

HEALTHCARE

POLICY

Politiques de Santé

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

Volume 15 + Number 2

**What Is Missing from “Patient-Oriented Research?”
A View from Public Health Systems and Services**

BERNADETTE PAULY ET AL.

**Retirement Decision-Making among Registered Nurses and
Allied Health Professionals: A Descriptive Analysis of Canadian
Longitudinal Study on Aging Data**

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**Medical Assistance in Dying (MAiD) in Canada: A Critical Analysis
of the Exclusion of Vulnerable Populations**

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**Envisioning Implementation of a Personalized Approach in Breast
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Data Matters + Discussion and Debate + Research Papers

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Politiques de Santé

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

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

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

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

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

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

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Adjunct Faculty, University of Victoria, Victoria, BC

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EDITORIAL DIRECTOR

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W. ANTON HART

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PUBLISHER & COO

REBECCA HART
rhart@longwoods.com

HOW TO REACH THE EDITORS AND PUBLISHER

Telephone: 416-864-9667; fax: 416-368-4443

ADDRESSES

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EDITORIAL

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EDITORIAL DIRECTOR

DIANNE FOSTER-KENT
dkent@longwoods.com

ASSOCIATE PUBLISHER, CAREERS & WEB

SUSAN HALE
shale@longwoods.com

ASSOCIATE PUBLISHER, CUSTOMER SERVICE & ADMINISTRATION

BARBARA MARSHALL
bmarshall@longwoods.com

EDITORIAL AND PUBLISHING COORDINATOR

SUSMITA DEY
sdey@longwoods.com

DESIGN AND PRODUCTION

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CREATIVE

ERIC HART

ADVERTISING

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

PUBLISHING

To discuss supplements or other publishing issues contact
Rebecca Hart at 416-864-9667, ext. 114 or by e-mail at
rhart@longwoods.com.

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Reflections on a Decade of *Healthcare Policy/Politiques de Santé*

S NOW FALLS OUTSIDE MY WINDOW AS I WRITE THIS EDITORIAL. THE END OF the year fast approaches, as does the end of my tenure as Editor-in-Chief of *Healthcare Policy/Politiques de Santé*.

It has been a fantastic opportunity to be the editor for this journal over the last decade. I have very much enjoyed being exposed to the broad range of health services and policy research papers that have been submitted to the journal – more than 1,000 manuscripts that reflect a diverse set of questions, approaches, contributors and conclusions.

The articles in this issue exemplify that diversity. Some themes continue to resonate strongly: health human resources, primary healthcare, and healthcare financing have been important topics since the journal was founded, for instance. But there have been changes too. Some topics – such as medical assistance in dying – have emerged as central questions in healthcare policy. We now see more research being undertaken with patients and communities. And the ratio of qualitative and mixed-methods research to quantitative analysis has risen.

Bringing authors' insights to publication is the work of a team. I am very fortunate to have worked with a cadre of talented editors throughout my time with the journal. While some of the names on the masthead have changed, each editor brought or brings a range of skills, knowledge and perspectives to the team. All share a commitment to finding and publishing high quality, informative work. Together, they have also been key to driving the journal's editorial policies, including supporting the SAGER Sex and Gender Equity in Research Guidelines, established guidelines for reporting research results disseminated by the Equator Network and the journal's policy on honest and constructive reviews.

The journal's Managing Editor, Ania Bogacka, has worked with all of us and the team at Longwoods throughout my tenure. She has been the constant point of connection between authors, reviewers, editors and the production team. Her commitment to advancing the journal and the work that it publishes has been steadfast and has driven major initiatives, such as having the journal indexed by the National Library of Medicine. Ania, too, is moving on to new opportunities, and we wish her all the best in the endeavours that will be fortunate to benefit from her time and talents.

From the Editor-in-Chief

In addition to the journal's editorial team and Ania, I owe huge thanks to all the authors who submitted their work to the journal, to the hundreds of reviewers who provided advice on how to ensure the best work is published and to the many readers who used insights from the journal's pages to advance their thinking and actions on healthcare policy. Learning and exchange are two key foundations for making healthcare better.

While I will miss this role deeply, I am also a believer in the value of renewal, and I am delighted that Dr. Jason Sutherland will become Editor-in-Chief as of January 2020. Many of the journal's readers will know Jason from his roles as a Professor in the Centre for Health Services and Policy Research in the UBC Faculty of Medicine, School of Population and Public Health and as a Scholar of the Michael Smith Foundation for Health Research. His research interests are broad, as is his commitment to connecting research with policy and practice.

As an ongoing reader of the journal, I look forward to seeing the innovations that Jason brings to the journal and the work that it publishes.

In the meantime, if you're planning on submitting an abstract for a presentation or poster at the upcoming Canadian Association of Health Services and Policy Research (CAHSPR) conference, keep in mind that *Healthcare Policy/Politiques de Santé* is partnering with CAHSPR and the *Canadian Journal of Public Health* to feature work from the conference in upcoming issues of both journals since the Advancing Health Equity: Identifying Barriers and Solutions theme straddles our mandates. See the CAHSPR website for more information.

JENNIFER ZELMER, PHD

Editor-in-Chief

Réflexions sur une décennie de *Politiques de Santé/Healthcare Policy*

LES FLOCONS TOMBENT ALORS QUE J'ÉCRIS CET ÉDITORIAL. LA FIN DE L'ANNÉE arrive à grands pas, tout comme celle de mon mandat en tant que rédactrice en chef de *Politiques de Santé/Healthcare Policy*.

Être rédactrice de cette revue à été pour moi une expérience extraordinaire. J'ai apprécié prendre connaissance d'une vaste gamme d'articles de recherche sur les services et les politiques de santé soumis pour publication dans la revue, soit plus de 1 000 manuscrits qui reflètent divers questionnements, approches, contributions et conclusions.

Les articles du présent numéro illustrent bien cette diversité. Certains thèmes ont une forte résonance : par exemple, les ressources humaines en santé, les soins de santé primaires et le financement des services de santé sont des thèmes de premier plan depuis la fondation de la revue. Mais il y a aussi eu des nouveautés. Certains sujets, comme l'aide médicale à mourir, se sont imposés dans le domaine des politiques de santé. Nous voyons aussi plus de recherche entreprises de concert avec les patients et les communautés. Et le nombre de recherches qualitatives ou de méthodes mixtes par rapport aux analyses quantitatives s'est accru.

Publier le travail des auteurs est une affaire d'équipe. J'ai eu le plaisir de travailler avec une équipe d'éditeurs talentueux tout au long de mon mandat. Certains noms ont changé, mais chacun des éditeurs a apporté ses compétences, ses connaissances et son point de vue. Ils se sont tous engagés à publier des travaux de grande qualité. Ensemble, ils ont contribué aux politiques éditoriales de la revue, notamment en souscrivant aux directives SAGER sur l'égalité entre les sexes dans la recherche, en adoptant les lignes directrices du réseau EQUATOR et en élaborant la politique de la revue quant aux examens critiques et constructifs.

La directrice de rédaction Ania Bogacka a travaillé avec nous et avec l'équipe de Longwoods depuis le début de mon mandat. Elle a été le point de connexion entre les auteurs, les examinateurs, les éditeurs et l'équipe de production. Son engagement envers la revue n'a jamais faibli et a mené à de nombreux accomplissements comme l'indexation de la

revue dans la National Library of Medicine. Mme Bogacka se tourne aussi vers de nouveaux défis et nous lui souhaitons tout le succès dans les projets auxquels elle consacrera son temps et son talent.

Outre l'équipe de rédaction et Mme Bogacka, je dois remercier les auteurs qui ont présenté leurs travaux à la revue, les centaines d'examineurs qui ont prêté conseil pour assurer la qualité des travaux publiés et les nombreux lecteurs qui ont tiré profit de la revue pour faire avancer leurs réflexions et leurs travaux dans le domaine des politiques de santé. L'apprentissage et l'échange sont deux piliers de l'amélioration des services de santé.

Bien que ce rôle me manquera énormément, je suis en faveur du renouveau. C'est pourquoi je suis heureuse de savoir que le Dr Jason Sutherland deviendra rédacteur en chef de la revue en janvier 2020. Plusieurs lecteurs connaissent M. Sutherland pour son rôle de professeur au Centre de recherche sur les politiques et les services de santé à l'École de santé publique et des populations de la Faculté de médecine (Université de la Colombie-Britannique) et de chercheur à la Fondation Michael Smith pour la recherche en santé. Ses intérêts de recherche sont aussi vastes que son engagement pour unir la recherche aux politiques et à la pratique.

En tant que lectrice assidue, je suis impatiente de voir les innovations qu'apportera M. Sutherland à la revue et aux travaux publiés.

Entre-temps, si vous prévoyez soumettre un résumé ou une affiche pour la prochaine conférence de l'Association canadienne pour la recherche sur les services et les politiques de la santé (ACRSPS), sachez que *Politiques de Santé/Healthcare Policy* a conclu un partenariat avec l'ACRSPS et *La revue canadienne de santé publique* pour présenter les conclusions de la conférence dans les numéros à venir des deux revues, puisque le thème choisi cette année – Faire progresser l'équité en santé : cerner les obstacles et les solutions – chevauche nos mandats respectifs. Pour plus de renseignements, je vous invite à consulter le site Web de l'ACRSPS.

JENNIFER ZELMER, PHD

Rédactrice en chef

What Is Missing from “Patient-Oriented Research?” A View from Public Health Systems and Services

Que manque-t-il à la « recherche axée sur le patient »?
Point de vue des systèmes et services de santé



BERNADETTE PAULY, RN, PHD
*Professor, School of Nursing and Scientist,
Canadian Institute for Substance Use Research
University of Victoria
Victoria, BC*

KAREN URBANOSKI, PHD
*Assistant Professor,
School of Public Health and Social Policy
University of Victoria
Scientist, Canadian Institute for Substance Use Research
Victoria, BC*

ELIZABETH HARTNEY, PHD, RPSYCH
*Professor, School of Leadership Studies
Royal Roads University
Victoria, BC*

SANA SHAHRAM, PHD, MPH
*Adjunct Professor, School of Public Health & Social Policy
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Assistant Professor, Nursing
University of British Columbia Okanagan
Kelowna, BC*

LENORA MARCELLUS, PHD, RN
*Associate Professor, School of Nursing
University of Victoria
Victoria, BC*

BRUCE WALLACE, PHD, RSW
*Associate Professor, School of Social Work
University of Victoria
Scientist, Canadian Institute for Substance Use Research
Victoria, BC*

MARJORIE MACDONALD, RN, PHD
*Professor, School of Nursing
University of Victoria
Victoria, BC*

TREVOR HANCOCK, HON FFPH
*Retired Professor and Senior Scholar
School of Public Health and Social Policy
University of Victoria
Victoria, BC*

Abstract

Patient-oriented research (POR) aims to increase patient engagement in health research to improve health research and health services. In Canada, the Strategies for Patient-Oriented Research (SPOR) framework provides guidance for conducting POR. We critically review the SPOR framework through the lens of public health systems and services research. The SPOR framework is primarily focused on engaging individual patients in health research without attention to broader structural forces that shape health and participation in health-care systems. Shifting from patient to public involvement and from patient to community engagement and being explicit about the range of health research that SPOR encompasses would enhance the framework and strengthen the potential of SPOR to improve health systems through health protection, promotion and prevention of disease and injury.

Résumé

La recherche axée sur le patient (RAP) vise à accroître la participation des patients afin d’améliorer la recherche et les services de santé. Au Canada, la Stratégie de recherche axée sur le patient (SRAP) offre des conseils pour faire de la RAP. Nous avons examiné de façon critique la SRAP selon l’angle de la recherche sur les systèmes et services de santé. La SRAP vise principalement à faire participer les patients à la recherche sans égard aux grandes forces structurelles qui influent sur la santé et sur la participation dans les systèmes de santé. Passer d’une participation du patient à une participation communautaire, et exposer de façon plus explicite la gamme de recherches en santé visée par la SRAP, améliorerait le cadre stratégique et accroîtrait son potentiel d’amélioration des systèmes de santé, notamment par la protection sanitaire et la prévention des maladies et blessures.

Introduction

The enhancement and sustainability of public health systems and services has repeatedly been identified as important to improving the health of the public through health promotion, protection, and disease and injury prevention efforts both within the health system and through collaboration with other sectors that impact health (Krever Commission 1997; The Standing Senate Committee on Social Affairs, Science, and Technology 2002). In addition, there have been specific calls to reorient health systems toward health equity to address structural injustices and social conditions that produce poor health (Commission on the Social Determinants of Health 2008; World Health Organization [WHO] 2011). These calls stem from analysis of the rising costs of medical care and the ineffectiveness of the current health system to address health inequities. In an analysis of the economic benefits of public health services, Mays and Mamaril (2017) found that investments in public health significantly offset health system costs, with larger offsets for low-income and low-resource communities. Reducing health inequities through upstream action on the social determinants of health is an economic, social and ethical imperative.

The field of public health systems and services research (PHSSR) emerged to bridge population health research and health systems and services research, with a unique focus on public health services, policies and programs. PHSSR examines “the impact of the organization, staffing, and management of public health systems on access to, delivery, cost, quality and outcomes of population-based services and interventions” (Van Wave et al. 2010). PHSSR aims to enhance the health of the public and reduce health inequities by understanding how public health systems and services work and identifying ways in which these might be improved.

Concurrent with the emergence of PHSSR, there has been a growing focus on patient involvement and engagement in the development and conduct of health research (Brett et al. 2010, 2012; Sacristán 2013). Terms such as patient-centred research, patient engagement in research, patient-oriented research and public involvement are used to capture the growing impetus to involve patients and service users in all types of research. We use the term “patient-oriented research” because that is the predominant term used in Canadian guidance documents (Canadian Institutes of Health Research [CIHR] 2014).

Patient-oriented research (POR) encompasses several aims. Some authors have described the moral aim of POR as the empowerment of patients in the process of research, to ensure more responsive and responsible research that benefits the public (Brett et al. 2010; White and Verhoef 2005). Others have emphasized the importance of optimizing research designs, enhancing validity and improving the effectiveness of knowledge translation and exchange (Bogart and Uyeda 2009; Brett et al. 2012; Caron-Flinterman et al. 2005). The ultimate aims of POR are to improve the effectiveness, efficiency and delivery of healthcare services, programs and policies.

Policy and funding initiatives have been launched to support POR and enhance the shift from primarily researcher-driven to patient-driven research: these include INVOLVE in the UK (<https://www.invo.org.uk/about-involve/>), Patient-Centered Outcomes Research Institute (PCORI) in the US (<https://www.pcori.org>) and Strategies for Patient-Oriented Research (SPOR) in Canada through the CIHR (2014). The aims of SPOR are identified as follows:

An important goal of Canada’s Strategy for Patient-Oriented Research (SPOR) is for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada. Since patients are at the heart of SPOR, they must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians. (CIHR 2014, p. 4)

POR commitments include engaging patients and the public to improve health research and, ultimately, health systems and services. This represents a significant shift toward

acknowledging the value of situational and experiential knowledge as a source of practical wisdom for improving health research, systems and services (Caron-Flinterman et al. 2005).

In this commentary, we critically examine the CIHR SPOR framework from the perspective of PHSSR. We examine three concepts central to the SPOR framework and to PHSSR – patients, patient engagement and health services – through a public health systems and services lens. We identify dominant underlying discourses of SPOR and discuss important contributions from public health and PHSSR that could strengthen the framework and improve the potential for health system improvements.

In the name of “patients” and communities

In SPOR, the “patient” is the focus of engagement or involvement. A patient is defined as “an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends” (CIHR 2014). The strengths of this definition include a focus on experience as a source of knowledge, the engagement of people with lived experience and the inclusion of caregivers, families and friends.

The very nature of the word “patients” as the primary human focus in the SPOR framework intentionally or unintentionally reinforces the dominant societal focus on individuals presenting with a health problem to be treated through acute or chronic healthcare services and, by extension, involving their caregivers and families. Public health does not have “patients” but focuses on primordial, primary and secondary prevention with families, groups and communities. The aims of public health are to promote health, strengthen community action for health, develop personal skills, promote supportive environments, build healthy public policy and reorient the health system toward health promotion and well-being (WHO 1986). Health promotion prevents people from becoming patients, thus reducing the burden of disease that the healthcare system has to manage. Moving upstream to focus on prevention and health promotion has long been a critical recommendation for reducing costs and enhancing health systems in Canada and worldwide (Commission on the Social Determinants of Health 2008).

Absent from the SPOR framework is recognition of the complex social, environmental, economic and policy conditions in which individuals, families, groups, communities and populations are embedded and that impact health through the social locations of individuals and collectives within systems of power and privilege. This “situated-ness” is central to public health thinking and approaches (Commission on the Social Determinants of Health 2008; Sadana and Blas 2013). The term “patient-oriented” implies that “patients” and “academic researchers,” “health service providers” (except informal caregivers) and/or “health policy makers” occupy mutually exclusive groups. This creates a binary or fixed understanding of categories of people, with little to no overlap, empathy or shared perspectives and little understanding as to how each is situated and/or the differences in power based on one’s position.

Along with an emphasis on social positioning, public health emphasizes self-determination, social context and social and environmental conditions that influence health and well-being that are implicated in the production of inequitable health outcomes (Commission on the Social Determinants of Health 2008; Sadana and Blas 2013). The degree to which individuals are autonomous is contextualized by the relative power they hold and their resources and social networks (Commission on the Social Determinants of Health 2008). This portrayal of “patients” as autonomous is rooted in a neo-liberal consumer model of healthcare that personifies patients as rational consumers choosing the best available product. It is also based on an inaccurate presupposition that there is equitable access to accurate, unbiased information and the full gamut of health services. Further, there is a failure to recognize differences in vulnerability based on group or community identification or status within a healthcare system that privileges the ultimate authority of the physician and emphasizes treating illness and injury rather than promoting self-determination and health. These understandings of social position and situatedness are critical to recognizing and addressing power inequities that permeate research and healthcare relationships and should be a fundamental principle of SPOR.

The focus on involving individual “patients” runs the risk of failing to represent groups impacted by structural inequities. When patients are involved, without attention to issues of power and privilege, tokenism and the co-optation of individuals and groups can reproduce systemic and structural inequities that are the root of poor health (Ocloo and Matthews 2016; Shimmin et al. 2017). For example, individuals may be selected to participate in SPOR projects specifically for their tendency to represent and, therefore, reinforce the status quo. Representatives may be chosen who present socially acceptable personas and/or do not threaten the existing power dynamics within the system. Public health approaches draw attention to the determinants that shape health and the constraints that affect participation of individuals, groups and communities. We would suggest, like others, that the use of the term “public” engagement better reflects broader collective involvement of individuals, groups and communities. Use of the term “public” also more readily makes space for consideration of the social, political, economic and historical conditions that impact resources and the ability to participate fully and in meaningful ways (Shimmin et al. 2017).

In the name of “patient” and community engagement

Patient engagement in the SPOR framework is primarily described through the delineation of various individual roles such as committee members and researchers and through guiding principles of inclusivity, support, mutual respect and co-building. We explore two relevant issues from a public health systems and services perspective: 1) use of the term “patient engagement” and 2) lack of attention to well-known and established participatory processes for research.

The focus on patient or individual engagement misses the important role of communities in creating supportive environments for health. In a recent scoping review of the

literature, Manafo et al. (2018) suggested that methods for patient engagement should involve patients early and throughout the research process and should support and value the expertise of patients. Community-based participatory research (CBPR) emphasizes the co-production and democratization of knowledge and action with recognition and valuing of the contributions of communities to the research as a means of generating action to improve health and health services. CBPR, and engaging communities as a source of knowledge in designing, developing, evaluating and researching health services, is central to PHSSR (Bogart and Uyeda 2009; Israel et al. 1998; Minkler 2010). Using a critical public health lens, rooted in the concepts of health equity and social justice, can help illuminate important differences in power between providers, policy makers and patients/communities that are central to authentic and meaningful participation in research. This is consistent with the democratic aims of CBPR.

Further, in relying on existing (and in our view limited) CIHR frameworks, SPOR seeks to engage individual patients and their families without paying sufficient attention to Indigenous wellness approaches and research processes. This is extremely problematic in the context of the Truth and Reconciliation Commission, which has outlined specific calls to action for improving health and healthcare (Truth and Reconciliation Commission of Canada 2015). This follows earlier reports on the failure of the health systems for Indigenous peoples, including the Royal Commission on Aboriginal Peoples (Aboriginal Affairs and Northern Development Canada 1996). These omissions reinforce and overlook important considerations in reorienting health systems and health research. Any attempt to improve health and health systems for Indigenous peoples has to account for the powerful, historical and ongoing colonization of healthcare systems and doing research “with,” not on, Indigenous people, with explicit attention to Indigenous methodologies to enhance cultural appropriateness, efficacy, relevance and fairness of health research, services and systems (Kovach 2018).

To address these issues, we suggest attention to 1) expanding the language of “patient engagement” to community or public engagement, thus including individuals, families, groups and communities; 2) explicitly incorporating principles of CBPR, specially the importance of an action orientation; and 3) paying specific attention to decolonizing health research and processes for the meaningful inclusion of Indigenous peoples, as well as Indigenous research methodologies and protocols.

In the name of “health research”

The SPOR framework refers to “health research.”

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system. (CIHR 2014)

Although this statement could be considered as inclusive of all health research, including PHSSR, such language is also subject to the dominance of an individually focused, bio-medically oriented healthcare system. Like the term “patient,” the use of the terms “health research” and “health services” is subject to biomedical discourses, with the main focus being on “patients” accessing acute or chronic healthcare services, not community-based, population-focused health-promoting care. Biomedical discourses focus primarily on the diagnosis, treatment and cure of diseases, which is the dominant focus within our Canadian health system (which is, in reality, an illness care system). The need for patient involvement in biomedical research has been a main driver of POR, and patient engagement in biomedical discourse is highly relevant to improving healthcare and individual health outcomes (Caron-Flinterman et al. 2005; Sacristán 2013; Shaywitz et al. 2000). However, many public health interventions are social, environmental, economic and policy focused in nature and aimed at changing these health determinants and the broader structural conditions that affect health. Public health approaches and interventions, which are often outside the dominant understandings of health services, aim to promote community or societal health and, in doing so, also promote individual health.

PHSSR, as one type of health services research, has the potential to produce knowledge that contributes to improvements in health systems that, in turn, will improve the health of populations. PHSSR achieves this by studying interventions that change the conditions that produce health inequities. Upstream thinking is needed at the population level to enhance early detection, support and intervention, particularly within vulnerable groups (PHAC, PHN, Stats Can and CIHI 2017). As identified at the outset of this paper, PHSSR is a highly recommended area for health systems improvements, with the potential to offset expensive acute care costs (Krever Commission 1997; Mays and Mamaril 2017; Romanow 2002).

We argue that specifying the full range of health research within the scope of SPOR would greatly enhance its potential to achieve its aims while also improving population health and reducing health inequities. In addition, using language that better reflects the full scope of healthcare functions, from health promotion, prevention and early intervention to diagnosis, treatment and tertiary care, will better position the role of health service users, within the context of their communities, as leaders in transforming the system. To realize health systems improvements, we need to move beyond dominant biomedical and individualized understandings of health and health services. Although the SPOR document does not exclude PHSSR, specific delineation of different types of health research would greatly enhance the potential of SPOR to move beyond dominant understandings to harness the potential of critical new areas of health research, such as PHSSR, to realize both health systems improvements and – more importantly – improvements in the health of populations and reduction in health inequality.

We argue that PHSSR, as a focus of health systems and services research, can improve health and reduce the large excess burden of disease and illness that the health system has

to manage at great expense. Prevention is a hallmark of quality care that contributes to improved health and reduced inequalities in health as well as improved patient satisfaction – nothing is more satisfying than not having the illness or injury in the first place – and reduced costs (Hancock 2017; Ministers of Health and Health Promotion/Healthy Living 2010). Indeed, public health and preventive services are argued to contribute to achieving the “Triple Aim” (Beasley 2009) and thus to the sustainability of the healthcare system (Hancock 2017).

Conclusions

In this commentary, we unpack the central SPOR concepts of patient, patient engagement and health research and argue for an expansion of these concepts in the SPOR framework to enhance potential for improvements in health systems and services. We provide a critical analysis of the dominant understandings of “patient,” “patient engagement” and “health research.” Implicitly, the SPOR framework revolves around individual patients, and, by extension, biomedicine and acute care, without capturing the full range of health research.

