

**Organization of health services for minority populations:
the role of organizational health literacy and an active offer of health
services in French in Ontario**

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Abstract

Background: Health systems around the world are facing significant shifts in demographic profiles due to increasing ethnic, cultural and linguistic diversity of populations they serve. However, the provision of health care and health services in the language of the minority has been difficult and inconsistent. The concept of the *health-literate organization* has been developed amid growing recognition that system changes are needed to align health-care delivery with the needs, skills, and abilities of the population. Despite the recent proliferation of research on health literacy, studies of organizational health literacy are still uncommon.

Objective: This dissertation addresses the concept and practical application of “organizational health literacy” in the context of an active offer of health services in French in Ontario, Canada. I attempt to answer the question “How can health literacy advance the development of health-care designs that are responsive and accessible to official language minority?”

Methods: My research consists of a three-part project that used health services research methodology and has been accomplished in academic partnership with the French Language Health Services Network of Eastern Ontario. I first conducted a review both of the literature on health literacy in linguistic minorities and of the content of organizational health literacy guides. Using a practical example of an *active offer* of French-language services in Ontario, I applied the organizational health-literacy framework in order to examine the strategies used by health-care organizations to provide for the active offer of health services in French. My analysis focuses on health-literacy dimensions (e.g., access and navigation, communication), quality improvement

characteristics (e.g., assessment, improvement actions), and also organizational-level changes (e.g., administrative strategies, direct client services, governance). A focus group of health-care administrators provided a unique insight into the planning and implementation of the active offer and organizational health literacy and associated challenges.

Results: Overall, my results show that, although organizational changes may be implemented with the purpose of improving the quality of care by providing linguistically appropriate services, these changes are largely insufficient to achieve this goal.

Conclusions: The concept of organizational health literacy has not yet received the attention it deserves, but its relevance is clear: Health-care organizations must be health-literate to be able to address healthcare needs of their diverse patients. There is a significant gap between where health services are and where they ought to be to satisfy the designation criteria for the active offer of services in French. The concept and the novel theoretical framework of organizational health literacy offers the potential of improving and strengthening the process of designation and planning of an active offer of health services in French.

Keywords: organizational health literacy; health services; minorities; Francophone; active offer

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Every man has enough power left to carry out that of which he is convinced.

~ Goethe

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Chapter 1

Introduction

Aim and outline of the dissertation

The health-care system of today lacks sensitivity and responsiveness to the population it serves. In this dissertation, I attempt to weave together several distinct concepts, frameworks, and methods to shed light on a topical issue of health care for minority populations. I chose to focus on the organization of services for linguistic minorities because there is a need to look for health-care designs that are responsive and accessible to both mainstream and minority populations (Beach, Cooper, & Robinson, 2005), but this line of inquiry has received little attention to date (Treloar et al., 2013). Specifically, I address the complexity of the state of health-care services for the Francophone population living in a minority situation in Ontario.

I begin my dissertation by introducing the reader to Canada's Francophone minorities and by revealing the troubling situation faced by this minority group with respect to access to health care services and organization of health care. Next, I define health services as one of the key determinants of health and introduce the concepts that are at the core of this dissertation, namely health literacy and organizational health literacy, and active offer of services in French. I draw reader's attention to the novel theoretical framework used in this dissertation (organizational health literacy) and explain the methodology and methods used to carry out this research.

Four individual articles make up this dissertation. Because it is not a monograph, some overlap of content occurs among the articles. However, the chapters and references follow the same format throughout the dissertation to enhance readability.

The first article presents results of a scoping review of literature on health literacy in linguistic minority populations published over the last 20 years. In the second article, I

focus on the critical review and analysis of guides for organizational health literacy and examples of their application by health-care organizations. The analysis focuses on health-literacy dimensions (e.g., access and navigation, communication, consumer involvement, workforce, leadership and management, meeting needs of population) and quality improvement characteristics of the guides (e.g., goal setting, assessment, health-literacy improvement actions). The third article presents the main results of the analysis of reorganization and management strategies taken by selected health-care organizations in Ontario to receive designation for an active offer of health services in French. Changes related to reorganization are categorized into administrative strategies, direct client services, corporate identity and communications, and governance and accountability. The fourth and final article focuses on main results of the focus group with health-care administrators on the topic of the active offer of French-language health services. The dissertation concludes that tangible improvements in the organization and delivery of health services for linguistic minorities require systemic changes informed by the concepts of organizational health literacy and active offer of services. These concepts have not yet received the attention they deserve in health services research, but their relevance is clear; health-care organization must be health-literate to be able to foster health-literacy skills and address the health-care needs of their clients and patients.

This thesis contributes to the field of population health by drawing attention to the health-literate health services important in the creation of health-care systems responsive to individuals' needs, particularly vulnerable populations such as official language minority, and improving the health of populations. The literature on the social determinants of health demonstrates that health services play an important role in shaping

the health status of individuals and populations (Mikkonen & Raphael, 2010; Public Health Agency of Canada, 2011; WHO Commission on the Social Determinants of Health, 2010). The burgeoning evidence about limited access to health services in French (Schofield & Gauthier, 2007), widespread health risk behaviours among Francophones (e.g. smoking, alcohol consumption, physical inactivity, poor diet) (Batal et al., 2013; DeWit & Beneteau, 1999; Imbeault et al., 2013), reports of fair or poor health (Bouchard et al., 2013), and lower life expectancy in Francophones compared to Anglophones (Melorose et al., 2015), emphasize that the issue of health services in French is undeniably affected by social determinants of health. However, despite increasing attention to health services for minority populations, key concepts in the field of population health, such as cultural concordance, responsiveness and cultural competence of health services and interventions aimed at improving care for all patients, are in need of further investigation. It is to this area of research that this dissertation contributes.

Canada's Francophone Minorities: A Brief Portrait

In Canada, the French-speaking minority has two origins: 1) original immigrants from Europe from the time of Canada's founding (Bouchard & Desmeules, 2011; Langlois, n.d.) and 2) more recent immigrants from French-speaking countries (Heller, 2007). Francophone minorities of Canada have been recently designated as official-language minority group (Government of Canada, 2007). The Francophone minority is defined as those citizens who live in a demographic or institutional minority and whose ethnolinguistic identity, social identity, and identity engagement come from French language and culture (Deveau, Landry, & Allard, 2005). Although the main concentration

of French-speaking Canadians is in Quebec, the only officially French-speaking province, around one million of Francophones dispersed across Canada, with the biggest concentration (611,500 people) living in a minority situation in Ontario (Office of Francophone Affairs, 2016).

Francophone Canada has a troubled history of oppression and transformation, which has occurred at an unprecedented rate for over a century (Behiels, 2005). Although a new, vigorous Francophone community has emerged more recently, this minority suffers from the impact of policies that cause social and health inequities (Behiels, 2005; Bouchard, Gilbert, Landry, & Deveau, 2006). Today, Francophone minority tends to be older, less educated, and poorer (Bouchard et al., 2006; Bouchard, Makvandi, Sedigh & van Kemenade, 2014; Corbeil & Lafrenière, 2010). They exhibit more high-risk health behaviours (e.g. smoking, alcohol consumption, physical inactivity, poor diet) than non-Francophone (Batal et al., 2013; DeWit & Beneteau, 1999; Imbeault et al., 2013) and experience limited access to French-language health services (Schofield & Gauthier, 2007). Earlier reports on literacy, such as Laflamme & Bernier (1998), Wagner & Grenier, (1992) and Jones (1993), consistently showed that Francophone minorities exhibited patterns in reading and writing different from those exhibited by Anglophone majority (S. Jones, 1993; Laflamme & Bernier, 1998; Wagner & Grenier, 1992).

Laflamme & Bernier observed that Francophone minorities of Ontario live in a *linguistic duality*; French is commonly a spoken language, while English is the language of listening (Laflamme & Bernier 1998). For Francophones, reading is further complicated because technology has made information available via multiple channels but primarily in English. Francophones are exposed to a great amount of messaging in English and are

compelled to understand, think, and express themselves in English. Unfortunately, Francophones living in a minority situation are not always proficient in English. Approximately 72% of Francophone seniors in Ontario are not capable of communicating in English with their physicians (Bourbonnais, 2008). These issues raise many questions about universality and accessibility of Canadian health care for Francophone minorities and about whether linguistic duality can be used to improve their health care.

In 2002, the Romanow Commission (Romanow, 2002) showed that access to health services in one of the official languages of Canada (i.e. English or French) is an important aspect of the Canadian health system and should take into account the patient's capacity to understand treatment and medical recommendations. The Commission went on to suggest an expanded definition of access to services:

Although access is traditionally looked at in terms of waiting times or distance, it can also be affected by social and cultural factors such as language, gender, education, and wealth. When people are receiving care in a hospital or another health-care program, both their access and the quality of care they receive may be inhibited by problems in communication, understanding or acceptance. (p. 154).

The Romanow Commission proposed that governments at all levels engage in the organization and development of health services for Francophone minorities in all Canadian provinces and territories.

In his 2016 report, the French Language Services Commissioner for Ontario noted the introduction of policies and new programs and services that have been manifestly designed over the last few years for the province's Francophones (Office of the French Language Services Commissioner of Ontario, 2016). While such work may be ongoing

across Ontario, little is known about the organization and development of health services designed for Francophone minorities.

Health Services as a Determinant of Health

A health-care system—even the best health-care system in the world— will be only one of the ingredients that determine whether your life will be long or short, healthy or sick, full of fulfillment, or empty with despair.

~ The Honourable Roy Romanow, 2004

It is well-established that health services are one of the social determinants of health and also a basic human right (Mikkonen & Raphael, 2010; Public Health Agency of Canada, 2011). Health services include a range of services from the promotion, maintenance and restoration of health as well as the diagnosis and treatment of disease (World Health Organization, 2016).

Of course, both limited access to health services and a poor quality of health services negatively affect health. Recent statistics from international health system performance surveys demonstrate that Canadian health services are disorganized and poorly managed. Canadians experience long wait times to access health care. The 2014 Commonwealth Fund Survey indicated that Canadians had the longest wait for access to primary care, with 53% of Canadians waiting at least two days to see a doctor or a nurse when they required medical attention, compared to the 11-country average of 32% (Canadian Institute for Health Information, 2015). More Canadians (37%) went to an emergency department for a condition that could have been treated in primary care than any other country, with the exception of uninsured Americans (39%); the 11-country

average was 28%. Canadians wait the longest to access specialist care of any of the 11 countries. Twenty-five percent of Canadians waited for at least 2 months to see a specialist as compared to the average of 15%. Unlike in most other countries, wait times in Canada have not been shortening since 2008.

Furthermore, according to the Organization for Economic Co-operation and Development (OECD) health data, Canada does not perform well on patient safety. The data reveals that 7% (158,000 a year) of all patients admitted to acute care hospitals in Canada will suffer a medical error (Canadian Institute for Health Information, 2013). Close to 60,000 of these cases are preventable. About 150 patients die a year as a result of adverse medical events.

Canada has relatively high diabetes and obesity rates. Canada also has low ratings on most patient safety indicators—particularly obstetric trauma and foreign bodies left in during a procedure. Canada performs poorly on lung cancer mortality, infant mortality, and the prevalence of diabetes.

Access to high-quality and comprehensive health services is particularly important for achieving health equity for all. Considerations of equity arise when one considers Canada's official bilingualism. The literature on this topic addresses Francophone minority communities (Bouchard, Beaulieu, & Desmeules, 2012; Drolet et al., 2014; Forgues, Bahi, Michaud, Boudreau, & St-onge, 2011; Forgues & Landry, 2006; Landry & Forgues, 2007) and documents the existence of a linguistic incongruence in the provision of health care that deleteriously impacts Francophones' health. Francophones tend to exhibit more high-risk health behaviours (e.g. smoking, alcohol consumption, physical inactivity, poor diet) (Batal et al., 2013; DeWit & Beneteau, 1999; Imbeault et

al., 2013), report having fair or poor health (Bouchard et al., 2013). Francophones have lower health literacy than non-Francophones (Canadian Council on Learning, 2008) and have limited access to health services in French (Schofield & Gauthier, 2007).

Alimezelli and colleagues found that health-care organizations and governments inadequately addressed the growing health-care access needs of Francophones living in a minority situation (Alimezelli, Leis, Karunanayake, & Denis, 2013, p. 2). Timony et al. examined the availability of services in French for Francophones in minority communities in Ontario and demonstrated a negative correlation between the availability of physicians and the number of Francophones: “As the number of Francophones increases in a community, the availability of French-speaking [family physicians and general practitioners] actually decreases, particularly in rural northern Ontario.” The authors noted a paradoxical relationship between the high number of family physicians in with French-language skills and the perceived lack of availability of medical services in French (Timony, Gauthier, Hogenbirk, & Wenghofer, 2013). The lack of French-language services is reported in other Canadian provinces with significant Francophone populations. De Moissac et al. (2012) found that only one quarter of Francophones in Manitoba receive services in French. The authors suggested that the lack of awareness of available French-language resources might have contributed to their perceived shortages (de Moissac et al., 2012). Moreover, the authors hypothesize that, in order to obtain services, Francophones might hesitate to identify themselves as Francophones.

Research suggests that Francophone communities living in a minority situation in Canada can be severely disadvantaged due to linguistic barriers in health care (Bouchard et al., 2010; Bowen, 2001; de Moissac et al., 2012; Forgues et al., 2011). The offer of

services in the language of the user's choice has been linked to quality and safety of care (Bouchard et al., 2012; de Moissac et al., 2012). Lack of comprehension has been suggested as a risk factor for poor adherence to medication regimens and refusal to consent to essential medical procedures (Bouchard et al., 2010; Lemonde, Dufour, & Desmeules, 2012). Lemonde and colleagues propose that the lack of comprehension is caused by the lack of education, insufficient level of bilingualism (English and French), lack of information, and lack of time taken by physicians to address issues during a short encounter with the patient (Lemonde et al., 2012).

Bouchard et al (2010) suggest that problems with communication in encounters with health-care providers stem from a “triple problem in literacy” involving low language proficiencies in English and French, low level of education, and insufficient understanding of medical jargon by Francophone patients.

Users of the health-care system who cannot properly communicate, whether due to the language of service or their own inability to read, do not have the same access to or quality of care as other citizens. These communication barriers make it harder to understand information, verbal or written, regarding prevention, prescriptions, or medical follow-ups. (Bouchard, et al., 2006 p. S18.).

Authors point not only to the person's capacity to interact with the health-care system, but also to the health system's lack of preparedness to deal with minority populations. It is apparent from the studies that the health-care system has an important role to play in the facilitation of successful interactions with and engagement of Francophone patients.

Research demonstrates a dire need for the health system to become more responsive and efficient as well as more accountable to all Canadians. The Romanow Commission (Romanow, 2002), the Kirby Senate Committee (Kirby & LeBreton, 2002),

and, most recently, in the Naylor report of the Advisory Panel on Healthcare Innovation (Advisory Panel on Healthcare Innovation, 2015) support that proposition.

The Naylor report emphasizes that Canadians expect to interact with a responsive system that is designed around their needs, not around the needs of the health-care system. While this expectation increases the pressure on the health-care system, it also provides an opportunity to improve health services, increase access to and use of evidence-based preventive services, improve quality of care, and potentially reduce the cost of care. It is important to simplify access to health care for linguistic minorities and to develop health-care organizations where staff members speak minority languages and are culturally sensitive.

Various concepts, guidelines, and normative approaches have been developed to date to help health systems around the world to improve the cultural and linguistic competence of their health-care delivery. A normative approach has been taken in the US with the introduction of the enhanced National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care (Koh, Gracia, & Alvarez, 2014).

CLAS includes provisions, which are supported by accreditation standards, to improve communication, cultural competence, patient-centred care, and the provision of language-assistance services. CLAS has proven itself in the US, and is garnering attention from key players in the provision of French-language health services in Canada (Tremblay, Angus, & Hubert, 2012; Tremblay & Prata, 2012).

The former Institute of Medicine has introduced the term *health-literate organization* and a guideline to help health-care organizations develop health-literate

systems of care (Brach et al., 2012). The guideline includes a set of 10 attributes that help health-care organizations become more responsive and align services with the health-literacy level of the organization's patient population. Although this concept, and the guideline, might require further refinement, the health-literate organization is designed to create an environment where everyone can contribute to and benefit from the health-care system.

In Canada, the concept of an *active offer* emerged as a necessity to improve the offer and provision of services for Francophone minorities (Office of Francophone Affairs, 2013). Below I'd like to introduce and discuss the concepts most relevant to this dissertation: health literacy, organizational health literacy and an active offer of health services in French.

Health Literacy and Organizational Health Literacy: What, Why and How.

The concept of *health literacy* was introduced in 1974 as part of an argument that literacy in health is just as necessary as literacy in other subjects (Simonds, 1974; Tones, 2002). Today, health literacy figures prominently in health and health-care debates worldwide. The understanding and definition of health literacy has changed over time from the narrow technical term that referred to the ability to read and understand medical prescriptions and labels to a multidimensional concept that has the potential to improve health and well-being, and to reduce health inequities (Frisch, Camerini, Diviani, & Schulz, 2012; Kickbusch, Pelikan, Apfel, & Tsouros, 2013; Mitic & Rootman, 2012; Rootman & Gordon-el-Bibhety, 2010; Sorensen et al., 2012). Conceived at first as an individual trait and a capacity, *health literacy* has also expanded to mean the capacity of

the health-care system to provide health-literate care (Hernandez, 2012; Palumbo & Annarumma, 2014; Parker & Hernandez, 2012). In its broad sense, health literacy is concerned with the capacities of individuals, communities, public, population and, most recently, the health system to meet the complex demands of health care in a modern society (Brach et al., 2012; Institute of Medicine, 2012; Kickbusch, Pelikan, Apfel, & Tsouros, 2013; Sorensen et al., 2012).

Early literature refers to health literacy as an ability to use printed and written health information in the context of medical care; this is known as *functional health literacy* (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Nutbeam, 2000). Throughout the 1990s and early 2000s, this narrow definition expanded on several occasions. Notably, in 1998, the World Health Organization (WHO) added cognitive and social dimensions to the definition of health literacy (World Health Organization, 1998). In 1999, the American Medical Association defined health literacy as a *constellation of skills* by adding a skill-based perspective (Ad Hoc Committee On Health Literacy, 1999). In 2000, Ratzan and Parker (Seldon, Zorn, Ratzan, & Parker, 2000) and the U.S. Department of Health and Human Services linked health literacy to preventive behaviours—launching a nationwide health-promotion and disease-prevention agenda, *Healthy People 2010*. In 2004, the former Institute of Medicine released its landmark report, *Health Literacy: A Prescription to End Confusion*, emphasizing that health literacy is “a shared function of social and individual factors” (Nielsen-Bohlman, Panzer, & Kindig, 2004). Of the definitions proposed to date, the ones adopted by the AMA, the former IOM, and WHO are cited most frequently in the literature (Sorensen et al., 2012). These definitions focus

on the individual's skills and abilities to obtain, process, and understand health information and services necessary in order to make appropriate health decisions.

In Canada, the Canadian Public Health Association convened an Expert Panel on Health Literacy in 2006, which adopted the definition of health literacy as “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (Rootman & Gordon-el-Bibhety, 2008, p. 2). Recently, a more comprehensive definition of health literacy has been proposed based on the review of 17 existing definitions. It includes competence, skills, abilities, purpose, resources, and context across the lifespan (Sorensen et al., 2012).

Definitions of health literacy developed amid tensions in the health and health-care field between individual and population approaches, and medical and public health perspectives. In the early 2000s, suggestions were made to shift focus from *compliance* to *empowerment* (Kickbusch, 2001; Nutbeam, 2000). The problem is that excessive focus on compliance increases the responsibility of an individual and takes away the responsibility from the health system. When attention is placed on skills, these role of social class and racial disparities are overlooked. Practitioners are faced with the dilemma on one side of encouraging individuals to comply with medical advice, and on the other side to support patients' personal autonomy (Gillis, 2009).

To facilitate the shift from compliance to empowerment, Kickbusch (2001) offered a Nussbaum's capabilities approach and the Royal Pharmaceutical Society introduced the notion of *concordance*, which is linked to the informed choice of an individual (see Mullen, 1997 as cited in Gillis, 2009).

By the late 2000s, two distinct views of health literacy as a *capacity* and as a *competency* emerged. Based on this, Nutbeam (2000) differentiated between health literacy as a *risk* and as an *asset*. The former developed in the context of medical care with the growing awareness both of the effect of poor health-literacy skills on health and need to lessen the negative effects of low health literacy. This view developed in the US and provided a basis for the IOM definition of health literacy (Nielsen-Bohlman et al., 2004) and a linking of health literacy to health outcomes (e.g. Paasche-Orlow and Wolf, 2007).

The view of health literacy as an asset evolved in Canada and Europe. In this view, health literacy is a competency reinforced by health education, communication, and social determinants of health that empowers individuals and communities to take control over their health. WHO (Kickbusch, Pelikan, Apfel, 2013), the Canadian Public Health Association (2008), and Sorensen et al (2012) approach health literacy as an asset.

Although health literacy is viewed increasingly as a multidimensional concept, there is an ongoing disagreement over the meaning of health literacy and its application (Sorensen et al, 2012). From the medical view, the capacity to function as a patient builds on cognitive capabilities, skills, and behaviours (Baker, 2006; Paasche-Orlow & Wolf, 2007; Speros, 2005), but from the public health perspective, health literacy is a complex phenomenon and includes scientific, civic, cultural, informational and media literacy elements (Frisch, Camerini, Diviani, & Schulz, 2012; Nutbeam, 2000; Zarcadoolas, Pleasant, & Greer, 2009). Frisch et al suggest that other literacy domains could integrate functional literacy, factual and procedural knowledge, awareness, and critical dimensions of health literacy.

