation for Economic Co-operation and Development website (https://www.oecd.org/health/).

More careful tracking of PDR and UPR could help identify hospitals that will need assistance before they can meet existing standards for quality. Including these metrics in regular reports on a national basis would be an important first step. And finally, further comparisons with other countries and an exploration of the relationship with our waitlist problem might help to stem the current trend towards long waits, increasing costs and an emergency-dominated hospital system. HQ

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How Appropriate Is All This Data Sharing? Building Consensus Around What We Need to Know About Shared Electronic Health Records in Extended Circles of Care

Josephine McMurray, Kelly A. Grindrod and Catherine Burns

Abstract

Background: **The bulk of healthcare spending is on individuals who have complex needs related to age, income, chronic disease and mental illness. Care involves many different professions, and interoperable electronic health records (EHRs) are increasingly essential.**

Objectives: **The objective of this paper is to describe the use of a nominal group technique (NGT) to develop a stakeholder-centred research agenda for clinical interoperability in extended circles of care that include social supports.**

Methods: **We held a day-long meeting with 30 stakeholders, including primary care providers, social supports, patient representatives, health region managers, technology experts, health organizations and experts in privacy, law and ethics. Participants considered, "What research needs to be done to better understand how EHRs should be shared across large healthcare teams that include social supports?" Following sensitizing presentations from researchers and participants, we used an NGT to generate and rank research questions on a 9-point Likert scale. We retained research questions that had a mean score of at least 6.5/9 by at least 70% of the participants over two rounds of consensus-building.**

Results: **Participants identified and ranked 57 research questions. Five items achieved consensus, related to 1) the impact of information sharing on care team outcomes, 2) data quality/accuracy, 3) cost/benefit, 4) what processes use what data and 5) regulation/legislation.**

Conclusion: **Healthcare reforms are increasingly focused on systems that integrate and coordinate multidisciplinary care, facilitated by EHRs. Research prioritization will ensure common concerns and barriers are addressed and resolved.**

Background

Modern healthcare is complicated, inefficient, expensive and messy. The World Health Organization (WHO) attributes healthcare's problems to a dependence on fragmented, hospital-centred care(WHO 2008). However, a growing number of North Americans are living with multiple chronic diseases and receive care from large healthcare teams that include family physicians, nurse practitioners, specialist physicians, physical and occupational therapists, pharmacists and home care providers (Foltz et al. 2014; Manns et al. 2011; Margolius and Bodenheimer 2010; McMurchy 2009; Ornstein et al. 2013). The response has been to build stronger community-based primary healthcare systems that efficiently coordinate care across all settings (Fooks 2013). Newer systems are emerging that go beyond diagnosing and treating chronic disease to recognize the importance of income, family support and education and the patient's right to self-determination in care (Starfield 1998; WHO 2008).

Clinical Interoperability and Ontario's Health Links

Canada lags behind other developed countries in the integration and adoption of electronic health records (EHRs) (Schoen et al. 2012), which are crucial for coordinating care (CMA 2011). According to the 2014 National Physician Survey, fewer than half (42%) of family and general practitioners were using office-based EHR exclusively to enter and retrieve patient data (RCPSC 2014). Recent boosts in EHRs can be partly credited to Canada Health Infoway, a national, government-funded initiative designed to accelerate a pan-Canadian EHR (Canada Health Infoway 2012). Wide adoption of office-based EHRs is essential to the building of systems that can coordinate data exchange across regions. Yet, national efforts can only go so far in achieving the goal of providers having "the right information when they need it" (Canada Health Infoway 2011). One Canadian study suggests that only 12% of information that could be shared is being shared electronically (McMurray 2013), with similar exchange rates in the US (Yeager et al. 2014).

Even with national guidance, each Canadian province is ultimately responsible for establishing and regulating their own EHR systems, and the provinces are increasingly shifting the responsibility to smaller health regions and healthcare organizations (CMA 2008). This has led to much variation in the adoption of EHRs across Canada (Webster 2010) and has slowed the exchange of electronic health data between healthcare providers.

In Ontario, over half of healthcare dollars are spent on a mere 5% of residents, with the bulk of spending on physician visits, acute care hospitalizations and prescription drugs (Wodchis et al. 2012). As elsewhere, the heaviest users of healthcare tend to be older and live with lower income, multiple chronic diseases and/or mental illness (Lemstra 2009; Muldoon 2013; Rosella 2014). In response, Ontario established large communities of care in 2012, known as "Health Links." A Health Link is a multi-disciplinary network of care providers that includes primary care, specialist care, hospitals, long-term care, social work and community supports such as disease education programs and home care (OMHLTC 2013). While different from Alberta's primary care networks and patient-centred medical homes in the US, the models all focus on improving access and care coordination to society's sickest. For some, the Health Links team may extend outside the traditional healthcare setting to include police, lawyers and foster families; the goal being to ensure people with complex needs have a coordinated care plan, support, and providers who understand the situation and can help (OMHLTC 2013).

As health records integrate across the province and care is coordinated through Health Links, what emerges is an "ultra-large-scale system," a complex, dynamic, software-reliant system founded on legacy applications and clusters of connected stakeholders (Rezaei et al. 2014; Sullivan et al. 2010). In the face of this technical Tower of Babel, three major questions arise: 1) who should have access to what data; 2) when should the data be made available; and 3) how will the data be exchanged, interpreted and acted on by such a diverse group of care providers. It is this third question – the question of clinical interoperability between clinical systems – that is the focus of this paper.

Even with national guidance, each Canadian province is ultimately responsible for establishing and regulating their own EHR systems …

Building Interoperable Health Records for Ultra-Large Care Teams

From a clinical perspective, interoperability is the ability of the EHR and its users to unambiguously interpret and act on health data (Rezaei et al. 2014). For example, in a fully interoperable system, when a pharmacist records that they administered an influenza vaccine to a patient in a pharmacy management system, the family physician, hospital and public health units who access the patient's record in their own systems would all be aware that the patient has been vaccinated and understand that the vaccine does not need to be re-administered for the remainder of the influenza season. Considering that Canada has long struggled to develop any sort of a vaccine registry, full clinical interoperability would be a major achievement.

Models exist that describe the maturity levels of interoperable systems and guide system development (McMurray 2013; Rezaei et al. 2014). At its most basic, interoperability requires a technology infrastructure that can share health data across electronic systems (technological interoperability). For EHRs to share information, health data also need to be formatted and recognizable to the EHRs that both send data and receive data (syntactic interoperability). Senders and recipients of data also need to have a common understanding of shared data to understand and act on it appropriately (semantic interoperability). Finally, the actions of healthcare providers need to reflect the shared goals of both the organization sending the data and the organization receiving the data (organizational interoperability).

One of the biggest concerns with integrating health records over expanded circles of care is that data quality will suffer (McLeod et al. 2011; McMurray et al. 2013). There is a significant gap in our understanding of how large and diverse social support and health networks, such as Ontario's regional Health Links, will perceive data quality, meaning and usefulness. Solving this problem should result in better community-based primary healthcare data, more useful health records and an overall improvement in the quality of healthcare. However, the main barriers to information exchange include cost, insufficient infrastructure,

data privacy and security (Vest 2010; Yeager et al. 2014). The objective of this paper is to describe our use of a nominal group technique (NGT) to develop a stakeholder-centred research agenda for clinical interoperability in an extended circle of care that includes social supports.

Methods

We obtained ethics clearance from the Offices of Research at the University of Waterloo and Wilfrid Laurier University. The meeting was funded by a planning grant from the Canadian Institutes of Health Research and held on December 5, 2014, in Waterloo-Wellington health network in southwestern Ontario. The following statement was used to set the tone for the day:

> "Imagine we live in a world where health data moves easily throughout the healthcare system. We also have a healthcare system called a Health Link where the patient's circle of care includes everyone from physicians, nurses and pharmacists to social workers, ambulance drivers and home care providers. What potential do you see? What are the challenges? Is this something we should pursue?"

Study population

We invited a purposive sample of 30 experts and stakeholders from the local region, and across North America (Table 1). While the focus of the meeting was on the general issue of integrating health records across ultra-large health systems, we used the local Health Links extended circle of care as a case study.

TABLE 1.
Stakeholder attendees

Primary care	Healthcare management	Social support	Patient advocate	Technology expert
Family physician	Health region managers	Social worker	Nurse navigator	Canada Health Infoway
Nurse practitioner	Hospital managers	Mental health nurse	Patient/ lay person	Data architect
Pharmacist	eHealth Ontario	Canadian Mental Health Association	Research ethics board	Clinical adoption specialist
Nurse	Hospital information technology manager	Medical ethicist	Privacy officer	Systems design engineering
Health services researchers	Family health team manager	Lawyer		Clinical interoperability

Nominal group technique

The NGT is a consensus-building strategy best used when the conversation involves different viewpoints or when creative decision-making is needed on a complex issue (Andersen and Fagerhaug 2000; Horton 1980). As described elsewhere, we have used the NGT previously to ensure stakeholders have an equal opportunity to generate and prioritize ideas related to interoperability and digital health innovations (Mercer et al. 2015; McMurray 2013).

As seen in the agenda (Table 2), we began the day by defining clinical interoperability, extended circles of care and patient-centred care teams. Three invited researchers from Canada and the US provided attendees with an overview of the research on clinical interoperability, shared decision-making and informed consent. Next, all attendees were given the opportunity to share their perspective on the meaning of clinical interoperability in a series of five-minute presentations that were punctuated by guided group discussions.

TABLE 2.
Stakeholder meeting agenda

Time	Activity
08:00–08:30	Welcome from organizers
08:30–09:00	Overview of interoperability in Ontario and Canada (eHealth Ontario, Canada Health Infoway)
09:00–10:15	Presentations by invited researchers (Bender, Abidi, Anderson)
10:15–10:30	Break
10:30–10:55	5 × 5-minute rapid presentations (health technology experts)
10:55–11:05	Group discussion
11:05–11:30	5 × 5-minute rapid presentations (healthcare providers)
11:30–11:40	Group discussion
11:40–12:05	5 × 5-minute rapid presentations (patients, ethicist, technology experts)
12:05–13:00	Lunch & group discussion
13:00–14:00	Small group case discussions
14:00–14:15	Coffee break
14:15–15:00	Group case presentations
15:00–16:30	Nominal group technique

After lunch, participants were divided into interdisciplinary groups of six to eight and asked to discuss the meaning of clinical interoperability and the expanded circle of care using patient cases (Table 3). Each small group presented their discussions to the entire group.

Following the presentations and case discussions, an experienced NGT facilitator asked participants to consider the following question: "What research needs to be done to better understand how electronic health records should be shared across large healthcare teams that include social supports?"

Following the Centers for Disease Control's guide to NGT, participants began by writing down ideas silently on their own for 15 minutes (CDCP 2006). Participants were asked to share one idea at a time, round-robin style, while the facilitator recorded the idea verbatim on a flip chart. After all ideas were shared, the facilitator guided a discussion to add, clarify or merge ideas.

TABLE 3.
Patient cases for multidisciplinary small group discussions of clinical interoperability in extended circles of care*

Case	Description
1	JN is an 86-year-old woman experiencing delirium and pain after a fall. She lives with her husband and receives care from her primary care provider, the Health Link team[§], a geriatrics team and home care. She has had several recent medication changes and her kidney and liver function are fluctuating. All care providers are accessing systems to get lab data, home care plan and medications and each manually enters it into their own EHR.
2	HP is a 47-year-old woman who has multiple chronic conditions, including mental illness and fluctuating cognition. She lives alone in an apartment and is a poor historian. She has a family physician and frequently visits the emergency department via ambulance or the police. She is new to the Health Link team[§]. Her care providers all use different EHRs and have limited access to her mental health assessments.
3	ST is a 29-year-old man who has Huntington's Disease and will soon need placement in long-term care. He is a single parent (11-year-old child) with no family support or income and receives social assistance. The child has been assisting with bathing, toileting and meals. The psychiatric manifestations of ST's illness are putting the child at risk. His care providers include a primary care nurse practitioner, the Health Link team[§], dietitian, family and child services, social series (income) and the police. Increasingly, his care is also involving the landlord, foster parents for the child, estranged family and a lawyer.

EHR = electronic health record.

*Fictionalized cases based on "typical" patients seen by Health Links teams.

[§]Health Link team includes a social worker/therapist, a pharmacist, a physical therapist, a physician assistant/nurse practitioner and two home care coordinators.

Once the final list of ideas was numbered and displayed in its entirety, participants rated each idea's relative importance using a 9-point Likert scale (1 = Strongly Disagree, 9 = Strongly Agree). The ratings were collected and electronically aggregated, and all ideas that failed to reach a mean agreement score of 6.5 by at least 70% of the group were removed. The remaining ideas were ranked again, creating the final list. Following the event, we thematically analyzed all research questions using NVivo 10 (QSR International Pty Ltd).

Results

Initially, participants generated 57 research ideas related to electronic exchange of health information in expanded circles of care (Appendix 1, available at: http://www.longwoods.com/content/24902). After the first round, eight research questions had a mean agreement of 6.5 by at least 70% of the participants. No questions related to the fundamental ethics of data sharing or usability progressed to Round 2. After the second round, five research priorities emerged (Table 4).

TABLE 4.
Important research questions identified using the nominal group technique

	Research question	Mean* (SD)	% Agree*	Round 1	Round 2
1	How does the sharing of information across an extended team impact outcomes?	7.81 (1.08)	85.71	Accepted	Accepted
2	How do we assure data quality and accuracy in a shared record?	7.40 (1.54)	80.00	Accepted	Accepted
3	What healthcare processes are going to generate and use the health data?	7.24 (1.51)	76.19	Accepted	Accepted
4	What are the costs and benefits of sharing information across an extended team?	7.19 (1.12)	76.19	Accepted	Accepted
5	What regulatory or legislative changes could be a barrier and what should be changed?	7.00 (1.90)	76.19	Accepted	Accepted
6	What information is suitable to be shared and what is the core data set?	7.09 (1.18)	66.67	Accepted	Not accepted
7	What is the circle of care in the context of the current health record from the provider, patient and system perspective?	6.62 (2.20)	66.67	Accepted	Not accepted
8	How can big data and predictive analytics be used to discover trends and patterns in this extended care team?	6.00 (2.00)	42.86	Accepted	Not accepted

SD = standard deviation.

*Round 2 mean agreement of 6.5 or higher by at least 70% of participants resulted in "Accepted".

We identified six thematic categories in the 57 ideas generated: Data, Evidence of Impact, Circle of Care, Potential Barriers, Usability and Ethics (Table 5).

Almost half of the questions, 27/57 (47.4%), focused on "Data," and of those, 10/27 (37%) were concerned with "Governance" around data custodians, confidentiality, breeches and data exchange constraints. Six items (22%) questioned "Data Quality" and asked how we assure it, how we

recognize inaccurate data, what we do about inaccuracies and the risk of false diagnosis. The remaining data issues covered four broad areas: 1) "Data Analytics," which asked about our ability to extract meaning from new data sets, how we interpret language, the need for alerts and the need for intelligent data summaries; 2) "Data Requirements," which sought to establish the best platforms to capture data while ensuring context is retained; 3) "Data Sources," which asked about the role of patient-generated data and about data mapping to ensure easy access; and 4) "Technical Needs" such as interoperability architectures and data models.

TABLE 5.
Research ideas by theme

Theme	Sub-theme	Number of ideas generated	Voting round 1	Voting round 2
Circle of care	Privacy	2		
	Relationships	4		
	Structure	3	1	
	Workflows	1		
	Subtotal	**10**	**1**	**0**
Data	Analytics	2	1	
	Governance	10		
	Interpretation	2		
	Minimum data set	2	1	
	Quality	6	1	1
	Requirements	2		
	Sources and uses	2		
	Technical needs	1		
	Subtotal	**27**	**3**	**1**
Ethics	**Subtotal**	**1**	**0**	**0**
Evidence of impact	Evaluation	10	2	2
	Process change	1	1	1
	Subtotal	**11**	**3**	**3**
Potential barriers	Change management	3		
	Patient attitudes	1		
	Regulatory/legal	2	1	1
	Subtotal	**6**	**1**	**1**
Usability	Minimum standard	1		
	Provider	1		
	Subtotal	**2**	**0**	**0**
Total		***57***	***8***	***5***

The "Evidence of Impact" theme generated 11/57 or 19.3% of the questions, with 10/11 focusing on the need for evaluation of health outcomes, cost–benefit, value, efficiency and meaningful use. Outstanding research questions included the unintended consequences of information sharing, the imperative to document and learn from failure, and the need to create high-impact use-cases for education.

Ideas related to the "Circle of Care" accounted for 10/57 or 17.5% of the total generated questions. Within the circle of care, the sub-theme of "Relationships" identified included the roles of vendors and non-medical stakeholders in interoperability, how to capture changing team dynamics, whether data should be shared selectively or comprehensively and when might interoperability be required outside the circle of care. Other sub-themes included the "Structure," which addressed issues such as defining the circle of care and their authority; "Privacy," which included questions about the patient's perspective on privacy, and the risk of inappropriate disclosure; and "Workflows," which addressed the wider issue of how we reimagine organizational and clinical workflows as a result of shared records.

"Potential Barriers" was addressed in 6/57 (11%) of research questions, with 3/6 questions focused on "Change Management" strategies such as training and organizational change. The need to understand patients' attitudes to sharing their medical information electronically within a larger circle of care was also identified for investigation.

Two of the 57 research questions addressed "Usability," including the minimum usability standards needed to determine what information is required in a shared record, and what facilitates ease of use. The final category contained the only Ethics question raised by a group who asked "How appropriate is all this data sharing?"

Discussion

Using an NGT with a diverse group of healthcare stakeholders, we identified five priorities for future research in clinically interoperable EHRs in expanded circles of care that include social supports: effectiveness, quality, cost–benefit, place in therapy and regulation.

Coordinated, multidisciplinary care can improve the functional outcomes for patients suffering from diseases such as diabetes, COPD, stroke and palliative care, where communication, care planning and multi-provider service delivery are important (Mitchell et al. 2008). Systems that facilitate the exchange of information between healthcare providers improve the speed of referrals (Warren et al. 2011) and access to test results (Fontaine et al. 2010), but also impact workflows and professional practice within organizations (Unertl et al. 2011). It is crucial to understand the impact of health information exchange on achieving the goal of integrating care across our

large and increasingly complex health systems. Within the massive change management process that is being conducted worldwide to digitize healthcare data, there is an implicit assumption that providers and patients trust that sensitive information can be safely shared (Bansal et al. 2010; Unertl et al. 2011) and that regulatory and policy changes are keeping pace (Adjerid and Padman 2011).

In our study, we observed that culture appears to influence all. There is a growing body of healthcare research that addresses interoperability, but it remains fragmented. Much of the theory informing interoperability in large systems is actually from the military, where it is critical for international forces to accurately, unambiguously and safely exchange information when working on joint operations. The System of Systems Interoperability model recognizes three types of activities needed to achieve interoperability: 1) the program needs to be managed (contracts, incentives, risk management); 2) the system needs to be constructed and sustained (architecture, standards); and 3) the system needs to be operated by users and other systems (Morris et al. 2004). Ostadzadeh and Shams' ultra-large-scale systems framework has added "culture" as a fourth category to reflect that socio-technical activities can also affect interoperability (Ostadzadeh and Shams 2013). The research priorities identified by our participants confirm the importance of culture when looking at clinical interoperability in ultra-large-scale systems such as extended circles of care.

The group consensus supported building a "business case" to avoid unintended consequences of interoperability in extended circles of care. Many of the concerns expressed are variations of questions already asked in the context of single providers adopting single systems. For example, studies that have focused on outcomes associated with health information exchange have been mixed (Graetz et al. 2014; Johnson et al. 2011; Overhage et al. 2002) possibly owing to the low uptake of clinical information between providers (Rudin et al. 2014). Different stakeholders also have different perspectives on value. There is evidence that loss of competitive advantage may be responsible for slow development of interoperable systems in health regions (Desai 2014). Yet, there is also evidence that interoperability can improve resource use (Frisse and Holmes 2007; Frisse et al. 2012; Hook et al. 2006). In terms of cost–benefit, interoperable systems have a mixed impact (Frisse and Holmes 2007; Halamka 2013), as information exchange can drive up costs owing to more care being delivered (Vest 2009), and can decrease costs by minimizing hospitalizations (Johnson et al. 2011), information searches, lab tests (Hebel et al. 2012; Ross et al. 2013; Sprivulis et al. 2007), radiology tests (Lammers et al. 2014) and costly communication (Hincapie et al. 2011).