The SPOR framework would be greatly enhanced by shifting from patient to public and from patient engagement to community engagement and by delineating a broad range of health research that is inclusive of and extends beyond PHSSR. These shifts are needed for the promise of SPOR to be realized, to address issues of power and privilege in the research process and to avoid unintended consequences. These consequences spring from dominant neo-liberal and biomedical understandings that permeate healthcare systems along with inattention to the social conditions that influence health outcomes and the ability to participate in healthcare research. Individual patients, families, communities and the entire population will be better served by this expanded framework.

Correspondence may be directed to: Bernadette Pauly, University of Victoria, Box 1700 STN CSC, Victoria, BC V8W 2Y2; e-mail: bpauly@uvic.ca.

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Retirement Decision-Making among Registered Nurses and Allied Health Professionals: A Descriptive Analysis of Canadian Longitudinal Study on Aging Data

Décision de retraite chez les infirmières autorisées et
les professionnels paramédicaux : analyse
descriptive d'une étude longitudinale canadienne
sur le vieillissement



SARAH J. HEWKO, RD, PhD

*Assistant Professor, Department of Applied Human Sciences,
University of Prince Edward Island
Charlottetown, PE*

TRISH REAY, PhD

*Professor
Alberta School of Business, University of Alberta
Edmonton, AB*

CAROLE A. ESTABROOKS, RN, PhD

*Professor, Canada Research Chair in Knowledge Translation
Faculty of Nursing, University of Alberta
Edmonton, AB*

GRETA G. CUMMINGS, RN, PhD

*Dean and Professor
Faculty of Nursing, University of Alberta
Edmonton, AB*

Abstract

A population's health is dependent on the availability of skilled health professionals. We know little about retirement decision-making among publicly employed Canadian registered nurses (RNs) and allied health professionals (AHPs). We identified and compared factors reported to influence early versus 65+ retirement decisions among RNs ($n = 794$) and AHPs ($n = 393$). RNs, on average, retired at 58.1 years and AHPs at 59.4 years. More than two thirds retired before age 65. Among RNs, caregiving demands predict early retirement – policies supporting employed RN caregivers may reduce early workforce exits among publicly employed RNs.

Résumé

La santé d'une population est tributaire de la disponibilité de professionnels de la santé compétents. On connaît peu de chose sur la prise de décision en matière de retraite chez les infirmières autorisées (IA) et les professionnels paramédicaux (PP). Nous avons identifié et comparé des facteurs qui ont une influence sur la prise de retraite précoce ou à plus de 65 ans chez les IA ($n = 794$) et les PP ($n = 393$). En moyenne, les IA ont pris leur retraite à 58,1 ans et les PP à 59,4 ans. Plus des deux tiers ont pris leur retraite avant 65 ans. Parmi les IA, les obligations d'aidant naturel sont un indice de retraite précoce – des politiques de soutien pour les IA proches aidantes pourraient réduire la perte précoce de main-d'œuvre parmi les IA employées par l'État.

THE FOUNDATION OF A HEALTH SYSTEM IS ITS WORKFORCE (ORGANISATION FOR Economic Co-operation and Development [OECD] 2016). A recent report projected a global deficit of skilled health professionals of 12.9 million by 2035 (Global Health Workforce Alliance and World Health Organization 2014). The aim of health workforce planning is to achieve short- and long-term balance between supply and demand of diverse health workers (Ono et al. 2013). To date, most workforce projections have focused on anticipating supply and demand for physicians and nurses (Amorim Lopes et al. 2015).

A primary barrier to sophisticated analysis of supply is a lack of information; workforce data deficits make system-wide planning impossible. Despite the strategic importance of effective health human resource management, the topic has received little attention in Canadian health policy research and academic literature (Wranik 2008).

In 2017, 301,010 registered nurses (RNs) were licensed to practice in Canada (Canadian Institute for Health Information [CIHI] 2018). RNs typically retire before the standard age of retirement (OECD 2016; Ono et al. 2013). In 2016, more than 10,500 allied health professionals (AHPs) were employed across Canada (CIHI 2017). We have defined AHPs as healthcare providers with a minimum of a required baccalaureate degree (e.g., pharmacists, dietitians, physiotherapists). Data on AHP supply and demand are limited (Solomon et al. 2015).

The purpose of this project, broadly, was to characterize retirement decision-making among publicly employed Canadian RNs and AHPs between the ages of 45 and 85 years in the interest of informing both workforce planning and development of targeted employment and social development policy. In this descriptive paper, we aim to provide Canadian workforce planners and health administrators with current, empirically derived average ages of retirement and average expected ages of retirement for RNs and AHPs. In addition, we aim to highlight factors associated with retirement decision-making among RNs and AHPs and cross-profession differences in approaches to retirement decision-making.

Methods

Data for this descriptive analysis were drawn from the Tracking and Comprehensive data sets of the Canadian Longitudinal Study on Aging (CLSA) (Raina et al. 2009). Baseline data (Wave 1) were collected between 2011 and 2015 (CLSA n.d.). A single researcher reviewed text entries (English and French) to occupation-related questions to identify those in the included professions. Respondents commonly reported profession simply as “nurse.” We included only those respondents who we were reasonably certain were RNs. Specifically, this meant that we included only those who either 1) explicitly identified themselves as RNs or 2) identified themselves as a nurse and had a baccalaureate level of education (minimum).

Participants who reported self-employment or retail employment were removed from the sample, as the objective was to provide information of direct relevance to administrators of Canada’s public healthcare system. In some cases, setting was unclear – “health care” or “healthcare” were accepted in the absence of further detail.

Measures

The CLSA questionnaire determined age of retirement by asking, “How old were you when you first retired/partially retired?” Those not yet retired were asked, “At what age do you plan to retire?” For our purpose, early retirement was defined as retirement before the age of 65 years. Respondents were also asked, “There are many reasons why people retire. Which of the following reasons contributed to your decision to retire?” Contributing variables of financial possibility, desire to stop working, pension qualification, desire to pursue hobbies, spousal support, caregiving, organizational restructuring (including job elimination) and (dis)incentives to retire were identified for inclusion based on previously developed conceptual models (Hewko et al. 2018).

Analysis

We conducted exploratory bivariate analyses using chi-square tests for comparison of independent proportions to explore differences across professional group and differences between early retirees and those who retired at age 65+. A respondent was deemed an early retiree if they had a valid response to the age of first retirement question and their response was less than 65 years.

Results

In total, 1,187 RNs and AHPs employed in the public system were included in the CLSA data set (Table 1, available online at longwoods.com/content/26074). “Other” AHPs include midwives, cardiac perfusionists, audiologists, radiation therapists and child life specialists. Notably, 70 respondents provided a valid response to the question related to age of retirement and to the question related to planned age of retirement. It is likely that these respondents had retired and then returned to the workforce – thus, for the latter question, they would be reporting their planned age for a second retirement.

Participating RNs ($n = 794$) retired significantly earlier than AHPs ($n = 393$) (58.1 vs. 59.4 years, $p < 0.05$). Across the allied health professions, average age of retirement (among those already retired) ranged from 55.8 among speech language pathologists to 60.3 among pharmacists (Table 2).

TABLE 2. Age of retirement (actual and planned) across professions

	<i>n</i>	No response for age of retirement or planned retirement age	Response for both age of retirement and planned retirement age	Age of retirement	Planned retirement age
				Age	Age
				Mean (SD)	Mean (SD)
Registered nurse (RN)	794	51	50	485	308
Age				58.1 (6.6)	61.6 (5.0)
Pharmacist	78	10	6	39	35
Age				60.3 (8.2)	62.8 (3.8)
Social worker (SW)	106	11	4	55	44
Age				59.7 (5.3)	62.2 (4.9)
Dietitian (RD)	44	7	0	16	21
Age				56.8 (7.0)	61.4 (2.9)
Occupational therapist (OT)	49	7	0	19	23
Age				59.2 (7.7)	61.8 (4.5)
Physiotherapist (PT)	76	11	6	35	36
Age				60.1 (5.3)	61.8 (5.0)
Speech language pathologist (SLP)	25	1	3	11	16
Age				55.8 (3.9)	61.8 (5.4)
Other AHP	15	0	1	2	14
Age				60.5 (.71)	62.7 (6.8)

Financial possibility and desire to stop working were the most frequently reported factors contributing to both early and 65+ retirement for RNs. Financial possibility was more often reported by those who had retired early, and the desire to stop working was more often reported by those who had retired at 65+. Agreement with spouse, caregiving requirements and organizational restructuring (including job elimination) were more frequently identified

as contributing to early rather than 65+ retirement. Sampled AHPs, regardless of retirement timing, were more likely than RNs to report that a desire to pursue hobbies contributed to their retirement decision (see Table 3).

TABLE 3. Factors contributing to retirements

	RN		AHP	
	Early	65+	Early	65+
Financial possibility [§]	197 (48%)	22 (31%)	71 (52%)	17 (43%)
Desire to stop working [§]	176 (43%)	37 (51%)	65 (47%)	24 (60%)
Qualify for pension	127 (31%)	20 (28%)	51 (37%)	18 (45%)
Desire to pursue hobbies ^{*.†}	113 (27%)	16 (22%)	53 (39%)	17 (43%)
Spousal support [§]	104 (25%)	7 (10%)	34 (25%)	6 (15%)
Caregiving [§]	71 (17%)	4 (6%)	20 (15%)	3 (8%)
Organizational restructuring [§]	54 (13%)	3 (4%)	14 (10%)	1 (3%)
Employee incentives to retire	22 (5%)	3 (4%)	11 (8%)	2 (5%)

Respondents could select more than one factor as having contributed to their retirement.

[†]p < 0.05, significant difference between early retiring RNs and AHPs.

[§]p < 0.05, significant difference between early retirees and 65+ retirees.

^{*}p < 0.05, significant difference between 65+ retiring RNs and AHPs.

Discussion

RNs and AHPs employed in Canada’s public health system frequently retire early (Table 2) – in 2018, on average, Canadians retired at age 64 years. In the public sector, broadly, the average retirement age was 62 years (Statistics Canada 2019). The profession-specific average ages of retirement may be valuable to workforce planners seeking to increase the accuracy of Canadian workforce planning model(s). In many of these professions, current supply does not meet existing and/or predicted demand. Experienced professionals exhibit explicit and tacit professional skills acquired over the length of their career (Perera et al. 2015). They also make significant contributions to training those new in the profession.

Early-retiring RNs and AHPs were more likely than those who retired at 65+ to indicate that an agreement with their spouse, organizational restructuring (including job elimination) and/or caregiving requirements contributed to their decision to retire.

For pragmatic purposes, we will focus the discussion on organizational restructuring and caregiving responsibilities as contributors to early retirement; this is because potential mitigation strategies for these factors, which can be implemented by health administrators and/or policy makers, have been reported in the literature. Organizational restructuring, which often includes elimination of jobs, is frequently implemented in response to budgetary shortfalls. As healthcare is the most significant government expenditure in most high-income countries, the demand on healthcare systems to cut costs is unlikely to disappear (Burke et al. 2015). Older workers are frequently perceived to be more expensive than younger workers (Hennekam 2015), as they are more likely to be at the top of the pay scale. They can also cost more to insure (whether for on-the-job insurance, disability benefits and/or extended

medical benefits; e.g., see Bailey 2014). Burke et al. (2015) proposed that negative human resource effects (such as a surplus of early retirements) of organizational restructuring can be mitigated when efforts are made to facilitate collaboration between professional unions and hospital management. Effective, frequent communication throughout restructuring may also lessen the uncertainty and worry experienced by employees, increasing the likelihood that fewer will opt for early retirement when faced with restructuring (Burke et al. 2015).

Existing research indicates that those who leave the workforce to act as a caregiver often struggle to re-enter once they are no longer needed as a caregiver (Lilly 2011). The impact of caregiving on retirement decisions of older RNs and AHPs could be mitigated through adoption of caregiver-friendly policies at the institutional, provincial and/or federal level. Policy options may include legislation enforcing employee rights to flexible work arrangements (Mountford 2013), institution-level introduction of flexible work arrangements, subsidization of paid caregiving to support unpaid family caregivers and expansion of leave policies acknowledging employees' needs to care for aging family members (Glenn 2010; Lilly 2011).

Limitations

Some of the respondents continued to work after retirement (or returned to it after a period of retirement), whether within or outside their profession. In this analysis, we looked exclusively at those who perceived themselves to be retired, regardless of whether they were currently working. A desire to continue working after retirement may have affected responses to specific questions (e.g., financial possibility).

Respondents' age ranged between 45 and 85 years – their responses to questions such as household income and number of children living at home reflected present circumstances and not necessarily their circumstances at the time of retirement.

Selection of eligible respondents was based on free-text responses to questions about employment. As a result, there was a possibility for human error, either/both at the data entry or/and the selection stage. It is possible that we failed to include RNs with less than a baccalaureate degree (if they indicated only “nurse” as occupation) and/or that we incorrectly included care aides and/or licensed practical nurses with a baccalaureate degree in a field other than nursing. In addition, as setting of employment was a free-text variable, it is possible that RNs/AHPs employed outside of the public sector were included.

Although the use of samples recruited using rigorous protocols to achieve national representativeness can maximize generalizability, the sampling frame for the CLSA was not specifically designed to ensure representativeness within individual professions or across settings of employment. We did compare the gender proportions within professions of our sample to those reported in CIHI resources and found them to be very similar (CIHI 2017). In addition, the proportion of respondents in our sample, as compared to total profession-specific population (as reported in CIHI [2017] for 2013), was consistently near 0.3%, indicating that no one profession was over-represented. In future, studies using survey data

to explore retirement decision-making among RNs and AHPs should aim to maximize representativeness across employment setting, province of residence, age, gender/sex and profession.

Last, in this descriptive analysis, we conducted bivariate comparisons, which do not correct for confounding. We have published additional analyses that account for potential confounding (Hewko et al. 2019).

Conclusions

Canadian RNs and AHPs retire well before 65 years. Average ages of retirement, by profession, may be of value to workforce planners. It will be important for administrators to consider long-term impacts of cost-cutting measures on the labour pool of skilled health professionals. Austerity measures provoking a disproportionate reduction in older, experienced professionals are likely short sighted. Clear communication surrounding organizational restructuring may extend the work lives of health professionals.

Policies supporting flexible work arrangements, expansion of paid-leave benefits and subsidization of caregiving services for employees may reduce the incidence of workforce exits triggered by caregiving demands. More research is needed to better understand the reasons for differences between the relative importance of specific factors on retirement decision-making, both between RNs and AHPs and between early and 65+ retirees.

Correspondence may be directed to: Sarah J. Hewko, Assistant Professor, Department of Applied Human Sciences, Health Sciences Building, 316, 550 University Ave., University of Prince Edward Island, Charlottetown, PE C1A 4P3; e-mail: shewko@upei.ca.

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Medical Assistance in Dying (MAiD) in Canada: A Critical Analysis of the Exclusion of Vulnerable Populations

Aide médicale à mourir (AMM) au Canada : analyse critique de l'exclusion des populations vulnérables



RICARDA M. KONDER, BSC

Medical Student

Dalhousie Medicine New Brunswick

Saint John, NB

TIMOTHY CHRISTIE, BA, MA, MHSC, PHD

Director of Ethics Services (Authority B) for Horizon Health

Saint John, NB

Abstract

Canadian medical assistance in dying (MAiD) legislation was introduced in 2016. Although Bill C-14 attempted to balance patient autonomy and the protection of the vulnerable, recent court challenges suggest that an ideal balance has not been achieved. Numerous advocacy initiatives as well as a parliamentary review currently focus on three specific populations: mature minors, patients requesting MAiD via an advance directive and patients with a mental illness as the sole underlying condition.

This article approaches these issues from an ethical and legal lens. We first outline a policy review on existing MAiD legislation in 11 jurisdictions. We then use the Oakes test (a critical assessment tool in the *Carter v Canada* case) to determine whether the restrictions on the three above-mentioned groups are consistent with the *Canadian Charter of Rights and Freedoms*. Finally, we consult our literature review to propose reasonable solutions that would be more consistent with the *Charter*.

Résumé

La loi canadienne sur l'aide médicale à mourir (AMM) a été adoptée en 2016. Même si le projet de loi C-14 tentait d'assurer un équilibre entre autonomie du patient et protection des vulnérables, les récentes contestations judiciaires portent à croire que l'idéal en matière d'équilibre n'a pas été atteint. Plusieurs initiatives de défense des droits, ainsi qu'une revue parlementaire, portent sur trois groupes de la population : les mineurs matures, les patients qui veulent pouvoir faire une demande anticipée d'AMM et les patients dont la maladie mentale est la seule condition sous-jacente.

L'article aborde ces enjeux du point de vue éthique et juridique. En premier lieu, nous décrivons les politiques d'AMM en place dans 11 autorités sanitaires. Ensuite, nous employons les critères de l'arrêt Oakes (outil d'évaluation critique dans le dossier *Carter c. Canada*) pour déterminer si les restrictions touchant les trois groupes mentionnés ci-dessus sont conformes à la *Charte canadienne des droits et libertés*. Pour terminer, nous avons consulté notre revue de la littérature pour avancer des solutions raisonnables qui sont plus conformes à la *Charte*.

Introduction

Canadian legislation on medical assistance in dying (MAiD) was introduced in June 2016, a year after *Carter v Canada* concluded that the provisions in the *Criminal Code of Canada* criminalizing the assistance in another's suicide violated the *Canadian Charter of Rights and Freedoms* (*Carter v Canada* 2015). The resultant Bill C-14 attempted to balance the individual autonomy rights of eligible patients and the protection of persons who may be vulnerable, that is, people who could be subtly coerced into ending their lives.

The first Supreme Court of Canada case on MAiD was filed by Sue Rodriguez in 1993. Rodriguez, suffering from amyotrophic lateral sclerosis, argued that section 14 (criminalizing the consent to have death inflicted upon oneself) and section 24.1 (b) (criminalizing assistance in another's suicide) of the *Criminal Code* jointly violated three *Charter* rights (*Rodriguez v British Columbia* 1993), most notably Section 7 ("the right to life, liberty and security of the person") (*Canadian Charter of Rights and Freedoms* 1982). The court concluded that section 7 was infringed; however, it was saved by section 1 of the *Charter*, which allows rights to be limited if "demonstrably justified in a free and democratic society" (*Canadian Charter of Rights and Freedoms* 1982). In Canada, the test for determining if a limitation is demonstrably justified is the Oakes test, which requires that:

1. the goal of the *Charter* restriction be pressing and substantial;
2. the restriction be rationally connected to the law's purpose;
3. the restriction minimally impair the violated *Charter* right; and
4. the restriction's benefits outweigh the costs (proportionality) (*R v Oakes* 1986).

In *Rodriguez*, the court ruled that a universal prohibition on MAiD was demonstrably justifiable as it served to protect the vulnerable (*Rodriguez v. British Columbia* 1993). *Rodriguez* lost with a five-to-four ruling, and the sections of the *Criminal Code* remained unchallenged until the joint case of Lee Carter and Gloria Taylor was heard by the Supreme Court of Canada in 2015. Carter and Taylor sued for legally accessible MAiD, drawing on many elements of *Rodriguez*'s case. This time, the section 7 infringement did *not* pass the Oakes test because of the reality that multiple other countries had implemented MAiD legislation since *Rodriguez*'s case. The restriction therefore no longer satisfied the minimal impairment requirement (*Carter v. Canada* 2015), thereby closely linking the concept of minimal impairment to the presence of pertinent legislation in other jurisdictions.

In the time between the *Carter* ruling and the proclamation of Bill C-14, MAiD was decriminalized but unregulated in Canada. When Bill C-14 was finally enacted in 2016, the following eligibility criteria were specified:

- (a) they [patients] are eligible – or, but for any applicable minimum period of residence or waiting period, would be eligible – for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care” (Bill C-14 2016).

Furthermore, the bill deliberately deemed three important groups ineligible for MAiD: mature minors, patients wishing to access MAiD at the direction of an advance medical directive and patients with a mental illness as the sole underlying medical condition (Bill C-14 2016).

The objective of this paper is to determine whether the *a priori* exclusion of these three populations meets the relevant ethical standard. In the words of Aristotle, it is not enough to do only the right thing; one has to do “the right thing at the right time, in the right way, and for the right reason” (Cahn and Markie 2002: 130). We do not think that the absolute exclusion of these patient populations without considering the relevant details of their particular circumstances is the best way of achieving the goal of protecting the vulnerable. We further want to clarify that, although the legislation explicitly states that the three groups are vulnerable, vulnerability is not actually defined anywhere in the bill. The object of this paper is not

to define this concept as this would be up to the courts. Instead, the object is to accept it as a framework. In addition to not meeting the relevant ethical standard, we do not think that the exclusion of these groups will withstand a *Charter* challenge. To demonstrate this, we will apply the Oakes test.

Methods

First, we summarize a literature review on international MAiD legislation. Countries are excluded if their MAiD laws had been overturned, if only passive means of dying (e.g., withholding life-sustaining treatment) are currently legal or if MAiD is not explicitly legislated. Second, we discuss each restriction in light of the minimal impairment requirement (Condition 3) of the Oakes test. If our analysis reveals that a restriction on a given population does not pass the Oakes test (i.e., the restriction is not demonstrably justifiable), we propose reasonable solutions based on practices in other jurisdictions.

We use the term “MAiD” to refer to the act (by a medical doctor or nurse practitioner) of performing either assisted suicide (prescribing a lethal medication to be self-administered) or active euthanasia (directly administering a lethal injection). The withholding or withdrawing of life-sustaining treatment (passive euthanasia) is a separate issue and will not be discussed.

Legislation in other jurisdictions

MAiD laws from 11 jurisdictions were included in the analysis. Table 1 provides a summary of each, grouped by country/continent and then subgrouped by date to demonstrate regional and temporal trends. For each country, a specifier is added for whether the legislation permits active euthanasia (aiding a person in taking their life, e.g., by lethal injection), assisted suicide (e.g., prescribing a medication for the patient to take on their own) or both. Belgium, the Netherlands and Luxembourg are the only jurisdictions to have adopted MAiD legislation for minors, via advance directive and in the situation where mental illness is the sole diagnosis.

Results

The exclusion of mature minors

Bill C-14 explicitly excludes minors from eligibility under the supposition that minors constitute a vulnerable population and need to be protected by the government (Bill C-14 2016). The motivation for excluding minors is pressing, substantial and rationally connected to the goal of protecting the vulnerable (thereby satisfying Conditions 1 and 2 of the Oakes test). However, a blanket exclusion of all minors regardless of their circumstances is not a minimally impairing restriction. For example, Belgium and the Netherlands have successfully determined how to provide the procedure to minors while simultaneously protecting the

TABLE 1. Main stipulations of MAiD laws included in the analysis

Jurisdiction	Year	Assisted suicide, active euthanasia or both?	Competency necessary on day of death?	Advance directives permitted?	Waiting period	Mental illness included?	Mature minors (< 18) included?
Canada (Bill C-14 2016)	2016	Both	Yes	No	10 days	No	No
Quebec (Bill 52 2013)	2013	Active euthanasia	Yes	No	None	No	No
Oregon (Oregon Death with Dignity Act 2017)	1994	Assisted suicide	Yes	No	15 days	No	No
Washington (Washington Death with Dignity Act 2017)	2008	Assisted suicide	Yes	No	15 days	No	No
Vermont (Act 39 2013)	2013	Assisted suicide	Yes	No	15 days	No	No
California (End of Life Option Act 2016)	2015	Assisted suicide	Yes	No	15 days	No	No
Colorado (End of Life Options Act 2016)	2016	Assisted suicide	Yes	No	15 days	No	No
Washington, DC (Act 21-577 2015)	2016	Assisted suicide	Yes	No	15 days	No	No
The Netherlands (Termination of Life on Request and Assisted Suicide [Review Procedures] Act 2001)	2002	Both	Not with advance directive	Yes	None	Yes	Yes – starting at age 12, with separate protocol for infants
Belgium (Wet betreffende de euthanasie 2002)	2002	Both	Not with advance directive	Yes	One month if death is not imminent	Yes	2002 – emancipated minors 2014 – mature minors
Luxembourg (Loi sur l'euthanasie et l'assistance au suicide 2009)	2009	Both	Not with advance directive	Yes	None	Yes	No

vulnerable. In Belgium, legislation for minors differs from that for adults. The minor must first be deemed mature and then be shown to endure constant physical suffering that will lead to death in the short term (note that, in Belgium, minors have to be terminal, whereas adults do not). In addition, a child psychiatrist or psychologist must examine the patient, and the patient's guardian(s) must explicitly consent (*Wet betreffende de euthanasie 2002*).