While estimates of the prevalence of low health literacy vary from 12% to 62% (Canadian Council on Learning, 2008; Doyle, Caffersky, & Fullam, 2012; Nielsen-Bohlman et al., 2004; Pelikan, Rothlin, & Ganahl, 2012), many countries in North America and Europe face what is now described as “a silent epidemic” of inadequate health literacy that affects the health status of vast populations (Palumbo & Annarumma, 2014; Parker, Ratzan, & Lurie, 2003; Pelikan et al., 2012). In Canada, the authors of a seminal report, *Health Literacy in Canada: A Healthy Understanding* (Canadian Council on Learning, 2008), concluded that the prevalence of low levels of health literacy is a serious population health issue: Approximately 60% of Canadian adults have the health-literacy skills necessary to appropriately access, understand, and evaluate health information. The report states that “differences in health status that are associated with differences in health-literacy are large enough to imply that significant improvement in overall levels of population health might be realized if a way could be found to raise adult health-literacy levels,” and that such improvement may lead not only to improved health but also “real savings for the health system and benefits for our health-care system and our national productivity” (Canadian Council on Learning, 2008, p. 29). Thus, health literacy is important due to the potential of its wide application in health care.

Health Literacy in the Context of Francophone Minorities in Canada

The cultural and linguistic aspects of health literacy were put in the spotlight in Canada with the release of a seminal report, *Health Literacy in Canada: A Healthy Understanding* (Canadian Council on Learning, 2008). Using data from the International Adult Literacy and Skill Survey, this report established a baseline prevalence of low

levels of health literacy in Canada and pointed to a relatively large gap in the health-literacy scores between the Francophone minorities and non-Francophones.

Masinda examined the meaning of health literacy and health education in a Francophone context (Masinda, 2007) and concluded that, although both terms had the same meaning on either side of the Atlantic, North-American Francophone authors used the terms *health literacy* and *health education* interchangeably, while, in French Europe, authors preferred the term *health education*, only. Masinda called for an in-depth theoretical debate on health literacy and health education in the Francophone context, and also to discuss health literacy at a community rather than individual level.

Unfortunately, it appears that the issue of terminology has not been resolved. By 2012, researchers found that there was still lack of common terminology and definitions of health literacy in a Francophone context (Centre for Literacy, 2012). There is still a limited amount of original research on health literacy regarding French-speaking populations in Canada because much of the research that exists in French has been translated from English (Centre for Literacy, 2012). Furthermore, no health-literacy projects on Francophones were identified outside New Brunswick or Quebec. The authors observed that community literacy groups play an important role in advancing the practice of health literacy, but only a few of them self-identify as *health-literacy* groups (Centre for Literacy, 2012).

Most recently, Zanchetta and colleagues explored the construct of health literacy in immigrant and Canadian-born Francophone families living in a linguistic-minority situation in Canada (Zanchetta et al., 2013). They suggest that Francophones in a minority situation may be invisible in health-care records; immigrants do not interact

with the health system because of, among other things, the lack of awareness about where to seek help, how to navigate the health-care system, and linguistic barriers. They also find that Francophone immigrants have limited social networks and this inevitably limits the development of their health literacy. The authors hypothesize that limited awareness about inequity in access to health-care services for Francophones, linguistic barriers, and social isolation delay the development of their interactive health literacy.

Organizational Health Literacy

There is now a growing recognition that health literacy depends not only on individual skills and abilities but also on the demands and complexities of the health-care system (Hernandez, 2012; Michael Paasche-Orlow, Schillinger, Greene, & Wagner, 2006; Palumbo & Annarumma, 2014). One way to raise predominantly low levels of health literacy in populations is to build *health-literate* systems of care. The term *health-literate organization* describes organizations that can make patient navigation easier and anticipate and meet the needs of all patients notwithstanding of their level of health literacy (Schillinger & Keller, 2011).

The rationale for creating health literacy at the organizational level is simple: 1) health-care organizations, which usually host most of the dealings between patients and the health-care system, are in the best position to enhance patients' ability to handle health information and to navigate the health system (Koh et al., 2012; Palumbo & Annarumma, 2014); 2) health systems and most health-care settings today are not designed to be able to enhance patients' ability to handle health information and to navigate the health system, and are ill-equipped to deal with the multilingual, multicultural demographics of their patients (Andrulis & Brach, 2007; Paasche-Orlow &

Wolf, 2010; Paasche-Orlow et al., 2006). Thus, to be able to raise low levels of health literacy in patients, health-care systems and individual settings must become health-literate and simplify patient navigation and introduce variety of tools and innovations to help enhance their health-literacy attributes (Brach et al., 2012).

Proponents of such a view call for a range of interventions to enhance organizational health literacy, from discrete organizational efforts (Calderon et al., 2014; Jones et al., 2011; Servellen et al., 2003; Swavely, Vorderstrasse, Maldonado, Eid, & Etchason, 2014) to large-scale changes in health-care delivery (Andrulis & Brach, 2007; Brach et al., 2012; Michael Paasche-Orlow et al., 2006). The transition from health-care organizations to health-literate health-care organizations is a radical process of change that extends beyond the enhancement of the user-friendliness of informational tools to both structural and cultural effects (Palumbo & Annarumma, 2014). In a health-literate organization, health literacy should be a core value and inform strategic and operational planning (Koh et al. 2013; Weaver, Wray, Zellin, Gautam, & Jupka, 2012). Despite its importance, empirical studies are uncommon that explore the application of health-literate designs at the system level and strategies used to transition to a health-care organization that meets the needs of patients with low health literacy.

Active Offer of Health Services in French: What It Is and Why We Need It

No single definition of the *active offer* has been accepted to date. Its meaning and application varies across provinces and territories; but, in essence, it is a set of measures that warrant visibility, availability and accessibility of French-language services (Tremblay & Prata, 2012). I have defined *active offer* as a series of measures taken by

health-care organizations to ensure that French-language services are clearly communicated, visible, available at all times, easily accessible and equivalent to the quality of services offered in English (Office of Francophone Affairs, 2014).

The concept of an active offer implies the shift of responsibility from the patient to the organizations that offer and deliver this health care (Bouchard & Desmeules, 2011). It is characterized by proactive offer of services by staff and health-care providers from the point of first contact; by the guarantee that subsequent services will be provided in French; and that these services will be equivalent in quality to those offered in English (Office of the French Language Services Commissioner of Ontario, 2016).

Although *active offer* may appear to be a novel concept, the need for the active offer of services in French was emphasized in 1967 by the Royal Commission on Bilingualism and Biculturalism. In its report, the commission stated:

We begin by rejecting a proposition that in our eyes is unacceptable – that is, the provision of services in the minority language only to the extent that the minority requests. A system of that kind would constitute no real guarantee; it would be at the mercy of more or less arbitrary interpretation by the authorities of the day. Moreover, ... in a province where services have never or rarely been offered in the official language of the minority, the minority may by force of habit have resigned themselves to the situation even when they considered it unjust. We need more objective criteria than this, criteria founded on something more tangible. (Royal Commission on Bilingualism and Biculturalism, 1967, p. 95).

Essentially, active offer addresses the imbalance of power between majority and minority languages in Canada. The use of French in public spaces does not only depend on the recognition of French by government bodies and the law, but also on the perception of French by the members of Francophone minority (Landry, 2015).

Landry (2015) differentiates between private and public language and explains that Francophones use French as a private language and English as a public language because the latter is the language of the dominant group and is the high-status language. For example, if a Francophone patient enters a hospital or a clinic where the signage is in English and the staff addresses them in English, they will most likely use English to obtain the service. In a minority context, English is inadvertently perceived as a language that has higher legitimacy than French has (Deveau, Landry, & Allard, 2009), and bilingual Francophones prefer to use English in contexts where this language is favoured. Active offer respects the principle of equity and is expected to help create an environment that will stimulate both the offer and the demand for services in French and will anticipate the needs of Francophones in their community (Office of the French Language Services Commissioner of Ontario, 2016).

In Ontario, the active offer is integrated in the designation process for French-language health services and is currently valid for 25 designated areas, where Francophones make up at least 10% of the population. Active offer is governed by a number of laws and regulations, including the French Language Services Act and Ontario Regulation 284/11 on the provision of French-language services by third parties and the criteria for designation under the Act; the Local Health System Integration Act, 2006 and Ontario Regulation 515/09, which establishes a collaboration between the Local Health Integration Networks and the French Language Health Planning Entities; and the Excellent Care for All Act, 2010, that defines the criteria for service quality and positive patient experience (French Language Health Networks of Ontario, 2015).

Under this legal and regulatory framework, the Ministry of Health and Long-Term Care (MOHLTC) holds Local Health Integration Networks accountable for the active offer of health services in French. The Local Health Integration Networks share this accountability with health-care organizations via funding and accountability agreements. Health-care organizations play a leadership role in the provision of active offer by committing to the active offer, by opening their governance to the Francophone community, by including active offer in their policies, by hiring linguistically and culturally competent staff, and by building capacity for the active offer (French Language Health Networks of Ontario, 2015). The responsibility for active offer is reflected in the Ministry of Health and Long-Term Care's plans, in Local Health Integration Networks integrated health service and business plans, and in health-care organizations' strategic and operational plans.

In the recent special report on active offer of services in French, the Commission for French-language services states that the offer of services in French in Ontario has failed to meet the objectives of the Ontario French Language Services Act for the past 30 years, even in the designated regions (Office of the French Language Services Commissioner of Ontario, 2016). The commissioner proposed an amendment to the French Language Services Act to define active offer and recommended that directors and managers responsible for implementing the active offer of services in French be provided with clear directives and best practices to guide their efforts.

Some argue that the active offer of French-language health services should involve more than offering services in the French language; rather, it should take into account the needs and preferences of this minority community in the planning and

providing of health services (Lortie & Lalonde, 2012). At the very least, the implementation of the active offer requires a shift in culture in which the use of French is valued.

Successful active offer is built on the awareness, engagement, and empowerment of Francophone communities, inclusion of the active offer in organizations' policies, and integration into the organizational culture, from the board of directors to direct service providers (Bouchard et al., 2012; Lortie & Lalonde, 2012). While implementation of the active offer is challenged by difficulties in recruitment and retention of Francophone staff and limited French-language information and clinical tools, it nevertheless offers an opportunity to improve the access to and quality of health care for Francophone minorities.

Research questions

The main research question guiding this study is “How can health literacy advance the development of health-care designs that are responsive and accessible to language minorities?” Several sub-questions were used to help answer the main question. They are:

- Within health literacy literature, what is the extent and nature of research and practice undertaken on linguistic minorities?
- What are the attributes of organizational health literacy as described in health literacy guides?
 - Is there evidence and if so, what is the evidence for the effectiveness of the application of the guides?

- What are the barriers and facilitators to implementing health-literate designs and strategies?
- What strategies do Ontario health-care delivery organizations use to adapt health care for an active offer of services in French?
- What are the perspectives of health-care administrators regarding the planning and implementation of an active offer of health services in French?

Theoretical Framework

A novel theoretical framework of organizational health literacy addressing changes in organizational commitment, infrastructure, workforce, policies and practices and communication supported this study. There is a growing understanding that health and health outcomes depend on the interplay between an individual's capacities to comprehend and apply health-related knowledge and the health-care system's health-literacy-related demands and attributes (Parker & Hernandez, 2012; Schillinger & Keller, 2011). Health-care organizations can apply a set of strategies to enable patients to optimally access and benefit from and interact with the range of health-care services and entities involved in contemporary health care (Brach et al., 2012; Schillinger & Keller, 2011). The theory of organizational health literacy identifies and describes these strategies that health-care organizations can adopt to improve access, quality, safety, and value of health-care services and to mitigate the negative consequences of limited health literacy (Schillinger & Keller, 2011). Organizations that have committed to improving and redesigning their structures and processes to better accommodate the needs of populations with limited health literacy are health-literate health-care organizations; those

adopt the notion that the health-care system shares the responsibility for promoting health literacy.

Schillinger and Keller (2011) developed several features of health-literate organizations and devised an organizational health-literacy pyramid for central principles and practices with respect to organizational structures, processes and workforce, and information technologies that enable patient care and population management “so as to mitigate the untoward effect of an individual’s limited health-literacy skills on their health and health-care costs.” (p. 6). These features provide concrete actions that organizations can take to create an environment that promotes cultural and linguistic competence and facilitates an active offer of care and services. Transition from health-care organization to health-literate health-care organization involves changes in organizational structures, processes, personnel, and technologies to improve access to and the quality, safety, and value of health-care services. Like active offer, organizational health literacy emphasizes the shift of responsibility from an individual to the health-care system (Palumbo & Annarumma, 2014).

In the pyramid, organizational commitment is the foundation of a health-literate organization (Schillinger & Keller, 2011). The infrastructure level includes support systems such as financial, clinical, and health information technology to support implementation of concrete and practical actions; the workforce level includes training and incentives to implement health-literate practices; the policies and practices level addresses situations in which providers routinely interact with patients and use health-literate practices and procedures that facilitate top level, bidirectional communication. Health-literate health-care organizations make patient communication a priority across all

levels of the organization and across all communication channels (Schillinger & Keller, 2011).

These organizations are aware that many of their systems are poorly designed to accommodate patients with limited health-literacy skills and act to mitigate these deficiencies in the design of care. Health-literate health-care organizations recognize that literacy, language, and culture are intertwined, and their efforts help reduce inequities in care and improve the organization's linguistic and cultural competence (Andrulis & Brach, 2007; Sudore et al., 2009). Thus, these organizations apply *universal precautions*, a public-health approach that ensures effective basic communication for the largest proportion of the population at the lowest cost, whereby clinician–patient communication is simplified to the greatest extent possible and comprehension is not assumed to be achieved unless it is verified. Health-literate health-care organizations pay attention to its most vulnerable populations by recognizing that system-redesign efforts may be needed to further simplify the system to better match the health-literacy demands of the health-care system with the skills of subpopulations (Schillinger & Keller, 2011). Even a modest adoption of most of the features of organizational health literacy will not only help create an organization that is responsive to individuals' needs, but will also make a contribution to improved population health (Brach et al., 2012).

Based on the definition of health-literate organization, I theorized that the concept of active offer, with its requirements of visibility, availability, and accessibility of services is a feature of the health-literate organization that makes it easiest for Francophone patients and their families to access and use services and relevant health information. The organizational health-literacy framework is particularly useful for this

study because it offers a practical lens to view and analyze the adoption and sustaining of active offer at the organizational level.

Methodology

In this dissertation, I adopted the approach inspired by *health services research*—a multidisciplinary field that has been broadly defined as the study of health-care access, cost, and effectiveness, with the purpose of developing successful strategies to organize, manage, finance, and deliver high-quality care (Lohr & Steinwachs, 2002; Nellans & Waljee, 2014). Specifically, health services research studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of health care, and ultimately health and well-being (Lohr & Steinwachs, 2002). Its research subjects include individuals, families, organizations, institutions, communities, and populations. The field of health services research is growing rapidly and developing a wide scope of new methods to apply to health care and health-care delivery questions. Health services research draws on methodology from different social and biomedical sciences, including anthropology, biostatistics, economics, epidemiology, political science, psychology, sociology, and statistics (Maciejewski, Weaver, & Hebert, 2011). However, health services research methods are not limited to methods employed in these disciplines. Because the field of health services research has been developed to facilitate the study of access to care, equity of service provision, and care outcomes, it is unique in its approach to medical and health-care delivery questions (U.S. National Library of Medicine, 2016). Health services research uses study designs, including focus groups and systematic

reviews; and analytic techniques, such as qualitative data analysis and other widely accepted methods. Health services research studies are closely linked to policy considerations, and are credited with the potential to enhance understanding of health-care systems and impact of care delivery on population level (U.S. National Library of Medicine, 2016).

There has been a proliferation of health-services research on issues related to access to care for linguistic minorities (Barr & Wanat, 2005; Bouchard et al., 2010; Bowen, 2001; Drolet et al., 2014; Lasser, Himmelstein, & Woolhandler, 2006; Ponce, Hays, & Cunningham, 2006; Yang & Kagawa-Singer, 2007), quality of care (Beach et al., 2006; Gaskin et al., 2008; Giebel et al., 2015; Miranda et al., 2003; Rounds, McGrath, & Walsh, 2013), and inequity and inequality in health services (Allin, Grignon, & Le Grand, 2010; Derose, Bahney, Lurie, & Escarce, 2009; Derose, Gresenz, & Ringel, 2011; Do, Soelaeman, & Hotchkiss, 2015; Zhong, 2010). Health services research is gaining recognition for its potential to contribute to the improvement of minority health and the reduction of health inequities in health-care settings. Based on the above, health services research has been identified as a good fit for the research presented in this dissertation.

Below follows description of the methods used in this dissertation and each article in more detail.

This research project had three phases, each with its own method. The first phase was exploratory. I conducted a general literature review in order to help me gather information on the issue of health literacy in the context of linguistic minority populations (Chapter 2, Article 1). The second phase, although also exploratory, focused on health systems and the concept of organizational health literacy, drawing on the method of

metanarrative systematic review (Chapter 3, Article 2). The last phase culminated in two empirical studies, one focused on the analysis of qualitative data from the designation plans describing adaptations made by health-care organizations in the pursuit of designation for an active offer of health services in French (Chapter 4, Article 3), and the second study explored perspectives of health-care administrators as part of the focus group dedicated to active offer, its implementation and associated challenges (Chapter 5, Article 4). The following section will highlight the description of methods used at each phase.

Phase 1. Scoping review. The Canadian Institutes of Health Research defines *scoping reviews* as “exploratory projects that systematically map the literature available on a topic” (Grimshaw, 2010). I chose the scoping review method as the most appropriate and feasible method to help me “map” relevant literature on health literacy and linguistic minorities. Following Arksey and O’Malley (Arksey & O’Malley, 2005), the scoping review included five steps: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting results. Several recommendations enhancing this methodology were adopted (Anderson, Allen, Peckham, & Goodwin, 2008; Levac, Colquhoun, & O’Brien, 2010). Specifically, I kept the research question broad: “Within health literacy literature, what is the extent and nature of research and practice undertaken on linguistic minorities?” but limited the scope of the review by using the concepts of *health literacy* and *linguistic minority*.

Phase 2. Metanarrative review. I chose to draw on the metanarrative review method to conduct my second review of literature—on organizational health literacy. *Metanarrative review* is a relatively new method of systematic review developed for

topics that have been conceptualized differently, and studied by different groups or disciplines of researchers (Greenhalgh & Wong, 2013). Because the metanarrative approach is intended for qualitative and mixed-method systematic reviews that identify and explore the diversity of research approaches to a topic (Greenhalgh & Wong, 2013; Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013), it was the best method to study organizational health literacy. According to Greenhalgh and Wong (2013), six principles (pragmatism, pluralism, historicity, contestation, reflexivity, and peer review) should be used to guide the metanarrative review. I'd like to emphasize that I drew on selected principles and did not apply the full-fledged metanarrative review method. Specifically, I used the principles of pragmatism, pluralism, and reflexivity to make sense of organizational health literacy (Greenhalgh & Wong, 2013).

Phase 3. Partnership with decision-makers and empirical studies. There is a growing view in health services research that partnerships between researchers and decision-makers (i.e., collaborative research teams) will enhance the effective translation and use of research results into policy and practice (Hofmeyer et al., 2012; Mitchell, Pirkis, Hall, & Haas, 2009). Empirical studies 1) analyze designation plans of a sample of health-care organizations to identify adaptations made for the provision of health services in French; and 2) evaluate a focus group of health-care administrators to explore their experience and perspectives regarding active offer of health services in French and its implementation. These have been effectuated in academic partnership with the French Language Health Services Network of Eastern Ontario. These studies have been developed in coordination with French Language Health Services Network of Eastern Ontario to meet the needs of this organization with respect to making improvements in

the designation process. French Language Health Services Network of Eastern Ontario approved and supported these studies by providing designation plans of 12 health-care organizations in Ontario and organizing the focus group.

Designation plans include both qualitative and quantitative data, but only qualitative data has been used as part of this study. The qualitative method now plays an increasingly important role in health services research and serves to improve the understanding of complex, real-world phenomena pertinent to the organization and delivery of health care (Bradley, Curry, & Devers, 2007). Designation plans describe strategies and include practices that allow the provision of quality health services in French. Qualitative data covers *administrative strategies* in nine areas: delivery of French language services, methods of identification of Francophone clients, staffing policy, recruitment policy, hiring policy, representation of Francophones on boards of directors and other committees and senior management, the French Language Services Committee, accountability for French language services; *direct services* in five areas: switchboard, reception, physicians, other direct services and human resources plans; and *other services* that affect Francophone clients, including communications strategies, signage, documents and information services, and correspondence. Qualitative data has been extracted and tabulated for further analysis.

Although focus groups remain a somewhat underutilized method in health services research, this method is essential to enable a “real life” view of the phenomena, exploration or description of a problem is are not amenable to quantification (Slaughter, Thiel, Blackstien-Hirsch & Paterson, 1999). Group interviews are often used as a quick and convenient way to collect data from several people simultaneously, but focus group

used in this study was part of the method to explore health-care administrators' perspectives and experiences in order to examine not only what they think but how they think about active offer and why they think that way. Participants were encouraged to talk to one another, exchange anecdotes and comment on each other's experiences and points of view. The discussion was audio-recorded and transcribed for further analysis.

Ethics

This study was eligible for exemption from the Research and Ethics Board (REB) review. The two reviews, the scoping and metanarrative reviews, do not require approval by REB. The two empirical studies, analysis of the designation plans and the focus group with health-care administrators, are exempt from REB based on Articles 2.2. and 2.4. of the latest edition of the Tri-Council Policy Statement (TCPS). According to TCPS, Article 2.2., research that relies on publicly available information does not require REB review when 1) the information is legally accessible to the public and appropriately protected by law or 2) the information is publicly accessible and there is no reasonable expectation of privacy. With regard to the designation plans, exemption from REB review is based on the designation plans being accessible in the public domain, and that the health-care organizations to whom these plans refer have no reasonable expectation of privacy.