Our participants clearly articulated the need for more research on the impact of the regulatory and legislative environment on interoperability adoption. The adoption of standards is critical for stakeholders to trust the quality of data exchanged and to realize the value of investments in interoperable healthcare records (Cao et al. 2009; Edwards et al 2010). Initiatives promoting standardization and semantic interoperability are ongoing, such as the development of the Health Level 7 (HL7) reference information model and messaging (Landgrebe and Smith 2011; Orgun and Vu 2006); the International Health Terminology Standards Development Organization, which maintains and develops the Systematized Nomenclature of Medicine – Clinical Terms terminology; and Integrating the Healthcare Enterprise's Cross-Enterprise Document Sharing (Bisbal and Berry 2011; Channin et al. 2001). However, standards adoption is just one piece of the puzzle. Data quality and accuracy can be highly variable, and there are often issues with the timeliness, completeness (Ranade-Kharkar et al.2014) and security of the data in organizational repositories (Yeager et al. 2014). Data problems in one system can be exponentially more challenging when dispersed throughout a system of systems (Shapiro et al. 2014). However, health information exchange benefits do not always accrue to those investing in functionality, and thus, research is required into innovative funding models that share both expenses and savings surrounding their implementation and maintenance (Lammers et al. 2014).

In terms of legislation, Canada has 31 privacy statutes in the provincial, federal and territorial governments (ITAC Health 2014), and whereas privacy is critical in healthcare, it can be a bewildering maze for providers who are reluctant to adopt a technology where confidentiality is not assured. Further, Canada does not have any legislation around meaningful use. In the US, by comparison, the 2009 HITECH Act provided over $600 million to develop electronic information exchange (Yeager et al. 2014). Through HITECH's Meaningful Use requirements, hospitals must be capable of sharing electronic summary of care documents in order to receive financial incentives.

… there is an implicit assumption that providers and patients trust that sensitive information can be safely shared … and that regulatory and policy changes are keeping pace …

Limitations and Strengths

One of the greatest challenges of this type of meeting is to bring meaningful engagement from a sample that is representative of all stakeholders, in particular patients. The topic of interoperability is complex and difficult to understand for people outside the technology and healthcare sectors. Although we tried several strategies to recruit patient representatives, we had minimal representation. We tried to mitigate this by weaving patient stories and patient cases throughout the event and including primary care providers, and a patient navigator, who work directly with our most vulnerable citizens.

Finally, we acknowledge that although our technological systems in healthcare have come a long way, they have limitations that become obvious when examining some components of shared meaning in teams. In "How Doctors Think," Montgomery has documented the role that context and judgement play in physicians' interpretation of data and clinical reasoning (Montgomery 2006). This goes beyond shared understanding of data to data interpretation – this important area lies outside the scope of this paper, as is research which is focused on understanding the language and communication patterns between multidisciplinary teams (Sheehan et al., 2007).

Conclusions and Implications

If just one message is to be taken from this research workshop, it is that while we know there are many barriers that must be addressed and overcome to achieve a greater degree of integration between providers and their health information systems, many of the crucial conversations have yet to take place in a meaningful way in Canada. These conversations include the effectiveness, quality, cost–benefit, place in therapy and regulation of interoperable health records across large care teams. This work is intended for researchers and policy makers to guide the support and investigation of key issues that are of shared importance to all stakeholders in a healthcare system, which is trying to achieve greater integration and improved patient outcomes. HQ

Acknowledgements

The authors would like to thank all the attendees, including eHealth Ontario, Canada Health Infoway, the Centre for Family Medicine, the Canadian Mental Health Association and the individual healthcare providers and citizens who joined to share their perspective. They are particularly grateful to invited speakers, Dr. Raza Abidi, Dr. Nicholas Anderson and Mr. Duane Bender.

The authors gratefully acknowledge the contributions of Dr. Mohamed Alarakhia, BSc (Hons), MD, CCFP, Director of eHealth Solutions, Centre for Family Medicine Family Health Team, and Assistant Clinical Professor, Department of Family Medicine, McMaster University; Parmit Chilana, PhD, Department of Management Sciences, University of Waterloo; and Justin St-Maurice, PhD (Candidate), Advanced Interface Design Lab, Department of Systems Design Engineering, University of Waterloo.

Funding

This project was made possible through funding from the Canadian Institutes of Health Research, Funding Reference No. 328278. The authors do not declare any conflicts of interest.

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The Development of a Quality Management Framework for Evaluating Medical Device Reprocessing Practice in Healthcare Facilities

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Abstract

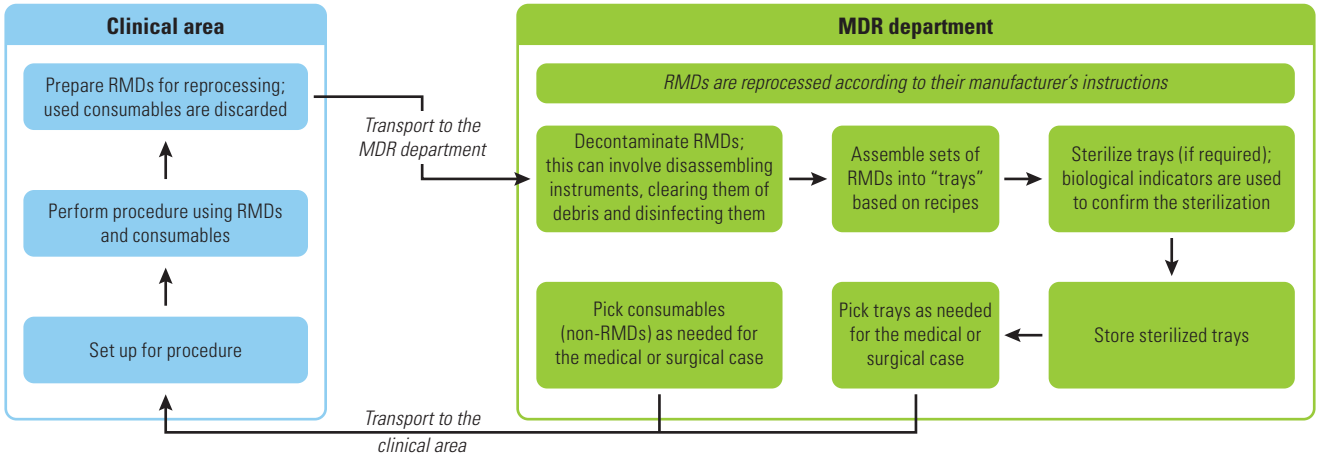
There is increasing awareness of the importance of medical device reprocessing (MDR) for the provision of safe patient care. Although industry service standards are available to guide MDR practices, there remains a lack of published key performance indicators (KPIs) and targets that are necessary to evaluate MDR quality for feedback and improvement. This article outlines the development of an initial framework that builds on established guidelines and includes service standards, KPIs and targets for evaluating MDR operations. This framework can support healthcare facilities in strengthening existing practices and enables a platform for collaboration towards better MDR performance management.

Background

Reusable medical devices (RMDs) are used in a variety of medical and surgical procedures, including the diagnosis, prevention, monitoring, treatment or alleviation of disease or injury (Public Health Ontario 2013). Medical device reprocessing (MDR) is the preparation of RMDs for their re-use. MDR is a critical service that many healthcare facilities rely on for the provision of safe, high-quality patient care. It is a complex process that includes cleaning, disinfecting, sterilizing and maintaining instruments to prevent microbial transmissions during use and reduce the risk of infection to patients (Figure 1). Improper handling and sterilization of RMDs can spread pathogens that can cause patient harm (MacKay and Burton 2015; U.S. Food and Drug Administration 2015) and is recognized as among the top patient safety concerns at hospitals (ECRI Institute 2015). Issues in MDR can also impact hospital operations through delayed and cancelled cases or extended patient anaesthesia time during surgery as RMDs are replaced or urgently "flash" sterilized for use.

Increasing awareness of the risks associated with MDR errors has led to greater attention being paid to the quality of MDR practices (Blackmore et al. 2013). In the United States, patient safety incidents related to improper MDR practice, including instances of patient death (MacKay and Burton 2015; U.S. Food and Drug Administration 2015), have prompted the Centers for Disease Control and Prevention (CDC) and U.S. Food and Drug Administration (FDA) to strongly advise healthcare facilities to review MDR protocols and ensure their policies and procedures are in compliance with current standards and guidelines (Centers for Disease Control and Prevention 2015). More recently in Canada, MDR-related incidents at Eastern Health led to over 500 delayed and cancelled surgical procedures (CBC News 2016), reiterating the urgency for tighter MDR quality control.

FIGURE 1.
MDR basics



MDR = medical device reprocessing; RMD = reusable medical device.

Given the intricate, multistep nature of MDR, careful control at every step of the process is imperative to the safe preparation of RMDs. In Canada, Accreditation Canada guidelines for MDR, which are based on Canadian service standards set by the Canadian Standards Association (CSA), are available to guide minimum acceptable practices. Although changes and additions to the 2015 guidelines reflect the broader movement towards more comprehensive and robust practices (Accreditation Canada Qmentum Program 2015a, 2015b), there remains a lack of published performance measures and industry benchmarks to support evaluation of current MDR practices and drive improvement.

Access to measurements and benchmarks are important, as they support MDR facilities in identifying the key metrics that define operational performance and ensuring acceptable standards of performance are being met. Accordingly, defined measurements and outcomes such as key performance indicators (KPIs) and targets for compliance are integral for monitoring operations. They offer clear, quantifiable assessments of performance quality and permit capacity for improvement by furthering capability to manage issues, identify process efficiencies and evaluate process change. From a broader perspective, measurements and benchmarks enable opportunity for standardized, controlled MDR practices across facilities.

Trillium Health Partners (THP) is committed to providing the highest quality of care to our patients. THP is a multi-site, academically affiliated community hospital in Mississauga, Ontario, that maintains the largest surgical program in the province. In 2014/2015, THP handled 63,525 surgical cases, which corresponded to the use of 410,427 sets of RMDs. Sets of instruments are organized in over 6,000 configurations and reprocessed across multiple sites. To enable this large and complex surgical platform, a robust supply chain is maintained with MDR being a critical component.

The current gap in published MDR evaluation tools created an opportunity for THP to build on established service standards and construct an initial MDR quality management framework that includes metrics and targets for supporting high-quality MDR practice. The MDR Quality Management Framework presented in this report incorporates: a) existing best practice, namely, an index of proposed service standards constructed from and referencing established service standards and guidelines; and b) objective, clearly defined KPIs, targets and an accompanying reporting tool to review and manage MDR performance on a routine basis.

High-quality MDR practices are integral to patient safety and effective hospital operations. THP recognizes that to maintain our commitment to exceptional patient care, there is a need to think and act differently and to take new and innovative approaches to deliver on the objectives of our strategic plan—to create a new kind of healthcare for a healthier community. We also recognize that doing so requires collaboration with our patients and partners in the healthcare community. By sharing this initial MDR Quality Management Framework, our intent is to encourage cooperative efforts that will initiate development of industry standards and benchmarks and set the foundation for standardized process and best practices across MDR facilities. Ultimately, the presented tools will support other healthcare facilities in better understanding their own MDR practices and build capacity for feedback and corrective actions that will collectively promote proactive performance management, continuous improvement and high-quality patient care services.

The Development of a Medical Device Reprocessing Quality Management Framework

The process of constructing our MDR Quality Management Framework began by identifying the needs of our patients and front-line staff who routinely use RMDs. Together, it was agreed that this initial framework must adhere to principles of quality and reliability in order to: 1) guarantee the highest standards of safety for our patients, and 2) deliver process efficiency ensuring that RMDs would be readily and reliably available to impacted stakeholders as needed.

Using these guiding principles, we derived service standards, KPIs and targets that would form the foundation of our framework to guide MDR performance management. We jointly referenced the 2015 Accreditation Canada guidelines (Accreditation Canada 2015a; 2015b) and the CSA Service Standards (Canadian Standards Association 2015) for MDR. Additionally, we included items that THP deemed important for review, specifically those that governed the quality of MDR output, such as MDR process error rates and surgeries impacted by these errors. A total of 25 service standards and 10 KPIs were identified and included in our framework. These service standards and KPIs represented the range of policies, procedures, outcomes and practices required to manage and monitor performance of a high-quality, reliable MDR operation. A detailed, full document with items referenced to their respective 2015 Accreditation Canada guidelines and CSA Service Standards is attached in Appendix 1 (available at: http://www.longwoods.com/content/24903).

Medical Device Reprocessing Service Standards

An index of service standards that assessed adherence to Accreditation Canada guidelines and CSA Service Standards for MDR were aggregated (Accreditation Canada 2015a; 2015b; Canadian Standards Association 2015). These proposed service standards were developed to govern MDR operations, staff development and performance improvement and should be assessed based on documented adherence to respective policies or processes evaluated at predefined intervals. An index of proposed service standards, categorized and with their recommended review schedule, is presented in Table 1. The use of process checklists, which are also periodically reviewed, has been a demonstrated, effective strategy for enhancing compliance to MDR best practices (Patterson 2013).

Medical Device Reprocessing Key Performance Indicators

KPIs evaluated MDR process and operation outcomes, e.g., MDR process errors, and their impacts on patients. KPIs were chosen, as they represented the measurable output of MDR that could be reviewed to quantify performance and identify issues. Considerations for defining KPIs were based on validity, simplicity and practicality. Measurements for KPIs were defined in partnership with industry experts and designed to be intuitive and objective. To maintain accessibility, we ensured that KPIs were based on data that could be readily quantified and generated by hospitals, such as from operating room management and incident reporting management systems. Next, KPI target levels required to achieve compliance were developed and assigned based on specification from the referenced 2015 Accreditation Canada guidelines, CSA Service Standard or hospital need. Derived targets were based on thresholds supported by MDR expert advice that would maintain patient safety and operational effectiveness. We recommend that KPIs are reviewed on a monthly basis in order to assess and mitigate issues and risk. An index of KPIs, measurements and targets is presented in Table 2.

Key Performance Indicator Reporting Dashboard

To promote tracking of KPIs and targets, THP has taken preliminary steps in developing a reporting process and template to implement information into practice. THP set out to create a Monthly MDR Performance Dashboard ("MDR Monthly Dashboard") based on the recommended monthly reporting schedules for KPIs, which has been implemented since May 2014. The objective of the MDR Monthly Dashboard is to enhance performance management through a summary of MDR operational outcomes and their impact on patient safety. It permits timely feedback and the capability to gauge and review MDR operations, determine areas of improvement and generate action items for addressing issues that impact service.

Furthermore, the MDR Monthly Dashboard supplements current incident management processes by providing an intuitive overview of MDR process and operational outcomes. Currently, our hospital incident reporting system is set up to track and monitor specific MDR incidents and any follow-up activities according to international best practice (WHO Patient Safety 2009). The MDR Monthly Dashboard is programmed to filter and aggregate this information with our operating room management system to display summary statistics of KPIs against their respective targets tracked within time ranges of interest for comparison (e.g., from the past year). This report was designed to be reviewed by leadership within the MDR Department on a monthly basis to quantify issues for mitigation. However, the MDR Monthly Dashboard can also be presented to key stakeholders, such as leadership from impacted departments and surgeons routinely, and as needed (e.g., on a quarterly basis), to promote transparency into MDR operations and to create opportunities for interprofessional feedback. A truncated sample of the Monthly MDR Performance Dashboard with fictitious data is presented in Figure 2.

TABLE 1.
Summary of MDR service standards

PROGRAM OPERATIONS These service standards relate to programs operations including quality control and resource management practices that should be conducted and documented routinely for effective daily operations. Service standards also include process checkpoints and preventative measures that ensure RMD, equipment and output integrity.		
Service standard	**Target compliance**	**Review schedule**
Maintenance and availability of SOPs	100% of necessary SOPs are documented, maintained and available to staff	Annual
Daily review of booked medical and surgical procedures	Review is completed daily 100% of the time	Monthly + annual
Daily review of instrument par levels	Review is completed daily 100% of the time	Monthly + annual
Daily supervisor huddles with MDR and OR staff	Daily huddles are completed daily 100% of the time	Monthly + annual
Daily maintenance & inspection	Daily audits to confirm clean and dirty work areas are kept separate 100% of the time.	Monthly + annual
Prepare recall report during event of instrument recall	100% completion of a recall report following circumstances requiring a recall	Monthly + annual
MIFU availability	100% of MIFUs for all instruments are reviewed and updated annually	Annual
Documentation of daily BI testing	100% completion of documented daily BI testing	Monthly + annual
Daily Bowie-Dick test in sterilizer	100% completion of daily Bowie-Dick test in sterilizer with documentation	Monthly + annual
BI use whenever change in sterilization process is implemented	100% completion of documented BI testing following a change implementation	Annual
IUSS biological testing records	100% completion of daily biological testing for all IUSS	Monthly + annual
Bowie–Dick and BI testing following major equipment or environment change	100% completion of documented Bowie–Dick and BI testing following a major equipment or environmental change	Annual
BI use in every production load	100% of production loads have documented BI use	Monthly + annual
Routine/preventative maintenance	100% completion of preventative maintenance and cleaning program records (both planned and unplanned)	Monthly + annual

BI = biological indicator; IUSS = immediate-use steam sterilization; MDR = medical device reprocessing; MIFU = manufacturer's instructions for use; OR = operating room; SOPs = standard operating procedures.

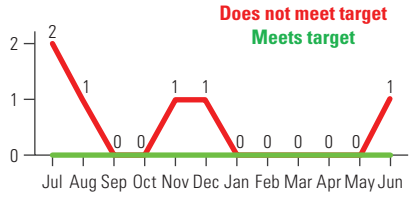
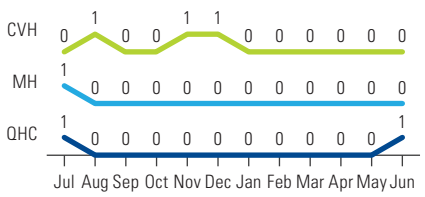
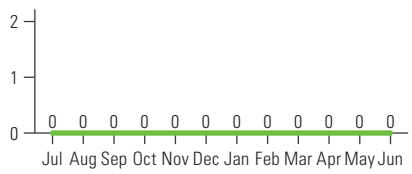
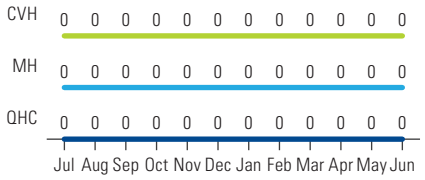
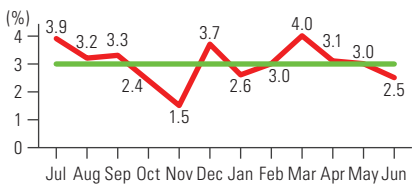
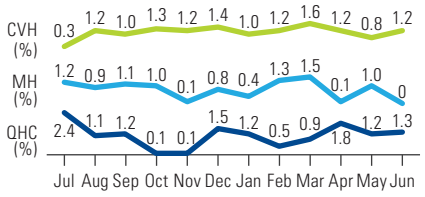
TABLE 2.
Summary of KPIs

KPI	**Measurement**	**KPI target**	**Review schedule**
Patient safety incidents	# of patient safety incidents per month	0 patient safety incidents per month	Monthly + annual
Delayed surgical cases	# of surgical cases or procedures delayed by reprocessing incidents per month	0 delayed surgical cases or procedures as a result of reprocessing incidents per month	Monthly + annual
Cancelled surgeries and procedures	# of cancelled surgeries and procedures as a result of reprocessing incidents per month	0 cancelled surgeries and procedures as a result of reprocessing incidents per month	Monthly + annual
% of affected surgical cases	# of surgical cases affected by reprocessing incidents as % of total monthly surgical cases	Less than 3% of surgical cases affected by MDR incidents as % of total surgical cases	Monthly + annual
Total reprocessing error rate	# of total errors as % of monthly trays reprocessed	Less than 0.6% errors as % of monthly trays reprocessed	Monthly + annual
Utilization of immediate-use steam sterilization	# of occurrences requiring Immediate-use steam sterilization per month	0 occurrences requiring immediate-use steam sterilization per month	Monthly + annual
Decontamination time	% of instruments decontaminated within 2 hours after receipt by MDR department	100% of instruments to be decontaminated within 2 hours after receipt by MDR department	Monthly + annual
Sterilization time	% of instruments to be sterilized within 8 hours after decontamination	100% of instruments to be sterilized within 8 hours after decontamination	Monthly + annual
Instrument available for use time	% of instruments to be shelved, accounted for and available within 6 hours after sterilization	100% of instruments are shelved, accounted for and available for use within 6 hours after sterilization	Monthly + annual
Tray turnaround time	% of trays turned around within 18 hours of total trays reprocessed	100% of trays turned around within 18 hours as % of total trays reprocessed	Monthly + annual

KPIs = key performance indicators.