In the Netherlands, patients aged 16–18 who are deemed mature may access MAiD as long as the guardians have been consulted, but guardians do not *have* to consent. If the patients are aged 12–16, MAiD is an option if the guardians agree with the decision (*Termination of Life on Request and Assisted Suicide [Review Procedures] Act 2001*). MAiD is also possible for infants via the Groningen protocol (Verhagen and Sauer 2005) under extremely stringent safeguards: the disease must be clearly diagnosed, the infant must be

suffering unbearably and there must be no reasonable chance of improvement. Both parents, as well as one other physician, must give their approval. After the procedure, all information along with the coroner's findings must be forwarded to the prosecuting authority, and each case is evaluated to ensure that proper procedure was followed (Verhagen and Sauer 2005).

The illegality of advance directives

Bill C-14 requires that immediately before MAiD is performed, the patient be given the opportunity to withdraw their consent. Should they not change their mind, they must provide express consent to receive the procedure (Bill C-14 2016). The intention is to give patients many opportunities to change their mind, thereby limiting their vulnerability. This necessitates that the patient be mentally competent and legally capable at the time of the procedure, which precludes the administration of MAiD solely at the direction of advance directives.

An advance directive is a legal document that outlines a patient's explicit wishes regarding the management of their healthcare. For example, patients may choose to specify in their medical directive that, should they become severely ill and lose competency to express their wishes directly, no extraordinary measures be taken to keep them alive. Most Canadian provinces have a legislation that regulates how these documents are drafted and accessed, but there currently exists no possibility for prespecifying wishes for MAiD via advance directive in Canada. A country that has taken this measure is Belgium, giving specific instructions as to how a directive should be written and stored, as well as a time frame for validity (five years) (*Wet betreffende de euthanasie* 2002).

We generally agree with the sentiment that an advance directive for MAiD with a time frame spanning many years would be inappropriate in the Canadian context. A practice of this sort would open up various possibilities for "false positives," risking the administration of a lethal procedure to potentially non-consenting patients. Therefore, a universal prohibition on MAiD via an advance directive spanning multiple years satisfies the minimal impairment requirement of the Oakes test as this is the only currently reliable means of protecting vulnerable patients in this setting. The fact that other countries (Belgium, Luxembourg and the Netherlands) have enacted legislation for MAiD via advance directives is insufficient to fail this criterion as thorough analysis of these laws fails to show sufficient safeguards to prevent false positives. Using the example of Belgium, we do not think that a five-year time frame of validity for an advance directive is sufficiently protective for potentially vulnerable patients. This lack of applicability may be explained in part by cultural differences. As a result of the arguments made in the *Carter* ruling, there is an explicit focus in Canada on the protection of vulnerable populations. As a result, these protections must be explicitly accounted for so that legislation can be deemed appropriate for the Canadian context. In other countries, this same focus is not as explicit in the legislation, leading to a potential lack of applicability of some stipulations that deal with especially vulnerable groups. This,

however, begs the question of whether some form of directive could be tailored to allow patients to request MAiD in the short term when they fear loss of competency.

Consider, for example, the case of a patient who wants the control of specifying a point in time within the next month to receive MAiD but fears losing their competency due to the large doses of pain medication necessary to keep them comfortable. It could be argued that having the ability to wait longer than the prespecified 10-day waiting period (Bill C-14 2016) implies that the patient's condition is not "intolerable" as prescribed by legislation, thereby excluding them from eligibility. However, we remain unconvinced of this argument as data to date show that a substantial number of patients undergo the initial eligibility assessment to have the option for MAiD without ever actually specifying a date and going through with it (Li et al. 2017). This suggests that the lack of control over their illness, not necessarily the illness itself, is central to some patients' subjective interpretation of intolerable suffering.

What further complicates this issue is that, as it stands, the illegality of advance directives still violates patients' right to life. By not allowing patients to specify a point in their illness at which they anticipate their quality of life to be sufficiently intolerable to end their lives, the law may drive patients to end their lives earlier than desired. This violates their right to life and exposes the law to the same arguments that were rendered unconstitutional in the *Carter* decision. We therefore need to seek a middle ground to balance the individual autonomy rights of patients and the adequate protection of the vulnerable, and the most logical solution would be that of a short-term advance directive under highly controlled circumstances.

To achieve this, we must ask ourselves what the eligibility criteria in Bill C-14 aim to achieve. There are generally two aims: to ensure that a patient is not vulnerable and to ensure that the patient is an appropriate candidate (i.e., that they meet the eligibility criteria outlined in Bill C-14). At the time of the request, the assessment of these two conditions is crucial; if the patient is determined to be vulnerable or not an appropriate candidate, they should be excluded from eligibility. However, if the patient is not vulnerable and is deemed an appropriate candidate, the fact that they may undergo a cognitive decline in the short term and may be unable to provide express consent at the time of the procedure does not make them suddenly vulnerable or inappropriate candidates. Therefore, competency at the time of the procedure should be considered of secondary importance unless new information emerges that changes one of these parameters. Naturally, a time frame for validity would need to be specified for directives of this sort. Foreign legislation provides little guidance with regard to this; however, we can likely agree on a minimum duration of validity, namely, 10 days (laid out by Bill C-14 as the mandatory waiting time between filing the request and receiving the procedure) (Bill C-14 2016).

The exclusion of persons with mental illness

Finally, Bill C-14 (2016) excludes *a priori* those who request MAiD based solely on a mental illness with the presumption that, by definition, these are vulnerable patients who need to be protected. The case of EF, a 58-year-old Alberta woman, demonstrates that there is a need for MAiD among this population. She applied for MAiD during the interval between the *Carter* ruling and the proclamation of Bill C-14. At that time, the terms “grievous” and “irremediable,” which were hallmarks of the *Carter* ruling, had not yet been defined; therefore, it was up to the court to determine whether mental illness was a condition that satisfied these terms. The court ruled that it was, and permission for MAiD was granted (*Canada [Attorney General] v. E.F.* 2016).

The topic of extending MAiD to patients with mental illnesses raises important questions. For example, Appelbaum (2017) asks whether it is possible to determine an individual’s ability to consent when their wish to die is an intrinsic property of their illness instead of a consequence. This is an important distinction because Bill C-14 defines vulnerability as subtle coercion by third parties. However, in this patient population, an added vulnerability (in addition to previously discussed extrinsic vulnerabilities, such as the potential for coercion and exploitation) is potentially a property of their disease. In their current form, the eligibility criteria of Bill C-14 do not appreciate this distinction.

An example of how vulnerability manifests in this patient population is that patients with mental illnesses may change their minds more often. Some Belgian data show that patients who request MAiD based solely on mental illnesses are more likely to rescind their requests than patients who file based on “physical” illnesses (Thienpont et al. 2015). If patients with mental illnesses tend to withdraw their requests more often, the universal exclusion of this population may be warranted to protect those who may change their minds. Other countries do not appear to have solved this problem. In jurisdictions where MAiD is permitted for mental illnesses, no explicit safeguards are added for this population. For example, the Belgian law simply mandates a waiting period of one month for all patients who are not terminal, which essentially *includes* those with mental illnesses (*Wet betreffende de euthanasie* 2002). Because no specific safeguards have been developed for this population, their exclusion fulfills the minimal impairment condition.

In comparison with the previous discussions, the exclusion of patients with mental illnesses is much more multifaceted. The complete exclusion of this population likely satisfies the minimal impairment condition because legislation in other countries does not safeguard the unique vulnerabilities of this population. This does not mean that no such solution exists, and we are not convinced that a blanket prohibition would satisfy the proportionality criterion (Condition 4) of the Oakes test. Furthermore, when placing this issue in the Canadian context, we can see that there is a legitimate demand for MAiD among these patients. Examples are provided by EF and by Adam Maier-Clayton, a 27-year-old man who died by unassisted suicide after a year of publicly advocating for the extension of MAiD to

persons with mental illnesses (Maier-Clayton 2016). In addition, 12–20% of depression cases may be treatment resistant (Mrazek et al. 2014), which would qualify some mental illnesses as both “grievous” and “irremediable.” Other countries also demonstrate that citizens tend to take advantage of this possibility when it is offered: in the Netherlands, mental illnesses made up 1% of MAiD requests in 2015 (Boztas 2016), and in Belgium, this number was 3.9% in 2013 (Dierickx et al. 2016). Granted, as there are no established safeguards, some of those patients might have been vulnerable, but others might not have been. Further research is required to help distinguish between these two patient categories.

In the absence of evidence-based guidance for the distinction between these two patient categories, we can derive some guidance from the case of *EF v. Alberta*. Here, the motions judge noted that “[...] persons with a psychiatric disorder are not deprived of exercising their rights, provided they can establish that they are both competent and clearly consent” (*Canada [Attorney General] v. E.F.* 2016). These two criteria therefore form the basis of our vulnerability assessment. To evaluate these criteria, the court deemed the professional judgment of physicians sufficient, concluding that, given due care and attention, physicians had the tools to adequately evaluate and comment on a patient’s decisional capacity (*Canada [Attorney General] v. E.F.* 2016). This case specifically focused on the judgment of what appeared to be EF’s general practitioner (GP) and an independent psychiatrist, deeming their impressions to be accurate testimonies to her capacity and the irremediability of her disease.

Discussion

The exclusion of mature minors

From an ethical and legal perspective, the objective of protecting vulnerable minors is appropriate; however, their universal exclusion is not minimally impairing; hence, there are other ways of meeting this objective while still respecting the rights of those for whom this procedure would be appropriate. The Dutch Groningen protocol combined with the law for minors suggests a useful strategy for Canadian legislation: safeguards should become increasingly strict with decreasing age (i.e., with increasing degree of vulnerability).

The illegality of advance directives

Within the context of MAiD, long-term advance directives are generally inappropriate; however, there will almost certainly be a need for short-term advance directives to allow for adequate pain control, unforeseen losses of competency and other factors that may potentially limit the competency of otherwise eligible patients in the short term. We therefore propose the implementation of a short-term advance directive (with a minimum validity of 10 days and a maximum validity to be determined by the courts). These directives should be an option for patients who meet the conditions of the initial assessment, thereby ensuring that they are not vulnerable and that they are appropriate candidates. These patients would

thereby constitute a unique subpopulation in which competency at the time of the procedure is not a necessary condition.

The exclusion of persons with mental illness

Ultimately, given the example of EF in 2016, it is very likely that there will be patients who request MAiD with mental illness as the sole criterion. It should be appreciated that vulnerability in patients with mental illnesses can be a result of internal factors and not just external coercion. Based on the reasoning provided by the judicial review of EF, we think that a mandatory consultation by either a psychiatrist or a GP with a long-standing relationship with the patient should be part of the assessment at the time of the initial request to assess the patient for decisional capacity and any other potential source of vulnerability. Although this is not a perfect solution, given that a significant proportion of persons with mental illness may not have a long-standing relationship with a GP, it does bring the legislation one step closer to diminishing false negatives by including those whose vulnerability can be adequately assessed.

Conclusion

Using the Oakes test as our framework, we conclude that the restrictions on minors and patients accessing MAiD solely at the direction of a short-term advance directive fail the condition of minimal impairment. We suggest adapting current legislation to extend MAiD rights to minors based on an age-tiered system (as modelled by the Netherlands) and to include the possibility of a *short-term* advance directive for patients who meet eligibility criteria and are deemed not vulnerable. We further conclude that the exclusion of patients with a mental illness as their sole underlying condition likely fulfills the criterion of minimal impairment, as other jurisdictions have not developed legislation that sufficiently protects this population. However, given the push for the inclusion of this population in the Canadian context, the restriction may not meet the proportionality requirement. There is potential for Canada to lead the way in legislating this population in a way that sufficiently protects the vulnerable, such as accounting for the different sources of vulnerability in this population and assessing their decisional capacity by mandating formal assessments by either a psychiatrist or a GP at the time of the initial request.

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Correspondence may be directed to: Ricarda M. Konder, BSc, Medical Student, Dalhousie Medicine New Brunswick, 100 Tucker Park Road, Saint John, NB E2K 5E2; tel.: 506-260-1003; e-mail: r.m.konder@gmail.com.

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Envisioning Implementation of a Personalized Approach in Breast Cancer Screening Programs: Stakeholder Perspectives

Envisager l'implantation d'une approche personnalisée dans les programmes de dépistage du cancer du sein : point de vue des intervenants



DAPHNE ESQUIVEL-SADA, PHD
Sociologist

*Centre of Genomics and Policy
Department of Human Genetics, Faculty of Medicine
McGill University
Montreal, QC*

EMMANUELLE LÉVESQUE, LL.M.
Lawyer and Academic Associate

*Centre of Genomics and Policy
Department of Human Genetics, Faculty of Medicine
McGill University
Montreal, QC*

JULIE HAGAN, MSc
*PhD Candidate
Academic Associate*

*Centre of Genomics and Policy
Department of Human Genetics, Faculty of Medicine
McGill University
Montreal, QC*

BARTHA MARIA KNOPPERS, PHD, OC
Professor

*Department of Human Genetics, Faculty of Medicine
McGill University
Montreal, QC
Director*

*Centre of Genomics and Policy
Department of Human Genetics, Faculty of Medicine
McGill University
Montreal, QC*

JACQUES SIMARD, PHD
Professor

*Department of Molecular Medicine, Faculty of Medicine
Université Laval
Québec City, QC*

Abstract

Background: Advances in genomics and epidemiology can foster the implementation of a risk-based approach to current age-based breast cancer screening programs. This personalized approach would challenge the trajectory for women in the healthcare system by adding both a risk-assessment step (including a genomic test) and screening options.

Objective: The aim of this study is to explore, from an organizational perspective, the acceptability of different proposals for each step of the trajectory for women in the healthcare system should a personalized approach be implemented in the province of Quebec.

Methods: We interviewed 20 professional stakeholders who are either involved in the current breast cancer screening program in Quebec or who are likely to play a role in the future implementation of a personalized risk-based approach.

Results and discussion: Preferences are split between proposals supporting self-management by the women themselves (e.g., solicitation through media campaign, self-collection of information and sample and results provided by letter) and proposals prioritizing more interaction between women and healthcare providers (e.g., solicitation by health professionals, collection of information and samples by a nurse and results provided by health professionals).

Résumé

Contexte : Les avancées de la science en génomique et en épidémiologie pourraient favoriser l'implantation d'une approche basée sur le risque dans les programmes de dépistage du cancer du sein qui sont actuellement basés sur l'âge. Cette approche personnalisée poserait des défis à la trajectoire des femmes dans le système de santé en ajoutant à la fois une étape d'évaluation du risque (incluant un test génomique) et des options de dépistage.

Objectif : L'objectif de cette étude est d'explorer, dans une perspective organisationnelle, l'acceptabilité de différentes propositions pour chaque étape de la trajectoire des femmes dans le système de santé si une telle approche était implantée dans la province de Québec.

Méthode : Nous avons mené des interviews auprès de 20 acteurs du milieu de la santé qui sont impliqués dans le programme actuel de dépistage du cancer du sein au Québec ou qui seraient appelés à jouer un rôle advenant l'implantation d'une approche personnalisée basée sur le risque.

Résultats et discussion : Les préférences des interviewés sont partagées entre les propositions qui favorisent l'autogestion par les femmes elles-mêmes (p. ex. sollicitation par des campagnes médiatiques, collecte autonome d'information et d'échantillon, résultat transmis par lettre) et les propositions qui favorisent plus d'interactions entre les femmes et les fournisseurs de soins (p. ex. sollicitation par des professionnels de la santé, collecte d'information et d'échantillon par une infirmière et résultat transmis par un professionnel de la santé).

Introduction

Several countries are running breast cancer screening programs that typically offer annual or biannual mammography for women 50 years and older. To mitigate the potential harms

of these age-based programs (e.g., overdiagnosis and false positives; Klarenbach et al. 2018), researchers are building evidence supporting a more personalized approach. This approach would adjust mammography frequency according to personal risk level, instead of using age as the only criterion. Such personalization could thereby allocate screening and healthcare resources to women at higher risk, including those under 50 years old (Davies 2017).

Such a personalized approach relies on genomics and clinical, familial and lifestyle factors to identify women most likely to benefit from tailored screening (Lee et al. 2019; Rudolph et al. 2018). Such screening could include more frequent mammograms or additional imaging technologies such as magnetic resonance imaging (Gagnon et al. 2016). This approach is expected to inform current screening strategies (Shieh et al. 2017; van Veen et al. 2018), be more cost effective (Pashayan et al. 2018; Schousboe et al. 2011) and improve the harms–benefits ratio, including decreasing overdiagnosis (Pashayan et al. 2018).

Future inclusion of this personalized risk-based approach to current screening programs has been described as “a radically new approach to prevention” (Dent et al. 2013, p. 94). This approach is in line with the precision public health model, which merges a population focus with an individual-centred perspective, enabling public health programs to provide “the right intervention to the right population at the right time” (Khoury et al. 2016, p. 398).

Despite the interest raised by this personalized approach, its implementation raises organizational issues (Chowdhury et al. 2013; Hall et al. 2013; Lévesque et al. 2018a; Rainey et al. 2018). Our previous work with stakeholders revealed that the implementation of the personalized approach in the province of Quebec would raise organizational challenges with regard to many steps of the screening trajectory in the healthcare system (Figure 1; Dalpé et al. 2017; Hagan et al. 2016; Lévesque et al. 2018b).

FIGURE 1. Steps in the screening trajectory likely to raise organizational challenges



At each step, challenges could arise from the addition of a genomic test, the complexity of the risk estimation process and the inclusion of a choice of screening pathway following personalized risk assessment. Current limitations to financial resources in publicly funded healthcare systems and to human resources (e.g., overworked health professionals) and the sheer scale of the group to reach (i.e., thousands of women each year) drove innovative proposals to address these challenges (Hagan et al. 2016; Lévesque et al. 2018b). These include, for instance: reduction of the reliance on health professionals to provide women with the information necessary to make an informed consent before risk assessment, consideration of self-collection of biological samples and extension of the duties of nurses to include the communication of the results of risk calculations and to advise on screening options.

The aim of our study is to explore, from an organizational point of view, the acceptability of different proposals for each step of the trajectory for women in the healthcare system if the personalized approach were to be implemented in the province of Quebec. Because stakeholders' opinions will likely influence the adoption of the personalized approach (Phillips et al. 2016), we conducted semi-structured interviews with stakeholders from the Quebec healthcare system. To our knowledge, this is the first qualitative study to analyze stakeholders' perceptions on the organizational issues of risk-based screening in the Canadian context.

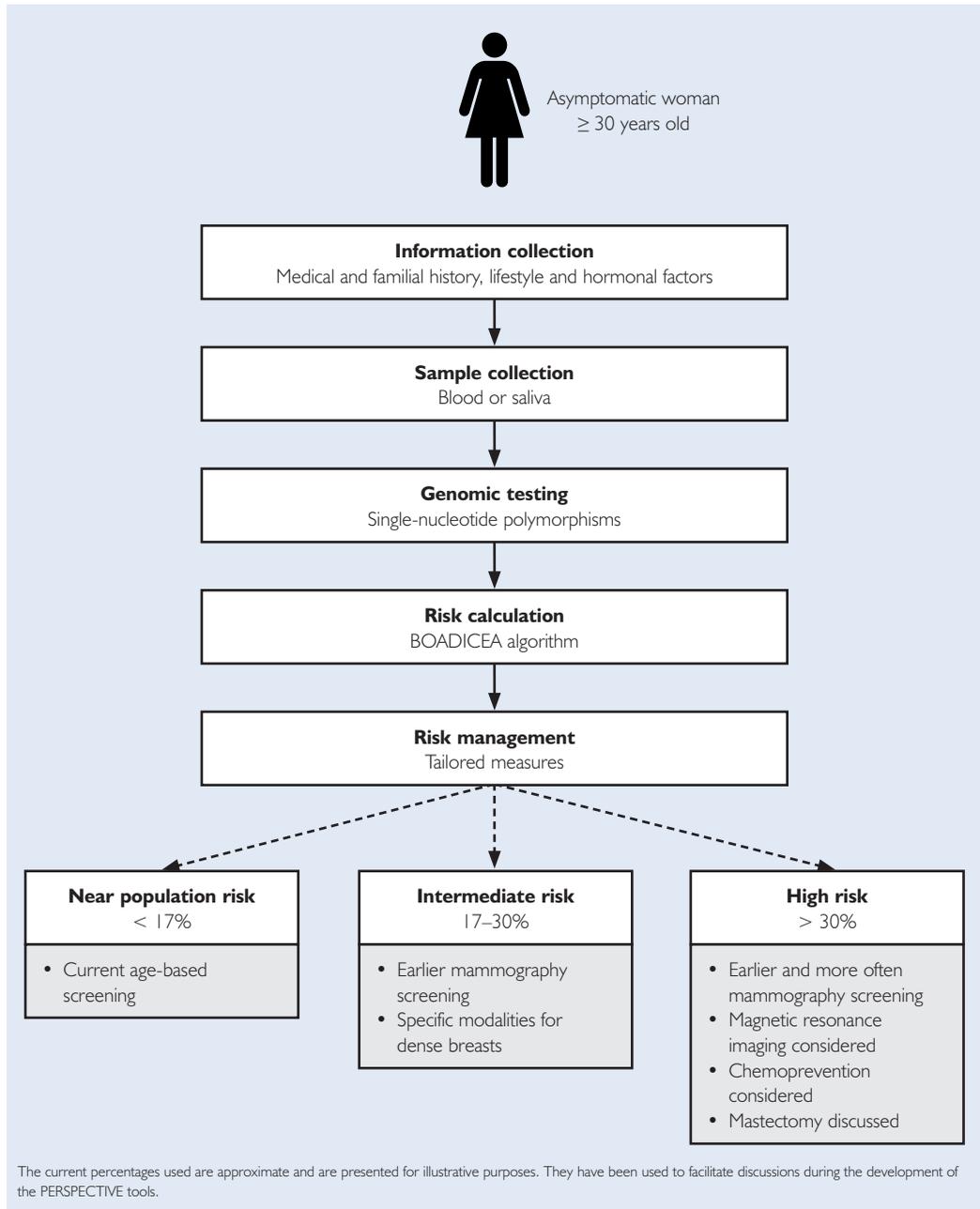
Background

Our study is part of a broader project called PERSPECTIVE (Personalized Risk Stratification for Prevention and Early Detection of Breast Cancer). The PERSPECTIVE project aims to develop tools for the implementation of a personalized approach to breast cancer screening in the Canadian context, including a calculation algorithm, a genomic test, an economic simulation model and screening policies (<https://www.genomecanada.ca/en/personalized-risk-stratification-prevention-and-early-detection-breast-cancer>). The approach of the PERSPECTIVE project is to then inform screening options by running the individual risk assessment on asymptomatic women aged 30 years and older through the Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) calculation algorithm (Figure 2).

The BOADICEA algorithm (<https://www.canrisk.org/>) provides personalized risk assessment using multiple risk factors as well as the results of a genomic test involving hundreds of single-nucleotide polymorphisms, each factor increasing the risk slightly (Lee et al. 2019; Mavaddat et al. 2018; Rudolph et al. 2018). At the end of this process, women would be provided with tailored screening and prevention measures depending on which one of the three risk categories they fall into (Gagnon et al. 2016). Our interviews with stakeholders are grounded on these scientific parameters of the PERSPECTIVE project.

Given that the PERSPECTIVE project had already developed clinical recommendations to manage risk results in the specific context of Quebec's breast cancer screening program (Gagnon et al. 2016), the Quebec program was seen as an appropriate focus for our study. As with other Canadian screening programs, this program invites women between 50 and 69 years old for a mammogram every two years. Upon receipt of an invitation letter at home, Quebec women can decide to access an imaging facility for a mammogram covered by the publicly funded healthcare system. In 2016, about 65% of the invited women participated in this program in Quebec (Institut National de Santé Publique du Québec 2018).

FIGURE 2. Risk assessment approach in the PERSPECTIVE project



Methods

An experienced interviewer with a background in sociology (JH) conducted semi-structured interviews with 20 purposefully selected stakeholders (Patton 2005). Potential interviewees were reached via e-mail, and our response rate was approximately 20%. This is most likely due to the fact that we recruited respondents through our network of collaborators and via

snowball sampling in addition to “cold calls” to respondents identified via public documents available on the Internet. The stakeholders selected would have a role at the organizational level in a future implementation of the personalized approach in Quebec because they are currently involved in the organization of the provision of oncology services, the conception/implementation of cancer screening programs or health professionals’ policy frameworks or the management of the current breast cancer screening program. We sought a balance between professionals involved at the provincial and regional levels, working in hospitals, in professional organizations or for the Ministry of Health (Table 1).

