

HEALTHCARE

# POLICY

## Politiques de Santé

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

**Volume 9 + Special Issue**

*Sociology Insights on Inequities  
in Health and Healthcare*

*Perspectives sociologiques sur les inégalités  
de santé et les soins de santé*

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# POLICY

## Politiques de Santé

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

VOLUME 9 SPECIAL ISSUE • OCTOBER 2013

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

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

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

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

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

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

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# Towards a Sociology of Health and Healthcare

IVY L. BOURGEOULT, CECILIA BENOIT AND LOUISE BOUCHARD

**W**E ARE PLEASED TO INTRODUCE THIS SPECIAL ISSUE OF *HEALTHCARE POLICY / Politiques de Santé* based on papers presented at a recent biennial conference of the bilingual Canadian Society for the Sociology of Health / Société Canadienne de Sociologie de la Santé.

## About the Canadian Society for the Sociology of Health

The Canadian Society for the Sociology of Health (CSSH) is a recently established professional association dedicated to the promotion of the sociological study of health, illness and healthcare issues in Canada in both official languages. The CSSH grew out of the hosting of the 2008 Interim Conference of the Research Committee on Medical Sociology of the International Sociology Association in Montreal. The conference served as an important crystallizing event for Canadian sociology of health scholars. The CSSH subsequently hosted its second biennial, bilingual conference in Ottawa October 28–30, 2010. The primary objectives of our second conference were to:

- bring together anglophone and francophone health sociologists to present cutting-edge research on a variety of critical topics;
- advance the discipline and our understanding of health and healthcare issues; and
- foster greater translation of the knowledge we create to key users to better address critical health issues in Canada and abroad.

The conference enhanced dialogue between sociology of health scholars, showcased the work of both established and emerging Canadian sociology to a national and international audience, fostered linkages with key users of this research, and helped to build capacity in a new generation of health sociologists.

Sociology of health has emerged as one of the key yet relatively unrecognized subfields of health research that spans the population health, health services and policy research fields. It has been an important contributing field to key policy decision-makers, pioneers of medicare and the growing field of health knowledge translation. Sociology of health researchers have

always been well positioned to critically examine the key health and healthcare issues that have topped public opinion polls because of the discipline's ability to appreciate the importance of broader contextual factors and to problematize positions that are often taken for granted. This approach has become even more salient in the context of continued health system reform and a growing awareness of the importance of the broader social determinants of health to achieving health equity for all Canadians. Our country's sociology of health scholars have also been among the international leaders in this field (sometimes without this being known to national audiences, especially across the anglophone/francophone divide).

One of the key linkages we intend to foster with this organization is between health sociology scholars working within the context of English and French Canada. Too long have these communities worked in isolation, when so many more advances could be made by knowing about one another's research and collaborating in joint research and writing endeavours. To date there has been relatively little dialogue between scholars undertaking important work in English and those who work in French across Canada. Although francophone and anglophone health sociology reflect problematics in their respective regions and communities, there is much overlap and synergies that remain untapped. This situation is particularly unfortunate when we find out about the important work being done in either setting from our international colleagues rather than directly, through our own national networks. Without a bilingual venue such as the one we offer, we will continue to work in our two solitudes rather than coordinate efforts to advance important Canadian contributions to the field of sociology of health and healthcare.

### About This Special Issue

Following the CSSH's second biennial conference, the editors issued a call for a selection of the papers presented there to be peer reviewed and considered for publication as an edited collection. We received over 20 submissions, and 12 were approved for publication. The papers have been organized into four thematic sections: Population Health and Equity, Social Aspects of the Delivery of Care, Gender and the Social Experience of Health and Illness, and Contemporary Issues in the Sociology of Healthcare in Canada.

We are particularly pleased to be partnering with *Healthcare Policy / Politiques de Santé* as the venue for our first Special Issue, largely because of its commitment to (a) publishing the work of sociology of health scholars, (b) bilingual publication – an issue we felt critical for our bilingual society and (c) open-access publication. We hope that the success of this Special Issue may spark interest in others to follow.

## Vers une sociologie de la santé et des soins de santé

IVY L. BOURGÉAULT, CECILIA BENOIT ET LOUISE BOUCHARD

**N**OUS SOMMES HEUREUX DE VOUS PRÉSENTER CE NUMÉRO SPÉCIAL PUBLIÉ DANS *Politique de santé / Healthcare Policy*, inspiré d'une récente conférence biennale de la Société canadienne de Sociologie de la Santé.

### La Société canadienne de sociologie de la santé (SCSS)

La Société canadienne de sociologie de la santé (SCSS) est une association professionnelle créée récemment, consacrée à la promotion de l'étude sociologique de la santé, de la maladie et des soins médicaux au Canada, et ce dans les deux langues officielles canadiennes. La SCSS est née suite à la Conférence intérimaire en 2008 du Comité de recherche sur la sociologie médicale de l'Association internationale de sociologie à Montréal. La conférence a été un événement marquant pour les chercheurs canadiens dans la sociologie de la santé. La Société a ensuite accueilli sa deuxième Biennale, une conférence bilingue à Ottawa qui s'est tenu du 28 au 30 octobre 2010. Les principaux objectifs de cette deuxième conférence étaient les suivants :

- de rassembler les sociologues francophones et anglophones de la santé afin de présenter des recherches de pointe sur une variété de sujets essentiels;
- de faire progresser la discipline et notre compréhension des questions de santé et de soins, et
- de favoriser un meilleur transfert des connaissances acquises par les principaux utilisateurs afin de mieux traiter les questions de santé cruciales au Canada et à l'étranger.

La conférence a renforcé le dialogue entre les chercheurs en sociologie de la santé, a présenté le travail émergent de deux chercheurs canadiens en sociologie de la santé à un public national et international, et a fait naître des liens entre les principaux utilisateurs de cette recherche, aidant ainsi à construire les capacités d'une nouvelle génération de sociologues médicaux.

La sociologie de la santé a émergé comme l'un des principaux sous-domaines encore relativement méconnus de la recherche en santé, qui comprend les champs de la santé des populations, les services de santé et la politique de recherche. Ce domaine sociologique importe aux

principaux décideurs politiques, aux pionniers de l'assurance-maladie, et au secteur croissant du partage des connaissances en santé. Les chercheurs en sociologie de la santé ont toujours été bien placés pour examiner de façon critique les principaux enjeux de santé et de soins qui ont été au cœur des sondages d'opinion publique en raison de la capacité de la discipline à apprécier l'importance des facteurs contextuels plus larges et à problématiser des positions qui sont souvent prises pour acquies. Cela est devenu encore plus saillant dans le contexte des initiatives de réforme du système de santé continues, ainsi qu'une prise de conscience croissante de l'importance des déterminants sociaux de la santé dans le but d'atteindre l'équité en santé pour tous les Canadiens. La sociologie des savants en santé de notre pays ont également été parmi les leaders internationaux dans ce domaine (parfois sans que cela soit connu sur le plan national – en particulier à travers la division anglophone/francophone).

L'un des principaux liens que nous entendons favoriser avec cette organisation est celui entre les chercheurs en sociologie de la santé travaillant en anglais et ceux travaillant en français. Ces communautés ont trop longtemps travaillé en vase clos alors que d'avantage de progrès pourrait être fait par la connaissance de la recherche de l'autre et la collaboration dans la recherche et l'écriture conjointes. Jusqu'à date il y a eu relativement peu de dialogue entre les chercheurs qui entreprennent des travaux importants en anglais et ceux qui le font en français partout au Canada. Bien que la sociologie de la santé francophone et anglophone reflète les problématiques dans leurs régions et communautés respectives, il y a maintes synergies et beaucoup de chevauchement qui restent inexploités. Il est particulièrement regrettable quand nous découvrons le travail important qui a été réalisé de la part de nos collègues internationaux plutôt que directement par nos propres réseaux nationaux. Sans un lieu bilingue comme celui que nous proposons, nous continuerons à travailler dans nos deux solitudes plutôt que de coordonner nos efforts pour faire progresser l'importante contribution canadienne à la sociologie de la santé et des soins de santé.

### Le numéro spécial de *Politiques de santé*

Après la deuxième conférence biennale, les rédacteurs ont lancé un appel pour une sélection des documents présentés par quelques sociologues lors de cette conférence afin que ceux-ci soient examinés par des pairs, dans l'espoir de les publier en tant que collection éditée. Nous avons reçu plus de vingt soumissions, desquelles douze ont été approuvées pour la publication. Les documents ont été organisés en quatre sections thématiques: la santé de la population et l'équité, les aspects sociaux de la prestation soins, le genre et l'expérience sociale de la santé et de la maladie, et enfin les enjeux contemporains en sociologie des soins de santé au Canada.

Nous sommes particulièrement heureux de nous associer à *Politiques de santé / Healthcare Policy* pour la présentation de notre premier numéro spécial, en grande partie à cause de son engagement à : a) la publication des travaux de sociologie des spécialistes de la santé; b) la publication bilingue (une question que nous estimions essentiel pour notre société) et c) le libre accès à la publication. Nous espérons que le succès de ce numéro spéciale pourra susciter l'intérêt et servir d'exemple à suivre.

# The Pandemic Subject: Canadian Pandemic Plans and Communicating with the Public about an Influenza Pandemic

La question pandémique : plans canadiens de lutte contre les pandémies et communication publique au sujet d'une pandémie d'influenza



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## Abstract

In this paper, I examine the goals for pandemic public communication as outlined in two Canadian plans for pandemic planning and infection control. I critique these strategies by drawing on Foucault's notions of governmentality and biopower. My argument is that the public health communication campaign goals reviewed rest upon a particular conceptualization of health in the context of pandemic planning as an individual/family duty, and that scientific/medical expert knowledge is most appropriate for guiding pandemic planning. This study contributes to a sociological understanding of how pandemic preparedness and infection control are represented in Canadian pandemic plans, how public health shapes pandemic communication messages in Canada, and the implications of those messages for subjectivity and notions of citizenship.

## Résumé

Dans cet article, j'examine les objectifs de communication publique de deux plans de communication canadiens visant la planification de lutte contre les pandémies et le contrôle de



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l'infection. Je critique ces stratégies à la lumière des notions de gouvernabilité et de biopouvoir définies par Foucault. J'avance que les objectifs de la campagne de communication en santé publique reposent sur une conception particulière de la santé, dans le contexte du plan de lutte contre les pandémies, où elle est considérée comme un devoir familial/personnel, alors que l'expertise et les connaissances scientifiques/médicales sont plus adéquates pour orienter un plan de lutte contre les pandémies. Cette étude apporte une compréhension sociologique de la façon dont la préparation à une pandémie et le contrôle de l'infection sont représentés dans les plans canadiens de lutte contre les pandémies, de la façon dont la santé publique donne forme aux messages des plans de communication canadiens et des répercussions de ces messages sur la subjectivité et la notion de citoyenneté.

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**I**N ORDER TO REDUCE INFECTION AND DEATH DURING INFLUENZA PANDEMICS, PUBLIC health agencies worldwide have developed comprehensive pandemic public education campaigns. The Canadian pandemic public education plans strongly advocate infection control practices at the level of the individual and family, such as hand-washing, vaccination and respiratory etiquette, to prevent infection and stop further transmission. From a social and political perspective, this focus is problematic owing to the implications of defining ourselves in relation to moral categories associated with infection control techniques (e.g., be a good parent and have your children vaccinated), while disregarding the social and structural factors affecting the severity of influenza pandemics (e.g., poverty and inadequate housing on First Nations reserves causing an H1N1 crisis). Thus, the ways in which pandemic flu is represented in official pandemic education messages shape the way we view pandemic scenarios and ourselves, collectively and individually, within them.

In this paper, I consider the ways in which the messages developed for Canadian pandemic influenza public education are dangerous. I first examine the goals for pandemic public communication as outlined in two Canadian pandemic plans, exploring how pandemic planning and infection control are invoked within those texts. Drawing on Foucault's notions of governmentality and biopower, I then engage in a theoretical critique of those public communication strategies.

My argument is that the public health communication campaign goals reviewed rest upon a particular conceptualization of health in the context of pandemic planning as an individual/family duty, and that scientific/medical expert knowledge is most appropriate for guiding pandemic planning. To close, I discuss the pandemic subjects made possible in the context of those pandemic public communication messages. My goal is to open up public communication to theoretical critique – to ask what ideas about pandemic influenza are rendered unthinkable, and therefore, what pandemic planning questions are rendered unaskable.

### Preparing the Public for a Flu Pandemic

The influenza viruses responsible for seasonal flu outbreaks are subject to antigenic mutations that allow new viral strains to develop. Cyclically, a strain develops to which the population

has little or no immunity, and a global epidemic or “pandemic” can occur. Although experts in the health fields anticipate periodic pandemics based on history, they are unable to forecast exactly when and where these may happen.

It is extremely difficult to predict the virulence and severity of a novel influenza strain to which the population has little or no resistance. The devastation and great loss of life recorded during key pandemics of the last century, however, serve to caution us as to the immense potential damage that influenza pandemics can bring. Given that these pandemics arise with little warning and have a major national and international impact, emergency planning and response are needed.

Communicating with the public is a key aspect of pandemic preparation and response, and Canadian pandemic plans place considerable emphasis on communication utilizing multiple channels. Communications developed by the Public Health Agency of Canada (PHAC) and the Ontario Ministry of Health and Long-Term Care (MOHLTC) have included web-based resource pages (PHAC 2011a), weekly bulletins (PHAC 2011b), an online campaign of Google and Facebook advertisements, and multiple posters and fact sheets, five million of which were distributed in 23 languages in 2006 alone (MOHLTC 2008a).

In a number of informational pamphlets developed for the public on PHAC and MOHLTC websites, individual- and family-level infection control actions are strongly promoted. These behaviours include vaccination (“flu shot”), hand hygiene, respiratory etiquette (e.g., the “sleeve sneeze”), self-isolation (e.g., limit travel, stay home when ill), social distancing (e.g., avoid close contact with others), monitoring one’s health, assessing and reporting suspected illness (MOHLTC 2008b).

Infection control behaviours are positively framed in these communication materials through association of these behaviours with such qualities as courtesy, responsibility, good parenting and preparedness. For example, covering one’s cough is called “good respiratory etiquette” (Health Canada and PHAC 2006). Parents are exhorted to “take care of yourself and your family” (MOHLTC 2007a) and “be a good role model” (PHAC 2006a) by ensuring children are vaccinated and taught proper hand hygiene. Readers are urged to encourage others to follow similar behaviours: “Make sure family members get a flu shot too!” (PHAC 2006a). For healthy travel during a pandemic, one is advised to compile a travel health kit, purchase supplementary insurance, and then once home, disinfect footwear and monitor health for 14 days (MOHLTC 2007b). Several pamphlets instruct the reader to “be prepared” by considering the state of pandemic contingency plans in their communities and workplaces (MOHLTC 2007c).

What ideas about pandemic influenza, public health and citizenship underlie these messages? To address this question, I will explore stated goals for communicating with the public about pandemic influenza in the Canadian Pandemic Plan (CPIP), the Ontario Health Plan for an Influenza Pandemic (OHPIP) and public communication guidelines from the World Health Organization (WHO).

### *Canadian Pandemic Influenza Plan*

At the federal level, the Canadian Pandemic Influenza Plan for the Health Sector delineates recommended pandemic control strategies and procedures, and serves as a guide for planning at the federal, provincial, territorial, municipal and organizational levels (PHAC 2006b: 1–2).

Plans devoted to communications surrounding a pandemic are detailed in CPIP’s Annex K. These plans are detailed and complex – they include a breakdown of the roles and responsibilities of Canada’s health partners concerning communications before, during and after an influenza pandemic.

### *Ontario Health Plan for an Influenza Pandemic*

Chapter 12 of the Ontario Health Plan for an Influenza Pandemic (OHPIP) covers the communications aspect of pandemic planning at the Ontario provincial level (MOHLTC 2008c). It begins with a stirring quote from historian John M. Barry writing about the 1918 pandemic, highlighting the need for public health authorities to retain the public’s trust (MOHLTC 2008c: 1).

The provincial public communication strategy is threefold: to educate, to reassure and to be accountable (MOHLTC 2008c: 1, 2). The OHPIP elaborates on the content of the public education messages according to the three pandemic phases:

- Interpandemic and pandemic alert phases: to “*raise awareness*” of pandemic risk, to inform people of and “*reinforce the importance of good hand and respiratory etiquette*” and to “*encourage cooperation and compliance with FRI screening and other precautions ...*” (emphases added) (MOHLTC 2008c: 2, 3).
- Pandemic phase: provide up-to-date pandemic information through a variety of communication channels, advising the public on “*what to do*” (MOHLTC 2008c: 3).

The emphasis on trust, compliance and self-protection seems to fit with the expected “role of the public” during an influenza pandemic, as stated in Chapter 2 of the OHPIP. The public is expected “to *actively participate* in efforts to reduce the spread of the influenza, to *comply* with any public health measures and to *participate in their own care* in a pandemic” (emphases added) (MOHLTC 2008d: 5).

### *Public Communication Recommendations from the World Health Organization*

Both the CPIP and OHPIP make mention of their cooperation and need for consistency with WHO pandemic planning recommendations for communication strategies (PHAC 2006b; MOHLTC 2008c). Within the Communications Annex, the CPIP specifically notes that the PHAC will utilize risk communications frameworks from the WHO (Annex K: 5). While those particular frameworks are not cited, it is useful to look at several WHO documents that outline steps for public communication during public health emergencies.

The strategies detailed within the outbreak communication guidelines (WHO 2005a) and the field guide, *Effective Media Communications During Public Health Emergencies* (WHO 2005b), clearly advocate communicating a message of trust in public communication messages. The WHO's recommendations for accomplishing this include citing "credible third parties," scientific research and published studies in particular, and demonstrating compliance with professional and scientific standards (WHO 2005b: 40).

From the pandemic communication plans and recommendations reviewed above, three main messages geared for the public seem readily apparent: (a) encouraging individual- and family-level infection control behaviours, (b) encouraging trust in authorities and compliance with their directives, which are (c) informed by expert scientific and medical knowledge.

There are numerous approaches to explore how the public interprets and responds to health and science communication, including critical and culturalist approaches to health and media studies (Zoller and Dutta 2008), the public understanding of science literature (Irwin and Michael 2003; Irwin and Wynne 1996) and within the Third Wave debate in science and technology studies (Collins and Evans 2002). However, in this paper I do not explore how pandemic influenza is constructed through particular messages or expertise claims, or how those messages are interpreted by the public – in other words, I don't address how well these communication approaches will "work." Instead, I raise the epistemological question of what kinds of pandemic subjects and citizens are made possible in the context of these specific pandemic public communication guidelines and goals. At this point, I turn to and briefly discuss several of philosopher and social theorist Michel Foucault's key theoretical concepts.

## Foucauldian Concepts in the Context of Pandemic Public Education

### *Medical/scientific knowledge-power*

The public communication goals and recommendations reviewed above emphasize adherence to and trust in the infection control techniques informed by a specific type of expert knowledge: that of scientific and (bio)medical experts. The tacit implication is that specialized scientific and medical knowledge is somehow more or most appropriate for guiding pandemic planning and response. Such an assumption about the legitimacy of scientific knowledge guiding public health and medical interventions would not be unique to the pandemic situation. Foucault traces the prominence of medicine in particular during the rise of those discourses of individuality and the body as privileged site of governmentality during the 18th century, and drawing from Foucault, O'Brien and Penna (1998), for example, have also noted the prominence of medical/scientific knowledge-powers more recently.

### *The individual as a medicalized subject*

The emphasis on individually targeted self-protection techniques (e.g., instructing individuals to wash their hands in such a way that will stymie the spread of infection) perhaps is not surprising. Petersen (1997: 197) notes that a focus on the individual in the self-management

of epidemiological risk is a key tenet of health promotion strategy – to empower through education. An example can be seen in smoking cessation campaigns that inform people about the risks of cigarettes so that they might make informed decisions and protect themselves from those risks (Brown 2000). The underlying assumption is that the information is being provided so that individuals are able to make the scientifically informed, risk-minimizing or risk-managing, correct choice – this approach is known as the “new public health” (Petersen 1997). These recommended infection control practices can also be understood as points of reference for individuals in constituting themselves as particular kinds of subjects (e.g., staying home when ill is considerate, responsible, doing my part, etc.) – in other words, Foucauldian technologies of the self.

### *The family as a medicalized subject*

To a slightly lesser degree, but still noteworthy, public communication guidelines spotlight the family in pandemic infection control. Foucault perceived the family as becoming “the most constant agent of medicalization” and a “target for a great enterprise of medical acculturation” since the mid-18th century (Rabinow 1984: 280). Not that this in any way negates the consideration paid to individual bodies in attaining population well-being as discussed previously. It was through the family that individual bodies were to be reached – families became constituted as the major force, the channel through which individuals would be shaped into medical subjects (Rabinow 1984: 281).

Foucault connects this role as an agent of medicalization with the family’s task of raising healthy children and the rise of discourses regarding what constituted “correct management” of the childhood stage (Rabinow 1984: 279). It became the family’s designated mission to ensure that children would live to adulthood. Thus, hygiene, fitness, nutrition and other things linked to “care” were regulated as the domain and responsibility of the family (Rabinow 1984: 280). Foucault also notes the family’s particular moral accountability for inoculation. With the family interpolated into this role, the way was made clear for “[a] ‘private’ ethic of good health as the reciprocal duty of parents and children to be articulated onto a collective system of hygiene and scientific technique of cure made available to individual and family demand by a professional corps of doctors, qualified, and as it were, recommended by the state” (emphases added) (Rabinow 1984: 281).

### *Health as a moral project*

O’Brien and Penna (1998: 116) refer to the behavioural regimes made possible through institutional discourses as a “moral-political code.” This resonates with the last point I will make about the public education plans: that the pursuit and protection of health in the event of a pandemic is positioned as a “moral” responsibility. I use the term “moral” in the same way I understand both O’Brien and Penna (1998) and Lupton (1999) to mean when arguing that subjects willingly take up recommended risk-minimizing health behaviours as a “moral enterprise relating to issues of self-control, self-knowledge and self-improvement” (Lupton 1999: 92–93).

Petersen (1997) claims that under the “new” public health system of individual-level health promotion strategies, a convergence between the public good and personal goals emerged. For our purposes, we can consider how the personal goal of avoiding infection and the public good of pandemic management are complementary. When merged, the two objectives form a mutually reinforcing moral project – practising self-protection at the individual level keeps me from becoming infected and protects others too, thus reducing infection levels in the population.

Several of the phrases taken from examples of current public education pamphlets, above, clearly illustrate this message of moral duty, particularly to one’s community and family. There appears to be a tacit expectation that the individual will want to adopt behaviours that are positioned as prudent, responsible and good, and are in alignment with current scientific expertise.

### How This Public Communication Is Dangerous

According to Foucault (2003: 172), “Critique does not consist in saying that things aren’t good the way they are. It consists in seeing on what type of assumptions, of familiar notions, of established, unexamined ways of thinking the accepted practices are based.” It is in this spirit that I will engage in a theoretical critique of the dangers of public education for pandemic flu. The danger lies not so much in the strategies themselves, but in the failure to examine the assumptions on which they are based. If we understand pandemic public communication plans as representative of and contributing to discourses on identity, the question then becomes: What kinds of pandemic subjects and citizens are made possible in the context of these pandemic public communication guidelines and goals?

#### *What does a good citizen look like in the context of pandemic planning?*

Higgs (1998: 189) argues that “governmentality locates itself within the idea of citizenship.” Technologies of the self – in our case, self-protective behaviours such as hand-washing – “are ordered by techniques from which the *model citizen can be created* out of a composite of norms, values and statistics” (emphasis added). O’Brien and Penna (1998: 120–21) similarly speak of the “identity categories” that are “a normative basis of social and political order.” The model pandemic citizen identity categories would certainly have moral implications as “signifiers of one’s moral worth” (Petersen 1997: 198). What I mean is that the divide between vaccinated/unvaccinated, or those following/disregarding recommended behaviours (for whatever reason), translates into responsible/irresponsible, cautious/incautious, more/less risky people. If we consider the goal and guidelines for pandemic public communication within the reviewed texts, good pandemic citizens are those who comply with infection control directions, particularly by adopting self-protective practices, who trust in the direction of scientific and medical experts and who actively embrace these strategies and goals as their own.



*A citizen who self-protects*

An ideal pandemic citizen is one who, after seeking out information on pandemic flu and prevention tips, says: “This is *my* health. I am in control and I need to protect myself.” Taking a cue from Foucault, such a stance towards pandemic influenza isn’t necessarily a bad thing. The individual gains knowledge and, as the assumption goes, gains improved ability to protect his or her health. The follow-up Foucauldian question is then: What unarticulated, unquestioned premises is this assumption based on?

Above, I noted that governmentality depends on individual compliance with the needs of the state (Lupton 1999). This is not an instance of one group or individual controlling another, but rather of a mutual creation and mutual reinforcing of desires. It would be appropriate, then, to look at the ways in which an ideal pandemic citizen fits with the interests of the currently predominant neoliberal state.

A neoliberal society values individuality, choice, free markets and a scaling back of government intervention. Numerous scholars trace the concurrent and mutually reinforcing discourses of individual responsibility for health and neoliberal ideology (Burchell 1996; Higgs 1998; Petersen and Lupton 1997). Lupton (1999: 86) asserts that contemporary governmentality and neoliberal ideologies are indeed complementary. Petersen (1997: 204) sees this as a new “politics of citizenship” based on duties, not rights. Higgs (1998) similarly argues that within neoliberal discourses, a new concept of citizenship has emerged; one that is not based on social security but on individual freedom and choice.

The work of these scholars sheds light on the link tacitly made within pandemic public communication plans between self-protection, individual responsibility and the population or community. Good neoliberal pandemic citizens are those who accept responsibility for and protect their own health through choosing to adopt individual techniques of the self, with the understanding that they cannot (and perhaps should not) expect to rely on state-sponsored healthcare if they fall ill.

*A citizen who takes personal responsibility*

It is important to note that any mechanism through which people might be held accountable for their adherence to or rejection of the desired behaviours in the event of a pandemic are undeveloped. Yet, from the CPIP and OHPIP we see an expectation of self-monitoring and self-surveillance (e.g., self-reporting of infection and self-imposed isolation when ill), which will comprise a major facet of outbreak management (PHAC 2006b, Annex N: 1–2).

Lupton (1999) notes that mass targeted media campaigns, in which we can include the pandemic public communication campaigns, are contingent upon individuals’ engaging in self-surveillance, classifying themselves as being at risk (in our case, of pandemic virus infection), borne from a sense of responsibility. Good pandemic citizens fix their gaze on themselves as a potential vector of disease and take steps to become guardians of population health through their individual actions.

A focus on individual responsibility can redirect responsibility away from public health authorities and the state to protect citizens (if only in the eyes of the individual reader of public communication materials) (Brown 2000; Sacks 1996). Issues of state-level and agency-level responsibility for infection control and pandemic management are rendered less visible.<sup>1</sup> However, as both those pandemic plans indicate in the breadth of their text, nearly all aspects of pandemic planning, including infection control, require collaboration across multiple sectors of government and medical, scientific and public health agencies. Although managing a pandemic outbreak requires action among multiple sectors of society and government, the goals directing pandemic public communication do not appear to reflect fully this complexity.

From a Foucauldian perspective, the emphasis on individual responsibility for infection control is significant because of its implications for subjectivity, and harkens back to governmentality critiques of the individualistic neoliberal state. Its emphasis on choice, free markets and reduced government intervention requires people to engage in their own vigilant self-governance, self-surveillance and self-evaluation, becoming “experts of themselves” (Rose 1996: 59) in order to keep from burdening society with illness that could have been prevented and managed without government interference (Petersen 1997). Neoliberal subjects must vigilantly monitor themselves in this way, for no “collective safety net” (Higgs 1998: 193) can be expected to catch them if they do become ill.

#### *A citizen who trusts in the scientific/medical expert knowledge*

This scenario assumes that a program of self-monitoring and self-protection will indeed result in protection from, or at least reduced chance of, infection. Embedded within is the presumption that even at the time of an influenza pandemic, control is to some degree in the hands of the individual (do your part, get a flu shot, wash your hands and your health can be protected), though the efficacy of recommended behaviours cannot be guaranteed. Communication messages that do not address scientific uncertainty may perhaps create unrealistic expectations of individuals’ ability to protect their health during a pandemic and could lead to public mistrust. A more Foucauldian critique, however, would be to address the seeming unassailability of the scientific and medical expertise that informs such self-protective behaviours.

While pandemic influenza certainly is a biomedical issue, it is not only a biomedical issue. It is also a social, cultural, political and ethical issue. Take, for instance, the sticky matter of providing “high-risk” groups with priority access to vaccines, which requires decision-making about which population groups should be given priority access to the influenza vaccine, a major component of the publicly funded healthcare intervention against outbreaks. Prevailing pandemic public communication guidelines emphasize the importance of scientific/medical expert knowledge and do not easily allow for questioning of that expertise, which renders questions about whether those without specialized medical expertise ought to contribute to pandemic planning largely unthinkable. Thus, decisions are made regarding issues that are explicitly positioned as being of a scientific/medical nature (infection rates, viruses) without



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equal attention (and, I suggest, perhaps without equal accountability) to their social, moral and political implications (e.g., fair resource distribution, housing, social justice). In another context, these issues might well be considered an appropriate matter of concern for the general public (and perhaps up for public debate or part of a political platform). In rendering it evident that scientific knowledge and biomedical methods ought to direct and inform pandemic planning, these expert knowledges have gained a legitimated dominance over planning and response for a complex and fundamentally social issue.

Although pandemic planners estimate that influenza pandemics will continue, it is difficult to gauge the virulence and pathogenicity of a virus to which the population has little or no immunity. It is perhaps more difficult to anticipate and manage the actions of populations that have not experienced a devastating, global epidemic of influenza in their lifetime. Yet this is what these pandemic public communication strategies aim to do: to teach self-protection for infection control, to reassure, to induce compliance to authority and trust in scientific and medical expertise – in short, to sell the public on the neoliberal goal of population well-being through individual action. These approaches indeed may result in decreased infection and death. In light of Foucault's cautions, however, the consequences of failing to investigate and make explicit the rationales for health promotion practices might have important social and political implications.

Recent decades have seen a violent upswing in the number of emerging infectious disease outbreaks – SARS, Ebola and MDR-TB, to name but a few. There is an urgent need for greater understanding of the ways in which infectious diseases are represented in public communication plans and messages, including the need to compare and explore the interrelationship between these and other national and regional pandemic plans. There is also a need to better understand the ways in which those representations are interpreted by the public and how various pandemic subject positions are taken up or resisted.

In this paper, I have attempted to open up Canadian pandemic public communication to theoretical critique. I have raised questions about the implications of those messages, challenged the unspoken assumptions on which they are founded, and in Harris's (1999: 27) lovely phrase, to "dislodge the certainties of the present." Our success in understanding and planning for future infectious disease outbreaks may depend upon our persistent willingness to do this.

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NOTE

1. Crowded conditions in industrialized poultry and swine farming are conducive to rapid spread and mutation of influenza viruses; ensuring hygienic practices in industrial factories is essential for control and prevention of pandemic influenza (Wiwanitkit 2010). As Link and Phelan (1995) state, the deregulation of food inspectors is an example of a “fundamental cause of disease” rooted in social and economic forces, which has led to the need for individual caution against disease. Thanks to the anonymous reviewer who pointed out this example.

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# La traduction territoriale du Programme national nutrition santé (PNNS) en Midi-Pyrénées, France

## Territorial Translation of the National Health and Nutrition Program in Midi-Pyrénées, France



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### Résumé

Inspiré de la tradition hygiéniste reposant sur une représentation du corps qui associe la santé à un exercice physique régulier et modéré, le Programme national nutrition santé (PNNS) instaure la sédentarité comme un des facteurs de risque de nombreuses maladies chroniques. Il participe ainsi du gouvernement des corps et reproduit l'injonction morale à développer un mode de vie physiquement actif conjugué à une alimentation saine. Visant l'amélioration générale de l'état de santé de la population en agissant sur la nutrition, le PNNS est axé sur

la prévention primaire, le dépistage et la prise en charge précoce de pathologies telles que les maladies cardiovasculaires, le cancer, l'obésité, l'ostéoporose ou le diabète. Programme incitatif inscrit dans la lignée des biopolitiques qui, durant les années 1970, voient dans l'éducation pour la santé une alternative au tout hospitalier, le PNNS est aussi un instrument d'action publique au service de la maîtrise des coûts.

## Abstract

Inspired by the Hygienist Movement, which associates good health with regular, moderate exercise, the National Health and Nutrition Program identifies a lack of physical activity as a risk factor for many chronic diseases. As such, the Program encourages people to take care of their bodies by inciting a moral obligation to develop a physically active lifestyle and follow a healthy diet. With the overall goal of improving the health of the population by acting on nutrition, the Program focuses on primary prevention, screening and early treatment of conditions like heart disease, cancer, obesity, osteoporosis and diabetes. As an incentive program developed in keeping with the biopolitical views of the 1970s that saw education as an alternative means to hospitals for achieving good health, the Program is also a good public action tool for controlling costs.

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## Introduction

Devant composer avec des configurations locales très variées, qu'une sociologie politique de l'action publique sanitaire permet de porter au jour (Hassenteufel 2008; Lascoumes et Le Galès 2007), le Programme national nutrition santé (PNNS) connaît, entre 2001 et 2010, des formes diverses de traduction territoriale (Lascoumes 1996). C'est particulièrement le cas en région Midi-Pyrénées où 14 communes et communautés de communes ont signé la charte « ville active » attestant par ce label leur inscription dans le programme national (Basson et al. 2010). L'activité de traduction à laquelle est confronté localement le PNNS s'apparente ainsi à des processus ambivalents d'appropriation, de bricolage, de négociation et, au bout du compte, de requalification du programme à l'aune de la gouvernance territoriale de l'action publique sanitaire qui prévaut ici et là, selon les différents niveaux d'échelle considérés (Clavier 2007; Loncle 2009). La santé publique locale opérant alors comme une scène commune, les « villes actives du PNNS » constituent autant de « figures urbaines de la santé publique » (Basson et al. 2013; Fassin 1998).