FIGURE 2.
Truncated monthly MDR performance dashboard presented with fictitious data

Reprocessing performance management dashboard – Current to July, 2014 (fictitious data)

Metric	Monthly summary	Target	Monthly metric values for all of THP, per month for last year	Reported incidents by site, per month for last year
Patient safety indicators				
Delayed surgeries/procedures # of delayed surgeries and procedures per month related to MDR	0.0	0		
Cancelled surgeries/procedures # of cancelled surgeries and procedures per month related to MDR	0.0	0		
# of affected surgical cases # of surgical cases affected by MDR incidents per month, including delayed or cancelled surgeries	2.5%	3.0%		

CVH = Credit Valley Hospital; MDR = medical device reprocessing; MH = Mississauga Hospital; QHC = Queensway Health System; THP = Trillium Health Partners.

Discussion and Conclusions

MDR is a critical service for the delivery of safe, high-quality patient care. Issues in MDR can have considerable impact on patient safety and hospital operations. During analysis of our own MDR practices, we consulted with industry experts and performed site visits across Canada to better understand practices and challenges in other organizations. A common theme from these experiences was a culture dedicated to service quality but that lacked the tools to objectively evaluate performance and guide improvements. Additionally, we discovered that although outcomes of MDR issues, such as delayed and cancelled surgeries, are carefully monitored by healthcare organizations, oftentimes not enough attention is given to monitoring the quality of MDR work needed to mitigate problems in the RMD supply chain. To facilitate MDR performance management, published performance measures such as KPIs and targets are invaluable in supporting healthcare organizations in adhering to recommended practices and notifying leadership of risks and/or deficient processes that require investigation. These tools also build capacity for process efficiencies by helping to identify process improvements and evaluate process change.

To better support MDR performance management, our goal was to share our experiences and a developed initial framework with the intent to initiate development of industry standards and benchmarks. The presented quality management framework consists of recommended service standards, objectives, clearly defined KPIs and targets and an accompanying reporting tool for implementing KPIs into practice. This framework was built upon established best practices and can strengthen existing MDR operations by enabling measurement of MDR quality and alignment of MDR operations to recommended quality standards. This framework can serve as a preliminary base for industry standards and benchmarks and provides a common platform for shared insights and collaboration. We encourage other MDR facilities to adopt this framework, as collaboration will better refine the framework, KPIs and targets and shape best practices across healthcare facilities.

Two aspects of this initial framework we want to highlight are its benefits to MDR safety and improvement, and emphasis on partnership. Safety is improved by better understanding the factors that contribute to errors. Our framework acts as a tool for continuous and purposeful evaluation of MDR in order to predict and proactively manage issues. Simultaneously, this framework, with its index of recommended service standards,

serves as a supporting mechanism to ensure that the correct processes are in place to maintain safety and for staff to identify, understand and mitigate risks. Further, this framework has better equipped THP to systematically review our own practices and drive process improvement by helping to identify process efficiencies and providing a baseline for evaluating their implementation. Several applications that have resulted from this work and that we intend, in future publications, to evaluate and share as lessons and considerations for other healthcare facilities include:

1. Standardization of RMDs and instrument sets. THP currently uses nearly 100,000 unique instruments presented in over 6,000 configurations. Having a great variety of instrumentation and user preferences increases the complexity of MDR practice. This complexity increases the likelihood of error and reduces efficiency of operations. Instrument standardization is a key enabler to simplifying and reducing instrument inventory and work processes, thereby reducing errors and increasing quality and efficiency of MDR practices. Further, having fewer types of instruments and sets allows greater interoperability of RMDs and reduces the risks of instrument unavailability.
2. Options for different models of multi-site MDR, their benefits (e.g., redundancy), risks (e.g., transport, database alignment) and considerations (e.g., inventory, contingency, layout) for maintaining process quality and minimizing delays and errors.
3. Contingency planning for maintaining MDR operations in both planned (e.g., routine and preventative maintenance) and unplanned (e.g., environment or infrastructure issues or equipment malfunction) situations. Considerations for effective plans include flexibility and multi-dimensionality to mitigate disruptions to clinical operations, and can include the development of partnerships with other healthcare organizations for reciprocal MDR support.
4. Full implementation of an integrated IT system to help manage RMD inventory and life cycles. This system also facilitates RMD tracking at different stages of reprocessing and use.
5. Development of a predictive model for estimating MDR demand based on historical case volumes and patterns. Demand modelling enables proactive alignment of staffing and resource allocation.
6. Further development of our MDR Quality Management Framework to improve capability in reviewing different types of errors, determine their root causes, document trends and manage these issues, including product recall. Improved analytics permit proactive identification of problems before they impact cases or reach the patient and help determine direct and indirect cost of MDR-related issues.

Nevertheless, despite adherence to identified service standards and regularly reported metrics, it is important that information collected from this framework not supersede the judgement of front-line staff, who should remain final decision-makers in assessing RMD safety before use. Accordingly, there is a need for front-line staff to remain vigilant and engaged. A critical feature of this framework is the emphasis on partnership between the MDR Department and its key stakeholders, such as the Surgical Department. In building this framework, we recognized the opportunity to change the perception of MDR as a peripheral service within the hospital to one that provides a critical service and is a partner in enabling and enhancing the hospital's core functions. When we designed this framework, we looked to strengthen the relationship between the MDR Department and their partners and better integrate them. Accordingly, this framework was developed with input from key partners and reviewed by them throughout the development process. This process encouraged collaboration through transparency and continuous improvement based on their feedback. Finally, elements of this framework, such as KPIs and the MDR Monthly Dashboard, benefit as educational tools to engage our partners and heighten their awareness of service expectations and how the MDR process is incorporated in their operations. For example at THP, KPIs are incorporated in our hospital quality framework and shared at team huddles that MDR and OR staff jointly attend.

THP recognizes the importance of high-quality MDR practices to patient safety and effective hospital operations. In alignment with our vision to work better together, we wanted to share this initial framework, including service standards, KPIs and targets, to support our partners in ensuring the best care for patients. As work continues in refining and implementing our framework to better match the needs of our organization, we encourage other facilities to adopt and refine these tools for their own uses. Adoption of this framework provides an opportunity to make MDR operations more transparent, strengthen existing MDR practices and foster partnership with stakeholders. This framework also enables a common platform for MDR facilities to share analytics and insights for comparison to complement the adoption of CSA and Accreditation Canada service standards and guidelines. Through broader collaboration, we move towards stronger MDR performance management and standardized practice shaped by collective experience and industry standards and benchmarks. HQ

Acknowledgements

The authors would like to thank Deloitte LLP, Sullivan Healthcare Consulting Canada Co and Mr. Louis Konstant, President of the Medical Device Reprocessing Association of Ontario, for their support and guidance in the development of service standards and KPIs.

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Key Advantages of a Targeted Incident Reporting System for Severe and Critical *Clostridium difficile* Infection Incidents

Hibak Mahamed, Camille Lemieux and Susy Hota

Abstract

There is little guidance on how to design and implement an incident reporting system (IRS) targeted at one of the most common types of adverse events in hospitals: hospital-associated infections. In this article, we describe an IRS for severe and critical *Clostridium difficile* infection incidents and highlight its key advantages.

Introduction

Since their introduction into the healthcare sector, incident reporting systems (IRSs) have been widely adopted as preemptive methods to monitor and address adverse events and improve quality of care. However, there is little empirical evidence linking incident reporting to improved patient safety outcomes (Mitchell et al. 2015). This is partially owing to the many challenges of using the IRS as a source of learning and improvement within a healthcare setting (Williams et al. 2015). Leading patient safety experts identified five notable challenges with most IRSs: "poor processing of incident reports, inadequate engagement of doctors, insufficient subsequent visible action, inadequate funding and institutional support of incident reporting systems and inadequate usage of evolving health information technology" (Mitchell et al. 2015). Despite these challenges, the IRS is still viewed as an important tool for patient safety if used in a targeted manner (Mitchell et al. 2015).

Hospital-associated infections (HAIs) are one of the most common types of adverse events in healthcare facilities, affecting more than 200,000 Canadian patients annually (PHAC 2013). At our multi-site organization, the University Health Network (UHN), an academic health sciences centre with 821 acute care beds and over 35,000 admissions per year, we first integrated occurrences of HAIs leading to significant patient safety impact into the organizational IRS in 2008. Our motivation was to ensure that HAIs resulting in severe sequela or death were debriefed in a formal manner and brought to the attention of senior administrators and clinical leaders. Here, we describe the results of a qualitative review of our IRS for severe and critical incidents involving *Clostridium difficile* infection (CDI) between 2009 and 2014, highlighting key challenges with the original system design and impacts of the system.

Methods

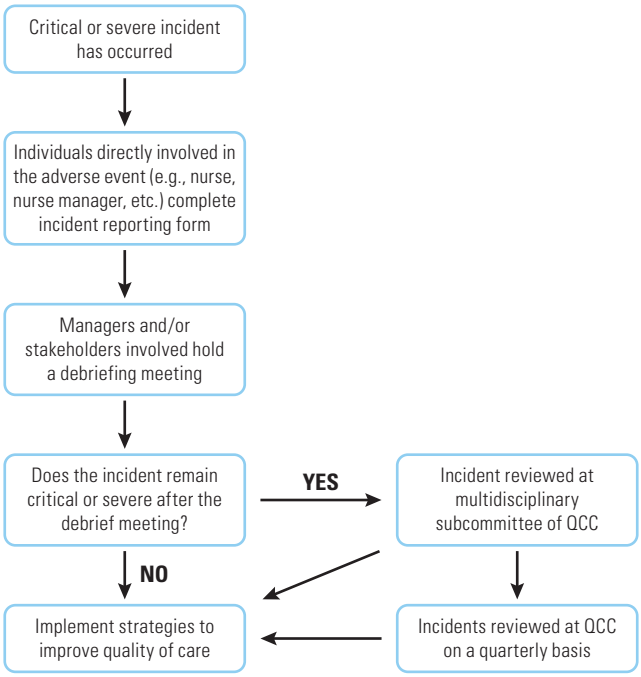
We conducted a retrospective, qualitative review of UHN's IRS for severe and critical CDI events spanning from 2009 to 2014, to characterize its design and potential impacts. For CDI events, a critical outcome is defined as any patient who died within 30 days of a nosocomial CDI diagnosis, whereas a severe outcome is defined as any patient who either underwent a colectomy (partial/full) due to nosocomial CDI or was part of a *C. difficile* outbreak. Data were obtained from the UHN

IRS database, critical/severe incident debrief reports (IDRs), meeting minutes from a multidisciplinary subcommittee of the quality of care committee and informal interviews with experts understanding the various aspects of the design and implementation of the IRS. Predominantly, these experts were infection prevention and control staff and review committee members. Recurrent themes, patterns and insights were extracted by one study team member to identify key challenges and impacts.

Results

The IRS for HAIs at UHN operates in a multi-tier capacity (Figure 1). During the reporting phase, an electronic IDR captures generic information, including incident location(s), impacted person(s) and a summary of the infection control issues. Incidents are classified by severity, ranging from minor to critical depending on the consequences to the patient. The individuals directly involved in an adverse event, such as a nurse manager, charge nurse or infection control professional, are responsible for completing the IDR. The IDR prompts the user to identify systematic and individual root causes of error by selecting from a predetermined list of factors.

FIGURE 1.
UHN's IRS flow chart for severe and critical CDI events



CDI = *Clostridium difficile* infection; IRS = incident reporting system; UHN = University Health Network; QCC = Quality of Care Committee.

A subsequent form called the critical/severe IDR is completed for all critical or severe incidents. This form captures more detailed patient safety information and recommendations following a formal investigation led by the relevant nurse manager. These reports are completed and signed off by the nurse manager but also require input from various stakeholders such as physicians involved in the patient's care, infection control professionals, housekeeping staff and administrators.

All infection control incidents classified as critical or severe are flagged for mandatory review by a multidisciplinary subcommittee of the hospital quality of care committee. This multidisciplinary committee ensures that contributing factors are identified and recommendations are put in place to prevent reoccurrence.

Patient safety learnings are aggregated and disseminated through two mechanisms: immediate dissemination to the appropriate units/staff by the nurse manager, and reporting on a quarterly basis to the hospital quality of care committee. The quality of care committee reports to the UHN Board of Trustees.

A total of 45 relevant incidents occurred during the study period: 31 severe and 14 critical. We reviewed 13 critical/severe IDRs and 38 meeting minutes, and performed informal interviews with seven experts. From this, we identified four key challenges with our IRS: limited input of clinical data surrounding the incident, difficulty maintaining diversity in the multidisciplinary review committee, shortage of measurable action items resulting from the IRS process and variable feedback wait time. As the IRS became increasingly accepted into the organizational safety culture, interviewed experts felt that participation in the review process by physicians and other key stakeholders improved. The other challenges continued to be observed to varying degrees over the entire study period.

A number of organizational changes and quality improvement initiatives have propelled forward in response to the IRS system for severe and critical CDI events (Table 1). Interviewed participants felt that these initiatives would not have gained the necessary traction with senior hospital administrators or engagement of important stakeholders without the IRS. They also remarked that introducing the new system helped to shift away from a culture of blame and policing associated with infection control and instead encouraged shared accountability and learning.

Discussion

We describe a multi-tiered IRS for severe and critical CDI events that elicits the input of various stakeholders and promotes interprofessional learning. Challenges identified with our system have been noted in previous reports of IRSs (Mitchell et al. 2015). Some of the problems, such as the quality of inputted data and feedback wait times, can be ameliorated with focused training of users. The shortage of measurable action items resulting from incident reviews is more difficult to change, as recommendations often involve policy changes

that would be resource-intensive to evaluate. Several important quality improvement initiatives were bolstered by the IRS, including introduction of a more rapid detection method for *C. difficile* and introduction of a sporicidal cleaning agent as the standard hospital disinfectant. These costly changes would otherwise have taken longer to implement or may not have gained approval by hospital administrators.

TABLE 1.
Quality improvement strategies that were influenced by the IRS

Change/initiative	Rationale
Augmentation of ASP	To support clinicians in reducing overuse of antibiotics
Replacement of enzymatic immunoassay with real-time PCR assay for laboratory detection of *C. difficile*	To improve turnaround time and sensitivity of *C. difficile* testing
Development of a comprehensive algorithm for management of first episode of CDI	To standardize and improve the quality of medical care so patients will experience prompt diagnosis, appropriate treatment and adequate monitoring for response to therapy
Development of policies to improve communication during transfer of isolated patients	To reduce transmission of the organism during patient transfers
Increased standardization of environmental services processes across hospital sites	To create uniform cleaning regimens across hospital sites and ensure appropriate resources were available to adhere with cleaning best practices, in order to reduce transmission between patients
Change to a sporicidal cleaning agent as the standard hospital disinfectant	To reduce burden of *C. difficile* spores from unknown chains of transmission and remove human error in selecting appropriate cleaning agents according to infection control needs

ASP = Antimicrobial Stewardship Program; *C. difficile* = *Clostridium difficile*; CDI = *C. difficile* infection; IRS = incident reporting system.

We note limitations to our study. Owing to the small number of cases meeting inclusion criteria and relatively short duration of the study, it was not possible to determine if a significant change in CDI colectomy and mortality rates occurred as a result of the IRS implementation. Our primary goal in undertaking this study was to understand the advantages and disadvantages of our IRS to guide process improvement and enhance resultant learnings. Second, the development of our IRS for severe and critical CDI incidents was an iterative process guided by our specific organizational priorities and needs. Other organizations considering implementing a similar system would have to contextually adapt this model prior to implementation. In addition, the findings and conclusions from our study can also be generalized and applied to all safety events within healthcare organizations. HQ

Acknowledgements

This research was supported by internal resources of the UHN Infection Prevention and Control Department.

All authors report no conflicts of interest relevant to this article.

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Emergency Department Use: Influence of Connection to a Family Physician on ED Use and Attempts to Avoid Presentation

Lynette D. Krebs, Scott W. Kirkland, Cristina Villa-Roel, Alan Davidson, Britt Voaklander, Taylor Nikel, Rajiv Chetram, Stephanie Couperthwaite, Garnet Cummings and Brian H. Rowe

Abstract

Some low-acuity emergency department (ED) presentations are potentially avoidable with improved primary care access. The majority of ED patients (74.4%) in this study had a family physician, but the frequency of visits varied substantially. The variable frequency of patients' visits to these providers calls into question the validity of linkage assumptions. Several sociodemographic factors were associated with having a family physician, including female sex, being married/common law, race (Caucasian), being employed over the previous 12 months and having received a flu shot in the past year. These factors need to be explored further.

Introduction

Emergency departments (EDs) are important healthcare settings for patients with acute healthcare needs. The demand for ED services has been increasing internationally (Tang et al. 2010). In Canada, volume increases have exacerbated ED crowding and its associated problems (Bullard et al. 2009; Schull et al. 2002). Crowding creates an inability to provide quality patient care, delays in time-sensitive treatments, premature termination of patient encounters and overwhelming anxiety for staff (Bond et al. 2007; Derlet and Richards 2000; Hoot and Aronsky 2008). Canadian data from 2014-2015 indicated that delays are common for discharged (mean = 7.6 hours) and admitted (who spend approximately five times longer in the ED) patients (AHS 2015). Compared with the UK system, where a 4-hour rule has been operational for more than a decade, these numbers are extremely high (Affleck et al. 2013).

Understanding the reasons for ED presentations is an important step in developing strategies to decompress EDs. In 2004, a survey of 894 adult patients presenting to two high-volume, academic hospital EDs in Edmonton, Alberta, was performed. The survey found that 21% of the patients had no link to a family physician, and multivariable logistic regression analysis identified that not having a family physician was significantly associated with not attempting to seek alternative care prior to ED presentation (Han et al. 2007).

Since then, many aspects of local and Canadian health delivery have changed. Restructuring of the health system has occurred in many provinces, and new initiatives to increase primary care access by linking residents with a primary care provider (PCP) and reducing ED use have been implemented. Up-to-date information on patients' linkage to family physicians, as well as barriers and facilitators to connection, is needed to prevent or avoid unnecessary ED presentations in the context of these system-level changes.

Use of the ED by non-urgent and low-acuity patients is documented in several studies (Burnett and Grover 1996; Richardson and Hwang 2001). Canadian data support that

the lack of a PCP and limited continuity of care with that physician are both associated with increased ED use (Ionescu-Ittu et al. 2007). Additionally, Canadian estimates suggest that less than 30% of ED patients seek care from a PCP prior to ED presentation (Afilalo et al. 2004). Further exploration is required to understand patients' PCP connection to assist in diverting non-urgent, low-acuity patients from the ED.

This study examines adult patients who presented to the ED and their "connection" to a family physician and explores the factors associated with PCP connection, as well as the reasons for not having a family physician.

Further exploration is required to understand patients' PCP connection to assist in diverting non-urgent, low-acuity patients from the ED.

Methods

Study design

A cross-sectional survey of patients presenting to the ED was completed from May 2013 to July 2013 at three hospitals in Alberta, Canada: the Royal Alexandra Hospital (RAH), Northeast Community Health Centre (NECHC) and the University of Alberta Hospital (UAH). The RAH and the UAH are major trauma referral centres and collectively manage over 130,000 ED visits annually. The NECHC is a community ED serving a high-density area. These hospitals manage a diverse patient population, including inner city (RAH) and ethnically diverse (RAH, NECHC) populations. Each of the hospitals is staffed by full-time emergency physicians and trainees.

Study participants

Patients presenting to the ED were eligible for inclusion, provided they were 17 years of age or older and were assigned a Canadian Triage and Acuity Scale (CTAS) score of 3 or higher (Beveridge et al. 1999). This valid and reliable five-level triage tool, used across Canada's EDs, determines the timing of patient assessment based on severity of presentation, with a score of 1 requiring immediate medical attention and a score of 5 being least urgent. The most responsible physician provided consent to approach patients with higher CTAS scores whose symptoms had resolved. Patients were ineligible for the study if they were cognitively impaired, deemed too unwell (e.g., nausea, pain or intoxication), had been previously enrolled, were direct consultations, presented to the ED for imaging tests only or a pre-set appointment for intravenous therapy or were under police escort. Where the ability of the patient to provide informed consent was uncertain (e.g., apparent intoxication, cognitively impaired), the attending physician or nurse was approached regarding the patient's ability to consent. Patients who were unable to read or communicate in English were excluded, unless a friend or family member was able to complete the questionnaire on their behalf.