TABLE 1. Participants’ characteristics

Characteristics	Total		
Gender	Female: 13	Male: 7	
Background	Physician: 10	Nurse: 6	Other: 4*
Direct involvement in the current breast cancer screening program	Yes: 8	No: 12	
Role level	Provincial: 9	Regional: 7	Professional organization: 4

*One is a health professional, and three participants did not disclose their background.

The interviews aimed to address the acceptability of organizational proposals for the different steps of the trajectory for women in a personalized approach. The steps and associated proposals for reform were identified in our previous study (Dalpé et al. 2017; Hagan et al. 2016; Lévesque et al. 2018b). The original design of the interviews comprised open-ended, close-ended and ranking questions (see Appendix A, available online at longwoods.com/content/26072). However, because many interviewees explained that their ranking would depend on the availability of resources, the interviewer (JH) chose to focus on the rationale supporting their preferences rather than on ranking questions. The one-hour interviews were conducted from September 2016 to February 2017 in French, either in person or by telephone. Analysis was conducted in the original language of the interviews, and only quotes included in this article were translated by the researchers. At the beginning, interviewees were informed of the core elements of the personalized approach, including a clarification that the genomic test covers only single-nucleotide polymorphisms that slightly increase risk – not genes associated with a substantial increase in familial risk (such as BRCA1/2) because these genes are already tested by genetics clinics, based on family history.

All interviews were audio recorded and transcribed. The interview transcripts were then analyzed thematically using the NVivo software. A first analyst (JH) developed the initial codes and coded the first half of the interviews. A second analyst (DES) coded the second half of the interviews, and in doing so refined the initial coding. The codes and categories identified by each analyst were then compared and discussed following the principles of thematic analysis (Attride-Stirling 2001; Braun and Clarke 2006). As the analysis progressed, new themes and codes were added to reflect the content that transcended the questions asked during the interviews (e.g., when the interviewees articulated the reasoning behind

their answers). In doing so, the analysts were able to interpret the interviewees' responses from a more theoretical point of view (Boyatzis 1998). The project was approved by the ethics review boards of the CHU de Québec–Université Laval and McGill University.

Results

Table 2, available online at longwoods.com/content/26072, summarizes the proposals preferred by the interviewees for the management of the organizational challenges in the trajectory for women.

Invitation and information

Implementation of the personalized approach would require proceeding to large-scale invitation of all asymptomatic women within an age range to have an initial risk assessment. Three main options for inviting women and offering them information on risk assessment emerged from the responses of the participants: postal letter, media information campaign and an encounter with a health professional.

Use of a postal letter was generally perceived as an accessible, manageable and feasible option. Many participants appeared confident in the effectiveness of such a method, given its current use within the Quebec screening program. Nevertheless, some interviewees pointed out the high cost of this option, given the scale of the population to be contacted, and the fact that postal letters tend to miss their target with regard to vulnerable women.

A second option favoured by participants was a media information campaign (traditional and social media). Some interviewees mentioned that such campaigns could be used in conjunction with postal letters as a means of publicizing the changes in screening practices. The interest of using social media was specifically mentioned in consideration of the younger targeted population (i.e., starting at 30 years). The third option preferred by interviewees was an appointment with a health professional, yet some recognized the impracticality of such a method (i.e., not all women have a primary care provider in Quebec).

Informed consent

In a personalized approach, consent to risk assessment would need to include specific information not currently provided by screening programs. Additional information on the distinct features of this approach (e.g., a genomic test and the use of a computer algorithm for a risk estimation), on potential insurability issues, on the limits of the genomic test (e.g., genes not covered) and on the accuracy of the estimation over time (i.e., changes in risk factors may modify the risk level) would need to be provided. This information is more complex than that provided in current age-based screening programs. Two main options were favoured in the interviews for the support of informed consent: the use of paper information tools and a conversation with a health professional.

Interviewees underlined the convenience of paper tools that could be sent along with the invitation letter. For some participants, such a handout could also be used in combination

with a website. However, interviewees recognized that the scope of such handouts is limited by the complex notions of risk estimation and genetics that would need to be explained.

Indeed, other interviewees considered it a necessity to offer women the option to have a discussion with a trained physician or a nurse. For a number of interviewees, only this one-to-one framework would allow women “to thoroughly appraise pros and cons” and ask questions. Furthermore, this would allow each woman to properly understand the information regardless of her level of health literacy. Such professional support would not need, however, to be systematically offered to each woman but to those who feel the need to have a discussion. Moreover, such a discussion would not need to take place in person. Remote communication (e.g., phone or telemedicine) could actually be an option according to many participants who favoured discussion with a health professional:

I think that it is really important that, for the women who have a bit more difficulty, that they can call a 1-800 service or something, with somebody at the end of the line who can explain, reassure them on aspects they worry about. (Public Servant, Provincial Level 1)

Other options were discussed by interviewees but not favoured, such as the use of a website and an explanatory video to guide informed consent.

Information collection

Under a personalized approach, risk assessment would be made by providing information on extended risk factors (such as clinical and family history as well as lifestyle information) to the Web-based BOADICEA risk calculation tool. As for the best ways to collect this information, two main tracks emerged in participants’ responses: by a nurse – in person or remotely – and by the woman herself. Most interviewees considered a mix of methods with nurse involvement and self-collection as the best option. Only a few interviewees regarded self-collection alone as the best method.

Many participants expressed some level of concern with the self-collection of information pertaining to risk factors. Their concerns include the complexity of information that women would need to provide (e.g., breast density assessed by mammography), how their literacy level might distort responses and the possible omission of key data. To address these issues, some interviewees suggested to “isolate a part of it that people are capable of answering for sure” and “try to have most options possible to favour the [women’s] participation.” According to a majority of participants, a nurse, either in person or via a phone centre, could ensure “validation” of the self-collected information, while helping to complete the more complex questions.

Meeting with a physician, a gynecologist or a pharmacist was not considered appropriate at this step, given the current organization of the Quebec healthcare system.

Biological sample collection

The genomic test used in the approach developed by PERSPECTIVE would use either a saliva or a capillary blood sample. With regard to sample collection, interviewees were split between self-collection and the involvement of a health professional to support each individual.

Self-collection was described by most participants as the most suitable option for a large-scale program. For most of them, self-collection would be better suited for a saliva sample than for a capillary blood sample. Women could get their self-collection kit either by mail or at a local healthcare facility. As for capillary blood sampling, some interviewees were worried that it might discourage part of the population and suggested “to have another option available for people who are going to feel uneasy to go that route” or for those who have disabilities. Many interviewees thought that the ideal approach for capillary blood sampling would be collection assisted by a nurse to assure not only proper sampling but also adequate storage and transportation.

Concerns were raised with regard to how “lay” conditions for storage and transportation could degrade the quality of self-collected samples. One of the interviewees also claimed that the genomic test must be highly reliable if self-collection were to be implemented:

[...] I can guarantee you that for this screening test to work, it has to be so simple that it is a no-brainer. The great difficulty is having an extremely strong test, [strong enough] to resist poor manipulations. (Professional Organization Representative 1)

Despite these concerns, the involvement of a physician in the collection of biological samples was not considered appropriate, as the nurse remained the most acceptable alternative to self-collection for a majority of respondents.

Return of results

The interviewees’ answers about the best way to communicate the results of the risk assessment to women are clearly differentiated by risk category. Participants largely approved sending a postal letter as the best way to communicate results to women ranking in the *near to population risk* category. However, some interviewees mentioned that a professional resource should also be made available if needed, for instance, via a call centre:

[...] We cannot imagine that we are going to meet everybody who has a risk near the general population individually. It is not feasible. I see rather making a mailing [saying that]: ‘your risk is near the general population and therefore when you turn 50-years-old, you will be reminded to have a screening every two years. If you have further questions, call this number, (Public Servant, Provincial Level 2)

Meeting in person with a health professional, whether a nurse or a physician, was not considered appropriate to return results in the *near to population risk* category.

Interviewees' preferences change significantly when it comes to communicating results to women in the *intermediate-* and *high-risk* categories, who would be advised to have earlier and/or more frequent mammography in respect to the clinical recommendations presented to the interviewees (Figure 1). This appears to mark a decisive turning point. Mailing results were seen as clearly unsatisfactory in such cases. As soon as "there are things to be done," as one of them said, an encounter with a health professional becomes necessary. Others explained their preference by the complexity surrounding risk assessment results and the importance to have a thorough discussion about the advantages and disadvantages of the screening options recommended. Regarding the type of health professional who should discuss the screening options with women in the *intermediate-risk* category, the interviewees were divided between the need to see a physician and the acceptability of seeing a nurse trained in risk assessment. For those open to a nurse having such a role, they mentioned that she should be able to refer women to specialized services. As for women in the *high-risk* category, interviewees showed a clear consensus on the need for an appointment with a physician rather than with a nurse. Their arguments relate to the therapeutic options and their implications, and physician credibility:

When we begin to speak of preventive mastectomy or preventive pharmacotherapy, we start having interventions which are not commonplace, they are invasive and far removed from the two-year mammogram everyone knows. (Professional Organization Representative 2)

Many mentioned that such physicians would need specific training in breast cancer risk assessment and risk communication.

Discussion

Interviewees' views on the organizational challenges for the trajectory for women in the healthcare system reveal two different approaches:

- a *relational approach* emphasizing dialogue and shared decision-making with the close involvement of a healthcare professional; and
- a *self-management approach* relying on the initiative of women regarding self-collection of information and sample.

The latter approach shares similarities with the "proactive approach" in women's decision-making process that was prioritized by the health professionals studied by Rainey et al. (2018).

Table 3 provides a comparison of these approaches to the organizational trajectory. The results presented in Table 3 merit discussion on three aspects: the tension between the focus of clinical ethics and public health ethics, the inherent constraints of a publicly funded healthcare system and the need for training healthcare providers.

Envisioning Implementation of a Personalized Approach in Breast Cancer Screening

TABLE 3. Comparison of the two approaches for each step of the trajectory for women

	Relational approach	Self-management approach
1. Invitation and information	Postal letter or discussion (nurse/physician)	Postal letter, media campaign or social media
2. Informed consent	Information document or discussion (nurse/physician)	Information document or online information
3. Information collection	Nurse	Self-collection (paper or online)
4. Biological sample collection	Nurse	Self-collection
5. Return of results		
Near to population risk	Nurse or physician	Letter
Intermediate risk	Nurse or physician	Letter or nurse
High risk	Physician	Nurse or physician

Tensions between the focus on clinical ethics or on public health ethics

The two approaches favoured by the interviewees reflect the tensions between the focus on clinical ethics or on public health ethics. The relational approach favours interaction with health professionals and is more in line with the perspective of clinical ethics that places the needs of the individual at the centre of its concerns (Callahan 2003; Kass 2004; Wardrope 2014). In contrast, the self-management approach is closer to public health ethics, which focuses on collective needs (Childress et al. 2002; Schmidt 2015).

The strongest proponents of the relational approach were interviewees who work more closely with patients or representatives from organizations responsible for the oversight of the professional practice of healthcare providers. Their stance seems grounded in the classical principles of clinical ethics such as beneficence (e.g., mitigating women's anxiety), autonomy (e.g., fostering informed consent) and non-maleficence (e.g., ensuring that results are not mis-handled; Beauchamp and Childress 2013).

The stakeholders who favoured the self-management approach were predominantly those involved in the management of public health services or clinical services. Oftentimes, the rationale for privileging self-management is that this method put less strain on the limited resources of the healthcare system. As such, their arguments were in line with the considerations of public health ethics such as maximization of benefits over costs (Childress et al. 2002), resource allocation (Kass 2004) and program effectiveness (Kass 2001).

However, some proponents of the relational approach came to adhere to the views of the interviewees who prefer the self-management approach once they considered the practicability of the implementation within a publicly funded population-based program. This reasoning evokes priority setting and allocation of scarce resources, which are core aspects of the public health ethics framework (Abbasi et al. 2018).

Constraints inherent to a healthcare system with limited resources

Resource limitations (e.g., human, financial and technological) are a major issue in

implementing genetic services in public health (Cornel and van El 2017) – even more so in a publicly funded healthcare system (Severin et al. 2015). When human resources – especially when specialized – are limited, allocation issues might become as relevant as allocation of financial resources.

Many interviewees expressed concerns about the capacity of the Quebec healthcare system to provide the appropriate human resources for the personalized approach. Preferences of interviewees about how to address the organizational challenges are grounded in these concerns. Many of those who prefer the self-management approach explained their choice by the necessity to minimize physician involvement due to resource constraints. However, some interviewees pointed out that leveraging nurse competencies to address this issue could also yield the same challenge considering the large workload of nurses and the important shortage of specialized nurse practitioners in Quebec (Gentile 2018).

One emerging screening option that could help minimize the overall use of resources is the reduction of mammography frequency for women at very low risk. For instance, women at a level of risk lower than the general population could be offered less frequent mammography. Howell et al. (2012) estimated that the detection ratio could remain the same if screening intervals were doubled for women at very low risk. This emerging screening option was not presented to our interviewees because it was not part of the PERSPECTIVE project approach. But it could be an option to consider in the future (Hall et al. 2013; Rainey et al. 2018), although its acceptability by women could be challenging (Henneman et al. 2011).

Training needs

Interviewees – whether they favoured the relational approach or the self-management approach – were concerned about the lack of knowledge of healthcare providers to support women with the social, clinical and legal issues raised by the personalized approach. This confirms the literature showing that the lack of specialized competencies among healthcare providers represents one of the main barriers for a successful implementation of personalized screening programs and precision medicine in general (Chowdhury et al. 2013, 2015; Cornel and van El 2017). Chowdhury et al. (2015) recommended conducting a formal education and training needs assessment to determine current gaps in genetics competencies before implementation. Collins et al. (2014) mentioned that health professionals report a lack of knowledge to implement a personalized approach and considered that appropriate support decision tools could fill this gap. Rainey et al. (2018) identified the “substantial knowledge deficit” of healthcare providers as a challenge to be addressed and suggested educational programs to improve competence in risk communication and screening options. Based on the answers of the interviewees, mastering risk communication skills would also be paramount in Quebec.

Many participants pointed to electronic communications as a solution for professional

training (e.g., online training) as well as for interactions with women. Some interactions with women could occur remotely, via phone or through telegenetics, including for genetic counselling (Buchanan et al. 2015). Indeed, there is growing evidence that telehealth can provide professional support to patients without compromising the quality of services (Casey et al. 2017; Melton et al. 2017; Pruthi et al. 2013).

Limitations

Our study focuses on the Quebec healthcare system; as such, results may not be readily generalizable. Nevertheless, our results might be informative for healthcare contexts with similarities to that of the province of Quebec (e.g., publicly funded healthcare system, thousands of women to be invited per year and limited number of specialized health professionals). Another limitation of our study is inherent to the use of purposive sampling in implementation research. Palinkas et al. (2015) have highlighted the trade-off between breadth and depth of qualitative data when relying on purposive sampling strategies. Selecting potential interviewees “on the basis of their role in the implementation process or who have a specific experience [...] may fail to capture the experiences or activities of other groups playing other roles in the process” (Palinkas et al. 2015, p. 539). However, selecting according to criteria such as role, experience and knowledge may provide a deeper understanding of the implementation process.

Conclusion

As Dent et al. (2013) explained, a risk-based screening program “is more complex to set up and manage than the current programs based on age eligibility” (p. 98). Our research offers insight into the organizational challenges anticipated in the context of a future implementation of the personalized approach in Quebec. The results show that stakeholders’ preferences to address such challenges are split between a relational approach and a self-management approach. The two approaches reflect tensions between clinical ethics and public health ethics. In turn, these tensions highlight the delicate issue of resource allocation in publicly funded healthcare systems and shed light on the need to provide specialized training to the health professional workforce. Although our results focused on the Quebec healthcare system, the literature suggests that the issues identified are relevant to other healthcare systems. These issues should be carefully considered by health authorities before implementing the personalized approach for breast cancer screening in a publicly funded healthcare system.

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Correspondence may be directed to: Emmanuelle Lévesque, LL.M, Lawyer and Academic Associate at the Centre of Genomics and Policy, Department of Human Genetics, Faculty of Medicine, McGill University; 740 avenue Dr. Penfield, bureau 5202, Montreal, QC H3A 0G1; tel.: 514-398-8279; e-mail: emmanuelle.levesque@mcgill.ca.

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Health Professionals' Insights into the Impacts of Privately Funded Care within a National Health Service: A Qualitative Interview Study

Point de vue des professionnels de la santé sur l'impact des soins financés par le secteur privé dans un service national de santé : une étude qualitative



SARAH C. WALPOLE, MD
*Honorary Lecturer
Hull York Medical School
University of York
Heslington, United Kingdom*

Abstract

Background: The UK's publicly provided National Health Service (NHS) is primarily publicly funded but treats some private-pay patients (PPPs). Little is known about impacts of treating PPPs within publicly provided health systems. This study explores NHS health professionals' experiences and understanding of this phenomenon.

Methods: Semi-structured interviews were carried out with NHS clinicians. The interview transcripts were then thematically analyzed.

Results: A total of 17 clinicians highlighted potential impacts in five areas: (1) availability of resources for non-urgent, publicly funded patients, (2) patient safety for publicly funded patients and PPPs, (3) health professional training, (4) NHS finances, and (5) NHS direction setting and values.

Conclusions: In a publicly provided health service that is increasingly treating PPPs, clinicians had limited knowledge of policies for PPP care. Clinicians were concerned about patient safety impacts of prioritizing PPPs over publicly funded patients. Potential cross-subsidies

from public to private funding were mooted. The issues raised here require further exploration and may inform research and policy development in the UK and other countries.

Résumé

Contexte : Le service de santé public du Royaume-Uni (NHS) est principalement financé par les deniers publics, mais traite certains patients payants privés (PPP). On connaît peu l'impact du traitement de PPP au sein des systèmes de santé publics. Cette étude se penche sur l'expérience et la compréhension de ce phénomène auprès des professionnels de la santé du NHS.

Méthode : Entrevues semi-structurées auprès de cliniciens du NHS. Analyse thématique.

Résultats : Dix-sept cliniciens ont dégagé des impacts potentiels dans cinq domaines : (1) disponibilité des ressources pour les patients non urgents du volet public, (2) sécurité des patients des volets public et payant, (3) formation des professionnels de la santé, (4) finances du NHS et (5) orientation et valeurs du NHS.

Conclusion : Dans un système public qui traite de plus en plus de PPP, les cliniciens ont une connaissance limitée des politiques pour les soins aux PPP. Les cliniciens se disent préoccupés de l'impact pour la sécurité des patients si les PPP sont priorisés par rapport aux patients du volet public. Un interfinancement potentiel du public vers le privé a été évoqué. Ces enjeux doivent être approfondis et pourraient éclairer la recherche et l'élaboration de politiques au Royaume-Uni et ailleurs.

Introduction

Similar to Canada, the UK's National Health Service (NHS) is funded primarily through general taxation (McKenna et al. 2017). NHS facilities are publicly owned and maintained. All UK residents are eligible to receive publicly funded treatment, and over 95% of patients treated in NHS hospitals are publicly funded. Although most privately funded care in the UK takes place in exclusively privately owned healthcare facilities, many NHS hospitals also accommodate private-pay patients (PPPs), who fund their care out of pocket or through private insurance. PPP bills include a consultant's fee and a tariff to the NHS organization for facilities and staff costs. In some hospitals, a section (ward or building) of the hospital is allocated to PPPs; this is termed a private patient unit (PPU). NHS beds that are not in PPUs are also occasionally used for PPPs.

NHS healthcare is provided by public sector corporations called "trusts," which either serve a specific geographical area or a specialized function (e.g., providing a regional or national service, such as cancer care). Trusts can choose the extent and type of PPP care that they allow or encourage, as long as the use of facilities and staff for PPPs does not impinge on services provided to publicly funded patients.

Under increasing financial pressures, PPPs are seen as a revenue source for trusts. Under the 2006 rules introduced by the Labour Government, the proportion of income that NHS trusts could generate from PPPs was capped at about 2% (with some regional variations).The

Conservative Government's *Health and Social Care Act 2012* changed this, allowing trusts to generate up to 49% of their income from PPPs (Watt 2014). Many NHS hospitals invested in PPUUs (LaingBuisson 2014). To identify whether PPPs are financially beneficial to the trust requires accurate identification of the full costs of treating these patients. Because few trusts have good patient-level costing systems (Gainsbury 2009), however, most trusts cannot be certain that the specific PPPs admitted are indeed financially beneficial or whether their care comes at no detriment to the provision of public services.

Under specific terms and conditions, consultant doctors (and occasionally other professionals, e.g., physiotherapists) employed by the NHS to treat publicly funded patients may also treat PPPs in NHS hospitals. They must gain prior agreement from their trust before using NHS facilities or staff for PPP care and ensure that any PPP care does not infringe on their NHS duties (Department of Health 2004).

NHS Commissioning Board (2013) guidance states that NHS and PPP care should be separated by location and care episode, to facilitate accurate accounting; yet, where publicly funded and privately funded elements of care are both delivered within a publicly owned NHS facility, the separation is not always clear. The UK is not alone in seeing successive policies blurring the boundaries between public and private funding and provision; insights into potential morale, equity, efficiency and cost implications of providing publicly and privately funded care under one roof have international relevance. In Canada, unlike in the UK, private *payment* (i.e., extra billing or user charges) for medically necessary hospital and physician care is currently prohibited under the *Canada Health Act* and through similar provincial legislation. An attempt was made to overturn this prohibition in 2005 in Quebec (Dhalla 2007), and the legal challenge of the constitutionality of the British Columbia *Medicare Protection Act* is currently under way. Were this challenge successful, it would imply that the *Canada Health Act* is unconstitutional, which would have nationwide implications.

This study explores perceptions of the effects of private payment within an otherwise publicly funded system. Impacts of NHS PPPs on NHS finances have been described (Gainsbury 2009; Scott et al. 2012; The King's Fund 2017), but little is known about other impacts of NHS PPP care. Experiences and perceptions of NHS healthcare professionals of varied professions, specialties, ages and regions may inform the discussion of potential impacts of NHS PPP care that merit further investigation.

Methods

Interviews were conducted between November 2016 and April 2017 by a female UK-trained doctor with four years of qualitative research experience. The researcher's motivations were experiencing ambiguity about the role of NHS-employed health professionals in PPP care and lacking relevant guidance and evidence.

An interview *pro forma* and consent form were designed by the author, then revised based on feedback from a health policy expert (Appendix 1, available online at longwoods.com/content/26071).

Inclusion criteria were being a health professional and working in the NHS. A non-representative sample was recruited. Participants were invited through e-mails sent to a mailing list for UK medical academics and to the author's work contacts in varied UK NHS hospitals. Snowballing identified further participants. Interviewees were informed of the research purpose. Only individuals who were acquaintances of the researcher knew her motivation.

Study information and a consent form were e-mailed to each participant pre-interview. Consent was given before each interview. Where practicable, interviews were conducted in person; otherwise, interviews were by voice call.

An approach to assessment of health systems, primarily their functions, financing, provision, resource generation and stewardship (Murray and Frenk 2000), was adopted as a conceptual framework to inform *pro forma* design and analysis.

Interviews were carried out in private at the interviewee's convenience, in a library or the interviewee's workplace or home. The interview was audio recorded and then transcribed in full. Results were stored securely, in an anonymous format, on a computer that only the author had access to. Field notes were made during interviews. Interviews lasted 20 to 60 minutes. Recruitment and interviewing continued until saturation was reached.

Transcripts were e-mailed to the interviewee for validation. Any edits were used in the analysis. No repeat interviews or further conversations for clarification were required.

Thematic analysis was used (Attride-Stirling 2001). No software was used for data analysis. First, the author read each transcript in full to identify themes derived from the data. Second, using line-by-line review of transcripts, quotations relevant to one or more themes were extracted and categorized. Third, data under each theme were analyzed and synthesized.

Advice was provided by an expert ethicist at the Centre for Health in the Public Interest, who reviewed the protocol, participant information sheet and consent form. Measures were put in place to ensure integrity of the research process, minimize risk of harm (including anonymization of transcripts and storage of information only on one password-protected computer), maximize benefit (rigorous approach to analysis and write-up and commitment to publish results), promote autonomy of participants (who were well informed and could withdraw at any stage) and avoid discrimination (facilitating participation of any person meeting inclusion criteria and transcription to facilitate fair approach to data analysis).