The focus group is exempt from REB review per Article 2.4 of the TCPS which says that REB review is not required for research that relies on secondary use of information so long as dissemination of results does not generate identifiable information. The FLSN staff organized the focus group with health-care administrators. Health-care

administrators were attending an event organized by the French Language Health Services Network of Eastern Ontario (FLHSN) which included a discussion on the topic of active offer. Thus, I did not recruit the participants; they were invited by the staff from FLHSN and I was invited to attend the event and facilitate this discussion. The focus group was conducted to inform the work of FLHSN and, as a secondary purpose, was made available to me to make a contribution to my research project.

Furthermore, the TCPS stipulates that some research is exempt from REB review where protections are available by other means. The use of data from the designation plans and the focus group is protected by the agreement with FLHSN (Appendix 4.1), which states clearly that data made available to a researcher can only be used for the purpose of this dissertation and is disseminated in coordination with FLHSN.

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Chapter 2

Linguistic minorities in Health Literacy Research and Practice: a Scoping Review

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Abstract

Background: Health literacy has gained traction as a strategy to reduce inequities in health and health care. However, inequities remain prevalent for minorities with language barriers. Knowing that language may be one of the most influential factors determining access to health services, health promotion, and preventive practices, it is important to investigate language in the context of health literacy and health-care systems.

Objective: To examine the extent and nature of research and practice involving linguistic minorities in the context of health literacy.

Methods: The scoping review method was applied.

Results: Evidence exists for the determinants, correlates, and outcomes of low health literacy, but these associations need to be further studied. Limited evidence exists about the effectiveness of interventions in delivery system redesign, decision support, and care transitions, patient–provider communication, and search and use of health information. This review identifies two research focuses, notably creation of patient-engagement-capable organizations and health-literate system redesign.

Conclusions: Improvements must be realized at the health-system level to make it possible for linguistic minorities to access, understand, and act upon information to maintain and improve health. Interventions to address low health literacy tend to “fix” patients. But there is a need to fix the system.

Keywords: health literacy; linguistic minorities; health systems; health services

Introduction

As an emerging field of study, health literacy made impressive strides in development from a narrow technical term referring to an ability to read medical labels to a multidimensional concept with the potential to improve health and well-being, improve health-care efficiency, and reduce the cost of health-care delivery (Kickbusch et al, 2013; Mitic & Rootman, 2012; Rootman & Gordon-el-Bihbety, 2010). The topic of health literacy is actively researched and practised; the literature expanded rapidly in the past decade, with more than 9,000 PubMed-listed publications to date (Primo December 2015). Several population-based surveys, including the 2003 National Assessment of Adult Literacy in the United States (AHRQ, 2010), the 2003 Adult Literacy and Life Skills Survey in 11 countries (Canadian Council on Learning, 2008), and the 2009–2012 European Health Literacy Survey in eight countries (HLS-EU Consortium, 2012), established a high prevalence of low health-literacy levels in general populations and even lower levels in linguistic minority groups. For example, the International Adult Literacy and Skills Survey in Canada showed that French-language minorities and immigrants scored significantly below the national average in health literacy—which makes these groups more vulnerable than others when navigating health issues and services (Canadian Council on Learning, 2008). The European Health Literacy Survey in Germany demonstrated that respondents who were immigrants scored significantly lower on health literacy measures compared to the general population (Kickbusch et al., 2013). Following these surveys, and amid mounting evidence that low health literacy can have far-reaching consequences for an individual’s health, the health-care system, and the society at large (Berkman et al., 2011; AHRQ, 2010; The Joint Commission, 2007),

health literacy has gained traction as a strategy to provide patient-centred care and to reduce disparities (Hasnain-Wynia & Wolf, 2010). However, inequities remain prevalent—particularly for minorities with language barriers. There is compelling evidence that language may be one of the most influential factors determining access to health services, health promotion, and preventive practices (Bowen, 2001; Britigan, Murnan & Rojas-Guyler, 2009; Hernandez, 2012; Leis & Bouchard, 2013; Marrone, 2007; The Joint Commission, 2007; Zanchetta & Poureslami, 2006; Zun et al., 2006). It is thus important to investigate and discuss language in the context of health literacy and health-care systems. To my knowledge, this is the first scoping review focusing on linguistic minorities that identifies avenues for research and application of health literacy. This review synthesizes a wide range of research literature and, although general in focus, provides unique insights into the extent and scope of research and practice of health literacy, and proposes research focuses to help improve health and health care for linguistic minorities.

Methods

Based on Arksey and O'Malley (2005), this scoping review included five steps: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting results. I adopted several recommendations by Levac and colleagues that enhance this methodology (Levac et al. 2010). Specifically, the research question was kept broad: “Within health literacy literature, what is the nature of research undertaken on linguistic minorities?” The number of concepts was limited to *health literacy* and *linguistic minority* in order to clarify and limit the scope of this dissertation; the quality of included reports was

assessed; a numerical summary and qualitative thematic analyses were incorporated.

Search Strategy

Four electronic databases were searched on December 23, 2014: OVID (Medline) (1946 to December Week 4, 2014), EMBASE (1974 to 2014 December 23), PsycINFO (1806 to December Week 4 2014), and PubMed. A sensitive search strategy was constructed with help of a librarian and conducted by filtering all articles, except those containing key terms, including “health literacy,” “minority populations,” “linguistic minorities,” “language barrier,” “communication” and variations of these terms. Detailed search strategy can be found in Figure 2.1. Manual searches of bibliographies of key relevant articles, websites of organizations, and journals, were conducted in January 2015.

Eligibility Criteria

Studies in English or French were included if they explicitly mentioned health literacy and focused on identifiable linguistic minority groups. Although all races, ethnicities, and cultural groups were eligible, only studies focusing on linguistic groups in a minority situation were included. No age limit, time frame, country, or study design restrictions were imposed. However, original research studies that provided details about methods and results, and included general population, were given preference. Relevant documents were imported to Mendeley (version 1.12.1).

Quality Assessment, Data Extraction, and Analysis

The title, abstract and keywords were screened for relevance and full texts were retrieved for further screening. After study selection, the quality of all reports was

assessed for fitness, reliability, and validity using tools from the Critical Appraisal Skills Programme (<http://www.casp-uk.net>). The majority of included articles had been through a formal publication peer review process. Because this review also included grey literature, quality assessment helped ensure that all included reports met the predefined standard of quality. Using an Excel spreadsheet, data extraction was completed for selected studies. Studies were grouped by theme and an abstraction template was customized for each group. Themes were derived from the thematic analysis of selected studies combined with the expanded chronic care model (Barr et al., 2003). The model aims to improve the quality of care and patient outcomes by achieving productive interactions between an informed and activated patient and a prepared, proactive health-care system. These interactions are facilitated by four interdependent elements of a health-care process: 1) self-management support, 2) delivery system design, 3) decision support, and 4) clinical information systems (Wagner et al., 2001; Barr et al., 2003). Elements 1–3 were used to organize the review. A logic model from a systematic review of health literacy (AHRQ, 2010) was used to help synthesize findings of the relationship between low health literacy and outcomes, and factors influencing health literacy.

Results

Figure 2.2 shows the PRISMA flow diagram with numbers of included and excluded references at each step of the review process. The full texts of 158 references were screened against eligibility criteria. Through this process, 54 articles comprising a total sample of 42,807 participants from five countries were included in the review. Reasons for excluding 104 references at full-text review were difficulty to identify linguistic minority group when not clearly stated (55); focus was not on health literacy or

linguistic minority or minority group was excluded from the analysis (21); reports were repeats of included studies and did not bring new information (10); full texts were not located (8); and the rest were excluded because they were in languages other than English or French, were commentaries, or were judged not relevant.

Critical appraisal revealed that the average score for all included references was 7.7 out of a possible 10, suggesting a fairly high quality of individual reports. All reports fit the purpose of this review and provide a wide range of research literature. Evidence exists for prevalence, determinants, correlates, and outcomes of low health literacy. Limited evidence was found for delivery system design and decision support, patient–physician communication, and search and use of health information. Common limitations included convenience sampling and representativeness of samples, self-reported data, and limited generalizability of individual studies, thus affecting the external validity of findings.

The earliest relevant record captured was published in 1995; a large number, 37 (70%), were published in 2011–2014. This substantial increase in the publishing rate in the past five years may be representative of a growing interest to the topic of linguistic minorities in health-literacy literature. The majority of articles, 40 (76%) were from the United States, nine from Canada, and the rest were from China, Australia, and Israel. Although some 26 linguistic minority groups were identified, more than half of the reports included Spanish-speaking minorities also described as *Hispanics* and *Latino*. In health-literacy literature, this group is likely to be the most researched to date. Participants were adults ages 18 to 60, typically of lower socioeconomic status. Studies were conducted in organized health-care settings such as hospitals, community-based,

primary care, or family medicine clinics and, in fewer cases, in tertiary-care facilities.

More than half of all studies covered screening, diagnosis, and care of chronic diseases.

Based on the information extracted from studies and drawing on the care model, results below are organized under five themes: 1) definition and theoretical frameworks, 2) prevalence, determinants, correlates, and outcomes of low health literacy; 3) self-management support and delivery-system redesign; 4) decision support and care transitions; and 5) patient–physician communication, search, and use of health information. In addition, three cross-cutting themes were identified and are addressed separately: inequities, health systems, and measurement of health literacy.

Definition and Theoretical Frameworks

Five studies discuss the definition of health literacy in linguistic minority context. Although health literacy is commonly described as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000), there is a growing sentiment that this definition should be revised to reflect complex interactions among the individual, language, culture, and health-care system (Andrulis & Brach, 2007; Masinda, 2007; Nishita & Browne, 2013; Zanchetta et al., 2013). Among Canadian Francophones, health literacy is a multifaceted construct that involves critical awareness of one’s condition within social, cultural, physical, and political environments (Zanchetta et al., 2013). Authors suggest that the identity of minorities should be linked to health literacy through incorporation of values, beliefs, and health practices that are mediated by language and intertwining social, cultural and historical processes.

Two studies explain health literacy in linguistic minorities. The Health Literacy Model For limited English proficiency populations depicts a causal relationship between health literacy and health outcomes for limited English proficiency populations (Yip, 2012). Because it applies to communications platforms such as social media, its wider utilization requires further adaptation. Andrulis and Brach (2007) propose an interrelationship between literacy, language, and culture and identifies key strategies for clinicians and health-care systems to support patients and deliver effective clinical care. Health literacy also has been included in the newly developed framework on transitional care for linguistic minorities (Nishita & Browne, 2013). The framework explores complex interrelationships that impact transitions between hospitals, home, and other facilities, and illustrates how health literacy and other factors can influence these processes.

Prevalence, Determinants, Correlates and Outcomes of Low Health Literacy

Thirteen studies comprising 32,126 participants from the US, Canada, and Australia examined health literacy in linguistic minority groups. Prevalence of low health literacy (quantified as *limited*, *inadequate*, or *marginal*) ranged between 1.5% and 74% (median 37.3%, interquartile range 45%) and varied by age, language, measurement, and population (general vs. specific). Health literacy increases with age—82.6% in those aged 70+, but decreases when measured in English. More than half of studies (8 out of 13) tested participants' level of health literacy in minority languages (e.g., Spanish, Chinese) and reported markedly higher health literacy than when tested in English. Six of 13 studies recruited specific populations: those with chronic diseases (Heinrich, 2012; Shaw et al., 2012; Treloar et al., 2013), those with sexually transmitted infections (STIs)

(Champion et al., 2013), Medicare enrollees (Gazmararian et al., 1999), and patients in an emergency department (Brice et al., 2008). A comparison of studies with general vs. disease-specific populations showed that the latter were likely to have higher prevalence of low health literacy (61.7% vs 65% respectively).

Twenty-one studies describe the determinants and effects of low health literacy. Language stands out as a powerful determinant of health literacy (Tsai et al., 2014; Sentell & Braun, 2012; Fang, Machtiger, Wang, & Schillinger, 2006; Jafri, 2012; Todd & Hoffman-Goetz, 2011; Garbers et al., 2009; Sudore et al., 2009; Leyva et al., 2005). The relationship between language and health literacy is complex and in linguistic minorities is influenced by acculturation and immigration. Several studies found that acculturation is a significant predictor of health literacy (Ciampa et al., 2013; Fry-Bowers et al., 2014; Pineda, 2014; Todd & Hoffman-Goetz, 2011; Geltman et al., 2013). This association points to an elevated risk of low health literacy among minorities with limited proficiency in English (Todd & Hoffman-Goetz, 2011). Being older than age 65, non-White ethnicity, female gender, no high school education, and low income are risk factors for low health literacy in linguistic minorities (Todd & Hoffman-Goetz, 2011; Ciampa et al., 2013; Ng & Omariba, 2010). Language appears to mediate the relationship between education and health literacy. Education in the minority's first language tends to predict performance on health-literacy tests; well-educated minorities have higher health literacy, even when tested in English (Todd & Hoffman-Goetz, 2011; Leyva et al., 2005). External factors, such as limited social networks, lack of literacy practices at home and at work, and having a mother who did not complete high school, are associated with low health literacy (Zanchetta et al., 2013; Ng & Omariba, 2010).

Low health literacy tends to correlate with knowledge deficits, poor communication skills, and poor adoption of health-promoting and preventive behaviours (Champion et al., 2013; Fang et al., 2006; Flores & Acton, 2013; Jafri, 2012; Yee & Simon, 2014; Garbers et al., 2009; Sudore et al., 2009). These associations are more pronounced in linguistic than in ethnic minorities with low health literacy.

Low health literacy is associated with poor health status (Chun Yu et al., 2009; Ng & Omariba, 2010; Sentell & Braun, 2012), poor quality of life (Wang et al., 2013), poor glycemic control (Schillinger et al., 2002), kidney diseases (Lora et al., 2011), poor oral health, and higher tooth decay (Geltman et al., 2013). However, directionality of this association is inconsistent across the studies. For example, Chun Yu et al. and Sentelle et al. found that low health literacy was associated with poor health status, but Ng and Omariba (2010) found an association with good health status in immigrant populations. The relationship appears to be moderated by length of stay: the more recent the person's immigration, the better their health status.

The relationship between health literacy and use of health services is illustrated by studies of screening for breast cancer (Garbers et al., 2009; Jafri, 2012) and cervical cancer (Flores & Acton, 2013). Language barriers and cultural beliefs act as deterrents to cancer screening in linguistic minorities. It is not uncommon for women to neglect screening in the absence of severe symptoms (e.g., pain).

Self-Management Support and Delivery System Redesign

Seven studies report on self-management support and delivery-systems redesign for monolingual or bilingual minority patients/clients who prefer using their mother tongue in health-care settings. Studies included Hispanic, Korean-American, and Indo-

Asian Canadian adults 18 years and older comprising 1,167 participants and were conducted in community-based clinics and primary-care practices. Programs were designed to address lack of knowledge and a mastery of information about diseases and adherence, and some also included health-system-related factors, such as communication with health-care providers. Bilingual and bicultural health educators, nurse practitioners, social workers, clinical psychologists, dieticians, and pharmacists delivered interventions. Three of the seven interventions included control groups (Servellen et al., 2003; Kim et al., 2013; Calderon et al., 2014) and two studies included an evaluation component (Servellen et al., 2003; Swavely et al., 2014). Interventions lasted an average of 7.7 weeks and was delivered in groups (up to 7 people) and/or individually. Programs included didactic and interactive group experiences and, in some instances, case management or telephone counselling. One study reported using a teach-back technique (Swavely et al., 2014).

The process of developing a tailored service or program often included several initial designs and repeated evaluation feedback loops with the use of patient and provider focus groups (Calderon et al., 2014; Swavely et al., 2014; Ramos & Alegria, 2014). Cultural adaptations of educational materials and self-management tools were performed in a structured 4- to 5-step process (Jones et al., 2011; Ramos & Alegria, 2014) and often included reductions in the number of sessions, addition of visual aids and relevant metaphors, and feedback from key stakeholders (Jones et al., 2011; Ramos & Alegria, 2014; Swavely et al., 2014; Servellen et al., 2003).

Overall, interventions were effective and resulted in improved outcomes, including increases in health-literacy levels and improvements in physiological outcomes

(e.g., blood pressure control, blood sugar level) (Swavely et al., 2014; Kim et al., 2013; Servellen et al., 2003; Ramos & Alegria, 2014). Tailored and simplified instructional support delivered in patients' language of preference enabled and empowered them to greater participation in their care (Servellen et al., 2003).

Decision Support and Care Transitions

In total four studies were included that examined the informed consent process (Evans et al., 2012; Tamariz et al., 2013), decisional conflict in treatment decisions (Trupin et al., 2012) and transitional-care planning (Nishita & Browne, 2013). Studies included older chronically ill adults from Chinese, Spanish, Japanese, Filipino, and Native Hawaiian minorities (Trupin et al., 2012; Tamariz et al., 2013; Nishita & Browne, 2013).

Informed consent is discussed in the context of clinical trials—where it is perceived as problematic due to the lack of advance knowledge about treatments, limited trust in research procedures, and challenges with cultural literacy (Evans et al., 2012; Tamariz et al., 2013). Several strategies that could improve the consent process were identified, including representation of minorities on health-care staff, use of minority languages with prospective minority participants, taking more time, and engaging in one-on-one interaction with study participants. Although issues with informed consent in health-care settings have been mentioned, these have not been addressed in detail in the selected studies.

The concept of *decisional conflict* is the extent to which patients lack adequate information and support to make an informed health-care decision (Trupin et al., 2012). Because both low health literacy and communication in a language other than English are

associated with greater levels of decisional conflict in treatment decisions, providing decision aid tools aimed at persons with low literacy and promoting shared decision-making may lead to treatment decisions that align with patient preferences and improve health outcomes. Care providers and health-care systems serving minority populations must account for care preferences, low health literacy, culture, and linguistic competence to improve the capacity for decision-making and engagement in planning the transition from hospital to home (Nishita & Browne, 2013).

Patient–physician Communication, Search for and Use of Health Information

Eight studies report on patient–physician communication, and search for and use of health information. Low health literacy and limited proficiency in English are identified as potent barriers to making a medical appointment, participating effectively during the medical encounter, and recalling and complying with follow-up instructions (Britigan, Murnan & Rojas-Guyler, 2009; Poureslami et al., 2011). Some suggest that health literacy may be able to act as a buffer against poor patient–physician communication when patients and physicians speak the same language (Sudore et al., 2009). However, in language-discordant encounters, adequate health literacy does not act as a buffer.

Health literacy may be a powerful moderator for health-information-seeking and use in linguistic minorities: the lower health literacy and language acculturation are, the more likely a person is to engage in independent seeking from sources other than their health-care providers and sharing of health information (Kontos et al., 2011). Linguistic minorities often turn to caregivers from local communities who can speak their language (Poureslami et al., 2011) and to the Internet to seek and share information and to engage

in online discussions instead of talking to their providers (Britigan, Murnan, Rojas-Guyler, et al., 2009; Kontos et al., 2011; Mesch et al., 2012; Rooks et al., 2012; Zanchetta et al., 2013).

However, these strategies can result in potentially bad consequences. For example, there is a risk of overuse of over-the-counter medications and underuse of preventive or rehabilitation care due to the prevalence of health beliefs that are not concordant with national recommendations (Kontos et al., 2011) and self-treatment of illnesses (Rooks et al., 2012) in linguistic minorities. All studies point to the lack of health information in minority languages. Information that exists is complex and difficult to understand, which may discourage future searches (Poureslami et al., 2011; Zanchetta et al., 2013). Although provision of tailored health information is necessary and likely to increase awareness and health-literacy skills, it may not help linguistic minorities act on health information. Comfort with speaking English (in contexts where English is a dominant language), longer residency or higher acculturation, and an effort by the health system to contextualize culture-specific health information would provide linguistic minorities with the confidence to use health-care safely and help build skills (Thomson & Hoffman-Goetz, 2012).

Cross-Cutting Themes: Inequities, Health Systems and Measurement of Health Literacy

Terms describing inequality such as *disparity* and *inequity* figure prominently in the literature on health literacy in linguistic minorities. Inequalities often include lower health status (Heinrich, 2012; Gansler et al., 2005); lower standard and quality of care (Penaranda et al., 2012; Beach, Cooper, & Robinson, 2005; Gansler et al., 2005); limited

access to and use of high-quality health care, including preventive and screening services and treatment (Heinrich, 2012; Penaranda et al., 2012; Gansler et al., 2005; Fang et al., 2006; Britigan, Murnan, Rojas-Guyler, et al., 2009; Ramos & Alegria, 2014; Wang et al., 2013). Health literacy is viewed as both a cause of (Gansler et al., 2005; Treloar et al., 2013) and a remedy to (Poureslami & Rootman, 2007; Simon et al., 2014) inequalities. Proposed strategies for reducing inequalities focus on health-care-system-level factors and include improvements in the practice of patient-centred care and cross-cultural training of health-care professionals (Poureslami & Rootman, 2007); increasing accessibility and use of medical care via increased self-efficacy of patients with low health literacy (Wang et al., 2013); standardizing treatment protocols (Fang et al., 2006); and, improving access to and use of health information in order to empower linguistic minorities (Rooks et al., 2012). Benefits of improving access to health information are described as particularly far-reaching in reducing individual-level communication inequalities and patient–physician interaction, and reducing the costs of illness by avoiding preventable health conditions (Rooks et al., 2012).

Health literacy is considered integral to patient-centred care, partnerships and shared decision-making, patient engagement, and patient activation (Trupin et al., 2012; Lora et al., 2011; Swavely et al., 2014; Fang et al., 2006; Jewell et al., 2010; Britigan, Murnan & Rojas-Guyler, 2009; Servellen et al., 2003; Penaranda et al., 2012). It is described as a prerequisite to fully engaging patients in prevention and self-management activities (Yee & Simon, 2014; Jacobs et al., 2014; Nishita & Browne, 2013; Rooks et al., 2012; Fry-Bowers, et al. 2014). However, application of health literacy appears to be insufficient in health-care settings—as evidenced by literature on self-management

support, delivery-system redesign, decision support, and care transitions. There are examples of undertreatment or withholding of therapy among eligible linguistic minority patients due to barriers to communication with providers and lack of comprehension (Fang et al., 2006), lack of compliance with discharge instructions given in written form, difficulties with consent procedures (Williams et al., 1998; Poureslami et al., 2011), and limited involvement of linguistic minority patients in decision-making (Trupin et al., 2012). There is a need at the health-care-delivery level and beyond for coordinated, systematic, comprehensive efforts and culturally tailored programs that address knowledge, attitudes, and behaviours related to prevention and treatment (Heinrich, 2012; Penaranda et al., 2012; Lora et al., 2011).