Survey methods

A non-stratified, cluster-based random sampling method was used. Using a computerized random number generator, each week was assigned to one of three ED registration periods: 0700–1300, 0900–1500, or 1300–1900. The randomization was balanced, ensuring each ED registration period occurred at least once at each site. During each registration period, patients were assigned a number based on their presentation time. A series of numbers from 1 to 30 were randomly generated, which identified the order in which patients were approached for the study.

The 47-item questionnaire used in this study was modified from a previously validated survey (Han et al. 2007). In addition to existing questions on demographic characteristics, health practices and care-seeking behaviour, the survey was modified to include additional questions on risky health practices. Individuals were able to complete the questionnaire independently (in paper or computerized tablet form) or in an interview with research staff. The questionnaire took approximately 15–20 minutes to complete.

Sample size

The sample size calculation method is described in detail elsewhere (Han et al. 2007). Briefly, based on estimates from previous research conducted at two of the study sites (UAH and RAH), the proportion of ED patients without a family physician was 21%. In order to obtain a precision of approximately 3% surrounding the point estimate, a sample size of approximately 500 patients from each site was required, for a total recruitment of approximately 1,500 patients. The sample size required for a more precise estimate was prohibitive, given the resources available for this study.

Statistical analysis

Data were entered into Microsoft Excel (Microsoft Corp., Redmond, WA) and analyzed using the Statistical Package for the Social Sciences (SPSS Inc., version 13.0, Chicago, IL). Dichotomous variables were reported as percentages; continuous variables were reported as means and standard deviations (SDs) or medians and interquartile ranges (IQRs), where appropriate.

Bivariate analyses (Student's t test, Mann–Whitney U test, chi-square test and Fisher's exact test, where appropriate) were used to compare those patients who had a PCP and those who did not. Using a multivariable logistic regression model (backward Wald techniques; model entry set at $p = 0.2$ and model removal set at $p = 0.15$), factors associated with ED patients having a family physician were identified.

Ethics

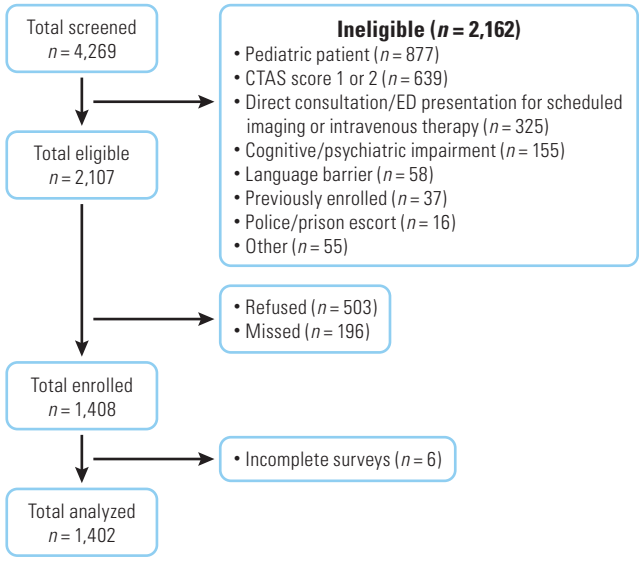
The study protocol and processes were reviewed and approved by the Health Research Ethics Board (Pro00039886) at the University of Alberta.

Results

Sampling

A total of 4,269 patients were screened. Of the 2,107 eligible patients, 503 patients refused and 196 were missed (i.e., research staff could not locate the patient at the time of their selection for participation). A total of 1,402 (66.5%) questionnaires were analyzed (Figure 1). Six participants were excluded from the analysis owing to a failure to report whether they had a family physician.

FIGURE 1.
Patient recruitment flow diagram



ED = emergency department.

Participant characteristics

Patient characteristics are summarized in Table 1. Briefly, among patients who reported having a family physician, the mean age was 48.9 years (SD: 20.0), which was higher than the group without a PCP (mean: 34.2 years; SD: 14.6). Patients with a family physician were predominantly female and Caucasian. The majority presented with complaints related to illness and/or injury, and most commonly had an initial CTAS score of 3.

Family physician connectivity

The majority of patients (n = 1,043 [74.4%]) reported that they had a family physician. Frequency of family physician visits varied substantially, ranging from the most recent visit 1 hour before ED presentation to the longest reported contact of 45 years previously (median: 4 weeks; IQR: 1, 12). Overall, 32.7% of the patients with a family physician presented to the ED with a recurring problem for which they were currently receiving treatment and 41.0% reported that they had visited the ED for this condition before. Approximately 35% of the patients reported seeing a physician prior to ED presentation. Of all patients who reported having a family physician, 18.6% reported visiting them prior to presenting to the ED.

Factors associated with having a family physician for ED patients

Several statistically significant differences were identified through the univariate analysis between patients who reported having a family physician and those who did not, primarily sociodemographic variables (Table 1). Individuals who were male, not married, non-Caucasian, had no more than a high school education,

TABLE 1.
Demographic characteristics of patients who do and do not have a family physician

Variable	Total participants; n = 1,402*	Has family physician; n = 1,043*	No family physician; n = 359*	MD (95% CI) or OR (95% CI)§
Female sex	751/1,371 (54.8)	611/1,021 (59.8)	140/350 (40.0)	2.24 (1.75, 2.86)
Mean age (SD), yr	45.2 (19.8)	48.9 (20.0)	34.2 (14.6)	14.70 (12.72, 16.67)
Preferred not to answer	60	46	9	
Marital status				
Married/common-law	625/1,356 (46.1)	517/1,011 (51.1)	108/345 (31.3)	2.30 (1.77, 2.98)
Not married¶	731/1,356 (53.9)	494/1,011 (48.9)	237/345 (68.7)	
Ethnic background				
Caucasian/European	962/1,340 (71.8)	748/1,001 (74.7)	214/339 (63.1)	1.73 (1.33, 2.25)
Non-caucasian/European¶	378/1,340 (28.2)	253/1,001 (25.3)	125/339 (36.9)	
Sexual orientation				
Heterosexual	1,177/1,238 (95.1)	884/929 (95.2)	293/309 (94.8)	1.07 (0.60, 1.93)
Non-heterosexual¶	61/1,238 (4.9)	45/929 (4.8)	16/309 (5.2)	

TABLE 1.
Continued

Variable	Total participants; *n* = 1,402*	Has family physician; *n* = 1,043*	No family physician; *n* = 359*	MD (95% CI) or OR (95% CI)[§]
Educational level				
≤High school	625/1,342 (46.6)	449/1,000 (44.9)	176/342 (51.5)	0.77 (0.60, 0.98)
>High school[¶]	717/1,342 (53.4)	551/1,000 (55.1)	166/342 (48.5)	
Employment status				
Employed	749/1,351 (55.4)	525/1,007 (52.1)	224/344 (65.1)	0.58 (0.45, 0.75)
Unemployed or other[¶]	602/1,351 (44.6)	482/1,007 (47.9)	120/344 (34.9)	
Residence				
Fixed address	1,319/1,360 (97.0)	989/1,013 (97.6)	330/347 (95.1)	0.47 (0.25, 0.89)
No fixed address/ Shelter/homeless[¶]	41 (3.0)	24 (2.4)	17 (4.9)	
Living situation				
Assisted living	23/1,345 (1.7)	21/1,006 (2.1)	2/339 (0.6)	3.59 (0.84, 15.40)
Independent living[¶]	1,322/1,345 (98.3)	985/1,006 (97.9)	337/339 (99.4)	
Health behaviours				
Consumes alcohol	778/1,371 (56.7)	550/1,022 (53.8)	228/349 (65.3)	0.62 (0.48, 0.80)
Drug use other than alcohol	160/1,327 (12.1)	99/997 (9.9)	61/330 (18.5)	0.49 (0.34, 0.69)
Current smoker	433/1,379 (31.4)	280/1,026 (27.3)	153/353 (43.3)	0.49 (0.38, 0.63)
Had a flu shot in the past year	454/1,369 (33.2)	384/1,021 (37.6)	70/348 (20.1)	2.39 (1.78, 3.20)
Injury and/or illness presentation	1,085/1,355 (80.1)	800/1,010 (79.2)	285/345 (82.6)	0.80 (0.58, 1.10)
Severity (CTAS score)				
Urgent	811/1,402 (57.8)	629/1,043 (60.3)	182/359 (50.7)	0.80 (0.63, 1.02)
CTAS score 2	1 (0.1)	1 (0.1)	0 (0)	
CTAS score 3	810 (57.8)	628 (60.2)	182 (50.7)	
Non-urgent[¶]	591/1,402 (42.2)	414/1,043 (39.7)	177/359 (49.3)	
CTAS score 4	510 (36.4)	372 (35.7)	138 (38.4)	
CTAS score 5	81 (5.8)	42 (4.0)	39 (10.9)	
Mode of arrival				
Independent arrival	527/1,400 (37.6)	360/1,041 (34.6)	167/359 (46.5)	0.61 (0.48, 0.78)
Non-independent arrival[¶]	873/1,400 (62.4)	681/1,041 (65.4)	192/359 (53.5)	

MD = mean difference; CI = confidence interval; OR = odds ratio; CTAS = Canadian Triage and Acuity Scale.

*Unless otherwise indicated. Total *n*-values presented here do not include respondents who selected "prefer not to answer" to the question. [§]Unadjusted. [¶]Reference group.

were employed in the previous year, had no fixed address, currently smoked, consumed alcohol or used drugs other than alcohol were all less likely to have a family physician. Non-significant variables (i.e., sexual orientation and current residence) were retained in the multivariable logistic regression owing to their potential clinical relevance in predicting ED patients' PCP connection.

The multivariable logistic regression identified several statistically significant associations with having a family physician. Individuals who were male, were not married, were non-white, had not received a flu shot in the previous 12 months and were employed over the previous 12 months were all less likely to have a family physician (Figure 2).

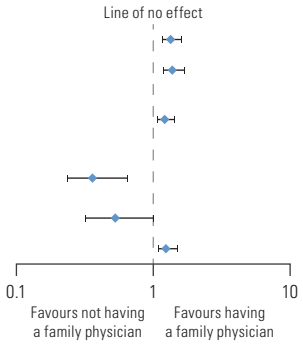
Reasons for not having a family physician

Among the 359 ED patients who reported not having a family physician, 334 (93.0%) provided reasons for this lack of connection. Reasons included having their previous physician leave, retire or die (66 [19.8%]); not attempting to find a family

physician (64 [19.2%]); having recently moved to Alberta (60 [18%]); being unable to find a family physician (55 [16.5%]); and not perceiving a need for a family physician (27 [8.1%]).

FIGURE 2.
Adjusted ORs for factors associated with having a family physician among 1,402 patients with non-urgent presentations to Edmonton emergency departments

Variable	Adjusted OR (95% CI)
Female sex	2.15 (1.58, 2.91)*
Married (vs. not married)	2.25 (1.64, 3.07)*
Caucasian (vs. non-Caucasian)	1.75 (1.25, 2.45)*
Employed (vs. unemployed or other)	0.60 (0.43, 0.83)*
Current smoker	0.75 (0.55, 1.03)
Flu shot	1.83 (1.28, 2.61)*



CI = confidence interval; OR = odds ratio.

*Significant at <0.05.

Point estimates are represented by circles and the 95% CI are represented by the lines and bars

Discussion

Overall, this study illustrated that a high proportion of ED patients have a family physician (74.4%); leaving an important 25.6% without this PCP. Only 18.6% of the patients who had a family physician visited them prior to ED presentation. Multivariable analysis highlighted that males, individuals who were not married, individuals who did not identify their racial background as white, individuals who had not received a flu shot in the past year and individuals who were employed over the past 12 months were all less likely to have a family physician. These factors highlight the impact of sociodemographic issues on patients' access to healthcare.

The results of this study corroborate previous research exploring vulnerable populations' access to family physicians. An Edmonton-based survey found 60% of homeless or substance-using patients reported having a family physician, compared with 76% of patients with stable housing and no current alcohol or substance use issues (Dong et al. 2013). In addition, only 43% of an adult homeless population in Toronto reported having access to a family doctor (Khandor et al. 2011). These findings may highlight one of the barriers vulnerable populations face in obtaining a family physician: physician restrictions on patient acceptance. As populations that are more likely to encounter this barrier (i.e., non-English speakers, cognitively impaired individuals) are often underrepresented in this type of research, the findings of this study may underrepresent the relationship between these sociodemographic factors and PCP connection.

Despite consensus surrounding the value of PCPs and a medical home for all patients, 15% of the general population in Canada report difficulty accessing routine primary care (Sanmartin and Ross 2006). Impaired access is exacerbated among immigrants, and higher hospitalizations have been demonstrated for indigenous peoples (when compared with the general population, geographic control group and socioeconomic control group) (Asanin and Wilson 2008; Sanmartin and Ross 2006; Shah et al. 2003). Differential use in physician services by socioeconomic status also persists (Dunlop et al. 2000). Cumulatively, this work suggests that these sociodemographic factors may be common – and may cluster – among many traditionally labelled "vulnerable" populations (e.g., immigrants, homeless and other transient populations) and highlights persistent inequities in primary care access. Intervening on common factors may provide more substantial effects than intervening by specific population groups. Better understanding of the barriers to securing a family physician for some populations as well as strategies to improve the timely access to a family physician or other PCPs by all patients require further study.

Many believe connection to a family physician is vitally important. Previous work in North America supports the importance of family doctors in reducing ED visits, with US estimates of nearly 50% of ED patients reporting barriers to primary care as their reason for ED presentation (Grumbach et al. 1993). US regions with more general practitioners and family physicians had lower hospitalization rates for conditions that are preventable or can be detected early (e.g., hypertension, pneumonia and diabetes mellitus) (Macinko et al. 2007). Similar findings are reported in Canada, where national data based on triage scores suggest approximately 50% of ED visits are less urgent or non-urgent and may be effectively handled in primary care settings (CIHI 2005). Despite an increasing number of PCPs and family physicians affiliated with a primary care network (PCN), accessibility to a PCP has decreased and a shortage of family physicians remains widely acknowledged, with only 17.5% accepting new patients without any restrictions (21.4% in the study region) (College of Family Physicians of Canada 2010; Safarov et al. 2012). Despite recent efforts to increase primary care access, more patients reported not having a family physician in this study (25.6%) than in similar surveys conducted in the region in 2004 (21%) (Han et al. 2007). This suggests that current strategies to increase PCP connection are failing and need to be revised in order to address the reasons patients in this study provided for lack of connection. It may be possible to increase PCP access in ways other than increasing the gross number of family practitioners, such as providing PCP access at multiple sites or outside of regular office hours, increasing the use of mid-level care providers such as physician assistants or nurse practitioners (as has been done in PCNs)

or implementing community outreach services to mitigate geographical or transportation barriers (Price et al. 2013). Additionally, current strategies to connect patients when they first relocate or when their PCP ceases to practice do not appear to be effective, given that the majority of patients without PCPs reported barriers to finding one rather than the perception of not needing one. Increased efforts in these areas are needed.

Although the majority of ED patients in this study had a family physician, few (18.6%) saw them before ED presentation. This finding is mirrored nationally and across North America, where the limited effect of having a family physician or a regular source of primary care on ED use is reported (Afilalo et al. 2004; Baker et al. 1994). These data suggest that future strategies to divert patients with low-acuity, non-urgent presentations from the ED will require a multi-faceted strategy beyond solely linking patients with a PCP. Increasing patient attachment to their PCP may also be important. Under attachment theory, four different styles of patient attachment have been linked to different levels of healthcare utilization, including primary care visits (Ciechanowski et al. 2002); however, the role of attachment styles in ED presentations has not been well studied. Ciechanowski et al. (2002) found differences in the frequency of PCP visits based on patients' attachment styles. In addition, others have observed that the majority of patients included in ED samples have insecure attachment styles (Klest and Philippon 2016; Maunder et al. 2006). These differences in attachment could help to explain the high rates of ED presentations among patients who report having a family physician, and may point towards improving physician–patient relationships through altered communication styles, especially for patients with insecure attachment types (Hooper et al. 2012).

Limitations

This study had several limitations. First, only CTAS 3-5 patients were eligible for the study and a higher proportion of CTAS 3 (moderate-acuity) compared with CTAS 4 or 5 (low-acuity) patients were enrolled in the study. One CTAS 2 patient was enrolled, following the resolution of their symptoms. Overall, more severe illness was underrepresented in the study population. We do not feel these observations represent a bias in the results, as CTAS 1 and 2 patients all clearly require ED services and any delays associated with their ED presentation would not be relevant to ambulatory care use of the ED. Second, the study was limited to three urban ED sites in one northern Canadian city, making the generalizability of these results unclear. Differences observed in patients' baseline characteristics suggest that regional variation in ED use may exist even within this community. Expanding this research to different areas (e.g., rural vs. urban, non-Alberta locations) may facilitate a more comprehensive understanding of patients' care-seeking behaviours. Third, this study only captured recent visits to family physicians; more granular details on PCP "connectivity" were not obtained. Fourth, previous Canadian data confirm the importance of ethnicity/cultural background and immigrant status in access to primary care, as well as geographic location (Asanin and Wilson 2008; Dunlop et al. 2000; Ionescu-Ittu et al. 2007; Shah et al. 2003). The current study excluded all non-English speakers and intoxicated and cognitively impaired patients and, therefore, may have underrepresented populations who experience greater difficultly connecting with a family physician. Further research is required to understand how these factors influence ED patients' access to and use of primary care services.

… the majority of patients without PCPs reported barriers to finding one rather than the perception of not needing one.

Conclusion

Notwithstanding the above potential limitations, the results of this study illustrate an increasing proportion of ED patients have no identified family physician. Furthermore, the study confirms that, of the large proportion of patients who can identify their family physician, few access their physician prior to visiting the ED. Rather, the ED is viewed as the most appropriate place for care at the time of the illness or injury. The results highlight that several sociodemographic factors, which are typically clustered in vulnerable populations, are associated with not having a family physician. These results should stimulate further research to identify common barriers that many patients face when trying to engage and connect with a PCP. This will be a necessary step in developing strategies to improve connectivity, particularly for complex populations. HQ

Acknowledgements

The authors would like the thank Danielle DeVuyst, Elfriede Cross, Dr. Don Voaklander and Dr. Maria Ospina for their assistance with this study. This research was supported by the Emergency Medicine Research Group (EMeRG) in the Department of Emergency Medicine at the University of Alberta, Alberta Health Services (AHS) through the Emergency Strategic Clinical Network (ESCN), Alberta Innovates Health Solutions (AIHS) through the Partnership for Research and Innovation in the Health System (PRIHS-2) grant and the Brain Care Centre (all in Edmonton, Alberta, Canada). Rajiv Chetram was supported by a Summer Studentship from the Alberta Centre for Injury Control and Research (ACICR) in the School of Public Health, University of Alberta. Bryn Holroyd was supported by an AIHS Summer Studentship. During the study, Dr. Villa-Roel was supported by the Canadian Institutes of Health Research (CIHR) in partnership with the Knowledge Translation branch. Dr. Rowe is supported by the CIHR as a Tier I Canada Research Chair in Evidence-based Emergency Medicine through the Government of Canada.

Contributions

The project was conceived by BHR, RC and GC. All named co-authors participated sufficiently in the project to claim authorship based on international standards for authorship. SWK coordinated the study; RC, AD, TN, BV, BH and SWK collected the data. Data management was provided by SC and CV-R. LDK completed the analysis. Funding was secured by BV and BHR. All authors contributed to editing the manuscript and are able to take responsibility for the finished product. The Government of Canada and funders played no role in the conduct of the study and take no responsibility for the content of this project.

Presentations: Presented in part at the Western Emergency Department Operations Conference (WEDOC) in Alberta, Canada, 2014; Canadian Emergency Physician Association (CAEP) Conference in Ontario, Canada, 2014; and the International Conference on Emergency Medicine (ICEM), in Hong Kong, 2014.

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Primary Care Collaborative Memory Clinics: Building Capacity for Optimized Dementia Care

Linda Lee, Loretta M. Hillier, Frank Molnar and Michael J. Borrie

Abstract

Increasingly, primary care collaborative memory clinics (PCCMCs) are being established to build capacity for person-centred dementia care. This paper reflects on the significance of PCCMCs within the system of care for older adults, supported with data from ongoing evaluation studies. Results highlight timelier access to assessment with a high proportion of patients being managed in primary care within a person-centred approach to care. Enhancing primary care capacity for dementia care with interprofessional and collaborative care will strengthen the system's ability to respond to increasing demands for service and mitigate the growth of wait times to access geriatric specialist assessment.