Results

A total of 17 health professionals were interviewed (Table 1), 14 face to face and three by voice call. One participant noted one error in their transcript; it was corrected. Five participants responded with information that was not mentioned at the interview that they wanted to add in retrospect. No participant withdrew from the study.

Five main themes were derived: (1) impacts on availability of resources for non-urgent publicly funded patients, (2) patient safety impacts, (3) training and service development impacts, (4) recuperation of PPP costs, and (5) direction setting and values.

TABLE 1. Interviewees by job role and location

Number for reference	Specialty	Job role	Region
A	Accident and emergency	Specialist trainee	Yorkshire and Humber
B	Anaesthetics	Registrar	Yorkshire and Humber
C	Cardiology	Consultant	London
D	Cardiology	Consultant	Yorkshire and Humber
E	Cardiology	Consultant	Yorkshire and Humber
F	Cardiology and imaging	Nurse	Yorkshire and Humber
G	Gastroenterology	Consultant	Yorkshire and Humber
H	General medicine	Core trainee	East Midlands
I	Infectious diseases/microbiology	Registrar	East Midlands
J	Intensive care	Nurse	London
K	Obstetrics and gynecology	Specialist trainee	London
L	Oncology	Registrar	North of England
M	Orthopaedics	Consultant	West Midlands
N	Pediatric cardiology	Registrar	North of England
O	Psychiatry	Registrar	London
P	Surgery	Registrar	London
Q	Urogynecology	Consultant	South East

Provision: Availability of resources for non-urgent, publicly funded patients

NHS PPP care does not necessarily lengthen NHS waiting lists; the alternative to privately funded care delivered in NHS facilities would be publicly funded NHS care or privately funded care delivered by NHS consultants in private hospitals, thus drawing on the same resources. Yet, interviewees indicated that running a parallel PPP system within an otherwise publicly funded NHS may negatively impact health equity, first, due to PPPs being prioritized over publicly funded patients and, second, if PPP care consumes disproportionately high quantities of NHS resources.

PPPs may “jump the queue.” Interviewees experienced PPPs being prioritized for ward-based care and for scans:

Seeing [PPPs] first on the ward round, or feeling an obligation to drop whatever else I'm doing to be able to prioritize them ... (L)

A nurse described how fitting PPPs into an NHS list can delay publicly funded patients' cardiac interventions (Quote 4, Appendix 2, available online at longwoods.com/content/26071). Although all urgent procedures are completed the same day to protect patient safety, non-urgent publicly funded procedures may be rescheduled.

Higher resource use may occur where providing PPP care takes longer relative to providing publicly funded patients' care and/or ambiguity or administration makes demands on health professionals' time. Some interviewees perceived, or were told by colleagues, that PPPs deserve more clinician time because they are paying.

[A consultant] may have more one-on-one contact with a private patient ... But I think that's probably what comes with when you pay. (P)

Interviewees suggested that extra time spent seeing PPPs often was health professionals' own time, rather than time that would otherwise be spent providing care for publicly funded patients:

If you think about our consultants, they might spend their time [seeing PPPs] perhaps, but then they stay in the hospital until 7 o'clock ... (N)

PPPs are sometimes transferred from privately funded care to publicly funded care, if an aspect of their care is outside private insurance cover or the PPU/private facility cannot meet the patient's needs. Doctors described that when a patient–doctor relationship is developed during private treatment, the consultant may spend extra time with that patient even during publicly funded elements of their care (Quote 6, Appendix 2).

A doctor described a children's magnetic resonance imaging (MRI) list running overtime when an adult PPP was added onto the list to have an MRI under general anaesthesia (not normally available for publicly funded adult patients). The NHS team worked beyond their paid and scheduled hours to avoid postponing scans, but had they not, publicly funded patients would have been deferred due to this PPP having a procedure (MRI under general anaesthesia) that takes longer than the procedure provided to publicly funded patients (MRI without general anaesthesia).

PPPs transferred from PPUs to publicly funded care were particularly time-consuming when information about previous investigations was lacking:

We didn't have access to her [private] scans or her clinic letter ... it was thyroid surgery, so you kind of need to see where the thyroid is on her scans. (B)

A nurse experienced a situation in which a patient wished to transfer from publicly funded care to a PPU. This required much administrative time without always resulting in the desired transfer, for example, if the patient's health insurance would not cover the cost (Quote 13, Appendix 2).

Health professionals said that they took longer to see PPPs because it was harder to locate PPPs' beds, navigate PPPs' notes and enact PPPs' care plans, due to organization

for PPPs being different to that for publicly funded patients and, hence, unfamiliar. Furthermore, seeing PPU patients consumed significant time due to the PPU's distance from the main hospital.

It was difficult because they have different notes, different record system ... That's the worst bit – it just takes you away, takes you away for an hour. (I)

Ambiguity about staff roles could take time:

Afterwards I kind of put it together and realized it was because it was a private patient and I wasn't supposed to [see them] ... It wasn't part of our job, because I was supposed to be looking after our ward and that wasn't our ward to cover. (K)

Health professionals had varying ideas about whether PPPs should be seen exclusively by consultants or also by junior doctors.

Interviewees expressed disappointment at the lack of reciprocity between privately and publicly funded care. By definition, PPPs received care provided using NHS resources, but interviewees reported that the resources purchased for PPUs are not available for publicly funded patients, which created inequity and inefficiency. One trust invested in an MRI scanner for a PPU on the hospital grounds; however, even when the scanner was not in use for PPPs, publicly funded patients were not scanned there.

Patients that needed MRIs were shipped to [hospital 45 km away] for their scans and then shipped all the way back again, when there was a scanner across the carpark. (H)

By contrast, upon reaching capacity within NHS services, PPU beds may be allocated for publicly funded patients when NHS bed capacity is reached (Quote 16, Appendix 2).

Provision: Patient safety for publicly funded patients and PPPs

Interviewees' patient safety concerns related, first, to safety impacts of decisions made on a basis other than clinical need and, second, to the quality of care in PPUs.

Interviewees experienced patients being admitted to inappropriate locations and prioritization of clinical review according to funding rather than clinical need, which poses particular problems, whereas the NHS has high bed and operating theatre occupancy. One doctor commented that use of ward side-rooms for PPPs could result in publicly funded patients with potentially infectious conditions not being isolated or being isolated with delay, although, conversely, PPU rooms could be used for publicly funded patients requiring isolation to prevent infection (Quote 16, Appendix 2). Other interviewees noted PPPs admitted

to their private consultant's NHS ward, even if their current presenting complaint was not related to their private consultant's specialty. The ward and its staff were not specialized for the PPP's complaint:

It was a cardiology patient admitted as an inpatient for a cardiologist but actually it was more to sort out a gastroenterology issue on the cardiology wards. And I thought that well, yeah, this guy has just come in to us because he's his private patient, rather than it was the right place for them to be ... It's a resource – a cardiology bed not getting used appropriately. (L)

Concerns about PPUs included the quality of nursing care and timeliness of medical review:

I think often, particularly for the more unwell patients, the nursing care was probably worse on that [PPU] ward. (H)

A junior doctor described one night being asked by the doctor at his hospital's PPU to provide advice on a critically unwell patient. The PPU staff were unable to follow simple treatment advice; therefore, the patient was transferred to publicly funded wards and experienced delayed care (Quote 18, Appendix 2).

The assertion by two interviewees that NHS PPUs often absorb high-quality nursing staff seems contradictory:

New initiatives often reduce the quality of staff on NHS wards because best staff go and work in the new facility. (D)

Two interviewees discussed PPPs receiving care outside of clinical protocols, which they feel compromised patient safety. A nurse described a PPP being prescribed medicines without following protocol (Quote 20, Appendix 2), attempting to meet the patient's expectations. A consultant judged that one patient was suffering from an infection with resistant bacteria due to inappropriate antibiotic treatment when he was a PPP:

That private patient took a lot of my time, and I do think that the reason that he took so much of my time was that he'd been treated irresponsibly. (I)

Another consultant said that in private pay practice even within the NHS, the consultant's financial incentive potentially drives overinvestigation and overtreatment (Quote 21, Appendix 2). An example is the PPP MRI under anaesthesia described in the previous section.

Resource generation: Training and service development

Interviewees found that PPPs present fewer training opportunities than publicly funded patients.

One consultant said that PPPs are not accessible “as training cases” (Quote 22, Appendix 2). Trainee doctors usually do not enter PPU, which are staffed by non-training grade doctors. Another said that PPPs were generally less willing to see trainees but would sometimes if they had history or examination features of particular learning value (Quote 24, Appendix 2).

Junior doctors described consultants leading most PPP (or ex-PPP) care, resulting in reduced training opportunities:

It may free up juniors’ time [when consultants lead PPP care], it’s also a loss of training opportunity, so it goes both ways doesn’t it? (A)

Although PPPs’ operations are usually performed by a consultant, surgical registrars sometimes assist, which may facilitate learning. A surgical registrar said that PPPs can provide opportunities to observe procedures that are not available on the NHS (although this may have a limited contribution to preparing the registrar for NHS consultant practice). Opportunities to assist PPPs’ operations usually are limited to more senior and more proficient registrars, to the disadvantage of registrars with most training needs:

To be asked to go and assist at a private operation is a bit of an honour as a registrar, so it’s recognising that you are good at what you do. (P)

The same interviewee said that cherry-picking for privately funded operations results in removal of simple cases from the publicly funded NHS operation pool, thus “removing a rung on the ladder,” leaving trainees seeing more complex cases without sufficient exposure to simple cases.

One interviewee stated, based on experience attending a private healthcare facility as a medical student, that trainees’ involvement in PPP care may improve their understanding of healthcare systems and patient experiences:

It was useful to have the comparison and to see the differences between the two systems, and start thinking about the impact that the system can have and the resources available ... it was quite a shock to see the difference ... (O)

Finances: Recuperating PPP costs

Most interviewees recognized that local and national guidance exists for the care of PPPs but did not know the content of the guidance. A consultant said that the rules were “left for you to figure out” (C). Interviewees unanimously had not received induction about PPP care, including their role.

For trusts to recuperate PPP care costs requires hospital staff to identify PPPs and mark investigation and treatment requests to facilitate correct billing of the PPP/private insurer. Should requests not be marked appropriately, it risks cross-subsidy of PPPs from public funds. A registrar and a consultant stated that they know when they have a PPP and mark requests appropriately; conversely, a nurse said that she and her colleagues did not know when they had PPPs and did not consider marking PPP investigations. Other interviewees were not aware that PPP investigations required specific marking.

Reliable systems are not in place for staff to identify PPPs:

If there's a private[ly funded] patient who's just mixed in with the ward, it might say on the board 'PP' or you'll just get the verbal communication from the nurse, that sort of thing. (B)

A surgeon said that in the operating theatres, all staff were aware of whether patients were privately or publicly funded, yet she did not consider it necessary to inform the trust:

I don't think it's necessary to tell them [the trust] that they're there. (P)

Some staff not only did not recognize the importance of identifying PPPs, they preferred not to:

I prefer not to know and treat them like any other patient. As doctors we don't have to really care whether the patient is private and paying for their care. (N)

A consultant said that other consultants may intentionally conceal PPP admissions to avoid administration or costs that they should pay to the hospital for use of facilities:

I think that, I suspect that a number of my colleagues are just simply adding them, private[ly funded] patients, to their NHS lists [without informing the trust]. (G)

Were this true, it would cause cross-subsidy from public to private funding.

Consultants described diverse approaches to tariff setting and payment sharing between the trust and the consultant. A consultant said that his trust sets PPP tariffs below the local private hospital's tariffs based on assumption of lower overhead costs, which reflects the responses of trusts. Two interviewees described informal arrangements for PPP treatment; for example, a consultant treats a PPP during an NHS operation list and in return does an extra half day treating publicly funded patients without payment.

Apart from consultants, who receive payment for PPP care from the PPP's bill, health professionals usually receive no payment on top of their NHS salary for being involved in

PPP care. An exception is that surgical registrars may receive an informal payment, its value determined by the consultant (Quote 35, Appendix 2). A consultant gave an example of a consultant paying an assisting registrar £200 of their £2,000 fee for a cardiac bypass.

Stewardship: Direction setting and NHS values

Consultants described NHS trusts having varying approaches to permitting or encouraging PPP care within the trust. Where privately funded care is not supported, administrative burden and stress may discourage consultants:

[Because of trust regulation,] I can't see private[ly funded] patients on NHS time. And actually, in reality that makes it really difficult to see private[ly funded] patients in the trust. It makes it cumbersome and complicated. (G)

In contrast, a London-based consultant said, "We've been encouraged as a body of consultants to see people privately if they want" (C). Another consultant said that his trust is "happy to have private admissions as long as it doesn't impinge on NHS work" (D).

Interviewees explored whether NHS PPP care is practicable. Some interviewees stated that with the NHS working at full capacity to provide care in the publicly funded system, trusts do not practically have human resources or facilities to plan and implement PPP care (Quotes 40–42, Appendix 2).

Interviewees explored whether PPP care provision aligns with NHS values. Some were concerned about increasing privatization exacerbating health inequities:

Some people would say if they pay then they deserve to go first. It's not fair, the NHS shouldn't be for that. The public system, we don't have to play that game. (N)

Opinions varied:

I think that people will jump the queue by being private, but that in the way is the market playing out isn't it? [sic] ... if you want something quicker you have to pay for it. (G)

Interviewees considered whether, if consultants provide PPP care, it is better that they do so within NHS premises. An advantage of consultants seeing PPPs within the NHS is their proximity to their other patients. A disadvantage is that health professionals who would not choose to treat PPPs may experience pressure to support PPP activity when it is delivered within NHS hospitals. Anaesthetists are essential to the delivery of many treatments, notably surgery, and it can be challenging to find sufficient anaesthetists for PPP operations:

In general, they actually struggle to cover the shifts, so ... people aren't like fighting over these [PPP operation] lists, it's potentially the opposite way around. (B)

One interviewee described feeling pressured into providing clinical microbiology advice for a PPP during publicly funded working hours, with insufficient patient information available (Quote 49, Appendix 2).

Consultants may be motivated to treat PPPs for freedom to stray from constraints of public funding (e.g., consultation length and types of intervention funded):

Private[ly-funded] practice is something that you do for fun in order that you can treat patients in the way in which you wanted to treat them when you went to medical school ... I won't make any real profit from my private practice. (G)

Such "freedom" may, however, risk overtreatment and patient safety.

Consultants described that seeing PPPs within the NHS is attractive. It reduces overhead costs (low or no consulting room fees), and more support is available from doctor colleagues compared to that in private facilities.

Discussion

By exploring health professionals' insights about PPP care in NHS-owned hospitals, this study highlights areas of potential concern and can help to build hypotheses about impacts of providing privately funded care within an otherwise publicly funded healthcare system. Participants may not fully understand the economy of NHS PPPs, yet their perspectives provide credible insights into the realities, benefits and problems of treating PPPs within NHS hospitals. Further, even where issues are perceived but do not actually exist, this can unveil misunderstandings and value judgments that are beneficial to address (Chalkley and Sussex 2018). These findings can inform health researchers and policy makers in the UK and abroad.

Regarding experiences and perceptions about NHS PPPs, even within this small sample of health professionals, there is great diversity. The study highlights that although consultants usually have a choice about whether to engage in PPP care, non-consultant clinicians had little or no choice regarding whether they are involved in caring for PPPs under the terms of NHS employment. Many interviewees opposed PPP care being provided within NHS PUs, believing that the NHS should exclusively treat publicly funded patients and want to retain choice about whether to contribute to providing PPP care. If privately funded care within the NHS continues to expand as predicted (LaingBuisson 2016), consultants who do not wish to care for PPPs may increasingly be obliged to support PPP care as part of NHS employment, for example, providing specialist advice or anaesthetics. Thus, although trusts may allow consultants to see PPPs within the NHS to reward or retain consultants (Walpole 2018), they risk adversely affecting other health professionals' experiences.

A further issue is the equity impacts of creation and support of a parallel system within the publicly funded NHS. Apart from the inequity of differentials in care arising from the existence of a parallel private-pay system, interviewees expressed concern that patients may be prioritized according to their funding rather than clinical need, resulting in delayed care for publicly funded patients and patient safety issues.

Regarding material impacts, front-line health professionals questioned whether hidden cross-subsidies from public to private may exist. Where elements of care are not measured (e.g., due to inaccurate marking of PPP investigations) or entire care PPP episodes are hidden (e.g., if PPPs have operations without appropriate permission and billing by the trust), trusts' ability to accurately measure and recuperate costs (financial and otherwise) of PPP services is compromised. Many interviewees were unaware of guidelines and policies for NHS PPP care, suggesting that procedures (such as marking PPP investigations) are unlikely to be followed. Interviewees correctly identified that NHS trusts often undercut private healthcare providers (Scott et al. 2012). Various formal and informal arrangements were described for payment of doctors and trusts for PPP care, which corresponds with the evidence of widely varying approaches to NHS PPP tariff setting (Walpole 2018), raising concern that costs may not always be covered. The Department of Health (2004) does not recognize the payment of registrars or other clinicians who contribute to PPP care and receive informal payment via a consultant.

Concerns were raised about patient safety in PPU. Although evidence suggests that quality in private hospitals is less well monitored and potentially lower than care in NHS PPU (Leys and Toft 2014), research about quality in PPU is lacking. Two consultants raised concerns that clinicians' earnings being linked to PPP activity drives overinvestigation and overtreatment, a concern that relates to privately funded healthcare regardless of location.

The suggestion that PPU absorb high-quality staff, reducing availability for NHS wards, is seemingly contradictory to the suggestion that PPU have lower quality standards but corroborated by Palley et al. (2011), who stated that expansion of private for-profit healthcare provision drains physicians from Canada's otherwise not-for-profit system. A possibility is that staff provide differing quality care depending on the patient's funding or the work environment; however, this was not explored in interviews.

Interviewees felt that PPPs offer some training opportunities but less willingly and often than publicly funded patients. Although the same number of patients may be receiving care, this quantitative equivalence in training opportunities may not translate to a qualitative equivalence. A hypothesis of practising healthcare professionals, relevant both as a perceived problem and potentially a real problem, is that training opportunities may be few when patients are private pay, as they do not perceive that they should be involved as "cases" in training.

Strengths and Limitations

This study was not intended to provide a representative sample of views. Recruitment via e-mail lists and snowballing causes sampling bias toward individuals with stronger views and those who felt most able to articulate opinions. There may be some merit in identifying stronger views, which can help to build hypotheses about this issue. Although the sample size was relatively small, the range of professionals interviewed is a strength.

Privacy and anonymity of interviews gave interviewees opportunity to express views that may not have been shared in focus groups or were participants identifiable. That interviews were transcribed in full and validated by participants enhances reliability. Ideally, “member checking” would also have been used to validate themes.

Limitations include single authorship, which makes reflexivity particularly important in interpretation of findings. The author has worked in the NHS and been asked to support PPP care there. She is a member of the People's Health Movement and Medact, organizations that advocate for publicly financed, publicly provided healthcare, and has worked with researchers from the Centre for Health in the Public Interest, which has exposed problems and fragmentation arising from private healthcare provision. Emphasis and interpretations of data emerging from the study may thus have been different to those that another researcher might have made.

Conclusion

The implications of this study of privately funded care provision within a publicly provided health service are relevant to other nations considering the efficiency of and/or looking to expand private healthcare funding. Many issues raised reflect challenges related to co-existing public and private systems as seen in multiple countries (Patel et al. 2015; Rannan-Eliya et al. 2016; Rosen et al. 2015). Like the UK, Canada has extended the scope of private for-profit healthcare delivery within a publicly funded healthcare system, as a result of politically perceived needs and resource limitations (Contandriopoulos et al. 2012; Palley et al. 2011).

Governments should consider that running privately funded services within otherwise publicly funded healthcare services may not provide the anticipated financial rewards unless careful attention is paid to tariff setting, activity monitoring and revenue collection with guidance and oversight in place. The issues raised here require further exploration through examination of local policy and practice and wider consultation and may inform research and policy development by governments and healthcare providers.

Registration + Protocol

The pre-determined protocol is available from the author. It was not submitted to a registry. The interview *pro forma* was first drafted at the time of developing the protocol and then revised based on feedback. The revised version is appended.

Ethical Approval

Ethical approval was gained from the Centre for Health in the Public Interest, whose committee included an expert ethicist. It was deemed that the study entailed very limited risk of harm and would not affect patients.

Correspondence may be directed to: Dr. Sarah C. Walpole, Honorary Lecturer, Hull York Medical School, University of York, Heslington, York YO10 5DD UK; tel.: +44 7517 243 783; e-mail: Sarah.walpole@hyms.ac.uk.

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Glossary

- Consultant/consultant doctor*: A senior physician specialist who has completed the training for their specialty.
- Cross-subsidy*: Funds generated from or resources allocated for one activity (in this discussion, publicly funded NHS care) being used to pay for a different activity (in this discussion, privately funded NHS care).
- Finished consultant episode*: A measure of hospital activity; the period during which a patient is continuously seen by one consultant, ending with discharge, transfer or death.
- Junior doctor*: A doctor who has completed medical school but not completed training, that is, who is not yet a consultant (or an associate specialist, an equivalent to a consultant).
- NHS Commissioning Board*: A public body, sponsored by the Department of Health and Social Care, established in 2012 to implement the reforms of the *Health and Social Care Act*. In 2013, its name changed to NHS England, but its roles remain the same, including leading the NHS by planning, commissioning and regulating NHS services.
- Non-training grade doctors*: Graduate doctors who work in paid roles delivering health services, not at the consultant level and without being enrolled in (and thus benefitting from the structure and support system of) a training program.
- Private patient unit (PPU)*: A section (ward or building) of an NHS hospital that is allocated to treatment of private-pay patients.
- Registrar*: A doctor in training who has completed foundation and core training and is undertaking specialist training.
- Surgeon*: A doctor who has chosen to pursue a surgical specialty, that is, a surgical registrar or surgical consultant.
- Tariff*: The set price for a service; the amount that is due to be paid.
- Trainee/trainee doctor*: A medical graduate working as a doctor below consultant level and in a foundation or specialty training scheme.
- Trust/NHS Trust*: An NHS organizational unit that serves a specific geographical area or serves a specialized function, such as provision of a regional or national service.

Comparison of Health Insurance Coverage for Hearing Aids and Other Services in Alberta

Comparaison de la couverture de l'assurance maladie pour l'aide auditive et d'autres services en Alberta



AMBERLEY V. OSTEVIK, BENG, MSC

Registered Audiologist

*Department of Communication Sciences and Disorders,
Faculty of Rehabilitation Medicine
University of Alberta
Edmonton, AB*

JORDAN HERST, BSC

Undergraduate Student

*Department of Communication Sciences and Disorders,
Faculty of Rehabilitation Medicine
University of Alberta
Edmonton, AB*

LINDSEY WESTOVER, PHD

Assistant Professor

*Department of Communication Sciences and Disorders,
Faculty of Rehabilitation Medicine and
Department of Mechanical Engineering, Institute for
Reconstructive Sciences in Medicine
University of Alberta
Edmonton, AB*

JACQUELINE CUMMINE, PHD

Associate Professor

*Department of Communication Sciences and Disorders,
Faculty of Rehabilitation Medicine
University of Alberta
Edmonton, AB*

HALEY GYNANE, BSC

*Graduate Student, Department of Communication
Sciences and Disorders*

*Faculty of Rehabilitation Medicine, University of Alberta
Edmonton, AB*

WILLIAM E. HODGETTS, PHD

Professor

*Department of Communication Sciences and Disorders,
Faculty of Rehabilitation Medicine and
Department of Mechanical Engineering, Institute for
Reconstructive Sciences in Medicine
University of Alberta
Edmonton, AB*

Abstract

Objectives: Of the several barriers associated with uptake and adherence to hearing services, cost is the most commonly identified barrier in Canada. This study evaluated health insurance plans for hearing care coverage within Alberta, Canada, and subsequent out-of-pocket expenses that would result if an individual chose to pursue treatment.

Methods: An investigation of eight companies that provide supplementary health coverage in Alberta was conducted. Categories of health service coverage included hearing, vision, speech-language pathology (S-LP), physical therapy related (PT-R; including massage therapy and chiropractic therapy) and alternative medicine related (AM-R; including osteopathy, acupuncture and naturopathy). All coverage amounts were corrected to a four-year term for comparison purposes.

Results: For a four-year term, the coverage amounts for hearing services were CAD 300–750; for vision services were CAD 0–900; for S-LP services were CAD 0–2,400; for PT-R services were CAD 1,400–10,200; and for AM-R services were CAD 0–10,200 per four-year term. The expected out-of-pocket expense for vision ranged from CAD 0 to CAD 2,766, whereas for hearing, it ranged from CAD 250 to CAD 11,700.