Health-literacy measures used most frequently in selected studies include Test of Functional Health Literacy in Adults (TOFHLA) and derivatives (including the short form in Spanish and Vietnamese), the Rapid Estimate of Adult Literacy in Medicine (REALM) and derivatives in Chinese, the Newest Vital Sign, and the Short Assessment of Health Literacy for Spanish-speaking Adults. There are advantages to using these standard and validated tools to allow comparisons of health literacy levels. However, these tools are often regarded as inadequate and inaccurate with linguistic minority groups because they are not reliable predictors of self-efficacy (Shaw et al., 2012) or oral competency when administered in English (Zun et al., 2006). This review identified two studies that attempted translation of S-TOFHLA and REALM (Han et al., 2011) and also the development and validation of a high blood pressure health-literacy scale for Korean Americans (Kim et al., 2012). Although translation did not lead to a valid assessment of health literacy, the high-blood-pressure scale proved to be reliable and valid. Difficulties

with translation of REALM and TOFHLA have been reported in studies that are not part of this review. For example, earlier efforts to translate REALM into Spanish and TOFHLA into Canadian French were unsuccessful (Nurss et al., 1995; Canadian Council on Learning, 2008). However, more recent translations and validation of S-TOFHLA into Turkish, German, Italian, and Swiss French were successful (Connor et al., 2013; Eyüboğlu & Schulz, 2015). Some suggest that assessments of health literacy in non-English-speaking minorities require systematic approaches and measures of comprehension of commonly used context-specific English terms (Han et al., 2011).

Future Research Directions

Based on discussions in the reviewed literature, this scoping review identifies two main focuses for research and interventions to improve health literacy in linguistic minorities. These are creation of patient-engagement-capable health-care systems and health-literate system redesign. Drawing on the work of Carman et al. (2013) in patient engagement and propositions for the role of health system (Fang et al., 2006), we define patient-engagement-capable health-care systems as those that are both responsive to minority populations and comprehensive in their systemic approach to bringing health-care delivery to an acceptable health literacy level to effectively assist and reach out to linguistic minority populations. *Health-literate system redesign* refers to organizational structures and processes aimed at improving access to, and quality of care for, linguistic minority populations. These two areas of improvement, subtopics associated with them, and suggested research questions, are described in detail in Table 2.1.

Discussion

In this article, we presented results of the scoping review of literature on health literacy in linguistic minority populations published over the last 20 years. The amount of original research in health literacy involving linguistic minority populations is growing, but is limited at this time. Reviewed literature is recent with three quarters of the included studies published within the last five years addressing mostly prevalence, determinants, correlates, and outcomes of low health literacy in linguistic minority populations. There is a paucity of studies addressing patient–physician communication, search and use of health information, definitions and theoretical frameworks, measurement of health literacy, self-management support and delivery system redesign, decision support and care transitions. These present important opportunities for future research and practice.

Prevalence of low health literacy is estimated to be high in linguistic minority groups, but it should be interpreted with caution. Prevalence rates have been established using primarily patient/disease-specific populations (Heinrich, 2012; Shaw et al., 2012; Treloar et al., 2013; Dimmitt Champion et al., 2013) and might have been overestimated in linguistic minorities because health literacy tends to be suboptimal in all patient groups (Adkinson et al., 2013). In addition, variations and limitations in the measurement of health-literacy tools, and the language in which they were administered, might have contributed to inaccuracies of its assessment in linguistic minority populations (Jewell et al., 2010; Mas et al., 2014; Ng & Omariba, 2010; Penaranda et al., 2012; Shaw et al., 2012; Simon et al., 2014).

The studies reviewed here showed that the language barrier and, specifically, low proficiency in English, is a risk factor for low health literacy in linguistic minorities.

While the association between risk factors, health literacy, and outcomes is clearly demonstrated, the specific hypothesis about the cause of low health literacy and its outcomes has yet to be validated. A number of factors mediate the risk factor-health literacy and health-literacy-outcomes associations in the context of linguistic minorities, including immigration, acculturation, culture, and beliefs. The complex interactions among these factors and the potential impact of health literacy on outcomes remain to be systematically studied.

The use of the Internet and other consumer information technologies are on the rise among selected linguistic minority groups (Talosig-Garcia & Davis, 2005; Kontos et al., 2011; Gibbons, 2011). On one hand, consumer information technologies presents an opportunity to address patient activation/engagement, access to care, health education, self-management support, and minority patient recruitment into clinical trials (Gibbons, 2011). On the other hand, Neter and Brainin (2012) warn that consumer information technologies are likely to reinforce existing social differences and bring on new inequities in digital health information. Considering that little research has been done to place patient-provider relationships and access to and use of health information by linguistic minorities in the broader context of health literacy, further research in this area is needed.

Our review identified a number of small-scale initiatives targeting improvements in care redesigns at a service or program level for linguistic minority patients. These improvements include linguistic and cultural adaptations to existing services for specific chronic diseases. Although beneficial to help build effective self-management skills and improve knowledge and attitudes toward health, diseases and their management, these improvements focus primarily on the health-literacy deficiencies of patients and do not

address systemic issues in health service design and care provision. Examples included in this review demonstrate that translating and adopting services for linguistic minorities requires considerable resources. Many organizations will likely benefit from the spread of successfully tested adaptations instead of investing resources to develop new ones. However, due to a lack of evaluation of existing adaptations (Shohet & Renaud, 2006), their spread is limited at this time. It remains unknown whether services and programs that have been tested persist beyond the pilot phase, whether they result in improved patient outcomes in the long term, and whether they could be applied in the context of other health issues.

Taken together, the studies reviewed here suggest that the design of health-care systems may not be conducive to improving health literacy and health outcomes in linguistic minorities. It seems intuitively obvious that, in order to realize improvements in health-literacy level in this vulnerable population, research should focus on health systems and on the provision of care that is sensitive to the needs of linguistic minority populations. Directions for research proposed in this paper are aligned with the growing interest and motivation for organizational health literacy (Brach et al., 2012; Brach et al., 2014; Koh et al., 2013; Koh & Rudd, 2015). In the US, health literacy has been incorporated in the enhanced CLAS in order to promote the cultural and linguistic competence of health-care delivery organizations (Koh et al., 2014). The CLAS includes provisions supported by accreditation standards targeting improvements in communication, cultural competence, patient-centred care, and provision of language-assistance services. The Institute of Medicine has introduced the term *health-literate organization* and a guideline to help health-care organizations develop health-literate

systems of care (Brach et al., 2012). Although the guideline might need further refinement, the idea is that health-literate organizations can create an enabling environment where everyone contributes to and benefits from the health-care system. Another approach that advocates for the involvement of all health-care professionals and all patients is that of *universal precautions* (Brega et al., 2015; Brown et al., 2004). The design and delivery of health care is based on the assumption that all patients have some difficulty with health literacy at some point in the process of care. A newly released universal precautions toolkit for primary care practices includes guidelines to address linguistic barriers with non-English-speaking patients (Cifuentes et al., 2015). Whether organizations choose the IOM ten attributes, the universal precautions, CLAS, or a combination of these, linguistic minority patients for whom these organizations are responsible are likely to benefit from the changes. Making changes will require time, resources, and knowledge of quality improvement, as evidenced by testing of the Health Literacy Universal Precautions Toolkit (DeWalt et al., 2011).

There are several limitations to our scoping review. Despite its specific focus on linguistic minorities, this review is rather general in its focus. Although we located and summarized 54 various reports on the topic, our synthesis precludes a comprehensive assessment of the diverse field of health literacy. Due to time and cost considerations, we included only English- and French-language publications. Confining the research to English and French and also a lack of indexing by keywords may have led me to miss some relevant research. The majority of the studies in this review included Hispanic population of the US and, therefore, the results may have limited applicability to the Francophone population. Despite a fairly high quality of evidence selected for this

review, the cross-sectional nature of the data and analyses in most studies limit the understanding of causalities and changes that occur over time.

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Chapter 3

Organizational Health Literacy: Review of Theories, Frameworks and Guides

This article has been submitted to the *BMJ Health Services Research*

Abstract

Background: Organizational health literacy refers to a series of measures that health-care organizations can take to make it easier for people to navigate, understand, and use information and services to take care of their health. Several organizational health literacy guides have been developed to assist organizations to transform to health-literate health-care organizations.

Objective: We reviewed the content of these guides and associated implementation studies. The central questions addressed in this paper are: 1) What are the attributes of organizational health literacy? 2) Is there any evidence of the effectiveness of application of organizational health literacy? 3) What are the barriers and facilitators to implementing organizational health literacy? and 4) How do organizational health literacy guides address the health-care needs of linguistic minorities?

Methods: Drawing on selected principles of metanarrative review and the Model for Improvement, we reviewed 44 publications, of which 14 dealt with the theories and operational frameworks of organizational health literacy, 19 presented organizational health literacy guides, and 11 addressed guided implementation of organizational health literacy.

Results: Five theories and six operational frameworks of organizational health literacy have been identified. Organizational health literacy is envisioned from a population health perspective but conceptualized as a safety- and a quality-improvement issue. Variations in theories and frameworks relate to differences in scopes, context, and purpose. Six health-literacy dimensions and nine quality-improvement characteristics

were reviewed and recorded for each organizational health literacy guide. Existing organizational health literacy guides miss specific recommendations for minority-friendly practices. Evidence about the effectiveness of organizational health literacy is limited at this time.

Conclusions: Further development of the concept of organizational health literacy requires a strong and a clear connection between its vision and implementation. Future conceptualization and operationalization of organizational health literacy has to reflect clinical and financial perspectives for organizations to embark on this transformative journey.

Keywords: health literacy; health-literate organization; quality improvement.

Introduction

Organizational health literacy has emerged amid the discussions about the role of health-care systems in addressing the challenge of predominantly low levels of health literacy in populations (AHRQ, 2010; Canadian Council on Learning, 2008), the need to address the quality of care and to investigate the context of health-care delivery and organizations, and health literacy practices (Baker, 2006; Brach et al., 2012; Hernandez, 2012; Koh & Rudd, 2015; Palumbo & Annarumma, 2014; Rudd, Rosenfeld, & Gall, 2007). *Health literacy* is commonly described as an individual trait, which consists of the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2000). Suggestions have been made that patients' health-literacy level directly affects the quality of health care provided to them (Andrulis & Brach, 2007; Penaranda, Diaz, Noriega, & Shokar, 2012; Schillinger et al., 2003). Lack of involvement of patients in decision-making, difficulties with informed consent, and patient-provider communication and discharge instructions have been reported for patients with limited health literacy—especially those with language barriers (Fang, Machtiger, Wang, & Schillinger, 2006; Heinrich, 2012; Ishikawa & Yano, 2008; Trupin, Barton, Evans-Young, Imboden, & Gross, 2012; Wang et al., 2013). Research demonstrates that health systems remain less responsive to patients with limited health literacy and the concern prevails that minorities with language barriers receive a lower standard of care compared to nonminorities (Paasche-Orlow, Schillinger, Greene, & Wagner, 2006; Paasche-Orlow, 2011; Penaranda et al., 2012). Patients' needs may be better met if health-care organizations transformed to more health literacy responsive ones delivering care in a way that supports health literacy best

practices and does not require advanced health-literacy skills of the patients (Altin, Lorrek, & Stock, 2015; Institute of Medicine & Committee on Quality of Health Care in America, 2001; Koh, Brach, Harris, & Parchman, 2013; Koh, Gracia, & Alvarez, 2014; Nielsen-Bohlman, Panzer, & Kindig, 2004; Palumbo & Annarumma, 2014). Proponents of organizational health literacy emphasize that challenges experienced by patients in the care process can only be understood within the organizational context of care because patients' ability to understand health information and to navigate the care-seeking process are related to the demands that health-care systems place on them (Baker, 2006; Koh & Rudd, 2015; Nutbeam, 2008; Paasche-Orlow et al., 2006; Rudd, 2005; Rudd & Anderson, 2006; Rudd, Groene, & Navarro-Rubio, 2013). Therefore, the organizational context where care is provided (e.g., simplified interface with health-care procedures, bilingual staff, and easy-to-understand information) may compensate for patients' limited health literacy (Kowalski et al., 2015). According to this perspective, health-care organizations are called to embrace health literacy as a safety and quality issue and to integrate it into organization's overall quality-improvement plan (Koh et al., 2013; The Joint Commission, 2007).

Several organizational health literacy guides have been developed over the past decade to assist organizations to transform from health-care organizations to health-literate health-care organizations. They include guided assessments of health-care settings for barriers to health literacy and recommendations for enhancing organizational health literacy. However, the content of these guides and their use have not yet been reviewed systematically. The current project aimed to review the organizational health literacy guides and also explore: 1) the attributes of organizational health literacy as described in

the guides, 2) the evidence for the effectiveness of the application of the guides, and 3) the barriers and facilitators to implementing health-literate designs and strategies. We also investigated how organizational health literacy guides addressed the health-care needs of linguistic minorities. Originally we set out to review health literacy guides and implementation studies. Our preliminary search turned out literature that included discussions about theoretical aspects of organizational health literacy. Intrigued by this finding, we added a question framed as, what theories and theoretical frameworks inform the concept of organizational health literacy?

With the understanding that application of health-literate designs requires a change in organizations' practices and processes, we drew on the Model for Improvement (Langley et al., 2009) and associated Plan-Do-Study-Act-based sequence to provide overall structure for the paper and to organize findings. The advantage of using the model is that it is highly adaptive, minimally prescriptive, and emphasizes empowerment, learning, and growth of knowledge among the users (Langley et al., 2009). The sequence for improvement built in the model includes four stages: developing a change, testing a change, making change part of the routine, and disseminating a change (Hernandez, 2012). The first three stages were adopted for the study and informed the content analysis of selected literature. The current study used an adaptation of the metanarrative review suitable where existing studies have been conceptualized differently and conducted by different researchers (Greenhalgh & Wong, 2013; Greenhalgh et al., 2005), and offers a means for synthesizing a range of literature. It provides unique insights into the extent and scope of research and implementation of organizational health literacy and discusses recommendations to help improve the delivery and quality of care. These findings have

relevance for researchers, health-care administrators, and quality-improvement specialists whose mandates include evaluation of quality of care and continuous quality improvement.

Methods

Drawing on principles of pragmatism, pluralism, and reflexivity of metanarrative review (Greenhalgh & Wong, 2013; Greenhalgh et al., 2005), a systematic search of literature was combined with narrative syntheses and analyses. A literature search in Medline (Ovid), Embase (Ovid), Healthstar (Ovid), and PubMed was performed in December 2015. Database searches were supplemented by bibliographic hand searches and grey literature. An initial search was conducted in September 2015 using ten keywords (organization, leadership, planning, workforce, patient, engagement, communication, navigation, education, and health system) combined (using Boolean operators and, or) with the term *health literacy*. This produced a list of 48 eligible articles. Full texts of 15 of them were reviewed to help refine the search strategy, and a new search was performed. A detailed search strategy is presented in Figure 3.1. All search results were then exported to Mendeley reference manager software and duplicates were removed. The search results are shown in Figure 3.2.

Studies were eligible for inclusion if they related to health literacy at organizational or system level and were published in English or French. No time limit, country, or study design restrictions were imposed. However, original research studies that provided details about methods and results were given preference. Each report was screened in two stages. In the first stage, titles and abstracts were reviewed for potential

relevance. In the second stage, full texts were obtained for further evaluation and screened to determine eligibility.

A content analysis was performed and selected articles were clustered by study topics into the following categories: 1) studies addressing the development of theory and concept of organizational health literacy), 2) organizational health literacy guides developed to inform the transition from health-care organization to health-literate health-care organization, and 3) studies reporting on the application of organizational health literacy guides. The guides were scanned for attributes of organizational health literacy conceived as health-literacy dimensions and quality improvement characteristics. To review and present findings about health-literacy-related content, we drew on six dimensions of health literacy developed by the New Zealand Ministry of Health (Ministry of Health, 2015).

The following health-literacy dimensions were captured for each guide: access and navigation, communication, consumer involvement, workforce, leadership and management, and the needs of the population. The following quality improvement characteristics were recorded for each guide: forming teams, setting specific aims, assessment/gap analysis, establishing measures, communicating/raising awareness, developing health-literacy improvement plan, testing changes, tracking progress, sustaining efforts, and scaling up.

Results

The database search, combined with reference tracking and grey literature, resulted in the initial identification of 513 relevant publications. Based on the application of the inclusion criteria to the full texts, 44 publications were retrieved, of which 14

explicitly dealt with the theories and operational frameworks of organizational health literacy, 19 presented the health-literacy guides, and 11 addressed the implementation of organizational health literacy and the use of guides.

Theories and Operational Frameworks of Organizational Health Literacy

Fourteen included studies have been identified as conceptual papers on organizational health literacy. Figure 3.3 lists these papers and presents a conceptual map of organizational health literacy. From this overview, it became apparent that conceptual approaches to organizational health literacy focus on the “what” and the “how”, where “what” represent theories that help create vision and the “how” propose operational frameworks to support action on organizational health literacy.

The “What” of Organizational Health Literacy

Five theories supporting organizational health literacy have been identified (Figure 3.3). These theories envision organizational health literacy primarily within population health and public-health perspectives. An ecological perspective has been proposed to guide needed transformations in the organization and delivery of health care to address limited health literacy (McLaren and Hawe, 2005). From this perspective, limited health literacy is viewed as a vulnerability that coexists and interacts with other social vulnerabilities, and that interventions addressing an array of influences on peoples’ lives are needed.

The Rawls’s theory of justice applies egalitarian concepts of justice to health care; i.e., each person should have equal rights to health-care services and their delivery (Coughlan, Turner, & Trujillo, 2013). The theory is aligned with an integrated approach

to the organization of health-care delivery proposed by Andrulis and Brach (2007), who recommend integration of health literacy, cultural competence, and language-assistance strategies to create culturally and linguistically competent health care. Lack of integration forces health-care providers to choose one of these approaches, but when used alone or in isolation, these approaches cannot improve communication, service delivery, quality of care, and health outcomes (Andrulis & Brach, 2007). The ideas of integration are also explored in health-literacy-friendly and healthy settings proposed by Kickbusch and colleagues (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). The concept is extended into a broader context, from healthy hospitals to healthy cities. Such a settings-based approach addresses limited health literacy broadly and across multiple risk factors, and is likely to be successful.

Based on the concept of the *health-literate organization* (Brach et al., 2012; Schillinger & Keller, 2011), Pelikan proposed an expanded theory of organizational health literacy that takes into account a broader understanding of health literacy, coproduction of health, quality, and safety, health promotion and “healthy settings” (Pelikan & Dietscher, 2015). The comprehensive organizational health literacy focuses on health literacy of patients, staff/health-care providers, community and organizations. It addresses health literacy in four domains (access to, living and working in the organization; diagnosis, treatment and care; disease management and prevention; and lifestyle development) and three implementation areas (organizational policies and capacity development for organizational health literacy implementation, monitoring of health-literacy structures and processes, and advocacy and networking for organizational

health literacy dissemination). Similar to Kickbusch et al (2013), Pelikan also calls for the wider application of health literacy beyond sickness and health care.

The “How” of Organizational Health Literacy

Six operational frameworks of organizational health literacy have been identified (Figure 3.3). While frameworks vary considerably, they all reflect an organization’s capacity to deliver health-literate care and the scope of its application (e.g., patient, program, organization, and health-system level). The first notions of organizational health literacy were linked to the Kaplan and Norton balanced scorecard—a performance framework in which organizations consider four operational perspectives: financial, customer, business processes, and learning and growth (Hernandez, 2012; Schillinger & Keller, 2011). In health care, the four perspectives were translated into people, health, experience, and affordability. Organizational health literacy was also linked to the framework presented in the Crossing the Quality Chasm report (Institute of Medicine & Committee on Quality of Health Care in America, 2001; Parker & Hernandez, 2012) and also to the chronic care model (Hernandez, 2012). The new Health Literate Care Model (Koh et al., 2013) could support improvement strategies that promote comprehensive system change, encourage transparency concerning quality problems, and provide incentives for delivering high-quality care.

Incorporating health-literacy themes and tools into self-management support, delivery system design, decision support, clinical information systems, and community partners can create a more integrated environment that nurtures patient engagement (Koh et al., 2013). The 10 attributes of health-literate organizations (Brach et al., 2012) are based on the organizational health literacy concept developed by Schillinger & Keller

(Schillinger & Keller, 2011). These attributes help make it easier for people to navigate, understand, and use information and services to take care of their health (Brach et al., 2012; Schillinger & Keller, 2011). However, the 10 attributes have been criticized for being developed inductively and for lacking theoretical backing (Pelikan & Dietscher, 2015).

Frosch and colleagues propose patient engagement as an operational framework to help create patient-centred care responsive to patients at all levels of health literacy (Frosch & Elwyn, 2014). To support organizational health literacy, health systems can engage patients in the design of services that serve them, focus on eliciting what is important to patients, and ensure that care is integrated in a way that serves their needs (Frosch & Elwyn, 2014).

Kurt Lewin's Force Field Theory is proposed as a strategy to identify and remove barriers to information, to services, and to care in order to improve health literacy (Rudd et al., 2013). Applied in change management, Lewin's analysis can help identify factors within the health system and/or organization that drive a person toward or away from a desired quality of care, quality of life and health status.

Approaches taken by organizations to foster organizational health literacy have been categorized as *formal* and *informal* (Palumbo & Annarumma, 2014). Formal approaches, which may be more effective than informal approaches, are related to systemic integration of health literacy. In contrast, informal approaches relate to health-care professionals' inclination to informally support patients and use teach-back or similar methods to enhance and assure patients' understanding.