## Méthodologie

Réalisée dans le cadre de deux contrats<sup>1</sup>, la recherche prend appui sur l'analyse des documents produits par les instances sanitaires nationale, régionale, communales et intercommunales et par les réseaux de santé engagés dans le PNNS : textes de lois, rapports publics, articles de presse, communications publiques, rapports d'activités, comptes rendus de réunions, dossiers et plaquettes d'information, sites électroniques... En parallèle, des entretiens semi-directifs

ont été réalisés avec six acteurs nationaux, 23 acteurs régionaux et 33 acteurs communaux ou intercommunaux liés au PNNS. Enfin, les 14 collectivités publiques de la région Midi-Pyrénées (dont Toulouse, la métropole) ayant souscrit au programme national ont fait l'objet d'une analyse ethnographique mêlant entretiens, observations et observations participantes en vue de dégager le mode de gouvernance sanitaire propre à chaque terrain empirique (Haschar-Noé et al. 2010).

Traditionnellement, en France, la mise en œuvre de l'action publique sanitaire obéit à une logique de « régionalisation » (Jabot et Demeulemeester 2005). Niveau pertinent de la gestion et de l'organisation du système de santé français (Bourdillon 2005; Coldefy et Lucas-Gabrielli 2008), l'échelon régional bénéficie de la déconcentration de la programmation et de la planification en matière de santé et constitue le terrain privilégié d'application des plans nationaux. Si le processus de décentralisation initié en 1982 confie des compétences sanitaires limitées aux différentes collectivités territoriales que sont les communes, les départements (via les conseils généraux) et singulièrement les régions (via les conseils régionaux), le cadre régional n'en est pas moins progressivement devenu le lieu de la reconfiguration des rapports entre acteurs institutionnels nationaux et acteurs non étatiques mobilisés localement. Soumis à un processus de construction de nouvelles significations et à des configurations d'acteurs spécifiques régentant la production d'accords localisés sur le sens des actions à mener en son sein, le PNNS fait ainsi l'objet, en Midi-Pyrénées, d'appropriations fortement différenciées. De telle façon que la temporalité de sa mise en œuvre (développée dans une première partie) et les conditions régionales de la signature de la charte « ville active » (présentées dans une seconde partie) en viennent à illustrer les tensions qui régissent les programmes nationaux et la gouvernance territoriale des dispositifs de santé publique (Simoulin 2007).

Située au sud-ouest de la France et regroupant 2,8 millions<sup>2</sup>, la région Midi-Pyrénées présente une espérance de vie (de 84,8 ans pour les femmes et de 79 ans pour les hommes) parmi les plus élevées du pays. De même, la prévalence de l'obésité contre laquelle le PNNS entend lutter prioritairement est, en 2009, de 13,6 % dans la région contre une moyenne nationale de 14,5 %<sup>3</sup>. Toutefois, la progression de 74,4 % du taux d'obésité, entre 1997 et 2009, en Midi-Pyrénées (contre + 70,6 % pour l'ensemble du pays) intime d'autant plus les acteurs publics à agir que les jeunes enfants sont les plus touchés.

### *Les deux temps de la mise en œuvre régionale du PNNS*

Les modalités territoriales d'appropriation et de mise en œuvre du PNNS en Midi-Pyrénées diffèrent selon la temporalité du programme. En effet, à chacune des étapes du PNNS 1 (2001 – 2005) et du PNNS 2 (qui lui succède entre 2006 et 2010) correspond une dynamique de « découplage » (Grossetti 2004) allant s'accroissant entre niveaux de gouvernement : du national au régional pendant la première période, puis du régional au communal (ou à l'intercommunal) dans le deuxième temps (Haschar-Noé et Basson 2010).

#### LE PNNS 1 : UNE CONCEPTION DÉCLOISONNÉE, EXPERTE ET LOCALISÉE DE LA SANTÉ PUBLIQUE

Lancé le 31 janvier 2001, le PNNS inaugure une politique préventive de santé publique dont l'objectif général est d'améliorer l'état sanitaire de la population en agissant sur l'un de ses déterminants majeurs : la nutrition, entendue comme la combinaison d'une alimentation saine et de la pratique régulière d'activités physiques (Hercberg et Tallec 2000). Confiée par la circulaire du 9 janvier 2002 du Ministère de la santé aux Directions régionales des affaires sanitaires et sociales (DRASS)<sup>4</sup>, la phase initiale de sa mise en œuvre s'organise, en Midi-Pyrénées, autour d'une configuration resserrée d'acteurs publics et hospitaliers concernés au premier chef par les priorités affichées par le programme national et regroupés au sein d'un comité technique régional nutrition santé (CTRNS) créé pour l'occasion.

Chargé de susciter, de coordonner et d'animer les programmes d'actions régionaux du PNNS, le CTRNS est alors placé sous la présidence d'une professeure de pédiatrie du centre hospitalier universitaire (CHU) de Toulouse. Membre du service de pédiatrie, d'endocrinologie, de génétique et de gynécologie médicale de l'Hôpital des enfants et particulièrement sensible à la dimension nutritionnelle du programme, elle crée, en 2003, le réseau de prévention et de prise en charge de l'obésité pédiatrique (RéPPOP) de Midi-Pyrénées. Trouvant appui auprès d'un professeur de physiologie du CHU de Toulouse, chef du service d'exploration de la fonction respiratoire et de la médecine du sport de l'Hôpital Larrey, le comité technique régional entreprend également de lutter contre la sédentarité. En effet, initiateur du réseau pour la santé par l'effort et la forme en Midi-Pyrénées créé en 2005, ce président de la Société Midi-Pyrénées de médecine du sport milite pour la prescription d'activités physiques et sportives aux personnes sédentaires atteintes de pathologies chroniques.

Ainsi la gouvernance territoriale du dispositif de santé publique élaborée par le comité s'organise-t-elle, dans les premières années (2001 – 2005), autour de trois promoteurs régionaux dominants : la DRASS et ses partenaires institutionnels (l'Union régionale des caisses d'assurance maladie et la Caisse primaire d'assurance maladie), les services déconcentrés d'autres ministères et plus particulièrement ceux en charge de la jeunesse scolarisée (Jeunesse et sports, Education nationale) et, surtout, les services du CHU de Toulouse. Dirigé par des médecins jouissant d'un fort ancrage local et d'une expertise reconnue nationalement (Schweyer 2004), le CTRNS sollicite prioritairement les réseaux de santé que ces derniers coordonnent et sélectionne deux des neuf objectifs proposés par le PNNS : la prévention de l'obésité infantile et la lutte contre la sédentarité qui constituent le cœur de l'activité professionnelle des deux médecins en question. Cette traduction territoriale du premier PNNS atteste un découplage entre niveau national et régional, le travail de mobilisation et d'enrôlement des acteurs publics et privés mené par ces réseaux s'apparentant à une conception décloisonnée, experte et localisée de la santé publique.

#### LE PNNS 2 : UNE CONFIGURATION RÉGIONALE HÉTÉROCLITE ET ÉCLATÉE DE LA SANTÉ PUBLIQUE

La mise en place, en 2006, du Groupement régional de santé publique ouvre le deuxième



temps du PNNS (2006 – 2010) et change radicalement la donne, le RéPPOP ne bénéficiant plus de la position centrale qu'il occupait auparavant au sein du comité technique régional. Un groupe thématique « nutrition et activité physique » lui est substitué et son pilotage confié directement à la DRASS. Réduit à une quinzaine de personnes, contre une cinquantaine dans l'instance précédente, il voit ses capacités de délibération, d'impulsion et de promotion des objectifs prioritaires du PNNS auprès des acteurs locaux se limiter fortement et ses modalités pratiques de travail changer radicalement : perdant ses qualités de rouage stratégique, décisionnel et volontariste, il devient un appareil administratif de contrôle, de validation et d'évaluation d'une myriade de projets de nature et de portée très variables et tente de coordonner une multitude d'acteurs divers dessinant une configuration régionale hétéroclite et éclatée. Le PNNS 2 se caractérise, en effet, par une multiplication et une diversification des acteurs engagés dans le programme en Midi-Pyrénées. On note, en premier lieu, une augmentation très sensible du nombre de communes et communautés de communes signataires de la charte « ville active » du PNNS pendant sa deuxième phase : les deux premières d'entre elles avaient procédé à la signature en 2005 (soit l'ultime année du PNNS 1), douze ont fait de même depuis 2006. L'apparition de nouveaux programmes publics se réclamant plus ou moins du PNNS et lui faisant potentiellement concurrence est également à relever. De nombreuses initiatives à mettre à l'actif des organes déconcentrés du Ministère de jeunesse et sport (le plus souvent en collaboration avec le mouvement sportif) alimentent ainsi de nouvelles propositions visant à prévenir et à lutter contre l'obésité et la sédentarité. De même, la mise en place des programmes régionaux de l'offre alimentaire par le Ministère de l'alimentation, de l'agriculture et de la pêche (MAAP) contribue également à brouiller les frontières du PNNS 2.

Enfin, le mouvement mutualiste, l'industrie pharmaceutique et les groupements professionnels issus des filières agroalimentaires sont quelques-uns des nombreux nouveaux acteurs privés entrant également dans le jeu de la gouvernance sanitaire territoriale. À ce dernier titre, la région Midi-Pyrénées présente la singularité de voir se développer une traduction économique et touristique (voire culturelle) du PNNS 2 : constituant un pôle économique majeur, l'agriculture et l'industrie agroalimentaire régionales intègrent, en effet, le programme national en mettant l'accent sur la nécessaire éducation gustative des jeunes générations afin de garantir et de promouvoir le patrimoine gastronomique local. Via le PNNS 2, les enjeux de santé publique en viennent ainsi à croiser des considérations de développement économique, de promotion des produits régionaux, d'attractivité touristique et de sauvegarde patrimoniale. Cette extrême diversité des traductions territoriales du programme rend alors illusoire toute prétention à l'harmonisation des actions envisagées dans ce cadre à l'échelle de la région. Les coordinations entre acteurs régionaux, mais aussi entre ces derniers et les acteurs infrarégionaux, apparaissent de fait plus contingentes et moins durables dans la deuxième étape de mise en œuvre du programme national qu'elles ne l'étaient à l'origine.

### *Les conditions régionales de la signature de la charte « ville active » du PNNS*

Les 14 communes et communautés de communes signataires de la charte « ville active » en



Midi-Pyrénées attestent également les modes d'appropriation, de mise en œuvre et de coordination contrastés dont le PNNS fait l'objet localement ainsi que les conceptions variables de la santé publique dont ils sont porteurs.

#### LA DIVERSITÉ DES MODES D'APPROPRIATION ET DE MISE EN ŒUVRE

Malgré un intérêt tardif manifesté à l'endroit du programme national, la région fait preuve d'un certain dynamisme en affichant un taux de couverture de la population de l'ordre de 24 %, contre 14,5 % à l'échelle nationale. Cependant de fortes disparités entre communes urbaines et rurales (ces dernières étant le plus souvent engagées dans le programme « Un fruit à la récré » proposé par le MAAP<sup>5</sup>) et entre les différents départements de la région marquent une traduction locale fortement différenciée du PNNS. La signature de la charte concerne essentiellement des communes situées en milieu urbain et deux départements en priorité : la Haute-Garonne et le Tarn totalisent villes signataires à eux deux, quand l'Aveyron, le Gers, le Lot et le Tarn-et-Garonne comptent chacun une seule « ville active » et aucune pour l' Ariège et les Hautes-Pyrénées.

De plus, les communes et communautés de communes signataires de Midi-Pyrénées affichent certaines singularités marquantes qui les distinguent des « villes actives » d'autres régions : elles pratiquent un moindre cumul d'adhésions à d'autres programmes concurrentiels au PNNS, ménagent une place importante aux actions de promotion de l'activité physique, nouent fréquemment des partenariats avec des associations interprofessionnelles et des entreprises locales, impliquent fortement les services de restauration collective et, enfin, mettent l'accent sur le secteur de la petite enfance (de zéro à cinq ans). Si la jeunesse scolarisée (surtout en écoles primaires et en centres de loisirs), les personnes âgées (essentiellement en maisons de retraite), les femmes enceintes, les habitants des quartiers prioritaires de la politique de la ville et les populations précaires sont également pris en considération par les différentes communes et communautés de communes souscrivant au PNNS, la signature de la charte constitue un levier d'action permettant à la collectivité publique de rendre visible son engagement en faveur de la santé des populations en recourant à un label unique et considéré, le plus souvent, comme valorisant.

La « caution PNNS » ne doit toutefois pas masquer la grande diversité des actions mises en œuvre à l'échelle de la région Midi-Pyrénées, l'éventail des possibles étant conditionné par les ressources humaines et matérielles localement mobilisables et par les traductions territoriales du programme ayant cours ici et là. Ainsi les dominantes privilégiées par le PNNS (alimentation, activité physique et nutrition) sont-elles inégalement réparties sur le territoire régional. Majoritaires, les actions portant sur le versant alimentaire constituent la « porte d'entrée » dans le programme dont elles incarnent, d'une certaine façon, le premier niveau de lecture. Ces dernières se déroulent de façon continue quand elles sont mises en œuvre par les services de restauration collective et de façon ponctuelle par l'organisation de manifestations telles que « La semaine du goût », « Mouvéat » ou « Fraich'attitude »<sup>6</sup>. Les actions développant le volet physique et sportif du PNNS sont moins fréquentes et visent en général à lutter

contre la sédentarité et à promouvoir une pratique physique régulière auprès des jeunes, parfois de leurs parents, des personnes âgées ou du grand public. Enfin, les actions à dominante nutritionnelle, c'est-à-dire combinant alimentation et activité physique au sens donné par le PNNS, sont plus rares, les acteurs de terrain faisant mal la différence entre nutrition et alimentation.

De même, les caractéristiques professionnelles et organisationnelles présentées par les promoteurs locaux des actions préconisées par le PNNS illustrent à nouveau la diversité des modes de mise en œuvre du programme national qui prévalent en Midi-Pyrénées. Le plus souvent constitués d'un duo élu-technicien territorial ou directeur de service, voire d'un trio quand une diététicienne est sollicitée, ces acteurs stratégiques à l'échelle locale attestent la grande variété des délégations des élus et des services labellisés « référents PNNS ». Ainsi huit des 14 communes et communautés de communes signataires de la charte ont-elles chargé des techniciens et des directeurs de services de mettre en œuvre le programme sur leur territoire : quatre proviennent des services de la restauration collective, deux des services de santé, un du service des sports, le dernier étant directeur général des services. De même, les six élus en charge du PNNS dans les communes restantes sont respectivement délégués à la santé (pour deux d'entre eux), aux affaires sociales (pour deux autres), les deux derniers se partageant, d'une part, une délégation à la jeunesse, au sport et aux loisirs et, d'autre part, une délégation aux relations avec les associations.

#### UNE TYPOLOGIE DES MODES DE COORDINATION

Le faible niveau de contrainte imposé par la signature de la charte dans la mise en œuvre locale du PNNS explique la variété des actions proposées et des formes pratiques de leur concrétisation. Il en va de même pour les modes de coordination entre les acteurs et les ressources, internes et externes à la collectivité, qu'ils mobilisent. Ainsi quatre différentes modalités de coordination interne président à la traduction territoriale du programme en Midi-Pyrénées : la forme intégrée se caractérise par une coordination intersectorielle, une action publique transversale et la constitution d'un comité local de pilotage du PNNS; la forme centralisée voit un secteur d'intervention (les services de la restauration collective, des sports, de la santé, de l'éducation ou de l'action sociale...) prédominer et orienter fortement le contenu du PNNS en local; la forme diffuse consiste, pour sa part, en des arrangements faiblement formalisés entre acteurs et en des actions non pérennisées; enfin, la forme éclatée présente une coordination entravée par des relations d'indifférence voire des conflits ouverts opposant plusieurs porteurs locaux se réclamant du PNNS et débouchant sur des mises en œuvre contradictoires du programme national à l'échelle de la commune ou de la communauté de communes.

Cette typologie est affinée par la mise au jour de deux modalités de coordination externe rendant compte de l'hétérogénéité des processus de mise en œuvre du PNNS en Midi-Pyrénées. Ainsi la forme ouverte différencie-t-elle les collectivités signataires de la charte « ville active » en capacité de mobiliser entre quatre et neuf partenaires extérieurs au territoire communal (ou intercommunal) et appartenant à des secteurs d'action différents (relevant le plus

fréquemment des domaines sanitaire et médical, agroalimentaire, sportif et éducatif) de celles disposant de peu de ressources de proximité mobilisables et jouissant d'une faible connaissance des réseaux et des institutions publiques susceptibles de les soutenir. Cette forme autarcique de coordination externe est propre à des collectivités de taille démographique modeste, géographiquement éloignées de Toulouse, la métropole régionale, et dont l'implication locale dans le PNNS est récente.

#### DEUX CONCEPTIONS VARIABLES DE LA SANTÉ PUBLIQUE

Les communes et communautés de communes signataires de la charte en Midi-Pyrénées accusent une dernière singularité témoignant des traductions différenciées du PNNS en région. Celle-ci tient à la dimension cognitive soutenant deux conceptions variables de la santé publique et orientant sensiblement différemment l'action publique locale de prévention sanitaire. Ainsi une première conception, très majoritairement présente au sein des collectivités souscrivant au plan national, développe les préceptes de l'éducation pour la santé selon lesquels les programmes préventifs doivent s'adresser en priorité aux individus et groupes sociaux désignés comme « à risques » pour les convaincre d'adopter de « bons comportements alimentaires et des pratiques physiques saines ». L'action publique de prévention sanitaire consiste alors, selon une logique normative et prescriptive, à assurer la diffusion la plus large possible des messages du PNNS par les instruments incitatifs, budgétaires et conventionnels mis à disposition. Toutefois, une seconde conception de la santé publique prend résolument le contre-pied de cette orientation dominante et, selon une option militante inspirée des principes de la promotion de la santé (au sens de la Charte d'Ottawa de l'Organisation mondiale de la santé), entend dépasser la seule inculcation de règles de santé et se focaliser sur les inégalités sociales et territoriales de santé engendrées par les facteurs environnementaux. Reprochant au PNNS son inclinaison moralisatrice, voire son penchant stigmatisant à l'endroit des populations défavorisées, émigrées ou en situation précaire, les partisans de cette voie alternative appellent à la participation des ressortissants (Warin 1999), au développement d'une « démarche communautaire en santé » privilégiant les actions de proximité et à la responsabilisation de tous les citoyens au sein d'une « démocratie sanitaire » à construire (Giraud et Warin 2008).

C'est là l'option de Toulouse<sup>7</sup>, métropole dans laquelle la traduction du PNNS prend, en effet, la forme d'un « transcodage » au sens où les activités cognitives et les processus de mobilisation et de négociation sur lesquels repose l'action publique sanitaire locale font l'objet d'un profond renouvellement (Lascoumes 1996). Au changement d'échelle territoriale vient ainsi s'ajouter une modification sensible du référentiel de l'action publique sanitaire (Muller 1995). Signataire, le 13 décembre 2006, de la charte du PNNS, la municipalité de Toulouse entend ne pas limiter sa politique de santé publique aux préconisations du plan national et travaille à s'inscrire dans une visée volontariste. Le rapport des acteurs publics de la ville au PNNS est, en effet, critique. Lui est reproché sa relative inadéquation aux demandes sociales les plus urgentes en matière de santé publique, son absence de fondement juridique et son incapacité

à générer des moyens supplémentaires. La ville s'engage alors dans la définition et la mise en place d'un plan municipal de santé qui repose sur une approche globale prenant en compte les dimensions physiques, psychologiques, sociales et environnementales et privilégiant les actions de proximité. Il s'agit également de favoriser la participation des habitants à la définition des modalités d'intervention publique qui leur sont prioritairement destinées, de permettre ainsi l'intrusion de la société civile dans le débat public et de veiller à l'intégration des savoir-faire associatifs nés des expertises militantes et profanes dans les programmes locaux d'action publique sanitaire.

## Conclusion

Localement située, la construction sociale du PNNS traduit donc les différents modes d'appropriation territoriale dont le programme national est l'objet. La sociologie politique de cette action publique sanitaire rend compte des formes de recomposition empruntées localement par l'État en action qui joue sur le caractère plus ou moins contraignant du cadre normatif qu'il entend faire valoir. Au-delà des préconisations des deux premiers PNNS (et préfigurant, en partie, la troisième période du programme national), c'est alors la question des inégalités sociales, et territoriales, de santé qui domine les enjeux de l'action publique sanitaire locale. Largement partagé et inscrit dans les grands textes fondateurs de la République, « l'objectif est d'améliorer l'état de santé de la population dans son ensemble et de chacun en particulier, quelle que soit son origine ou son appartenance sociale » (Haut conseil de santé publique 2010). En effet, on sait, d'une part, que la détérioration graduelle des indicateurs de santé connaît de fortes disparités territoriales et, d'autre part, que les déterminants de santé ne concernent pas uniquement l'accès aux soins. Éducation, emploi, logement, revenu, patrimoine, modes de consommation ou pratiques culturelles... l'ensemble des paramètres sociaux qui déterminent les conditions de vie propres à un environnement donné, et qui constituent autant de facteurs à risque potentiels, vont s'accumulant tout au long de la vie (le processus est bien rendu par l'épidémiologie biographique : Lang 2010; Lang et al. 2009), jusqu'à faire système. Voyant « une situation sanitaire globale relativement bonne [tolérer] des inégalités sociales de santé particulièrement fortes » (Leclerc et al. 2008; Spira 2010), le « paradoxe français » appelle ainsi un mode d'intervention public à la hauteur des déséquilibres constatés.

Si les stratégies volontaristes mises en place au Royaume-Uni et aux Pays-Bas sont en mesure d'inspirer l'action publique sanitaire française (tant nationale que locale), c'est manifestement du côté du Québec que cette dernière semble se tourner prioritairement. Engagé, depuis 1998, dans un vaste programme de lutte contre les inégalités sociales de santé mêlant les milieux médicaux, politiques et associatifs, le directeur de la santé publique de Montréal indique n'avoir « qu'un seul patient : Montréal » (Direction de la santé publique de Montréal, 1998; Frohlich et al. 2008). « Renforcer la concertation dans les quartiers, outiller les populations locales pour la prise en charge de leurs conditions de vie, intégrer et coordonner l'action des divers intervenants, développer un observatoire et des indicateurs de surveillance des inégalités sociales de santé, c'est ainsi que les acteurs de santé publique de Montréal redéfinissent

alors leur pratique » (Potvin 2010) et font figure d'experts auprès des promoteurs du plan municipal de santé de Toulouse.

Toutefois, si l'exercice de sociologisation et d'historicisation de l'action publique sanitaire locale tenté ici présente le mérite de valoriser le volontarisme dont fait preuve la quatrième ville de France en la matière, il témoigne plus fondamentalement du processus général de dérégulation du système de santé français dont les vertus étaient internationalement vantées jusque-là. Comptant parmi les nombreux programmes de prévention primaire impulsés « d'en haut », dans un contexte de réduction drastique de la dépense publique, le PNNS ne dispose pas d'autre moyen que de recourir à l'injonction morale à l'exercice physique d'entretien du corps. Abusant ainsi de la rhétorique de l'auto-responsabilisation par laquelle il est intimé à chacun de se prendre en main et de renoncer à continuellement solliciter une intervention publique aujourd'hui dépourvue de moyens, l'appel à l'estime de soi et le discours récurrent de la mobilisation citoyenne et de l'empowerment ne parviennent pas à masquer le retrait de l'État de la question sanitaire. Reportant la charge sur les collectivités territoriales (dans la confusion de leurs différentes échelles d'action et de la répartition de leurs compétences respectives), le désengagement de l'État donne, en effet, libre cours au jeu des concurrences entre une myriade de fiefs locaux diversement dotés et qui décident, ou non, de mettre la santé à l'agenda public.

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#### NOTES :

1. Placés sous la direction de Nadine Haschar-Noé, le premier (Sport et santé publique, sociologie politique des programmes de lutte contre la sédentarité) est financé par l'Institut de recherche en santé publique, le second (Activité physique, nutrition et santé : la mise en œuvre du Programme national nutrition santé en Midi-Pyrénées) par le Conseil régional de Midi-Pyrénées.
2. Selon l'Institut national de la statistique et des études économiques en 2009.
3. Les données sanitaires sont extraites de : Observatoire régional de la santé de Midi-Pyrénées, 2009, *La santé observée en Midi-Pyrénées. Faits marquants. Surpoids et obésité*, Toulouse, ORSMIP.
4. Services déconcentrés de l'État, les DRASS, remplacées depuis juillet 2009 par les agences régionales de santé (ARS), se voient confier la mission de relayer les objectifs, principes et repères des programmes de santé sur les territoires et de susciter la participation des acteurs locaux dans une perspective de construction collective de l'action publique sanitaire. À ce titre, elles sont chargées d'organiser l'animation et le pilotage d'un partenariat multi-niveaux avec les acteurs publics et privés intéressés.

5. Visant à modifier les habitudes alimentaires des enfants et des adolescents, le programme consiste, depuis 2009, en une distribution gratuite, hebdomadaire et hors restauration scolaire de fruits (des pommes, le plus souvent) dans les écoles, les collèges et les lycées.
6. Inaugurée en 1990 par un critique gastronomique, « La semaine du goût » promeut une éducation gustative (prioritairement auprès des responsables de restauration collective et des enfants des écoles) visant à combiner plaisir, patrimoine culinaire et comportements alimentaires favorables à la santé. Par ailleurs, depuis 2007, le programme « Mouvéat » défend, par des journées d'animation ponctuelles, une définition de la nutrition conjuguant alimentation équilibrée et activité physique régulière. Enfin, par la « Fraich'attitude », l'association interprofessionnelle de la filière des fruits et des légumes frais incite, depuis 2005, les enfants à « découvrir ou redécouvrir » ses produits.
7. Chef-lieu de la région Midi-Pyrénées, du département de la Haute-Garonne et quatrième ville de France avec 439 453 habitants, Toulouse connaît, depuis les années 1990, la plus forte croissante démographique du pays.

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# Les minorités linguistiques du Canada et la santé

## Linguistic Minorities in Canada and Health



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### Résumé

Les minorités de langue officielle (les francophones hors-Québec et les anglophones du Québec) représentent près de 6,4 % de la population canadienne. Bien que le français et l'anglais aient un statut d'égalité juridique selon la Constitution canadienne, il y a lieu de s'interroger sur leur égalité dans le domaine de la santé : les communautés francophones et anglophones du Canada, selon leur statut de minorité ou de majorité, présentent-elles le même profil santé ? Ont-elles accès aux mêmes services de santé et dans les mêmes conditions ? L'objectif de cet article est de rendre compte des enjeux de santé reliés au fait d'appartenir à une minorité linguistique. Nos recherches permettent de mettre en évidence des disparités sociales et de santé qui peuvent être attribuées au fait minoritaire. Dans le contexte canadien des deux langues officielles, une politique de santé équitable devra dorénavant prendre en considération la situation linguistique minoritaire comme déterminant de la santé.

### Abstract

Official language minorities (Francophones outside of Quebec and Anglophones in Quebec) make up about 6.4% of the Canadian population. Even though the Canadian constitution



gives legal equality status to French and English, there is still room to ask if this equality is maintained in the health sector. In other words, do Francophone and Anglophone communities of Canada have the same health profiles regardless of their minority or majority status? Do they have access to the same health services and in the same conditions? The objective of this paper is to identify the health issues associated with belonging to a linguistic minority. Our research allows us to highlight the social and health disparities that can be attributed to belonging to a minority. In the Canadian context, which has two official languages, an equitable health policy will have to take into consideration language as a determinant of health.

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## Introduction

L'objectif de cet article est de rendre compte des enjeux de santé reliés au fait d'appartenir à une communauté de langue officielle en situation minoritaire du Canada : les francophones vivant dans les provinces et territoires majoritairement anglophones et les anglophones vivant au Québec, seule province majoritairement francophone du pays.

À la suite d'une recommandation de la Commission royale d'enquête sur le bilinguisme et le biculturalisme (1963–1971), le gouvernement fédéral canadien a adopté la Loi sur les langues officielles (1969) faisant de l'anglais et du français, d'égal statut, les langues officielles du pays. D'abord abrogée en 1988, la Loi a été modifiée en 2005 : l'adjonction (point 41.2) modifia la Loi en renforçant le caractère exécutoire des dispositions incombant au gouvernement fédéral (Gouvernement du Canada 2011). Par l'article 41, le gouvernement fédéral s'engage à : soutenir le développement des minorités linguistiques; promouvoir la pleine reconnaissance des deux langues officielles; prendre des mesures pour assurer la progression vers l'égalité de statut et d'usage du français dans la société canadienne.

Considérant cette obligation constitutionnelle de protection des communautés de langues officielles en situation minoritaire et cette responsabilité quant à la prise de mesures propres à assurer la progression vers l'égalité de statut et d'usage du français et de l'anglais dans la société canadienne, aucune étude n'avait à ce jour vérifié le lien entre la situation minoritaire et la santé au Canada. Nos différents travaux de recherche s'y sont affairés, dévoilant à nouveau l'importance de la position sociale comme déterminant de la santé (Bouchard et Meunier 2011).

### *Les minorités de langue officielle au Canada*

D'entrée de jeu, un portrait de la situation linguistique canadienne s'impose. Des 10 provinces et trois territoires, seule la province de Québec est majoritairement francophone (85,7 % francophone / 13,4 % anglophone; 6 373 225 francophones / 994 275 anglophones). Parmi les provinces et territoires majoritairement anglophones, le Nouveau-Brunswick (32,7 % francophone / 67,2 % anglophone) et l'Ontario (4,5 % francophone / 93,4 % anglophone) ont les plus forts pourcentages de francophones. Par ailleurs, c'est en Ontario, la province la plus peuplée du Canada, que l'on retrouve le plus grand nombre de francophones hors-Québec, à savoir

537 595 francophones sur les 997 125 francophones au pays (excluant le Québec); ils représentent ainsi tout près de 54 % de la population francophone hors-Québec. Sur cette échelle, le Nouveau-Brunswick suit avec 23,5 %; suivent l'Alberta (6,3 %) et la Colombie-Britannique (6,2 %). À l'échelle nationale, on compte ainsi tout près de 2 millions (1 991 850) de Canadiens vivant en contexte linguistique minoritaire, en anglais au Québec et en français dans les autres provinces et territoires canadiens.

TABLEAU 1. Les minorités de langue officielle au Canada

Province / territoire	Population francophone	Population anglophone
Canada (excluant le Québec)	997 125	22 368 330
Ontario	537 595	11 230 380
Nouveau-Brunswick	235 130	483 845
Alberta	62 785	3 154 380
Colombie-Britannique	61 735	3 891 885
Manitoba	43 120	1 080 230
Nouvelle-Écosse	32 225	869 565
Saskatchewan	14 850	935 865
Île-du-Prince-Édouard	5 135	129 030
Terre-Neuve-et-Labrador	1 935	497 915
Yukon	1 185	28 890
Territoires du Nord-Ouest	1 005	39 730
Nunavut	425	26 610
Québec	6 373 225	994 725

Source : Statistique Canada 2007.

### *La situation des minorités linguistiques au Canada*

Le gouvernement canadien a le devoir de définir un plan de mise en œuvre des dispositions législatives pour remplir son engagement à l'égard de l'égalité des deux communautés linguistiques. Cette planification a culminé en 2003 avec le document intitulé « Le prochain acte : un nouvel élan pour la dualité linguistique canadienne » (Gouvernement du Canada 2003). Suivant ce plan, l'État fédéral entend revitaliser la dualité linguistique. Il cible son intervention en cinq axes : l'éducation, le développement des communautés, la fonction publique fédérale, la petite enfance et la santé. Dans le domaine de la santé, le plan s'appuyait sur les recommandations des comités consultatifs des communautés francophones en situation minoritaire et des communautés anglophones en situation minoritaire (Santé Canada 2001). Ces rapports fai-

sant état des difficultés rencontrées par ces communautés au sein du système de santé canadien ont conduit à deux initiatives nationales comme solutions potentielles aux problèmes relatifs au domaine de la santé : la création du Consortium national de formation en santé, dédié à la formation des professionnels de la santé dans le but de desservir les minorités linguistiques, et le réseautage des acteurs de la planification et de l'organisation des services de santé sous l'égide de Société Santé en français et du Community Health and Social Services Network of Québec.

Du côté de la recherche en santé, grâce à un financement de développement des capacités de recherche des Instituts canadiens de recherche en santé (IRSC) de cinq ans (2006–2011), un réseau de recherche sur l'Étude des facteurs socio-environnementaux, culturels et structurels qui agissent sur les disparités en matière de santé chez les francophones en situation minoritaire (RISF) a été constitué (Leis et Bouchard 2006). Le RISF s'était donné comme mission de mieux comprendre les disparités de santé qui touchent les populations francophones vivant en milieu minoritaire au Canada et contribuer à leur réduction.

### *Le cadre conceptuel*

Au Canada, comme ailleurs, les inégalités de santé sont de mieux en mieux documentées et mettent en relief l'importance des déterminants sociaux comme facteur explicatif des différentiels de longévité et de santé. Depuis la parution du rapport Lalonde en 1974, intitulé « Nouvelle perspective de la santé des Canadiens » (Lalonde 1974), la santé commence à être envisagée de manière multidimensionnelle considérant à la fois le rôle des facteurs biologiques, comportementaux, environnementaux et médicaux. Durant les années 1980, la charte d'Ottawa pour la promotion de la santé identifie trois grands défis canadiens en matière de santé : 1) réduire les inégalités de santé, 2) accroître la prévention, 3) créer des milieux sains (Epp 1986). Enfin, durant les années 1990, un groupe de chercheurs de l'Institut canadien de recherches avancées (ICRA) propose une approche plus intégrée de la santé qui deviendra l'approche santé des populations. L'ouvrage intitulé « Être ou ne pas être en santé » (Evans et al. 1996) propose un cadre d'analyse de l'ensemble des déterminants de la santé et de leurs interactions. Les auteurs soulèvent un paradoxe inouï pour des pays développés, à savoir l'existence, mais surtout la persistance d'inégalités de santé.