Conclusion: A considerable range and discrepancy were reported between hearing care and most paramedical services. In addition, the coverage amounts for hearing care were inconsistent with treatment costs, resulting in considerable out-of-pocket expenses for most consumers. The potential implications of such cost-related barriers on public health are an important consideration as our understanding of the impact of untreated hearing impairment continues to increase.

Résumé

Objectifs : Parmi les multiples obstacles qui touchent le recours aux services d'aide à l'audition, le coût est le facteur le plus souvent mentionné au Canada. Cette étude évalue les régimes d'assurance pour les services d'audiologie en Alberta (Canada) et les dépenses personnelles subséquentes si un patient choisit de suivre un traitement.

Méthode : Nous avons mené une enquête auprès de huit compagnies qui offrent une protection supplémentaire en matière de santé en Alberta. Les catégories couvertes comprennent : l'audiologie, les soins de la vue, l'orthophonie, la physiothérapie (incluant les massages thérapeutiques et la chiropratique) et la médecine alternative (incluant l'ostéopathie, l'acupuncture et la naturopathie). Aux fins de la comparaison, les montants de la couverture ont été corrigés sur une période de 4 ans.

Résultats : Pour la période de 4 ans, les montants de la couverture pour les services d'audiologie étaient de 300 à 750 \$ CA; pour les services de soins de la vue, de 0 à 900 \$ CA; pour les services d'orthophonie, de 0 à 2 400 \$ CA; pour les services de physiothérapie, de 1 400 à 10 200 \$ CA; pour la médecine alternative, de 0 à 10 200 \$ CA. Les dépenses personnelles estimées pour les soins de la vue étaient de 0 à 2 766 \$ CA, tandis qu'ils allaient de 250 à 11 700 \$ CA pour l'audiologie.

Conclusion : Il y d'importantes divergences entre les services d'audiologie et la plupart des services paramédicaux. De plus, le montant de la couverture pour les services d'audiologie était incompatible avec le coût des traitements, entraînant des dépenses personnelles considérables pour la plupart des consommateurs. Les répercussions potentielles liées aux obstacles

financiers en matière de santé publique méritent notre attention, notamment avec l'apport continu de nouvelles connaissances sur l'impact des déficiences auditives non traitées.

Introduction

In spite of the steady advances in technology, uptake and adherence to hearing aids remain surprisingly low. Estimates put the proportion of Canadian adults using a hearing aid who could benefit from one at approximately 20% (SAC Hearing Aids Infographic 2018). The public health implications of untreated hearing impairments has become a topic of much discussion (Deal et al. 2017; Lin and Albert 2014; Livingston et al. 2017), in turn leading to additional inquiries into the uptake of hearing aid services. The reasons for poor uptake, commonly defined as barriers, have been extensively studied and found to be complex and multifactorial (Knudsen et al. 2010). Many of these barriers, such as inherent personality traits and attitudes, can be challenging to quantify and cannot be easily modified. However, the influence of some external factors, particularly cost, is easier to measure and potentially change (i.e., by way of decreasing cost or increasing insurance coverage).

Cost is consistently identified as one of the most common reasons individuals do not obtain treatment for hearing loss (Abrams and Kihm 2015; Knudsen et al. 2010; O'Rourke 2014). And, although removal of cost entirely (i.e., Scandinavian countries where hearing care is completely covered) does not lead to a drastic change in uptake and adherence of hearing services, cost is the most commonly reported barrier (whether perceived or real) in Canada and, thus, is a patient-oriented concern that requires better understanding. The retail range for hearing aids reported in the literature and news media is sizable, from a few hundred to upwards of \$10,000 (Grundfast and Liu 2017; O'Rourke 2014). Investigators from the Canadian Broadcasting Corporation's Marketplace, a seasoned consumer watchdog program, reported difficulty obtaining details about hearing aid prices and costing ("Hearing Aids: Our Insider's Take" 2013). It is not surprising then that the purchasing process is challenging and intimidating for a novice consumer with a communication impairment. This confusion over what constitutes a fair price, along with individual financial constraints, possibly leads to avoidance, which likely contributes to low adoption rates.

To remove cost as a barrier, an individual must be able to receive treatment with zero or very minimal out-of-pocket expenses. However, with Canadians having access to both public and private health insurance plans that vary significantly from province to province, it can be difficult for individuals to understand how to minimize their costs. Furthermore, hearing care, including funding, programs and services, falls outside of the mandate of the *Canada Health Act* (O'Rourke 2014). Under the Act, provincial and territorial health plans are only required to provide insured residents (i.e., those with a valid health card) with "reasonable access to medically necessary hospital and physician services" (Canada Health Act Division 2011). This broad definition allows for different interpretations between provinces.

Currently, the gaps in publicly funded coverage, be these provincial, territorial or federal programs (e.g., Veteran Affairs Canada), must be filled out of pocket by the consumer or

by extended health insurance plans. Before any recommendations can be made with respect to modifications of insurance coverage for hearing treatment, or before information can be provided to individuals seeking coverage for hearing impairment, a comprehensive review of insurance plans needs to be documented to describe the current gaps in coverage.

The objective of this study was to evaluate private, supplementary, and non-group health insurance plans for hearing care coverage within Alberta, Canada, and to compare the coverage amounts with other paramedical health services. A second objective was to provide a description of the coverage range and subsequent out-of-pocket expenses that would result if an individual chose to pursue treatment for hearing loss with and without insurance coverage.

Methods

An investigation of insurance companies that provide supplementary health coverage in Alberta was conducted using publicly available data found through Internet searches done in April and May of 2018. Eight companies were identified and considered (labelled A through H in Table 1, available online at longwoods.com/content/26070). The included companies had an online presence and plan information that could be accessed online or over the phone. Supplementary health coverage is insurance provided by insurers to reimburse expenses not covered by government plans (e.g., prescription drugs and dental services).

The plans evaluated were non-group benefits available to adult Canadians (i.e., 18–64 years of age inclusive) with minimal restrictions for enrolment. In Alberta, most individuals under 18 and over 64 years of age qualify for hearing benefits through the Alberta Government program Alberta Aids to Daily Living. These benefits include new amplification purchases (e.g., hearing aids and personal listening devices) and repairs. And although the full details of this program are beyond the scope of this study, its availability to Alberta residents is the reason this investigation focused on the age group (i.e., 18–64 years of age inclusive) that typically cannot access these resources unless they are below a defined low-income level (Alberta Health 2018). Group plans were also not reported, as these are only available to a select portion of individuals (e.g., employer-sponsored health plan for eligible employees). Other provincial, territorial or federal programs (e.g., Veterans Affairs Canada, Workers' Compensation Board and social-based programs) were also not included, as enrolment numbers and coverage amounts were not publicly available.

Categories of health service coverage were defined as hearing, vision, speech-language pathology (S-LP), physical therapy related (PT-R) (including physiotherapy, massage therapy and chiropractic therapy) and alternative medicine related (AM-R) (including osteopathy, acupuncture and naturopathy). Minimum and maximum coverage amounts were determined for each company, as supplementary health plans often contain several levels of coverage choices (e.g., basic vs. upgraded).

All coverage amounts were corrected to a four-year term for comparison purposes. Five companies offered hearing service coverage every four-year benefit period, and three companies had a five-year benefit period for hearing services. This contrasts with the one-year benefit period for the other categories of coverage, excluding vision. Seven companies offered a two-year benefit period for vision services, and one company offered a three-year term. The term correction was achieved by dividing the coverage amount by the benefit period and then multiplying this amount by four. For example, a company that offered CAD 500 every five-year benefit period was corrected to CAD 400 (i.e., CAD 500/5-year benefit period \times 4-year benefit period).

Minimum and maximum customer monthly plan costs (i.e., the range consumers would pay for coverage; higher costs equated to more coverage) were also recorded for each company. This information was readily available on most company websites. Those companies that required limited information (i.e., age and sex) about the applicant before releasing a quote or plan rates were provided with profiles of a 30-year-old man and 60-year-old woman who resided in Edmonton. Numerous factors contribute to a company's proprietary calculation of monthly plan rates. However, if health insurance costs were to vary by age and sex, these were assumed to increase as policyholders got older ("How Insurance Companies Set Health Premiums" 2018) and be higher for women (Rimler 2016).

Retail price ranges for hearing aids were determined from three local Edmonton, Alberta, dispensaries, including two audiology clinics (Dispensers 1 and 2) and a bulk discount warehouse store (Dispenser 3). Similarly, retail price ranges for vision correction were estimated from three local dispensaries for a single complete pair of glasses with frames and lenses. We chose to obtain only treatment cost estimates for vision to compare with hearing aids, as optometry and audiology have similar assessments and both consistently provide corrective devices for sensory impairment. These treatment costs were compared with the insurance coverage amounts to estimate the coverage range and the expected out-of-pocket expenses, if any.

Results

Table 1 shows the minimum and maximum coverage corrected to a four-year term for services across all company plans considered along with the associated monthly plan costs. For hearing services, the coverage amounts ranged from CAD 300 to CAD 750 per four-year term, whereas vision services ranged from CAD 0 to CAD 900 per four-year term. For comparison, coverage for S-LP services ranged from CAD 0 to CAD 2,400 per four-year term, combined coverage for PT-R services ranged from CAD 1,400 to CAD 10,200 per four-year term and combined coverage for AM-R services ranged from CAD 0 to CAD 10,200 per four-year term. The monthly cost for plans considered in this study ranged from CAD 25.00 to CAD 225.42.

For a single hearing aid, cost estimates ranged from CAD 1,000 to CAD 6,000 (Table 2). The price point was dependent on the level of technology, included accessories and

Comparison of Health Insurance Coverage for Hearing Aids and Other Services in Alberta

services (e.g., length of warranty period). The lower end quote was each dispenser's most basic, least expensive model and service package, whereas the higher end quote was the newest, most expensive technology and comprehensive service package. The cost estimates for a complete pair of glasses ranged from CAD 139 to CAD 1,383 (Table 2). The frames and lenses were priced separately at each dispenser. Frames ranged in price from CAD 49 to CAD 610, whereas the lenses ranged in price from CAD 90 to CAD 780. The minimum costs for lenses were determined for basic single-vision plastic lenses with a mild prescription (-1.25) without coatings or protection. The maximum costs for lenses were determined for high-end progressive lenses with maximum anti-glare and other coatings.

TABLE 2. Cost for hearing care (i.e., single hearing aid) and vision care (i.e., single pair of glasses)

Dispenser	Hearing aid cost (CAD)		Dispenser	Glasses cost (CAD)	
	Min	Max		Min	Max
1	1,000	6,000	4	245	1,383
2	1,200	6,000	5	200	1,178
3	1,000	1,700	6	139	1,039
Average*	1,067	4,567	Average*	195	1,200
Median	1,000	6,000	Median	200	1,178

*Average rounded to the nearest dollar.

Discussion

In this study, we set out to describe, compare and evaluate health insurance plans for hearing care coverage within Alberta, Canada, to better understand the potential out-of-pocket expenses that would result if an individual chose to pursue treatment. Given that cost is the most commonly reported barrier to uptake and adherence to hearing services, a targeted analysis of this factor is an important step to identify and address the challenges faced by Canadians in need of a hearing device. Our findings are discussed in the context of coverage amounts and out-of-pocket expenses for comparable healthcare services to provide a more comprehensive description of the potential impact of cost barriers.

Coverage amounts

Not surprisingly, coverage amounts varied substantially across the various services we explored. For example, although the exact treatment estimates were not reported for SL-P, PT-R and AM-R services, the corrected four-year benefit coverage range was quite large (CAD 0–2,400, CAD 1,400–10,200 and CAD 0–10,200, respectively). With this large range, it therefore behooves the consumer to contrast and compare plan coverage and pricing for S-LP, PT-R, AM-R and vision care. In addition, the treatment costs for these therapies vary substantially, as these are largely service driven, whereas audiology and optometry primarily focus on dispensing medical devices for treatment. For example, hearing coverage had

a much more limited range (CAD 300–750). Although our investigation was not exhaustive, in general, our results indicate that consumers should expect fairly similar coverage amounts between companies and plan levels (e.g., basic vs. advanced) for hearing care.

A confounding factor in “equating” coverage amount was the differing coverage length across the health services. Although we attempted to overcome this factor by correcting coverage to a four-year benefit period, ultimately, the range of S-LP, PT-R and AM-R services may have been artificially inflated. That is, the company-specified benefit period for these categories is one year, meaning that unused coverage does not carry over. In addition, many companies put limits on reimbursement (e.g., CAD 25 per visit), making it difficult for consumers to maximize their coverage without incurring significant out-of-pocket expenses. However, even if we ignore the correction, most categories are still able to access similar coverage amounts each year (i.e., CAD 0–850), whereas hearing care is restricted to a minimum four-year benefit period. Such discrepancies in coverage amounts could potentially lead to perceived differences in importance, utilization and adherence of recommended services. Ultimately, future work that specifically addresses the impact of differing coverage amounts on perceptions and/or beliefs around these constructs is warranted.

A somewhat surprising finding of the current work was that less scientifically substantiated health treatment categories (e.g., homeopathy and other offerings within the AM-R classification) receive comparable or additional coverage to hearing services (NHMRC Statement on Homeopathy 2015; Zhang and Zehnder 2016). Individuals with hearing loss have scarce alternatives for treatment and, as already noted, untreated hearing loss has health implications that can be quite severe (Deal et al. 2017). Although a very small percentage of individuals may be eligible for corrective surgery or implantable devices, most will be required to purchase hearing devices to treat their disability for the remainder of their lifetime. Ultimately, longitudinal studies will need to be carried out to test the magnitude of costs that insurance companies (and/or individuals) incur as a result of untreated hearing loss and whether there are any cost-saving benefits associated with a reallocation of resources.

Out-of-pocket expenses

At first glance, there are no large differences between the range in coverage for hearing and vision care, with a difference in maximum coverage of CAD 150 (i.e., the maximum vision coverage available is CAD 900 from Company A, whereas the maximum hearing coverage available is CAD 750 from Company B). Hearing coverage is consistently lower (with the exception of Company B), but every company offers some financial relief. However, this comparison becomes considerably unbalanced when linked with treatment costs and subsequent out-of-pocket expenses. Treatment estimates for a single hearing aid can be magnitudes higher than vision correction, with the maximum cost for a pair of glasses approximating the price of a single basic-level hearing aid across all companies. This discrepancy increases further when we consider that most individuals who require treatment present with bilateral hearing loss and are recommended two hearing aids (“Hearing Loss of Canadians” 2016).

The cost range for a pair of hearing aids is then doubled to CAD 2,000–12,000 (Table 2). Proper treatment is important to achieve binaural hearing to improve listening ease and clarity, localize sound, avoid auditory deprivation and be able to listen in challenging environments such as background noise (Mencher and Davis 2006).

As was stated earlier, the coverage amounts for hearing care were for a four- or five-year benefit period across all companies. Aids typically need to be replaced every four to seven years, as hearing changes with age and electronics wear with use (O'Rourke 2014). With vision care, all but one company expressed coverage as a two-year benefit period. We will therefore assume that glasses are typically replaced every two years, which doubles the treatment cost estimate in Table 2 for a four-year benefit period. The cost range of two pairs of glasses is then corrected to CAD 278–2,766, which is still substantially less than the range (CAD 2,000–12,000) for two hearing aids.

Using the presented ranges along with hearing and vision care coverage amounts of CAD 300–750 and CAD 0–900, respectively, it is possible to obtain prescription eyewear with no out-of-pocket expenses (or 100% coverage) using individual insurance, as coverage amounts can meet or exceed treatment costs. However, an individual may still be required to pay up to CAD 2,766 out-of-pocket (or 0% coverage), as one company's basic plan includes no vision coverage. It was also observed that several companies had designated amounts (e.g., CAD 50) for eye examinations every benefit period, which was included in the insurance coverage amounts reported. No termed amounts for hearing assessments were noted for any company.

Out-of-pocket expenses for hearing aids cannot be avoided if an individual does not have access to any programs outside of their supplementary health insurance plan. These expected costs will range from CAD 250 to CAD 11,700 and will depend on the number of aids and chosen level of technology/service. It should be noted that most out-of-pocket expenses for medical devices and services are eligible to be used for non-refundable tax credits on income tax and benefit returns.

Increased insurance coverage, or decreased out-of-pocket expenses, is reported by 51% of non-hearing aid owners to be the most persuading factor that would facilitate adoption or uptake (Abrams and Kihm 2015). However, adoption rates in countries such as Norway, where hearing aids are fully subsidized (i.e., no out-of-pocket expenses), do not exceed 43% (Kirkwood 2015). Therefore, the contribution of cost as a barrier to hearing aid uptake requires further investigation, as its removal does not necessarily improve adoption rates. For example, stigma is also a highly reported factor that contributes to low uptake of hearing devices, whereby people report “not wanting to look old” and “not wanting people to think they are deficient” as reasons for not getting a hearing device (Wallhagen 2009). In keeping with the notion that uptake of hearing services is complex and multifactorial (Knudsen et al. 2010), it is likely that the removal of barriers needs to occur in conjunction with hearing education and knowledge regarding the pathway to hearing services, just to name a few.

Without proprietary information from the insurance companies, it is not possible to state how a consensus (i.e., comparable amounts and benefit periods) on hearing care

coverage was arrived at across the companies sampled. The amounts are far removed from current treatment cost estimates and do not seem to consider the increased incidence of bilateral hearing loss. Packer (2017) speculates that companies view hearing aids as an elective treatment, with hearing loss being a “likely risk” or an eventuality. In isolation, this high risk, with an aging population, combined with high treatment costs, may weigh heavy on the bottom line, making the inclusion or improvement of hearing care coverage in both public and private health insurance plans unlikely without mandated, lawful directives.

Further, there is some preliminary evidence that illustrates a link between hearing loss and possible risks for subsequent health issues (e.g., dementia; Deal et al. 2017; Livingston et al. 2017), which would likely have a more substantial impact on coverage costs for insurance companies (private and public) than the treatment of hearing impairments early on. These potential cascading effects need to be a consideration in future decisions about insurance coverage amount/length specific to hearing services. Such conversations should also be informed through future work that compares coverage across various sub-populations (e.g., veterans, disabled persons), provinces and countries. Although the targeted approach taken here on a large “cohesive” Canadian population (i.e., 18–64 years of age inclusive) allowed us to summarize the data into meaningful conclusions, there are many more factors to investigate that will undoubtedly complicate the matter. For example, although dementia is more common among individuals of age more than 65 years and the cohort studied here was 18–64 years of age inclusive, the hearing loss–dementia relationship is a product of several compounding factors that may be mitigated by adjustments to hearing coverage in this younger group. For example, with increased coverage may come increased hearing education, increased uptake of routine hearing assessments/screening, shifts in stigma around age and hearing loss as younger individuals seek hearing care, more preventative care with access to earlier hearing devices if needed/prescribed, etc. We hope that by concretely illustrating the disparities in hearing care coverage compared to both treatment costs and other paramedical services, as well as the out-of-pocket expenses incurred by those seeking treatment, we can stimulate discussion and advocacy for more hearing coverage.

Conclusion

This study evaluated individual or non-group insurance coverage for hearing care in Alberta, Canada, across eight companies for adults 18–64 years of age inclusive and provided a comparison with other common paramedical services. A considerable range and discrepancy were reported between hearing care and most paramedical services when values were corrected to equivalent benefit periods. In addition, the coverage amounts for hearing care were inconsistent with treatment costs, resulting in considerable out-of-pocket expenses for most consumers. Although the reasons for limited coverage for hearing services could only be speculated, as little information is available to the public, the potential implications of such cost-related barriers on public health are an important consideration as continued evidence is provided about the connection between hearing loss and increases in cognitive decline and dementia.

Correspondence may be directed to: William E. Hodgetts, PhD, R. Aud, Professor, Department of Communication Sciences and Disorders, University of Alberta, Edmonton, AB; tel.: 780-492-0834, 780-492-9333; e-mail: bill.hodgetts@ualberta.ca.

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What Changes Would Manitoba First Nations Like to See in the Primary Healthcare They Receive? A Qualitative Investigation

Quels changements les Premières Nations du Manitoba souhaiteraient apporter aux soins de santé primaires? Une enquête qualitative

GRACE KYOON-ACHAN, JOSÉE LAVOIE, WANDA PHILLIPS-BECK,
KATHI AVERY KINEW, NASER IBRAHIM, STEPHANIE SINCLAIR AND ALAN KATZ

Abstract

Background: First Nations (FN) have unique perspectives and experiences of health and healthcare services, which are critical to the provision of effective community-based primary healthcare (CBPHC).

Objective: This paper shares FN perspectives on primary healthcare (PHC), taking geographical, cultural and historical realities into account, to elucidate opportunities to improve current healthcare services.

Methods: Semi-structured in-depth qualitative interviews were completed with 183 residents of 8 Manitoba FN communities. Grounded theory-guided data analysis was conducted.

Results: Improving PHC performance requires delivering timely and holistic healthcare that integrates traditional health knowledge, comprehensive CBPHC increasing services such as healthcare and medical transportation, healthy food as an important preventative measure and a culturally informed workforce backed by local leadership and promoting cultural respect.

Conclusion: The relationship between self-determination and health is a critical factor in the implementation of CBPHC. FN must be respected to decide healthcare priorities that reflect the needs and visions of each community.

Résumé

Contexte : Les Premières Nations (PN) ont un point de vue et une expérience uniques quant aux services de santé, dont la compréhension est essentielle pour offrir des soins de santé primaires communautaires (SSPC) efficaces.

Objectif : Cet article vise à mieux comprendre le point de vue des PN sur les soins de santé primaires (SSP) – en tenant compte des réalités géographiques, culturelles et historiques – afin de repérer les possibilités d'amélioration pour les services de santé actuellement en place.

Méthode : Des entrevues qualitatives semi-structurées approfondies ont été menées auprès de 183 résidents de communautés autochtones du Manitoba, suivi d'une analyse des données selon la théorie ancrée.

Résultats : L'amélioration du rendement des SSP demandera une prestation des services en temps opportun et une vision holistique des soins qui intègre les connaissances traditionnelles; plus de services complets pour les SSPC, comme les transports pour raison médicale; une saine alimentation comme mesure de prévention; et une main-d'œuvre sensibilisée au respect culturel avec l'aide d'intervenants locaux.

Conclusion : Le lien entre autodétermination et santé est un facteur clé de la mise en place des SSPC. Il est important de respecter les PN dans le choix de priorités en santé qui répondent aux besoins et à la vision de chacune des communautés.

To view the full article, please visit longwoods.com/content/26069/healthcare-policy/what-changes-would-manitoba-first-nations-like-to-see-in-the-primary-healthcare-they-receive-a-qual



Development and Validation of a Brief Hospital-Based Ambulatory Patient Experience Survey (HAPES) Tool

Développement et validation d'un outil d'enquête sur l'expérience des patients ambulatoires en milieu hospitalier

SHABNAM ZIABAKHSH, ARIANNE ALBERT AND EDWINA HOULIHAN

Abstract

Recognition of the value of the patient perspective on services has led healthcare organizations to measure patient care experiences. A brief, generic and psychometrically sound scale to measure patient experiences in ambulatory/outpatient settings in Canada would be useful and is currently lacking. The purpose of this study was to develop and validate an English-language hospital-based ambulatory patient experience survey tool in a Canadian context. Based on a review of more than 20 instruments measuring experiences predominately in non-acute care settings, we initially selected 27 items to be included in the questionnaire, addressing quality dimensions of access, communication, continuity and coordination, shared decision making, emotional support, trust/confidence, privacy, patient-reported impact and physical environment. The survey instrument was subsequently tested among 1,219 ambulatory patients, and its psychometric properties were assessed. A final questionnaire was produced with 14 items and two emerging subscales: Patient–Provider Communication and Overall Quality of Experience, as determined by a factor analysis. The items within the scale showed high construct validity. Reliability was also excellent for the instrument. The applicability of this tool in supporting quality improvement initiatives is discussed.