Guides and Toolkits for Organizational Health Literacy

Nineteen organizational health literacy guides were identified (Table 3.1). Guides vary in their scope (single- to multiple-issue guides) and context. The majority of guides were developed for health-care organizations in general; six are specialized for primary-care practices, hospitals, and pharmacies and one is designed to support health-literate nursing practices. Most guides combine an assessment and implementation of the plan of action for improving organizational health literacy. Guides were assessed based on their health-literacy dimensions and characteristics.

Health-literate dimensions of OHL guides

Although few guides address all six dimensions of health-literate organizations, communication and access and navigation are consistently included in all guides (Table 3.2). *Access* and *navigation* refer both to the physical environment and the services provided by the organization. Services do not only include health care, but also telephone systems and print materials—such as medical history forms, directives, and consent forms that are accessible and are easy to use (Brach et al., 2012; Cifuentes, Brega, Barnard, & Mabachi, 2015; Rudd & Anderson, 2006).

Verbal and written communication is included in all activities undertaken by a health-literate organization. A variety of tools and methods, such as the use of plain language, teach three, and teach-back methods are recommended to improve the delivery of health information and assure its comprehensibility, understanding and use (Brega et al., 2015; French, 2015; The Joint Commission, 2007; Weidmer, Brach, Slaughter, & Hays, 2012). A great number of guides include recommendations for improvements in specific care processes such as admission and discharge, disease- and self-management

practices, medication reconciliation and creation of shame- and stigma-free care environments. Recent guides recommend consumer involvement in different activities, including organizational health literacy assessment, quality improvement efforts, development of education materials, and service redesign. The role of patients and workforce has also changed and expanded to include active participation both in the process of care and in patient involvement in creation of a health-literate environment. The guides emphasize the critical role leadership in the integration of health literacy in an organization's vision, mission and strategic planning.

Quality improvement characteristics of OHL guides

Elements of quality methods are found in every reviewed guide, although those developed since 2010 more consistently link health literacy to safety and quality improvement (Table 3.3). Two elements, health-literacy assessment and development of improvement plans, are commonly recommended as part of health-literate actions. Several guides recommend that the Model for Improvement (Langley et al., 2009) inform the development and implementation of health-literacy improvement plans. Assessments help identify strengths, barriers, and opportunities for improvement, and also focus on promotion of services (how well services are advertised and how “user-friendly” the physical environment is to facilitate access and navigation) and provision of clear print and verbal communication. Some also include review of policies and protocols, specific professional practices, and technologies. Assessments often consist of a facility tour and a staff survey, and include scoring. Staff, partner organizations, or external auditors can conduct such assessments.

Actions for improvement are recommended in two broad areas: 1) communication and 2) organization of health care. Communication actions range from systemic improvements facilitating productive interactions (e.g., adoption of universal precautions in all patient encounters) to targeted improvements in existing health information materials and forms using plain language and the languages commonly spoken by patients. Organization of health care includes a wide range of changes in structures and processes facilitating improvements in the navigation and design of services and programs, policies, protocols, procedures, and preparation of workforce to deliver health-literate care. These improvements also include both systemic (addressing the entire organization) and targeted improvements in specific procedures, such as referrals for a service, development of personal care plans, and use of patient portals. The guides often recommend using Plan-Do-Study-Act cycles to test changes before spreading them through the organization.

Addressing Minority Health and Cultural Competence

Minority populations, including linguistic minorities, are described in organizational health literacy guides as vulnerable populations that experience inequities in access to, and quality of, health care. Linguistic minorities have fewer opportunities to participate in their care, communicate expectations, respond to the information, and to understand when variations or transgressions occur in their care (The Joint Commission, 2007). Health-literate organizations should recognize that literacy, language, and culture are intertwined and direct their efforts to improve their organization's linguistic and cultural competence and capacities; they should also improve systems that are currently poorly designed to accommodate limited health-literacy skills (Schillinger & Keller,

2011). To encourage cultural competence, service and accreditation standards essential to safe, high-quality care have been developed by the Office of Minority Health (Koh et al., 2014) and The Joint Commission (The Joint Commission, 2007). To improve poorly designed systems, health literacy guides recommend engaging linguistic minorities at the point of care and also in system redesign. The guides recommend the development of effective practices for assessing and implementing language-assistance needs of consumers, identifying the organization's capacity for language-assistance services (Thomacos & Zazryn, 2013), and assessing barriers to health information and services provided by the organization (Jacobson et al., 2007). The guides also propose specific actions to help identify the information needs of linguistic minority patients and build "culture-proofing" into the process of information production (Deasy, Fitzgerald, Kennedy, McGuane, & O'Brien, 2009).

Implementation of Organizational Health Literacy

Limited number of reports on application of organizational health literacy has been identified. These reports suggest that the guides have been used mostly for the assessment of health-literacy issues, while actual implementation is still lacking. One or more guides are used simultaneously to lead the assessment and, in one case, the implementation effort.

Initial results and reflections on using the OHL guides

Assessment tools were used successfully, required few organizational resources, and caused little to no interference with patient care (Groene & Rudd, 2011). They were regarded as a useful and feasible exercise to provide direction for improvement (Groene

& Rudd, 2011; Johnson, 2014; Weaver, Wray, Zellin, Gautam, & Jupka, 2012).

Assessment conducted at a health centre revealed that some health-literacy practices were already implemented but were not recognized as such due to the lack of familiarity with health literacy (Weaver et al., 2012). Although selected studies do not comprehensively assess evidence of the effects of organizational health literacy, they do show that application of health literacy guides facilitate action to remedy health literacy barriers (Groene & Rudd, 2011; Weaver et al., 2012), adoption of health-literate practices (Briglia, Perlman, & Weissman, 2015; Callahan et al., 2013), and understanding of the complexity of health literacy and the factors influencing health-literate practices (Batterham et al., 2014; Weaver et al., 2012). In addition, a health-literacy universal precautions toolkit has been adapted for use in the context of chronic disease management (Callahan et al., 2013) and health promotion and disease prevention interventions (White et al., 2013).

Barriers and Facilitators of OHL

Eleven key barriers (conceived also as facilitators) were identified, covering three broad themes: barriers 1–4 describe organizational and institutional culture and leadership; 5–10 relate to the design and planning of improvement interventions; and 11–13 refer to human resources (Table 3.4). For many organizations, becoming health literate will require multiple, simultaneous, and radical changes (Briglia et al., 2015; Palumbo & Annarumma, 2014). Although literature on this topic is scarce, reports suggest that there is no systemic approach to addressing health literacy within health-care organizations (Barrett, Puryear, & Westpheling, 2008; Palumbo & Annarumma, 2014; Zanchetta et al., 2013). Organizational commitment toward health literacy is described as

weak and efforts to enhance organizational health literacy via policies, planning, and programs are inadequate (Palumbo & Annarumma, 2014; Zanchetta et al., 2013). Due to the lack of awareness about health literacy and its impacts on health outcomes and sustainability of the health system, health literacy is not typically integrated into organizations' mission, vision, and strategic planning (Barrett et al., 2008; Palumbo & Annarumma, 2014).

When there is support and interest in improving communications and the role of health literacy, organizations may not have a mechanism for staff to train and learn about health literacy (Weaver et al., 2012). The presence of advocates for change is critical (Shoemaker, Staub-DeLong, Wasserman, & Spranca, 2013). However, their success depends greatly on support from the leadership. The existence of a management structure and a culture that supports service development and quality improvement is regarded as essential.

Discussion

The results of this review highlight a variety of theories, operational frameworks, and guides of organizational health literacy. On one hand, such variety allows organizations to make informed decisions about which theory, framework, or guide to select based on the best evidence available for their unique situation; on the other hand, such variety may lead to confusion about the vision and implementation of organizational health literacy strategies. Although no specific theory dominates, literature reviewed for this analysis demonstrates that organizational health literacy is envisioned from a population health perspective but conceptualized as a safety and a quality improvement

issue. Theorization of organizational health literacy from the population health perspective is consistent with recent research on health literacy within a broader public-health model (Greenhalgh, 2015), however this perspective may be problematic for organizational health literacy for a number of reasons.

The public health model is not a universal model and is not specific to organizational health literacy. Thus, it may not provide a clear vision across the continuum of care. There is a disconnect between theory as public health model and practice from a quality improvement perspective. The tendency is to apply the public health model intersectorally—i.e., beyond the walls of an organization—while quality improvement typically applies within the organization. Moreover, from a population health perspective, organizational health literacy is envisioned as an equity issue. However, equity cannot be fixed at the level of the entire health system and delivery of health care because health care is not designed, but is produced by society and equity remains the characteristic of the social system (Coughlan et al., 2013).

Because inequities are produced and maintained by unfair social arrangements outside of health care, inequity in health care should be addressed by attending to social determinants and structural inequities (Kickbusch et al., 2013). It is not clear if the vision of organizational health literacy proposed by researchers aligns with the perspectives from which health-care organizations are prepared to approach health literacy. Organizational health literacy has to make sense from clinical and financial perspectives in order for organizations to embark on such transformative journey (Hernandez, 2012). Current conceptualization and operationalization of organizational health literacy does not seem to reflect these practical perspectives.

Although the importance of patient-centred care (PCC) is emphasized, the connection between PCC and organizational health literacy often lacks operationalization in the organizational health literacy guides. PCC has been defined as “care that is respectful of and responsive to individual patient preferences, needs, and values” (Institute of Medicine & Committee on Quality of Health Care in America, 2001). Efforts to make the health-care environment more responsive to patients’ needs, preferences, and values fall in the realm of organizational health literacy. Taking this view, organizational health literacy can be considered the “how” of PCC, the strategy and the catalyst for making health information available, for transferring this information to patients and among providers, for improving accessibility and access to care, and for engaging patients in their care (Audet, Davis, & Schoenbaum, 2006; Davis, Schoenbaum, & Audet, 2005; Greene, Tuzzio, & Cherkin, 2012; Paasche-Orlow et al., 2006). It may make sense to recognize organizational health literacy as an attribute of PCC and to include it in PCC best practices.

The literature reviewed in this analysis highlights that organizational health literacy guides target improvements in health care that benefit primarily vulnerable populations with low health literacy, such as linguistic minorities. However, many guides are missing specific recommendations for minority-friendly practices. We suggest that organizational health literacy guides either include or identify common PCC practices adopted for ethnic minority groups as additional resources.

Factors perceived as barriers and facilitators for implementing organizational health literacy have been experienced by health-care providers involved in quality improvement projects in general (Argyris, 1993; Dixon-Woods, McNicol, & Martin,

2012; Mayberry, Nicewander, Qin, & Ballard, 2008; McNeil, 2001; Pexton, 2009; Solomons & Spross, 2011). Cultural change, both dominant and the culture of organization, is an essential and perhaps the most elusive of all challenges. For most organizations, such change would be a complex process unfolding likely over many years. Key factors that would facilitate this transformation include supportive leadership, supportive external stakeholders and professional allegiances, ownership of changes, and subcultural diversity within health-care organizations and systems (Scott, Mannion, Davies, & Marshall, 2003; Willis et al., 2014). This change might be supported by PCC, requiring organizations to prepare for an active offer of services, proactive planning and provision of care, and extensive collaborations.

There are several limitations to this review. Due to time and cost considerations, I included only English and French-language publications. This, and a lack of relevant keywords in the indexes of relevant research, may have led to the omission of some relevant reports. Furthermore, the generalizability of these results may be limited because the majority of studies included organizational health literacy guides from the US.

Conclusions

Organizational health literacy is designed to help build a person-centred, evidence-based, and quality driven health care. Guides have improved tremendously to support its development. Although complex, these guides provide evidence-based recommendations and best practices to support health-literate actions, include explicit quality improvement methods, and help build the case for organizational health literacy. A variety of theories and operational frameworks of organizational health literacy exist. Their application may require specialized knowledge and an effort to connect the theory

and practice; this is necessary for further development. It may be beneficial to recognize organizational health literacy as an attribute of PCC and to include it in PCC best practices. More research and reports are necessary to establish whether and how organizational health literacy works.

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Chapter 4

Active offer of Health Services in French in Ontario:
Analysis of Reorganization and Management Strategies
of Health-care Organizations

Abstract

Background: The availability of health services in French is not only weak but is often inexistent in some regions in Canada. As a result, estimated 78% of more than a million of Francophones living in a minority situation in Canada experience difficulties accessing health care in French. To promote the active offer and delivery of health services in French, publicly funded organizations are encouraged to take measures to ensure that French-language services are clearly visible, available, easily accessible, and equivalent to the quality of services offered in English.

Objective: This study examines the reorganization and management strategies taken by health-care organizations in Ontario that provide health services in French.

Methods: We conducted review and analysis of designation plans of a sample of health-care organizations to identify adaptations made for the provision of health services in French.

Results: Few health-care organizations providing services in French have concrete strategies to guarantee availability, visibility and accessibility of French-language services.

Conclusions: Implementation of the active offer of French language services is likely to be difficult and slow. The Ontario government must strengthen collaboration with health-care organizations, Francophone communities and other key actors participating in the designation process to help health-care organizations build capacities for the effective offer of French language services.

Keywords: active offer, French, health services, health literacy

Introduction

Although French and English have equal legal status in Canada's constitution, their parity is questionable when it comes to the Canadian healthcare system. An estimated 17% to 78% of more than a million of Francophones living in a minority situation outside of Quebec (Bouchard & Desmeules, 2013; Statistics Canada, 2011), Canada's only Francophone majority province, experience difficulties accessing health care in French. It is well-known that, in a minority context, the status of the minority language determines the language of service. In Ontario, where more than half a million Francophones live in a minority situation, only 3% of health-care professionals report offering services in both languages (Forgues, Bahi, Michaud, Boudreau, & St-onge, 2011). When English has a higher status than French and the social context favours English, bilingual Francophones living in a minority context will often adopt English (Deveau, Landry, & Allard, 2009). As a result, only 20% of Ontario's Francophone adults use French when seeking health care (Corbeil & Lafrenière, 2010). Providers of services tend to reduce their offer of services in French when there is no demand or because Francophones do not use them (Forgues et al., 2011).

A special report from the Office of the French Language Services Commissioner suggests that the way the demand and supply of services in French are connected creates a vicious cycle, in which weak supply results in weak demand, and this prompts providers to not offer services in French (Office of the French Language Services Commissioner of Ontario, 2016). Surveys, however, demonstrate that the overwhelming majority of Francophone respondents consider receiving health services in French as very

important or important (Corbeil & Lafrenière, 2010) and are prepared to use them when the offer is made (Deveau et al., 2009). The French Language Services Commissioner of Ontario suggests that preference should be given to the “active offer of services in French” to break the vicious cycle (Office of the French Language Services Commissioner of Ontario, 2016). The solution to this unhealthy dynamic involves creating an organizational climate that supports active offer and makes staff comfortable offering services in French (Bouchard, Beaulieu, & Desmeules, 2012; Cardinal, Plante, & Sauvé, 2010).

Active offer refers to series of measures taken by publicly funded organizations to ensure that French-language services are clearly communicated and publicized, visible, available at all times, easily accessible, and equivalent to the quality of services offered in English (Office of Francophone Affairs, 2016b). The concept of an active offer implies the shift of responsibility from the patient, who would otherwise be expected to ask for health services in French (Bouchard et al., 2012). Active offer is, thus, characterized by proactive offer of services by staff from the point of first contact; by the guarantee that subsequent services will be provided in French; and by the promise that they will be equivalent in quality to the services offered in English (Office of the French Language Services Commissioner of Ontario, 2016). Active offer is expected to help create an environment that will stimulate the demand for services in French and will anticipate the needs of Francophones in their community. Therefore, active offer of services in French should become part of organizations’ policies and integrated into the organizational culture, from the board of directors to direct services (Bouchard et al., 2012). Such measures call for changes in how services are organized and managed.

This study aimed to examine the reorganization and management strategies taken by Ontario health-care organizations in the pursuit of an active offer for French language services. My study addresses the following issue: “What strategies do Ontario health-care delivery organizations use to adapt health care for an active offer of services in French?” Using organizational health literacy and the 10 attributes of health-literate organizations (Brach et al., 2012; Schillinger & Keller, 2011) as analytical framework, this project for the first time provides unique insight into the changes undertaken by health-care organizations to achieve visibility, availability, and accessibility of health services in French. Similar to the active offer, the 10 attributes help create an environment that enables people to access and benefit from the range of health-care services.

Four additional elements that emphasize the importance of an active offer of French-language services require to be reviewed: language and culture as determinants of health and access to health care; legislative context in relation to the active offer; designation for French-language services; and (organizational) health literacy.

Language, Culture and Health

Today, both language and culture are recognized as the determinants of health and access to health care (Khan, Kobayashi, Lee, & Vang, 2013; Public Health Agency of Canada, 2011). Linguistic barriers are associated with increased risk of hospital admission, errors in prescribed medication, greater number of reported adverse drug reactions, and lower rates of pain medication (Bowen, 2001). Specifically, lack of comprehension poses a serious limitation on access to health-care services, adherence to medication regimens, and consent to essential procedures in older Francophone adults living in a minority situation (Bouchard et al., 2010; Lemonde, Dufour, & Desmeules,

2012). When patient and health-care provider cannot understand each other, the quality of service can be compromised and patient's satisfaction can also suffer (Louise Bouchard et al., 2012). The use of interpreters and translation of documents do not convey cultural context and have shown to lead to diagnostic errors and inadequate treatment (Bowen, 2001; Ouimet, Trempe, Vissandjée, & Hemlin, 2013).

Active assimilation into a dominant Anglophone majority has stalled the development of institutions supporting the Francophone community and forced them to adopt English to be able to access health care (Bouchard & Desmeules, 2011). Contrary to common beliefs, Francophones living in a minority situation are not always proficient in English. An estimated 72% of Francophone older adults in Ontario are not capable of communicating in English with their physicians (Bourbonnais, 2008). Burgeoning research demonstrates that large numbers of Francophone minorities report poorer health, more chronic illnesses, more difficulties with activities of daily living, and higher rates of obesity than those observed for Anglophone majority (Bouchard & Desmeules, 2011). Francophones consistently exhibit more health-risk behaviours (e.g., smoking, alcohol consumption, physical inactivity, poor diet) than non-Francophones (Batal et al., 2013; DeWit & Beneteau, 1999; Imbeault et al., 2013). They also tend to be older, less educated, poorer, and living in economically disadvantaged regions (Bouchard, Gilbert, Landry, & Deveau, 2006; Louise Bouchard & Makvandi, 2014; Corbeil & Lafrenière, 2010). It is, thus, essential to assure provision of health services in French and to be forthcoming about the option to receive services in the language of the patient's choice. For health-care organizations, this means making Francophone patients aware that services in French are available and accessible.

Legislative Context

In Ontario, the French Language Services Act of 1986 provides the main legal framework for the provision of health services in French. The French Language Services Act guarantees the right to receive services in French from Government of Ontario ministries and agencies in the 25 designated areas where Francophones make up at least 10% of the population (Office of Francophone Affairs, 2016b). To counter the effects of English dominance, the federal Official Languages Act of 1969 and the Canadian Charter of Rights and Freedoms of 1982 provided Francophones living in a minority situation with the opportunity to live and thrive in French (Bouchard et al., 2012; Office of the French Language Services Commissioner of Ontario, 2016).

But an analysis of the legal context in relation to the active offer of services in French reveals some limitations. For example, the Canadian Charter of Rights and Freedoms does not obligate government agencies and institutions to actively offer services in both official languages. Furthermore, the French Language Services Act does not require providers to offer services in French in all circumstances. The French Language Services Act gave the government the power to designate providers of health services in French. The responsibility for designation for health services in French is shared among several organizations: the Ministry of Health and Long-Term Care; the Office of Francophone Affairs, and Local Health Integration Networks, 14 local health authorities created in Ontario in 2006 as part of the regionalization reform; French Language Health Planning Entities that work with Local Health Integration Networks to facilitate the planning and provision of health services in French; and a health service provider that delivers services in French. The Office of Francophone Affairs revised

criteria for designation in 2013 to guarantee services and follow the principles of active offer. The designated agency must: 1) permanently offer French-language services by employing people with requisite level of French-language skills; 2) guarantee that French-language services can be provided for all or some services and during business hours; 3) ensure that Francophones sit on boards of directors and committees in proportion to the Francophone population in the community; 4) have Francophones in senior management in proportion to the local Franco-Ontarian population; and 5) make directors and senior managers accountable for the quality of French-language services.

However, changes to the criteria are only administrative in nature and do not create legal rights and obligations (Office of the French Language Services Commissioner of Ontario, 2016). Moreover, while designated agencies must implement the principle of active offer, government agencies or institutions are not required to do so.

In the context of health care, the French Language Services Act has shown to be of limited usefulness: Access to health services in French remains limited and poorly publicized (Office of the French Language Services Commissioner, 2016). It is thus necessary to adopt measures that increase the effectiveness of language rights.

Designation for French-language Services

Designation is an official recognition of organization's capability to actively offer services in French according to criteria set out by the Office of Francophone Affairs (French-language Health Services Network of Eastern Ontario, n.d.; Office of Francophone Affairs, 2016b). It refers to organization's commitment to French Language Services, either for all (full designation) or for some (partial designation) of its programs

and services. Organization may be identified for designation by French Language Health Planning Entities and ordered by the Ministry of Health and Long-Term Care or Local Health Integration Networks to obtain designation, or choose to do it voluntarily. The designation process involves multiple steps and actors (Figure 4.1). Services for which the organization requests designation must be available and provided on permanent basis when designation plan is submitted. Organizations that make request for designation receive support from the French Language Health Planning Entities for preparation of the designation plan. The designation plan helps determine to what extent the health services provider meets the designation criteria. The plan is assessed by several organizations before the health service provider is granted designation. As evidence of compliance, every three years, designated health services provider must provide a report to the Ministry of Health and Long-Term Care in which they demonstrate how they maintain the active offer of services in French. Eighty-nine health-care organizations have been designated to date, of which 22 are hospitals, 11 are long-term care homes, and 4 are community health centres (the Ministry of Health and Long-Term Care, 2016).