Les inégalités sociales se définissent comme résultant d'une répartition injuste des ressources telles que l'argent, l'éducation et le pouvoir et fondent la théorie des inégalités de santé (Wilkinson 1996). La thèse principale qui prévaut dans ce domaine de recherche est celle de la position sociale, le « Status syndrome », comme l'appelle Michael Marmot (2004), le chercheur pionnier du domaine; les individus au bas de l'échelle sociale sont plus malades et meurent plus précocement, et ce quel que soit le problème de santé. Ainsi, le sentiment d'infériorité, les conditions de vie dans la pauvreté, l'adversité, les événements stressants de la vie et les rapports de pouvoir constituent les déterminants sociaux à la source du gradient de santé, c'est-à-dire des disparités de santé entre individus et groupes sociaux.

## Les résultats de recherche

La documentation disponible sur la santé des minorités de langue officielle n'est pas très abondante et souvent partielle. D'une part, pour des raisons techniques, du fait que la variable linguistique est soit absente, soit non standardisée dans nos systèmes d'information (données administratives de santé, données d'enquêtes populationnelles), et d'autre part en raison de faibles infrastructures de recherche et du faible nombre de chercheurs. À cela s'ajoute l'absence, jusqu'à tout récemment, de préoccupations gouvernementales envers les minorités linguistiques.

L'étude issue de nos travaux sur les déterminants de la santé en situation minoritaire dans le cadre de l'Enquête nationale de santé dans les collectivités canadiennes (ESCC) (Bouchard et al. 2009c) avait été précédée par deux autres études : les études du Programme de recherche, d'éducation et de développement en santé publique (REDSPP) du Ministère de la santé de l'Ontario dirigées par Louise Picard (Picard et Allaire 2005) et l'étude sous la direction de Léandre Desjardins sur la santé au Nouveau-Brunswick (Desjardins 2003). Les principaux résultats démontraient que la population francophone de l'Ontario est plus âgée, qu'elle est moins scolarisée et qu'elle a un revenu inférieur à la moyenne provinciale; qu'elle se perçoit en moins bonne santé, ressent davantage de limitations dans ses activités quotidiennes et adopte un style de vie plus nuisible à la santé en termes de tabagisme, de consommation d'alcool et de régime alimentaire (Boudreau et Farmer 1999). Quant aux francophones du Nouveau-Brunswick, si l'état de santé s'est amélioré depuis 1985 (Robichaud 1985), le rapport de Desjardins (2003) montre que certaines régions continuent de présenter des indicateurs plus défavorables à la santé, ainsi que des défaillances notables en termes d'infrastructures et d'équipements hospitaliers, notamment dans les régions de Campbellton et de Miramichi. Des disparités prononcées entre le nord et le sud de la province en ce qui a trait au ratio médecin – population ont été relevées.

Il faut également souligner la production d'un rapport par Sarah Bowen (2001), qui a documenté la question des impacts des barrières linguistiques en santé touchant différents groupes minoritaires dont les Premières nations, les communautés culturelles ne parlant aucune des langues officielles, les malentendants et les communautés de langue officielle minoritaire. Le rapport illustre clairement les impacts négatifs des barrières linguistiques. Les limitations qu'elles causent pour les communautés de langue officielle en situation minoritaire se traduisent en réalités observables.

Les analyses secondaires de l'ESCC que nous avons conduites ont permis d'une part de confirmer les observations des études antérieures, mais cette fois-ci à l'échelle canadienne, et d'autre part d'objectiver une relation entre la situation linguistique minoritaire et la mauvaise santé perçue (Bouchard et al. 2009a).

Dans un article paru en 2009, nous avons pu démontrer une association entre le fait d'être francophone en situation minoritaire et la santé perçue. L'étude rapportait que la

minorité francophone se percevait en moins bonne santé que la majorité anglophone, tant chez les hommes que chez les femmes, mais lorsque nous ajustons pour diverses variables sociodémographiques et sanitaires il demeure chez les hommes francophones un résiduel de disparité que nous pourrions attribuer au facteur de « vie en situation minoritaire. »

Ces résultats soulèvent un fait important qui n'avait jamais été exploré dans le contexte canadien des langues officielles. Comme l'a amplement démontré la littérature, l'âge, le sexe et le revenu sont les principaux déterminants de la santé, mais le fait de vivre en situation linguistique minoritaire n'avait pas, jusqu'à maintenant, été documenté. Ainsi, le rapport minoritaire–majoritaire semble traduire une inégalité sociale et d'accès aux ressources qui, en s'ajoutant à d'autres déterminants de la santé, contribue de facto aux disparités de santé. L'étude montre l'importance d'approfondir et de mieux comprendre l'ensemble des déterminants de la santé ainsi que les interactions entre les contextes, les milieux de vie locaux, l'impact des politiques et la santé.

TABLEAU 2. Santé des minorités linguistiques

Indicateurs	Francophones minoritaires <sup>1</sup> (%)	Anglophones majoritaires <sup>1</sup> (%)	Francophones majoritaires <sup>2</sup> Québec (%)	Anglophones minoritaires <sup>2</sup> hors-Montréal (%)
Mauvaise santé perçue	16,65	13,14	12,26	13,69
65 ans et plus	19,46	17,74	17,69	24,16
< niveau d'études secondaires	20,73	12,39	20,37	17,62
Faible revenu (0–19 <sup>e</sup> percentile)	20,43	17,28	17,48	21,04
Région rurale	29,53	17,75	20,91	30,12
> 2 maladies chroniques	20,08	17,17	15,66	20,26
Difficulté à accomplir une tâche	18,28	15,96	14,69	16,33
Pas de médecin	9,90	10,36	23,82	21,49
< 5 portions de fruits & légumes	60,35	60,54	57,54	57,66
Fumeur régulier et occasionnel	72,43	65,83	72,95	67,56
Buveur régulier et occasionnel	81,39	79,30	84,4	78,01
Inactif (au plan physique)	53,69	52,21	57,92	57,25
IMC + 30 *	18,26	16,55	14,37	18,71

Source : Bouchard et al. 2009c.

<sup>1</sup> Canada, sans le Québec: Données pondérées sur un échantillon de 256 966 personnes : 12 584 francophones et 244 382 anglophones.

<sup>2</sup> Québec : Données pondérées sur un échantillon de 42 996 personnes : 4 240 anglophones et 38 756 francophones

### *La minorité francophone vs la minorité anglophone*

Au niveau général, comme l'indique le tableau 2, le profil de la minorité francophone à l'extérieur du Québec montre qu'une proportion plus élevée se perçoit en mauvaise santé,

**TABLEAU 3.** Accès général aux services de santé dans la langue minoritaire par région géographique

Région géographique	Trouve qu'il serait difficile d'obtenir des services de santé dans la langue minoritaire (%)	A utilisé la langue minoritaire avec le médecin de famille régulier (%)	A utilisé la langue minoritaire avec l'infirmière (%)
Terre-Neuve-et-Labrador	78	9	–
Île-du-Prince-Édouard	66	–	5
Nouvelle-Écosse	57	17	11
Nouveau-Brunswick (total)	11	79	85
Région Nord	6	92	97
Région Sud-Est	8	82	88
Région Centre et Sud-Ouest (reste)	45	27	30
Québec (total)	26	81	60
Région Estrie et Sud	31	75	46
Région Est	37	68	67
Région Montréal	23	89	67
Région Ouest	26	78	54
Région Québec et environs	57	15	8
Reste du Québec	50	51	37
Ontario (total)	40	33	36
Région Nord-Est	30	37	42
Région Ottawa	30	49	50
Région Sud-Est	17	76	70
Région Toronto	69	6	–
Reste de l'Ontario	64	8	8
Manitoba	40	16	16
Saskatchewan	72	–	–
Alberta	67	3	–
Colombie-Britannique	71	–	–
Territoires (regroupés)	63	–	–
Canada moins le Québec	35	41	51

Source : Gagnon-Arpin et al. 2013.

est plus âgée, est moins éduquée, est plus pauvre, déclare au moins deux maladies chroniques, une difficulté à accomplir une tâche, fumer et boire et avoir un indice de masse corporelle supérieure à 30 kg/m<sup>2</sup>. La minorité anglophone du Québec, quand nous en extrayons la population de Montréal, présente un profil similaire. Quant à la proportion de répondants se déclarant inactifs, qu'ils soient en situation minoritaire ou non, elle est significativement plus élevée au Québec que dans le reste du Canada. De même, le pourcentage déclarant ne pas avoir de médecin est le double au Québec (23 %) par rapport au reste du Canada (10 %).

Le profil santé de la minorité francophone est très diversifié selon la province de résidence. Si le pourcentage moyen des perceptions de la mauvaise santé est de 17 %, au Nouveau-Brunswick c'est le fait de 20 %, en Nouvelle-Écosse de 19 % comme en Saskatchewan (19 %). Si nous examinons l'indicateur d'indice de masse corporelle supérieure à 30 kg/m<sup>2</sup>, un indicateur d'obésité et de maladies chroniques, les francophones de quatre provinces se situent au-dessus du pourcentage moyen canadien de 18 % : 21 % en Nouvelle-Écosse, 20 % au Nouveau-Brunswick et au Manitoba et 25 % en Saskatchewan.

Au Québec, la minorité anglophone la plus défavorisée habite l'est du Québec : 18 % de cette population se perçoit en mauvaise santé, 44 % a moins d'un diplôme secondaire, 33 % se situe dans le niveau de revenu inférieur (0–19<sup>e</sup> percentile), 53 % est inactive sur le marché du travail, 37 % n'a pas de médecin de famille, 47 % déclare plus de deux maladies chroniques et 29 % se situe dans la catégorie de l'indice de masse corporelle au-dessus de 30 kg/m<sup>2</sup>.

L'enquête postcensitaire de 2006 qui a porté sur la vitalité des communautés de langue officielle du Canada (Corbeil et al. 2007) permet de jeter un éclairage nouveau sur l'offre et l'utilisation de services de santé en langue minoritaire (Tableau 3). L'analyse secondaire que nous en avons faite (Gagnon-Arpin et al. 2013), indique que c'est à Terre-Neuve que la proportion de répondants qui affirme qu'il est difficile d'obtenir des services de santé en langue minoritaire est la plus élevée (78 %), puis en Colombie-Britannique (71 %), et c'est au Nouveau-Brunswick où elle est la plus faible (11 %), bien que la région centre et sud-ouest détone (45 %), alors que le pourcentage moyen canadien, sans le Québec, est de 35 %.

L'utilisation de la langue minoritaire avec le médecin est le fait de 41 % des francophones et avec l'infirmière de 50 %. La proportion de répondants sur cette question est la plus élevée au Nouveau-Brunswick, sauf encore pour la région centre et sud-ouest. Au Québec, 80 % de la minorité anglophone s'exprime dans sa langue avec le médecin, mais 60 % avec l'infirmière. Dans la région de Québec et environs, seulement 15 % déclarent parler anglais avec le médecin et 8 % avec l'infirmière.

## Conclusion

Force est de constater que le champ de recherche sur les minorités de langue officielle du pays a permis de mettre en évidence des disparités sociales et de santé qui peuvent être attribuées au fait minoritaire. Le rapport minorité–majorité, nous semble-t-il, traduit une inégalité sociale et d'accès aux ressources qui s'ajoute aux autres déterminants sociaux.



Ces premières études au niveau national montrent que le contexte politique et le cadre législatif dans lesquels vit la minorité peuvent expliquer la variation qui traverse le pays. Ainsi, nous constatons qu'au Nouveau-Brunswick, province officiellement bilingue, bien que les déterminants sociaux soient défavorables, la minorité francophone apparaît mieux desservie dans sa langue. Au Québec, province francophone mais anglo-dominée historiquement, la minorité anglophone présente deux portraits distincts selon qu'elle habite la région métropolitaine de Montréal ou les autres régions de la province. Montréal est reconnue pour ses grandes institutions publiques anglophones et le Québec a incorporé dans sa loi sur les services de santé un article assurant l'offre de services en anglais. Par contre la minorité anglophone vivant dans l'est du Québec semble particulièrement vulnérable. Ces résultats laissent suggérer une relation entre l'affirmation nationale francophone et une situation sanitaire défavorable plus marquée pour la minorité anglophone des régions. En Ontario, la minorité francophone bénéficie d'une loi sur les services en français mais le poids de l'assimilation a eu ses effets négatifs sur la vitalité d'une population qui a dû s'angliciser pour accéder aux ressources. Plus nous nous éloignons vers l'ouest, plus ce fait est marqué, particulièrement en Saskatchewan où le profil de la minorité francophone montre des signes d'un vieillissement plus prononcé, avec les problèmes de santé qui peuvent s'ensuivre.

La langue est en première ligne de la communication entre les professionnels de la santé et la population et les impacts des barrières linguistiques sur la santé sont de mieux en mieux documentés. Dans le contexte canadien des deux langues officielles, une politique de santé équitable devra dorénavant prendre en considération la situation linguistique minoritaire comme déterminant de la santé.

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# Beyond 'Run, Knit and Relax': Can Health Promotion in Canada Advance the Social Determinants of Health Agenda?

Au-delà de « courir, tricoter et relaxer » : la promotion de la santé au Canada peut-elle faire progresser les déterminants sociaux du programme de santé ?



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## Abstract

Can health promotion in Canada effectively respond to the challenge of reducing health inequities presented by the WHO Commission on Social Determinants of Health? Against a background of failure to take seriously issues of social structure, I focus in particular on treatments of stress and its effects on health, and on the destructive congruence of Canadian health promotion initiatives with the neoliberal "individualization" of responsibility for (ill) health. I suggest that the necessary reinvention of the health promotion enterprise is possible, but implausible.

## Résumé

La promotion de la santé au Canada peut-elle vraiment relever le défi d'une réduction des inégalités en matière de santé, tel que présenté par la commission des déterminants sociaux de la santé de l'OMS? Dans le contexte où les enjeux de la structure sociale ne sont pas vraiment pris au sérieux, je me penche sur le traitement du stress et ses effets sur la santé ainsi que sur la congruence destructive entre les initiatives canadiennes de promotion de la santé et l'« individualisation » néolibérale des responsabilités quant à la (mauvaise) santé. J'avance qu'une réinvention nécessaire du projet de promotion de la santé est possible, bien que peu plausible.

THE REMARKABLE 2008 REPORT OF THE WHO COMMISSION ON SOCIAL determinants of Health (“the Commission”), chaired by Sir Michael Marmot, began with the observation that “social injustice is killing people on a grand scale” (Commission 2008; for an overview, see Marmot et al. 2008). As suggested by the reference to social justice, the Commission’s approach was explicitly and unapologetically normative, organized around the imperative of eliminating health inequities – “systematic differences in health” that “are judged to be avoidable by reasonable action.” Perhaps unfortunately, the Commission did not elaborate on the major philosophical arguments in support of this position, or on what might constitute “reasonable action” and who should define it. Unfortunately as well, the Commission did not pay much attention to issues of implementation beyond calling for a global social movement. However, it is clear that the Commission was willing to challenge underlying economic and social inequalities and the processes that generate and sustain them. Its report characterized the “unequal distribution of health-damaging experiences” as “not in any sense a ‘natural’ phenomenon but ... the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics” (Commission 2008: 1).

Shortly after the Commission’s report appeared, Australian researcher Frances Baum, who had been a member of the Commission, wrote that implementing its recommendations would require “reinventing health promotion for the twenty-first century” with a focus on macro-level aspects of social organization, as “the core of a social movement which advocates for new healthy, equitable and sustainable economic and social structures globally and within countries” (Baum 2008).

In this paper, I explore key challenges in the Canadian context to the reinvention that Baum suggests, focusing on how health promotion continues to emphasize individual-level factors and behavioural rather than structural interventions. I suggest that although the reinvention in question is not impossible, it is implausible. Against that background, it is worthwhile to rethink the future of the health promotion enterprise as a whole.

### The Pervasiveness of Lifestyle Drift

Although a solid historical sociology of the post-1986 institutionalization of health promotion has yet to be written, useful observations are provided in the second edition of a widely cited book, *Health Promotion in Canada* (O’Neill et al. 2007a). In one of the overview chapters, O’Neill and Stirling (2007: 35) note that a terminological shift from the earlier vocabulary of health education to health promotion recognizes the limits of “just working to change individual lifestyles,” but little evidence suggests that the terminological shift has meant anything in practice. Indeed, the book’s editors concede that “the practice of health promotion in all jurisdictions has still largely been based on individual lifestyle change” (Dupéré et al. 2007: 373), and the authors of one of the few chapters that is cautiously critical of health promoters’ emphasis on “personal skills” and individual-level risk factors concede that a “larger focus on increasing the options available to people to exercise more control over their own health and their environments ... has been, for the most part, more evident in rhetoric than in practice” (Frohlich and Poland 2007: 47; see also Low and Thériault 2008).

This is the phenomenon described by British researchers Popay and colleagues (2010) as lifestyle drift: “the tendency for policy to start off recognizing the need for action on upstream social determinants of health inequalities only to drift downstream to focus largely on individual lifestyle factors.” Lifestyle drift is endemic in Canadian health promotion and public health; only a few examples can be presented here. A report on how to make the province of Ontario a leader in population health argues for a focus on improved health behaviours such as healthy eating, physical activity, maintaining healthy body weight, avoiding tobacco and reducing stress (Manuel et al. 2009). The authors acknowledge that “[i]t is fundamentally unfair to try and change social attitudes or to tell poor people they should take more responsibility for their health if governments do not remove societal barriers which might prevent them from doing so” (Manuel et al. 2009: 6). However, in the text of the document as a whole there is one reference to poverty, one to unemployment, no reference to food insecurity (despite a substantial body of research on the topic; see, e.g., Dachner and Tarasuk 2002; Kirkpatrick and Tarasuk 2009; Tarasuk and Vogt 2009; Tarasuk et al. 2009), but 65 to health behaviours, health behaviour strategies, health behaviour targets and the like. A survey of initiatives related to healthy eating and physical activity in Ontario and British Columbia (Gore and Kothari 2012) found a preponderance of lifestyle- or environment-based rather than structure-based initiatives, even using a broad and inclusive definition of the latter category – this despite an accumulation of research evidence that the pathways leading to overweight and obesity are multiple and complex, and involve such factors as income distribution, various aspects of the built environment and the marketing strategies of the food and beverage industries, as well as “individual responsibility” (Glickman et al. 2012; Moodie et al. 2013; Shih et al. 2012).

An especially egregious example of indifference to structural factors involves a widely neglected mechanism of influence on individual health and two high-profile organizations: the Heart and Stroke Foundation (HSF) and the Canadian Mental Health Association (CMHA), which are among Canada’s largest health-related non-profits. The initiative in question, which serves to illuminate key issues related to how health promoters attribute responsibility for health and illness, is a brochure, “Coping with Stress” (HSF and CMHA 2009), that begins with a 25-item stress quiz (Table 1). The individualized focus of this checklist is indicated by the generic “Do *you*” prefix (emphasis added): every item focuses on the behaviour of the person experiencing stress, not on its sources. The brochure then warns people with high scores to “Stop. Re-think. Change your lifestyle. Improve your diet. Make physical activity a regular routine, and above all, try to find ways to relax. Is it running? Knitting? Spending time with your kids? Try to positively alter your attitudes.” Readers are further enjoined to “[w]atch out for stressors!” and “live healthy and to try to avoid things that cause [stress],” assuming that these options are routinely available. Lest there be any doubt about where responsibility for stress and its health consequences is located or what remedies are considered appropriate, readers are told that “[i]t’s how *we* think, or react, that makes us feel over-stressed” (emphasis added), but that doctors – or, if financial concerns are a source of stress, credit counselling services – can help.

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TABLE 1. Heart and Stroke Foundation stress quiz

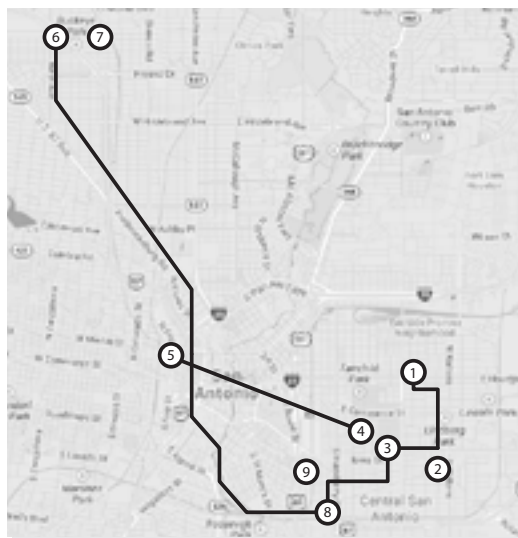
Do you frequently...	Yes/No		Yes/No
Neglect your diet?		Use sleeping pills or tranquilizers without consulting a doctor?	
Try to do everything yourself?		Not get enough rest?	
Blow up easily?		Get angry when you are kept waiting?	
Seek unrealistic goals?		Ignore stress symptoms in your habits and attitudes?	
Fail to see the humour in situations others find funny?		Put things off until later?	
Act rude?		Think there is only one right way to do something?	
Make a "big deal" of everything?		Fail to include relaxation time in your day?	
Look to other people to make things happen?		Gossip?	
Have difficulty making decisions?		Impatiently try to race through your day?	
Complain you are disorganized?		Spend a lot of time complaining about your past?	
Avoid people whose ideas contradict your own?		Fail to get a break from noise and crowds?	
Bottle up everything inside?		<b>Score 1 for each "YES" answer.</b>  <b>TOTAL YOUR SCORE</b>	
Avoid or neglect physical activity?			
Have few or no supportive relationships?			

Source: HSF and CMHA 2009.

It is useful to contrast this approach with Marmot's eloquent description of how daily financial exigencies and the threat of job loss – factors that are increasingly widespread and entirely out of the control of those experiencing their consequences – affect line workers, on the one hand, and factory owners/managers, on the other; and of how combining the contrast with well-established findings about the physiology of stress helps to explain socio-economic gradients in health that are ubiquitous in societies rich and poor alike (Marmot 2004: 109–41). Marmot made his name in epidemiology by way of two prospective studies that identified socio-economic gradients in a wide variety of health outcomes among British public servants who were conspicuously not exposed to such material hazards as serious undernourishment, chronically insecure and precarious employment, or gender discrimination (at least in the case of the Whitehall I cohort, who were all male). Socio-economic gradients were central to the descriptive work of the WHO Commission that he subsequently chaired. Two evocative sets of research findings, generated using quite different methodologies, demonstrate the value of Marmot's perspective.

First, after 1996 US welfare “reform” legislation dismantled decades-old guarantees of income support (Newman and Massengill 2006; Ridzi and London 2006; Seccombe 2009), social scientists used “geo-ethnography,” a combination of ethnographic fieldwork with the use of geographic information systems, to generate narratives and maps of the daily activities of more than 200 families in three cities (Matthews et al. 2005). A hypothetical composite map of the daily activities of a single mother with two small children reveals a day that consists of leaving home at 6:30 a.m. to drop off children at daycare and school, followed by a bus trip of more than an hour to arrive at a place of work more than five miles away by 8:30 a.m. The researchers drily noted that “[t]he return journey home can be more complicated,” for example, if grocery shopping – via a different bus route – has to be done (Figure 1). Not a lot of time is left for “find[ing] ways to relax,” as HSF and CMHA would have us do.

**FIGURE 1.** A hypothetical journey to work for a young mother in San Antonio, TX (time: 2 hours one way). The journey must be a hypothetical composite, since describing an actual journey could identify the research participant.



- 1. Residence**  
(leave home around 6:30 a.m. to walk to daycare centre with two children)
- 2. Daycare centre**  
(arrive at daycare at 6:45 a.m. and drop off youngest child, then leave at 6:50 a.m.)
- 3. Elementary school**  
(arrive at 7:00 a.m. and drop off older child, then leave at 7:05 a.m. to walk to bus stop)
- 4. Bus stop**  
(arrive at bus stop at 7:12 a.m. to catch first bus around 7:17 a.m.)
- 5. Bus depot**  
(arrive around 7:44 a.m., wait to catch second bus around 7:54 a.m.)
- 6. Bus stop**  
(arrive at bus stop near place of work around 8:22 a.m., then begin short walk to work)
- 7. Place of work**  
(arrive at work at 8:30 a.m.)

The return journey home can be more complicated. For example, the mother may shop in area (9) near the school and daycare centre, which requires a different bus route – between the bust depot (5) and bus stop (8). After grocery shopping, the mother walks to the elementary school and daycare to collect her children, and then continues home.

Source: Matthews et al. 2005: 80. Reproduced with the kind permission of Stephen Matthews.

The picture generated by geo-ethnography is a static or short-term one; a significant insight from population health research is that the consequences of various forms of adversity accumulate over the life course (Bartley et al. 2006; Blane 2006; Hertzman and Power 2005; Morenoff and Lynch 2004;). In the second set of findings, Geronimus and colleagues (2006) used 10 indicators of allostatic load – a key concept in the physiology of stress (McEwen 2000, 2007) – to generate allostatic load scores for participants in a national survey in the US. Scores were higher for the poor than for the non-poor, and higher for Blacks than for Whites in all age groups, an effect that was not explained by the higher prevalence of poverty among



Blacks. Scores of Black women were consistently higher than for Black men; scores increased over the life course for all groups, but scores were highest, and the increase over the life course most pronounced, among Black women. Strikingly, “[i]n each age group, the mean score for Blacks was roughly comparable to that for Whites who were 10 years older” (Geronimus et al. 2006: 831). These findings are strongly supportive of the proposition that stresses attached to subaltern positions in a society that is stratified on multiple dimensions (i.e., by income, race and gender) wear out the human body over time in biologically measurable ways.

### Neoliberalism and the Limits of Health Promotion

The individualized focus of health promotion does not necessarily rest on explanations of patterns of population health that are wrong, in the sense that they are falsifiable, although they may be seriously incomplete. That focus does, however, reflect choices not to look too far or too inquisitively for what Rose (1992) famously termed the “causes of the causes” of health disparities – a concept that was central to the thinking of the WHO Commission (2007). Whatever values or politics drive such choices, they must be defended on that terrain, i.e., as what Shrader-Frechette and McCoy (1993: 84–101) describe as methodological value judgments – that is, decisions about research design that are not grounded solely in the canons of science *qua* science. (This does not mean that the work that ensues is in any sense unscientific; studies using different methodologies will yield quite different kinds of results even if each is exemplary in terms of the chosen methodology.) And because the aim of health promotion is to be regarded as in some way authoritative – a health promoter to whom no one listens is by definition ineffective – the choices must also be interrogated as exercises of power that define the boundaries of “permissible political discourse” (Walker 1986: 1237).

The values and boundaries in question are, if not derived from neoliberalism, then at least congruent with it. Neoliberalism, which has come to dominate the policy environment of the last few decades, is the doctrine that markets are the normal, natural and preferable way of organizing most forms of human interaction; that any departure from markets and the allocation of resources they generate requires justification to a high standard of proof; and that the primary function of the state is to ensure the functioning of markets, even when this requires intrusive or coercive measures (Peck and Tickell 2002; Robinson 2003: 147–294; Somers 2008: 73–92; Wacquant 2009: 304–14; Ward and England 2007). Ward and England (2007) analyze neoliberalism as comprising simultaneously a policy or program, a pattern of reorganizing state institutions and an ideology. The ideological element is essential to securing consent, or at least acquiescence, to the neoliberal reorganization of social institutions, exemplified by the post-1980 retreat from social provision in Canada and elsewhere, which has compounded the effects of growing inequalities in market income.

An indispensable treatment of the neoliberal reconstruction of public policy in Canada, and the ways we think about it, provides a finer-grained description of that ideological element in terms of individualization: “the process whereby a broad range of social issues is being reconstituted, both with respect to causes and solutions, in highly individualized terms.

Healthcare and poverty are treated as individual shortcomings, products of poor individual choices, to be remedied by emphasizing individual responsibility” at the expense of social and structural analyses (Fudge and Cossman 2002: 21–22, citations omitted). In the health policy context the effect, if not the intent, of individualization is to divert attention from what Diderichsen and colleagues (2001), in a discussion of social disparities in health that informed the work of the WHO Commission, described as “those central engines in society that generate and distribute power, wealth, and risks.”

Canadian health promoters appear reluctant to engage directly with questions of how those engines operate, or who operates them. Indeed, the introduction to the text cited earlier treats the post-1990 assault on the welfare state as a “general trend” (O’Neill et al. 2007b: 11), without further inquiry into its origins or beneficiaries. The trend is more accurately and responsibly viewed as part of a process of fundamental social reorganization, driven by specific domestic and international economic interests, that is directly relevant to the future of population health and the distribution of opportunities to lead a healthy life (Benatar et al. 2011; Harvey 2006). Practical manifestations of this political reluctance include the fact that programs to promote healthy eating ignore the simple affordability of a healthy diet for people like those reliant on social assistance (as shown by Association of Local Public Health Agencies 2009; Ottawa Public Health 2012; Dietitians of Canada 2012; Williams et al. 2012). For HSF and CMHA, it is individuals’ responsibility to make healthy choices about coping with stress and its origins. Nothing is said about the origins of stress in social organization: how and why labour markets are reducing employment security and expanding precarious employment (Vosko 2006); the fact that market incomes are stagnant or declining for much of the population (Yalnizyan and Schrecker 2010); that Canadian governments have retreated from redistributive social policies, which had the potential to offset increases in market income inequality (Heisz 2007; OECD 2011); and that public sector spending cuts, driven by the perceived imperative of deficit reduction, complicate the daily lives of those who rely on such services as public transportation, social housing and subsidized child care.

The “run, knit and relax” prescription may be an extreme example, albeit one that emanates from thoroughly mainstream organizations, or it may not be; a systematic content analysis of the health promotion messages emanating from all major non-profits would be valuable. Nevertheless, it is clear that the operating assumptions of health promotion as it has evolved in Canada routinely instantiate what Fudge and Cossman (2002) call individualization. Conversely, these assumptions are incompatible with one of the WHO Commission’s three overarching recommendations: to “tackle the inequitable distribution of power, money, and resources.” This contrast may be attributable, in part, to the institutional location of key practitioners, many of whom work in departments or agencies of government that are subject to strict political direction and control, and have little direct influence on broader social determinants of health. However, this cannot explain or excuse the indifference to structural issues of academic researchers or of non-profits. The contrast may also reflect protagonists’ training

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in such disciplines as medicine, nursing or epidemiology, which are (with rare exceptions) relentlessly focused on the individual patient or client, and on micro-level interventions that address just one aspect of daily life, with the randomized controlled trial as the gold standard (for a discussion of the limits of this focus in the context of preventing mental illness, see Schrecker et al. 2001).

The social position of researchers and practitioners may also be an issue. As an academic with a long history of precarious employment, I have spent much time over the past several years slowly and carefully explaining to supremely comfortable colleagues who own vacation homes how unemployment and economic insecurity might adversely affect health. Such colleagues are, to put it mildly, ill-equipped to respond to Donna Haraway's memorable injunction about "trusting especially the vantage points of the subjugated; there is good reason to believe vision is better from below the brilliant space platforms of the powerful" (Haraway 1988: 583) – a course of action that would seem indispensable to any serious effort to carry forward the Commission's equity-oriented agenda. And the fact that explanations of the importance of structural influences are necessary does not augur well for the reinvention of health promotion that Baum (2008) proposes.

In the Canadian context, that reinvention will require that health promoters acquire a higher level of methodological self-consciousness; recognize the congruence of their current focus with the presumptions of neoliberalism; and rethink that focus in a way that explicitly confronts neoliberalism and articulates alternatives at the levels of policy formation and quotidian practice. Such reinvention is possible, but implausible. A number of Canadians working in health promotion concede the inadequacy of more than two decades' worth of gestures towards taking structure seriously, but conceding the inadequacy of one's past approach is one thing; changing course in an increasingly inhospitable political climate is quite another. Meanwhile, an urgent corollary arises from a basic axiom in health ethics: first, do no harm. At issue is not just a shift in emphasis, but a contest among incommensurable paradigms in the Kuhnian sense. Health promotion initiatives that neglect structural influences on health and reinforce or legitimize neoliberal attributions of responsibility are not just irrelevant to the health equity agenda advanced by the WHO Commission; they are actively destructive of that agenda and its commitment to social justice. If such initiatives cannot be reinvented quickly and comprehensively, it is worth considering whether equity would be best served by shutting them down.

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# La flexibilité des médecins offrant des soins de première ligne aux personnes en situation de pauvreté : la compétence sociale revisitée

## Adaptability of Physicians Offering Primary Care to the Poor: Social Competency Revisited



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### Résumé

Cet article tente d'approfondir le thème de la compétence sociale des médecins offrant des soins de première ligne à des populations en situation de pauvreté à Montréal. La flexibilité ainsi que l'adaptation de la pratique des médecins pour correspondre aux attentes, besoins et capacités des patients se sont révélées comme étant importantes dans l'articulation du concept de compétence sociale. Le cas du paternalisme est utilisé pour démontrer comment une approche médicale historiquement et socialement contestée est réappropriée par les acteurs dans certains contextes afin de mieux répondre aux attentes des patients. Cet article présente des données obtenues dans le cadre d'une recherche qualitative reposant sur 25 entrevues semi-dirigées avec des médecins reconnus par leurs pairs pour avoir développé des pratiques exemplaires en milieu de pauvreté à Montréal.

### Abstract

This paper attempts to go deeper into the topic of social competency of physicians who provide primary care to populations living in poverty in Montreal. Adaptability as well as



the ability to tailor practices according to patient expectations, needs and capabilities were found to be important in the development of the concept of social competency. The case of paternalism is used to demonstrate how a historically and socially contested medical approach is readapted by players in certain contexts in order to better meet patient expectations. This paper presents data collected in a qualitative study comprising 25 semi-supervised interviews with physicians recognized by their peers as having developed exemplary practices in Montreal's impoverished neighbourhoods.

## Introduction

Les personnes en situation de pauvreté vivent souvent des expériences négatives de soins et se sentent parfois jugées par les médecins qui les soignent (Hutchison 2007; Loignon 2006; Loignon et al. 2009; Mercer et al. 2007; Reid 2007). Ce constat est d'autant plus regrettable que la qualité de la relation thérapeutique entre les médecins et les patients est un facteur clé de l'efficacité des soins (Bedos et al. 2003; Bedos et al. 2005; Loignon et al. 2009). La distance sociale qui subsiste entre les médecins et les personnes en situation de pauvreté est l'un des facteurs majeurs qui nuit à l'établissement d'une alliance thérapeutique.