Introduction

With the aging population and anticipated increase in the prevalence in dementia over the next two decades, the healthcare system will be challenged to meet the complex care needs of these individuals (Smetanin et al. 2009). Dementia is underdiagnosed and undertreated, resulting in a high burden of suffering, excessive emergency department visits, hospitalizations and high healthcare costs (Bradford et al. 2009; Koch and Iliffe 2010). As high as one-quarter to two-thirds of persons with dementia remain undiagnosed (Bradford et al. 2009), placing them at increased risk for delirium, motor vehicle accidents, medication errors and early institutionalization (Sternberg et al. 2000). Underdiagnosis has been attributed to lack of knowledge about dementia, inadequate training for diagnosis, limited use of validated assessment tools and system challenges such as insufficient time to manage chronic conditions (Aminzadeh et al. 2012; Bradford et al. 2009). Even when the diagnosis is made, primary care physicians are not confident in their ability to manage dementia, describing it as more difficult to manage than other chronic diseases (Harris et al. 2009); consequently, there is a high reliance on specialist physicians for the diagnosis and management of dementia (Logiudice et al. 1999; Luce et al. 2001). Yet, Canada faces a critical shortage of geriatricians (Hogan et al. 2012) and wait times to access specialist care can be lengthy, commonly 6 to 12 months (Massoud et al. 2010), which can further impede early diagnosis and intervention and result in loss of control of other chronic conditions.

It is increasingly recognized that primary care has an important role to play in the management of chronic diseases, which in comparison with specialist care can increase equitable access to care, reduce care costs with early community-based interventions that can prevent crises that result in hospitalization and increase access to more appropriate services, resulting in improved health outcomes (Starfield et al. 2005). As well, primary care is well-positioned to provide person-focused care (Starfield 2011). Recently, the American Geriatric Society has

emphasized the importance of a person-centred care approach to care, which can meet the aims of improving healthcare safety, quality and coordination, as well as quality of life for older adults (American Geriatrics Society Expert Panel on Person-Centred Care 2016). Given the escalating demand for elder care, which exceeds what specialists can provide, new care delivery models are needed to build capacity in primary care for person-focused dementia care.

An innovative model in Ontario leverages the strengths of primary care and specialist care in a collaborative approach to person-focused care. In 2006, the Centre for Family Medicine (CFFM) Family Health Team, Kitchener, Ontario, developed a primary care-based collaborative memory clinic (PCCMC) model as a unique collaborative care approach to building capacity for dementia care at the primary care level for timely access to comprehensive assessment and high-quality, proactive, person-centred care for persons with dementia and other memory disorders. This family physician-led care model uses an evidence-informed, interdisciplinary team approach, with synergistic information sharing and a shared care approach, optimizing efficiency of dementia care. Described in detail elsewhere (Lee et al. 2010; Lee et al. 2014b), this care model is based on a the Chronic Care Model (Wagner et al. 1996) and represents an ideal chronic disease management approach in that it triages patients based on need, maintaining care for the majority at the primary care level and referring to specialists only the most complex of cases that require high-intensity management (Scott 2008). A flow diagram of the clinic model is presented in Figure 1. Within this care model, assessment consists of evidence-based multi-domain cognitive and functional ability tests and in-depth information obtained from the patient and care partner (Lee et al. 2010). Comprehensive and proactive care plans are customized to the need of each patient–care partner dyad, which, along with the support of the interdisciplinary team, enhance the capacity of local family physicians to provide better dementia care.

In 2008, an accredited training program was established to facilitate the establishment of PCCMCs in other primary care settings. This training program, which consists of a two-day workshop, one-day observership and two days of individualized mentorship, is rooted in current learning theory that supports active engagement of participants, role-modelling, situated learning experiences and opportunities to apply new learning in practice (Mann 2002). This program is described elsewhere, and several studies have demonstrated the effectiveness of this training program in changing clinical practice and its success in establishing new PCCMCs (Lee et al. 2011; Lee et al. 2013, 2014c).

There is growing interest in PCCMCs. By the end of 2015, over 500 healthcare professionals working in 77 primary care settings completed the training program, resulting in new PCCMCs being established across the province of Ontario; these clinics serve over 1,000 family medicine practices with a combined patient base of over 1,500,000, representing 1/10 of Ontario's population base. These multidisciplinary clinics consist, at a minimum, of family physicians; nurses (registered nurses, registered practical nurses or nurse practitioners); and, as available, social workers, pharmacists, occupational therapists and other allied healthcare professionals. Some teams include representatives from the local Alzheimer Society to facilitate timely integration with community-based services and support. Specialists (geriatricians, geriatric psychiatrists) are designated to each clinic and agree to provide telephone, videoconferencing or e-mail consultation support to team members and, when necessary, direct patient consultation by referral. Specialists also support the collaborative endeavour by participating as invited speakers in annual regional "booster" days for the PCCMCs, which serve as an opportunity to provide updates in dementia care and strengthen the collaborative relationship between the clinic teams and supporting specialists. Typically, the PCCMCs operate one day per month initially, and the frequency of clinics may increase to as often as one day per week depending on wait times for assessments.

This paper aims to describe the significance of PCCMCs within the system of care for older adults with dementia in Ontario, supported with data from ongoing evaluation studies documenting outcomes related to access to care, referrals to specialists and person-centred care.

Methods

This study was approved by the McMaster University Integrated Research Ethics Board.

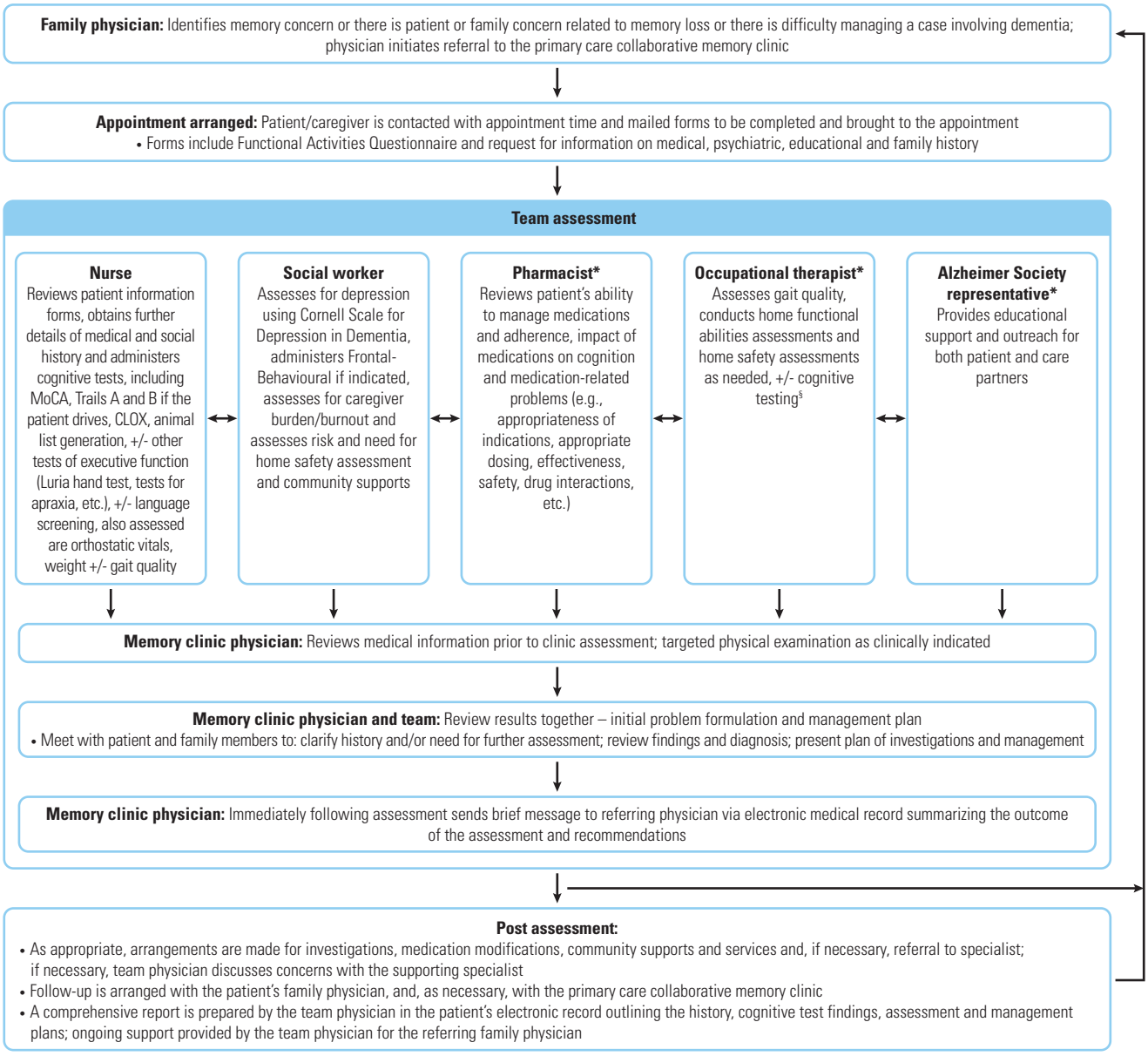
Participants

All individuals (N = 364) representing family health teams (FHTs) and community health centres (CHCs) in 15 PCCMC training program sessions held from October 2008 to June 2014 were invited to participate in this study. Attendees represented 46 primary care settings (N = 41 FHTs; N = 5 CHCs), in addition to individuals (N = 2) being trained for the flagship CFFM PCCMC.

Study design and outcome measures

This study used a survey methodology and prospective tracking of referrals to the PCCMCs. Training program participants completed online surveys prior to the training workshop and six months following completion of the program. The pre-program survey gathered information on participants' discipline, years in clinical practice and how well their academic training prepared them to manage cognitive impairment, as rated on a 5-point scale (1 = not at all; 5 = extremely well). In the post-program survey, participants were asked to identify at least one way in which patients or family members have benefited from the PCCMC (open-ended responses).

FIGURE 1.
Flow diagram of the primary care collaborative memory clinic model of care



*Although all clinic teams consist, at a minimum, of physicians and nurses, some teams also include other disciplines, most commonly pharmacists, occupational therapists and representatives from the local Alzheimer Society chapter. The inclusion of these disciplines is dependent on available resources.

§The occupational therapist is, consistent with their scope of practice, able to assume many of the same functions as a registered nurse (functional and cognitive assessment).

PCCMCs were considered sustained when they continued to assess patients for at least six months, as verified with referral data provided by each clinic. Thirty-two memory clinics collected information related to patient date of referral, referral status (urgent vs. non-urgent as deemed by the referring physician), age, gender, assessment diagnosis and outcomes and referrals to specialists. Wait time to assessment was calculated as the difference between the date of referral and date of assessment. To characterize the practice settings, clinics were asked to report the number of medical practices and patient base served.

Although all training program participants were invited to complete training program surveys, owing to resource constraints, it was not possible for all clinics to track clinic referrals.

Statistical analyses

Descriptive statistics (frequencies, means, standard deviations) were generated for numeric variables using SPSS 23.0 software. Content analysis (Stemler 2001) was used to identify reoccurring themes in response to open-ended survey questions.

Results

Training program participants

A total of 363 (99.7%) participants completed the pre-program survey; 198 (54.4%) completed the post-program survey. Using identification codes created by participants, it was possible to match 180 pre- and post-program surveys. Sixty percent of the participants were physicians (*N* = 94; 25.8%) and nurses (*N* = 124; 34.1%), with 40% representing various other disciplines (social work, pharmacy and other allied health professionals), and representatives from local Alzheimer Societies. On average, participants were in clinical practice for 13.5 years (standard deviation [SD] = 11.4; range = 0.5–40). Overall, participants did not perceive themselves to be well prepared to manage cognitive impairment (mean ratings of preparation = 2.7, SD = 95).

Established primary care collaborative memory clinics

Of the 46 teams that were trained, 44 established a PCCMC. One team attended the training program but did not intend to establish a clinic; given their strong existing geriatric program, they participated in the training as a capacity-building opportunity. A second team did not sustain their clinic over time, as management indicated that existing timely access to specialists and specialized services precluded their need for a PCCMC. Established PCCMCs served a total of 517 primary care practices, with a combined patient base of 659,702; this is likely much greater as some PCCMCs' open referrals to other local medical practices.

The PCCMCs varied in composition; the number of team members trained per clinic ranged from 3 to 17 (mean = 7.8, SD = 2.9), with some team members being trained to replace departing team members. At a minimum, each clinic trained at least one family physician and one nurse (nurse practitioner or registered nurse), with others also including other disciplines. Twenty-seven clinics trained at least one representative from the local Alzheimer Society, but as some representatives have been trained to support multiple clinics, it is likely that many more clinics have this resource support.

Access to care

Referrals were tracked by 32 PCCMCs from the time of inception of the clinic for up to 23 months (mean = 9.1 months, SD = 4.2, median = 9 months, range = 1–23 months). In total, 1,553 patients were referred for assessment, of which 75% completed an assessment during the study period (Table 1). Of those not assessed, frequent reasons for this included patient refusal, acute illness, hospitalization resulting in assessment elsewhere or death prior to assessment. Few referrals (6%) were deemed urgent. The average wait time for assessment was 1.5 months, though 35% of the patients were assessed within a month of referral. Fewer than 20% of the patients waited more than three months to be assessed. The majority of urgent referrals (80%) were seen within two months of referral. In some cases, patients waited longer (6–10 months) for assessment, most frequently because patients were hospitalized or acutely ill, cancelled multiple appointments, waited for a family member to be available to attend the assessment or were awaiting return from winter sojourns in warmer climes.

TABLE 1.
Referrals to 32 PCCMCs, assessments completed and wait times

Clinic referrals	*n* (%)	Mean (SD) range across clinics
Patients referred	1,553	48.5 (25.6) 6*–125
Patients assessed (% referred)	1,166 (75.1)	36.4 (20.7) 6–84
Patients referred but not assessed (% referred)	173 (11.1)	5.4 (6.5) 0–31
Patients awaiting assessment (% referred)	213 (13.7)	6.2 (8.2) 0–30
Urgent referrals (*N* = 30[§]; % referred)	100 (6.4)	3.3 (3.4) 0–12
Wait time to assessment, months (*N* = 895)		
Within one month referred	315 (35.2)	1.5 (1.8) 0[¶]–10
One to two months	403 (45.0)	
Three or more months	177 (19.8)	
Wait time to assessment for urgent referrals, months (*N* = 69)		
Within one month referred	33 (47.8)	(1.7) 0[¶]–10
One to two months	29 (42.0)	
Three or more months	7 (10.1)	

PCCMCs = primary care collaborative memory clinics; SD = standard deviation.

Note: Percentages may not sum to 100% owing to missing information.

*6 patients from a clinic that was not sustained were included in this study. When this outlier is removed, mean = 49.9 (SD = 24.8), median = 49 and range = 15–125.

[§]Urgency (as deemed by referring physicians) was not tracked by two clinics.

[¶]Zero indicates assessments conducted in less than one month of referral.

Assessment data were available for 1,113 patients who were, on average, 77 years of age (SD = 9.5; range = 38–100); 55% (*N* = 615) were female. The majority of patients (61%;

N = 686) received a diagnosis of dementia (34%; *N* = 383) or mild cognitive impairment (27%; *N* = 303); 5% (*N* = 59) were found to have memory complaints being attributable to other issues or subjective cognitive impairment. The remaining patients were diagnosed with other types of dementia or cognitive deficits associated with other conditions, or a diagnosis had not yet been established. Assessment recommendations were varied and included further investigations, pharmacological recommendations, including new therapies and deprescribing, vitamin and mineral supplementation and various non-pharmacological interventions.

Referrals to specialists

Across all 32 clinics, 9% (*N* = 104/1166) of the patients were formally referred for geriatrician or neurologist assessment (excluding informal consultation between the clinics and their specialist supports). Patients were referred to specialists when diagnosed with suspected frontotemporal or Lewy body dementia, rapidly progressive decline in functioning or cognition, early age-onset dementia or in cases where the diagnosis of dementia was complicated by multiple comorbidities.

Patient-related impacts associated with the PCCMCs

A number of benefits for patients and caregivers associated with the PCCMCs were identified by training participants at follow-up (Table 2), highlighting benefits related to improved and timely access to care close to home, improved quality of care with collaborative team-based care and improved continuity of care.

Discussion

This study demonstrates impacts on capacity building for dementia care in Ontario, Canada, through spread of an innovative healthcare delivery model emphasizing multidisciplinary teamwork and collaborative relationships between primary care and specialist care. There is increasing evidence that collaborative care approaches within primary care can provide effective dementia care (Callahan et al. 2006; Guerriero Austrom et al. 2004). Improved health outcomes have been demonstrated with multidisciplinary team approaches to disease management (Bodenheimer et al. 2014; McAlister et al. 2000; Renders et al. 2001) and when specialists are well integrated into primary care models of care (Vedel et al. 2011). The PCCMC model addresses the need for timely access to care for patients and caregivers in a location close to home, within their primary care setting. The average wait time for assessment in a PCCMC is 1.5 months, comparing very favourably with lengthy wait times to access specialist care, which have been estimated at 6–12 months (Hogan et al. 2012; Massoud et al. 2010), driven by limited supply of geriatricians and cognitive neurologists across Canada. With the enhanced expertise of PCCMC clinicians (Lee et al. 2014), early detection afforded by these clinics ensures that persons with dementia and caregivers have access to treatment, education, counselling and other services that can delay decline, prevent crises, ease caregiver burden and reduce the heavy societal costs associated with long-term institutionalization (Brodaty et al. 1997; Leifer 2003). In other countries, better primary care management has demonstrated significant health system cost savings primarily from reduced hospitalizations and institutionalization (Greaves and Greaves 2011; Greening et al. 2009).

Evidence from this current evaluation study, building on evidence from other studies of the PCCMC model (Lee et al. 2014a; Lee et al. 2010), demonstrates that the PCCMC model makes efficient use of system resources, managing the majority of dementia cases at a primary level with only 9% of patients served in these clinics being referred to specialists, in contrast to up to 82% referral rates of persons with dementia in typical family practice (Pimlott et al. 2006). Consistent with ideal models of chronic disease management (Scott 2008), reduced reliance on specialist referrals contributes to much more efficient use of geriatricians, allowing this limited resource to be reserved for the most complex of cases. To our knowledge, there are no other models of dementia care in the published literature that have demonstrated reduced reliance on referrals to specialist physicians while enhancing quality care at the primary care level. With only 242 geriatricians practicing in Canada (Hogan et al. 2012), the PCCMCs are linked to this essential resource but are also able to alleviate some of the pressure of its use. As wait times to access specialist care can be up to 12 months (Massoud et al. 2010), reducing the number of referrals to those more complex cases that cannot be adequately managed in primary care has the potential to significantly reduce the wait time for specialist care for those who urgently need it. In contrast to usual care for dementia, PCCMCs offer patients and caregivers a new pathway for holistic integrated and collaborative care offered in their home communities, within a familiar environment and with familiar care providers, thereby reducing patient and caregiver stress and supporting more person-centred care. The PCCMC care model is consistent with accepted standards for person-centred care, now considered the gold standard of geriatric care (American Geriatrics Society Expert Panel on Person-Centred Care 2016), including essential elements such as the development and ongoing review of individualized, goal-oriented care plans based on the person's preferences, interprofessional team-based care, active coordination among all healthcare and service providers, continual information sharing and integrated communication (Kogan et al. 2016; Prorok et al. 2013).