Organizational Health Literacy and Active Offer

Although *health literacy*, the capacity to obtain, process, and understand basic health information and needed services, is commonly described as an individual trait (Ratzan & Parker, 2000), it is now recognized that health literacy does not only depend on individual skills and abilities but also on the demands and complexities of the health-care system (Andrulis & Brach, 2007; Brach et al., 2012; Hernandez, 2012; Paasche-Orlow, Schillinger, Greene, & Wagner, 2006; Palumbo & Annarumma, 2014; Parker &

Hernandez, 2012). *Organizational health literacy* describes a set of measures that can help health-care organizations make it “easier for people to navigate, understand, and use information and services to take care of their health” (Brach et al., 2012). The framework of organizational health literacy is represented in Figure 4.2 (Schillinger & Keller, 2011).

Organizational commitment is the foundation of a health-literate organization. The infrastructure level includes support systems such as financial, clinical, and health information technology to support the implementation of concrete and practical resolutions; the workforce level includes ways in which the workforce is trained and encouraged to use health-literate practices; the policies and practices level addresses situations in which providers routinely interact with patients and use health-literate practices and procedures that facilitate top level, bidirectional communication, which can be considered an outcome. Health-literate health-care organizations recognize that literacy, language, and culture are intertwined, and their efforts help reduce inequities in care and improve the organization’s linguistic and cultural competence (Andrulis & Brach, 2007; Sudore et al., 2009).

The transition from health-care organization to health-literate health-care organization involves changes in organizational structures, processes, personnel, and technologies to improve access, and the quality, safety, and value of health-care services. The 10 attributes provide concrete, practical actions that organizations can take to create an environment that promotes cultural and linguistic competence and facilitates active offer of care and services (Brach et al., 2012). A health-literate health-care organization:

- 1) has leadership that makes health literacy integral to its mission, structure, and operations;
- 2) integrates health literacy into planning, evaluation measures, patient safety,

and quality improvement; 3) prepares the workforce to be health literate and monitors progress; 4) includes populations served in the design, implementation, and evaluation of health information and services; 5) meets the needs of populations with a range of health-literacy skills while avoiding stigmatization; 6) uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact; 7) provides easy access to health information and services and navigation assistance; 8) designs and distributes print, audiovisual, and social media content that is easy to understand and act on; 9) addresses health literacy in high-risk situations, including care transitions and communications about medicines; 10) communicates clearly what health plans cover and what individuals will have to pay for services.

Like active offer, organizational health literacy emphasizes the shift of responsibility from an individual to the health-care system to support patients in navigating information and services, steering them toward timely and appropriate care (Palumbo & Annarumma, 2014).

Methods

The study was implemented in two consecutive phases: 1) analysis of designation plans of a sample of health-care organizations to identify adaptations made for the provision of health services in French; 2) creation of a focus group with health-care administrators to explore their experience and perspectives regarding active offer of French-language services and its implementation. Results from the focus group are reported in Chapter 5.

Data

Designation plans of 12 organizations that had undergone designation were provided by the French Language Health Services Network of Eastern Ontario, a French Language Health Planning Entity for Eastern and Southeastern Ontario, which advises two Local Health Integration Networks on all issues affecting Francophone health (<http://www.rssf.on.ca/en/>). The designation plan includes qualitative and quantitative data. Qualitative data describes strategies and best practices that allow the provision of quality health services in French. It covers administrative strategies in nine areas: delivery of French language services, methods of identification of Francophone clients, staffing policy, recruitment policy, hiring policy, representation of Francophones on board of directors and other committees and senior management, the French language services committee, accountability for French language services; direct services in five areas: switchboard, reception, physicians, other direct services and human resources plan; and other services that affect Francophone clients, including communications strategy, signage, documents and information services, correspondence and other (RSSF, 2013). Qualitative data has been extracted and tabulated for further analysis.

Conformity Scale

In the absence of an exiting measure, I developed a conformity scale to determine to what extent organizations meet designation criteria for health services in French (Table 4.1). Based on the French Language Health Services Network of Eastern Ontario evaluation grid for designation plans, the Ministry of Health and Long-Term Care template for designation plan (Office of Francophone Affairs, 2016a), and attributes of health-literate organizations (Brach et al., 2012), the scale is composed of 20 items

comprising four domains: administrative regulations, direct client services, corporate identity and communications, and governance and accountability. Sum of all the items produces a score from 0 to 100%.

Data Analysis

Data analysis was inspired by the deductive qualitative content analysis. This method allows the examination of meanings, themes, and patterns that may be manifest or latent in a particular text and make inferences from it (Mayring, 2000). It allows researchers to guide their analyses using a specific theory and understand certain reality in a subjective but scientific manner. Data was abstracted in the categories predefined in the designation plan. Based on the organizational health literacy framework and the designation criteria, data was analyzed for evidence of organizational commitment and leadership accountability for French language services, supportive infrastructure to guarantee access to services based on the principle of an active offer, the availability staff fluent in French, policies and practices to offer quality French language services on a permanent basis, and to support effective communication. “Horizontal” analysis (comparison of approaches across organizations) helped identify similarities and differences in the ways in which organizations operationalized domains of the conformity scale.

Results

Characteristics of Selected Organizations

In total, 12 health-care delivery organizations were included in the study. Of these, three were hospitals (two medium-size community hospitals and one large teaching hospital); three community health centres and one community care access centre; five were specialty organizations (a heart institute, a long-term/continuing care facility, two community mental health programs and one community program for substance abuse). Located in Eastern Ontario, these organizations contribute to the care provided to more than 1.6 million people, 15.4% of which are Francophones. These organizations were established between 1953 and 2007 and made numerous and significant changes over time—expanding and/or adding new programs and changing funding sources and operational models. These organizations were designated for French language services between 2007 and 2015. Three of 12 organizations applied for partial designation and the rest applied for full designation. Two organizations (a large teaching hospital and a heart institute) have previously received full and partial designation in 1989 and 2001, respectively, and renewed their designation in 2015 and 2008. Francophone patients with preference to be served in French make up an average of 37% (range 6%–100%) of the clientele at these organizations. Three of 12 organizations operate in French, although both French and English are used when preferred by patients and/or providers.

Conformity to Designation Criteria

Organizations conformed to the designation requirements to a varying degree. An average conformity score of 77% (range 40%–100%) suggests that organizations may or

may not fully and equally well (or poorly) conform to all designation criteria (Table 4.1). Our analysis showed that all 12 organizations had either difficulties with or failed to comply with the following criteria: 1) making a distinctive announcement about the offer and delivery of French-language health services; 2) setting policies and procedures to address active offer of French language services/language assistance in high-risk situations, including care transitions and communications about medicines; 3) integrating active offer of French language services into planning, evaluation measures, service users safety and quality improvement initiatives; and 4) putting in place consumer surveys, or other means of obtaining feedback on services delivered, including French language services. In contrast, all organizations succeeded in conforming to the following criteria: 1) put in place a committee to support the planning and provision of French language services; 2) have a French version of their website; 3) make external signage available in French or in both French and English; 4) make publications and communications intended for general public available in French; 5) facilitate translation of all documents intended for public use; 6) have an adequate representation of Francophones on the board of directors.

Results of the analysis of designation plans are presented according to the domains of the conformity scale, namely administrative strategies, direct client services, corporate identity and communications, and governance and accountability.

Administrative Strategies

As part of administrative strategies, organizations are required to support the provision of French language services, develop human resources plans which include provisions for the recruitment and hiring of health-care providers with French-language

skills, and procedures to effectively identify Francophone patients. A typical French-language services policy expresses an organization's vision and commitment to offering services in both English and French. It also specifies client services that must be permanently available in French, aspects of governance and accountability with respect to French-language services, the role of the French language-services committee and its terms of reference, aspects of communication and translation services, recruitment and hiring, and French-language training. All but one organization (a hospital) have either developed new or revised an existing French-language services policy at the time of submitting their designation plan. The hospital missing the French-language services policy indicated that the provision of bilingual services is the mandate of this organization, so it does not need a specific policy.

Websites, pamphlets, brochures, annual report and signage are used as standard ways of informing the public about the availability of French language services. Although the designation guide (RSSF, 2013) calls for a communication strategy to inform public about the availability of French language services, it does not appear that organizations develop such strategies or make additional effort to announce availability of French language services.

The human resources plans that support the provision of French language services were included in the French language-services policies and/or staffing policies and involved internal (by senior management and/or French language services committee) and/or external evaluations of job descriptions to determine what positions require proficiency in French (designated bilingual positions) and what level of competence in French is required for each of those positions (five levels, from elementary to superior);

adoption of practices allowing current employees to test and/or train for French; and development of procedures for new employees applying for bilingual positions to undergo appropriate interviewing and testing (typically by an external agency).

Designated bilingual positions require an advanced or superior level of French and are determined based on several factors, including consideration of client's needs, the nature of contact with clients and public, and the responsibility level of the position. Some 50% to 80% of positions have been designated as bilingual at most organizations and included direct-care providers (nurses, physicians, specialists, and allied providers) and administrative and leadership staff. Primary-care clinics and community-care access centres also designated information and referral specialists, care connectors, case managers, and team assistants as designated bilingual positions. Three Francophone organizations (a teaching hospital, a Community Health Centre and a community mental health program) designated all of their positions as bilingual or primarily French. Some organizations assigned the responsibility to ensure that clients receive services in the language of their preference to managers and health-care providers. However, human resource plans clearly specified that none of the currently employed staff would be dismissed due to insufficient competence in French. On the contrary, French-language training is provided by the organization to those who require or desire to improve their language skills.

To ensure the presence and availability of bilingual providers at all times and in all departments and programs, organizations used three distinctive strategies. A temporary *job shadowing* was used most frequently in all types of organizations to allow a bilingual provider from other departments or programs to either replace or assist a

unilingual staffer to interact with or provide care to a Francophone client and/or family. For example, a community-care access centre developed a procedure to engage a case manager from a centralized intake team for all locations which did not have designated bilingual positions. Adoption of *creative scheduling* is used primarily, but not exclusively, at hospital settings. For example, a hospital human resources plan called for a minimum of one bilingual professional per shift and relied on creative scheduling in all departments. Similarly, a community-care access centre instituted a policy that required each client-services team to have sufficient coverage during hours of operation for bilingual employees. Organizations lacking staff or services in French also rely on *referrals* to other organizations with bilingual or Francophone staff.

Organizations that self-identify as Francophone appear to have well-developed strategies to successfully recruit bilingual or primarily Francophone staff compared to other organizations in this sample. They do not rely solely on bilingual advertisements for designated bilingual positions on their own or other career websites, but hire recruitment agencies to identify and recruit health-care providers, including students, residents, and recent graduates from schools and universities where French is the language of instruction and also from bilingual or French provinces (New Brunswick and Québec). They also actively engage in annual recruitment fairs in other provinces or organize them locally. When recruitment of bilingual staff is unsuccessful, the French-language services policy at non-Francophone organizations allows senior management to offer candidates a training plan under the condition that individuals hired in designated positions would learn French within two years. Selection processes for designated bilingual positions include interviews where at least one member of the selection

committee is Francophone and conducts part of the interview in French, and evaluations for both oral and written proficiency in French—often by an external agency. Some organizations have developed a standard procedure to evaluate language proficiency internally by using language proficiency levels tools and the Language Proficiency Evaluation Form provided by the Ministry of Health and Long-Term Care.

Direct Client Services

In order to actively offer information related to client services in both official languages, 10 of 12 organizations reported that they made efforts to assure that the switchboard (either by a person or an automated phone system and/or the receptionist) was capable of answering all inquiries in English and French on a consistent and permanent basis. Positions with responsibility for the reception and switchboard are designated bilingual positions, and staff has the capacity for providing services in both English and French. In addition, staff is using a greeting protocol and is encouraged to practice active listening. Although physician positions are included in designated bilingual positions, an estimated 30% to 50% of physicians working in these organizations possess French-language skills (from elementary to superior level). In contrast, three organizations that self-identify as Francophone succeeded in filling 90% to 100% of designated bilingual positions for physicians and other medical doctors. Smaller organizations, such as primary-care clinics, contend that they have a limited capacity to recruit French-speaking doctors because they do not typically bring large numbers of physicians to the geographic area. These organizations often advertise a list of physicians who speak French but state that it is up to the patients to select a French-speaking doctor.

All but one organization (a hospital) developed specific procedures or an algorithm to identify Francophone clients by identifying the language of preference for verbal and written communication (also referred to as *the language of service* or *mother tongue*, or both *language of preference* and *mother tongue*). Language preference is typically determined via initial contact (registration and/or admission) and recorded in a mandatory field in the client's electronic file or chart. Primary-care and specialty-care organizations also coordinate the language of preference with providers and services assigned to the client (e.g., a patient self-identifying as Francophone and opting for French language services is assigned a case manager or a provider with French-language skills).

Corporate Identify and Communications

Overall, organizations met most of the designation criteria for French language services related to corporate identity and communications (Table 4.1). However, several opportunities for improvement have been identified. Specifically, most organizations appear to be missing policies and procedures for the offering of language assistance in high-risk situations, including care transitions and communications about medicines. Although these procedures may be embedded within other protocols, they have not been explicitly mentioned in the designation plans. Also, there is no consistent policy about whether employees who speak French should be identified as such by their identity cards and signage or wear badges to facilitate the active offer. As a result, clients may not always recognize French-speaking providers.

Governance and Accountability

Obtaining designation for French language services requires organizations to make changes to governance and accountability. Specifically, organizations are expected to include representatives of the Francophone community on their boards of directors and associated committees, and also on senior management committees. According to the designation criteria, the number of Francophone members on boards of directors has to be proportional to the number of Francophones in the organization's service area but no fewer than three. Eleven of 12 organizations declared having at least three or more Francophones on boards of directors. Compared to boards of directors, representation of Francophones on Senior Management Committee (SMC) is less consistent, ranging from zero to 13 members across 12 organizations. An organization (a community hospital) that did not have Francophones on its SMC had, in fact, designated 2 positions out of 5 to be bilingual, but has not filled them; they contended that they relied on other bilingual resources within the organization to assist SMC when needed. The SMCs of three organizations were composed entirely of Francophones. The ratio of Francophone to non-Francophone members on the SMC varied from 1:1 to 1:3 in eight organizations, respectively. A high-ranking manager, typically general director or CEO, president, or vice-president, were responsible for the planning and delivery of French language services in all organizations.

Designation plans provide little to no evidence of an integration of active offer of French-language services into planning, evaluation, safety, and quality improvement. Half of all organizations reported monitoring the provision of French-language services via a formal complaint process and/or annual satisfaction survey. Formal complaints are

presented to the French-language services committee that reports to the SMC and the boards of directors. Two organizations have connected complaints and survey results to quality improvement policies and initiatives. For example, a Francophone teaching hospital established a process where results of the survey were passed to the quality improvement committee that oversees implementation of quality improvement at the hospital. A Community Care Access Centre (CCAC) embedded monitoring of client satisfaction in their work with contractors and ensures that results are communicated back to CCAC on quarterly basis. Clients who have expressed a language preference and who have not been served in the official language of their choice can file a complaint with their case manager through the formal complaint, appeals, and feedback process or file a complaint with the provincial Office of the French Language Services Commissioner.

Discussion

This study examined the reorganization and management strategies taken by Ontario health-care organizations in the pursuit of the designation for an active offer of health services in French. A novel theoretical framework of organizational health literacy addressing changes in organizational commitment, infrastructure, workforce, policies, and practices and communication supported this study. The analysis showed that few health-care organizations providing services in French put in place concrete strategies to guarantee availability, visibility, and accessibility of French language services. In the absence of such strategies, implementation of the active offer of French language services is likely to be difficult and slow. Nevertheless, some organizations have made active offer a standard of health service and developed expertise in the planning of French

language services. Specifically, organizations where French was a working language employed a variety of strategies and took a comprehensive approach to the active offer compared to some of the organizations where English was a working language.

Organizational culture may influence how the management approaches the planning and operationalization of the active offer of French language services and warrants further investigation.

The analysis revealed that plans for change with regard to French language services are integrated only in some organizational policies and processes. Organizations that make an explicit commitment to developing responsive care must use a whole organization or systemic approach rather than permitting individual projects that are not structurally embedded in the organization (Seeleman et al., 2015). Commitment to French language services should be integrated with organizational and leadership commitment to effective communication, cultural competence, and patient- and family-centred care, concepts of which should then be integrated into existing policies. Organizations could also adopt organizational health literacy, the framework used for this study, as a novel approach to responsiveness to care. Organizational health literacy addresses elements such as navigation, recognition of patients with low health literacy, integration of health literacy into planning, evaluation measures, patient safety, and quality improvement, care transitions, communications about medicines, preparation of workforce, and cultural and linguistic appropriateness of services. A great number of resources have been developed to assist organizations with transition from health-care organization to health-literate health-care organization and could be used for promotion of French language services (e.g., Ten Attributes of Health Literate Health Care Organizations, Health Literacy

Universal Precautions Toolkit). In the absence of systemic changes, it is not clear how organizations' leaderships plan to promote their commitment to quality French-language services within the organization.

All designation plans emphasize the importance of quality care for Francophone clients, but strategies for achieving it seem to be reduced to the availability of providers with (some level) of French-language skills and availability of information translated into French. These strategies will not be sufficient to assure the provision of an active offer of quality French language services. Designation plans should address important elements of health care, such as responsiveness to the needs and wishes of patients (beyond language preference), patient participation in the care process, reduction of communication barriers, availability of understandable patient information materials, and patients' rights (Lortie & Lalonde, 2012; Seeleman et al., 2015). There is very little evidence of an integration of an active offer of French language services into performance measurements, evaluations and quality improvement. It remains unknown how organizations intend to measure the effect that active offer will have on accessibility and quality of care. Without this information, it will be impossible to know whether organizations that offer services in French are meeting the needs of Francophones (Office of the French Language Services Commissioner of Ontario, 2016).

A significant emphasis is placed in the designation plans on the development of staff or workforce to assure provision of French language services. Language competency is a central theme in staff training available to all employees who wish to learn or improve their French-language skills. To build cultural competence and ensure successful offer of French language services, language training should be

complimented by a separate training for all staff in the provision of responsive care to diverse clients (Lortie & Lalonde, 2012; Seeleman et al., 2015). Such training would allow making full use of the staff's linguistic and cultural skills to serve Francophone clients (Lortie & Lalonde, 2012). Approaches to organizations' cultural competence, such as CLAS (Culturally and Linguistically Appropriate Services), recommend increasing diversity among staff to make the workforce representative of the general population it serves, and to help further equity by improving linguistic and ethnic concordance between clients and staff. Considering that Ontario's Francophone population is culturally diverse and includes people born in Canada and also those who emigrated from other French-speaking countries (e.g. France, Belgium, Haiti, Congo, or Morocco) (Heller, 2007), increasing diversity of health-care organizations' workforce would help meet both linguistic and cultural needs of Francophone clients.

Several organizations stated that due to shortage of Francophone human resources (physicians) they use *job shadowing* and *creative scheduling* to provide services in French. While these strategies may be effective as temporary interventions, they are unsustainable as a guarantee of permanent services and are unlikely to result in quality care. Moreover, approaches such as CLAS advise against using untrained, informal interpreters such as untrained staff or family members. Organizations that experience difficulties recruiting bilingual staff should consider language-assistance measures, such as professional interpreters or intercultural mediators. Organizations are responsible for informing clients of their right to language assistance and of ensuring its quality and competence (Seeleman et al., 2015). A study examining the distribution of French-speaking physicians in Ontario found that the shortage is explained by the maldistribution

of such services, not by their absence (Gauthier, Timony, and Wenghofer 2012). The authors suggest that organizations must make efforts to attract French-speaking physicians to areas where there is the greatest demand.

A study of approaches to cultural competence (Seeleman et al., 2015) identified elements that help build organizational infrastructure to improve responsiveness of services. They include the creation of an environment that reflects the populations served and involvement of clients in the development of services. Health service providers are recommended to conduct self-assessments to examine barriers to access related to physical space, signage, design of the facility, and other attributes (Center for Substance Abuse Treatment, 2014; Rudd & Anderson, 2006; Seeleman et al., 2015). Although designation plans for French language services call for translation of all signage, documentation and information used in the process of care, health service providers are not required to assure that their facilities are easy to navigate or that all information is produced at an appropriate level of literacy in French or is easy to understand. With regard to the involvement of clients and community in the development of services, the argument is simple: “A health care organization serves a community; therefore the community has to be enabled to exert influence on what happens in the organization” (Seeleman et al., 2015). Active offer of French-language health services should involve more than offering services in the French language, but rather an approach that takes into account the needs and preferences of this minority community for planning and provision of health services (Lortie & Lalonde, 2012). The advantage of such participation is that clients and communities can contribute to the implementation of changes and help build more responsive care. Without an infrastructure that supports cultural competence at

organizational level, it will be difficult to ensure an active offer of quality French language services.

The results from this study suggest that organizations may be underestimating the importance of active communication. The offer of services becomes active only when the organization uses all possible means to communicate and inform the public and patients that it has the capacity to offer quality services in French (Bouchard et al., 2012). Health service providers need a comprehensive communication strategy that includes all oral, written, or electronic communications related to the service that helps to increase awareness about availability and accessibility of French language services. Health service providers also need protocols supporting communication in high-risk situations (e.g., care transitions, stopping, or changing medications) and methods promoting patients' understanding of information (e.g., teach-back, ask me three). Effective communication can encourage the demand for French language services and promote equity and inclusion of Francophones (Bouchard et al., 2012).