Résumé

La reconnaissance de la valeur du point de vue du patient sur les services a mené les organisations de santé à mesurer l'expérience des patients. Il serait utile d'avoir, au Canada, une brève échelle générique et psychométriquement solide pour mesurer l'expérience des patients en consultation ambulatoire ou externe. Le but de cette étude était de développer et de valider un outil d'enquête de langue anglaise sur l'expérience des patients ambulatoires en milieu hospitalier dans un contexte canadien. Sur la base d'une analyse de plus de 20 instruments mesurant l'expérience principalement dans des établissements de soins non actifs, nous avons sélectionné 27 éléments à inclure au questionnaire et qui portent sur les aspects qualitatifs de l'accessibilité, la communication, la continuité et la coordination, la prise de décision partagée, le soutien émotionnel, la confiance, la vie privée, l'impact signalé par le patient et l'environnement physique. L'instrument d'enquête a ensuite été testé auprès de 1 219 patients ambulatoires et ses propriétés psychométriques ont été évaluées. Cela a donné lieu à un questionnaire final comportant 14 items et deux sous-échelles émergentes : la communication patient-prestataire et la qualité globale de l'expérience, telles que déterminées par l'analyse factorielle. Les éléments de l'échelle présentent une validité de construit élevée. La fiabilité de l'instrument est également excellente. L'applicabilité de cet outil aux initiatives d'amélioration de la qualité est abordée dans l'article.

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What Changes Would Manitoba First Nations Like to See in the Primary Healthcare They Receive? A Qualitative Investigation

Quels changements les Premières Nations du Manitoba souhaiteraient apporter aux soins de santé primaires? Une enquête qualitative



GRACE KYOON-ACHAN, PHD
*Research Fellow, Departments of
Community Health Sciences and Family Medicine
Max Rady College of Medicine
Rady Faculty of Health Sciences
Ongomiizwiin Research – Institute of
Indigenous Health and Healing
Winnipeg, MB*

JOSÉE LAVOIE, PHD
*Director, Manitoba First Nations Centre
for Aboriginal Health Research
Professor, Department of Community Health Science
Rady Faculty of Health Sciences
Winnipeg, MB*

WANDA PHILLIPS-BECK, RN, BN, MSC
NANAANDAWEWIGAMIG
*Nurse Manager
First Nations Health and Social Secretariat of Manitoba
Winnipeg, MB*

KATHI AVERY KINEW, PHD
NANAANDAWEWIGAMIG
*Research Manager
First Nations Health and Social Secretariat of Manitoba
Winnipeg, MB*

NASER IBRAHIM, MSC, PHD
*Research Associate
Ongomiizwin Research –
Indigenous Institute of Health and Healing
Department of Community Health Sciences
College of Medicine
University of Manitoba
Winnipeg, MB*

STEPHANIE SINCLAIR, MA
NANAANDAWEWIGAMIG
*Research Coordinator
First Nations Health and Social Secretariat of Manitoba
Winnipeg, MB*

ALAN KATZ MBCHB, MSC
*Director, Manitoba Centre for Health Policy (MCHP)
Professor, Departments of Community Health Sciences
and Family Medicine
Max Rady College of Medicine
Rady Faculty of Health Sciences
Winnipeg, MB*

Abstract

Background: First Nations (FN) have unique perspectives and experiences of health and healthcare services, which are critical to the provision of effective community-based primary healthcare (CBPHC).

Objective: This paper shares FN perspectives on primary healthcare (PHC), taking geographical, cultural and historical realities into account, to elucidate opportunities to improve current healthcare services.

Methods: Semi-structured in-depth qualitative interviews were completed with 183 residents of 8 Manitoba FN communities. Grounded theory-guided data analysis was conducted.

Results: Improving PHC performance requires delivering timely and holistic healthcare that integrates traditional health knowledge, comprehensive CBPHC increasing services such as healthcare and medical transportation, healthy food as an important preventative measure and a culturally informed workforce backed by local leadership and promoting cultural respect.

Conclusion: The relationship between self-determination and health is a critical factor in the implementation of CBPHC. FN must be respected to decide healthcare priorities that reflect the needs and visions of each community.

Résumé

Contexte : Les Premières Nations (PN) ont un point de vue et une expérience uniques quant aux services de santé, dont la compréhension est essentielle pour offrir des soins de santé primaires communautaires (SSPC) efficaces.

Objectif : Cet article vise à mieux comprendre le point de vue des PN sur les soins de santé primaires (SSP) – en tenant compte des réalités géographiques, culturelles et historiques – afin de repérer les possibilités d'amélioration pour les services de santé actuellement en place.

Méthode : Des entrevues qualitatives semi-structurées approfondies ont été menées auprès de 183 résidents de communautés autochtones du Manitoba, suivi d'une analyse des données selon la théorie ancrée.

Résultats : L'amélioration du rendement des SSP demandera une prestation des services en temps opportun et une vision holistique des soins qui intègre les connaissances traditionnelles; plus de services complets pour les SSPC, comme les transports pour raison médicale; une saine alimentation comme mesure de prévention; et une main-d'œuvre sensibilisée au respect culturel avec l'aide d'intervenants locaux.

Conclusion : Le lien entre autodétermination et santé est un facteur clé de la mise en place des SSPC. Il est important de respecter les PN dans le choix de priorités en santé qui répondent aux besoins et à la vision de chacune des communautés.

Introduction

The importance of primary healthcare (PHC) in improving overall health outcomes and healthcare experience cannot be overstated. Its capacity to support people in preventing illness and managing various conditions, thereby reducing pressure on hospitals, is well known (Beaglehole et al. 2008; Starfield et al. 2005; World Health Organization [WHO] 2008). Its usefulness, is, however contingent upon the ability to provide comprehensive and relevant preventative and disease management healthcare to individuals and communities (WHO 2008). Building on a broader understanding of the health disparities and ongoing challenges faced by First Nations (FN) communities (Freemantle et al. 2015; Martens et al. 2005; Shen et al. 2016; Smylie 2012), this article aims to (1) illuminate community-based primary healthcare (CBPHC) experiences and perspectives of FN communities in Manitoba, (2) highlight potential ways to build on existing strengths in addressing health gaps, and (3) outline key areas to collaboratively optimize culturally informed PHC based on unique models of healthcare that are influenced by the context of FN communities in Canada.

Background

Health inequities experienced by FN communities contribute to higher rates of chronic conditions. Poor quality of life and outcomes are also reflected in the continued inability to meet specific health needs due to ongoing colonization and ill-fitting policies and legislation (Alfred 2009; Allan and Smylie 2015; Brondolo et al. 2009; Browne et al. 2016; Lavallee and Poole 2010; Lavoie et al. 2010). FN access health services through a complex jurisdictional maze of federal, provincial and FN community-based services. This maze is informed by a policy and legislative patchwork that has to date failed to clarify what services FN are entitled to and from whom (Lavoie 2013; Lavoie et al. 2012, 2016). Even where there is some clarity as to what is available and who should be providing services, policies and funding do not support the effective provision of those services. To illustrate, the federal government funds, and to a limited extent delivers, a complement of CBPHC services on FN reserves. Since 1989, FN communities may have been exercising some control over their community-based health services, but this control is limited by paucity of funds (Lavoie et al. 2007). Local service delivery also faces a number of structural and personnel challenges. To begin, PHC nurses remain employed by the First Nations and Inuit Health Branch of Health Canada (FNIHB). This appears to be true for all FN communities where PHC nurses practise, with the exception of 33 FN communities in northern Saskatchewan, one community in Manitoba and, since 2013, FN communities in British Columbia who are not working with the First Nations Health Authority. For various reasons, nursing vacancy has been a long-standing problem for FNIHB, and communities depend on contracted “agency” nurses to fill in temporarily. Agency nurses, however qualified, have a limited relationship with the communities they serve and little time to develop necessary relationships (two weeks to a few months), and this way of working does not promote continuity of healthcare (Minore et al. 2001; Tarlier et al. 2007).

Methods

Study design

A community-based participatory research framework was implemented from the conception of the study, data gathering, analysis and interpretation to knowledge dissemination (Kyoon-Achan et al. 2018). The study was guided by grounded theory (Charmaz 2006; Engward 2013). Qualitative and Indigenous methods were appropriate, in that these adopt a decolonizing approach, are storied and are collaborative. Semi-structured and open-ended interviews encouraged expanded responses to questions (Chatwood et al. 2015; Chilisa 2012; Flicker et al. 2015; Kite and Davy 2015; Smith 1999). Interviews were completed between April 2014 and December 2015.

Ethics

Ethics approvals were granted by the University of Manitoba Research Ethics Board and First Nations Health Information Research Governance Committee (HIRGC). HIRGC oversees ethics processes on behalf of Manitoba FN. Data collectors obtained written informed consent from respective communities and individuals prior to conducting interviews. In keeping with FN research ethics principles, agreements signed between the communities and researchers outlined community protocols within the parameters of ownership, control, access and possession of data. These principles are intended to regulate and guide research involving FN peoples, to ensure research is conducted respectfully and meaningfully for and with FN (National Aboriginal Health Organization First Nations Centre 2007).

Participants

Participants included 8 of 63 FN communities in Manitoba, representing four of five local languages – Dakota, Dene, Cree and Ojibwe. Each community indicated interest to participate through a written Band Council Resolution. Selection was based on tribal origin, geography, size, governance and health delivery model, that is, nursing stations and health centres. Access to PHC varies with each model. Nursing stations are nurse-managed and provide limited PHC services. Health centres generally provide health promotional information and minimal public health services.

Data collection and analysis

Purposive sampling targeted male and female community members, FN and non-FN healthcare workers, health services users and elders. In all, 183 key informant interviews and three focus groups were completed across all communities. A small community of about 800 people conducted 10 interviews, and four other small and medium communities of fewer than 3,000 people conducted about 20 key informant interviews. Further, three larger

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communities of up to 5,000 people each had 30 interviews and focus groups, and the largest community of 8,000 people had over 50 interviews. Local research assistants were trained to collect data and translated questions and responses into respective local languages or English as necessary. Interviews were audio-recorded, transcribed verbatim and sent back to communities for validation. (For research questions, see Appendix A at the end of this document). Preliminary analysis was completed manually by two university-based researchers, a nurse research manager and a policy analyst at First Nations Health and Social Secretariat of Manitoba (FNHSSM) using an open coding system to identify key ideas and themes. Preliminary results were presented to respondents and community members at community data presentation sessions in each participating community. In this way, all communities co-interpreted and validated their data, highlighting key ideas and messages. In so doing, we significantly reduced the “researcher effect” on the analysis (Miles and Huberman 1994). Data were organized by participating communities and by interview questions, then uploaded. Results were developed from both interview data and discussions that had taken place during community data presentation and validation sessions.

Results

Elements to improve quality primary healthcare for FN

The following themes represent common and majority views of all eight participating communities. They sum up the stated CBPHC needs of the respondents.

Redefining quality healthcare

Timely access to whole person healthcare was said to be crucial. Respondents maintained that in accordance with traditional teachings, health results from a balance of the physical, spiritual, emotional and mental aspects of a person, and healthcare needs to recognize and take that approach in providing healthcare to FN patients.

Quality healthcare means that we are meeting the needs of the community; individuals, families and community in a holistic way. So, we are meeting not just their physical health, but their emotional and their spiritual health ... because there is such a history of colonization, the residential schools, all of that soul sickness. We need to address all that. (A001)

It’s just being timely [care]. As long as you know you can get in and within a reasonable amount of time. (E004)

Respondents considered quality healthcare to be how quickly they could access needed care within or outside their communities, and whether the care given took a holistic rather than fragmented approach.

Inequity in resources and equipment

Respondents worried that they may not currently have access to qualified healthcare providers or updated technologies. Thus, they feared possible inaccurate diagnosis and erroneous treatments as a result. One respondent said,

The X-ray machine is so old that they can't even get an accurate picture sometimes ... they send first-year students to use our community as guinea pigs and that's not right. That was my only beef with our nursing station here; they send first-year student to diagnose our people and all the equipment here is old. They need to update them. (GFG004-1)

Respondents expressed the need for better technology, advanced equipment and qualified providers to support diagnosis and treatments as part of improving CBPHC. Many were concerned they might continue to receive substandard PHC unless qualified providers were retained and equipment frequently updated.

Community-based healthcare

Respondents wanted care brought closer to their communities, so members did not have to leave their communities and families for extended periods to access healthcare in towns and cities. They described quality healthcare as "... getting the services that we require and not having to relocate" (B006). Personal difficulties were reported when accessing healthcare off-reserve, which include leaving young children, spouses and aged parents behind; not having family members or friends to accompany patients; feeling lonely and confused in urban centres; and managing illnesses while struggling to navigate larger, unfamiliar health centres and hospital environments.

That's scary for a lot of people ... especially elderly persons, they don't even know how to speak the language, English or whatever they speak, they don't know. And then they don't know where they're going. It's hard for us. Especially when you get shoved out alone, by yourself. A lot of times I was taken out by myself, nobody was with me. I didn't know the city, nothing, I was just there. And then we didn't get to my room until 2 o'clock in the morning ... it's hard. (G002)

This situation was said to be even more difficult for elderly persons travelling alone, some of whom do not speak English and may feel disoriented just by leaving familiar environments.

Homecare

Elders relocating for long-term and/or palliative care were said to leave a vacuum in the community. Echoing others, one respondent emphatically stated, "We don't want to leave;

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we don't want our Elders to leave" (C006). Another expressed being disheartened when elders have to be transported out of their homes for healthcare in facilities far away from their families.

There's a lot of our Elders that are in personal healthcare homes far from the reserve whereas a lot of family members have a hard time getting to them even just to visit on a daily visit. If we had a personal care home here it would be more access to not only immediate family but like grandchildren, friends and relatives to visit on a daily basis. (H002)

Conversely, many expressed concern that elders who remain in communities often do not have adequate care when they have to be confined to their homes because of illness, suggesting that an investment in homecare presents a real opportunity to improve CBPHC. All communities wanted "Elders' lodges" with more healthcare aides in each FN community, so elders could be at home, closer to family and friends, to be cared for within an appropriate cultural context.

Medical transportation

Respondents said getting to and from healthcare facilities off-reserve or even within the community can be difficult for those without a means of transportation. Most communities do not have taxis, public transportation system or ambulance services. Many respondents wanted medical transportation service or, where it already existed, more and better vehicles with drivers.

Well to me, why I find it [medical transportation] a big part of our First Nations, just helping with transportation to and from your medical appointments ... to many resources that are off-reserve. (B017)

[W]hy don't [this community] have their own ambulance ... ? They should have somebody there all the time on call. (D002)

Some communities had one van to service the entire population, ranging from fewer than 1,000 in small communities to over 8,000 people in larger ones. Some did not have drivers around the clock to transport patients in emergencies. It was suggested that increasing the number of vehicles and drivers per community could ensure timely transportation to health facilities on- and off-reserves for more people, potentially improving access to healthcare and reducing cost of medical evacuations otherwise.

Supports when accessing healthcare off-reserves

Respondents pointed to the need for better accommodations and adequate emotional

supports when leaving for healthcare outside FN communities. They reported difficulties associated with leaving to receive care in provincial facilities located off-reserve.

Better accommodations, not just Third World conditions when we have to go to a hotel and it's full of bugs or something like that, where we're treated like third-class citizens ... The whole thing of going out of town on day [medical] trips, needs to be examined and things have to change. People have to be dealt with fairly. (A009)

I was very very upset. Where was I going to go? I had no money, I had no room. Where was I supposed to go? I had eye patches on my eyes and I couldn't take care of myself. I couldn't. Someone had to lead me around. I couldn't take care of myself. That was very very upsetting to know that there was no room available for me. And then they try and shove you in a place that nobody would want to sleep at. (B009)

Others mentioned not having adequate food allowances while receiving treatment off-reserve and going hungry. Respondents continued to be upset long after returning to their home communities and remained fearful of leaving again for healthcare or trusting arrangements made on their behalf.

Healthy food

Access to affordable healthy food was reported to be of high priority for FN health improvement. Respondents reported either not being able to afford healthy food options or nutritious food simply not being available for purchase in community grocery stores. One respondent lamented the state of food in his community:

I do have access of course to the grocery stores and what's provided is what people buy. I understand that and that's the way the system works. It upsets me that there is not more healthy food provided. It upsets me that food is not subsidised in northern communities, that food security is such an issue, that the food that's available is garbage, it's not food. Its food-like products. I feel incredibly strongly about that. Also, when you're unhappy you're going to eat food that makes you feel better, so those are the foods that are high in sugar, high in salt, high in fat and that's what people go for, right. It's cause they're self-medicating. I think that [healthy food] is a huge contribution to the health and well-being of the community. (A001)

A clear association is made between food and health. It was suggested that people will purchase healthy food when those options are available and affordable. They will otherwise rely on unhealthy alternatives, which may also be used to soothe negative emotions when facing difficult life circumstances.

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More and better prepared health workers

Respondents called for additional health workers in their communities so as to reduce wait times and improve local access to care.

Having access to a doctor instead of having to wait four months, have a doctor here in the community. To have what the south has, dentist, doctors, and specialists in the community. Easy access to it at least and not wait, forever. When somebody is sick [in the community], they wait for five months. They could get more sick. In the four or five months the problem might be too late ... those kind of services would help. (F002)

More training and certification were also requested to increase the skills of community-based service providers.

Promoting continuity of care through cultural orientations

Respondents also want all health workers to be adequately oriented to community-based contexts. This, they said, would facilitate communication and promote continuity of care. Respondents discussed the current state of affairs in some communities.

There's probably one full-time nurse that lives in the community ... to fill in the gaps are the agency nurses that come in from different places and there's just lack of consistency for clients. They [agency nurses] don't know the clients; they don't know the community, and then the clients or the patients have to tell their whole story again in a 15-minute span. So the consistency is not there when we have agency nurses coming in or when it's not fully staffed. (GFG004-1)

Agency nurses, because of their short stay, may not develop the relationships needed for continuity of care. Although perhaps an adequate stop-gap measure, the system's reliance on agency nurses is problematic for long-term, culturally safe healthcare delivery. Appropriate contextual understanding of the history, culture, language and ongoing experiences and maintenance of consistent provider–patient relationships were desired. In the absence of these, misunderstandings and missed information, which could prove costly to individuals' health, may result.

Local leadership

The role of band council leadership in healthcare decision-making was also emphasized. One respondent echoed others in saying:

Our Chief and Council need to be more involved in the health services to make the health services delivery better. They need to be there to speak up for the community. (C007)

Community leadership is seen as advocating for and negotiating healthcare on behalf of communities. Respondents want their leaders to articulate needs and seek resources to support the health of the community by sitting at relevant policy and implementation tables within local, regional and national health authorities. This is not yet the case for many FN communities; therefore, their perspectives are often missed.

Jurisdictional cooperation

Respondents argued that jurisdictional confusions create difficulties in collaboratively delivering health programs in FN communities.

For me, I would like to tap into the provincial services more where mental health is concerned. [However] in order for me to tap into provincial services, I would have to relocate my client [off-reserve] because we are federal here and we can't tap into provincial services because of where we are. That's why if I want to tap into provincial services, I would have to relocate my client. That is, it can't be done, especially for mental health. (B006)

Respondents suggested that fewer restrictions and more intentional cooperation policies from federal and provincial jurisdictions would allow for better resource sharing and access for patients.

Integrating traditional health knowledge

Several respondents called for recognition and collaboration between conventional medicine and traditional health knowledge.

An integrated health centre ..., so you would have your doctors, you would have your nurses, you would have your diagnostic things, but you would also have your traditional people working alongside in the same building. And you have all of these things where you can have traditional healers coming in, you can have traditional work being done, ceremony being done, in the same building where you have your nurses and your doctors and your social workers and whatever, an integrated approach where you can have both working alongside ... That collaboration is essential. I don't think you can have two separate organizations working towards the health of the community independently. I think they need to come together and be integrated. (A001)

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Endorsement of this collaborative system will mean that communities are equally supported to access both options seamlessly as needed without associated discouragements, guilt or shame as currently tends to be the case.

Focus on the community

Respondents also envisioned a PHC system that places community at the centre of health-care, “a system that’s responsive to those served” (C008). It was said that all PHC providers within this system would make an effort to understand the histories, experiences, geographical limitations and opportunities of the people they serve. An absence of such understanding is seen as leaving room for harmful assumptions and stereotypes leading to discrimination and poorly delivered healthcare.

Discussion

Creating a functional primary healthcare system for FN

Primary healthcare principles advocate for individuals, communities and countries to define and create what health and well-being means for them (WHO 2008). The implicit position is that with the right supports in place, individuals and communities can chart appropriate courses of action toward attaining and sustaining optimal health (Browne et al. 2016; Eggington 2012; Greenwood et al. 2015). It is clear from the results in this study that FN communities know what factors would contribute toward their health. However, appropriate and adequate supports are required to improve CBPHC and the health of the communities. A recent report has again stated the need for supports, echoing others before it (Missing and Murdered Indigenous Women and Girls 2019). It emphasizes the need for timely access to comprehensive healthcare and adequate resources to support structures and initiatives aimed at prevention and public health. It also emphasizes the recognition and incorporation of traditional health knowledge (THK) as necessary in the pursuit of holistic health for FN people. THK is an existing and vibrant part of community-based PHC, with many turning to traditional medicines, practices and knowledge to prevent and/or treat diseases. However, this existing system is neither supported by nor integrated into the formal system (Letendre 2002). This gnawing gap still exists in the health and healthcare services of FN peoples and communities (Kyoon-Achan et al. 2019). It can be addressed by reviewing and updating relevant policies (Lavoie 2018).

Basically, the FN communities that participated in this study have made calls that align with the Truth and Reconciliation Call to Action #18 to “recognize and implement the healthcare rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties” (Truth and Reconciliation Commission of Canada [TRC] 2015). The recommendation to improve cultural orientations of healthcare workers in FN communities also addresses the TRC Call to Action #28, which recommends education for

professionals working with FN people to “... include the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, Indigenous law, and Aboriginal–Crown relations. This will require skills-based training in intercultural competency, conflict resolution, human rights, and antiracism” (TRC 2015). Although many of these recommendations have previously been made by others (Browne et al. 2016; Haggerty et al. 2018; Katz et al. 2017; Lavoie 2013; Lavoie et al. 2007), these do not appear to have been heeded considering the continued dismal health indices. The missing link appears to be a stark lack of policy action. The Manitoba FN who participated in this study have once again clearly identified areas of actionable change. A real opportunity lies in implementation. We therefore call on Indigenous and non-Indigenous healthcare policy experts to consider these viewpoints in planning a new direction for FN health.

Study limitations

The study included 8 of 63 FN communities and does not claim to speak for all FN communities.

Future Research

Jurisdictional cooperation between federal and provincial health systems and services, if done intentionally, can potentially transform CBPHC and significantly improve healthcare delivery to FN peoples and communities. This relationship as well as specific areas of active cooperation beyond funding agreements can and should be studied to provide evidence-based cooperative strategies to both jurisdictions.

Implications

Acting on the findings of this study could significantly improve the current CBPHC landscape in FN communities. First, the federal and provincial jurisdictions should work collaboratively to address existing jurisdictional barriers to adequate healthcare delivery for FN patients. Removing confusing jurisdictional bureaucracy when navigating healthcare services, for both patients and healthcare providers, will increase access to relevant primary and specialized healthcare. Second, health human resource planning and development will ensure that current vacancies are filled with qualified workers in FN communities. A long-term strategy to eliminate this gap is to train FN people who will commit to long-term service in their own communities. This strategy, besides reducing attrition rates and promoting continuity of care, presents the additional benefit that FN health workers already know the contexts and can implement culturally safe healthcare delivery. Third, owing to the different models of healthcare in FN communities, ongoing collaboration with regional health authorities and other healthcare facilities is necessary to augment the services available in communities. These relationships can be negotiated and reviewed on a regular basis for

continued learning and improvement. Finally, FN leaders, chiefs and councils should be represented at all levels of healthcare planning and implementation, so as to provide context and articulate specific conditions and needs of the people.

Correspondence may be directed to: Alan Katz, MBChB, MSc, CCFP, Director, Manitoba Centre for Health Policy (MCHP), Professor, Departments of Community Health Sciences and Family Medicine, Max Rady College of Medicine, Rady Faculty of Health Sciences, 408-727 McDermot Avenue, Winnipeg, MB R3E 3P5; tel.: 204-789-3442; fax: 204-789-3910; e-mail: Alan_Katz@cpe.umanitoba.ca.