TABLE 2.
The ways in which patients and family members benefit from the primary care memory clinics (as identified by participants in the post-program survey, *N* = 198)

Key themes	Illustrative quotes
Care close to home, in a familiar environment	"Receiving service within their community with familiar healthcare providers." "Less stress and concern for assessments done within their team's environment." "Convenience and familiarity for patient to be assessed in their family physician's office, is less intimidating, especially for the elderly."
Improved access to care Subthemes: Timely access to assessment Early access to detection and intervention	"Assess without having to wait and see a geriatrician." "Able to have assessment in timely fashion - seen within 1-2 months (as compared to specialist)." "Much improved access to the team over traditional long wait referrals to specialists."
	"Earlier identification of cognitive deficits through use of our memory clinic." "Early pick up of dementia - patients are started on cognitive enhancers as soon as dementia identified." "Assessed some patients early with reversible causes; once they implemented recommended changes, tested within normal range."
More comprehensive assessment than can be provided within regular family practice Subthemes: More time devoted to assessment Expert/ knowledgeable care team	"A more thorough, complete assessment from beginning to end with recommendations and treatment options." "Very complete assessment of all issues involved (cognition, mood, coping, driving concerns etc.)." "Enjoy 'one stop shopping' for complete review of all comorbidities."
	"More time to discuss options and voice concerns." "More time during appointment to do a comprehensive review of medical management."
	"Addressing memory concerns in a timelier manner with an individual who has training to properly assess." "A more confident and educated GP."
Improved quality of dementia care* Subthemes: Team approach to assessment/care Holistic approach to management Improved access to community services Improved care coordination Improved medication management	"Access to interdisciplinary practitioners." "Able to provide families with many resources from the multi-disciplinary team." "Team assessment is beneficial. It allows us to see the person in multiple dimensions."
	"Holistic approach – defining memory loss as not a normal part of aging and being able to provide hope." "They are receiving more thorough care as well as resources to help them with their diagnosis." "Slowing decline of memory concerns through diet, lifestyle and medications."
	"Improved local support through integration with Alzheimer's Society" "Has provided a link with community resources specific to their individual needs." "Improved access and appropriate resources in place for aging well at home." "Working in a team we seem to have better access and understanding about resources available and a good partnerships have been established."
	"More coordinated education and support." "More closer interaction with different agencies."
	"Improved cognition off narcotics and benzodiazepines." "Reduction of potentially inappropriate medications."
Increased understanding of their health condition and optimal management	"Their questions and concerns have been answered and addressed through education." "Patients and families have a better understanding of the nature of their diagnosis and of how certain areas of function can be affected." "They have a clearer understanding of how to approach the problem."
Improved continuity of care – access to follow-up care, monitoring	"Relief of knowing that there is somewhere they can stay connected to medically and get support." "Ongoing monitoring and support." "Support for when situation worsens."
Access to caregiver support Subtheme: Family involvement in care	"Team approach, involves lessening burden for caregivers." "People are receiving more care/resources in the home to prevent care giver burn out and great safety/ independence in the home." "Families have had support in dealing with driving issue." "Caregivers role acknowledged as vital and also understanding their challenges and supporting them."
	"The assessment includes the family which moves them often from feeling hopeless to manageable." "Family involvement in the diagnosis and treatment strategy is very helpful and appreciated by all involved."

*Over what can be provided within regular practice.

Importantly, PCCMCs demonstrate high levels of patient and family member satisfaction with care provided (Lee et al. 2010; Lee et al. 2014b). Care planning resulting from the PCCMC assessment is strength-based, focusing on patient and caregiver capacity to self-manage with the provision of assistance from both primary care-based services and community supports and services, to proactively prevent crises. Because PCCMCs are established by local practitioners already embedded within community support networks, patients (and pertinent medical information) are able to move seamlessly across the spectrum of necessary healthcare providers throughout the course of illness, which serves to reduce fragmentation of care, increase the efficiency and effectiveness of care and increase information sharing among care providers.

There are some limitations to this study. A key limitation of the evaluation of the PCCMC model is the lack of a comparison group; randomized study designs would provide a more objective evaluation of this model. Resource constraints limited the consistent collection of data across all clinic sites. Although previous studies have demonstrated physician and patient and caregiver satisfaction with the clinic (Lee et al., 2010; 2014), qualitative studies are currently under way examining the patient and caregiver experience with the clinic and family physicians perceptions of the clinic, particularly the impacts on their practice. There is a lack of data on the economic benefits associated with this model; future studies intend to examine the impact of the PCCMCs on health system utilization. More detailed information on the lessons learned in implementing PCCMCs is presented elsewhere (Lee et al. 2014c).

PCCMCs may have an increasingly important role to play in the system of care for older adults. They represent an innovative approach to building capacity for quality dementia care at the primary care level, creating a broader base of dementia care expertise. This enhanced capacity will be of paramount importance as the population ages and the prevalence of dementia increases. Enhancing primary care capacity for dementia care with interprofessional and collaborative care will support more efficient use of system resources, thereby strengthening the system's ability to respond to increasing demands for service and mitigating the growth of wait times to access specialist assessment. Care that is person-, caregiver-, provider- and community-centred has the potential to improve health and social outcomes throughout the disease process, resulting in better lived experiences for persons with memory disorders and their care partners. HQ

Acknowledgements

This evaluation study was funded by the Department of Family Medicine Pilot Research Project Funding, Faculty of Medicine, McMaster University; Canadian Institutes of Health Research – Institute of Health Services and Policy Research Catalyst Grant Program: Primary and Community-Based Healthcare, Grant No: 212207; the North East, South West and Champlain Local Health Integration Networks, and Ontario Brain Institute. The Canadian Mental Health Association Waterloo Wellington Dufferin funded data analysis and manuscript preparation. The authors wish to thank the Primary Care Collaborative Memory Clinic team members for their participation in the evaluation study and their collection of data to support the evaluation, as well as the geriatricians and geriatric psychiatrists who support these clinics. The authors also wish to acknowledge the efforts of the interprofessional team involved in training the newly formed memory clinics.

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Lessons Learned from an Advanced Access Trial Within a Canadian Armed Forces Primary Care Clinic

P. Tony Singh

Abstract

Accessibility is a key element of an effective primary care system. Literature has outlined that primary care practices have successfully employed an advanced access scheduler to improve accessibility to booked appointments and consequently enhance patient experience and outcomes. In 2015, a Canadian Armed Forces (CAF) primary care facility in Ottawa trialed an advanced access scheduler. Based on the unique characteristics of a CAF medical clinic and the patient population, this trial produced six critical lessons, which include maintenance of a stable base of clinicians, correcting rostering mismatches, eliminating appointment backlogs, acquiring required information systems, improved understanding of patient demand and communicating changes effectively. These lessons may be utilized by similar organizations to successfully integrate an advanced access scheduler within their primary care facilities.

Introduction

The World Health Organization (1978) states that accessibility is an essential characteristic to an effective primary care system. Among other benefits, accessibility to comprehensive primary care has been correlated with better patient health outcomes (CFHI 2013). Furthermore, access to timely primary care appointments is a critical element in providing patient-centred care (College of Family Physicians of Canada 2011). Thus, many primary care practices are soliciting ways to improve their accessibility. Recently, the focus has been on implementing various scheduling methodologies. In particular, over the past decade, primary care facilities have been experimenting with open or advanced access scheduling, which has yielded tangible benefits.

In 2015, a military primary care clinic in Ottawa implemented a pilot project with an advanced access schedule. The main drivers for this trial were to improve the overall patient experience, enhance staff satisfaction and ameliorate the accessibility to booked appointments with primary care providers. An advanced access trial was deemed appropriate to address these objectives, as the organization was experiencing human resource constraints, which inhibited any augmentation of administrative or clinical staff members. The purpose of this paper is to describe the lessons learned by a Canadian Armed Forces (CAF) primary care clinic during an advanced access trial, which may benefit similar organizations in their own journey towards implementing an advanced access model.

Primary Care Services Within a Canadian Armed Forces Medical Clinic

Primary care services within the CAF are delivered in a relatively standardized manner across the 34 military medical clinics throughout Canada, as it is based on a single primary

care delivery model referred to as the CAF clinic model (CFHS 2004). This model was created, evaluated and adopted after an internal review by the Department of National Defense Chief Review Services revealed numerous issues with the previous healthcare delivery model (CFHS). The new model concentrated on providing "… patient-focused, accessible and capable …" healthcare (CFHS, p.A-1-2). The model is centred around a care delivery unit (CDU), which is a multidisciplinary team that provides a range of primary care services to an established number of rostered patients (~1,500–2,500 patients per CDU) (CFHS 2004). Each CDU is composed of a team of clinical and administrative staff, including military physicians, civilian physicians, nurse practitioners, primary care nurses, physician assistants, medical technicians and medical receptionists (CFHS 2004). The number of CDUs within each medical clinic is determined by the size of the population being served (CFHS 2004). For example, Canadian Forces Health Services Center Ottawa (military medical clinic for the Ottawa region) has a patient population of approximately 10,000 members and therefore has a total of five CDUs. When patients are transferred to a base, they are rostered to a specific CDU and although they are assigned to a primary care provider, they may be followed up by any of the CDU team members in a collaborative, team-based care delivery system (CFHS 2004).

Patients are able to access primary care services in two ways: booked appointments and a walk-in service (CFHS 2004). There are several types of booked appointments, such as periodic health assessments (physicals) or periodic follow-ups. These appointments can either be booked via an email or phone request and are normally with their primary care provider. Patients are also able to access care through a walk-in service commonly referred to as "sick parade." Sick parade is normally offered for the first 2–3 hours of the day; however, most clinics permit patients to access walk-in services throughout the business hours of the clinic. These patients are not necessarily seen by their primary care providers and they are normally limited to one or two health issues per visit. Some larger clinics have an urgent care area, where they will provide treatments (IV infusions or dressing changes) or attend to patients with acute health issues.

In terms of scheduling methodology, the clinic model was designed to utilize a carve-out scheduling model, as all clinics were instructed to template "emergency" appointment slots within each provider's schedule. Additionally, most providers would be available during the morning hours (timings based on facility) to provide patient care to any possible walk-in clients. After several years with this schedule, most of the clinics recognized that their provider schedulers were completely full (no emergency slots) with excessively long third next available appointments. Clerical staff and clinicians resorted to using any available appointment slots to fit in urgent appointment requests (including walk-in services slots). Unfortunately, this created an access issue for the patients and further reinforced the use of walk-in services.

The model is centred around a … team that provides a range of primary care services to an established number of rostered patients …

Why advanced access within a CAF medical clinic?

In 2014, Canadian Forces Health Services Center Ottawa began preparing to pilot an advanced access schedule within the clinic to improve continuity, access and patient satisfaction. The impetus for this trial was based on several factors, including:

1. *Lack of clerical and administrative support:* Based on a number of vacancies throughout the CDUs in terms of medical receptionists, it was difficult for the existing clerks to manage the current patient scheduler. The patient scheduler was also cumbersome to manage for various reasons (numerous different types of appointments, variations in scheduling based on clinician type and preference, last-minute rescheduling owing to transient clinicians [civilian and military] and triaging of urgent appointments). This resulted in high clerical staff turnover, increased sick leave and generally low staff satisfaction. Implementing a simple, straight-forward scheduling methodology was seen as a potential solution to address some of these identified issues.
2. *Staff burnout:* This convoluted scheduling system and the lack of staff resulted in burnout and an elevated level of stress for the clinical and administrative staff within the CDUs. Although no formal exit interviews were completed with former staff members, many did indicate that the work environment was very stressful. The lack of capacity or access within their schedule was also an identified concern.
3. *Patient complaints:* In 2014, the clinic management identified that the patient experience offered was less than ideal based on the number of patient complaints received. The majority of the complaints were based on the inability to receive a booked appointment with their primary care provider. A few cases were particularly troublesome, as the wait times were approximately three months in duration, which could have resulted in adverse patient outcomes or a patient safety issue. In order to address these concerns and improve the overall patient experience, the clinic management were acutely aware that the level of provider continuity and accessibility would need to be improved.
4. *Accessibility:* Based on the targeted third next available appointment of 14 days, which was the only metric being monitored to measure patient accessibility, the numbers

were much higher than desired. Although trending data outlined that the third next available appointment had increased slightly over the past several years, it was clear that the numbers remained at a high, unacceptable level. Considering the limited resources available, improving accessibility through work process improvements or new scheduling methodologies was solicited.

Based on the concerns identified, it was clear that certain measures would need to be taken in order to improve accessibility, patient experience and staff satisfaction. Based on the documented benefits of advanced access, it appeared to be a potential solution or means to achieve our goals. Additionally, a detailed literature review revealed a vast number of articles regarding employment of an advanced access scheduling system; however, there was limited information on the use of advanced access within a military primary care facility (Aiello 2005). Moreover, there are no identified trials of an advanced access scheduling methodology being utilized within a CAF primary care facility. Therefore, based on the unique needs of the CAF, we felt it was warranted to trial this scheduling methodology. Although we were not sure what results it would yield, we were certain that it would provide important information on how we could improve the delivery of care in the future and whether there is a place for this type of scheduler within the CAF clinic model.

Lesson learned

In May 2015, the trial of an advanced access scheduler was initiated and it continued for six months, at which time, the patient schedule was reverted to the original scheduling methodology. The following sections list the six crucial lessons that we have learned during the trial.

Lesson 1: It is essential to maintain a stable base of clinicians

When the primary care practitioner supply was calculated across the five CDUs, it appeared that there was an abundance of supply to meet the demand calculated. Unfortunately, the clinic routinely experiences highly variable staffing levels of primary care practitioners owing to deployed military physicians and physician assistants, high turnover of civilian physicians and delays in the hiring process for public service and contracted employees. Each time a clinician leaves a CDU (temporary or permanently), there is a significant impact on the ability of other clinicians to maintain adequate access for all of the patients within the CDU. This resulted in frustration for the staff and patients, as same-day appointments were not available with the departure of one or two clinicians and the continuity of care was negatively impacted. Another issue was that most CDUs had a mix of part-time clinicians, some of which were only providing a 0.2 full-time equivalent. Based on the rostered philosophy, many of these clinicians maintained their own patients, and therefore, some patients would be extremely disappointed when they were unable to access their own provider for a portion (or sometime most) of the week based on their work schedule. Owing to the difficulties in recruiting civilian physicians, the clinic permitted civilian providers to choose their work days, which resulted in excessive capacity on certain days and not enough on others. All of these identified human resource-related issues negatively impacted the success of the trial. Potential solutions that could be considered by primary care facilities are to focus recruitment efforts on attracting full-time primary care providers, exploring retention opportunities and smoothing out clinician work schedules based on identified patient demand.

… we were certain that it would provide important information on how we could improve the delivery of care in the future …

Lesson 2: Rostering mismatches must be identified and corrected

Based on the transient nature of the CAF population, the number of patients rostered to a certain CDU and a certain provider is constantly changing. Routinely, it was noted that some clinicians and CDUs would have either a spike or sharp decline in patients based on numerous factors such as patients posted to another base or released/retired from the military. Of particular interest, it was identified that a select few primary care clinicians that had been employed at the clinic for several years had accumulated a large patient population, which also had more co-morbidities or chronic health issues. Although patients were very satisfied with the quality of care provided by these practitioners, they were also frustrated, as the accessibility to booked appointments was difficult. After implementation of the trial, the patients were even more frustrated that the same-day appointments offered were limited and filled very quickly. Related to this issue, it was noted that there were regular unused same-day appointments within particular CDUs or with certain practitioners (particularly newer primary care clinicians who did not have many patients rostered to them). Potential solutions to address this issue are to obtain timely data of patient demand and the number of rostered patients. These two metrics together will assist the management team in adjusting the rostering of newly posted patients. Additionally, the rostered population of all primary care providers should be thoroughly analyzed and adjusted in order to ensure they all have an appropriate patient load. Furthermore, primary care clinics could consider having part-time clinicians share rostered patients to maintain accessibility throughout any given week.

Lesson 3: Booked appointment backlog should be eliminated prior to implementation

Over the years, many of our clinicians have developed an appointment backlog, which has resulted in a third next available appointment ranging from a few weeks to a few months. Interestingly, the backlog has been relatively steady for most of our providers or had marginally increased over the past several years. Prior to the launch of our trial, we identified the amount of backlog for each clinician and attempted to eliminate it by soliciting assistance from additional primary care providers. Unfortunately, owing to competing demands for these providers and the inability to hire additional providers, we were unable to significantly reduce this backlog before the start of the trial. We decided to continue with the trial with the existing backlog, which frustrated patients attempting to book follow-up appointments. It appeared for many patients that the trial had actually lengthened the wait times for pre-booked appointments. For many providers and patients, the trial was perceived as a failure from Day 1 as a result of this existing appointment backlog or wait list. For an advanced access system to be perceived as a positive change and have a chance for adoption, the backlog should be almost completely eliminated prior to implementation.

Lesson 4: Required information systems should be in place before the change

Prior to the launch of the trial, several issues were identified with the process the patients utilized to obtain a same-day appointment. Primarily, each patient would need to call a centralized number that would redirect them to their appropriate CDU. In each CDU, one medical clerk would be available during business hours to address their request. Based on fiscal and policy constraints, the phone system could not be upgraded to allow for a queuing system, which would allow patients to be placed in a queue and have their request answered in priority sequence. As a result, if the CDU clerk was utilizing the CDU line, the patient would be redirected to a voicemail message, which informed them that they must continue to call-back and speak to a staff member to obtain a same-day appointment. Understandably, this resulted in a large amount of dissatisfaction with the patients, as many would call the CDU line numerous times with no assurances that they would receive a same-day appointment. Many patients had simply given up and decided to use the walk-in services based on this identified issue. The solutions identified by both the patients and the staff were to either install a telephone queuing system or have a centralized clerk who is only dedicated to scheduling same-day appointments. An online self-scheduling system may also address this issue, assuming that it is feasible for the practice.

Lesson 5: Comprehensive understanding of the patient demand is critical to implementing an appropriate scheduler

Literature indicates the importance of collecting data on patient demand and provider supply (Murray 2003). The clinic collected and analyzed total patient demand over the span of three months to understand the variation in demand by day of the week, by CDU and by provider. Although these data were helpful in the creation of the proposed provider schedule, the quality of the data was extremely poor based on several factors, including gaps in the data and data collector errors. Additionally, the data sample was extremely limited, as it only covered three months (February, March and April 2015), which did not represent the patient demand throughout various times of the year. As the military population within Ottawa and across the country has specific health-related needs, which fluctuate based on the time of year, having this limited amount of data was insufficient to establishing a workable advanced access schedule. Therefore, it would be critical for a primary care practice to collect data on patient demand over a significant period (at least six months) to have a true understanding of the demand variations of the rostered patients.

Lesson 6: A robust communication campaign is a critical element for success

Although the clinic did identify the need for a well-developed communication plan utilizing multiple means (emails, presentations, pamphlets and website notifications) to communicate the change to ~10,000 military members within the clinic catchment area, the importance and the difficulty of this task were heavily underestimated. Therefore, the communication plan implemented was less than ideal based on three reasons. Firstly, it was difficult to communicate a clear message to such a large population employed in various areas throughout the national capital region, especially considering website and email messages were unread by the majority of the population. Secondly, military members are transient, as they are often required to travel for training, operations or postings; therefore, sending out a few messages over a short period would not be sufficient for this population. Thirdly, military members have accessed care in the same manner (particularly via "sick parade") for decades, so any deviation from this institutionally engrained practice would require a comprehensive communication plan to solicit buy-in from the members and all levels of leadership. Essentially, the importance of how the change is communicated cannot be underestimated and must be carefully planned by any organization implementing an advanced access system.

Conclusion

Advanced access scheduling has shown tangible benefits to primary care practices throughout Canada, and it is a model that has the potential to improve patient outcomes, experience and accessibility within various types of primary care models. Although this small trial was a step forward in exploring how this scheduling methodology could be utilized within a CAF medical clinic, it is simply the beginning. Further investigation, research and trials need to be conducted in order to truly assess the viability of this concept within various types of practices. The identified lessons learned may assist practices in understanding the barriers to adopting such a model and ways to overcome these challenges. Although this scheduling methodology is not currently being adopted within CAF medical clinics, the time and resources invested to optimize patient scheduling yielded valuable lessons learned that will continue to be utilized to enhance the care delivered to the patient population. HQ

Acknowledgements

I would like to sincerely thank all of the working group team members from Canadian Forces Health Services Center (Ottawa) for their tireless work and dedication to this important project. The command team (at the unit and higher headquarters) should also be acknowledged for their unwavering support throughout the project. Finally, I would like to thank all of my colleagues that provided insightful feedback to this publication.

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Primary care scheduling methodologies

There are different types of scheduling methodologies used nationally and internationally within the primary care domain. The College of Family Physicians of Canada (2012) identifies four types of models a primary care practice may use to schedule patients:

1. Traditional model – The patient scheduler is entirely composed of appointment slots that are booked in advance. There are no appointment slots to accommodate for immediate or urgent appointments, so many practices using this model will either reschedule existing appointments or double-up appointment slots in order to address urgent patient issues.
2. Carve-out model – The schedule is composed of two types of appointments, pre-booked routine and same-day urgent or emergency appointments. Patients requiring non-urgent booked appointments would be booked into appointment slots sometime in the future.
3. Access by denial model – The schedule is composed of entirely same-day appointment slots, which are used based on a first-come, first-served basis. When all of the appointment slots are filled, patients are told to try again the next business day.
4. Advanced access model – The practice has a certain percentage of booked appointment slots and a certain percentage of same-day appointment slots, which are used for urgent and non-urgent reasons. Although majority of the appointments would be same-day, the percentage would vary based on several factors, such as the age of the patients and the number of patients with chronic diseases requiring regular follow-up. This model is focused on providing patients access to appointments when they need it.