D'une part, les personnes en situation de pauvreté éprouvent des difficultés à comprendre le langage et les recommandations des médecins, qui sont souvent exprimées dans un jargon biomédical (Boltanski 1971; Delruelle-Vosswinkel 1992). D'autre part, les médecins comprennent mal les personnes en situation de pauvreté et éprouvent des frustrations lorsque ces dernières ne suivent pas leurs recommandations. Cela engendre une attitude négative à leur égard (Hall et al. 1988; Milgrom et al. 1999; O'Shea et al. 1983; Rouse et Hamilton 1991) : les médecins tendent à être plus directifs avec eux, leur accordent moins de temps de consultation et leur donnent moins d'information sur les traitements (Hall et al. 1988). Les médecins se sentent également dépassés et peu outillés lors des consultations, car ces patients accumulent les problèmes de santé (Loignon et al. 2009; Malat 2006; Parizot 2003).

En bref, il est difficile pour les médecins d'établir une bonne relation thérapeutique avec leurs patients lorsque la distance sociale est importante. Surmonter cette distance sociale requiert donc une « compétence sociale » de la part des médecins. La compétence sociale est un processus qui repose sur des connaissances, des habiletés et des dispositions permettant une interaction fructueuse entre un soignant et un patient malgré la distance sociale qui les sépare. Elle permet aux médecins de soigner leurs patients en comprenant mieux leurs conditions de vie et en s'adaptant à leurs besoins comme à leurs capacités. Deux études récentes menées au Québec par notre équipe (Loignon et al., 2010a; Loignon et al. 2010b) auprès de dentistes soignant les démunis indiquent que cette compétence sociale contribue à renforcer l'alliance thérapeutique (Loignon et Boudreault-Fournier 2012).

Dans le cadre du projet de recherche « La compétence sociale des médecins dans la dispensation des soins aux personnes en situation de pauvreté » (Loignon et al. 2010a), nous avons tenté de discerner les compétences et les savoir-faire acquis par les médecins travaillant avec des personnes en situation de pauvreté et de déceler comment ces outils relationnels

contribuent à l'élaboration d'une alliance thérapeutique positive avec le patient. Notre recherche tente de répondre à la question suivante : est-il possible de construire un modèle de compétence sociale des médecins travaillant en contexte de pauvreté? Sans fournir une réponse complète à cette question, cet article élabore, d'un point de vue critique, le thème de la compétence sociale en s'attardant à la spécificité des réalités sociales et de la santé de l'individu.

Pour ce faire, nous utiliserons les données recueillies lors d'entrevues semi-dirigées réalisées avec des médecins reconnus par l'un de leurs pairs pour avoir acquis une compétence sociale en soignant des personnes vivant en situation de pauvreté à Montréal. Dans cet article, nous allons aborder le sujet controversé du paternalisme en médecine, ce qui nous permettra de suggérer que les médecins de notre échantillon possèdent une grande capacité à adapter leur pratique afin de combler les besoins spécifiques des patients. Ainsi, nous nous pencherons sur la flexibilité des médecins à adapter cette pratique et considèrerons cette habileté comme une forme de compétence sociale qui s'acquiert au fil du temps et de l'expérience.

Avant d'approfondir l'aspect de la flexibilité et de l'adaptation de la pratique, nous expliquerons brièvement le modèle conceptuel qui nous a permis de nous pencher sur la notion de compétence sociale. Puis, nous présenterons brièvement les quatre dimensions de la compétence qui ont émergé lors de nos entrevues. Cependant, dans le cadre de cet article, nous insisterons davantage sur la quatrième dimension émergente, soit *l'offre de soins primaires adaptés aux besoins, demandes, priorités et conceptions de la santé des patients*. Cette dernière dimension nous permettra de préciser comment les médecins ayant acquis une compétence sociale auprès des populations confrontées à la pauvreté parviennent à adapter leur pratique en diapason avec les attentes et capacités de leurs patients.

### *Cadre méthodologique*

Nous avons effectué 25 entrevues semi-dirigées avec des médecins offrant des soins primaires dans la grande région métropolitaine. Les entrevues ont été conduites de novembre 2009 à mars 2011. La sélection des médecins s'est effectuée à l'aide d'une technique qualitative de collecte de données appelée « boule de neige ». Cette méthode consiste à demander aux participants de recommander de potentiels collaborateurs pour ainsi bâtir un échantillon. Le terme « boule de neige » est utilisé métaphoriquement afin de suggérer que les relations se forment à travers des associations mutuelles, des connexions sociales et professionnelles qui ont le potentiel de générer une profusion de données. Cette technique a comme avantage de fournir une variation maximale des composantes de l'échantillon. Ainsi, la variation de l'échantillonnage demeure émergente et séquentielle (Lincoln et Guba dans Maykut et Morehouse 1994 : 57).

Nous avons demandé aux médecins interviewés de nous recommander d'autres collègues qui auraient, selon eux, acquis des habiletés et élaboré des stratégies, donc une compétence sociale, avec les populations vivant sous le seuil de pauvreté à Montréal. Tous les médecins recommandés devaient offrir des soins de première ligne et devaient pratiquer dans la grande région de Montréal. Nous avons donc rencontré des médecins travaillant avec des populations considérées comme « vulnérables » ou « en situation de pauvreté ». Les médecins interviewés

offraient des soins à une ou plusieurs des populations suivantes : personnes sur l'assistance sociale, immigrants et réfugiés, toxicomanes, itinérants, familles à faible revenu, jeunes de la rue, autochtones en milieu urbain, travailleurs précaires et mères monoparentales.

Nous n'avons pas tenté préalablement de définir en quoi consistait un « patient pauvre » ou une clientèle dite « vulnérable », car nous nous intéressions également à la construction de ces concepts du point de vue des médecins. En outre, l'une des questions posées aux médecins lors des entrevues concernait le pourcentage de leurs patients vivant en situation de pauvreté. Selon les propos rapportés par les médecins, entre 60 et 98 % de leur clientèle était composée de personnes en situation de pauvreté.

Pour notre recherche, nos entrevues ont été conduites par l'une des auteures (Boudreault-Fournier), qui a à son actif une très bonne expérience en recherche qualitative. Un guide d'entrevue, mis sur pied par la chercheuse principale (Loignon), en collaboration avec les co-chercheurs, a été utilisé pour diriger les entrevues. Les entrevues ont été enregistrées. Après chaque entrevue, un rapport sommaire a été rempli dans lequel les recommandations pour les prochaines entrevues (raffinement des questions, thèmes à ajouter, etc.) ont été inscrites. Nous avons effectué un retour sur chaque entrevue, sous forme de discussion entre Boudreault-Fournier et Loignon ainsi qu'avec d'autres membres de l'équipe de chercheurs. Enfin, la chercheuse principale s'est assurée de la fiabilité de la démarche en consultant les informations contenues dans les rapports d'entrevue et en se référant aux enregistrements audio ainsi qu'aux transcriptions.

Les entrevues ont duré en moyenne 1 heure et se sont déroulées la plupart du temps dans le bureau des médecins. Certains ont préféré faire l'entrevue dans un endroit public (café) ou privé (à leur demeure). Le choix du lieu, de l'heure et du jour de la rencontre était laissé à la discrétion des médecins. Nous avons obtenu un taux de participation élevé; tous les médecins contactés ont accepté d'emblée de participer à notre étude. Nous avons interviewé 12 femmes et 13 hommes, médecins de famille, ayant de 2 à 40 années d'expérience de pratique. Tous les médecins interviewés pratiquaient en milieu urbain.

Les entrevues ont été retranscrites intégralement puis codées grâce au logiciel NVivo (QSR). La réduction des données a été effectuée à l'aide de la codification qui consistait à étiqueter, verbatim par verbatim, les différents éléments abordés dans les entrevues. Nous avons établi une liste sommaire de codes correspondant aux différentes variables à l'étude. Cette liste s'est précisée en cours d'analyse avec l'apparition de codes induits et le raffinement des codes préexistants. Les résultats ont été présentés aux chercheurs sous forme de tableaux qui résumaient les données obtenues pour chacune des 25 entrevues.

### *De la compétence culturelle à la compétence sociale*

Il n'existe pas à ce jour de modèle qui porte sur la relation médecin-patient dans un contexte de différence sociale, par exemple entre médecins et personnes recevant de l'assistance-emploi, où la distance sociale est très marquée (Loignon et al. 2009; Malat 2006). Par ailleurs, la montée du phénomène de diversité culturelle aux États-Unis a donné lieu à un foisonnement de

travaux qui ont débouché sur des modèles de soins dans un cadre interculturel. Par exemple, le modèle de développement de la sensibilité interculturelle de et plus récemment le modèle de Campinha-Bacote (2002) sur la compétence culturelle (Bennett 1993; Campinha-Bacote 2002).

Le modèle de Campinha-Bacote comprend 5 dimensions : 1) sensibilité culturelle; 2) connaissance culturelle; 3) habileté culturelle; 4) rencontre culturelle; et 5) désir culturel. Campinha-Bacote définit la sensibilité culturelle « cultural awareness » comme une prise de conscience de son milieu culturel et professionnel pour reconnaître ses préjugés et parti pris culturels. Cette prise de conscience permet aux professionnels de la santé de ne pas imposer leurs croyances et valeurs sur d'autres cultures. La connaissance culturelle « cultural knowledge » consiste à l'acquisition de connaissances sur les patients provenant de divers groupes culturels et ethniques pour comprendre leur vision du monde, un facteur décisif dans l'interprétation du bien-être et de la maladie chez les patients. L'habileté culturelle « cultural skill » quant à elle réfère à la compétence d'amasser des données culturelles pertinentes sur le problème d'un patient « incluant une évaluation physique sensible à la dimension culturelle » pour ainsi mieux répondre aux spécificités de l'individu. La rencontre culturelle (cultural encounters) est le processus qui encourage le professionnel de la santé à s'engager directement dans des interactions interculturelles avec des patients de différentes origines. L'acquisition d'une compétence linguistique ou l'utilisation d'interprètes sont des exemples concrets de ce processus. Enfin, le désir culturel « cultural desire » correspond à la motivation que possède un professionnel de la santé à s'engager dans différentes relations culturelles. Ce désir implique une approche attentionnée; une motivation réelle à apporter des soins, en considérant le facteur culturel comme un facteur significatif dans la dispensation des soins.

De nombreux auteurs ont reproché au concept de compétence culturelle, et aux travaux qui en découlent, d'être a-théoriques et de ne proposer qu'une série de trucs à faire et à ne pas faire, avec le risque de stéréotyper les différents groupes ethniques. Nous avons retenu le modèle de Campinha-Bacote car celui-ci propose de concevoir la compétence culturelle comme un processus d'interaction sociale qui s'acquiert avec le temps et la motivation. Ce modèle s'avérerait pertinent comme point de départ pour appréhender d'un point de vue sociologique le processus d'interaction clinique où il existe des différences en termes d'appartenance de classe ou de distance sociale (Loignon et al. 2010a).

Ainsi, nous définissons la compétence sociale comme un processus qui repose sur des connaissances, des habiletés et des dispositions permettant une interaction fructueuse entre un soignant et un patient malgré la distance sociale qui les sépare. La compétence sociale telle que nous l'entendons prend forme dans le contexte des soins centrés sur la personne. Cette compétence a pour but de réduire la distance sociale qui prévaut entre le médecin et le patient démuné. Elle comprend les cinq dimensions de Campinha-Bacote : la sensibilité sociale, la connaissance sociale, l'habileté sociale, la rencontre sociale et le désir social.

Comme Campinha-Bacote, nous considérons la compétence « sociale » comme un processus d'acquisition d'habiletés et d'outils pour mieux rejoindre les besoins des patients et non

comme une fin en soi. L'acquisition de compétences est un processus qui a été mentionné par plusieurs médecins interrogés. Ils ont souligné l'importance de l'expérience dans cette acquisition, et ce, particulièrement dans un contexte social caractérisé par la pauvreté. Nous aimerions ajouter que l'acquisition de l'expérience ne se fait pas seulement en contexte médical; elle peut aussi s'acquérir à l'extérieur de celui-ci (Tervalon et Murray-Garcia 1998), y compris, toujours selon nos entrevues, lors de stages de coopération internationale et d'une pratique avec les populations amérindiennes vivant dans le Nord du Québec.

En outre, Campinha-Bacote (2002 : 181) mentionne qu'il y a une relation directe entre le niveau d'adéquation des soins de santé offerts par les médecins et la sensibilité culturelle qu'ils possèdent envers leurs patients. Brach et Fraserirector (2000) nous rappellent cependant que nous possédons peu de preuves pour identifier les compétences culturelles qui peuvent être considérées comme concluantes et encore moins de preuves sur la façon de les implanter. Cependant, une analyse préliminaire des données recueillies dans le cadre d'une recherche en cours (Loignon et al. 2010b) démontre que les patients en situation de pauvreté reconnaissent de façon générale les compétences fondamentales que devrait posséder leur médecin de famille.

#### *Les cinq composantes de la compétence sociale des médecins*

En nous partageant leurs expériences de pratique en milieu de pauvreté urbaine, les médecins interrogés font référence indirectement et spontanément aux cinq composantes du modèle de compétence sociale. Ainsi, ils reconnaissent que ces compétences font partie de ce que devrait constituer une relation positive qui favorise les soins et encourage les patients à s'investir dans la prise en charge de leur santé. Cette relation positive augmenterait l'autonomie du patient en lui procurant une forme d'« empowerment ». Ainsi, une telle approche encouragerait la participation du patient à l'amélioration de son bien-être au sens large.

Nous avons fait ressortir quatre thèmes qui correspondent à des approches mises de l'avant par les médecins concernant les soins offerts aux individus en situation de pauvreté. Ces thèmes reflètent sous plusieurs perspectives le modèle de compétence sociale que nous avons adapté à celui proposé par Campinha-Bacote. En outre, ces quatre thèmes nous permettent d'approfondir notre analyse de ce que pourrait constituer l'ensemble des compétences sociales des médecins travaillant en contexte de pauvreté.

Le premier thème qui a fortement émergé lors de nos entrevues est la reconnaissance du statut privilégié du médecin. Plusieurs médecins reconnaissent qu'ils occupent une position économique et sociale avantageuse et prestigieuse au sein de la société. De plus, ils apprécient le caractère privilégié de leur relation avec leurs patients, une relation qui est fondée sur le témoignage privé et personnel de ceux-ci. Plusieurs ont conscience de leur rôle en tant que médiateur de la santé dans la société et s'engagent dans des activités de défense des patients.

Le deuxième thème émergeant est la connaissance aiguisée qu'ont les médecins des réalités socio-économiques vécues par leurs patients. Ils possèdent une fine connaissance des conditions de leurs patients au quotidien et ils comprennent les dynamiques sociales liées à la pauvreté qui ont un impact direct sur la vie de ceux-ci. Enfin, ils possèdent une empathie et

une sensibilité envers des situations difficiles ainsi qu'envers les limites socio-économiques qui restreignent leurs patients par rapport aux changements qu'ils doivent apporter à leurs habitudes de vie.

Le troisième thème est la promotion d'une alliance thérapeutique positive qui respecte les conditions sociales des patients. L'approche du médecin est fondée sur (mais non limitée à) l'empathie, l'écoute en profondeur, le respect, une attitude sans jugement, des habiletés de communications adaptées et une continuité dans l'intervention et le discours adoptés. Enfin, les médecins évitent une approche paternaliste non sensibilisée.

Le quatrième et dernier thème émergent est l'offre de soins primaires adaptés aux besoins, demandes, priorités et conceptions de la santé des patients. Les médecins reconnaissent l'existence de plusieurs perceptions de la santé parmi leurs patients qui proviennent de divers contextes sociaux. Ils adaptent conséquemment leurs approches thérapeutiques ainsi que leurs stratégies d'intervention selon les attentes et conceptions de la santé des patients.

Ce quatrième thème suppose donc une prise de conscience des priorités et des conceptions du patient ainsi qu'une transformation de la pratique pour ainsi encourager une rencontre entre les perspectives du médecin et du patient. La transformation de la pratique et des approches de soins nécessitent une grande flexibilité de la part du médecin. La flexibilité est donc conçue comme un effort d'adaptation du professionnel de la santé à une diversité de patients vivant des situations sociales complexes. Les médecins démontrent à travers leurs récits une adaptation constante et ce, pour l'ensemble des patients qu'ils rencontrent.

Certains médecins ont suggéré que des transformations organisationnelles pouvaient également être apportées pour ainsi faciliter cette rencontre, et, par le fait même, encourager une approche positive des soins et services offerts aux patients en situation de pauvreté. Par exemple, l'un de nos participants, qui travaille dans un quartier ayant un pourcentage élevé de nouveaux immigrants, expliquait qu'il a décidé de transformer son horaire de travail en consacrant une plus grande partie de son temps aux périodes sans rendez-vous offertes à ses patients. Selon lui, l'attente trop longue pour obtenir un rendez-vous engendrait un fort taux d'absentéisme dans sa clinique. Toujours selon lui, n'étant pas habitués à une attente aussi longue, plusieurs immigrants optaient pour d'autres moyens plus rapides ou laissaient tomber leur rendez-vous sans l'annuler. Pour éviter cette situation, ce médecin a donc décidé d'agir en adaptant son horaire et celui de sa clinique à la conception des services de santé de cette population en particulier. Sa flexibilité ainsi que celle de son institution d'attache lui a permis de réagir à une situation qui nuisait à sa pratique ainsi qu'à la santé de ses patients.

### *Le cas du paternalisme revisité*

Dans le contexte nord-américain, l'approche centrée sur le patient est reconnue comme un standard de « bonne pratique » de la médecine familiale. Le recours à cette approche par les médecins a démontré des bénéfices importants pour les patients (Laine et Davidoff 1996; Stewart et al. (eds) 2003). La place centrale accordée au patient dans le processus de décision est un thème dominant à l'intérieur de la discipline médicale (Murphy 2008).



Conséquemment, les médecins sont généralement réticents à adopter une attitude paternaliste puisqu'elle est perçue négativement. Tous les médecins de famille que nous avons interviewés appuient cette idée générale, qui reflète une définition restreinte<sup>1</sup> du paternalisme.

Cependant, plusieurs de nos participants ont explicitement et abondamment rapporté que les compétences se transforment en fonction du contexte et de la dynamique sociale auxquels ils ont à faire face. Selon notre perspective, ceci suggère que la flexibilité d'un médecin ainsi que son pouvoir de jugement doivent être considérés comme des facteurs fondamentaux constituant une approche de soins centrée sur le patient. De plus, ces nuances ajoutent à la complexité de la notion de compétence sociale en plus de faire ressortir sa relativité. En d'autres termes, acquérir une compétence sociale suppose une capacité d'adapter sa pratique en relation avec les caractéristiques spécifiques rencontrées à un temps donné. L'acquisition de compétences est donc un processus qui nécessite une adaptation constante.

Pour illustrer notre point, nous nous proposons d'analyser le cas du paternalisme. Dans un chapitre tiré du recueil « Patient-Centered Medicine: Transforming the Clinical Method » Brown, Weston et Stewart (2003) nous rappellent que parvenir à un accord commun sur le rôle du patient dans le processus de prise de décision ne suppose pas nécessairement que le patient adopte un rôle actif. Certains patients peuvent renoncer à leur pouvoir de décision en déléguant leur pouvoir décisionnel à leur professionnel de santé (p. 91). Scherger (2009) soulève également cette idée en mentionnant qu'il y aura toujours des patients qui voudront être pris en charge et qui réclament une attitude paternaliste de leur clinicien. Les médecins, souligne-t-il, doivent posséder l'habileté de se transformer tel un caméléon qui s'adapte au gré de chaque patient (p. 287). Ces nuances nous permettent d'entrevoir un modèle de compétence sociale flexible et aligné avec les réalités du patient.

En ce qui concerne les personnes vivant une situation de pauvreté, plusieurs médecins interviewés nous ont confié qu'il peut être bénéfique d'adopter une attitude « paternaliste » bienveillante avec certains de ces patients dans des circonstances spécifiques. Ce point a été abordé particulièrement par les médecins qui offrent des soins aux patients : (1) vivant une problématique complexe de toxicomanie; (2) d'immigration récente ou réfugiés; et (3) âgés et vivant une situation de précarité sociale. Les médecins ont reconnu opter pour une approche plus « paternaliste » dans ces situations particulières où ils considèrent qu'elle serait bénéfique pour leurs patients.

Un bref survol de ces circonstances spécifiques nous permettra de démontrer comment la flexibilité ancrée dans l'adaptation de la pratique des médecins (quatrième thème majeur) permet d'offrir des soins qui sont appropriés aux besoins et aux demandes des personnes en situation de pauvreté.

#### CONTEXTE PROBLÉMATIQUE DE TOXICOMANIE

L'un de nos participants, un médecin qui travaille depuis plus de neuf ans au centre-ville de Montréal avec une majorité de patients ayant des problèmes de consommation de drogues, nous a confié qu'il vérifie fréquemment la véracité d'une information transmise par l'un de ses



patients en le confrontant directement et ouvertement.

Ce médecin précise qu'il peut, par exemple, appeler un pharmacien lors d'une consultation avec son patient pour vérifier si ce dernier a consommé sa dose habituelle de méthadone. Cette technique, qui découle a priori d'une attitude paternaliste, pourrait être perçue comme inappropriée par certains. Cependant, ce médecin nous a confié que cette attitude lui permettait d'établir ses limites avec des patients qui ont une forte tendance à lui mentir compulsivement.

Ainsi, dans le cadre d'une problématique en toxicomanie où les patients ont des comportements prononcés de rechute et de non-conformité, les médecins ont mis sur pied des stratégies de suivi serré, comprenant l'imposition de limites et l'adoption d'une approche d'encadrement stricte, mais bienveillante.

#### CONTEXTE D'IMMIGRATION ET DU STATUT DE RÉFUGIÉ

D'après nos entrevues, certains médecins décident d'adopter une approche « paternaliste » auprès de certains patients immigrants ou réfugiés. Selon eux, des patients peuvent demander à leur médecin de combler un rôle plus autoritaire; certains d'entre eux s'attendent à ce que leur médecin leur dise quoi faire, car c'est à ce type de relation qu'ils ont été habitués dans leur pays d'origine. Les médecins peuvent décider de reproduire cette attente dans le contexte canadien parce que les patients le réclament.

Ainsi, nous pouvons présumer que certains immigrants habitués à une relation médecin-patient caractérisée par une attitude autoritaire peuvent s'attendre au même décorum dans leur terre d'accueil. Il est bien possible que dans certains cas où le stress d'adaptation à la société canadienne est déjà présent, une approche plus informelle et basée sur le dialogue et la négociation des soins de la part des médecins peut devenir une source d'inconfort et d'incertitude pour certains immigrants. C'est en considérant cette réalité précaire que ces médecins peuvent décider d'adopter une telle approche plus encadrante.

#### CONTEXTE DE PRÉCARITÉ SOCIALE DES PERSONNES ÂGÉES

En parlant de la relation de soins qui existe entre les patients et eux-mêmes, plusieurs médecins utilisent l'expression « négocier l'agenda ». Cette approche relationnelle en médecine familiale vise à donner une autonomie aux patients en leur procurant un espace de parole et de décision à propos des soins qui leurs sont offerts. Cette approche soutient que le patient est expert de son corps et qu'il est donc le mieux placé pour prendre des décisions sur sa vie. Néanmoins, l'implantation d'une approche médecin-patient orientée vers une négociation de l'agenda en médecine familiale est récente.

En effet, nos aînés ont connu une réalité bien différente de la médecine, caractérisée jusqu'à tout récemment par un modèle paternaliste fondé sur des intentions de bienfaisance. Certaines personnes âgées peuvent donc s'attendre à une relation plus autoritaire avec leur médecin. Ainsi, dans certaines circonstances, elles ne désirent pas nécessairement avoir à négocier les traitements qu'elles devraient suivre ou non puisqu'elles n'ont pas nécessairement été habituées à le faire dans le passé.

Les médecins interviewés ont mentionné qu'ils ont des patients âgés qui désirent recevoir des indications claires sur ce qu'ils doivent faire plutôt que de négocier un agenda. Aux yeux des médecins, ces patients ont besoin de se faire rassurer. Une figure médicale plus autoritaire peut leur procurer ce réconfort.

Il est clair qu'au cours des années, des changements de mœurs dans les sociétés québécoise et canadienne ont influencé les approches de soins en médecine familiale. Il est donc concevable que l'on puisse observer diverses attentes chez différentes générations d'une même population. En étant sensibles à ces nuances générationnelles, les médecins qui ont acquis une compétence sociale peuvent donc mieux adapter leur approche pour ainsi répondre d'une manière plus efficace et satisfaisante aux besoins de leurs patients.

### Quelques remarques pour conclure

Une approche humaniste du paternalisme devrait être entendue comme une forme d'accompagnement qui émerge grâce à une approche flexible et une compréhension en profondeur des conditions sociales et de santé du patient (Loignon et Boudreault-Fournier 2012).

Nos données portant sur la compétence sociale des médecins nous permettent de faire ressortir deux critiques principales adressées au concept de compétence culturelle. Cette analyse nous permet de mieux comprendre comment nous utilisons ce concept dans le contexte de soins avec des populations en situation de pauvreté.

Premièrement, comme illustré par l'exemple du paternalisme, l'acquisition des compétences sociales ne peut être conçue comme une recette, c'est-à-dire une liste de trucs à faire et à ne pas faire (Kleinman et Benson 2006). Nous croyons plutôt que le pouvoir de jugement et l'habileté à changer et à adapter les stratégies de pratique d'un médecin selon les besoins du patient est à la base d'une approche sensible des soins. Nous concevons la notion de compétence comme un continuum d'habiletés qui sont acquises, élaborées et appropriées tout au long de l'expérience du médecin.

Deuxièmement, certains anthropologues ont critiqué le fait que le modèle de compétence culturelle ne reconnaît pas la diversité des entités qui existent à l'intérieur de groupes culturels (Carpenter-Song et al. 2007 : 1363). L'exemple du paternalisme nous permet de répondre en partie à cette critique en démontrant que la population vivant en situation de pauvreté est complexe et composée d'individus aux réalités sociales diverses. Nous ne pouvons donc pas parler d'une seule réalité de la pauvreté, mais bien d'une multitude de contextes sociaux qui s'expriment à travers les trajectoires individuelles et qui influencent le quotidien des personnes. Ainsi, en adoptant une vision de la compétence qui s'inscrit dans un continuum au lieu d'être perçue comme une liste de recommandations prédéterminées et décontextualisées, nous contribuons à la déconstruction d'une version homogénéisée de la dite « population vulnérable ».

Enfin, comme suggéré dans cet article, adopter une attitude paternaliste dans certains cas coïncide paradoxalement avec les objectifs d'une approche centrée sur les besoins et les demandes du patient. Adapter sa pratique à ces conditions suppose une flexibilité et un pouvoir de jugement, deux habiletés acquises grâce à l'expérience et la compréhension en

## La flexibilité des médecins offrant des soins de première ligne aux personnes en situation de pauvreté : la compétence sociale revisitée

profondeur de la situation et des conditions de vie d'un patient. Ainsi, une approche flexible des soins dans un contexte de pauvreté appuie le quatrième thème dominant qui a fortement émergé lors de nos entrevues, c'est-à-dire l'offre de soins primaires adaptés aux besoins, demandes, priorités et conceptions de la santé des patients.

La flexibilité de la pratique des médecins encourage une approche positive des soins offerts aux patients en situation de pauvreté. En référence aux différences culturelles, certains ont souligné l'importance de l'humilité dans l'approche des soins (Trevalon et Murray-Garcia 1998). Nous préférons dans ce contexte spécifique parler de flexibilité, parce qu'elle nécessite un effort du médecin afin d'adapter sa pratique pour répondre à un besoin ou à une demande du patient. C'est cette volonté d'action qui démontre, bien plus que l'humilité et l'empathie, le désir de rejoindre l'autre et de répondre à ces attentes au meilleur de ses possibilités.

### NOTE

1. Buchanan (2008) utilise le terme « strong » pour se référer à cette version du paternalisme.

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# Standards and Stories: The Interactional Work of Informed Choice in Ontario Midwifery Care

## Normes et narration : travail interactif autour des choix éclairés dans l'exercice des sages-femmes en Ontario



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### Abstract

This paper uses a discourse-rhetorical approach to analyze how Ontario midwives and their clients interactionally accomplish the healthcare communicative process of “informed choice.” Working with four excerpts from recorded visits between Ontario midwives and women, the analysis focuses on the discursive rendering during informed choice conversations of two contrasting kinds of evidence – professional standards and story-telling – related to potential interventions during labour. We draw on the concepts of discursive hybridity (Sarangi

and Roberts 1999) and recontextualization (Linell 1998; Sarangi 1998) to trace the complex and creative ways in which the conversational participants reconstruct the meanings of these evidentiary sources to address their particular care contexts. This analysis shows how, though very different in their forms, both modes of evidence function as hybrid and flexible discursive resources that perform both instrumental and social-relational healthcare work.

## Résumé

Cet article emprunte une démarche rhétorique pour analyser la façon dont les sages-femmes et leurs clientes en Ontario accomplissent de façon interactive les processus de communication en santé pour faire des « choix éclairés ». À l'aide de quatre extraits enregistrés lors de rencontres entre sages-femmes et femmes en Ontario, l'analyse se penche sur le rendu discursif de deux types distincts de données – les normes professionnelles et la narration d'anecdotes – au cours de conversations portant sur un choix éclairé au sujet d'une possible intervention pendant le travail. Nous employons les concepts de l'hybridité discursive (Sarangi et Roberts 1999) et de la recontextualisation (Linell 1998; Sarangi 1998) pour retracer les chemins complexes et créatifs qu'empruntent les participantes pour reconstruire la signification des sources de données afin d'aborder leur propre cas. Cette analyse montre comment, bien que sous des formes différentes, les deux modes de données fonctionnent comme des ressources discursives hybrides et flexibles qui agissent tant au niveau instrumental que socio-relational.

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**T**HIS PAPER EXAMINES HOW ONTARIO MIDWIVES AND THEIR CLIENTS interactionally accomplish “informed choice” in clinic visits by calling on and negotiating two contrasting kinds of evidence: (a) authoritative guidelines articulated in professional standards and community protocols and (b) social stories told by midwives as they talked with women about healthcare options. How do participants recontextualize the meanings of these different evidentiary sources to address their particular care contexts? Our analysis indicates that participants invoke evidence in ways that combine instrumental and social talk to perform both clinical and relational functions. The interaction thus enacts a hybrid discourse, simultaneously reflecting and reproducing midwifery’s relational-feminist goals and the requirements of regulated healthcare.

## Context

In Canada and internationally, informed choice is recognized as integral to midwifery care (e.g., International Confederation of Midwives; Canadian Midwifery Regulators Consortium). In Ontario, the first province to regulate midwifery as a primary care profession (*Ontario Midwifery Act* 1991), the College of Midwives (1994/2005) defines informed choice as involving “a co-operative and collaborative information exchange between the midwife and the woman” that supports “the woman as primary decision-maker.” Consonant with its roots in the alternative childbirth and women’s health movements of the 1970s, this model explicitly

values the exchange of diverse forms of evidence, including emotional, intuitive, spiritual and narrative ways of knowing along with more biomedical and scientific modes (Davis-Floyd and Davis 1996; James 1997; MacDonald 2006).

However, Ontario midwives also practise within a network of professional responsibilities and provincial regulations (Bourgeault 2006). According to MacDonald (2007), the practical and ideological challenges of becoming regulated have resulted in a complex, dynamic reworking of the relationship between midwifery's "alternative" philosophy of "natural" childbirth and biomedical approaches to pregnancy. Contemporary midwifery therefore somewhat uneasily combines both the holistic, woman-centred ideology of pre-regulation practice and the dominant biomedical discourses that shape regulated Canadian healthcare (Spoel 2006, 2007).

Because of midwifery's position at the intersection of mainstream and alternative healthcare ideologies, informed choice functions as an important communicative process for negotiating healthcare norms, knowledges and identities. According to Spoel (2010), discursive hybridity constitutes a defining feature of Ontario midwifery's informed choice communication. Discursive hybridity "captures the complex and multi-layered nature" of healthcare work and communication practices by conceptualizing the "shifting modalities" that characterize these practices and situations (Sarangi and Roberts 1999: 62). Here, we explore how midwives and women creatively and strategically invoke and negotiate diverse forms of evidence during informed choice conversations to address "the ever-changing demands and contradictions of real social situations" (Sarangi 2000: 12).

## Methodology

Our data set comprises transcripts of 48 clinic visits between Ontario midwives and clients. McKenzie recorded single visits in 15 southern Ontario midwifery practices between 40 women and each woman's midwife. Spoel and James recorded eight northern Ontario visits, four each for two women and their midwifery teams. Our data, collected between 2002 and 2007, provide a window into the midwife–woman interaction at an important period in the development of regulated midwifery in Ontario. Our research conforms to Canadian ethical guidelines (CIHR et al. 2003). Practices have been anonymized, and all participants are identified here by role (midwife, client, student midwife).

Our discursive-rhetorical approach focuses on "the study of language in use" (Wetherell et al. 2001: 2). First, we analyzed our transcripts thematically to identify informed choice conversations. We then analyzed these discussions discursively, attending to the ways midwives and women discuss evidence relating to the decision to be made. Our analysis focuses on the characteristics of the talk itself: we closely studied the details of language and attended to similarities and variations both within and across accounts. We thereby identified the forms of evidence used, the strategies speakers used when making a case, the rhetorical functions that cases or counter-cases might serve and the potential consequences of such presentations. The analytic method is similar to constant comparison (Strauss and Corbin 1990), but with the goal of identifying and describing the presentation of evidence rather than developing grounded theory.



For this paper, we highlight discussions of potential interventions during labour. We interpret “evidence” broadly to mean diverse formal and informal types of information that participants draw on directly and indirectly to explain, challenge or support decisions. Such information includes, for example, professional standards and protocols, clinical and alternative healthcare research, records and test results, personal and professional experience, and popular culture.