While health-care organizations play a key role in the delivery of health services in French, development of language competencies at the organizational level requires collaboration among health-care organizations, the communities, and the government/health-care system (Aucoin, 2008; Office of the French Language Services Commissioner of Ontario, 2016). This collaboration can help build organizational capacities by providing a legal framework, human, material and financial resources, tools, directives, and best practices to make possible taking language into account when organizing health services (Office of the French Language Services Commissioner of Ontario, 2016). Although designation has made an important contribution to the

provision of health-care services in French, the results show that there is a need for effective accountability measures to not only ensure an offer of services in French, but also safeguard their quantity and quality (Bouchard et al., 2012). Without accountability and surveillance, it will be difficult, if not impossible, to ensure that the active offer is implemented. There is a need for the Ontario government to “take concrete measures and acquire the necessary instruments to ensure that ministries, agencies, entities and third parties that provide services on the government’s behalf implement the active offer of service in French” (Office of the French Language Services Commissioner of Ontario, 2016).

This study has limitations. My analysis has been conducted based on the content of designation plans. Plans may have been imprecise, inaccurate, and not reflective of the actions taken with regard to French language services. In addition, as noted by Palumbo et al. (2014), organizations and their workforces might have introduced informal strategies supporting French language services instead of formalizing their efforts. Interviews with the organizations’ administrators and providers could help enhance the content of the plans and shed light on their implementation. We reviewed designation plans of 12 out of 89 designated health-care organizations. This small sample may not be fully representative of all designated organizations. We used an unvalidated measure (the conformity scale) and introduced the researchers’ bias in the constructs and domains that we measured. Future studies will need to identify wording problems, fully conceptualize constructs and delineate the domains to purify this measure.

Conclusion

There is room for improvement in the designation process with regard to the planning and evaluation of culturally and linguistically competent health services in French. Efforts must be made to improve the active offer of quality French language services among health-care administrators and providers. Commitment to French language services must be integrated with organization's commitment to cultural competence, patient- and family-centred care, and organizational health literacy, a novel approach to responsiveness to care. Designation plans should address responsiveness of care to the needs and wishes of patients, patient participation in the care process, communication strategies and barriers, availability of understandable patient information materials, measurement and evaluation of French language services, and systemic approaches to the active offer and patients' rights. If this is not done, the provision of quality French language services and its active offer will likely remain slow and difficult. The Ontario government must strengthen collaboration with health-care organizations, Francophone communities and other key actors participating in the designation process to help health-care organizations build capacities for the effective offer of French language services. The planning and implementation of the active offer of French language services has to be further researched to be able to make improvements in the provision of health care in French and its quality.

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Chapter 5

Planning and Implementation of an Active Offer of Health Services in French in Ontario: Perspectives of Health-care Administrators

Abstract

Background: Health-care organizations have the responsibility for creating the environment, introducing policies, allocating resources, and training programs to adapt to designation criteria and offer services in the language and culture of the Francophone communities they serve. Improvements in the delivery of the active offer of health services in French depend on our understanding of organizational context in which organizations operate.

Objective: This study explores the perspectives of health-care administrators regarding the planning and implementation of an active offer of health services in French. By applying a novel theoretical framework of organizational health literacy, this study explored the transition to the successful, consistent offering of health services in French.

Method: A focus group with health-care administrators was held and data was analyzed for evidence of organizational commitment and leadership accountability, supportive infrastructure to guarantee access to services, availability of workforce with French-language skills, and policies and practices to offer quality services on a permanent basis and to support effective communication.

Results: The following main themes were identified: integration of the active offer, workforce, engagement of Francophones at organizational level, misrepresentation of the active offer of services, and sustainability of services in French.

Conclusions: Taken together, results of this study suggest that there is a significant disparity between where the services are in terms of the level of their preparedness for delivery of services and where they ought to be to satisfy the designation criteria for the

active offer. Numerous structural and institutional barriers need to be removed to make active offer a reality and a norm in health care. Cultural change is needed within the health-care system to remedy the way that government officials, health-care organizations, health-care professionals, and the public look at, and deal with, health-care services in French for the Franco-Ontarian community. The Ontario government must support health-care organizations to build capacities for the effective active offer of health services in French.

Keywords: active offer, health services, French, health-care organization, designation

Introduction

A common language between patients and health-care providers is an important element of access to health-care services and the quality of the services received. Conversely, a language barrier compromises access and quality of care (Bouchard & Desmeules, 2011; Bouchard & Leis, 2008; Drolet et al., 2015; Lemonde, Dufour, & Desmeules, 2012). As a result of the language barrier, some members of the community are less well -served by health-care services than others (Corbeil & Lafrenière, 2010). In Ontario, the largest Canadian province by population and a home to more than half a million of Francophone minorities, the majority of Francophones report using English when consulting health-care providers and other health-care resources and facilities. Lack of knowledge of French among health-care providers, as perceived by the respondents, is the main reason why Francophones resort to English in their interactions with the health-care system (Corbeil & Lafrenière, 2010).

When there is no demand or because Francophones do not use services that (might be available) in French, providers of French-language services tend to reduce their offer of services (Forgues, Bahi, Michaud, Boudreau, & St-onge, 2011). The way the demand and supply of services in French are connected creates a vicious cycle, in which weak supply results in weak demand and vice versa (Office of the French Language Services Commissioner of Ontario, 2016). The solution to this unhealthy dynamic involves adopting an active offer of services as well as creating an organizational climate that supports active offer and makes staff comfortable offering services in French (Bouchard, Beaulieu, & Desmeules, 2012; Cardinal, Plante, & Sauvé, 2010; Office of the

French Language Services Commissioner of Ontario, 2016). Active offer is expected to help create an environment that will stimulate the demand for services in French and will anticipate the needs of Francophones in their community.

Active offer refers to series of measures taken by publicly funded organizations to ensure that French-language services are clearly communicated/publicized, visible, available at all times, easily accessible and equivalent to the quality of services offered in English (Office of Francophone Affairs, 2016). The concept of an active offer implies the shift of responsibility from the patient who would typically need to ask for a health service in French to the organizations that would first offer and deliver this service (Bouchard et al., 2012). For the active offer to be implemented, provision of services in French should become part of organizations' policies, integrated into the organizational culture, from the board of directors to direct services (Bouchard et al., 2012). Such measures call for changes in how health services are organized and managed at both organizational and system level.

At the system level, providers of health services comprise mainly Anglophone (occasionally bilingual) institutions governed by varying administrative and legislative structures from one province to another (French Language Health Services Working Group, 2005). These institutions are not subject to national quality standards. Neither are there standards to provide a framework for linguistically and culturally adapted health services such as, for example, CLAS (Culturally and Linguistically Appropriate Services) in the US (Koh, Gracia, & Alvarez, 2014; Office of Minority Health, 2002) or the Strategic Framework for Welsh Language Services in Health, Social Services and Social Care in the UK (Roberts & Burton, 2013). In Ontario, the French Language Services Act

of 1986 provides the main legal framework for the provision of health services in French (Bouchard et al., 2012; Office of the French Language Services Commissioner of Ontario, 2016). The French Language Services Act guarantees the right to receive services in French from Government of Ontario ministries and agencies in 25 designated areas, an area where Francophones make up at least 10% of the population. However, the French Language Services Act has shown to be of limited usefulness in health care: Access to health services in French remains limited and poorly publicized (Office of the French Language Services Commissioner, 2016).

The French Language Services Act is associated with a process of *designation*, according to which health-care institutions can voluntarily chose to provide the population with health care services in French or can be identified and ordered to provide such services. Designation is an official recognition of organization's capability to actively offer services in French according to designation criteria (French-language Health Services Network of Eastern Ontario, n.d.; Office of Francophone Affairs, 2016). The process of designation involves several actors: The Ministry of Health and Long-Term Care; Office of Francophone Affairs; Local Health Integration Networks, 14 local health authorities created in Ontario in 2006 as part of the regionalization reform; French Language Health Services Network that works with Local Health Integration Networks to facilitate the planning and provision of health services in French; and a health service provider that delivers services in French. French Language Health Services Network of Eastern Ontario supports health-service providers in their quest for designation. The Office of Francophone Affairs revised its criteria for designation in 2013 to guarantee an active offer of services. Designated agency must 1) offer French-language services on a

permanent basis by employing people with requisite level of French-language skills; 2) guarantee French-language services can be provided for all or some services and during business hours; 3) ensure Francophones sit on boards of directors and committees in proportion to Francophone population in the community; 3) have Francophones in senior management in proportion to the local Franco-Ontarian population; and 4) make directors and senior managers accountable for the quality of French-language services. These criteria have been criticized for lacking legal obligations toward health-care organizations (Office of the French Language Services Commissioner of Ontario, 2016).

In the past, neither the Ministry of Health and Long-Term Care, nor designated health service providers, have had to be accountable for the provision of health-care services in French (French Language Health Services Working Group, 2005).

“Maintenance and development of health-care services in French have been plagued by the minimalist and reductionist attitude of past governments in dealing with health-care services for the Franco-Ontarian community. Health care services in French are usually an afterthought. Too often these services are provided only after there have been community pressures or when ordered by the courts.” (French Language Health Services Working Group 2005, p. 5). It is in this environment that health service providers must make effort to meet the designation criteria for the active offer of services in French.

At the organizational level, health service providers have the responsibility for creating the environment, introducing policies, allocating resources, training and educational programs to adapt and offer services in the language and culture of the Francophone communities they serve (Tremblay & Prata, 2012). The establishment of an active offer of health services in French affects not only the organization of health-care

delivery and associated service planning; allocation of human, financial and technological resources; and implementation of care processes; but also their management. Organizations engaging in the provision of services in French are expected to make these services a norm and integrate them in organization's management and its strategic priorities. Thus, improvement of health services in French also depends on effective leadership (Vézina & Andrew, 2007).

Along with leaders and managers, health-care professionals also play an important role in the organization of services in French, (Tremblay & Prata, 2012). In fact, health service providers are at the core of linguistically and culturally appropriate health services in Ontario. Improvements in the delivery of the active offer of French language services will be slow and difficult to make if organizational context in which health service providers operate is not understood. However, there has been a paucity of studies exploring the planning and implementation of the active offer of health services in French at organizational level. This study contributes to this particular area of research by exploring the perspectives of health-care administrators regarding the planning and implementation of an active offer of health services in French.

A novel theoretical framework of organizational health literacy (Schillinger & Keller, 2011) is applied to this study. Organizational health literacy includes a set of measures that can help create a health-literate organization that makes it "easier for people to navigate, understand, and use information and services to take care of their health" (Brach et al., 2012). Health-literate health-care organizations recognize that literacy, language, and culture are intertwined, and their efforts help reduce inequities in care and improve the organization's linguistic and cultural competence (Andrulis &

Brach, 2007; Sudore et al., 2009). Organizational health literacy posits that transition from health-care organization to health-literate health-care organization involves changes in organizational structures, processes, personnel, and technologies to improve access to and the quality, safety, and value of health-care services. The 10 attributes provide concrete, practical actions that organizations can take to create an environment that promotes cultural and linguistic competence and facilitates an active offer of care and services (Brach et al., 2012). A health-literate health-care organization 1) has leadership that makes health literacy integral to its mission, structure, and operations; 2) integrates health literacy into planning, evaluation measures, patient safety, and quality improvement; 3) prepares the workforce to be health literate and monitors progress; 4) includes populations served in the design, implementation, and evaluation of health information and services; 4) meets the needs of populations with a range of health literacy skills while avoiding stigmatization; 5) uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact; 6) provides easy access to health information and services and navigation assistance; 7) designs and distributes print, audiovisual, and social media content that is easy to understand and act on; 8) addresses health literacy in high-risk situations, including care transitions and communications about medicines; 9) communicates clearly what health plans cover and what individuals will have to pay for services.

Like active offer, organizational health literacy emphasizes the shift of responsibility from an individual to the health-care system to activate and support patients in navigating information and services, steering them toward timely and appropriate care (Palumbo & Annarumma, 2014).

Methods

This focus group is part of the study of reorganization and management strategies taken by health-care organizations in Ontario to deliver an active offer of health services in French. It includes the analysis of designation plans of 12 health-care organizations to identify adaptations made by health service providers for the provision of health services in French. The focus group discussion was convened on December 11, 2015 in Kingston, Ontario as part of the meeting organized by the French Language Health Services Network of Eastern Ontario (<http://www.rssf.on.ca/en/>) with identified health service providers in Southeastern Ontario. Nine representatives, which included midlevel and senior managers who had responsibility for the designation plan within their organizations from 8 out of 12 identified health service providers were present. The meeting was held to review health service providers' progress on designation plans and to discuss bilingual staffing and recruitment of Francophone board members. Health service providers included one general hospital, one specialty hospital, three community health and social service organizations, one community mental health program of a local public health agency, and a community care access centre. The meeting and the focus group were held in English.

The focus group was moderated by the author. It began with a brief presentation of the concept of health literacy and the health-literate organization. Before proceeding to the discussion, participants were introduced to the protocol (e.g., taking turns to speak, allowing everyone to express their opinions and respecting them) and ethical aspects of their participation in the focus group (right to withdraw, not answer questions, no

personal health information or identifiers are collected, no names used in the resulting publication). An interview guide has been developed to guide the focus group discussion (Appendix 5.1). The discussion lasted 68 minutes and, upon its completion, the participants were handed an exit survey and instructed to return the survey to the moderator before leaving the meeting.

The survey assessed the degree to which health-care organizations identified for designation for French language services have made changes to achieve visibility, availability, and accessibility of health services to help Francophone patients to navigate, understand, and use their information and services in French (Appendix 5.2). Items in the survey questionnaire are based on the attributes of health-literate organizations (Brach et al., 2012), the CLAS (Office of Minority Health, 2002), health literacy universal precautions toolkit (Brega et al., 2015), and a validated health-literate health-care organization 10-item questionnaire (Kowalski et al., 2015). The survey consists of 15 statements organized in four categories: leadership, visibility, accessibility and quality of care. It took 5–10 minutes to complete. Using the scale from “absolutely not” to “to a very large extent”, the questionnaire assesses the extent to which an organization takes measures to promote visibility, availability and accessibility of French language services.

The focus group discussion was audio-recorded using Voice Recorder Pro application and manually transcribed for further analysis.

Data Analysis

Deductive qualitative content analysis was applied to the data. This method allows examining meanings, themes and patterns that may be manifest or latent in a

particular text and make inferences from it (Mayring, 2000). Using specific theory to guide the analysis makes it possible to understand reality in a subjective but scientific manner. In this study, features of organizational health literacy (Schillinger & Keller, 2011) were used as an initial framework to identify features and experiences related to the planning and implementation of an active offer of health services in French. The deductive category application process described by Mayring (2000) was applied to the data. The data was analyzed for evidence of organizational commitment and leadership accountability for French language services, sufficient supportive infrastructure to guarantee access to French language services, availability of workforce with French-language skills, and policies and practices to offer quality French language services on a permanent basis and to support effective communication. Based on the analyses, the following categories of data were identified and are reviewed below: integration of the active offer, workforce, engagement of Francophones at organizational level, misrepresentation and sustainability.

Results

Integration of the Active Offer

The discussion begun with the participants exploring the definition of an “active offer” of French language services adopted within their respective organizations. The participants reacted immediately and unanimously by identifying two issues that they perceived integral to French language services, *accessibility* and *integration*.

The fact that we are jumping there [accessibility and integration] is because by the experience (laughter) of folks who are local health

providers, our experience is if we take it that way [in isolation] it will not translate into anything, it will not be accepted [by the leadership, management and staff]. (Participant 07)

Accessibility is described as “being out there, making things available and meeting patients where they are at,” as an effort that increases awareness and makes the organization, its services and processes known and transparent, as knowing the needs of your patients and being proactive offering a needs-based care and information. Participants stated that conversations about the provision of French language services give rise to discussions about the provision of services in other languages reflecting the needs of other minorities served by the organizations. In this context, the prevailing concern is about equitable offer of services in languages preferred by the patients: “If we provide services in English and French, should we not satisfy such need for other groups?” ask the participants. Accessibility of French language services should be also looked at as a service that is accessible to Francophones with various disabilities, including limitations in hearing and vision.

From the point of view of the participants, providing French-language services represents a facet of organizational culture and mission and cannot be tackled on its own. The active offer of French language services should be more than an individual project; it has to become part of an organizational value, integrated deeply and explicitly into all of the organization’s activities, including both strategic and operational planning.

Isolation is an easy way out. We will never get anywhere if we do not integrate FLS in everything else we do. (Participant 03)

While integration was seen as necessary for the promotion of French language services, the majority of participants revealed that their organizations struggled to decide

which department should lead the French-language-services-related work and also to identify activities under which French language services should be included. Participants identified corporate-support services and health-care quality improvement and patient safety as the most appropriate departments and strategic operational planning and patient-centred care as the most appropriate activities under which to implement the French language services. One participant from a large hospital shared that their organization placed French language services in its strategic plan under PCC because “active offer is about being patient-centric.” Participants observed that placing French language services under human resources is limiting for French language services and does not help to integrate successfully into organization’s mission and functioning. The importance of the practical definition of *active offer* was emphasized in one instance where French-language services were framed and presented to the board of directors as accessibility issue. The participant shared that French-language services was not getting the attention it needed from the leadership until it was made into a business case relevant for the organization and made both clinical and financial sense.

The necessity of integration has been discussed from the perspective of *intersectorality*. Specifically, participants emphasized the importance of integrating an active offer of health services with an active offer of the area’s municipal and social services. One participant brought up the issue of invisibility of Francophone community in Kingston and related difficulties with the active offer in health-care with the absence of an active offer of French language services in other sectors.

I am a Francophone and am aware of the vibrant Francophone community in Kingston, but nobody else knows that. It is not something that comes up at city council, or the city of Kingston strategic plan and because it is not coming up there when we talk about it at our board, they are questioning

why is it coming up here [health care]. ... You ride a city bus it is not as though the Kingston transit is bilingual. ... The city of Kingston was designated under the act; it is a surprise why only health-care agencies invest resources and not some of the other institutions. (Participant 07)

Workforce

The availability of sufficient numbers and properly trained personnel able to provide French-language services is a major issue in the active offer of health services.

Health-care organizations struggle not only with the lack of Francophone human resources in the geographic area where they operate but also with the retention of bilingual staff in designated bilingual positions.

At some point we were able, you know, to attract and hire four staff that were fluently bilingual, and within six weeks I lost two of them because they went to an organization that had a bigger carrot. You know, you are investing time, energy, training, you are setting up practices or changing maybe a process, and then the rug gets pulled out from underneath you. So, you start back again (sigh). It is a huge challenge, and I think we all recognize that. (Participant 04)

It is almost like we are competing (laughter) with each other for the same resources! When you are smaller, non-for-profit organization in the community, the people that come and work with you quite often they are there gaining experience and that sort of thing in order to progress with their career. So, you have them for a while, and then... then they are scooped up because there is a better opportunity somewhere. So, the scarce resources and everybody is competing for the same [resources]. (Participant 05)

Participants reported to have relied on grants from Local Health Integration Networks/the Ministry of Health and Long-Term Care and help from interns and practicum students to be able to make progress with French language services. Continuous budget cuts do not permit to allocate sufficient fiscal and human resources necessary to effectively and efficiently meet French language services goals.

As an organization we are looking at how to manage lack of staff. Because you just cannot go and train everybody up to an intermediate level of French for no money (laughter). (Participant 07)

Participants stated that hiring bilingual staff is not enough to assure provision of high quality French language services; providers of French language services should possess professional skills, have proficiency in both French and English, and be culturally competent. As a result, individuals with sufficient language skills but insufficient professional qualifications may be hired to fill bilingual positions. However, hiring for language skills tends to result in tensions among staff members and a poor quality of service. Participants feel that while they try to satisfy the language need for one group of patients, many more end up receiving poor service.

As a response to the shortage of Francophone staff, organizations often adopt strategies that permit French-speaking staff from other departments or programs to shadow English-speaking staff as translators. However, according to participants, such strategies rarely work. Medical care requires specialized knowledge and Francophone staff is not always able or prepared to assist with translation.

I have a director who went to university and [did] schooling in France, who is a pharmacist, she cannot describe chemo in French... and the number of times that she would need to do that, she is not comfortable... and the skill level that she would need to maintain to be able to provide equal [to English] service. So, it is no service or equal [service]... They [staff] are just not comfortable in saying I can do something and then be not 100% confident. (Participant 06)

Other concerns of staff shadowing include risks associated with inaccurate translations, ethical aspects and privacy issues in the context of medical care, and overburdening of front-line staff.

With the cutbacks front-line staff members are at their max. You ask them to do one more thing than what they are already doing and they will loose their minds! (Participant 07)

That is why we have so much turn... because they get burned and tired in one area and they like “meh, that place is looking better I am going there,” and because we all are hiring regardless of language because we cannot fill all our vacancies! (Participant 06)

As potential solutions to the above-mentioned issues, participants proposed establishing a shared pool of part-time Francophone employees and/or rotation of bilingual staff among the organizations designated to provide French-language services. The participants agreed that such a pool of part-time employees would meet the needs of Francophone patients and the needs of organizations that do not require full-time bilingual staff. Such arrangements could be attractive for bilingual employees, too, but would require discussions about provision of pensions and benefits to part-time staff.

New language requirements and revisions in job descriptions make unilingual staff feel vulnerable in their employment and create “resistance” to changes, according to participants. This discomfort brings up issues with unions that require revision of collective agreements. Participants anticipate that health-care organizations with highly unionized environments will face issues with premiums and also superseniority as they advance with the implementation of the active offer of French language services because collective agreements do not include provisions for French language at this time.

Engagement of Francophones at the Organizational Level

With few exceptions, participants feel that their organizations are not yet ready to support patient engagement at organizational level. There is a need for a bilingual person, such as service coordinator, to facilitate the engagement of the Francophone community.

Large organizations engage Francophones by establishing structures such as a Client Advisory Committee or Council that represents clients and provides direct access to their feedback. Smaller organizations do not have the capacity for a service coordinator and/or Client Advisory Committee and instead may engage with Francophones only at the individual level (patient's own health and health care). Organizations face barriers that do not allow them to maintain the momentum with client engagement due to frequent and unforeseen changes.