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Development and Validation of a Brief Hospital-Based Ambulatory Patient Experience Survey Tool

Développement et validation d'un outil d'enquête sur l'expérience des patients ambulatoires en milieu hospitalier



SHABNAM ZIABAKHSH, PHD
Evaluation Specialist
BC Women's Hospital + Health Centre
Vancouver, BC

ARIANNE ALBERT, PHD
Biostatistician
Women's Health Research Institute
Vancouver, BC
Adjunct Associate Professor
University of British Columbia
Vancouver, BC

EDWINA HOULIHAN, RN, BSCN, MBA
Senior Director, Patient Care Services
BC Women's Hospital + Health Centre
Vancouver, BC

Abstract

Recognition of the value of the patient perspective on services has led healthcare organizations to measure patient care experiences. A brief, generic and psychometrically sound scale to measure patient experiences in ambulatory/outpatient settings in Canada would be useful and is currently lacking. The purpose of this study was to develop and validate an English-language hospital-based ambulatory patient experience survey tool in a Canadian context.

Based on a review of more than 20 instruments measuring experiences predominately in non-acute care settings, we initially selected 27 items to be included in the questionnaire, addressing quality dimensions of access, communication, continuity and coordination, shared decision making, emotional support, trust/confidence, privacy, patient-reported impact and physical environment. The survey instrument was subsequently tested among 1,219 ambulatory patients, and its psychometric properties were assessed. A final questionnaire was produced with 14 items and two emerging subscales: Patient–Provider Communication and Overall Quality of Experience, as determined by a factor analysis. The items within the scale showed high construct validity. Reliability was also excellent for the instrument. The applicability of this tool in supporting quality improvement initiatives is discussed.

Résumé

La reconnaissance de la valeur du point de vue du patient sur les services a mené les organisations de santé à mesurer l'expérience des patients. Il serait utile d'avoir, au Canada, une brève échelle générique et psychométriquement solide pour mesurer l'expérience des patients en consultation ambulatoire ou externe. Le but de cette étude était de développer et de valider un outil d'enquête de langue anglaise sur l'expérience des patients ambulatoires en milieu hospitalier dans un contexte canadien. Sur la base d'une analyse de plus de 20 instruments mesurant l'expérience principalement dans des établissements de soins non actifs, nous avons sélectionné 27 éléments à inclure au questionnaire et qui portent sur les aspects qualitatifs de l'accessibilité, la communication, la continuité et la coordination, la prise de décision partagée, le soutien émotionnel, la confiance, la vie privée, l'impact signalé par le patient et l'environnement physique. L'instrument d'enquête a ensuite été testé auprès de 1 219 patients ambulatoires et ses propriétés psychométriques ont été évaluées. Cela a donné lieu à un questionnaire final comportant 14 items et deux sous-échelles émergentes : la communication patient-prestataire et la qualité globale de l'expérience, telles que déterminées par l'analyse factorielle. Les éléments de l'échelle présentent une validité de construit élevée. La fiabilité de l'instrument est également excellente. L'applicabilité de cet outil aux initiatives d'amélioration de la qualité est abordée dans l'article.

Introduction

In the past two decades, the focus of patient feedback tools has shifted from probing about “satisfaction” to inquiring about “experiences” (Cleary 1999; Doyle et al. 2013; LaVela and Gallan 2014). While satisfaction surveys measure attitudes about care, they say very little about the nature of the services received. Experience surveys, on the other hand, focus on whether processes or events occurred during the care encounter, providing more actionable insights (Jenkinson et al. 2002). Patient experience refers to any process perceptible by patients. This can include subjective experiences (e.g., felt supported), objective experiences (e.g., waited 15 minutes) and observable experiences (e.g., answered questions; Price et al. 2014). Regardless of how experiences are processed, likely filtered through a subjective

experience lens (LaVela and Gallan 2014), research has shown that better patient care experiences are associated with higher levels of adherence to treatment, better clinical outcomes, better safety and less care utilization (Boulding et al. 2011; Doyle et al. 2013; Glickman et al. 2010; Issac et al. 2010; Price et al. 2014).

The importance of capturing patient voice has led organizations to measure and monitor patient care experiences. Continuous monitoring of patient experiences using self-reported tools, combined with feedback mechanisms to managers and healthcare providers, can lead to service improvements and a culture of quality and patient engagement (Boyer et al. 2006; Jangland et al. 2012; Larsen 2011; Rogers and Smith 1999). Using patient feedback for improvement does require a concerted effort, often requiring an existing culture of quality improvement to support potential changes (Davies and Cleary 2005; Luxford and Sutton 2014) and a robust feedback mechanism for service providers involving structured debriefing activities (Larsen 2011).

Having a validated and standardized tool to measure hospital ambulatory (outpatient) experiences is timely, especially in light of standardization of patient experience measurement across acute settings in Canada (Canadian Institute for Health Information [CIHI] 2014). Despite a number of patient experience tools that measure care in both primary and some ambulatory settings, to our knowledge, a brief, validated and generic instrument that measures hospital ambulatory experiences is currently lacking in Canada. The standardized tools that do exist are often lengthy, not generic (Benson and Potts 2014; Sjetne et al. 2011), may have a primary care focus and may lack the important dimensions of patient experience (Sjetne et al. 2011; Wong and Haggerty 2013).

Wong and Haggerty (2013) identified a need for a standardized tool to measure patient experiences in the primary healthcare system in Canada. We argue that the need can be extended to the ambulatory settings. Ambulatory/outpatient care is distinct from primary care in that ambulatory patients may receive care from a team of specialized care providers, patients may visit different providers at each care encounter and care is often discontinuous, with the expectation that patients will return to their primary care provider for ongoing support.

Looking at existing non-acute survey tools, a few are notable. The Picker's ambulatory surveys often have between 60 and 100 questions, depending on the patient population (NRC+Picker 2003; Picker Institute Europe 2015). Survey length is a major barrier to survey completion, often contributing to survey fatigue and low response rates (Benson and Potts 2014; Haggerty et al. 2011a; Hojat et al. 2011; Patwardhan and Spencer 2012; Sjetne et al. 2011). Shorter tools sometimes used in ambulatory settings have a predominately primary care focus. The CAHPS Clinician and Group Survey, one of the widely used surveys in the US, and also used in ambulatory clinics, is a 31-item questionnaire with provider-specific questions, including questions regarding relational continuity (e.g., "Is this the provider you usually see if you need a checkup, want advice about a health problem or get sick or hurt?"; AHRQ 2015). The 34-item Massachusetts Ambulatory Care Experiences

Survey, despite its name, has also a primary care focus, with most questions framed toward “your personal doctor” (Safran et al. 2006). The General Practice Assessment Questionnaire, widely used in the UK, consists of 46 items and, as the name implies, focuses on patients’ primary care experiences. Benson’s and Potts’ (2014) howRwe tool is a very brief (four-item) tool that can be used in a variety of care contexts for continuous feedback but does not address all of the experience quality dimensions important to patients (Price et al. 2014).

Hence, there is a need for a validated, ambulatory-focused instrument that is brief, comprehensive and yet generic enough to be used across a wide range of ambulatory clinics. This article describes the development and validation of an English-language hospital-based ambulatory patient experience survey tool in one Canadian context.

Methods

Questionnaire development

Existing validated patient experience tools used in non-acute care settings were reviewed. This review was predominately informed by the work of Wong and Haggerty (2013), who conducted a scoping review and identified 17 publicly available instruments from Canada, the UK and the US that measure patients’ experiences in non-acute care settings, including the CAHPS Clinician and Group Survey, the Ambulatory Care Experiences Survey and the General Practice Assessment Questionnaire. In particular, the 87 questions they selected as the result of their review and deemed as important in capturing dimensions of patient experience were assessed. In addition to the instruments/questions identified by Wong and Haggerty, a number of publicly available tools were identified and reviewed, namely, the Ontario Primary Care Patient Experience Survey (Health Quality Ontario [HQO] 2015), the Australian Bureau of Statistics (2014) Survey, the Massachusetts Health Quality Partners (2009) Survey, the Communication Assessment Tool (Makoul et al. 2007) and the Patient Experience Questionnaire (Steine et al. 2001). The review also included the Canadian Institute for Health Information’s (2014) Canadian Patient Experiences Survey. This tool, developed to support pan-Canadian comparisons of acute patient experiences, is currently being used in many health jurisdictions across Canada. Due to the relevancy of this tool in the Canadian context, it was important to explore its potential for adaptation to the ambulatory/outpatient setting. In fact, all of the survey instruments noted earlier were reviewed for applicable questions across a wide variety of ambulatory/outpatient environments.

Questions from the above-mentioned survey tools were compiled and organized by the following experience domains: access, communication, continuity and coordination, shared decision-making, emotional support, trust/confidence, privacy, patient-reported impact, physical environment and overall assessment/satisfaction. These domains are similar to the quality dimensions proposed in the literature, namely, the Picker Institute’s dimensions

of patient-centred care (Gerteis et al. 2005; Jenkinson et al. 2002; Kitson et al. 2012). Questions pertaining to in-patient care (e.g., response time to call bell) were omitted from this compilation.

A working group ($n = 9$) comprising BC Women's Hospital + Health Centre (BC Women's) managers and directors was formed. A few members of the working group had clinical backgrounds and were involved in direct patient care in their previous roles. Some of the members were public health professionals. One manager was a quality and system improvement expert, and a few of the working group members were involved in research and had expertise in questionnaire development. Working group members reviewed each question and voted on its inclusion/exclusion via a modified Delphi process (Hagen et al. 2008). Voting was done in private; individuals selected the items they favoured to keep and sent their choices back to the first author. The instruction was to keep at least one item from each experience domain (e.g., communication). Results of the voting rounds were presented to the group, followed by discussion to reach consensus on which questions to retain and how to best modify/adapt them as necessary. Three rounds of voting and discussion resulted in the inclusion of 23 questions. Another four questions were added to the questionnaire related to the use of interpretive services, ease of wayfinding and the "Hello, My Name Is" campaign, an initiative to encourage providers to introduce themselves by name to establish rapport and show respect (National Health Service [NHS] 2013).

Many of these questions were selected and/or modified to address patient care and flow in ambulatory environments. For example, questions pertaining to "communication between team members," "coordination of appointments," "provider introducing himself/herself by name" and "wayfinding" are particularly relevant in hospital ambulatory care settings. Other questions were not selected due to their primary care focus (e.g., "How often were you taken care of by the same person?" "When you made an appointment for a checkup or routine care with this provider, how often did you get an appointment as soon as you needed?"). Some of the questions were also *rephrased* to ask about *experience* as opposed to satisfaction. Response scales were similarly kept consistent across questions, as much as possible, for ease of completion. The response categories of "yes," "somewhat" and "no" were opted wherever applicable (Jenkinson et al. 2002) because experience, as opposed to satisfaction (e.g., excellent, very good), was mainly assessed. Furthermore, the frequency of care (e.g., always, sometimes), often gauged in acute and primary care surveys (CIHI 2014; HQO 2015), was not evaluated because in ambulatory settings, patients' contact with healthcare providers and staff may be time-limited.

The resulting questionnaire included questions addressing access, environment, continuity and coordination, communication, shared decision-making, emotional support, trust/confidence, privacy, self-reported impact and overall assessment dimensions that are deemed as important for measuring patient experience (Gerteis et al. 1993; Price et al. 2014; Wong and Haggerty 2013).

The new 27-item questionnaire was pretested with 20 patients from various BC Women's ambulatory clinics. The instrument was pretested in English. After survey completion, patients were asked about length, flow, clarity, simplicity and importance. For example, questions regarding importance included the following: "Were the questions included important to ask?" "Anything about your experience that we did not ask in the survey?" All of the patients provided favourable responses and viewed all questions as relevant. After the pretest, minor revisions (wording changes) were made to the survey, and no changes were made to the flow or order of the questions. Table 1 (available at www.longwoods.com/content/26068) shows the final questionnaire before psychometric testing, including the instrument from which the questions originated or were adapted from and the service/care domain these represent.

Participants and procedures

The paper survey was distributed to all unique patients who visited BC Women's ambulatory clinics in the month of October 2016. BC Women's ambulatory clinics, with over 30 outpatient clinics and approximately 60,000 patient visits annually, provide diverse services ranging from high-risk maternity care and diagnostics (e.g., Diabetes Clinic, Hematology Clinic, Internal Medicine), gynecology, sexual and reproductive health (e.g., Recurrent Pregnancy Loss Clinic, Continence Clinic, Abortion and Counselling Services) and specialty services such as medical genetics, HIV care, complex chronic diseases program, heart health program and health services for new immigrants. The questionnaire was distributed at the time of check-in by clerical staff at each of the ambulatory clinics. Patients were instructed to complete the anonymous survey after their visit (on-site) and to place the completed survey in designated collection boxes. Patients who had already completed the survey during the survey month were not asked to complete it again. Staff were fully briefed and trained before survey launch. In total, 1,411 surveys were completed, resulting in a 55% response rate.

Data preparation

Among the 1,411 returned surveys, the second page was not completed (Questions 15 to 27) in 192 (14%) of the cases. Hence, those surveys were excluded from further analysis, bringing the survey count to 1,219. Questions that had more than 10% of missing or non-applicable responses or had categorical responses were removed from the subsequent factor analysis (see Table 2 for description, available at www.longwoods.com/content/26068). However, questions omitted from the analysis do not necessarily need to be removed from the survey (Floyd and Widaman 1995; van der Eijk et al. 2012). All remaining ordinal or binomial items were used in the factor analysis, except the overall assessment questions (Questions 26 and 27).

Data analysis

Psychometric properties of the survey tool were assessed using exploratory factor analysis (EFA) to reveal underlying constructs and to calculate construct validity and internal reliability. All analyses were carried out in R version 3.5.0 (R Core Team 2018). The EFA was based on polychoric correlations because the items were mostly ordinal with three or five options (Revelle 2016). The polychoric correlation matrix was used in a minimum residual factor analysis with oblique rotation. The number of factors to include was chosen using a combination of the very simple structure criterion (Revelle and Rocklin 1979) and the Velicer (1976) minimum average partial criterion. Any items with < 0.3 loading on any factor were removed, and the factor analysis was rerun until all items had loadings ≥ 0.3 on a factor.

Once factors (scales) were identified, scale scores were constructed by summing the values of the items that were included in that scale. If the scale contained items with different numbers of possible responses, the values of the responses were centred and scaled before summation. Validity was assessed by calculating a Spearman's ranked correlation between the scale scores and the overall experience rating (Question 26). Correlation would suggest that the scales are measuring experience in a meaningful way. Construct validity was also assessed by determining the strength of the relationship between all individual questions and the overall experience score. This allowed further assessment of the merit of the questions that were not pulled into any scale. Polyserial correlations were calculated assuming ordinal, binary or categorical structure of the items where appropriate. Question 24 (on courtesy and respect) was excluded because of lack of variance in the responses, with 1,179 (96.7%) responding that they had been treated with courtesy and respect.

Internal reliability was evaluated using ordinal alpha, as calculated from polychoric correlations (Zumbo 2007) for the overall instrument and within each identified scale. An alpha value of > 0.70 was considered an indication of reliability.

This study was conducted for quality improvement and monitoring and, therefore, did not fall under the scope of the Research Ethics Board, as per the University of British Columbia Guidance notes, Article 4.4.1 and Tri-Council Policy Statement 2 (TCPS2) Article 2.5. However, verbal consent was gathered by the clerical staff at the time of survey distribution. Data collection occurred in accordance with the agency's privacy laws.

Results

Factor structure

After two rounds of EFA, 14 items remained in the analysis. Two factors emerged as the best solution by the very simple structure criterion and one factor by the Velicer minimum average partial criterion. However, the two-factor solution makes the most sense from a construct validity perspective. The first factor contains Items 13, 15, 16, 17, 18, 19, 21, 22 and

23 and relates to provider–patient communication. The second factor contains Items 1, 2, 6, 8 and 24 and relates to the quality of the experience in relation to operations and interaction with providers. Table 2 gives a summary of the item loadings on the factors.

Construct validity

There was a strong and significant negative correlation between the scale scores and the overall experience score (Question 26; Factor 1 Spearman's $\rho = -0.38$, $p = < 0.0001$, and Factor 2 Spearman's $\rho = -0.51$, $p = < 0.0001$). The correlation is negative because the scale scores are higher for those who had a worse experience.

In addition, polyserial correlations were calculated for all survey items with the overall experience score (Question 26; Table 2). Most of the correlations are negative because the items are scored such that increasing scores indicated poorer experiences. The two exceptions were Questions 5 and 25, which were reverse scored relative to the other items. The strongest item correlations with overall experience were for Question 21 (“Did you feel supported by the clinic team?”) and Question 23 (“Did you have confidence in the healthcare provider(s) treating you at the clinic?”). Most items had fairly high correlations with overall experience (> 0.3), whereas only four items had correlations lower than 0.2 (Questions 5, 10, 11 and 12). These questions include wayfinding, the need for interpretation and introduction of health-care provider by name.

Internal reliability

Overall ordinal alpha, for all 14 items, was 0.91. For the first scale, the ordinal alpha was 0.90, and for the second scale, the ordinal alpha was 0.83 (Table 2), indicating very good internal reliability of these scales.

Discussion and Conclusion

Following a review of existing non-acute patient experience survey tools, a valid instrument to measure ambulatory patient experiences was developed. This 14-item tool, with its two subscales – Patient–Provider Communication and Overall Quality of Experience (both covering provider and operational issues) – is brief and can be completed quickly (in five minutes) in waiting rooms. The items within the scale showed strong correlation with the overall experience score, suggesting that the scale has high construct validity, measuring some aspect of positive care experience. Reliability is also excellent for the instrument as a whole and within its subscales. Furthermore, the low proportion of missing or “not applicable” responses of the items retained in the scale indicates good acceptability and applicability of this tool across a wide range of health services – making it suitable as a generic tool (Sjetne et al. 2011).

The success of experience measurement tools lies in the extent to which these reflect what matters most to patients (LaVela and Gallan 2014). Both patient–provider communication and interaction are important components of experience (Dang et al. 2012) that were captured by this tool. The Patient–Provider Communication subscale measures the

communication aspects of the clinical encounter, whereas the Overall Quality of Experience subscale includes items related to the quality of patient–provider/staff interaction, in terms of feeling respected and having a positive first contact. Results showed that the strongest item correlation with overall experience was the question on “feeling supported.” This finding concurs with other studies that have shown patient–provider interaction far exceeding other components of experience in terms of predicting positive patient experiences (Dang et al. 2012; Sjetne et al. 2011; Steine et al. 2001; Van de Ven 2014). The importance of patient–provider communication for promoting treatment adherence and improved health outcomes has also been well documented (Gordon et al. 2007; Street et al. 2009; Zolnierek and Dimatteo 2009). Hence, the fact that conceptually we are measuring what matters most to patients in their care experience provides weight to the relevancy of this scale.

Implications for practice and policy

Decision-makers need to provide directions to support site- and agency-wide patient experience surveys and initiatives. Ideally, the measurement systems should be consistent and used across organizations, have scientific rigour, be brief and generic to be accepted and applicable in a variety of settings and should be translated into quality improvement plans and inform the delivery of patient-centred care. Given the move toward standardization of in-patient experience survey in Canada (CIHI 2014), a validated hospital-based ambulatory survey tool becomes all the more timely.

The value of having a validated patient experience survey tool lies in not only how well it is implemented (e.g., in terms of appropriate sampling and response rate) but also the extent to which the findings are used in patient improvement initiatives (Patwardhan and Spencer 2012). Often a quality improvement culture becomes a prerequisite to organizational change; otherwise, surveys may be used as accountability checks, without any meaningful improvement intentions behind them. Coulter and colleagues (2014) argued that “it is unethical to ask patients to comment on experiences if these comments are going to be ignored” (p. 3). They further argued that only a limited number of hospitals take actions on patient experience survey findings. Factors that increase an organization’s likelihood to make changes as a result of patient feedback include commitment of leadership, clarity of objectives, identification of champions, patient and family engagement, skillfulness of staff, training and capacity, availability of resources and depth of understanding of the patient perspectives (Luxford et al. 2011). Hence, it is not enough to just have the right tool and use the right methods, but to also have a plan of action within a culture that supports patient-centred improvements.

Limitations and future research directions

This study has several limitations. The results are based on a single organization, which may limit generalizability, although the services at BC Women’s are quite diverse, with over

30 clinics that serve both pregnant and non-pregnant women and their families. Nonetheless, the vast majority of patients at BC Women's are women, requiring further investigation of the acceptability of this tool in other populations and ambulatory settings.

The survey was pretested with patients before survey launch, but the initial questionnaire development phase could have been strengthened from participation of patients in the survey instrument review process. Patients were not included in this process due to the level of time commitment it would have required. However, the working group members often put on their patient hats and/or their review took shape in the context of patient/family feedback they had received as seasoned managers and leaders. Nonetheless, it can be argued that the working group members may have been more inclined to select survey questions pertaining to the areas that they could impact and improve upon. Given that few organizations take actions based on survey data (Coulter et al. 2014), survey selection being tainted by its actionability may not necessarily be a bad thing. Yet, a more balanced approach would be to include the patient voice early on in the survey development process, as it is consistent with a more patient-centred approach (Stevenson 2002).

Pretesting of the survey with patients (once it was developed) yielded positive feedback, and patients deemed all of the selected questions as very important. However, cognitive or "think-aloud" interviewing with patients during pretesting in order to gain a more in-depth understanding of how they comprehend and respond to survey questions would have benefited the pretesting and is highly recommended for any future survey development work (Willis and Artino 2013). The next iteration of this tool should ideally include both cognitive interviewing and patient engagement in question selection and prioritization.

Patients were instructed to complete the survey on-site immediately after their encounter; this method was easy to administer, was not resource intensive and proved to provide a reasonable response rate (55%). However, the timing of survey distribution has been shown to impact patient-reported experiences, with less favourable ratings ensuing as more time lapses after the care encounter (Bjertnaes 2012). Hence, survey mode and timing should be given due consideration before any agency-wide decision on survey distribution, and standardization should be implemented in order to avoid timing and survey mode as confounding variables (Bjertnaes 2012).

It was beyond the scope of this study to collect patient outcome data; thus, future studies can examine the predictive validity of this tool by exploring the relationship between scale scores and outcome indicators (e.g., treatment adherence). Discriminant validity can also be looked at in future studies to determine differences in scores based on known operational or resource issues (e.g., wait time). Test-retest reliability can similarly be studied in repeated measures within a patient sample.

Furthermore, the validity of this tool was not examined across clinic types (e.g., maternity services, gynecology/sexual health services and specialized programs), but rather a set

of generic questions were identified that would be applicable across all services. To develop a generic tool, many questions were not considered for inclusion (in the review process), and some of the included items that received high percentage of “not applicable” or missing responses were subsequently excluded from the scale (in the validation process). The decision to use a generic tool versus lengthier contextualized measures ultimately lies in the purpose of the patient evaluation. In addition, the resultant 14-item tool can be used in conjunction with other clinic-specific outcome and patient-reported experience measures when deemed necessary (Kingsley and Patel 2017). Regardless, having a brief set of standardized questions that can be applied across a wide variety of ambulatory services is highly valued and greatly needed.

Although not a limitation per se, it can be argued that questions that were omitted from the scale can potentially be used on a per-item basis, when scores are not pulled into particular scales (van der Eijk et al. 2012). The questions that are highly correlated with the overall experience score (Questions 20, 9, 3, 14, 25 and 7) are likely the best candidates for such usage. Some of these items did not make the scales due to a high number of non-applicable or missing responses. Survey items should be applicable to as many respondents as possible, especially when developing a generic tool, because non-applicability leads respondents to view the entire instrument as not relevant (Jenkinson et al. 2002; Sjetne et al. 2011). If the nature of the service makes these questions more applicable, then it may be worthwhile to consider including them in the questionnaire, but treating them as single items, rather than as part of the scale. Yet, single items normally require larger sample sizes to achieve reliable results (Streiner and Norman 2003).

Future studies showcasing how patient experience survey findings can promote organizational change and improvements are also needed. Such studies can highlight successful strategies on how to make survey data more actionable.

Finally, it should be noted that patient experience can be captured through a variety of means, other than self-reported surveys. In fact, qualitative methods may elicit a deeper understanding of the patient experience and can provide added insights if used in conjunction with experience surveys. Besides the standard qualitative approaches, such as interviews and focus groups, some new innovative methods have begun to emerge, including ethnographic approaches, photovoice and guided tours (LaVela and Gallan 2014).

Conclusions

The results support the reliability, validity and acceptability of an ambulatory patient experience questionnaire with emphasis on patient–provider communication and overall quality of care experience, with a focus on both provider and operational issues. The relevance of this tool in other ambulatory settings and populations requires further investigation.

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Correspondence may be directed to: Shabnam Ziabakhsh, PhD, BC Women's Hospital + Health Centre, 4500 Oak Street, Vancouver, BC V6H 3N1; tel.: 604-875-2424; ext. 6486; e-mail: sziabakhsh@cw.bc.ca.

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