Our concept of evidence aligns with the rhetorical distinction between extrinsic proof (“facts” or objects of evidence that exist outside of or prior to the rhetorical exchange) and intrinsic proof (the art of creating persuasive arguments, often through the discursive interpretation of extrinsic sources of evidence). Because extrinsic evidence cannot speak for itself, rhetoric crafts proofs that allow us to share understandings, form judgments and take actions (Hauser 1986; Hill 1995).

When participants in a rhetorical exchange invoke extrinsic sources of evidence, they do not simply transfer the meanings of these sources into their exchanges. Rather, they engage in recontextualization: “the dynamic transfer-and-transformation of something from one discourse/text-in-context ... to another” (Linell 1998: 144). Recontextualization is “a re-rendering of context”: through creative and strategic uses of prior text, participants redefine the context. Context is dynamic, acting as both resource and constraint on participants’ meaning-making (Sarangi 1998: 307). Aspects of discourse that may be recontextualized include “linguistic expressions, concepts and propositions, ‘facts,’ arguments and lines of argumentation, stories, assessments, values and ideologies, knowledge and theoretical constructs, ways of seeing things and ways of acting towards them, ways of thinking, and ways of saying things” (Linell 1998: 144–45).

Here, we highlight two types of recontextualized extrinsic evidence within informed choice conversations: (a) references to professional healthcare standards or protocols and (b) recounted stories based on participants’ prior experience. Invocations of these two different sources of evidence may be understood as enacting correspondingly different discursive modes: an expert-professional, instrumental mode led by the midwife, versus a mode that is more clearly sociable, collaborative and relational (Holmes and Marra 2005; McCourt 2006; Spoel 2010). The discursive hybridity of informed choice communication occurs, in part, through the mixing of these contrasting invocations. However, each mode likewise may be accomplished in hybrid ways such that “professional” talk about healthcare protocols also enacts relational functions, and sociable talk also accomplishes instrumental clinical tasks. Below, we explore these hybrid interactions and functions by analyzing two excerpts that reference healthcare protocols and two story-telling excerpts.

## Findings and Discussion

### *Professional standards and informed choice*

Professional standards and protocols are one source of extrinsic evidence that midwives and clients draw on in informed choice discussions. These standards range from those officially

articulated by professional bodies such as the College of Midwives of Ontario and the Society of Obstetricians and Gynaecologists of Canada to more situated community standards and institution-based policies as well as best practice developed by local hospitals and physicians. Because these protocols simultaneously enable and constrain the options available to midwives and women, their invocation within midwife–client conversations functions as an important space of discursive negotiation across professional–institutional boundaries, as well as within professional–client encounters (Sarangi 1998: 302).

The following two excerpts focus on protocols concerning testing and treatment for Group B Streptococcus (GBS), a key topic of informed choice discussion in midwifery care. GBS is a common bacterium, present in 10%–30% of women. Although colonization is typically temporary and asymptomatic, GBS infection is the leading cause of life-threatening infectious disease in newborns. The overall incidence of neonatal GBS disease in Canada is 0.64 per thousand live births, with mortality rates ranging from 5%–20%. Risk factors for neonatal infection include prolonged rupture of membranes before delivery (Money and Dobson 2004). In the past 10 years, North American clinical guidelines have changed rapidly and have been inconsistent across Ontario communities (Burkell and McKenzie 2005).

EXCERPT (A):

Midwife: And too, you know, [client], things may have changed since last time around in community clinical standards and options you have.

Client: Yeah.

Midwife: Ruptured membranes without labour. Now they're offering inductions [after] 6 to 12 hours, when maybe they were offering it at 18. We still will wait until 18. ...

Client: Are you, are you bound by anything?

Midwife: Our college, our college says we must consult at, ah, when it's a prolonged ruptured membrane, ah, without labour and it's still technically being defined as ... the 18 hours. There's no absolute gold standard definition ... . In other communities, they don't intervene until 24 or 48 hours ... . So, and you have the option to wait. Remember you always have a choice to say, "I choose ... ."

Client: Yeah.

The second excerpt addresses standards concerning “swabbing” for GBS and the potential implications for permissible time lapse between ruptured membranes and induction:

EXCERPT (B):

Midwife: If you were in care with a physician or an obstetrician here in [city], the community standard is not to do a swab.

Client: Okay. So, that’s fine.

Midwife: So, and the Society of Obstetricians and Gynaecologists, they put out a protocol for that and they said there are two equally acceptable strategies. And one is what’s happened here in [city], where nobody gets swabbed with, you know, physicians and obstetricians. But what they do instead of giving the swab, is if in labour you develop a risk factor, that’s when they would give you antibiotics. So, if you have fever, if your water had been broken for a very long time, that kind of thing.

Client: Okay.

Midwife: For people ... , when we look at those risk factors. People who, uhm, would think about if your water had broke and you didn’t go into labour. If you’re a person who did want to push the limit and give your body every chance to go into labour on its own, it may be a good idea to have the swab, to give you extra information.

Client: Yeah.

Midwife: Ah, here in [city], the community standard says if your water breaks and you’re not in labour by, you know, 6 to 12 hours, they are recommending that you go in and do a consult and have antibiotics. Our college, the College of Midwives, says 18 hours.

Client: Right.

Midwife: So, I would be required to consult at 18 hours. But typically, with OBs they, they’ve even become more conservative here. ... the other factor that plays into this is the community in which we work, practise with. We peer-review with [other Ontario city]. They have people with ruptured membranes for 7 days. [laughing] And it, you know, it’s very different. Here, we have a 12-hour ... . So it’s, it’s really, you know, and unfortunately I guess anybody who lives here gets, unh you have to, you know, you ... work with where you’re, where you’re practising.

Client: Yeah.

Midwife: But at the same time, you have choices.

Client: Mhmm.

Midwife: And you can say, “Well, I think they do this differently in some places than in [this city].”

These excerpts show the dynamic, situated ways in which the participants recontextualize the professional protocols that structure the choices available to women. The standards’ meanings and functions are reconfigured within the exchange to “fit” (Linell 1998: 144) the context of each midwife–client situation. Although these excerpts recontextualize in unique ways, they share discursive features that may indicate characteristic ways in which Ontario midwives and women reconstitute the evidentiary authority of extrinsic standards within informed choice communication. A discussion of these characteristic ways follows.

#### 1. NAMING SOURCES OF AUTHORIZATION

The midwives identify the sources of authorized standards by naming specific professional-regulatory bodies, by referencing the more ambiguous source “community” and through plural personal and impersonal pronouns (“our,” “they”). The midwife in Excerpt (a) refers to “community clinical standards and options.” Her subsequent reference to the standard of “our college” (i.e., the College of Midwives of Ontario) contrasts with the “they” of the medical profession or local hospital. This juxtaposition constructs the context as involving potentially conflicting regulatory frameworks, that of the local medical community and that of the provincial midwifery college.

Similarly, the midwife in Excerpt (b) provides context for her client’s decision by explaining that the Society of Obstetricians and Gynaecologists of Canada (SOGC), subsequently identified as “they,” has “put out a protocol” on this. She also refers to “the community standard” concerning how much time may elapse between a woman’s membranes rupturing and labour being induced, and contrasts this with the protocol of “our college, the College of Midwives.” In so doing, she discursively establishes the distinctiveness of midwifery care in contrast with physician care, yet at the same time represents the context as shaped by diverse but interacting standards.

#### 2. NAMING THOSE WHOSE DECISIONS THESE STANDARDS SHAPE

The midwives and the clients name themselves – mainly through the pronouns “we” and “you” – as those whose decisions and actions are affected by the protocols being discussed. Midwives use “we” to identify themselves as members of the midwifery profession; “you” identifies the other speaker in the interaction. However, the specific attributions are ambiguous:

“We,” for example, seems to refer partly to the whole midwifery profession and partly to each localized midwifery practice, with its situated strategies for negotiating “community standards.” Similarly, the pronoun “you” when used by each midwife refers both to the specific client being addressed and to a generic “you” who may (or may not) be affected by the protocols being discussed. In Excerpt (b), “you” becomes “people.” This substitution ambiguates the context as one in which the midwife recommends a strategic action to this specific client in light of the SOGC protocol and one that is generically, but perhaps not specifically, applicable to this woman’s decisions.

### 3. VERBS OF PERMISSION

The presence of verbs signifying the boundaries of permission and prohibition strongly indicates how protocols affect the context of informed choice. The client in Excerpt (a) asks whether the midwife is “bound by anything.” Her midwife replies, “our college says we *must* consult at ... 18 hours.” The midwife in Excerpt (b) says that she “would be *required* to consult at 18 hours” (our emphases). These verbs index participants’ concern about how diverse standards define the possible courses of action they may take. Notably, the midwives represent themselves as accountable principally to their own profession’s standards rather than “community” or medical protocols, though in a way that avoids directly opposing non-midwifery standards.

### 4. CHARACTERIZING STANDARDS AS SITUATIONAL

Concomitantly, the midwives unsettle the constraining authority of the invoked standards by alluding to the situational, interpretable nature of healthcare protocols. By stressing that “in other communities, they don’t intervene until 24 or 48 hours,” the midwife in Excerpt (a) frames the context as one in which protocols are variable and interpretable. The midwife in Excerpt (b) likewise notes, “you have to ... work with where you’re ... practising,” such as working with obstetricians who have “even become more conservative here.” This rendering of local context reinforces how the meanings and functions of standards are contingent and at least somewhat negotiable across and within professional-institutional boundaries.

### 5. RE-ASSERTING “CHOICE” AS CONTEXTUALLY RELEVANT

This discursive move reconfigures the context as one in which (despite appearances to the contrary) the principle of informed choice still applies. The midwife in Excerpt (a) uses the evidence that “other communities” have different guidelines for the length of time women may avoid intervention after membranes rupture as the warrant for reminding her client that “you have the option to wait. Remember you always have a choice to say, ‘I choose.’” Similarly, the midwife in Excerpt (b) closes the sequence by contrasting the “conservative” standards of the local community with the client’s right to make her own choices. Both discursively construct the hypothetical context in which clients might claim their right to choose by rehearsing, through future-oriented reported speech, what women can say. By representing the client as

able to question the authority of “community” standards, the midwives enact the possibility that the principle of informed choice is not compromised by these standards. However, the clients’ non-committal response tokens (“yeah”; “mhmm”) suggest they are less concerned than the midwives about the possible infringement on their right to informed choice.

Although these excerpts perform primarily a kind of instrumental, task-oriented “business talk,” in which the midwife fulfills her role as expert information provider to the client as information receiver (Spoel 2010), they also accomplish important relational functions – interprofessionally, intraprofessionally and between midwife and client. These excerpts render the context of interprofessional relations as one that calls on midwives to “work with” physicians in the community even when midwifery and medical standards differ; intraprofessionally, the individual midwives position themselves as relationally accountable to the corporate authority of “our college”; most significantly, how the midwives recontextualize the protocols strengthens their relational alignment with their clients because it presumes and reinforces shared concerns about the need to respond strategically to “conservative” medical protocols. This mixing of instrumental professional discourse with more relational-social discourse likewise occurs in the story-telling evidence discussed below, though here the interactions’ social functions are initially most obvious.

### *Story-telling and informed choice*

In interactions between healthcare professionals and their clients, social talk may be inextricably enmeshed with more instrumental talk, and relational and instrumental goals may be interdependently achieved (Ragan 2000; Sharpe 2004). The enmeshing of social talk into clinical midwifery care reflects the explicitly woman-centred goals of the profession, and the telling of informal stories helps to accomplish these goals. The following two excerpts show how informal story-telling that appears initially to be entirely social also does the professional work of informed choice.

The first excerpt comes from a visit between a woman and the midwife who had attended her previous birth. A student midwife was also present. After discussing the woman’s ambivalence towards epidural pain relief, the client told a story about using nitrous oxide gas during her previous labour, and the midwife responded with a story of her own.

EXCERPT (C):

Client: It makes me kinda laugh because it was, like, I remember when it was time to take the gas for pushing and you said, “I think it’s time,” and [starts laughing as she talks] I remember thinking, “I’m gonna kill you!”

All: [laughter from all sides]

Client: I was looking at [midwife] thinking, “I’m gonna kill you.”

All: [laughter]

Midwife: You wouldn't be the first person.

Midwifery student: [laughs]

Client: No, I know.

Midwife: [changing voice to imitate woman in labour] "What do you mean I have to give it back?"

All: [laughter]

Client: You don't like to, ah, be the one to deliver the bad news.

Midwife: Yeah. Well, I had, ... I think it was the first person actually that we had her baby at [birthing centre], ... and it was ... her first baby and she was about 8 centimetres dilated, and so she was kind of needing something, so we gave her the gas and she sorta took one big hit off it and she stood up on the bed and said, "I love this stuff!!"

All: [laughter]

Client: On the bed?

Midwife: On the bed!

All: [laughter]

Midwife: Woo!!

Client: Oh my goodness.

Midwifery student: Wow.

The second excerpt is from a conversation of home birth plans. It begins partway through a discussion of plans for labour and birth in the basement, after which the midwife tells a story:



EXCERPT (D):

Midwife: Of course we want you to stay on whatever level you are on for the first day roughly.

Client: Yeah.

Midwife: No long trips up stairs.

Client: That's fine, yeah. Yeah, because there's eight, six [steps], plus another eight to get up.

Midwife: Lots of landings, so –

Client: Yeah, so the, yeah –

Midwife: Or [partner] will have to carry you [laughs].

Client: Yeah, oh god!

Midwife: Come have a seat really quick so I can do your blood pressure.

Client: Let me take this off.

Midwife: I had clients and it was very funny, they wanted a home birth so I had home visits because they do live fairly locally. Of course, we do visits in our primary care area, but for people who live that far away ... we tell them call an ambulance, the reason being, you're far enough out that we're not going to get to you in time.

Client: Um-hum.

Midwife: So I didn't know that she had four flights of stairs in her apartment building that she had to walk when she went home.

Client: Oh, my gosh!

Midwife: Yeah [silent 4 seconds] – one-ten on sixty. So I gave them a call, we had a daytime birth, I gave them a call just to say how are things going, are you accelerating nicely, all of that, and she went, “Oh, everything went fine, well, except for me getting light-headedness” and I went, “Oh, well, tell me about it” and she told me that she tried to do all flights at once.

Client: Oh, my.

Midwife: Yeah.

Client: Well, that's what I could kind of see happening.

Midwife: I felt awful, doing the home assessment without identifying that...

Client: Oh.

Midwife: So, I had to change the assessment when we do prenatal [to], "So, what's the layout, are you going to be walking up four flights of stairs?"

Both excerpts include much laughter, and the casual tone suggests comfortable conversations that build rapport but seem only marginally related to professional tasks. We argue, however, that these stories were also clinically relevant. The following micro-interactional characteristics indicate the stories' combined social-instrumental function.

#### 1. ACTIVE PARTICIPATION

As is typical in women's friendly conversation, each story recontextualizes the immediately preceding discussion by mirroring the topical talk or specific elements of a previous story: a woman's strong positive response to nitrous oxide in labour and a birth in a dwelling with many stairs. Second, all participants actively contribute to the lighthearted telling of the stories through shared narration, encouraging responses (e.g., "wow") and sympathetic laughter (Coates 1996). These also are stories of benign misadventure that may show the teller in a self-deprecating light.

#### 2. INTEGRATING STORIES WITH THE "WORK" OF THE VISIT

The stories flow from focused talk about potential interventions or bubble up in quiet spaces afforded by routine physical activities such as taking blood pressure. The casual conversation therefore does not interfere with the business of the encounter. As a result, these forms of talk appear inconsequential, yet they may unobtrusively accomplish – or assist in accomplishing – significant professional tasks.

#### 3. NAMING EXPERIENTIAL AUTHORITIES

In both excerpts, midwife and woman recontextualize their prior experiences as a source of authority. The client's initial story draws on the extrinsic evidence of her previous labour, while the midwives also invoke their past experiences as caregivers during labour and represent themselves as witnesses of women's experiences. Using this technique allows the midwife simultaneously to validate women's embodied experiences and to present herself as an authority on those experiences (McKenzie and Oliphant 2010).

#### 4. SPECIFYING THE EXPECTED RESPONSE

In each excerpt, the teller recontextualizes past events in a story to be heard as humorous, thus shaping how the listener should interpret it. The tellers of these remembered stories are accorded the authority to prescribe the meaning of the story for the current context. Although listeners may challenge prescribed meanings, they do not do so in these excerpts.

#### 5. GIVING ADVICE WITHOUT APPEARING TO DO SO

Although these stories exhibit characteristics of lighthearted social talk, they are by no means “merely” social or off-topic. Midwives’ stories, especially, can be seen as doing informed choice work in an interactionally delicate situation: giving advice without appearing to do so. Ontario midwifery’s ideal of informed choice divides the cognitive labour: informing is the midwife’s responsibility; deciding is the client’s job (McKenzie 2009: 166). Many midwives in our sample interpreted this division as a directive to present information in a neutral way and actively resisted giving their clients direct advice. In this situation, story-telling may function as an important discursive strategy for indirectly advising women.

In Excerpt (c), the midwife uses a humorous story of another woman’s experience to recontextualize the client’s desire for pain relief as legitimate and tacitly endorses gas as a form of pain relief consistent with a “natural” midwife-assisted birth. In Excerpt (d), the midwife’s story develops a negative exemplar of what might go wrong if the client chooses a course of action different from the one just proposed. Recontextualizing a course of action within a humorous story meets each midwife’s combined social–clinical goals for a particular client and a particular visit, in a way that subtly guides the woman’s choices to align with the midwife’s professional opinion. Social stories about past experiences allow the midwife to assert her expert-professional authority to arbitrate the woman’s choices without being seen to compromise her right to choose.

## Conclusion

For midwifery in many Canadian as well as international jurisdictions, informed choice is a central but complex dimension of its woman-centred model of care. The diverse kinds of “evidence” that midwives and women draw on in their healthcare conversations constitute an important rhetorical space for negotiating the possibilities of informed choice in the context of regulated healthcare.

Closely analyzing excerpts in which participants invoke professional protocols and informal stories illustrates the multi-layered, dynamic ways in which these Ontario midwives and women construct the meanings and functions of these forms of evidence. Our analysis adds to the scholarly conversation about authoritative knowledge in maternity care by showing that these forms of evidence are not simply pre-established, external sources of information to which participants refer; rather, through each situated interaction, midwives and women recontextualize what these evidentiary sources mean within that particular setting. Despite notable differences between professional standards and story-telling as modes of evidence, both function as hybrid and flexible discursive resources, performing both instrumental and

social-relational work. This finding contributes to our understanding of the complex, creative ways in which midwives and their clients interactionally accomplish informed choice. It also confirms the value of using a discourse-rhetorical approach to researching healthcare communication.

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# Home Healthcare and Family Responsibility: A Critical Discourse Analysis of Talk and Text

## Soins à domicile et charge familiale : analyse critique du discours parlé et écrit



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### Abstract

This paper addresses how families' roles and responsibility for care are constructed within home health (in contrast to the responsibility of home health). A discourse analysis informed by a critical theoretical approach was used to analyze qualitative interviews with 13 home health managers and clinical leaders in British Columbia, alongside home care documents. When referring to family involvement, there was an emphasis on the importance of supporting a client's choice to stay at home. Government and agency documents describe family members as primary providers, with home health having a supplementary role. Agencies seek to avoid "substituting" for family care. Family responsibility is characterized as having both moral and structural value. Nonetheless, some participants advocated flexibility and recognized potential caregiving challenges. Data provide examples of how agency expectations are communicated to clients and families and become embedded within practice and policy. Findings are viewed within the broader organizational context as representing the "responsibilization" of support.

## Résumé

Cet article aborde la façon dont le rôle et la charge des familles sont définis au sein des services de soins à domicile (par contraste à la charge des organismes de soins à domicile). Une analyse du discours, sous-tendue par une démarche critique théorique, a été employée pour analyser des entrevues qualitatives auprès de 13 gestionnaires de soins à domicile et responsables de cliniques en Colombie-Britannique, de pair avec de la documentation portant sur les soins à domicile. Là où il y avait référence à l'implication de la famille, j'ai dégagé l'importance de soutenir le choix d'un client de demeurer au domicile. Les documents gouvernementaux et ceux des organismes décrivent les membres de la famille comme principaux fournisseurs de soins, alors que les organismes de soins à domicile jouent un rôle complémentaire. Les organismes ont tendance à éviter d'agir comme « substitut » des soins familiaux. Une des caractéristiques de la charge familiale est qu'elle revêt une valeur à la fois morale et structurelle. Néanmoins, certains participants plaident pour une flexibilité et reconnaissent les défis potentiels auxquels font face les soignants. Les données montrent des exemples sur la façon dont les attentes des organismes sont communiquées aux clients et aux familles et sur comment elles sont enchâssées dans la pratique et dans les politiques. Dans un contexte organisationnel plus général, les résultats sont considérés comme une représentation de la « responsabilisation » du soutien.

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**F**AMILIES – ESPECIALLY WOMEN – PROVIDE MOST OF THE CARE FOR CHRONICALLY and terminally ill Canadians, yet face increasing expectations for their involvement in and responsibility for this care, in part due to changes in healthcare policies and service delivery. Such changes potentially increase burden (Chappell 1993; Fast and Keating 2000: 25). Although many family members welcome involvement, at times some may feel pressured and unprepared, or desire greater support (Björnsdóttir 2009; Stajduhar 2003).

Whether such shifts are accompanied by discursive expectations of family responsibility in home health policy and practice has yet to be fully examined. This study asks: How are families' roles and responsibility in care provision for chronically and terminally ill persons constructed in home health discourse, in contrast to the roles and responsibility of home health? I have applied a critical discourse analysis methodology to interview data from home health managers and clinical leaders in one Canadian province (British Columbia), as well as to relevant home care documents. The analysis focuses on discursive constructions of expected family and home health involvement, interpreted in the broader context of home health and healthcare.

This paper focuses on expectations of family versus government (“home health”) involvement in and responsibility for care provision, as interpreted within home health (by managers and clinical leaders, and in home and community care documents). Examining organizational expectations can help identify ways to mitigate potential negative effects on families, while continuing to promote positive effects (such as empowerment).



## Methods

As part of a larger study of empowerment in home care, qualitative interviews were conducted in three health agencies in British Columbia. Potential participants were identified by the project team as regional home care decision-makers and opinion leaders who could describe organizational interpretations of family empowerment in their agencies (a research question of the primary study). To ensure maximum variation, participants from varying position types and levels were included (e.g., managers, clinical leaders, administrators, decision-makers).

Nine documents from all five regional health agencies and the Ministry of Health were also identified. These represented the population of relevant publicly available web- or handbook-based home and community care (HCC) documents in the province at that time (Fraser Health [no date]; Interior Health Authority 2007; Northern Health Authority [no date]; Vancouver Island Health Authority 2009; Vancouver Coastal Health Authority [no date]). They were developed and distributed by the agencies for clients and families, and outline expected roles and available services. Similar material from the provincial government (Ministry of Health Services 2006, 2007) was also included, as were the only two caregiver handbooks developed by any of the agencies that could be located (Fraser Health Authority 2005; Vancouver Coastal Health Authority 2010).

A critical discourse approach guided the analysis (O'Connor and Payne 2006; Powers 1996). This focused on the identification and analysis of meanings and discursive frameworks and the broader contexts shaping these meanings. Attention was paid to statements that appear "natural" or commonsense (Cheek 2004; Smith 2007) as well as keywords, emphasis, ambiguities, contradictions, dichotomies, assumptions and silences (Powers 1996).

## Findings

### *Staying at home as a personal choice, and the best care option*

Several participants described how the healthcare system is moving towards a philosophy or policy of "home first" for chronically and terminally ill persons (e.g., initiatives to promote client discharge from institutional care). Participants frequently emphasized the importance of clients' staying at home and suggested that this choice reflects client wishes, healthcare resource limitations and institutional discharge pressures. Public HCC documents, while emphasizing client choices to stay at home, did not mention resource or institutional pressures.

Independence was frequently equated by participants with clients' ability to remain at home. The health agency's role is described as, for example: "to ensure that you [the client] can remain as independent as possible and live at home for as long as possible." Independence was also closely connected to a philosophy of self-care and a self-management model in chronic disease. Service limitations were at times rationalized with reference to the need for self-care, equated with client independence from service use. For example, one manager maintained that providing too much service can create dependence and "the expectation is that we try to empower them to be able to manage as much as possible on their own until they're no longer able to."

One participant, referring to the early discharge of older persons from hospitals, described the implications for families: "It's like, 'these [clients] are going home. You need to provide the care and we can supplement a little.' But I think we're a bit more forceful with pushing families to take people home." However, this participant also noted the existence of practice pressures operating in the reverse direction, to promote hospice admission in cases where families were highly anxious or stressed, because the home care nurses' workload "doesn't allow them the time to respond to that family or see them more frequently."

### *Having family members take primary responsibility for care*

In participant talk, family involvement tended to be interpreted as almost synonymous with client independence and self-care, and in contrast to system responsibility. For instance, in responding to questions about family care involvement, participants commonly invoked the ideal of client independence and self-management. As another example, one HCC guide (Fraser Health Authority [no date]: 5) explained that nurses promote client independence in part by enhancing "client or their families' abilities to provide care" (emphasis added).

Alongside constructions of staying at home as clients' personal choice, health agency responsibility was circumscribed and service limitations implicitly rationalized. One specialist characterized the role of the health agency by invoking the idea of goals (i.e., choices): "We will not complete your goal; we will try and help you support what your goal is." In addition, family responsibility was interpreted as a natural consequence of client choices. For example, an ideal of autonomy was used by one manager to justify family responsibility and define the agency's role: "Clients have their own lives. They are responsible for their medications ... we don't 'own' the medications. It's the family's [and client's] responsibility." Family involvement (or privately hired services) was constructed as essential if a client wishes (chooses) to remain at home. Family involvement was viewed as a necessity, as stated by this director: "Our system could never work without informal care. Seventy per cent of care in the community is done by informal [sources]." In the absence of sufficient family involvement, participants stated that client choices to stay at home would be unmet. As such, one specialist referred to a "huge expectation" of family care "if patients want to stay at home."

As a client choice, being at home was then constructed as a client and family responsibility. One health agency's newest document supporting the "home is best" philosophy (Fraser Health Authority 2011) relates a fictional example in which an older, hospitalized client (Marjorie) wants to go home. The latent message is that keeping Marjorie at home respects her wishes, and that this is the moral imperative.

Family members were constructed as primary care providers by participants, with home health as supplementary or supporting, "assisting them to do for themselves." Participants contrasted home health roles against "paternalistic" approaches involving "doing for," "taking over" or "rescuing" families. One manager described one family caregiver as a "martyr" and "overburdening herself." This woman injured herself providing care; while she was recovering from surgery, the agency needed to send two workers to lift the client. The family wanted this care

to continue after the caregiver's recovery because she received medical advice not to lift the client. The manager suggested that this situation turns the health agency into the primary care provider, which is untenable and unfair to other clients, citing the need for fiscal responsibility and for home health to avoid taking on long-term responsibility.

Some participants spoke of increasing expectations of family responsibility as connected to service cutbacks, deficit recovery situations and restrictive home support guidelines. As an example, reduced home support hours have been accompanied by "a stronger expectation that family is the primary [care provider] and home support really is just to support what the family is able to offer." In contrast, other participants described family involvement as a founding cornerstone of home care philosophy, reflecting the value of independence that should be institutionalized regardless of resources. One director suggested that "we all have a responsibility for managing our health, and for self-care. It's not the system's responsibility."

### *Communicating messages of family responsibility*

The companion video for the recent "home is best" initiative in one health agency (Fraser Health Authority 2011) states, "we don't rely just on family to provide [care at home]." Nonetheless, participants in the present study explained how expectations of responsibility are communicated to families in multiple ways. For instance, one director described how nurses communicate agency expectations by speaking of family members as "primary caregivers." Another director stated: "Something we push [families to do] is to take responsibility, and that's part of our discussions." A clinical specialist spoke of "unspoken expectations" that if family were present, it was assumed they would provide care (unless they said otherwise).

Participants described how home health emphasizes the primary responsibility of family caregivers in public materials, particularly through the language of home health's "supplemental" role (as representing the organizational position). One director expressed: "A lot of our policies say these services are to supplement the care provided by the family. So it embeds into the policy that there is a responsibility that rests with the family." The provincial HCC document referred to by one participant states: "Services complement and supplement, but do not replace" both self- and family care (Ministry of Health Services 2007: 1). This phrase, or similar ones emphasizing non-replacement, are echoed in three regional documents (Fraser Health Authority [no date]: 1; Interior Health Authority 2007: 3; Vancouver Island Health Authority 2009: 4) and one caregiver handbook (Fraser Health Authority 2005: 42).

In the caregiver handbooks, family members are encouraged to perform a wide variety of care tasks, but also to ask for and accept support from others (e.g., "It begins with doing all you can for yourself, and then learning to accept help, when help is needed"; Fraser Health 2005: 38). However, there is relatively greater weight placed on asking for help from informal rather than formal sources. One HCC guide describes care tasks that home support cannot provide, suggesting to the client, "There are many things we cannot do for you. This is where your family, friends and neighbours can help" (Vancouver Island Health Authority 2009: 19).

Participants spoke about how family involvement in all levels of care, or at least “as much as they are willing and able to do,” was promoted by skilled practitioners. One specialist stated: “The nurses and other staff are really skilled at, at least getting [families] to provide the care that they are able and willing to provide.” One director described how she coached staff to promote empowerment and family involvement through asking such questions as: “Why are we doing that if there’s family there and able to do that?” She also hired nurses skilled in teaching, mentoring and encouraging families.

Promoting family involvement in practice was described by participants as consisting of developing relationships; teaching care tasks; reassuring and negotiating with families; convincing families that agency involvement may harm their independence or empowerment; educating them about home health’s role and limitations; and emphasizing the benefits of family care. For instance, one director expressed: “As a rule, we do not present family involvement so much as a responsibility but sort of a blessing.” Benefits mentioned included those for the client (death at home, quality of care, autonomy) and family (quality time, bonding, self-efficacy, skill development for future self-care).

Professionals’ perceptions of available family support were described as influencing client need assessments and determinations of access to services. For instance, one HCC document states that service needs are determined not only by client symptoms and well-being, but “the support available through family, friends and close community ties” (Fraser Health Authority [no date]: 3). One director explained that if two clients with similar assessed clinical need have different family networks, the more networked client will receive less formal service. This approach is explained by this participant with reference to fiscal responsibility and system sustainability in the context of an aging population.

Revised personal assistance guidelines referred to by one participant further support this model, wherein one criterion for delegating a task to a home support or community health worker is that “there is no other person in the client’s support system to do the task” (Ministry of Health Services 2008: 8). Clients are also encouraged to purchase private services if needed. Such an approach implicitly views informal care (and private purchase) as a substitute for formal care. In contrast, one agency claims publicly that “care provided by family members is ... not a substitute for formal supports in the home” (Fraser Health Authority 2011: 12).

### *Flexibility and appropriate system intervention*

Some participants qualified expectations of family responsibility or suggested that their practical application could be flexible, as in “family involvement is what they decide is enough or not enough”; “different families are capable of doing what they can”; “it’s very important that we don’t overburden the family”; and “to expect to empower them to the point where they actually deliver the physical care may not be accomplished.”

In part, an emphasis on flexibility involved recognizing challenges involved in caregiving. Some participants expressed that it is not always possible for families to provide certain levels of care (e.g., they may live away or be estranged, have health problems, work full time or have young children). Caregiving strain was also noted, as in: “We need to let them off the hook

when they've reached their limit and allow them to resume their role as the wife/husband or daughter, and not the caregiver." One caregiver handbook states: "Being a caregiver does not mean doing it all – all the time" (Fraser Health 2005: 50), particularly when there are challenges; it suggests that families discuss involvement preferences with healthcare teams. Lastly, one clinical specialist emphasized respecting non-involvement: "Sometimes I would almost say, 'If only they would be able to be more involved ... it would just help so much.' Yet, this is not my journey."

As a less dominant theme, some participants described exceptions when providing support is necessary. One specialist stated: "The client's primary care provider is, in addition to their family, in the system, the home care nurse." A manager likewise suggested that the self-care model could not be applied universally; nurses should make individual assessments, and the system should provide care that families cannot (though as a result, home death may not occur).

Nonetheless, other participants characterized some professionals as being inappropriately overinvolved and paternalistic (believing they hold primary responsibility for clients), "taking over" rather than helping families do it themselves. As such, one director believed that promoting family responsibility requires practice standardization and restructuring "so that there isn't the same structure that people are reporting to, with the sense [of] 'new eyes, new ears, new questions.'"

Reference to flexible expectations of family was more predominant in talk and text about clients with terminal illness. Some participants suggested that expectations of self and family responsibility were less strongly applied in these situations, where the approach involves providing more support or making more "waivers or exceptions." More intensive services are usually available for defined, short-term palliative situations. The provincial HCC guide describes palliative services as focusing on symptom management, "so that those facing death and their loved ones can devote their energies to embracing the time they have together" (Ministry of Health Services 2007: 6). The provincial end-of-life framework (Ministry of Health Services 2006) also includes home care nurses (i.e., not only family members) in its definition of primary caregivers. As one director stated, for chronic clients or those with longer/more ambiguous terminal trajectories, "we don't want to ... promote a dependence upon us"; home support hours are more limited, and more financial costs are family responsibilities. Further, one specialist described organizational attempts to "tighten up" the current six-month prognosis criterion for palliative designation "because [palliative services are] really meant to help people die at home, not for long-term support."

### *Dissonance between system and public expectations*

Participants commonly described family expectations of system responsibility as incongruent with organizational realities. Indeed, an emphasis on family responsibility in text and talk may partly reflect agencies' attempts to manage public expectations about available HCC services, particularly since these may differ considerably from in-patient services (which are covered under the *Canada Health Act*).