Benefits of advanced access

Unfortunately, there is no clear answer as to which type of scheduling model contributes to the most optimal patient outcomes, a high level of practice efficiency and an excellent patient experience. There are a plethora of factors that need to be considered, such as age and demographics of the patients, location of the practice, number of patients served or types of providers employed. Although this issue is multi-faceted, literature has suggested that an advanced access or open-access scheduling model may yield some benefits for primary care practices, the providers and their patients.

From an overall practice perspective, an advanced access scheduler can result in a reduction in the overall cost of care per patient, as patients are seen without delay by their provider (Murray 2005; College of Family Physicians of Canada 2012). Additionally, practices may be more efficient with this type of methodology, as booked appointments do not need to be triaged, which reduces interruptions to the work of physicians and significantly reduces patient call-backs (College of Family Physicians of Canada 2012; Murray 2003). As most patients are booking their appointments the same day, the number of no-shows was shown to decrease, which will minimize the amount of time wasted by the practice (Murray 2003).

From a provider point of view, elimination or significant reduction of the appointment backlog has been shown to result in an overall improvement of provider and staff satisfaction (Aiello, 2005; College of Family Physicians of Canada 2012; Knight et al. 2005; Murray 2005;). This scheduling methodology has also been linked with an increase in provider efficiency and quality of clinical notes (Murray 2005). Finally, advanced access has been associated with improved collaboration amongst the primary care team (College of Family Physicians of Canada 2012).

From a patient perspective, enhancing accessibility through advanced access scheduling has been shown to improve patient experience and outcomes (Aiello 2005; College of Family Physicians of Canada 2012; Murray 2005). Improved patient outcomes have been suggested, as patients would be seen earlier for health issues before complications occur or before the exacerbation of a chronic issue (Knight et al. 2005: Murray 2005). Reduction in the use of walk-in clinics or emergency departments has also been correlated with advanced access, which will not only enhance patient experience or satisfaction but also overall costs to the health system (Aiello 2005; College of Family Physicians of Canada 2012).

Although it can be argued that not all of the aforementioned benefits have been proven by statistically significant results from randomized control trials, there does exist some convincing evidence on the benefits of advanced access. A systematic review completed by Rose et al. (2011) that analyzed 24 studies on advanced access scheduling in primary care practices revealed that all practices demonstrated an improvement in accessibility (third next available appointment) after implementation of an advanced access scheduler. No-show rates were also shown to improve in most studies (Rose et al. 2011). Unfortunately, the impact on continuity, clinical outcomes and patient satisfaction was not clear, as there were mixed results across the studies analyzed (Rose et al. 2011). Although it was recommended that further randomized studies are required to make more definitive conclusions, the benefits related to access have been demonstrated (Rose et al. 2011).

– P. Tony Singh

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Implementation of Behavioural Supports Ontario (BSO): An Evaluation of Three Models of Care

Michelle Grouchy, Nancy Cooper and Tommy Wong

Abstract

Behavioural Supports Ontario (BSO) was launched to enhance the healthcare services for Ontario's seniors, their caregivers and families living and coping with responsive behaviours associated with dementia and other neurological conditions. The implementation of the program varied across and within the local health integration networks (LHINs). By 2015, there were three BSO models operating within the long-term care (LTC) home sector: in-home BSO teams, a mobile team that serves multiple LTC homes within a sub-area of a LHIN and a LHIN-wide mobile team that provides services to all homes. A survey was undertaken to identify the differences among the BSO models of care in relation to care planning, collaboration and team building and home-level resident outcomes. We found that three years after implementation, LTC staff reported that the in-home BSO model out-performs the mobile team across all key measures. There is a role for mobile teams to provide expertise and sharing of best practices across the regions, but future policy and funding should focus on supporting the development of in-home BSO teams.

Background

Behavioural Supports Ontario (BSO) began in 2010 to enhance the healthcare services for Ontario's seniors, their caregivers and families living and coping with responsive behaviours associated with dementia, mental illness and other neurological conditions. Responsive behaviours are actions, words and gestures that are often intentional, that express something important about their personal, social or physical environment. At times, these behaviours can be aggressive, which can cause distress to the residents and those around them. It can often be difficult to identify the triggers and meaning of these behaviours, which is why BSO teams are important to providing quality care to seniors living with dementia.

BSO provides services to individuals living in long-term care (LTC) homes, independent living settings and acute care environments. This article is focused on the BSO supports implemented in LTC, where more than 46% of the 100,000-plus residents cared for each year exhibit responsive behaviours or are at risk (CIHI 2015).

The province initially invested $40 million to support this initiative across Ontario. There was wide variation in the way the funds were allocated, based on demographic and population health statistics related to the over 65 and "at risk" population in each local health integration network (LHIN). Each LHIN determined its own implementation of the BSO program and rolled-out different models, training and support for BSO staff, and focused on different partnerships among health service providers and community agencies.

By 2015, three distinct BSO models were operating within the LTC sector:

1. In-home BSO teams are where a team of one or two BSO staff, typically a registered nurse (RN) or registered practical nurse (RPN) and a personal support worker (PSW), works on-site and is dedicated to the residents of one LTC home.
2. A sub-LHIN mobile team model is where multiple LTC homes within a LHIN sub-area are served by one BSO team that travels to homes to provide service.
3. A mobile team model is where the team is located in one LTC home but serves all LTC homes across the LHIN.

The Ontario Long-Term Care Association conducted a survey in 2015 to identify any differences (or not) among the three BSO models of care in relation to key aspects of care, including care planning and provision, collaboration and team building and home-level resident outcomes.

An analysis was also conducted to compare homes with in-home BSO teams against homes with mobile BSO teams on restraints, antipsychotics and aggressive behaviour metrics to determine if there are any significant differences among the groups.

Ontario has the largest, longest-running data collection and reporting system in Canada for quality of care information on LTC homes …

Methodology

The Ontario Long-Term Care Association conducted a voluntary survey between May 19 and June 1, 2015, using a 5-point Likert scale measuring agreement/disagreement with statements related to aspects of care, and yes/no responses to impact statements related to admission and management of responsive and chronic mental health behaviours. All 440 LTC homes that belong to the Association were invited to complete the online survey. There was a response rate of 59% (259 homes), indicating significant interest in BSO teams and the results of this survey.

The Ontario Long-Term Care Association Quality Committee members, composed of senior quality leaders in LTC organizations, reviewed questions for ease of understanding (clarity) and comprehensiveness.

The survey outlined the three BSO funding models and respondents were asked to identify the funding model applied to their home:

1. Funding was provided directly to the LTC home for RN, RPN and PSW teams. Fifty percent of the sample homes (125) are identified as BSO Model 1, also described as in-home teams.
2. Funding was provided to a sub-LHIN area for multiple homes to create and share a mobile staffing of an RN, an RPN or/and a PSW hosted by a LTC home to serve the homes in the sub-region. Thirteen percent of the sample homes (32) are identified as BSO Model 2, also described as mobile teams that serve a sub-LHIN area.
3. Funding was provided to a single LTC home to create a single mobile team to serve all LTC homes across the LHIN. Thirty-eight percent of the sample homes (96) are identified as BSO Model 3, also described as mobile teams that serve an entire LHIN.

In addition to the survey, we completed a separate analysis examining key metrics drawn from key administrative databases. Ontario has the largest, longest-running data collection and reporting system in Canada for quality of care information on LTC homes and has been publicly reporting on various dimensions of quality since 2009. These data are used for public reporting on quality indicators by the Canadian Institute for Health Information (CIHI) and Health Quality Ontario (HQO).

We chose to examine two indicators related to safe, effective care: the appropriate use of antipsychotics and the use of physical restraints. High uses of antipsychotics or restraints are associated with increased risks of negative outcomes and issues of poor quality of life and loss of dignity. (HQO 2015) Antipsychotics and physical restraints are sometimes inappropriately used to manage behavioural symptoms associated with Alzheimer's and other dementias (HQO 2015), which could be more appropriately treated with behavioural management strategies such as those used by BSO.

We also examined the weighted averages of resident scores for the InterRAI Aggressive Behaviours Scale (ABS). We then compared performance trends between homes with in-home and mobile teams between 2012 and 2014. The BSO program was fully implemented provincially in 2012.

The ABS score is a measure of aggressive behaviour based on the occurrence of verbal abuse, physical abuse, socially disruptive behaviour and resistance to care. Scale scores range from 0 to 12, with higher scores indicative of greater frequency and diversity of aggressive behaviour. A score of 1 to 4 on the ABS indicates mild to moderate aggressive behaviour, whereas a score of 5 or more represents the presence of more severe aggression. This scale has been validated against the Cohen Mansfield Agitation Inventory (InterRAI 2015).

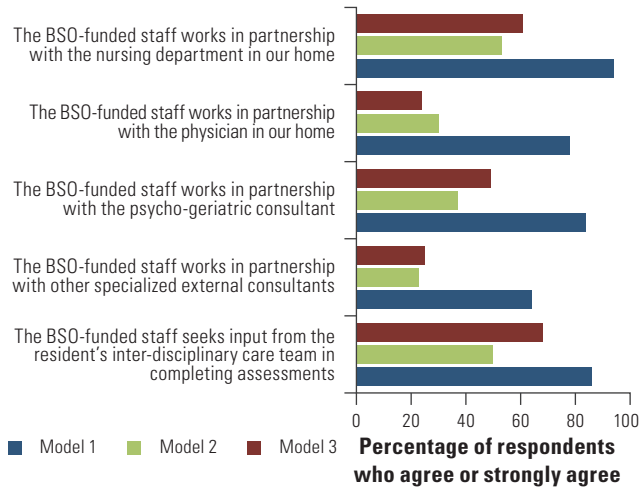
We identified three LHINs where in-home BSO programs were implemented (Mississauga Halton, Central West and Waterloo Wellington, with 87 homes total) and five LHINs where mobile BSO programs were implemented (North Simcoe Muskoka, Hamilton Norfolk Haldimand and Brant, Central, Toronto Central and South East, with 235 homes

total). Models 2 and 3 are combined, as data were not available to identify the type of mobile team within these LHINs. Significance testing was completed for the two quality indicators and the weighted averages.

Findings

Almost three years after implementation, LTC staff directly involved in ensuring the safety and comfort of residents with dementia have strongly indicated that the "in-home" model outperforms the mobile teams on all key aspects of care (Figure 1), including care planning and provision, collaboration and team building and home-level resident outcomes.

FIGURE 1.
Collaboration and team building for three types of BSO team



BSO = Behavioural Supports Ontario. Source: Ontario Long-Term Care Association survey.

Care planning and provision

More than 80% of the respondents agreed that an in-home BSO team (Model 1) has:

- enabled point-of-care education on successful interventions for care staff;
- supported staff to assess and determine individualized interventions to manage resident behaviours; and
- provided structure for internal support for homes' behaviour management program.

Fewer than 40% of the respondents agreed that mobile teams (Models 2 and 3) have supported or enabled these functions that support care planning and provision. Fifty-nine percent of the homes with in-home teams agreed that timely access to individualized assessments for residents experiencing challenging behaviour had occurred, whereas only 30% of the homes with a mobile team within a sub-LHIN area (Model 2) and 43% of the homes with a mobile team that serves an entire LHIN (Model 3) agreed.

Collaboration and team building

The in-home (Model 1) outperforms on all measures related to collaboration when compared with the mobile teams (Models 2 and 3).

Respondents indicated that the in-home BSO teams (Model 1) helped the care team staff to feel more confident about keeping residents safe during daily routines (78%), provided accessible and comprehensive resident assessments that the care team can implement (84%) and sought input from residents and family in completing assessments (89%).

By contrast, respondents reported that mobile teams were significantly less likely to help the care team staff feel confident about keeping residents safe during daily routines (23% for Model 2 and 32% for Model 3).

Respondents reported that mobile teams were also less effective with assessments. A smaller number of respondents in homes served by mobile teams reported that the BSO team provided accessible and comprehensive assessments that the residents' care team can implement (31% for Model 2 and 47% for Model 3). Homes served by mobile BSO teams also reported that fewer teams sought input from residents/families in completing assessments (40% for Model 2 and 57% for Model 3).

Home-level resident outcomes

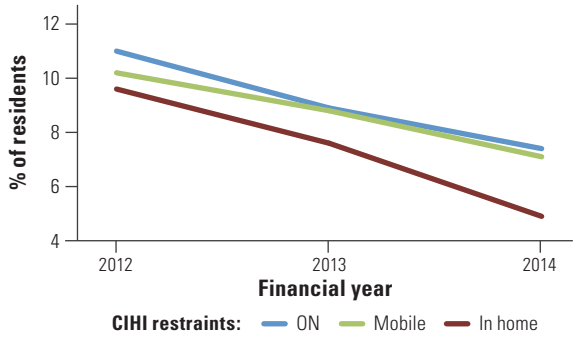
More than 70% of the respondents reported that in-home BSO teams (Model 1) have helped to better manage residents with chronic mental health problems, helped families better understand challenging and responsive behaviours and contributed to quality improvement, specifically related to improvements in residents' behaviour. Fewer than 30% of the respondents with mobile teams, either Model 2 or 3, reported a positive impact in these areas.

The use of restraints and the inappropriate use of antipsychotics have been declining in Ontario LTC homes in recent years (CIHI 2015). Based on our analysis, homes with in-home BSO teams have significantly lower rates of both restraint use (Figure 2)and inappropriate antipsychotic use (Figure 3).

Although there were no significant differences in the restraints indicator in 2012 between the homes with mobile BSO teams and those with in-home teams, they were significantly different by 2014 ($p < 0.05$). Similar results were found for the antipsychotics indicator ($p < 0.05$).

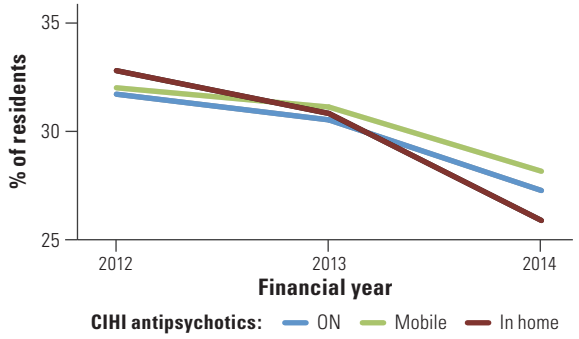
Between 2012 and 2014, homes with in-home BSO teams have reduced aggressive behaviours (with an ABS score of 6 or more) from 7.2% to 5.8%. Whereas, homes that are serviced by mobile teams only showed a decrease from 6.9% to 6.6% in the same period.

FIGURE 2.
Use of restraints in homes with in-home BSO teams and mobile teams from 2012 to 2014



BSO = Behavioural Supports Ontario. Source: CIHI 2012, 2014, 2015.

FIGURE 3.
Use of antipsychotics in homes with in-home BSO teams and mobile teams from 2012 to 2014



BSO = Behavioural Supports Ontario. Source: CIHI 2012, 2014, 2015.

Limitations

There are many challenges in using surveys for research because of the potential for bias. We are aware of the real potential for response bias in a membership survey, especially where strong points of view exist regarding the importance of the BSO program to resident quality of life and safety. Testing of survey questions was limited to ensuring clarity and comprehensiveness.

Discussion

Survey respondents strongly indicated that dedicated support for residents with Alzheimer's and other dementias is necessary to reduce the distress of the residents affected and ensure the safety and comfort of all residents. A review of the literature on effective care and management of behaviours supports the notion that "consistency of care" provides higher-quality care. The impact of adopting practices that support consistency of care can be far-reaching, and have been associated with changing the culture of care from a focus on carrying out custodial tasks to a focus on the individual, with the residents and/or their family integrated into and directing care. "Consistency of care" is a staffing approach supported by research as the best way to maximize opportunities for meaningful interactions between staff and residents, including those with Alzheimer's and dementia, resulting in greater mutual trust (Chappell et al. 2014). HQO, the government agency tasked with monitoring quality in Ontario, has encouraged the LTC sector to adopt this model of care, as it allows staff to know the residents better and focus on resident preferences and routines, which improves the quality of life of residents and assists in the early detection of emerging health problems (HQO 2014)

The ability of the in-home BSO teams to provide timely assessments and individualized interventions that are effective based on the culture and operations of the home is a major advantage. In-home BSO teams work within the home, so they are able to work flexible hours and vary the timing of their shifts to meet the needs of residents. They are also able to build capacity in the home, so that other staff have the knowledge and skill to manage responsive behaviours. Wait times of more than 10 days were identified by approximately one-quarter of the survey respondents relying on the BSO mobile teams. Generally, mobile teams are only available during weekday and daytime hours, which can be challenging for homes when the responsive behaviour does not occur when the mobile teams are able to provide service to their home.

Our secondary analysis of publicly reported quality indicators and weighted average ABS scores has limitations, owing to the limited number of LHINs and homes analyzed. These data do not consider other potential regional or cultural differences that may be impacting these data. However, it does indicate a potential correlation between the contribution of in-home BSO teams to overall improvements in these quality metrics. The homes included in the sample with an in-home BSO team outperformed, on average, the Ontario-wide result for all three metrics studied. Further studies are required to understand the factors on how in-home BSO teams contribute to the improvement of the publicly reported quality indicators.

Conclusion

Understanding the success factors arising from multi-pronged approaches to the assessment and management of responsive behaviours is fundamental to sustainability of the BSO program.

Almost three years after implementation, LTC staff directly involved in ensuring the safety and comfort of residents with Alzheimer's and dementia have strongly indicated their experience; in-home BSO teams outperform mobile teams across all key measures related to care planning and provision, collaboration and team building and resident outcomes.

Our further analysis of publicly reported indicators and resident ABS scores in homes with in-home or mobile teams

indicates that in-home teams contribute to overall improvements in the quality metrics of restraints, antipsychotics and weighted average ABS scores.

In the 2016 provincial budget, the government committed another $10 million a year for the next three years for the BSO program. Further study to examine success factors related to both in-home and mobile teams would yield valuable information to guide the scale and spread of the BSO program and ensure that these dollars are spent on the most effective and appropriate model. HQ

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The Ontario Long-Term Care Association is the largest association of long-term care (LTC) providers in Ontario and the only association that represents the full mix of LTC operators – private, not-for-profit, charitable and municipal. Our members provide care and accommodation services to over 70,000 residents annually in nearly 440 LTC homes in communities throughout Ontario.

Longitudinal Evaluation of a Parent and School Team-Mediated Workshop Intervention for Reducing Challenging Behaviours in Children with Autism Spectrum Disorder

Brea Chouinard and Shawn Reynolds

Abstract

Children with autism spectrum disorder often develop persistent challenging behaviours. A previous study in this journal (Reynolds et al. 2011) reported effective implementation of strategies immediately following involvement in a comprehensive positive behaviour support workshop for parents/school personnel. The current study assessed long-term efficacy more than six months after workshop completion. Parent and school behaviour scores suggested maintained improvement in child behaviour. Parent responses to a verbal questionnaire revealed important perceptions of what made workshop participation beneficial. This study provides evidence for long-term benefits from this innovative approach for caregivers working with children with challenging behaviours.

Autism spectrum disorder (ASD) is a developmental disability characterized by two core areas of impairment: difficulty relating socially to others, and the use of repetitive and stereotypical patterns of behaviour (American Psychiatric Association 2013). Additionally, children with ASD often develop persistent challenging behaviours (Bradley et al. 2004; Jang et al. 2011; Matson et al. 2010), which influence parent confidence (McConachie & Diggle, 2007) and stress (Estes et al. 2009; Lecavalier et al. 2006).

In 2010, a workshop was developed for staff and families in 11 school divisions around Edmonton, Alberta, Canada, to address the needs of children with ASD with challenging behaviours. The workshops utilized a positive behaviour support (PBS) behaviour management framework, focusing on: (1) decreasing challenging behaviours by understanding how they may be serving a communicative purpose; (2) building socially appropriate skills; and (3) reinforcing use of appropriate behaviours (Durand and Carr 1985; Meyer and Evans 1989). The workshop aimed to decrease severe behaviours of children with ASD by increasing community capacity to recognize, address and prevent behavioural challenges (Reynolds et al. 2011). Immediately following the completion of the original set of workshops, Reynolds et al. (2011) found treatment gains on quantitative measures of parenting self-efficacy and child behaviour. The current study: (a) assessed whether behavioural gains were maintained more than six months after workshop completion, and (b) identified aspects of the intervention that were especially salient to parents.