Families' expectations were often characterized as inappropriate, for example: "Their expectations of the system probably far exceed what we can honestly provide." One director heard frequent complaints from families that the agency was "downloading" and placing too many expectations on families; she described these as reflecting inappropriate expectations. A manager spoke about conflict over who "owns the situation," suggesting that families expect the health system to do "everything for everybody." A specialist further implied that some families, rather than being grateful for formal services as a "bonus" to help them provide care, view it as an entitlement. Another director described how public expectations conflict with policy directions favouring de-institutionalization: "When clients and families take their loved ones to acute [care], they think, 'Granny's been driving us nuts. They'll take care of her. They'll place her.' Not so much. Basically, we are moving to more of a 'home first' philosophy." Concern about dissonance between system and public perceptions led some participants to emphasize public education about services, and practitioner negotiations with families.

Participants believed that high expectations were related to such factors as denial of impending death, culturally specific beliefs or isolation from the dying process (i.e., resulting in low self-efficacy) and an older, paternalistic healthcare culture and previous acute care experiences that generate a sense of entitlement, especially among assertive families with high levels of wealth or education. When families resist responsibility for particular tasks, their expectations were described as needing to be negotiated and managed, for example, by explaining the limitations of formal services ("If they don't know what that limitation is, they don't know how much they're responsible for").

## Discussion and Conclusions

Examining organizational positions on family responsibility is a challenging task, given that individual staff may interpret policy and practice directives in differing ways. This study could have been strengthened by using a larger sample of a wider range of organizational positions (e.g., including home care nurses), though larger samples often limit the extent of rich, in-depth data for analysis.

In these data, dying at home was constructed as a client choice, and service limitations and family responsibility as an almost natural consequence of this choice. Overall, of course, care at home is a positive trend with the potential to enhance client well-being. However, practitioners need to be cautious in universally promoting it in all cases, an approach that can create situations whereby staying at home – and, by default, family caregiving – becomes less of a choice and more of an imperative. Ultimately, service access decisions remain under the control of professionals and administrators. Will client choices to stay in hospital, or enter residential care, be respected equally as the choice to stay at home? Will the family's choice of their level of care involvement be considered? With a few exceptions, the texts and talk remain silent in this regard.

An emphasis on choice in the context of organizational constraints can reflect a process called "responsibilization" (Burchell 1996; Rose 1996), wherein government concerns (i.e.,



de-institutionalization, cost containment) become institutionalized within taken-for-granted individual choices. These individuals (and their families) are then viewed as needing to take responsibility for the outcomes, and caregiving becomes interpreted as a private family concern (McDaniel 2004). From a critical perspective, this process aligns with economic and political goals of many contemporary governments. Values of choice, independence and both personal and family responsibility in home care practice and policy can support task transfer to families (Funk et al. 2011; Purkis et al. 2008; Ward-Griffin 2001). In this process, the role of cost constraints is obscured, and families who provide inadequate levels of care may be blamed for incorrect moral choices.

In Canada and other developed nations, healthcare budgets are under increasing scrutiny; climates of constraint in fiscal and human resources align with practice frameworks supporting independence and empowerment. Attempts to minimize institutional costs have led to increasing reliance and demand on home care services not protected under the *Canada Health Act*. Over time, there has been curtailment or a lack of expansion of public home care services in British Columbia (McGrail et al. 2008; Penning et al. 2006), as elsewhere.

In this context, there is an increased reliance on and expectations of families to take primary responsibility for care, as reflected in these findings. While there may be positive benefits for families who desire greater involvement, there is also potential to increase care burdens. The Canadian Caregiver Coalition maintains that family caregiving should not be viewed only as “a substitute for public responsibility in health and social care” (Canadian Caregiver Coalition 2008: 3).

Nonetheless, many healthcare organizations tend to view families as a substitute for formal services. Further, participants (and policies) in this study constructed formal services as supplementing but not replacing family care, implicitly assuming that providing formal services risks replacing family care. However, evidence indicates that formal services do not in practice erode either family or self-care (Penning and Keating 1999; Penning 2002).

That expectations of family responsibility are often implicitly gendered was not mentioned in the texts or interviews; the reality of gendered care provision is obscured under the neutral term “family.” Women provide the majority of family care and tend to face higher expectations for the amount, extent and quality of care they provide as well as their emotional investment in the role (Aronson 1992; Calasanti and Slevin 2001).

Further, both text and talk remained silent regarding how socio-economic resources can constrain some families’ abilities to manage care responsibilities by purchasing services privately. The federal Compassionate Care Benefits program (introduced in 2004) reimburses some wages lost when caring for a family member, yet coverage is restricted to six weeks, to persons normally eligible for employment insurance benefits (e.g., in the paid labour force) and only in situations of diagnosed terminal illness.

Though many family members welcome care involvement, there are ethical concerns that some “may be pressured into assuming a role they feel unprepared for” (CHPCA 2004a: 7) or not fully understand what is involved when they make the choice (Stajduhar and Davies



2005). Both the Canadian Hospice Palliative Care Association (2004a,b) and the Canadian Caregiver Coalition (2008) emphasize the importance of informed choice about care involvement, open discussions and the provision of supportive services. Staying and dying at home, while potentially beneficial, should not be idealized as a universal good, because it can also involve negative outcomes for caregivers (Canuscio et al. 2002; Chentsova-Dutton et al. 2000; Fredman et al. 2008; Stajduhar 2003). Training of home health workers and professionals should strive to promote nuanced understandings of family involvement and empowerment (along with skills in reflexivity, critical thinking and dealing with moral distress).

Future research should clarify public expectations of the roles and responsibility of subsidized home health services. There should also be public discussion about the roles of clients, family members, communities and governments in home-based care, towards “a clearer delineation of social responsibility and family responsibility” (CHPCA 2004b: 14). The input of the public and caregiver advocacy groups will help ensure that families are adequately supported as well as have opportunities for care involvement where they are able and willing to contribute.

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# Lifestyle as a Health Risk for Family Caregivers with Least Life Satisfaction, in Home-Based Post-Stroke Caring

Dans les soins à domicile qui font suite à un accident vasculaire cérébral, le mode de vie des aidants familiaux présentant une moindre satisfaction à l'égard de la vie est un facteur de risque pour leur santé



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## Abstract

Our purpose was to clarify that caregiving roles represent a situation of risk for the health of family caregivers, in home-based caring two years after cerebrovascular disease. Our aim was to determine the social and emotional repercussions of the event on family caregivers. Family caregivers living at home with stroke survivors were identified by a national survey. The Life Satisfaction (LS) national indicator for Luxembourg is 7.9/10, while in Canada it stands at 7.7. Caregivers with a LS level  $\leq 7$  were more likely to care for survivors affected by motor, sensory and memory neurological impairments. For a great majority, these impairments led to serious upheaval among families, and for spouses it was “a drama.” For family caregivers with a least life satisfaction, their lifestyle poses a real health risk for the public health system.

## Résumé

Notre propos a été de mettre en lumière que le rôle d'aidant représente une situation à risque pour la santé des aidants familiaux dans les soins à domicile, deux ans après un accident vasculaire cérébral (AVC). Notre objectif a été de déterminer les répercussions sociales et émotionnelles de l'évènement chez les aidants familiaux. Les aidants familiaux vivant à leur domicile avec les victimes d'un AVC ont été identifiés lors d'une enquête nationale. L'indicateur national de SV du Luxembourg étant de 7,9/10 (en comparaison d'avec le Canada qui obtient 7,7), les aidants avec un niveau de satisfaction à l'égard de la vie (SV)  $\leq 7$  sont plus nombreux à s'occuper de victimes atteintes d'affections neurologiques motrices, sensorielles et de la mémoire. Pour une grande majorité, cet accident a entraîné de sérieux bouleversements dans leur famille, et pour les conjoints, ce fut "un drame." Pour les aidants familiaux avec un degré moindre de SV, leur mode de vie contient un réel risque sanitaire pour le système de santé publique.

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CEREBROVASCULAR DISEASES ARE AN IMPORTANT PUBLIC HEALTH POLICY CONCERN because of their high prevalence and the long-term disability that survivors often experience; it is the principal acquired cause of handicap, and one of the most common causes of death in countries such as Luxembourg and Canada (WHO 2010). In the present economic climate, in which costly in-patient rehabilitation is giving way to home-based healthcare (Jungbauer et al. 2008), lifestyle-related risks (Massé 2007), as well as the positive experiences of home caregivers (Han and Haley 1999), require investigation. Stroke patients and family caregivers tend to have a relatively short time to get used to their new situation (Green and King 2007), in which the unexpected health circumstances and specific family issues affect satisfaction with life as a whole (Bergstöm et al. 2011). For Frohlich and Poland (2006), lifestyles reflect the interrelations between orientations, resources and health behaviours adopted by groups of individuals in response to their social, cultural and economic environment.

In Canada, nearly half of family caregivers of stroke patients are at risk of developing psychological and social issues (Teasell et al. 2009). These individuals, who have suffered lasting changes as a result of cerebrovascular disease, are significantly challenged to maintain high life satisfaction, defined as a global measure of the degree of discrepancy between individual aspirations and achievements, or general contentment. The Conference Board of Canada (2013) and the European Foundation for the Improvement of Living and Working Conditions (2010) find the monitoring of the social progress of citizens, as well as their position in society, to be important in informing public health policies. The Grand Duchy of Luxembourg is one of the smallest countries in Europe, yet has a very high gross domestic product (GDP) per inhabitant (\$107,476 vs. \$52,219 in Canada) (World Bank 2012). Along with Canada, Luxembourg is among the top countries in terms of life satisfaction, with a score of 7.9 (Conference Board of Canada 2013; European Foundation 2010). A recent study showed

that, two years post-stroke, family caregivers' life satisfaction was positively associated with survivors' quality-of-life dimensions of feelings (less independent, life changed, depressed, useless, less control because of stroke) and emotion (get more emotional, fear of another stroke or of becoming dependent on others), and with their own quality of life (Baumann et al. 2012b). Life satisfaction after a stroke has been considered a significant issue in rehabilitation for care recipients (Low et al. 1999) and also for family members.

Taking a micro-sociological approach, we intended to explore whether home care for stroke survivors is a good idea if the repercussions create a lifestyle that represents a health risk for family caregivers. If the needs, resources, skills and will of the family caregivers for "taking care of the other" are hardly taken into account, the questions for the future are: How can the physical and psychological exhaustion of family caregivers be prevented? How might this change be approached in a positive way, as for instance, with innovative initiatives, involvement of the private sector or other forms of support, or services for caregivers that include opportunities for exchange of competences and resources?

Caregivers who have low life satisfaction also have lower health-related quality of life, a greater prevalence of stress and depression, more economic problems and an impoverished social life (Brännholm et al. 1996). As with the interconnectedness of other couple-related factors, such as emotional well-being, the quality of a couple's interpersonal relationship and the way they cope together with life problems are positively associated with the life satisfaction of each partner (McCarthy et al. 2011). Studies have shown that couples who are dissatisfied with life perceive a greater level of caregiving burden compared to couples in which both spouses are satisfied (Ekstam et al. 2010).

During the first year post-stroke, spouses caring for male survivors reported lower life satisfaction (Forsberg-Wärleby et al. 2004) and were more often depressed than women caregivers generally (Berg et al. 2005). In addition, spouses or companion caregivers faced with physical, psychosocial and emotional problems are more exposed to burnout, particularly if they are women and if they are older (Navaie-Waliser et al. 2002). Women believe that their families let them care alone for the stroke-patient relative, making it difficult to find relevant help, which would in turn have a considerable impact on their own health (Bucki et al. 2012).

Factors already identified as associated with low caregiver life satisfaction include care recipient with physical and cognitive impairments (Forsberg-Wärleby et al. 2004), a decline in the caregiver's health due to caregiving demands (Forsberg-Wärleby and Möller 2001) and couples failing to adapt to the post-stroke situation at home (Green and King 2007). For example, one year post-stroke, life satisfaction was found to decline for patients (because of motor impairments, limitations in daily activities and post-event depression) and increase for those family caregivers who reintegrated into normal patterns of living and gained confidence in their healthcare work (Ostwald et al. 2009).

Studying individuals two years post-cerebrovascular disease creates an opportunity to gather valuable information on the survivor-caregiver dyad over time. In the chronic phase, patients and their family caregivers may have reorganized their daily lives and become accustomed to caregiving. Some studies of home-based stroke healthcare showed that caring for

patients has an impact on family caregivers' life satisfaction, and analyzed the stroke-related impact on the patient–caregiver couple relationship (Green and King 2007) and the factors associated with caregiving that affect spouse–caregivers' life satisfaction (Carlsson et al. 2007; Ostwald et al. 2009).

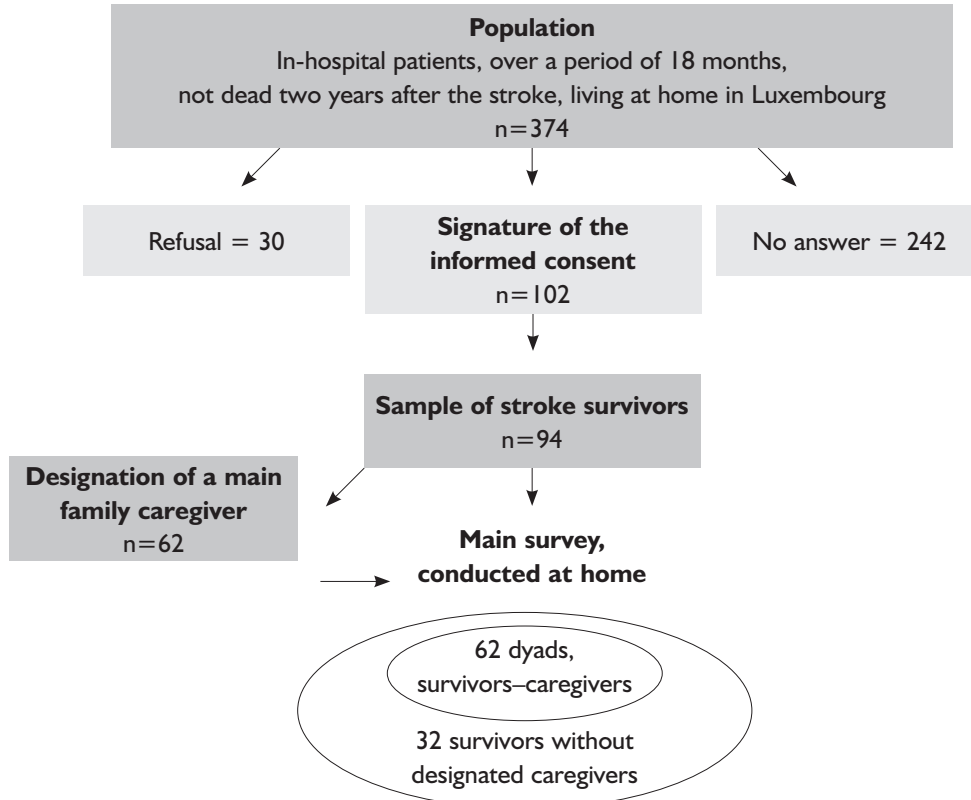
The strength of our project relies on the application of a self-assessment instrument to measure life satisfaction, as previously used in quality-of-life surveys, as well as the impact of the stroke on social lives and the experience of the caregiving role. Our aim was to determine the emotional and social repercussions of stroke on family caregivers with low life satisfaction, their sociodemographic characteristics and the associated neurological impairments of the survivors two years after cerebrovascular disease.

## Methods

### *Participants and procedures*

Over a period of 18 months, all stroke survivors (797 patients) admitted to all hospitals in Luxembourg and living at home two years post-stroke were identified from the *Inspection générale de la sécurité sociale*, the only relevant national database (see Figure 1).

FIGURE 1. Design of the national Luxembourg study





We sent a letter to 374 patients who lived at home, explaining the aims of the survey and inviting them to participate. The consents of the main family caregivers were obtained when the research teams went to the stroke survivors' homes to undertake the survey. After receiving each patient's signed informed consent, the research team telephoned to make an appointment at the patient's home with the main caregiver whom he or she had identified as "the person who mostly takes care of [the patient] since the stroke event."

As Luxembourg is a multilingual country, our questionnaires were written in five languages. Most of the instruments were already validated in French or English. The German, Portuguese and Luxembourgish versions were translated, back-translated and proofread by native-speaking professional translators.

### *Data collected from patients*

The Life Satisfaction (LS) Scale provides a subjective appraisal by asking respondents to self-rate their LS: "On a scale of 1 to 10, where would you place your level of satisfaction with your life?" (10 being the highest level).

Neurological impairments and residual disabilities, as formulated by the American Heart Association Stroke Outcome Classification (AHA.SOC), is a validated system that synthesizes stroke-related problems in single summary scores (Kelly-Hayes et al. 1998). Deficiencies were documented in motor, sensory, vision, cognition, language function, continence and memory abilities, and in personality disorder.

Sociodemographic characteristics (see Table 1) were collected for mean age, sex, educational level, occupation at the time of stroke and current occupational status.

### *Data collected from family caregivers*

With regard to life satisfaction and socio-economic characteristics, the same tools and procedures as for the survivors were applied; information about the relationship with the care recipient (i.e., spouse/partner or other) was added.

The experience of caregiving (see Table 2) was gauged using the items of the Caregiver Reaction Assessment instrument (Given et al. 1992 for the English version; Antoine et al. 2010 for the French version), which explores caregiver esteem, lack of family support, financial strain, impact of caregiving on scheduled activities and health problems.

Family and couple relationships (see Table 3) were assessed based on a previous qualitative study (Baumann and Aïach 2009). The items covered were disruptions within the family relationship and changes in the distribution of roles within the couple.

## Lifestyle as a Health Risk for Family Caregivers with Least Life Satisfaction, in Home-Based Post-Stroke Caring

**TABLE 1.** Sociodemographic and stroke-related characteristics: mean (standard deviation) and percentage

				LS groups of family caregivers		
		Patients n=62	Family caregivers n=62	LS ≤7 n=31	LS >7 n=31	p
Age		64.4 (15.8)	59.3 (13.7)	59.1 (12.2)	59.3 (15.1)	0.962
Sex	Women	40.3	65.6	75.9	55.2	0.167
	Men	59.7	34.4	24.1	44.8	
Relationship with survivor	Spouse / Partner	–	82.3	79.3	92.6	0.254
	Child / Other	–	17.7	20.7	7.4	
Educational level	Under 12 <sup>th</sup> grade	44.4	42.4	48.3	34.5	0.424
	12 <sup>th</sup> grade and above	55.6	57.6	51.7	65.5	
Occupation at the time of stroke <sup>1</sup>	Never employed	20.4	17.5	21.4	14.3	0.328
	Manual worker	22.2	14.0	21.4	7.1	
	Employee / Intermediate professional / Technician	35.2	49.1	42.9	53.6	
	Manager / Liberal profession	22.2	19.3	14.3	25.0	
Occupational status, two years post-stroke	Working	19.6	35.6	31.0	42.9	0.650
	At home without activity	23.2	30.5	32.1	24.1	–
	Retired	57.1	33.9	37.9	32.1	–
Current AHA.SOC <sup>2</sup> impaired functions and disabilities	Motor	43.5		65.5	27.6	0.008**
	Visual	22.6		27.6	20.7	0.760
	Sensory	53.2		69.0	41.4	0.064 <sup>§</sup>
	Language	32.3		41.4	27.6	0.408
	Memory	38.7		55.2	27.6	0.061 <sup>§</sup>
	Personality disorder	22.6		31.0	17.2	0.358
	Incontinence	14.5		20.7	10.3	0.470

p: Significance level (<sup>§</sup> ≤0.1; \* ≤0.05; \*\* ≤0.01; \*\*\* ≤0.001).

<sup>1</sup> For unemployed and retired people as well as for those in vocational training at the time of the event, the last occupational activity was recorded.

<sup>2</sup> American Heart Association Stroke Outcome Classification (AHA.SOC) (Kelly-Hayes et al. 1998).

### *Statistical analysis*

According to the mean Luxembourg LS value (7.9), two groups were built: one with the respondents having a  $LS \leq 7$  versus the other with a level  $> 7$ . Quantitative variables were compared using the Student's t-test or the Mann-Whitney test, and the categorical variables using the Fisher's exact test. Percentages indicate the proportions of those answering "completely agree" or "agree."

## Results

The participation rate was  $94/374 = 25.1\%$  (Figure 1). Comparisons between the sociodemographic characteristics (age, gender, nationality, place of residence, number of admissions to hospital) of the study sample and the general population of stroke victims showed no differences. Among the 94 patients (mean age 65.5 years), 32 had no designated caregiver (67.6 years) and 62 had a family caregiver (64.4 years) (Baumann 2012b).

### *Socio-economic and stroke-related characteristics*

Two groups of 31 family caregivers (average age 59.3 years; on average, 5 years younger than the patients they cared for) were obtained. More family caregivers with a  $LS \leq 7$  cared for stroke patients affected by neurological impairment of motor abilities (66% vs. 28%, including speech and swallowing, muscle power and tone, reflexes, balance, gait, coordination and apraxia), sensory deficits (69% vs. 41%, including loss of primary sensations or perception, numbness, tingling or altered sensitivity) and memory-related residual disability (55% vs. 28%) (Table 1).

### *The experience of caregiving*

No significant difference was found between the various aspects of the caregiver esteem dimension. However, fewer family caregivers with a  $LS \leq 7$  reported that their "family works together at caring." More found that caregiving affected their schedule; they felt "tired all the time" and were exhausted of physical strength owing to caregiving tasks (Table 2).

### *The family and couple relationships*

A great majority of the family caregivers with a  $LS \leq 7$  reported that stroke "entails serious upheaval in [their] family," but for 3/5, "social life goes on as before." Among the spouses (25 respondents with a  $LS \leq 7$  vs. 27), a majority of those with a  $LS \leq 7$  recognized that stroke was "a drama" that caused "serious upheaval in [their] couple relationship" which meant "the end of plans for the future." For a quarter, stroke "often put a distance between [them] and [their] children." Most declared they "cannot leave the stroke-affected person alone for too long" and they now have more "household responsibilities" (Table 3).

## Discussion

Our study aimed to explain why the caregiving role, in home-based post-stroke caring with its familial, social and emotional repercussions, constitutes a lifestyle with a health risk. In our

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findings, more family caregivers with low life satisfaction, living at home with stroke survivors, cared for patients affected by motor, sensory and memory impairments. For a great majority of family caregivers – in particular, spouses with low satisfaction – their experience of caregiving reflects a lifestyle that puts their health at risk.

**TABLE 2.** The experience of caregiving (%)

		Life satisfaction		
		LS ≤7	LS >7	p
Caregiver's esteem	I really want to care for him/her.	65.2	63.6	0.330
	I feel privileged to care for him/her.	87.0	95.2	1.000
	I enjoy caring for him/her.	65.2	90.5	0.113
	Caring for him/her makes me feel good.	65.2	71.4	0.325
	Caring for him/her is important to me.	87.0	90.5	0.609
	I will never be able to do enough caregiving to repay him/her (reversed).	34.8	47.6	0.556
Lack of family support	I resent having to care for him/her (reversed).	13.6	4.8	0.421
	It is very difficult to get help from my family in taking care of him/her.	21.7	0.0	0.081 <sup>§</sup>
	Since caring for him/her, I feel my family has abandoned me.	13.0	0.0	0.103
	My family (brothers, sisters, children) left me alone to care for him/her.	45.5	23.8	0.402
	My family works together at caring for him/her (reversed).	34.8	71.4	0.007**
	Others have dumped caring for him/her onto me.	30.4	22.7	0.806
Impact on finances	It is difficult to pay for him/her.	8.7	4.8	0.288
	Financial resources are adequate (reversed).	78.3	71.4	0.247
	Caring for him/her puts a financial strain on me.	8.7	0.0	0.037*
Impact on schedule	I have to stop in the middle of my work or activities to provide care.	34.8	4.8	0.030*
	I have eliminated things from my schedule since caring for him/her.	47.8	9.5	0.021*
	My activities are centred around caring for him/her.	59.1	31.8	0.225
	I visit family and friends less since I have been caring for him/her.	54.5	14.3	0.021*
	The constant interruptions make it difficult to find time for relaxation.	39.1	9.5	0.074 <sup>§</sup>
Impact on health	It takes all my physical strength to care for him/her.	73.9	71.4	0.092 <sup>§</sup>
	I am healthy enough to care for him/her (reversed).	82.6	81.0	0.120
	My health has gotten worse since I've been caring for him/her.	23.8	4.8	0.257
	Since caring for him/her, it seems like I'm tired all the time.	56.5	14.3	0.013*

p Significance level (<sup>§</sup> ≤0.1; \* ≤0.05; \*\* ≤0.01).

Percentages indicate the proportions of respondents who "completely agree" or "agree."

Stroke patients with physical impairments require family caregiver support in their self-care (help with showering, dressing, taking transport, preparing food, managing the shopping) and with mobility (walking, managing stairs, bending down while unsteady on their feet, standing for any length of time). As a consequence, we observed in our findings that those family caregivers with low life satisfaction were more likely to perceive themselves as in a permanent state of fatigue and to feel that caregiving was taking all their physical strength. This constant fatigue may be attributable to the constant disruptions in their routine activities related to their caregiving role that make finding time for relaxation and social life difficult. Swedish law has recognized the repercussions on family caregivers in a 2009 amendment that calls for assistance in minimizing the caregiving burden (Bergstöm et al. 2011).

TABLE 3. Social and couple relationships (%)

		Life satisfaction		
		LS ≤7	LS >7	p
Family relationships	The stroke has brought serious upheaval to my family.	82.8	51.7	0.024*
	Some time after the stroke event, my family worked together in taking care of the stroke-affected person.	81.5	78.6	1.000
	The stroke has strengthened family bonds.	68.0	69.0	1.000
Social isolation	The bonds between us (relatives, friends) remained as they were before or are stronger.	75.9	93.1	0.144
	We have lost many friends.	10.3	10.3	1.000
	Social life goes on as before.	58.6	96.6	0.001***
	Now we are ashamed of seeing our friends.	6.9	0.0	0.491
Disruptions within the couple relationship	The stroke brought serious upheaval to us as a couple.	57.1	25.9	0.029*
	I have perceived the stroke as a drama that my couple relationship could not overcome.	54.2	7.4	0.000***
	The stroke has meant the end of plans for the future that we had as a couple.	45.8	11.1	0.011*
	When a couple's relationship is already conflictive, a stroke worsens it.	31.8	48.0	0.373
	A stroke brings changes to a couple's relationship.	45.8	34.6	0.565
	Stroke often puts a distance between our children and us.	23.1	0.0	0.010*
Distribution of roles within the couple	I am more in charge of the housekeeping, cooking and shopping.	24.0	4.0	0.111
	I take care of the administrative affairs now.	16.0	15.4	0.540
	I organize the holidays and the leisure time now.	8.7	4.2	0.040*
	I am more in charge of our relationships with professionals (health professionals, cleaning professionals, etc.).	33.3	36.8	1.000
	I have more household responsibilities.	38.1	10.5	0.069 <sup>§</sup>
	The responsibilities are shared as before.	79.2	81.5	0.000
	I cannot leave the stroke-affected person alone for too long.	60.7	17.2	0.001**

p Significance level (‡ ≤0.1; \* ≤0.05; \*\* ≤0.01).

Percentages indicate the proportions of respondents who "completely agree" or "agree."

Neurological impairments in sensory and memory-related functions can change survivors' cognitive processes. Loss of cognition has more impact if the affected skill was central to pre-stroke self-defining activities; day-to-day required efforts to concentrate were perceived as a new source of frustration. Associated with memory loss, the survivor's ability to concentrate was reduced. At the same time, reduced memory led patients to lose their sense of context and time perspective, and resulted in a perception of being distanced from those around them, including family, community and social networks. For our family caregivers with the lowest level of life satisfaction, stroke entailed serious familial upheaval, a finding in line with earlier research on caregivers' reactions (Lucas et al. 2003; Ostwald et al. 2009). For some, their social lives went on as before, but others perceived a negative readjustment of their daily interpersonal relationships. This was particularly true of the caregivers who found it difficult to get family help. Lack of social support can generate fear about current and future functioning, and alter expectations of improvement. This finding reflects the psychological difficulties of caring for patients, in particular those with memory disorders (Baumann et al. 2011).

More family caregivers with a low level of life satisfaction eliminated engagements from their schedule and visited family and friends less. In other words, home-based caring is determined by the constant dependency of the stroke patient on his or her caregivers. The caregiving role creates a privileged relationship with the care recipient, but in some situations social isolation is one of the negative consequences. A decrease in leisure time, as demonstrated elsewhere, also affects how caregivers assess their lives as a whole (Cook et al. 2005). Moreover, impoverished relationships have been associated with low self-perceived LS in studies in the field (Carlsson et al. 2007). In such a situation, support from family and friends may increase in value. Following the acute phase, the caregiver's individual appraisal of both the personal consequences of the stroke and his or her coping capacity affects psychological well-being more than does the objective disability of the patient (Forsberg-Wärleby and Möller 2001).

Caregiver esteem shows that their caregiving-related daily activities made sense to them and that they appreciated caring for their relatives. However, the lifestyle and experience of caregiving depends on the cultural context in which it is carried out, as well as material life conditions. Particularly for family caregivers having a low satisfaction with life, caring produces strain because of their financial situation. In our sample, the majority of caregivers were retired. Despite the socio-economic differences between care settings and domestic assistance, stroke is a life-threatening and potentially disabling event, as well as an important family issue. On the one hand, difficulties are likely to intensify as the family reaches a situation of greater social vulnerability with the attendant health risks. On the other hand, social factors, particularly socio-economic status, play a large role in determining access to services (Braveman 2010).

For half of the spouse-caregivers with low satisfaction, the partner's stroke brought disturbances to their relationship; it was a "drama" that ended the couple's plans for the future. Self-confidence in a couple's stability may favour their emotional recovery from the upheavals of stroke and acceptance of the irreversible. Confidence increases the preparedness of the

spouse to assume the caregiving role (Ostwald et al. 2009). Moreover, as caregivers accumulate day-by-day experience of healthcare tasks and their caregiving role, their perspective needs to be incorporated in guiding these interventions. Improving our understanding of these experiences, principally the repercussions on familial and couple relationships, social lives and plans for the future, can contribute to our ability to sustain home-based care for those stroke survivors willing to continue to live at home. Stroke distances some family caregivers with low life satisfaction from their children. Therefore, stroke onset must be considered not only as requiring an adaptation to changes in material conditions but also as a painful family experience involving emotional and relational adjustments.

Accordingly, spouses may assume new responsibilities that imply a reconfiguration of the relationship with the care recipient (Green and King 2007). Regarding changes in the distribution of duties, more spouses with low life satisfaction recognized that they could not leave the stroke-affected person alone for too long, or easily organize household responsibilities, holidays and leisure time. A fulfilling family and social environment helps provide the resources to readjust future plans to the present situation and increase confidence when assuming the caregiving role. Efforts to determine how the caregivers of stroke-affected people could be better supported and prepared by healthcare, social services and education professionals is a topical question that is directly relevant – or soon will be – to a large number of us. Interventions to enhance community-based rehabilitation should be designed on the basis of sound information (Oupra et al. 2010).

### *Limitations*

Our protocol – follow-up 24 months after onset of cerebrovascular disease – remains rare because it is expensive and difficult to organize. Numerous survivors died, lived in institutions, changed their residence (e.g., moved in with an adult child) or failed to respond to our request for an interview. The estimated participation rate was small but similar to that of recent studies (27%) (Bergstöm et al. 2011). Our sample was built from volunteers who agreed to take part, but were identified after the patients gave their consent by a posted letter; this option reduced the response rate. Finally, the interviews took place at home, which may have discouraged some potential participants.

Finally, a self-rated life satisfaction indicator must be interpreted cautiously because an objective life situation is not always associated with a corresponding subjective judgment (Ferring et al. 2010). A life situation described with respect to objective standards may be good but subjectively evaluated as bad, or on the contrary, described by objectively bad conditions but subjectively judged as good.

### **Conclusion**

The responsibilities of supporting and caring for stroke patients are often assumed by a single family caregiver. Adjusting to life at home, coping with dependencies and disabilities, and learning how to resume psychosocial roles is a complex process. In Canada, nearly half of



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caregivers of stroke patients are reportedly at risk for clinical depression and reduced involvement in social and occupational life, a finding that represents a cost both for families and for the healthcare system (Teasell et al. 2009). The Global Mental Health Action Plan produced a set of recommendations to prevent social suffering and psychic disorders, and promote well-being (WHO 2013). These recommendations are based on the same principles as the report of Hachinski and colleagues (2010), which proposes a multisectoral approach in professional practice and empowerment of patients and families.

Adapted to health, the theoretical foundation of the capability approach offers insights for developing family caregivers' well-being by means of both individual initiatives and a collective determination (Bucki et al. 2012). Successful home-based healthcare requires that family caregivers, along with stroke patients, find new ways of solving problems, communicating and dealing emotionally with others. Managing this situation involves one specific rearticulation of the different risk dimensions centred on strategy integrating such concepts as lifestyle at risk (Massé 2007). An approach based on the analysis of lifestyles would enable a better accounting of behaviours, social contexts and structural constraints (social inequalities, differing social reports).

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# Sharing Bodies: The Impact of the Biomedical Model of Pregnancy on Women's Embodied Experiences of the Transition to Motherhood

Partage des corps : impact du modèle biomédical de la grossesse sur l'expérience de la métamorphose des femmes dans leur passage à la maternité



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## Abstract

This paper explores how a medicalized view of pregnancy shapes the process of pregnant embodiment and women's experiences postpartum. Analyzing interviews with 42 pregnant women and new mothers, I show that while women's experiences of pregnant embodiment are shaped by biomedical notions of pregnancy, women also bring new meaning to the biomedical guidelines. Women view pregnancy as a process of sharing their bodies with their children, and they continue to share their bodies with their newborns during the postpartum period. I conclude the paper by reflecting on the role of the body in shaping our understanding of medicalized phenomena.

## Résumé

Cet article explore comment un point de vue médical de la grossesse donne forme au processus de métamorphose de la grossesse et à l'expérience du post-partum. Par l'analyse d'entrevues auprès de 42 femmes enceintes et nouvelles mères, je démontre que bien que les notions biomédicales de la grossesse donnent forme à l'expérience de la métamorphose du corps, les femmes attribuent aussi de nouvelles significations aux régulations biomédicales. Elles voient

la grossesse comme un processus de partage du corps avec l'enfant et elles continuent de partager leur corps avec le nouveau-né pendant la période du post-partum. Je conclus l'article par des réflexions sur le rôle du corps dans la compréhension des phénomènes médicalisés.

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ONCE UPON A TIME, PREGNANCY WAS NOT MEDICALIZED. REFERRING TO THE magic of nature or other mysterious forces, women might understand their pregnancy as a blessing or a curse from God. None of us can remember this time. For most women who grew up in Western culture, the nature of pregnancy and birth is anything but mystical. We know how and why women can become pregnant, we know the mechanics of pregnancy and birth, and we make sure that women stay on medically established track during pregnancy.

The medicalization of pregnancy has taken away more than just its mystical aura. Many feminist scholars have criticized biomedicine for transferring control over reproduction from expectant mothers to medical specialists (Davis-Floyd 1990; Katz Rothman 1993; Oakley 1980). This transition is seen as alienating for many women, separating them from their bodies and making them passive recipients of medical care (Martin 1984).

The medicalization of pregnancy has notably changed women's experiences of the transition to motherhood. At the same time, women experience their pregnancy as a process, as a change that is happening to and inside their bodies. Therefore, while medicalization exerts a powerful influence on women's perceptions of pregnancy and childbirth, in carrying a child, women can revise their beliefs about pregnancy.

This paper explores how women experience their transition to motherhood as a process of embodiment that is shaped by biomedical culture. Analyzing qualitative interviews with 42 pregnant women and new mothers, I examine (a) how women experience their pregnant and postpartum bodies and (b) how their embodied experiences are different from, yet facilitated by, the biomedical model of pregnancy and the postpartum period.

## Understanding Embodiment

This paper applies the concept of "embodiment" to the analysis of women's experiences of pregnancy and the postpartum period. According to Turner (2004: 71), embodiment is "a life process that requires learning of body techniques such as walking, sitting, dancing, and eating. It is the ensemble of such corporal practices which produce and give a body its place in everyday life ..."

Approaching the process of embodiment from a symbolic interactionist framework, I refer to embodiment as the inseparable transformation of body and self. Waskul and Vannini (2006) note that the interactionist conceptualization of the body is always social and constructed through social interactions. Therefore, it is often impossible to distinguish between the body of a person, his or her self, and interactions that facilitate the construction of self; the body is inseparable from the process of embodiment. Relying on this view of embodiment,

this paper draws on the concept of phenomenological body, or body as a province of meaning, a notion inspired by Schutz (1962, 1964) and Merleau-Ponty (1962). The phenomenological body uncovers the meaning of the world through the detailed description of the lived experience and the production of the “bodies of meaning” constructed by human actions and interpretation of these actions (Waskul and Vannini 2006: 9).

The analysis of women’s experiences of pregnancy and the postpartum period as a process of embodiment reveals how women experience their transition to motherhood vis-à-vis medically established norms of pregnancy. Clearly, biomedical notions about pregnancy and reproduction shape women’s experiences of pregnancy. Experiencing pregnancy and the postpartum period through their bodies, however, allows women to re-evaluate preconceived biomedical notions.

### Medicalization, Alienation and Pregnancy

According to Conrad (2000: 324), medicalization is “a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders.” Conrad (2000) further suggests that there are at least three levels at which medicalization can occur: (a) the conceptual level, when medical vocabulary has been adopted to define a problem as medical; (b) the institutional level, when organizations approach a problem as medical; and (c) the level of interactions, where the problem is defined and treated as medical in the context of provider–patient communication. These levels of medicalization are easily identified in women’s experiences of pregnancy:

- Although pregnancy is not an illness, it is treated at a conceptual level as a medical condition by physicians and an overwhelming majority of the general public (Katz Rothman 1993; Litt 2000).
- Institutionally, pregnant women are expected to access prenatal care and to give birth in hospital.
- Besides the interactions between care providers and women, many other social encounters define pregnancy as a “medical” condition (Brubaker and Dillaway 2009).<sup>1</sup>

One of the direct consequences of the medicalization of pregnancy, which has been criticized by feminist scholars, is the loss of women’s autonomy over their bodies and the transfer of control into the hands of physicians both during pregnancy and during labour (Davis-Floyd 1994; Katz Rothman 1993). Technology has allowed physicians to observe and to monitor the process of child development “trapped” in a woman’s body for nine months (Mutman and Ocak 2008). In this context, the woman’s body is portrayed as merely a machine or a container, carrying an unborn child (Katz Rothman 1989).

While the literature has contributed significantly to our understanding of the medicalization of pregnancy, it deals mainly with the societal impact of medicalization. Yet, at the level of individual experiences, the medicalization of women’s bodies in general, and women’s repro-

ductive health in particular, is not necessarily perceived as a form of patriarchal control over women's bodies. Lock and Kaufert (1998) introduced the concept of "pragmatic women" to suggest that women's choices to use or to refuse medical services and technologies should be understood as a pragmatic decision made in a particular cultural context, rather than simply the result of the oppressive nature of medicalization.

The context in which pregnancy and birth occur plays an important role in shaping women's perceptions of medical care and their attitudes towards medicalization. Analyzing the experiences of teenaged African-American mothers, Brubaker (2007) demonstrated that while young women refused some aspects of medicalization, they embraced the opportunity to enrol in prenatal care and to follow medical advice on pregnancy. On a similar note, interviewing middle-class pregnant women about their transition to motherhood, Copelton (2004) argues that instead of being passive recipients of medical advice on pregnancy, women actively seek the advice and construct their mothering identities around the lifestyle modifications that they make during pregnancy.

It is evident that medicalized notions of pregnancy shape women's experiences of the transition to motherhood and play a role in constructing their identity as a mother. At the same time, a focus on the experience of pregnancy as shaping attitudes, beliefs, social roles and identities downplays the importance of the embodied, physical experiences of the transition to motherhood. The decisions to seek or not to seek medical advice, to accept or to refuse it, can be shaped by bodily experiences. While some scholars do introduce the concept of embodiment into their analysis of the experiences of pregnancy (see, for example, Bailey 2001; Davidson 2001), they mainly deal with social perceptions of the pregnant body and the construction of identity, and pay less attention to the interplay between somatic and social experiences of pregnancy.

This paper takes a different direction from analysis of the relationship between the biomedical notions on pregnancy and the process of pregnant embodiment. Rather than seeing this relationship as linear and direct, I demonstrate that it is complex and constantly changing in response to the somatic experiences of pregnancy. Consequently, to fully understand women's attitudes towards biomedical advice on pregnancy, more attention should be paid to the ways in which their bodies become salient in their decisions to support or to challenge medical norms.

### Invisible Postpartum

While pregnancy attracts significant attention of scholars, sociological contributions to the research on women's experiences of the postpartum period are somewhat scarce. A considerable number of studies about the transition to motherhood include in their analysis the experiences of the postpartum period (Elvey 2003; Fox 2009; Oakley 1980), but relatively few researchers directly target postpartum experience as a central focus of their analysis (however, see Dworkin and Wachs 2004; Rosenberg 1987; Upton and Han 2003). Scholars who



have explored the transition to motherhood in the postpartum period have reported that new mothers often find themselves in social isolation (Fox 2009; Oakley 1992). Managing new mothers' responsibilities, women are also expected to return to their previous bodies and selves as soon as possible (Dworkin and Wachs 2004). Postpartum bodies have tended to be constructed as being in need of repair, with new mothers being urged to return to their pre-pregnancy shape (Upton and Han 2003).

The transition from pregnancy to the postpartum period happens within hours. In giving birth to a child, a woman undergoes significant physiological and emotional transformations. Scholars have noted that during the postpartum period, women often experience a profound transformation of self (McMahon 1995), and the focus on women's social roles, emerging mothering identity and the social support received postpartum dominates sociological scholarship inquiring into this phase of the process (Fox 2009). The postpartum body is not regarded as playing a major role in the adaptation to the postpartum period. Rather, new mothers are expected to regain control over their bodies and to erase from them the experiences of pregnancy and birth (Upton and Han 2003). Despite the increasing social pressure to breastfeed and the impact of breastfeeding on the body (Avishai 2007; Shaw 2004; Wall 2001), the postpartum body is seen as in need of dissociating itself from its maternal work. While the focus on the social transformations of the postpartum period is undeniably important, the existing literature does not fully address the somatic, embodied experiences of postpartum, which may shape the construction of mothering and which can be observed once the work of caring for the child is recognized as hard, physical activity.

## Methodology

This paper is based on the qualitative analysis of 42 interviews with pregnant women and new mothers. The interviews were conducted for a study examining women's embodied experiences of pregnancy. I sought to understand how women experience their transition to motherhood. To analyze how the embodiment of pregnancy changes over the course of pregnancy, I interviewed 17 women who were still pregnant (8 weeks to 39 weeks); the rest, who had given birth to a child within the past 12 months, were asked to reflect on the process of transition to motherhood overall. The interviews were conducted with women of diverse age groups, including teenaged and older mothers, novice and experienced mothers, Canadian-born and immigrant women (see Table 1).

I conducted the interviews in 2007–2008 with women residing in Ontario, Canada. About half of the respondents were recruited via snowball sampling through my personal networks and the networks of my key respondents; the rest were recruited via municipal prenatal care services. This study received ethics approval from the Research Ethics Board of McMaster University.

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**TABLE 1.** Summary of participants' profiles

Pseudonym	Age	Weeks of pregnancy	Children	Marital status	Socio-economic status	Immigration and ethnicity
Abigail	36		8 and 6 years, 6 months	Married	Middle	Immigrant, Middle Eastern, Muslim
Amanda	35		4.5 months	Married	Middle	Caucasian
Andrea	34		3 months	Married	Upper	Caucasian
Anna	33		11 years, 6 months	Married	Upper	Jewish
Anna (follow-up)	34	34 weeks	11 and 1 years			
Audrey	17		7 months	Single	Lower	Spanish
Beverly	34	36 weeks	3 years	Married	Middle	Caucasian
Brenda	20		3 months	Married	Middle	Caucasian
Catharine	19		12 months	Common-law	Lower	Caucasian
Chelsea	31		5 months	Married	Middle	Caucasian
Claire	32		3 years, 3 months	Married	Middle	Immigrant, Eastern European
Debra	34		2 years, 1 month	Married	Upper	Caucasian
Deena	33	26 weeks		Married	Middle	Jewish
Donna	38		1 year, 2 months	Married	Upper	Immigrant, Muslim
Geena	26	37 weeks		Married	Middle	Caucasian
Helen	37	30 weeks	3 years	Married	Middle	Caucasian
Jane	28	24 weeks	4 and 1 years, 6 months	Married	Middle	Caucasian
Jasmin	26	20 weeks		Married	Lower	Immigrant, Muslim
Jenna	33		1.5 months	Married	Middle	Immigrant, Muslim
Jennifer	40		6 and 2 years, 5 months	Married	Middle	Jewish
Jessica	28	18 weeks		Married	Middle	Caucasian
Jessie	24	29 weeks		Married	Lower	Immigrant, Muslim
Judith	34	28 weeks	8, 5 and 2 years	Married	Middle	Immigrant, Eastern European
Kimberly	18		4 months	Boyfriend	Lower	Caucasian
Leah	35	36 weeks	5 and 3 years	Married	Middle	Caucasian
Lindsey	15		1 month	Single	Lower	Caucasian
Lisa	19		1 year	Boyfriend	Lower	Caucasian

TABLE 1. Continued

Pseudonym	Age	Weeks of pregnancy	Children	Marital status	Socio-economic status	Immigration and ethnicity
Louisa	27		3 months	Married	Middle	Immigrant, Middle Eastern, Muslim
Madeline	31	28 weeks		Married	Middle	Caucasian
Maria	31		7 years, 3.5 months	Married	Middle	Immigrant,
Muslim						
Mary	38		18, 16 and 5 years, 3 months	Married	Middle	Immigrant, Asian
Michele	31		2 months	Married	Middle	Caucasian
Miranda	42	35 weeks	4 years	Common-law	Middle	Caucasian
Monika	16	26 weeks		Single	Lower	Native
Natalie	33		6 and 4 years, 3 months	Married	Middle	Immigrant, Eastern European
Nicole	37		6 and 3 years, 7 months	Married	Middle	Immigrant, Asian
Rachel	31	8 weeks	3 years (died)	Married	Middle	Caucasian
Rebecca	19	13 weeks		Single	Lower	Caucasian
Sam	19		1 year	Boyfriend	Lower	Caucasian
Susan	18		5 months	Boyfriend	Lower	Spanish
Vanessa	29	24 weeks		Married	Middle	Caucasian
Vicky	19		2 months	Boyfriend	Lower	Native

The interviews were semi-structured and focused on women's transition to motherhood. We discussed women's experiences of pregnancy, the chronology of their pregnancy, their sensual and emotional experiences, their body image during pregnancy and in the postpartum period, and the changes in their communications with others during pregnancy. Women who had given birth before the interview were asked to reflect on their past experiences and compare their previous pregnancies with the more recent one. The interviews lasted between 60 and 90 minutes and were recorded and transcribed verbatim. Because many women found allocating time to an interview difficult, they were informed that they could choose between participating in a phone or a face-to-face interview. About half of the respondents preferred to be interviewed over the phone. No differences in content were identified between the in-person and telephone interviews.

The interviews were coded in NUD\*IST 6 and analyzed for emerging themes. The initial, free coding was later formed into structured (i.e., tree) coding, reflective of the relationship between different themes, as discussed by the respondents.

## Discussion

The theme of pregnant embodiment and the notion of “sharing” the body with a child (both born and unborn) emerged during the analysis.

### *Medicalization and the pregnant embodiment*

While the biomedical establishment usually defines pregnancy as a physiological condition, the majority of women in this study regarded pregnancy as an activity, a constant and meticulous work that was triggered by social, psychological and physical changes associated with pregnancy. The medicalization of pregnancy redefined many signs of pregnancy as “symptoms.” Some symptoms, such as absence of menstruation, were often immediately associated with pregnancy. Other symptoms (changes in mood, eating habits, etc.) were constantly evaluated in relation to pregnancy.

My respondents often evaluated their somatic experiences as a confirmation that their pregnancy was progressing as expected, and when some symptoms did not manifest themselves clearly, women often saw it as a threat to their pregnancy:

I had nausea and I was really tired and I had unbelievably sore breasts ... [and] it was all kind of a psychological basket thing. I was pretty sure that I was pregnant, but then the symptoms kind of stopped and I thought that I had a miscarriage. (Miranda, 42-year-old mother of one, 35 weeks pregnant)

Like many other of my interviewees, once asked about her pregnancy, Miranda referred to the “set of symptoms” that are associated with pregnancy. Labelling their bodies as “pregnant,” women adopted the medical vocabulary to describe their somatic experiences and constantly “diagnosed” their bodies as exhibiting or not exhibiting signs of pregnancy. Considering how they should feel, worrying about not feeling anything, or feeling something that “does not feel like pregnancy,” the women learned to see and feel their bodies as pregnant and to interpret their experiences in relation to their beliefs about how pregnancy should be felt or experienced:

This pregnancy... they call it morning sickness and for me it was nausea all day long. (Nicole, 37-year-old married mother of three)

I had no emotional changes. I was the opposite of that. I was completely not emotional. I actually couldn't understand what they are talking about, all this emotional roller coaster stuff. (Anna, 33-year-old married mother of two)

The assessment of somatic experiences in relation to the biomedical “norm” of pregnancy and constant monitoring of the body further increase medicalization of pregnancy, but at the same time, can lead to the development of a more intimate, responsive relationship with the

body. Listening to their bodies and trying to evaluate their senses and emotions in relation to pregnancy allowed these women to “feel in touch” with their bodies and to regard their personal experiences as unique, distinguishing them from those of “other” pregnant women. Both Nicole and Anna compared their bodily experience to the norm, but saw their pregnancies as “different” or even the “opposite” of the normative pregnancy, which made their experiences of carrying a child unique and personalized.

### *Pregnant embodiment as a physical activity*

A considerable amount of the educational literature on pregnancy is devoted to advice on caring for the pregnant body (Copelton 2004; Marshall and Woollett 2000). Expectant mothers are responsible for learning the “do’s and don’ts” of pregnancy and for adopting behaviours that will ensure the safe development of their unborn children (Copelton 2004; Marshall and Woollett 2000). Following such advice, the women had to be constantly aware of the (potential) impact that each activity might have on a child. Navigating through endless recommendations was especially confusing for the first-time mothers, who relied heavily on medical advice:

I definitely changed what I was eating. I was eating more healthy foods and I was trying to eat more protein because I knew that he [baby] needed it ... I am also very happy that I took prenatal classes because I didn’t know many things ... I didn’t know, for example, what I could and couldn’t eat. ... There were just so many restrictions! (Brenda, 20-year-old mother of one)

Brenda, a first-time mother, was amazed by the amount of information that she had to absorb in order to protect her unborn child from potential harms that her consumption practices might cause. Incorporating the biomedical advice on prenatal nutrition into her daily life, she, like many other mothers, carefully monitored her diet and made sure that she followed the advice. Learning about dietary restrictions, Brenda felt that she was taking an active role in establishing a nurturing, welcoming environment for her unborn child. Considering everything she consumed as “good” or “bad” for the baby, she redefined her diet as sharing the food with her child.

While Brenda took an active role in deciding what her baby needed for healthy development, some women allowed their bodies to make these decisions:

I did not have cravings, but I couldn’t eat pork and fast food. My body didn’t want me to eat it. I really wanted to eat red meat and I ate a lot of Oreos – not the best choice, but my body really wanted it. (Louisa, 27-year-old married mother of one)

Louisa experienced her body as guiding her food choices, and thus she “gave in” to it. She saw her pregnant body as intimately close to nature and involved in active, reproductive work

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in carrying a child. She believed that the work of the expectant mother was to listen carefully to her body's needs and help the body to do its work.

All the interviewees made adjustments to their diet and lifestyle during pregnancy. These modifications, however, were mostly understood as "sacrifices" that they had to make to accommodate the needs of their unborn children. Monitoring their heart rate during a workout or refusing an offered drink, expectant mothers repeatedly reconstructed their bodies as pregnant through modified physical activity and consumption. The meaning of being "with child" became articulated through the repetition of bodily practices that marked their bodies for them as different, as shared with their children.

*Pregnant embodiment as sharing*

The women in this study regarded pregnancy as an activity that required many adjustments to accommodate their changing bodies and, even more so, to fulfill their role as nurturing mothers. Making daily decisions about what they could eat, drink or do, these women learned to understand their bodies as inseparable from the life of the child growing inside them:

I think that during pregnancy a mother is already educating her child. ... And I think that if she is looking at the mirror too much that would affect the child. And during this time a woman should listen to classic music and not go party. A woman has to think and to take care of her child ... . (Mary, 38-year-old married mother of four, immigrant from Asia)

Mary described the development of her relationship with her child through the care that she provided to her pregnant body. She shared with the child not only food but also her mood and her social environment. Incorporating the required modifications into her daily routine, Mary took on the role of a nurturing mother.

While the embodiment of pregnancy happened long before quickening, feeling the baby move marked a change in the relationship from unidirectional (i.e., from the mother to child) to interactive:

For me the most important event was when the baby started kicking. ... I absolutely love the feeling of feeling the baby and its movement and knowing that I am nurturing it and taking care of it through the choices that I make in terms of how I take care of myself and what I eat. (Geena, 26-year-old and married, last trimester of pregnancy)

This account from Geena depicts the meaning that most of the interviewees attached to medically established prenatal restrictions. Following the advice of pregnancy experts and making the "right choices" allowed Geena to take an active role in pregnancy by caring for her

child. She was not simply carrying the baby inside her body; she was nurturing her child, sharing her body with her baby. Quickening further intensified this feeling as it established an active, physical connection between the bodies of the mother and her child.

### *Sharing the body in postpartum*

The majority of the study participants (n=36) had already had the experience of giving birth prior to being interviewed. Reflecting on their experiences of the postpartum period, women talked about being constantly tired to the point of exhaustion, and often feeling unprepared for having a child. The difference between the amount of information provided during pregnancy and the lack thereof in the postpartum period was striking:

After pregnancy, women are not needed anymore. I remember that after I came home I had some [medical complications] and I couldn't find any information about it and I remember I was saying to my husband that if [the] hospital would send us [home] with just [a] one-page summary of what is going to happen, that would really help a lot. (Chelsea, 31-year-old mother of one)

Many first-time mothers described being unprepared for the physical changes happening postpartum. As Chelsea commented, new mothers also lose their special status as a pregnant woman and are seen as women whose "job is done" and who are "not needed anymore." The immediate transformation from being "special" to being redundant and alone while trying to deal with a newborn baby was a central motif in the narratives of first-time mothers describing their postpartum experiences.

The feeling of being inadequately attended to during the postpartum period was intensified by these women's persistent view of their bodies as being still very active in the reproductive process. Redefining every movement and action of their bodies in relation to pregnancy for a relatively prolonged period of time, the women were often unable to cease viewing their bodies as different. The social pressure to "get your body back," both physically (by returning to the pre-pregnancy shape) and socially (by losing the status of a pregnant woman), was perceived by many interviewees as confusing or annoying. Breastfeeding and providing constant care to the newborn in the first months postpartum, many women felt that they continued to share their bodies with their children:

[Your body] is not really back when you are breastfeeding because you are really around the clock and your body is still not yours. ... I used to be really flat and now I have huge boobs and I feel like it is really different. ... So I still feel like my body is not my own and I still feel very attached [to the baby]. ... So ... your body is still not quite yours because it is still so important in someone else's life, whereas before it was only important in your own life. (Michele, 31-year-old mother of one)



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For Michele, being pregnant and having a baby is a continuous event, which is different from “before” by the level of autonomy that is given to her own body. Whereas before pregnancy her body was important only to herself, once she became pregnant, her body became “attached” to her daughter. Reflecting on her pregnancy and her postpartum experience, Michele linked the end of pregnancy to having her “body back,” yet she was uncertain whether she had it back three months after the birth. Breastfeeding her child and providing ongoing care signified the continuation of sharing her body with her child, even when the child was no longer in her womb.

### Conclusion

This paper has demonstrated that unlike the biomedical discourse, which assesses the pregnant body in terms of its reproductive capacities and functions, the women in this study undergoing the transition to motherhood experienced pregnancy as a process. This process was always managed in the context of medicalized pregnancy, but the meaning that the women attached to it was shaped by their somatic experiences of pregnant embodiment. The “norm” of pregnancy was constructed around the biomedical notion of pregnancy, the adoption of medical vocabulary and medicalized restrictions regarding prenatal care. At the same time, the embodiment of pregnancy made the transition to motherhood a personal, unique experience that altered medicalized notions of pregnancy and gave them new meanings. Constantly monitoring their bodies, these women learned to understand them and to embody the transition to motherhood as a personal, sensual process that distinguished their experiences from the medically established “norm.” Following prenatal advice regarding nutrition and exercise, these women used the information as a tool that allowed them to care for their unborn children and to develop a relationship with them. This relationship was built around sharing the maternal body and responding to the child’s needs by following prenatal restrictions. Therefore, it seems unrealistic and impossible for women to “come back” to their old selves in the early postpartum months – they continue to share their bodies with their children, even if the contact occurs outside (and not inside) the body.

Analyzing the complexity of women’s responses to medicalization, Lock and Kaufert (1998) proposed that women are pragmatic in making choices about the use of biomedicine. This study suggests a need to delve more deeply into the process that facilitates women’s acceptance of, or resistance to, biomedical conceptualizations of pregnancy or any other heavily medicalized condition. These decisions, I suggest, are not necessarily made in the form of abstract, intellectual analysis. Often, somatic, embodied experiences call for redefinition of previously held ideas and give new meaning to medicalized phenomena. Our understanding of the world is interpreted through the body and by the body (Merleau-Ponty 1962). Therefore, it is important to understand the role of the body in shaping our perceptions of the medicalization of pregnancy and the postpartum period, as well as other somatic experiences.

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NOTE

1. It should be noted that midwifery does not treat pregnancy as an illness. Rather, midwives take a more natural and holistic approach to pregnancy and childbirth (Brubaker and Dillaway 2009). Nevertheless, especially in places where midwifery has been institutionalized, one cannot ignore the existence of some similarities between the institutionalized experiences of women in obstetrical and midwifery care (Brubaker and Dillaway 2009).

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# Comparing Approaches to Integrating Refugee and Asylum-Seeking Healthcare Professionals in Canada and the UK

Comparaison des approches d'intégration des professionnels de la santé ayant le statut de réfugiés et de demandeurs d'asile au Canada et au Royaume-Uni



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## Abstract

In this paper, we examine barriers to the integration of refugee doctors and nurses in Canada and the United Kingdom. Key obstacles impeding the integration of internationally trained health professionals are well documented, but less attention has been paid to the integration of refugee health professionals, particularly in Canada. Based on documentary analysis and semi-structured interviews with 46 Canadian and 34 UK stakeholders, our research shows

that there are no simple solutions to mitigating the core obstacles that prohibit the professional integration of refugee doctors and nurses into host countries. The targeted approach adopted in parts of the UK does provide some promising practices for Canada, which has yet to develop policies and initiatives specific to health professional refugees. This study is intended to contribute to our understanding of how immigration and health human resources policies have shaped the economic integration of refugee healthcare professionals in the UK and Canada in distinct ways.

## Résumé

Dans cet article, nous examinons les obstacles à l'intégration des médecins et infirmières réfugiés au Canada et au Royaume-Uni. Les principaux obstacles à l'intégration de professionnels de la santé formés à l'étranger sont bien documentés, mais il y a peu d'études portant sur l'intégration des professionnels de la santé ayant le statut de réfugiés, en particulier au Canada. À l'aide d'une analyse de documents et d'entrevues semi-structurées menées auprès de 46 personnes concernées au Canada et 34 au Royaume-Uni, notre recherche fait voir qu'il n'existe pas de solution simple pour atténuer les principaux obstacles à l'intégration professionnelle des médecins et infirmières ayant le statut de réfugiés dans leur pays d'accueil. L'approche ciblée adoptée dans certaines régions du Royaume-Uni fournit des éléments de pratiques prometteuses pour le Canada, qui n'a pas encore développé de politiques ou initiatives visant précisément les professionnels de la santé ayant le statut de réfugiés. Cette étude entend contribuer à la compréhension des rôles distincts que jouent, respectivement au Canada et au Royaume-Uni, les politiques en matière d'immigration et de ressources humaines en santé dans l'intégration économique des professionnels ayant le statut de réfugiés.

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**S**IMILAR TO OTHER COUNTRIES, IMMIGRANTS COME TO CANADA AND THE UK FOR both economic and humanitarian reasons (Castles and Miller 2003; Salt and Millar 2006). An economic migrant, one that is attracted to a host country primarily for the purpose of gainful employment (Salt and Millar 2006), differs from a refugee, who is forced from his or her country of origin owing to fear of persecution (UNCHR 2011). What sets refugees apart from other immigrants in host countries is not only their forced migration and associated need for protection, but their ability to “establish economic potential” (Yu et al. 2007).

In this paper, we consider the fundamental challenges to the integration that refugee doctors and nurses in the UK and Canada face as they attempt to pursue careers in their chosen professions. Whereas the UK offers examples of a more targeted approach, relatively little specific attention has been paid in Canada to this group of refugees, even though research shows that when refugees are successfully integrated they become a significant asset to local healthcare systems (NHS Employers 2009). Although we argue that there are no simple solutions to eliminating or mitigating the many barriers that prohibit the integration of health

professional refugees into host countries, a targeted approach seems promising. Through greater awareness, sensitivity and continued commitment, the economic integration of refugee healthcare professionals can be more fully realized. Whether this is likely remains nebulous. This paper contributes to our understanding of how immigration and health human resources (HHR) policies have shaped the economic integration of refugee healthcare professionals in the UK and Canada in distinct ways.

### **Immigrant Health Professionals**

The literature shows that although refugees coming to host countries are relatively well educated, they also tend to have limited employment opportunities (Bloch 2007; Charlaff et al. 2004; Krahn et al. 2000; Yu et al. 2007). Structural and individual constraints impede the integration of refugees and asylum seekers. For example, studies in the UK have highlighted how asylum seekers are economically compromised owing to restrictions on their residential mobility and access to paid employment (Charlaff et al. 2004; Clements 2007; Hubbard 2005; Smith et al. 2007; Wren 2007; Zetter and Pearl 2000). Similarly, in Canada, research indicates that current immigration policies can impede refugee and asylum seekers' eligibility to attend integration programs and to receive services, while tightened security measures delay applications and leave individuals with little or no financial support (Yu et al. 2007). Gender has also been found to affect employment opportunities, with women refugees being more disadvantaged than men (Adams and Kennedy 2006; Bloch 2007; Kofman et al. 2005; Refugee Council 2005). Fuelled by public discourse decrying refugees as a "threat," some resistance towards the settlement of refugees has arisen in various communities in the UK (Lewis 2006). Biography also matters. Difficulties in accessing the labour market are further hindered through experiences of torture, loss of family members, trauma and various health problems (Charlaff et al. 2004).

Over the past decade, the UK has embraced a coordinated, top-down approach to the integration of refugees and asylum seekers, with collaborative efforts at both the local and national levels. The policies shaping the integration of refugees and asylum seekers in the UK are detailed in a number of Home Office documents (see Home Office 2000, 2002, 2005, 2006). HHR policies, concerned with workforce planning, have complemented immigration policies. As a result, a number of mentorship, financial assistance and orientation programs were designed to improve language proficiency and to prepare refugee health professionals to enter and adapt to the UK workforce (Department of Health 2003).

Similarly in Canada, immigrant health professionals are supported through various initiatives. In contrast to the UK, however, current HHR policies – which are, for the most part, provincially or regionally controlled – are not coordinated with immigration policies, which are largely directed federally. Researchers recognize that there is much work to be done to improve integration policies and initiatives so that the diverse circumstances and potentials of "newcomers" to Canada may be more adequately addressed (see Pressé and Thomson 2007; Walsh et al. 2008).

Despite these efforts, there are recognized obstacles that impede and prolong the integration of refugee health professionals. These include lack of information, language proficiency, credential documentation, references, support networks and financial resources, as well as interruptions in training (Adams and Kennedy 2006; Overseas Doctors Sub-Group 2000; Stewart 2003, 2005; Winkelmann-Gleed 2006).

### Employability: An Analytical Concept

In this research, we draw on the theorization of integration as a two-way process (Raghuram 2007: 2247) wherein humanitarian rights are provided and individual identity is preserved within the economic, cultural and civic parameters of the host country. We use the term “employability” to capture the barriers discussed by representatives of the various policy communities with respect to health professional refugee and asylum-seeker integration (see Bloch 2007: 21). Employability encompasses those obstacles that deter refugee doctors and nurses from practising in their chosen fields, and is inclusive of pertinent aspects of social and cultural integration that influence the career paths of refugee and asylum-seeking health professionals (adapted from Raghuram 2007). Social integration refers to relational social characteristics, such as gender and ethnicity, and cultural integration includes factors intended to ease or enhance adaptation into the host country, for example, ethnic community support or mentorship programs.

In utilizing “employability” as an analytical concept, we found that initial obstacles to integration include the professional registration process and the career path directions open to refugee and asylum-seeking health professionals. These barriers intersect with refugee status, professional status, gender and ethnic community support, and are further implicated in the policies, initiatives and programs that fluidly enhance or constrain integration. Our analysis demonstrates that refugee integration in the UK has been framed as a “win–win” situation, whereas Canadian policy makers have yet to specifically target the issue of integrating refugee health professionals.

### Methodology

We examine the barriers to employment that refugee doctors and nurses face in host countries with data derived from structured interviews with 46 Canadian and 34 UK stakeholders involved in the integration of healthcare professionals. The interviews, conducted in 2007, were completed largely via telephone and included representatives from immigration, health professional regulation, health human resources planning, health professional associations, educational training, and program development policy communities in both countries. Intensive documentary analysis of federal and provincial official websites and reports began in 2006 and continued until 2009. Periodic reviews ensued in 2010, 2011 and 2012.

The interview data were analyzed using the computer-assisted management systems NUD\*IST 6 and NVivo 7. The systematic comparative analysis involved a constant iterative



process of going back and forth between documents and interviews. Key segments from the documents were excerpted and organized according to common themes that began to emerge from the data. Relationships between themes and between the responses of different participants were then identified. Integration was a particularly salient theme within the UK data but emerged less frequently in Canada.

### Barriers to Employability of Refugee and Asylum-Seeking Health Professionals

The following analysis highlights the response of key stakeholders in the UK and Canada with respect to the integration of health professional refugees. The comments emphasize how language proficiency is measured, how language courses are taught and the dilemma that lack of proof of credentials poses for both refugees and regulators. These conditions are often coupled with uncertainty over residency, legal restrictions that in some instances limit access to paid employment, and financial hardship. These issues have a cumulative impact on one's career path. For many, the quest ends here. Even for those who are able to prove their professional competency, limited options with respect to retraining, difficulty in finding orientation placements, lack of support, underemployment and discrimination further deter refugee health professionals from their chosen professions. The following accounts demonstrate the complexity and cumulative impact of these intersecting barriers.

Stakeholders in the UK and Canada stressed first and foremost that language proficiency is fundamental to moving through the registration process. Notably, passing the exam does not guarantee that one has reached a level of proficiency that satisfies employment requirements. Similarly, in the UK, the barriers associated with becoming linguistically proficient are reflected in the skill level of the individual refugee, the availability of training and mentorship, and the generic design of the assessment tool. In some instances, it was not the program but rather the assessment tool that stakeholders considered unsuitable and in need of redesign. They stressed the importance of tailoring language programs to better meet the needs of those they serve. This is no simple matter, as it may require increased personnel and greater financial investment than more traditionally designed orientation approaches.

We have included language tutors completely within our academic program and ... it's relatively expensive to run. Because we realized we were trying to teach nursing to people who we don't understand how you learn in a different language. If you're learning a subject in a different language, you need to be taught in a different way because you're constantly translating and retranslating. And we needed to look at how we were teaching because our traditional teaching methods weren't working that effectively. (UK Nursing Stakeholder S2)

Both countries have invested only in a limited way in the advanced language training necessary to meet employment requirements or to redesign programs.