Method

For the current study, parents with valid contact information who had completed the workshop between September 2011 and December 2012 were contacted. Parents were asked to again complete the Aberrant Behaviour Checklist (ABC; Aman and Singh 1986) and the Parenting Sense of Competence scale (PSOC; Johnston and Mash 1989), and were also asked to

participate in a verbal questionnaire (interview). As a preamble to the verbal questionnaire, parents verbally provided or denied consent for their child's current school personnel to be contacted by e-mail to rate the child's behaviour using the ABC. The goals of the present study were to compare scores for child behaviour from pre-workshop to the follow-up time point (i.e., more than six months after workshop completion) and to evaluate the change in self-reported measures of parenting competence over the same period. Ethics approval for this study was provided by the University of Alberta Health Research Ethics Board. Participation in the study was completely optional, with no impact of their decision on future services or opportunities. All participants gave verbal consent (i.e., participated in the questionnaire) and/or showed assent by completing and submitting standardized quantitative measures.

Measures

Aberrant behaviour checklist

The ABC is a 58-item measure assessing child behaviour from the perspective of an adult familiar with the child (i.e., parent, school personnel). The ABC has been used to measure behavioural challenges for children with ASD (Ozonoff et al. 2005; Tomanik et al. 2004). Lower scores represent less disruptive or fewer behavioural challenges. The ABC is a standardized assessment used to evaluate child behaviours, and hence could be used even if the teacher had not completed the workshop (noting many had not, as this was given in a later school year). Although there was the potential for different school-based raters at follow-up (e.g., new teacher) than at pre-/post-, the ABC was thought to still provide a valid measure of the child's current behaviour at school. The ABC Total Score was used as an outcome measure.

Parenting sense of competence

The PSOC is a 16-item measure assessing parent perceptions of satisfaction and efficacy in their parenting role. The PSOC has been used as a measure to assess parent perceptions across a range of child challenges (for examples, see Cefai et al. 2010; Cunningham and Boyle 2002). Higher scores represent better self-perception regarding parenting skills.

Verbal questionnaire

A brief semi-structured verbal questionnaire (five presupposition questions and one open-ended question, see Table 1) was developed and administered over the phone. The questions allowed parents to use their own words to express their views and attempted to: (1) reveal general impressions of the effectiveness of the workshop from parents' perspectives, and (2) identify key factors that may have contributed to the parents' impressions.

TABLE 1.
Questions asked during verbal questionnaire

No.	Question
1	To what extent do you feel that the workshop is still influencing your life?
2	What was the most important experience you had in the workshop?
3	What are some of the things you learned from the workshop that you still use? What do you do now that you didn't do before the workshop?
4	If I followed you through a typical day or week, which workshop strategies would I see you using?
5	What are some things that were said that really stuck with you?
6	Is there any other comment you would like to make that was not covered in these questions?

All of the verbal questionnaires were presented by the same researcher (author BC) and lasted from 5 to 20 minutes, depending on detail in parent responses. Parent answers were typed by the researcher as the parents responded and were not audio-recorded (for examples of other studies using this approach, see Beatson and Prelock 2002; Hutton and Carron 2005; Rogan et al. 2000). The researcher attempted to capture word-by-word transcription of what was being said, but the primary focus was on recording key phrases or the essence of much longer responses. If a parent response was distilled into shorter statements, or if clarification was required by the researcher or parent, the researcher would read back what she had typed to see if the parent agreed with the written statement. No follow-up questions were asked.

Participants

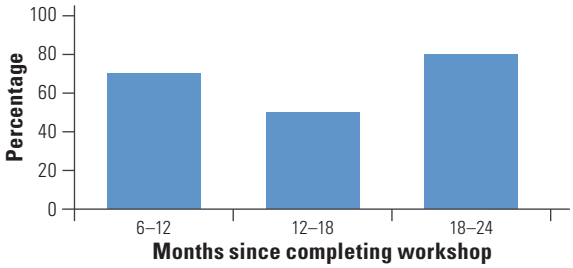
From September 2011 to December 2012, a total of 37 teams completed the workshop, and 36 of those teams had contact information available for the parent lead(s). However, at the follow-up time point, only 30 of the contact numbers were still in service. For each valid number, the participant was called a minimum of two times. If there was no answer and no answering machine, the researcher called back on a different day at a different time. If an answering machine was reached, the researcher left a message with non-specific details to maintain confidentiality ("We are doing follow-up interviews regarding a workshop you attended for your child back in 2011") and requested a call back.

Verbal questionnaire sample

Of the 30 parents phoned, 22 parents (73%, or 59% of the 37 who completed the workshop) were eventually reached and completed the verbal questionnaire. Parents had completed the workshop 6-24 months earlier. The response rate of the verbal questionnaire was comparable with or higher than similar studies that used informal interviews (33%; Beatson

and Prelock 2002) or telephone interviews (53%; Coon et al. 1997). The workshops were provided through a community health organization via different school boards, and the phone calls were made from a phone number that had neither a community healthcare nor a school board prefix. The unrelated number suggests that parents did not know the call was related to the workshop. Therefore, we felt the random sample of parents who answered the call from this unknown telephone number provided a fair representation of the overall group of parent workshop completers. Notably, all parents who were reached by phone consented to participate in the verbal questionnaire. See Figure 1 for a chart describing participation by length of time since the workshop.

FIGURE 1.
Percentage of parents who completed the workshop and participated in the verbal questionnaire, stratified by time since the workshop



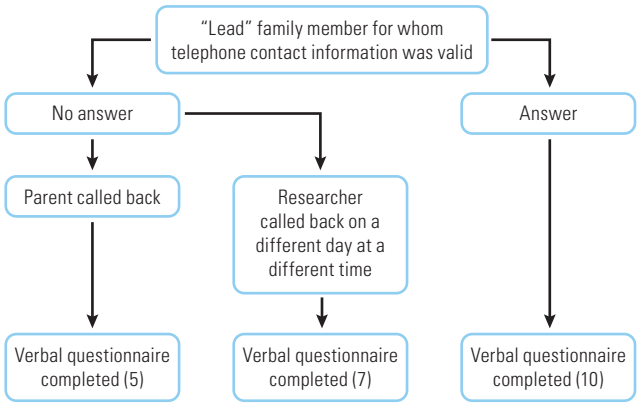
Results

Child behaviour (ABC)

Twenty-two of these 30 (73%) parents agreed to complete the ABC again after this interview. After parent consent and provision of contact information, 20 school personnel were e-mailed and 19 (95%) replied, agreeing to fill out the electronic version of the ABC. However, only nine parent ABCs (41%) and 11 school ABCs (58%) were completed. When school and parent ABCs were received for the same child, the scores were averaged; otherwise, the single score obtained from either the parent or the school was used. This approach resulted in follow-up scores for 15 children (68% of the teams for whom a parent was spoken with; 48% of the teams for which there was contact information; 41% of the teams that completed the workshop), and these were compared along with comparisons just using parents and teachers separately. See Figure 2 for a detailed flowchart.

A repeated-measures *t*-test was applied to compare the 15 ABC follow-up scores to pre-workshop scores obtained in the original study. The measure of whether the workshop afforded long-term results depended on whether the child's ABC scores still revealed improvement at the follow-up time point compared with before the workshop. Significant differences were found from pre-workshop to follow-up ($t(14) = 3.37$; $p = 0.005$; ES = 0.80). When analyzed separately, statistical significance was found for parent comparisons ($t(8) = 3.76$; $p = 0.006$; ES = 1.27), but not for school responses ($t(10) = 1.60$; $p > 0.1$; ES = 0.31).

FIGURE 2.
Data collection stream for verbal questionnaire



Parenting perceptions of parenting skill (PSOC)

Distribution and collection of the follow-up PSOC was the same as for follow-up parent ABCs. In total, 11 PSOCs were completed. A repeated-measures t-test was applied to compare follow-up and pre-workshop PSOC scores. The results approached statistical significance with our smaller sample ($t(10) = 2.15$; $p = 0.057$; ES = 0.42), with effect size slightly lower than the pre-post comparison in the original study ($t(22) = 3.63$; $p = 0.001$; ES = 0.68) (Reynolds et al. 2011).

Verbal questionnaire data interpretation

Six identifiable categories emerged and an additional "General" category absorbed non-specific feedback. The findings are summarized below (see Table 2 for examples).

Value

There were benefits in the information received and the new perspectives (of both self and others) gleaned from the workshop. Even when workshop content was familiar: (a) the information was still important, (b) attending the workshop was a good review and (c) the content was valuable to other participants to whom it was new.

Workshop presentation

The value of the workshop was enhanced by the structure of the workshop, especially the positive effect of sharing experiences with other workshop participants.

TABLE 2.

Codes and categories generated by conventional content analysis, with exemplars

Categories and codes	Data	Number of participants (%)
VALUE New knowledge New perspective Nothing new Recommend it	• I gained new knowledge I didn't have before. • [The workshop] explained that a lot of other people don't understand [and] might misinterpret behaviour. • It was information [I] had already received … had heard it before. • I wish more people could access it; would absolutely recommend it to anyone.	16 (57)
WORKSHOP PRESENTATION Community Limitations Suggestions Time investment Timing of the workshop	• Found comfort in the other parents talking about something I could relate to; I was not the only one going through this. • Parents were flipping through those books [so] as a parent I couldn't sit back and categorize. • More resources as to where to go next. • It was not a waste of time for three and a half days (positive); people started to feel like it was hard to make the arrangements (negative). • The information came so late in the year. This can be a big problem for transitions.	15 (54)
FACILITATOR Empathy Funny Skilled Knowledgeable and unbiased	• How can we fix it? (for the child) How can we make it feel better? • Really inspirational, how excellent he was. • Presented the info in such a way that made it very accessible for the teachers and EAs; the (presenters) were good at really defining the behaviour from the complex down to something we could change. • Someone else, a professional, say "This is what we see"; I could check with the school, but that's different than an outside objective person following up.	12 (43)
POST WORKSHOP Accountability Follow-up/Review	• Is there some way when you sign up to make some accountability; schools need a bit more accountability to put the things in place. • A check back would be a good thing for the staff, about four to six weeks after the workshop; it would be nice to have a follow-up session a few months later.	14 (50)
CAPACITY BUILDING Benefit to school Influence on policy Integrated Long-term benefits Parent empowerment Skills are generalizable Results	• It's pretty helpful for the schools. • Trying to move [the whole] staff towards a PBS model; a paradigm switch, what does inclusion mean? • Some of them are so ingrained that I'm not even aware I'm using them; I just do it now, I don't even think about it. • The training was more [for the] long term. • The PBS training gave me the vocabulary, I'm not just a mom being protective. • Now use part of the strategies in my new job as an education assistant. • Sterner about not giving in; before (PBS) I had to pick him up 10 out of 15 days from school … when triggers were identified for the teacher … only had to pick him up one or two times.	25 (89)
TEAM Better communication amongst the team Connections/relationships Dedicated time Speak the same language Other's perception of the family That they came together as a team To be on the same page Team members change	• The workshop opened up communication between the home and the school; meetings are more in depth … we are more of a team. • Child's teacher got an opportunity to know him; made some good connections. • Devoted time together; people were committed and invested … people were totally into talking about (child) and planning for (child). Totally focused on (child) and that was incredible. • To have everyone hear it first hand was great. That way they had the shared language. • Helping the school team understand the trauma, and why he does the things he does; you tell stories and they realize that you are real and that you want to be successful. • Having the team there was a positive, better than just me and my husband; the team approach and hearing all the different disciplines come together and seeing their thoughts on the situation and brainstorming … • Definitely overall beneficial to have teachers, parent, everyone who works with the kid to be on the same page. • It's great for the parent to learn it, but I couldn't do it every year. How do we transfer it to the next teacher?	20 (71)
GENERAL Lots of info Negative Neutral Can't remember/time since workshop Positive	• Learned so much in a little bit of time; so much information overload. • Nothing seems to be working to address a (big behaviour) … even though we've been trying the techniques. • It was good stuff, it just didn't help my situation. • I can't remember specifics about the workshop; I couldn't remember strategies explicitly; it was too long ago. • It helped lots, we got lots out of it; overall the whole thing was positive; professionally it helped a great deal, and personally it influences my life.	26 (93), of which: 22 (85) positive 4 (15) negative

Facilitator

It was important to have someone not affiliated with the current care-team facilitate the workshop (e.g., the workshop facilitators were novel to the team). "Who" was presenting the material and how they presented it influenced parent impressions of the workshop. An educated, professional and unaffiliated facilitator was a vital component of parent satisfaction with the workshop.

Post-workshop

There was a desire for someone besides the parent to hold school personnel accountable for using workshop strategies. There was a willingness to participate in further sessions in the workshop series and a desire for feedback about the use of workshop strategies or an extension of the workshop.

Capacity building

The workshop increased parent abilities and confidence to interact with professionals and to manage problem behaviour. The workshop influenced aspects of school, work and family life beyond the intended child.

Team

The workshop directly influenced the team's ability to work together cohesively and efficiently, especially the improved communication amongst the team. Impressions of the workshop were heavily influenced by participation of school staff; as important as the workshop content was, it was also important to have the school team there in order to improve communication, to build relationships and to have committed time to focus on an individual child.

General

Of the respondents who had a comment in the "General" category, 84% had positive comments about the workshop and 16% had neutral or negative comments. A repeated sentiment in the "General" category regarded length of time since workshop completion. This supported the remarks of parents who recommended a follow-up or refresher workshop. However, even when parents were unable to label a workshop strategy explicitly, they provided examples of their continued use of workshop strategies or talked about fundamental components of the workshop strategies they had learned.

The longitudinal gains suggested that the skills learned in the workshop continued to serve parents in managing their child's difficult behaviours even after workshop completion.

Discussion

The goal of this research was to assess the long-term effectiveness of a workshop designed to help educators and parents who care for children with behavioural challenges associated with ASD and to determine whether certain aspects of the workshops were more or less helpful over time. Prior analysis had shown immediate significant pre-/post-workshop differences, and our research question involved determining whether these gains were maintained long-term. Areas assessed included child behaviour as rated by parents and school personnel, self-perceived parent confidence and effectiveness and parent impressions about the workshop. Parent and school ratings were evaluated 6 to 24 months post-workshop. Pre-workshop and follow-up changes for the combined ABC scores were statistically significant, with a large effect size, indicating long-standing changes in child behaviour by adult report, more so at home than school. PSOC ratings improved between the pre-workshop and the follow-up time point, approaching statistical significance, near the level found in pre-/post-comparisons (Reynolds et al. 2011), suggesting continued gains in parenting self-efficacy. The longitudinal gains suggested that the skills learned in the workshop continued to serve parents in managing their child's difficult behaviours even after workshop completion. The verbal questionnaire portion supported the quantitative findings and revealed components of the workshop that should be incorporated into future workshops.

The information gleaned from the analysis of the verbal questionnaire responses supported prior research and highlighted important components to consider for future implementation of such workshops. Importantly, the most influential facilitator appears to be a facilitator who is educated, professional and independent from the current care-team. Although PBS does not require a specific expert in the development of the support plan (Becker-Cottrill et al. 2003), our qualitative findings suggested that positive perception of the PBS workshop was influenced by facilitator impartiality. It was noteworthy that even more than six months after completing our PBS workshop, parents were still willing to commit to more education or performance monitoring, especially within a team. Our PBS workshop led to improvements in feeling like a team and in the perceived effectiveness of the team.

Perhaps most importantly to service providers, "capacity building" emerged most often (89% of participants), which encompassed comments that reflected benefit to the school, influence on policy, integration into personal life, perceived long-term benefits, parent empowerment, the generalizability of the skills and the results. Findings of capacity building paralleled the quantitative outcomes, enhancing the notion that parent-mediated intervention provided in a large group setting could increase community capacity to recognize, address and prevent behavioural challenges (Reynolds et al. 2011). Capacity building is an important component of an intervention if the benefits are to continue once the funding is removed (Spoth et al., 2004), and certainly a goal of this workshop series was to improve community capacity in addressing challenging behaviours throughout the region. Administrators seeking to build

such a program at their site would likely do best to have a plan for training a wide range of future potential facilitators, so that this work can be disseminated throughout the community. (Though detail is beyond the scope of this paper, we have also provided several "Train the Trainer" sessions to help build this capacity outside of our organization.)

In line with other studies indicating the effectiveness of training parents of children with ASD (Diggle and McConachie 2003; Jocelyn et al. 1998; McConachie and Diggle 2007; Roberts et al. 2011), our findings revealed that scores for child behaviour and parenting self-competence were improved as compared with before the workshop, with gains persisting even more than six months following workshop completion. The improvements in behaviour found in the current study seemed unlikely to be owing to spontaneous recovery or maturation, as challenging behaviours often end up being chronic in children with ASD if they are not unlearned (Murphy et al. 2005). We propose that maintenance of decreased problem behaviours may have resulted from integration of the skills learned in the workshop and continued use of the skills to manage challenging behaviours. This was certainly reflected in the near significance of the parent ratings of self-competence, and the verbal questionnaire findings regarding capacity building. That PSOC scores stayed generally improved six months following workshop completion resonates with Green et al. (2010), who suggested that improved parenting and personal capacities (reflected in our study by PSOC scores) may have a cumulative effect on the target child's development. Considering the verbal questionnaire data in which 89% of the parents commented that abilities continued to influence aspects of school, work and family life, we are confident that the workshop has had a positive impact on parent confidence.

Further longitudinal studies are needed to determine whether gains resulting from parent-mediated communication therapies generalize to the family and generate cumulative effects (Green et al. 2010; Jocelyn et al. 1998; McConachie and Diggle 2007). Ours was one of the first longitudinal studies to report maintained improvements in child behaviour and parent self-perceptions of competence more than six months after leaving the supportive workshop environment.

Our findings support the measurable and also the more subjective value of the PBS workshop. A reduction of negative behaviour with this at-risk population should translate into decreased need for intensive resources (e.g., behaviour-specific classrooms, emergency room visits, out-of-home placement), resulting in more positive outcomes for children and reduced systemic cost to educational, health and welfare services. Increased capacity of parents and improved self-reports of competence have the potential to generalize to other aspects of the family environment (Green et al. 2010), including other offspring (Laski et al. 1988). Administrators can consider these costs in comparison with the costs of delivering the program and of future care for these children. Further cost–benefit analysis of this study would be interesting to determine whether costs related to facilitation and coverage for front-line staff participating in the workshop result in diminished costs to the system as a whole.

A reduction of negative behaviour with this at-risk population should translate into decreased need for intensive resources …

Our findings, of course, should be interpreted in light of the study's limitations. Our small sample leads to less certainty about the size of long-term effects. The wording of our verbal questionnaire may have unintentionally biased parents towards positive responses. Some questions pre-supposed that parts of the workshop were memorable, which could have been construed as "positively memorable" by parents, and one question contained the word "important," potentially steering responses towards positive points of view. Other potential sources of bias were the online typing of parent responses, instead of audio-recording them for later transcription, and the use of a single researcher to interview, rate and code the data, instead of having multiple coders/raters. Parents were assured that their comments were anonymous and knew the interviewer was not one of the facilitators, so we are confident that parent impressions were genuine. However, a greater number of negative comments may have occurred if the parents were completing the questionnaire more anonymously (say, over e-mail) instead of in-person/over the phone.

The long-term follow-up sample size was quite small. It will be important to evaluate similar programs with larger samples to determine whether additional effects are detected. Also, it is possible that teams were registering for our PBS workshop when the child's behavioural challenges were escalated. As such, regression towards the mean may account for some of the changes in child behaviour, noting it is more likely for challenging behaviours to become chronic if they are not managed (Murphy et al. 2005). A wait-list control group could help determine the degree to which improvements over time can be specifically attributed to this workshop and the benefits conferred by the workshop. Our study did not address other interventions received between the end of our workshop and follow-up, as it was assumed that all children were receiving intervention either non-specifically through classroom interventions or directly via medication/therapy. Our study accepted all teams put forward by the respective school boards, with no exclusion criteria, resulting in a rather heterogeneous sample. Future studies may want to focus on collecting demographic data as a way to stratify outcome results or compare between families who did and did not follow up. Another avenue for future studies would be to collect the perspectives of school personnel involved in the workshops through verbal questionnaires in order to compare with parents' perspectives.

Conclusion

Children with ASD often present with a high degree of behavioural challenges. The current study was designed to follow up results of a prior study (Reynolds et al. 2011) that indicated improvements in child behaviour at home and school, as well as parent satisfaction and efficacy, following a workshop designed to address these challenges. Long-term (i.e., 6–24 months) follow-up indicated that gains from the workshop were maintained or increased over this extended time, suggesting the long-term value of this workshop series for participants. HQ

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