## Comparing Approaches to Integrating Refugee and Asylum-Seeking Healthcare Professionals in Canada and the UK

While language proficiency influences many aspects of integration, credentialing issues are central obstacles to acquiring professional registration. These encompass program recognition as well as individual proof of credentials:

One of the things that we've had is, in a lot of situations, they're refugees and therefore they've got no documentation and therefore they can't provide a lot of the paraphernalia that we demand, you know, voluntary migrants to provide. They sometimes can't provide, you know, their references from the school of primary medical qualification. They haven't got the sort of portfolios of evidence to demonstrate specialist training. They may have been out of clinical work for a sustained period of time while they've been going through the whole refugee process and therefore ... they do actually have to be treated rather uniquely. (UK Medical Stakeholder 1)

This situation closely resembles that in Canada, where difficulty in gaining recognition for foreign educational credentials and professional experience is common. The variation in training in different countries also poses a challenge for regulators and is summed up in a comment made by a Canadian stakeholder:

So the policy issue is to figure out kind of how do we take a candidate and credentials that seem very foreign to us and how do we plug them into our system in a meaningful way to figure out what they really are. ... [T]o figure out how to measure them is the huge challenge right now. (CA Government Stakeholder 1)

Hence, the refugee's ability to prove his or her professional competence is coupled with the receiving country's way of measuring proficiency. Further barriers to health professional employment may be related but are not limited to the registration process. There are other career path obstacles that may impede a refugee's chances of acquiring employment as a healthcare professional.

### *Career path*

Career path obstacles are an extension of the previously described barriers and involve difficulties associated with not being able to pursue one's chosen profession, the inability to attain an entry-level position that reflects former career status and the problems associated with achieving career promotion. These hurdles were more widely and explicitly acknowledged in the UK context. Without proof of qualifications, one of the few options involves retraining within the same profession:

I had a guy who was a plumber and a nurse. And we looked into getting his qualifications from Iraq and were basically told that ... they're not worth anything. He's going to have to requalify. And similarly, I worked with a lady who was a nurse in

Zimbabwe and she's now just about to finish her degree here in nursing. She went back and requalified. And I mean, obviously, I think it would depend on what country you came from, you know, how your qualifications would be accepted. You know, in my experience they tend to be advised to go back and start again. (UK Integration Stakeholder S1)

Stakeholders also recognized that refugee and asylum-seeking health professionals face greater disadvantages due to law-enforced restrictions on their employment, mobility and lack of finances. Such barriers further preclude the integration process for asylum seekers:

But also in terms of whether they are legally permitted to work or get paid work because of the restrictions ... if you're recognized as a refugee it's okay, but if you're seeking work on an asylum-seekers basis, then there are all sorts of problems about both being able to work and accessing benefits which are quite complex, and god knows how they understand them. (UK Nursing Stakeholder 2)

Severe financial hardship is a salient deterrent both to obtaining registration and to retraining:

Indeed, they don't have very much money in the first place. They're really very poor. Some of them may even be on benefits. (UK Nursing Stakeholder 1)

This situation was also acknowledged by some stakeholders in Canada:

It's intensely emotional for some of the people who are involved because you know that people are literally, like, don't have enough money, like, they're making choices because they don't have enough money. You know, they can't get gas in their car to drive to their practicum. (CA Employer Stakeholder 1)

Retraining is additionally problematic because it is time-consuming and places added burden on individuals. Such scenarios contribute to the difficulties of refugees as they try to rebuild their former careers. Many are forced to abandon such hope, and integration workers are obliged to impress upon individuals that it may not be possible to continue in their chosen profession:

The most important thing with people is not necessarily training to pass exams, but career advice and having somebody having a very good relationship with them so they are able to say after a period of assessment okay, here's the situation. You can try for another year or however long to pass this exam but let me tell you, you probably won't get a job at the end of it because you're either too old, have been out of practice

for too long, you're in a field that is highly competitive. ... You're not going to make it as a doctor here. It doesn't mean you're not a good doctor. It just means the system is such that you won't make it through. (UK Nursing Stakeholder 3)

Impressing this "reality" on refugees applies to nurses as well as doctors:

It's about being able to offer some hope in relation to utilizing existing skills and knowledge in an alternative health career, and the same goes for nurses. There are some who won't be able to register and can be supported to develop in a different direction. So alternative health careers are also an issue that we're trying to address in terms of managing expectations. (UK Nursing Stakeholder 1)

Although refugee health professionals face similar obstacles in the UK and Canada, the policy responses are framed in contrasting ways.

### Responses to Refugee Health Professional Employability Barriers

There is a striking difference in the way that issues facing refugees and asylum-seekers have been framed in the UK and Canada. In the UK, the reasons provided by stakeholders for increased support for refugees relate to the obvious, "because we have huge numbers of refugees" (UK Academic Stakeholder 2). Perhaps because there is "some kind of tradition or some event [that] occurred in the UK and so people are more aware" (UK Nursing Stakeholder 4). Still others pointed to the mutual benefit, or the "win-win" situation, that accommodating refugees had for the UK during a time when there were workforce shortages:

I think it's partly because we've got such large numbers of refugees per se that there is an awareness that they should be ... that it's better for the UK economy and for integration and all the social reasons if they can be enabled to get back into their professions, whatever those professions are. (UK Medical Stakeholder 1)

"Making use" of refugee health professionals was also seen as a convenient way to provide care for other non-English-speaking refugees:

I think the reason why the NHS or the Department of Health or the UK Home Office is trying to promote the development of the refugee nurses in particular is that they can get employed in different trusts in the long-term future so that if local non-English-speaking refugees come and use the service, then they would tap into that particular knowledge as well. (UK Nursing Stakeholder 6)

Although the benefit is claimed to be reciprocal, if the refugee does not get permanent residential status the local health authority still profits from the volunteer labour provided by the refugee and comes out the "winner" in the situation:

When we have a captivated group of people who have skills, so why are we not using them? ... So they volunteer their time, and in a way they benefit by retaining their skills and eventually, if they do get the status, it would give them the opportunity to access the job market because they would ... know how the system works and, you know, ... the health system would be familiar to them. So we would employ people that we're familiar with. ... So yes, it is a win-win situation if everything adds up at the end of the day. (UK Nursing Stakeholder S1)

Alternatively, in Canada, some stakeholders tended to dismiss the idea that refugee health professionals should be considered separately from internationally educated health professionals in general because of their small numbers: "When I look at the breakdown of what we see with the clients, I think it would be fairly small in comparison to those coming through as independent class" (CA Integration Stakeholder 2). Secondly, a notion of targeted support is not considered because it remains outside the boundaries of specific policy departments:

I won't be able to give you a turn on refugees either, because we have a different refugees group here that deals with that. My focus is more on the labour market integration side generally, and we tend not to think of refugees in the main. (CA Government Stakeholder 1)

Other stakeholders argued that there is no need to treat refugees differently than other migrants because it is unfair to give them an advantage over economic migrants:

Well, I don't even know if you can [differentiate between those two groups of immigrants]. I mean, why would it be fair to make it easier for refugees to become a doctor than someone who has done this through the processes that we have in place? (CA Government Stakeholder P2)

The notion of a "refugee advantage" is one that was also expressed by a stakeholder in Scotland as a result of recent changes in immigration rules affecting overseas doctors in the UK:

There's been a big huge change ... in the permit-free training and regulations in the UK, which has caused huge problems for overseas doctors who want to come and work in the UK or train in the UK. And that really has created a big issue, and probably we're still to feel the full repercussions of that. So you know, obviously for the refugee doctors it's not a problem because if they're refugee status, they have the same rights as a British citizen; so they don't need a work permit, so it's not a problem. But for other overseas qualified doctors it's now much, much more difficult to get in and get a training post in this country. (UK Government Stakeholder S1)

Fairness takes on a different dimension when the situation of refugees is considered:

When we talk to refugee doctors and you ask them “Is it fair?” I mean, that’s one of the questions I actually do ask them. ... And they’ll say, “Of course it’s fair,” and it’s the fundamental reason about why they fled their home countries. You know, “They haven’t been through what we’ve been through,” you know, “They can go home,” you know, “They don’t worry about families they’ve left behind.” ... So basically, it’s a psychosocial element of being a refugee versus being an economic migrant. (UK Government Stakeholder 3)

Undoubtedly, tension and competition occur between and within groups when competing for scarce resources. Nevertheless, this dynamic exacerbates the precarious position of refugees and further fuels resentment and discrimination:

What’s very clear is the whole stigma of being known as a refugee doctor is very high, and so there’s kind of like – again, this decision about when you use the refugee card and when you don’t. You know, sometimes it opens doors and sometimes it doesn’t. (UK Government Stakeholder 3)

The importance of context cannot be overstated. In the UK there have been some unintended consequences despite good intentions. Owing to a variety of circumstances involving changes to medical training, coupled with an underestimation of the number of applicants applying for medical training positions and an overabundance of entry-level doctors in the UK, there has been stiff competition for entry-level jobs. This situation has exacerbated the difficulties facing refugee doctors, undermined the accomplishments of integration initiatives and programs, and culminated in the creation of the “unemployed box” where “a lot of these people got a huge amount of help. But at the end of the day what it didn’t give them was jobs. It made them job-ready.” (UK Medical Stakeholder 3)

## Discussion

Overall, the central barriers to integration are illustrative of those identified by other scholars who have examined the employability of refugees (Ager and Strang 2008; Beiser and Johnson 2003; Bloch 2007; Charlaff et al. 2004; Krahn et al. 2000; Lamba 2003) and, more specifically, refugee and asylum-seeking internationally educated health professionals (Baumann et al. 2006; Blythe and Baumann 2009; Jeans et al. 2005; Krahn et al. 2000). Unlike previous studies, this comparative analysis emphasizes how two destination countries confront and manage the economic integration of refugees in distinctly different ways. Economic integration is not only fundamental to successful overall integration; it is the first step in the initial phase of integration, as employment influences “economic independence, future plans, socialization, language skill development, self-esteem and self-reliance” (Ager and Strang 2008: 166).

Also crucial to integration is language proficiency, but it remains one of the most formidable barriers to employability (Bloch 2007; Henin and Bennet 2002; Hyndman and Walton-Roberts 2000; Krahn et al. 2000). Although language proficiency ultimately rests with the individual, how proficiency is attained and to what degree, and how such competence is determined is more complex. This study supports research indicating that professionals often need to improve profession-specific language competency (Bloch 2007; Krahn et al. 2000; Blythe and Baumann 2009) and that although some refugee doctors and nurses may have completed their training in the host country's official language (Stewart 2003) this instruction may not make them proficient (Blythe and Baumann 2009; Smith et al. 2007).

Recognition and proof of credentials are essential to moving through the registration process, and for refugees, this is where the process is particularly challenging. Stakeholders in both countries recognize the barriers facing refugee doctors and nurses, the limitations of existing initiatives and programs, and ways to assess competencies. There is a stark contrast in the way that the UK has politicized and explicitly confronted the integration of refugee and asylum-seeking health professionals (Athwal and Bourne 2007; Hubbard 2005) and Canada's relatively silent response (see Blythe and Baumann 2009).

In the UK, government investment in health and immigration infrastructure through a nationally directed effort contributed to the notion of a "win-win" situation, although there is less evidence to support the notion of "win" on the part of the refugees. Alternatively, Canada has lagged behind in explicitly acknowledging the potential of refugee health professionals apart from other internationally educated health professionals. Unlike the UK trajectory, there are no infrastructure changes on the horizon and no injection of federal or provincial funds in this regard in the foreseeable future.

These conditions are coupled with signs of insensitivity or neglect on the part of some policy communities with respect to the unique circumstances facing refugees. Internationally, the humanitarian responsibilities of both countries are undermined through increasingly restrictive immigration policies. At the national and local levels such policy serves to isolate rather than integrate refugee health professionals. Certainly there is more work to be done in this area, but broader contingencies – such as the current global recession and continued political unrest – further jeopardize what has already been achieved.

Overall, this paper contributes to our substantive understanding of how immigration and HHR policies do or do not intersect to shape the economic integration of refugee healthcare professionals in the UK and Canada in distinct ways. Such cross-national comparisons are lacking in the current literature. Conceptually, broadening the analytical concept of "employability" contributes to a more comprehensive understanding of not merely the initial but rather the fundamental and complex challenges impeding the successful economic integration of refugee healthcare professionals and, indeed, immigrant refugees more generally.

In conclusion, recognizing that refugees have unique issues and may need different and additional forms of support poses further challenges to policy developers and service providers. As a number of stakeholders have pointed out, reforming and implementing innovative



## Comparing Approaches to Integrating Refugee and Asylum-Seeking Healthcare Professionals in Canada and the UK

initiatives may require program redesign, increased personnel, greater financial investment and a move away from traditional ways of teaching and testing skills and knowledge toward more refugee-tailored approaches. “Managing” the expectations of refugees and streaming those who are unable to meet system requirements towards a “realistic” career path translates into directing refugee health professionals into underemployment. Greater sensitivity regarding refugees, as well as commitment with respect to improving how early integration is handled, is necessary. Early intervention, along with sustained effort, can improve refugees’ chances of economic integration.

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# Exploring Stigma by Association among Front-Line Care Providers Serving Sex Workers

## Explorer la stigmatisation par association chez les fournisseurs de soins de première ligne auprès des travailleurs du sexe



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### Abstract

Stigma by association, also referred to as “courtesy stigma,” involves public disapproval evoked as a consequence of associating with stigmatized persons. While a small number of sociological studies have shown how stigma by association limits the social support and social opportunities available to family members, there is a paucity of research examining this phenomenon among the large network of persons who provide health and social services to stigmatized groups. This paper presents results from a primarily qualitative study of the workplace experiences of a purposive sample of staff from an organization providing services to sex workers. The findings suggest that stigma by association has an impact on staff health because it shapes both the workplace environment as well as staff perceptions of others’ support. At the same time, it is evident that some staff, owing to their more advantaged social location, are better able to manage courtesy stigma than others.

## Résumé

La stigmatisation par association, aussi appelée « stigmatisation de courtoisie », implique une désapprobation publique évoquée comme conséquence d'une association avec des personnes stigmatisées. Bien qu'un petit nombre d'études sociologiques aient démontré comment la stigmatisation par association limite le soutien social et les possibilités sociales pour les membres d'une famille, il y a peu de recherches qui se penchent sur ce phénomène dans le vaste réseau de personnes qui fournissent des services de santé et sociaux à des groupes stigmatisés. Cet article présente les résultats provenant d'une étude principalement qualitative de l'expérience en milieu de travail d'un échantillon choisi à dessein parmi les membres du personnel d'un organisme qui fournit des services à des travailleurs du sexe. Les résultats font voir que la stigmatisation par association a un impact sur la santé du personnel parce qu'elle donne forme à l'environnement de travail aussi bien qu'à la perception, par le personnel, du soutien reçu par les autres. En même temps, il est évident qu'en raison d'une situation sociale plus avantageuse, certains membres du personnel sont plus en mesure que d'autres de faire face à la stigmatisation par courtoisie.

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**S**OCIOLOGIST ERVING GOFFMAN (1963) DEFINED STIGMA AS A SOCIAL ATTRIBUTE that is discrediting for an individual or group. Stigmas are typically regarded as having a negative impact on self-concept and identity formation (Corrigan et al. 2004; Link and Phelan 2006; Scambler 2009). Expanding on Goffman's social interactionist definition of stigma, Link and Phelan (2001) conceptualize stigma as the co-occurrence of labelling, stereotyping, separating, status loss and discrimination. Their definition, with its focus on structural contexts in addition to relational contexts, has fostered stigma research in two additional areas: (a) the translation of stigmas into broader socio-cultural traditions and institutions, including social welfare policies and (b) the interaction of stigmas with other determinants of health advantage or disadvantage (Link and Phelan 2006; Stuber et al. 2008).

While the bulk of studies have concentrated on the situation of those who experience stigma directly, Goffman (1963: 30) suggested that stigmas also affect those who are closely associated with them – “the problems faced by stigmatized persons spread out in waves of diminishing intensity among those they come in contact with.”

There is a small body of work addressing stigma by association or courtesy stigma experienced by family members whose relatives are affected by cognitive disability, HIV/AIDS or psychiatric illness (Corrigan and Miller 2004; Gray 2002; Green 2003; Khamis 2006; Thomas 2006). Studies of parents of children with a disability highlight how stigma by association, much like direct stigma, contributes to inhibited and negative social interactions because parents may perceive judgment and blame with regard to their child's disability or behaviour, or the manner in which they care for their children (Green 2003; Norvilitis et al. 2002; Turner et al. 2007). Stigma by association places strains on the relationship between marked individuals and their family members, ultimately affecting the capacity for social support in this context (Green 2004).

Corrigan and Miller (2004) note that narratives of blame, shame and contamination give rise to stigma by association. Narratives of blame suggest that the associates of stigmatized persons are culpable or responsible for the negative social implications of the stigma, while narratives of contamination suggest that associates of stigmatized persons are likely to have similar values, attributes or behaviours – “being known by the company we keep” (Kulik et al. 2008; Neuberg et al. 1994; Sigelman et al. 1991).

Existing studies of courtesy stigma among those who provide health and social care support the existence of narratives of blame and contamination. Using a longitudinal design, Snyder and colleagues (1999) found higher rates of turnover among volunteers supporting persons with AIDS compared to other hospice volunteers, which they linked to lower social support for the work in the personal networks of AIDS volunteers. Another study found that physicians who performed abortions faced significant workplace stigma, resulting in reluctance to speak about work publicly and in personal networks, politicization of their workplace purpose and workplace strain (Harris et al. 2011).

In addition to a social-psychological basis for character ascription and ideas of culpability, support for the notion of stigma by association can also be located in sociological studies of “dirty work,” which involves things or subjects the public perceives as menial, physically disgusting, socially degrading or morally dubious (Hughes 1962). Dirty work has been associated with a vast range of occupations, including waiting on tables, personal support, garbage collection, abortion support and the sex trade (Harris et al. 2011; Hughes 1962; Twigg et al. 2011). Scholars studying dirty work have investigated, in particular, the various ways that workers interpret and ascribe meaning to their work in the face of public derision (Harris et al. 2011).

While these studies provide a foundation for exploring the concept of stigma by association among workers, very few studies have examined the ways in which the particular social location of workers interacts with stigma in the workplace. This paper undertakes this task, investigating the reasons some staff who engage in morally contested work – specifically, the provision of outreach and related services to sex workers – might be more vulnerable to stigma by association than others.

## Research Design and Methods

The data are drawn from an ethnographic investigation combining participant observation, semi-structured interviews and a short, self-administered questionnaire. A single research site – Peers Victoria Resources Society (PEERS), where services are provided to sex workers – was chosen because of the deeply negative stigmas associated with the “prostitute” identity, and because of an existing community–academic collaborative relationship (Hallgrimsdottir et al. 2006). Given the rarity of studies on stigma by association among professional service providers, we chose an exploratory research design that involved repeated, open-ended interviews and participant observation (Guba and Lincoln 1994). Sampling was based on purposive selection, which focused on selective recruitment with the aim of reaching saturation in rela-

tion to the main research objectives (Glaser and Strauss 1967). Respondents from each of the program areas were included in the study. In total, 12 staff participated in repeated qualitative interviews, and 17 staff completed the supplementary questionnaire. The open-ended interview questions explored work experiences, including job satisfaction, job autonomy, stress and social support, while the self-administered closed-ended measures were used to describe demographic characteristics of the workforce at PEERS and served as a general indicator of workplace health and experiences of stigma.<sup>1</sup>

The questionnaire data were analyzed using SPSS, and the resulting descriptive statistics were used to contextualize the qualitative data with a demographic summary of the sample, to select case comparisons (i.e., persons who had post-secondary education versus persons who did not) and to confirm the qualitative findings (i.e., confirm that respondents experienced occupational devaluation). Analysis of the transcribed qualitative interviews was facilitated by the use of NVivo. The qualitative analysis focused on identifying themes and concepts repeated in the data, case-to-case comparison, and sorting the data according to overriding theoretical questions and research objectives, which focused on the existence and character of stigma by association, as well as variations in experiences of stigma by association. Interpretation and verification were established through discussion with expert informants, select research participants and academic colleagues.

## Findings

### *Demographic characteristics*

Table 1 summarizes a description of the age, gender, race, household income and family composition of staff who worked at PEERS during the study period. All persons who took part in the interview identified as female or male-to-female transgendered. The median age of participants was 44 years (mean=42), suggesting that the work is predominantly performed by women in the middle stages of their careers. Workers at PEERS report comparable levels of educational achievement with those in the broader social service community (FCSS 2008, 2009). Despite educational achievement, 77% of participants indicated their annual household income was equal to, or less than, the census metropolitan area (CMA) average. In addition, it is noteworthy that 35% of participants were currently lone parents, while only 12.7% of families in the region are classified as female single-parent families (Statistics Canada 2007). These demographic statistics support the available literature concerning the overrepresentation of female and other marginalized identities (lone parents, in this case) in care work, as well as the limited financial rewards associated with many forms of care work (Benoit and Hallgrimsdottir 2011).

In the course of interviewing and observation, close to two-thirds of the individuals who participated in the research volunteered that they had formerly worked in the sex industry, while approximately one-third of participants noted they had not. Whether or not one had



a background in the sex industry was of interest in the research as an example of co-occurring stigma, and this formed one aspect of the case comparison in the qualitative analysis. However, we assumed that several dimensions of social experience, including participants' varied experiences of the sex industry, substance abuse, ethnicity and socio-economic status, would likely influence how staff experienced stigma by association.

**TABLE 1.** Descriptive characteristics of PEERS staff

Variable	PEERS staff	Victoria (CMA) (Statistics Canada 2007)
Median age	44	N/A
% Female	94 .1	52.3
% Visible minority	5.8	10.4
% Aboriginal	5.8	3.4
% Completed high school	82.3	91.2
% Completed university degree	35.2	28.3 (persons aged 35–64)
Household income (median)	\$38,000	\$53,310 (all households)
% Reported being a female single parent	35.2	12.7 (among census families)

### *Workplace benefits and constraints*

As other studies of personal service work have found, front-line service workers at the research site felt positive about their opportunity to provide care for those in need, underscoring the notion that for some individuals, service work has significant normative implications (Zelizer 2002):

[The] philosophy, which I think is really important here, is that you accept people where they are ... they have the right to have service, and I think that's quite unusual. (R#3)

When asked about the greatest challenges of the job, most participants pointed to a systemic dearth of resources to fill the care gap:

We have to work really hard here, a lot harder in this environment to get help for the clients or to move issues forward. We have to work way harder than other agencies or other causes do ... (R#6)

Workers at PEERS, like others who perform morally contested work, also described their activities with clients as a social justice activity, adding an additional element of pride to their caregiving roles (Harris et al. 2011):



I really identified with the idea of using experience as a basis for knowledge, and I liked that we grew hope in our clients and even in the community. Many people came forward against the stereotypes ... . (R#10)

Patterns in program funding may be one of the key areas where stigmas against clients intersect on a structural level with the workplace experiences of those who serve them (Link and Phelan 2006; Stuber et al. 2008).

You're fully responsible for finding all the money and then to discover that that happens every year ... . I'd sort of pictured, going into it, [that] we'll spend a year stabilizing things [financially], but then I realized at the end of year one that all you can really do is reinvent the same year over and over again ... . (R#2)

While short-term and contingent funding is arguably a universal stressor in the non-profit sector, organizations providing services to stigmatized groups must actively negotiate this stigma in their search for financial resources. In this context, defining the client population and organizational purpose is a task continually fraught with tension:

When talking about strengths and de-criminalization, lots of people are kind of angry, but when I talk about it in terms of women being victims, when I start telling these sad stories, then everyone is like "oh," like there's no animosity. You don't come from a place of victim, you don't get funding. (R#11)

Depictions of PEERS's clientele as victims of the sex industry was a strategy used to maximize public and funder support for the organization, but many workers felt such framings were in conflict with their personal views and experiences of the sex industry (Hallgrimsdottir et al. 2006):

The perception [that] "oh, so you're saving those victims"... stigmatizes me because then I feel like I'm being put into the same category. (R#8)

The following section provides a closer look at stigma in the context of day-to-day work and the private sphere.

### *Contexts of stigma by association*

Table 2 contains a selection of questionnaire responses to measures of stigma operationalized as expectations of devaluation and discrimination (Link 1987). These descriptive statistics provide clear evidence of perceived devaluation associated with working in an organization providing services to sex workers.

**TABLE 2.** Expectation of devaluation and discrimination

Question (adapted from Link 1987)	% Agree
1. Funders are supportive of the work conducted by PEERS Victoria	29%
2. I have been treated unfairly by others when they have learned I worked at PEERS Victoria	35%
3. I worry that others see me unfavourably because I work at PEERS Victoria	59%
4. Most people think less of a person that works at PEERS	76%
5. Once they know a person works at PEERS, most people will take their opinions less seriously	88%

Certain staff noted a variety of contexts, both at home and on the job, where they encountered stigma by association. While most noted that their friends and families accepted the work they performed as important, in many cases, family members were either not comfortable talking about the job or found such conversations wearisome and value laden – “we don’t discuss it” (R#8). Another respondent stated:

You know, my mother has had to struggle with it, too. ... I think my mother sometimes feels the stigma from me being in this line of work. (R#12)

Not being able to talk openly with family and friends about their job for fear of disapproval, or a reluctance to burden others with tensions that surround the work, resulted in a sense of isolation for some staff, a finding that supports other research regarding withdrawal of social support for stigmatized work (Harris et al. 2011; Snyder et al. 1999).

Although my friends were very supportive of my involvement at PEERS, it seemed difficult for them to express interest in what I was doing. ... I seldom said anything to anyone unless they asked, so at times it felt like a lonely venture. (Volunteer #1)

Staff at PEERS also described both instances of poor treatment as well as fear of discrimination when representing the organization in public contexts, leading to a heightened sense of vigilance regarding representation and discrimination:

I saw the look on her [social worker’s] face and I knew that if I gave her the “yes” answer she would see me as less than professional, so I gave her a “not everybody at PEERS has to [have a history] in the sex trade.” (R#3)

I was in a store with my husband, [I] think it was an electronics store, and we were buying something and the guy said to me, “Where do you work?” and I said, “PEERS,” and he said, “What is that?” And there was a lot of people at the counter

and it was the first time that I stopped myself before right out saying prostitute, you know, and I could feel my face flushing bright red and I don't know why that was.

(R#5)

Supporting the notion of contamination narratives as a means of stigma transmission, several staff noted that their involvement with the organization led to questions and assumptions regarding personal background:

Even identifying that I work at PEERS, right, has, you know, [implications].

Depending upon how much the population knows about PEERS already, they will have formed an idea in their head of who I am ... (R#9)

The above passages also illustrate how stigma by association at PEERS was complicated by the organization's explicit practice of hiring people who had been involved in the sex industry:

All of a sudden I became this token sex worker ... . A lot of people got really [hurt by] that, including me, so we've had to really change the way we think about public education and who's gonna go out and talk about their experience and who's not.

(R#11)

Public response to the idea of working in an organization that supports sex workers was described as varied and unpredictable and included valourizing, belittling, disdainful or voyeuristic reactions. Anticipating discrimination, some staff described uncertainty about how to share their work with others:

I've become very used to it now after all of these times ... . Whoever invited you to speak is interested, right, but the rest of the room, half of them right away, they are not interested. ... It's been tricky to figure out how do you speak to that room. (R#2)

Some people are really fascinated and just want to hear about it, but it's, you know, it's like a, it's a neat story ... and it can be frustrating. (R#7)

In addition to feeling pressure to stage their work to generate a favourable response, workers who held formal educational credentials used their training to establish professional authority when faced with stigma by association. One worker described how she believed her professional education offset the discrimination she might otherwise experience as someone with a history in the sex industry:

The language you use [is important]. If you speak like you may have been university educated, you get results, otherwise you don't. (R#11)

People are really open when I speak to them on a professional level [but] they ... just don't know how to react to that personal piece. (R#5)

These examples of impression management support available literature, which argues that workers feel pressure to draw on markers of professionalization as a strategy to distance themselves from the stigmas associated with their clientele (Baines et al. 1992).

Regardless of credentials and experience, participants whose lives were marked by co-occurring stigmas – which in this project were most likely to be due to personal history of one or more of sex industry work, substance use and lack of educational credentials – were less likely to speak authoritatively about their ability to neutralize stigmas through various strategies:

I find that I'm not really taken seriously because of the way that I've come from being a client and moved up like that, like I sometimes feel like I don't know if I'm imagining it. (R#1)

Staff who were able to draw on other sources of prestige and authority could more easily distance themselves from the stigma associated with working at PEERS:

Now for me, it is a bit different because I came from a position of [advantage] and I carry the benefits of that into this job ... . (R#2)

The findings presented here suggest that education, co-occurring stigmas and work experience moderate the effects of stigma by association, but it is likely that a range of other factors – including gender, age, ethnicity, income – also interact with stigma by association when an intersectional model is considered (Hankivsky and Cormier 2009).

### *Health implications of stigma by association*

[Working at PEERS] took a tremendous toll on my health – [on] my mental health more than anything. (R#2)

The questionnaire findings support the descriptions provided by PEERS staff of the health consequences of stigma by association. A significant minority of staff (41.2%) reported taking a leave of absence for health reasons while at PEERS, and experiencing five or more days of sickness-related absence (29.0%) in the last six months (see Table 3).

TABLE 3. Health indicators

Measure	PEERS Staff
% Report work to be "quite a bit" or "extremely" stressful	64.7
% Report health-related leave of absence	41.2
% Report "five or more sick days" in last six months	29.0
Mean emotional exhaustion 27 or greater = high	26.7
Mean personal accomplishment 39 or greater = low	41.7
Mean depersonalization 7–12 = moderate	6.9

According to the results of the Maslach Burnout Inventory, workers at PEERS demonstrated, on average, high levels of emotional exhaustion and a low sense of personal accomplishment, a finding that fits with respondents' descriptions of the job as being mired in systemic issues such as unstable and insufficient funding and uneven public support (Maslach and Jackson 1981). As a point of comparison, staff at PEERS reported higher mean emotional exhaustion and lower mean personal accomplishment than sex workers and healthcare workers in Denmark (Vanwesenbeeck 2005).

## Discussion and Conclusion

The findings presented above indicate that stigma by association is a discernible feature of the everyday reality of PEERS staff (Phillips et al. 2012). They described inconsistent social support from family and friends regarding their work activities, as well as feelings of being treated poorly by professionals in other service organizations and by the public at large. While some staff, armed with a strong belief in their mission and service philosophy, managed to develop strategies to deal with others' misinformation and stereotypes, the high turnover of PEERS staff and their reflections on the advantages of employment in another line of work suggest that stigma by association does take a toll over time. At the same time, they articulated varying levels of concern about, and resiliency to, the negative implications of stigma. Those with higher education showed the most confidence in advancing counter-narratives in the face of discrimination against the work they performed, whereas staff who had previously been in the sex industry or had limited education or work experience were more likely to describe experiences of courtesy stigma as more damaging.

Assessing the relative impact of direct and associative stigmas vis-à-vis other determinants of health (which interact with and transmute stigmas) is a complex issue and one that cannot be reconciled here given the small, single sample. Nevertheless, the insights of scholars who highlight the interconnectedness of various axes of marginalization, as well as the interaction between social determinants of health, are useful in this context (Link and Phelan 2001, 2006; Scambler 2009). Link's (1987) research on the expectations of devaluation and discrimination draws attention to the role of stigma (and by extension, stigma by association) in activating a

range of secondary outcomes such as withdrawal from social and economic contexts. Viewed from this angle, stigma by association may be more pivotal to the organizational culture of PEERS than it would appear on the surface. The combination of perceptions of others' limited and conditional support for their work, and the stresses described in relation to acquiring and maintaining funding, likely played a role in the low sense of accomplishment reported by PEERS staff. Furthermore, strained social relations between PEERS staff and other allied service organizations curtailed opportunities for successful collaborations that might have improved client support capacity. Stigma by association is thus a sometimes subtle, yet far-reaching, workplace stressor that potentially permeates many aspects of workplace activity and worker health.

The available research suggests that unhealthy working conditions and high turnover among service providers are transmitted to service recipients through various suboptimal service delivery practices (FCSS 2008; Yoo and Brooks 2005). Thus, an additional implication of the findings, and an area for further research, concerns how stigma by association affects service capacity (Green 2004).

This study is not without important limitations. Foremost, the small, single-site sample limited the investigation of the factors that intersect with stigma by association. In addition to a need for research with a more diverse and larger sample, comparative research on workers serving more and less stigmatized populations, and among workers who experience different levels of structural disadvantage and varying co-occurring stigma configurations, is recommended. If supported by further research, the findings presented here could have long-range implications for various professions across both the health and social service sectors.

Despite their exploratory nature, the findings of this research support a number of policy and program recommendations. First, echoing others who have suggested that health and social service sites are primary locations for stigma remediation, this research suggests that it is important to educate staff about stigma, but also to invest in employee wellness strategies that take into account how workers may be co-located with their clients in processes of social marginalization (Wieloch 2002). It is also important to consider a collaborative, intersectoral and coalitional approach that focuses on developing partnerships between groups of persons whose health is affected by stigma in various ways. An upstream approach to stigma is likely to have a greater impact on public awareness and public policy than approaches that treat stigmas as disconnected phenomena. This is because stigmas are inevitably relational and are thus not the property of stigmatized groups alone. Such coalitional approaches, to the extent that they foster diversity and more nuanced understandings of social location, help to overcome the tendency for essentialist discourse to emerge regarding stigmatized identities, while also effectively addressing the complex interconnections among processes of social and economic marginalization.

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NOTE

1. Measures of workplace health included the Beck Depression Inventory (Beck et al. 1979), the Job Content Questionnaire (Karasek et al. 1998) and the Maslach Burnout Inventory (Maslach et al. 1996). Findings from the Maslach Burnout Inventory, which measures three dimensions of burnout – emotional exhaustion, depersonalization and sense of personal accomplishment – are reported in this paper.

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## Exploring Stigma by Association among Front-Line Care Providers Serving Sex Workers

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