We did not have the capacity to reach out to Francophone community until we hired somebody... so, we do not know a whole lot about Francophone community because they do not know what we offer. So, we are just trying to get out there and build relationships and kind of let them know about the services. With a small team it is really difficult to be accessible to all different types of communities. For us with French language services it is two steps forward one step back. We'll have it [capacity] and then we have a staff change or a board change... and then I do not have a Francophone board member anymore... I had one for five minutes... great! It is always like that, always. (Participant 07)

As a strategy for client engagement, organizations use regular satisfaction or experience surveys to collect feedback about services provided. However the surveys are not specific to French language services and do not include items such as language and culture. As a result, current surveys do not allow delineating aspects of care experience or satisfaction with French language services.

Misrepresentation and Sustainability

While organizations make efforts to satisfy the designation criteria for French language services, many participants expressed concerns about misrepresentation of care in French. The continuum of health-care services in French is lacking severely, and

bilingual signage and welcome in both official languages misleads clients about the extent to which French language services is actually offered.

We have done the signage, interior and exterior ... when [clients] come in they can see bilingual signage, and I feel like we are misrepresenting because they are going to go like I want to have this, you know, I want all my services [in French], well, there is no way... I can get you an interpreter, but I cannot guarantee capacity. I have bilingual staff whose first language is French and they said to me I am not comfortable other than saying “there is the washroom.” (Participant 06)

Having some bilingual staff does not guarantee the provision of French language services across the continuum of services within the organization. Bilingual staff cannot be reliably used as translators and employees proficient in French should not be assumed to be able to act as translators in all health-care situations. Inaccurate translations and misrepresentation of the capacity for full French language services may have insurance and/or legal consequences. The issue of misrepresentation of French language services extends further to third party contracts for specialized services and geographic continuity of French language services. The concern is that organizations will not be able to ensure that a third party providing a service on their behalf can take appropriate measures to deliver highly specialized services in French. Such actions may mislead patients to believe that all services are available in French. In terms of geographic continuity, organizations that have multiple branches struggle to offer and deliver health care in French in catchment areas where there is low concentration of Francophones. The matter is that organizations do not only serve these areas but also recruit from there, which makes it difficult to guarantee French language services.

According to participants, active offer of French language services is accomplished mostly by front-line staff, but to become sustainable, it has to be integrated

into strategic planning and recognized as one of organizational priorities. It also has to be aligned well with health-care reforms and changes that organizations must undergo.

Participants believe that such integration and alignment are not yet happening well to be able to support French language services.

We are going through a very large redesign process with the LHIN... when you think of change, and time and resources, everything is put into that... and the limited resources that we have to do our own job and work on that stuff [redesign process], and (emphasis) do French-language designation... unfortunately it becomes less of a priority... (Participant 08)

Organizations identified for designation of French language services face multiple barriers to offering health services in French. They include lack of health human resources with proficiency in French, constant staff turnover, limited financial resources and constant budget cuts, limited support from staff and leadership to advance French language services, low prioritization of French language services, isolation of French language services efforts and lack of intersectoral integration of French language services. The sustainability of French language services may be problematic if these barriers are not addressed.

Sometimes I get discouraged, to be honest, and I feel that the active offer and the designation are unattainable. Sometimes it gets put on a backburner because everything else that is pressuring takes over and that is not right, and it should not happen, but it is reality. So, you are struggling not knowing where to invest your scarce resources. (Participant 05)

Survey Results

Seven out of 9 participants filled out the survey. Overall, results suggest that issues of leadership, visibility, accessibility and quality of care for Francophone clients were addressed from some to very little extent: organizations scored an average of 43

(range 30–62) out of possible 90. At this time, identified organizations make little effort to promote French-language services through appropriate policies, planning, practices, and allocated resources, and do not engage in regular assessment of community health assets and needs of Francophones living in the service area (Annex 2, items 1 & 2). Issues of visibility (items 3–8) have been addressed to some extent, while very little effort has been made to ensure the competence of Francophone providers. All items of accessibility (10–12) have been addressed to a very little extent. Similarly, the quality of care (items 14–15) has been addressed to a very little extent. Identified organizations do not conduct assessments of French-language-related activities and do not integrate them into quality improvement initiatives at this time.

Discussion

Qualitative data from a focus group with health-care administrators and results of the exit survey provide a unique insight into the planning and implementation of the active offer/organizational health literacy and associated challenges. Essentially, this article illustrates that most organizations applying (voluntarily or as identified health service providers) for the designation of the active offer of French language services and operating in a predominantly English environment have to make significant changes to establish an actual active offer of French language services and assure its visibility, accessibility, and quality. It appears, that there is a significant gap between where the services are and where they ought to be to satisfy the designation criteria for the active offer of French language services. Similar disparity is also noted by Drolet and colleagues for Eastern Ontario, which has the official bilingual label and the actual level of services available in French in that area (Drolet et al., 2014). Numerous structural and

institutional barriers need to be dealt with or removed to make the active offer a reality and a norm at most if not every health-care organization serving Francophone communities. Our results reveal an intuitive fact that although organizational changes are implemented with the purpose of establishing an active offer of French language services, these changes are unlikely to be sufficient to ensure visibility, availability, and accessibility of health services from the point of offering services to their actual delivery. Ontario government must strengthen collaboration with health-care organizations to help them build capacities for the effective active offer of French language services. A set of guidelines, standards, tools and best practices relevant to the provision of health services in French must be adopted or developed, where necessary, and offered to health service providers pursuing the active offer of French language services beyond the examples provided by the French Language Health Services Network of Eastern Ontario as part of their support with the designation.

Ontario's health-care system should be built with the recognition that Franco-Ontarians are one of the founding peoples of this country and that the Canadian government has constitutional and legal obligations to protect its Francophone minority. If these sentiments were shared by the decision-makers in health care, that alone would help bring in the necessary cultural change that needs to be made to Ontario's health-care system (French Language Health Services Working Group, 2005). Cultural competence of health-care organizations is not a favour done by health-care professionals or health-care organizations to Francophone minorities; rather it is an entitlement as fundamental as access to, safety of, and equity in health care (Aucoin, 2008).

Our findings about challenges with recruitment and retention of Francophone staff due to lack of Francophone professionals, unavailability of these professionals in certain geographic areas, lack of appropriate incentives, added workload, linguistic challenges, fatigue, and stress common among bilingual staff who sometimes have to serve as translators and interpreters have been corroborated by two other studies (Drolet et al., 2014; Lortie & Lalonde, 2012). Drolet and colleagues report that health-care professionals encounter numerous challenges in the actual provision of services to minority Francophones inherent in the active offer of health services in French (Drolet et al., 2014). Authors state that Francophones are subject to societal expectations of higher levels of spoken French and English, and, as a result, many Francophones harbour a sense of linguistic inferiority and a profound awareness of their minority status (Boudreau & Dubois, 2008). Because of this, health-care professionals have to be flexible and modify their spoken French in order to be understood, and to support and accommodate their patients' access to services every step of the way (Drolet et al., 2014).

Similar to participants in our study, all participants in the study conducted by Drolet et al. pointed to limited organizational resources, a shortage of Francophone or bilingual staff who could offer a full range of services in French, and a lack of Francophone or bilingual organizations to which patients could be referred (Drolet et al., 2014). Hiring bilingual health professionals to adapt services to French helps optimize communication between patients and health professionals (Ouimet, Trempe, Vissandjée, & Hemlin, 2013). Although using bilingual professionals for interpretation purposes is a widespread practice, it has limits. First, it may reduce productivity, because bilingual staff must interrupt their work to be able to assist their colleagues. Second, bilingual staff

may express considerable dissatisfaction with being frequently called upon to provide interpretation services (Ouimet et al., 2013). They may not always feel competent as interpreters and are almost never compensated for these services. Ouimet and colleagues point to another important fact that may be underestimated by health-care administrators, that health professionals' salaries may be higher than those of interpreters, and using them as interpreters may not be the best option from the resource management point of view (Ouimet et al., 2013).

A study of the offer of health services in French in Ontario, Nova Scotia, and New Brunswick (Forgues et al., 2011) reveals that staff report having insufficient training opportunities to improve their French-language skills. Other researchers suggest that time-limited training opportunities to learn French may in fact be less effective than expected because such training does not permit the development of sufficient language and cultural skills necessary to provide full-fledged services in French (Ouimet et al., 2013). Both Forgues et al. (2011) and Ouimet et al. (2013) suggest that such training programs must be studied and evaluated to determine their effectiveness and, if necessary, to suggest viable alternatives.

Forgues and colleagues report that health-care organizations do not engage with the Francophone communities and may have little to no information about linguistic profiles of their patients (Forgues et al., 2011). This is consistent with what the French Language Health Services Working Group discussed in its report more than a decade ago: Historically, the Francophone community has not been engaged in the planning of health-care services (French Language Health Services Working Group, 2005). It seems

that engagement of Francophone communities in the design and delivery of care has not yet become a norm in Ontario.

Participants in the focus group raised concerns about the misrepresentation of the extent of health services provided in French. Forgues et al. (2011) and our study demonstrate that organizations tend to prioritize assuring active offer of French language services in the reception and making bilingual signage. However, health services are not usually guaranteed beyond these efforts. Forgues et al. (2011) also report that provision of services in French and consideration of French language vary greatly across hospitals' departments. This points to the necessity of standardizing the provision of French language services not only across the continuum of care and organizations, but also across the departments and programs in one organization.

Conclusions

The objective of this qualitative study was to explore the perspectives of health-care administrators regarding the planning and implementation of an active offer of health services in French. A novel theoretical framework of organizational health literacy (organizational health literacy) (Schillinger & Keller, 2011) was applied. Organizational health literacy posits that transition from health-care organization to health-literate health-care organization involves changes in organizational structures, processes, personnel, and technologies to improve access to and the quality, safety, and value of health-care services. By applying this framework to the active offer of health services in French, this project provides a glimpse into the transition from health-care organization to health-care organization actively offering health services in French. Data was analyzed

for evidence of organizational commitment and leadership accountability for health services in French, supportive infrastructure to guarantee access to services in French, availability of workforce with French-language skills, and policies and practices to offer quality services on a permanent basis and to support effective communication. Based on the analyses, the following categories of data were identified and reviewed in this paper: integration of the active offer, workforce, engagement of Francophones at organizational level, misrepresentation, and sustainability. Taken together, the results of this study suggest that there is a significant gap between where the services are and where they ought to be to satisfy the designation criteria for the active offer. Numerous structural and institutional barriers need to be dealt with or removed to make the active offer a reality and a norm in health care. Results presented here reveal that, although organizational changes are implemented with the purpose of establishing active offer of health services in French, these changes are unlikely to be sufficient to ensure visibility, availability, and accessibility of health services from the point of offering to their actual delivery. Ontario government must strengthen collaboration with health-care organizations to help them build capacities for the effective active offer of services. A cultural change is needed within the health-care system (and beyond) in the way government officials, health-care organizations, health-care professionals and the public look at, and deal with, health-care services in French for the Franco-Ontarian community.

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Chapter 6

Conclusions

Conclusions

The research in this dissertation *Organization of health services for minority populations: the role of organizational health literacy and an active offer of health services in French in Ontario* weaved together the concepts, literature, and knowledge on health literacy, linguistic minorities, organizational health literacy, and active offer of health services in French in order to explore solutions to contemporary challenges of health-care delivery for linguistic minority populations. The outcome of this research illustrates that the design of health-care systems may not be conducive to improving health literacy and health outcomes in vulnerable populations such as linguistic minorities. While health-care organizations may make changes to improve the access to and the quality of care for linguistic minorities, these changes are too often insufficient to change the status quo; they require systemic integration and connection to organization-wide continuous quality improvement efforts. Although the concept of organizational health literacy has not yet received the attention it deserves in health services research, its relevance is clear: Health-care organizations must be health-literate themselves to be able to foster health-literacy skills in their clients and patients. The novel theoretical framework of organizational health literacy may offer the potential of improving and strengthening the process of designation and planning of an active offer of health services in French. Transformation from health-care organization to health-literate health-care organization is not a simple process and will require an increased attention and support from researchers, decision-makers and practitioners.

This research resulted in four key outputs—notably, a scoping review on health literacy in the context of linguistic minority populations, the subject of the first article.

Among other findings, results of this review suggest that the design of health-care systems may not be conducive to improving health literacy and health outcomes in linguistic minorities. Future research should focus on health systems and on the provision of care that is sensitive to the needs of linguistic minority populations to be able to realize improvements in health-literacy levels in this vulnerable population. Specifically, I identified two main focuses for future research and quality improvement efforts to improve health literacy in linguistic minorities: the creation of patient-engagement-capable health-care systems and the health-literate system redesign. Drawing on the work of Carman et al. in patient engagement (2013) and the propositions of Fang, Machtiger, Wang, & Schillinger (2006) for the role of health system in elimination of low health literacy, I define patient-engagement-capable health-care systems as those that are responsive to the needs of minority populations, comprehensive in their systemic approach to bring health-care delivery to the level of health literacy appropriate for the provision of assistance to linguistic minority populations. In turn, health-literate system redesign refers to organizational structures and processes aimed at improving access to and quality of care for linguistic minority populations. While these two approaches may sound similar and aim at similar level of redesign, they differ: The former aims to engage patients while the latter creates the environment for the patients to engage in their healthcare process and experience.

Findings of the scoping review led me to continue my investigations into health-literate health-care redesigns. In the second article, I focus on the critical review and analysis of guides for organizational health literacy and examples of their application by health-care organizations. Having reviewed the content of 19 organizational health

literacy guides developed in 2006–2015, I observe that the guides have improved tremendously to help build a person-centred, evidence-based, and quality driven health-literate health care. Although complex, these guides provide evidence-based recommendations and best practices to support health-literate actions. I also found that the concept of organizational health literacy is theorized and operationalized from several different perspectives. While no theory dominates thinking about organizational health literacy at this time, I nonetheless conclude that organizational health literacy is envisioned predominantly from a population health perspective, but conceptualized as a safety and a quality improvement issue. I see a host of issues coming out of this disconnect between the theory and the practice of organizational health literacy and discuss them in my second article. While I raise concerns about this apparent disconnect, I do not propose any alternatives except making a recommendation for further development of the concept of organizational health literacy. Few examples of the application of organizational health literacy guides that I was able to identify in published literature are limited to the assessment of health-literacy barriers at health-care organizations (i.e., they have not advanced from the assessment to implementation of organizational health literacy). Assessment tools were used successfully, required few organizational resources, and caused little to no interference with patient care (Groene and Rudd, 2011). They were regarded as a useful and feasible exercise to provide direction for improvement (Groene and Rudd, 2011; Johnson, 2014; Weaver et al., 2012). An interesting finding, according to Weaver and colleagues (2012), is that health-care professionals already implement some of the health-literate practices, although informally. However, these practices are not recognized as health-literate due to the lack

of familiarity with the concept of health literacy (Weaver et al. 2012). It would make an interesting and pertinent project to investigate implementation of organizational health literacy designs as the topic continues to gain prominence and the uptake of the organizational health literacy guides increases over time.

Having previously worked on the provision of health services for Francophone minorities in Ontario and being closely familiar with the concept of an active offer of health services in French, I began to see similarities between the concept of organizational health literacy and the active offer which I have addressed in chapter one of this dissertation. When an opportunity came to access data of 12 health-care organizations that have begun implementation of the active offer, I decided to try to apply the organizational health literacy framework to examine reorganization and management strategies taken by these health-care organizations to receive designation for an active offer of health services in French. The analysis that I conducted focuses on health literacy dimensions (e.g., access and navigation, communication, consumer involvement, workforce, leadership and management, meeting needs of population) and quality improvement characteristics of the guides (e.g., team, goal setting, assessment, health-literacy improvement actions), and also organizational-level changes categorized into administrative strategies, direct client services, corporate identity and communications, and governance and accountability. Results of this analysis made the topic of my third article, which reveals that few health-care organizations providing services in French put in place concrete strategies to guarantee availability, visibility and accessibility of French language services. I found that strategies for achieving quality of care were often reduced to the availability of providers with French-language skills and availability of information

translated into French, which may not be sufficient to really improve the quality of care for the Francophone minorities. I observed that plans for change were often integrated only in some organizational policies and processes and that there was little evidence of an integration of an active offer of French language services into performance measurements, evaluations and quality improvement. I propose organizational health literacy as a novel approach to responsiveness to care for organizations building capacity for health services in French and make several recommendations that will help improve the provision of quality French language services and its active offer. I must add that the active offer of health services in French is a highly controversial topic, and the results of this research may suggest that there may be a lack of enthusiasm or reluctance on the part of health care organizations to engaged with and assure provision of health services in French. In fact, the results must be interpreted with consideration of the context in which these organizations operate. As I described in article 4 (chapter 5), this context is far from favourable and urgent changes are necessary for the active offer to succeed.

This research would not have been complete without also exploring the perspectives of health-care administrators and professionals about the active offer of French language services/organizational health literacy. In my fourth, and final, article I present findings from a focus group with health-care administrators from organizations that have been identified as providers of French language services and are currently preparing their designation plans for French language services. This article provides a unique insight into the planning of the active offer of French language services/organizational health literacy and associated barriers ad facilitators. Essentially, this article illustrates that most organizations applying (voluntarily or as identified health

service providers) for the designation of the active offer of French language services and operating in a predominantly English environment are largely unprepared to implement the active offer; there is a significant gap between where the services are and where they need to get to; there are numerous structural and institutional barriers that need to be dealt with or removed to make the active offer a reality and a norm. While health care organizations continue to struggle with numerous barriers including the lack of integration of French language services in non-health care sectors (e.g., transportation, social services), there is unlikely to be a significant progress with the visibility, availability, and accessibility of health services in French in Ontario (and elsewhere).

As I discussed in chapter 1 and chapter 4, the social dynamic in Ontario, including health-care settings, favours English. The use of French in health care requires cultural changes to promote parity of care between Anglophones and Francophones in Ontario. Despite the existence of the French Language Services Act and other legislative acts that guarantee language rights, social relations continue to influence behaviours in all spaces where they apply. From this perspective, research presented in this dissertation reveals an intuitive understanding for the importance of the active offer to help redirect social norms. There is a need to continue to empower linguistic minorities to access and use health services to take care of their health. However, responsibility for the offer of services, their delivery, and adequate quality, should be shifted to health-care organizations. Coproduction of health can only occur when both patients and health-care organizations and the entire health-care system are designed and are prepared to engage effectively in this process. A prominent blogger, “Doctor as designer,” Dr. Joyce Lee, writes:

We all know that the “operating system” and “user experience” of health care is complicated and problematic; yet we expect the user to adapt to our impossible to navigate systems and respond to our difficult to understand communication tools. If the user fails to master our obtuse system, we label them as having low “health literacy” (check out over 7000 articles published on the topic in PubMed!). I am reminded of the patient “adherence” problems that I have written about before, which leads to me ask: Is it a patient literacy problem or a health-care design problem? Shouldn’t the design of the system be created so that anyone at any level of health literacy can navigate the system for themselves or for their loved ones? Shouldn’t the user interface be so intuitive, so “smart,” that any user could be successful at achieving health?” (Lee, 2016).

Lee warns that by labelling patients with low or high health literacy we inadvertently create a divided society. Those with high literacy supposedly mastered the nuances of our increasingly complex health care and those with low health literacy are left to try and fail. I agree with Dr. Lee that the term *health literacy* indeed becomes a euphemism for a health-care apartheid. I firmly believe that design of health-care could help us change this injustice.

In addition to the limitations described in detail in each article, I’d like to add that my research into health-literate designs and the active offer remains incomplete without also exploring the perspectives of the Francophone users of health care. It would be important to gather their ideas about the redesign and management of the active offer of health-literate health services in French and share these findings wide with health-care administrators across health-care settings in Ontario. This leads me to another limitation of my dissertation, which relates to the spread and implementation of the active offer of health services in French in nondesignated areas—i.e., areas where Francophone make up less than 10% of the population. In spite of the research that describes the negative impact of language barriers on health care (Bouchard and Desmeules, 2011; Bouchard et al., 2009; Bowen, 2001, 2004), few health jurisdictions or institutions have implemented

policies that would require some form of language access service to be provided to all patients (the Ministry of Health and Long-Term Care, 2009). Future research should address reorganization of health services in nondesignated areas to improve quality and cultural competence of health services everywhere in Ontario.

The research presented in this dissertation has a number of strengths, including protocol-driven reviews, comprehensive searches of literature, careful quality assessment, and properly conducted mixed methods studies. This research generated rich, detailed data that leave the participants' perspectives intact and provide multiple contexts for understanding the phenomenon of the active offer of French language health services. This research vividly demonstrates realistic views of the lived experiences with the active offer of French language services in the predominantly English environment in Ontario. It draws attention to and facilitates understanding of the concept of health-literate health services important in the creation of responsive health-care systems for linguistic minorities by offering: 1) the first ever review of linguistic minorities in the context of health literacy; 2) a unique analysis of literature on organizational health literacy (theories, guides and their implementation); 3) the first ever analysis of strategic designation plans of healthcare organizations focusing on linguistic minorities in the context of health literacy. It uses of a novel theoretical framework of organizational health literacy that offers the potential of improving and strengthening the process of designation and planning of an active offer of French language health services.

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Figures

Figure 2.1: Detailed search strategy PubMed

Pubmed platform¹ & search terms:
("health literacy"[MeSH Terms] OR ("health"[All Fields] AND "literacy"[All Fields]) OR "health literacy"[Title/Abstract] AND ("minority groups"[MeSH Terms] OR ("minority"[All Fields] AND "groups"[All Fields]) OR "linguistic"[All Fields] OR ("ethnic groups"[MeSH Terms] OR ("ethnic"[All Fields] AND "groups"[All Fields]) OR "ethnic groups"[All Fields] OR "ethnic"[All Fields]) OR ("communication barriers"[MeSH Terms] OR ("communication"[All Fields] AND "barriers"[All Fields]) OR "communication barriers"[All Fields] OR ("language"[All Fields] AND "barrier"[All Fields]) OR "language barrier"[All Fields]).

¹ Above search modified for OVID (Medline), EMBASE and PsycINFO

Figure 2.2: PRISMA Flow Diagram

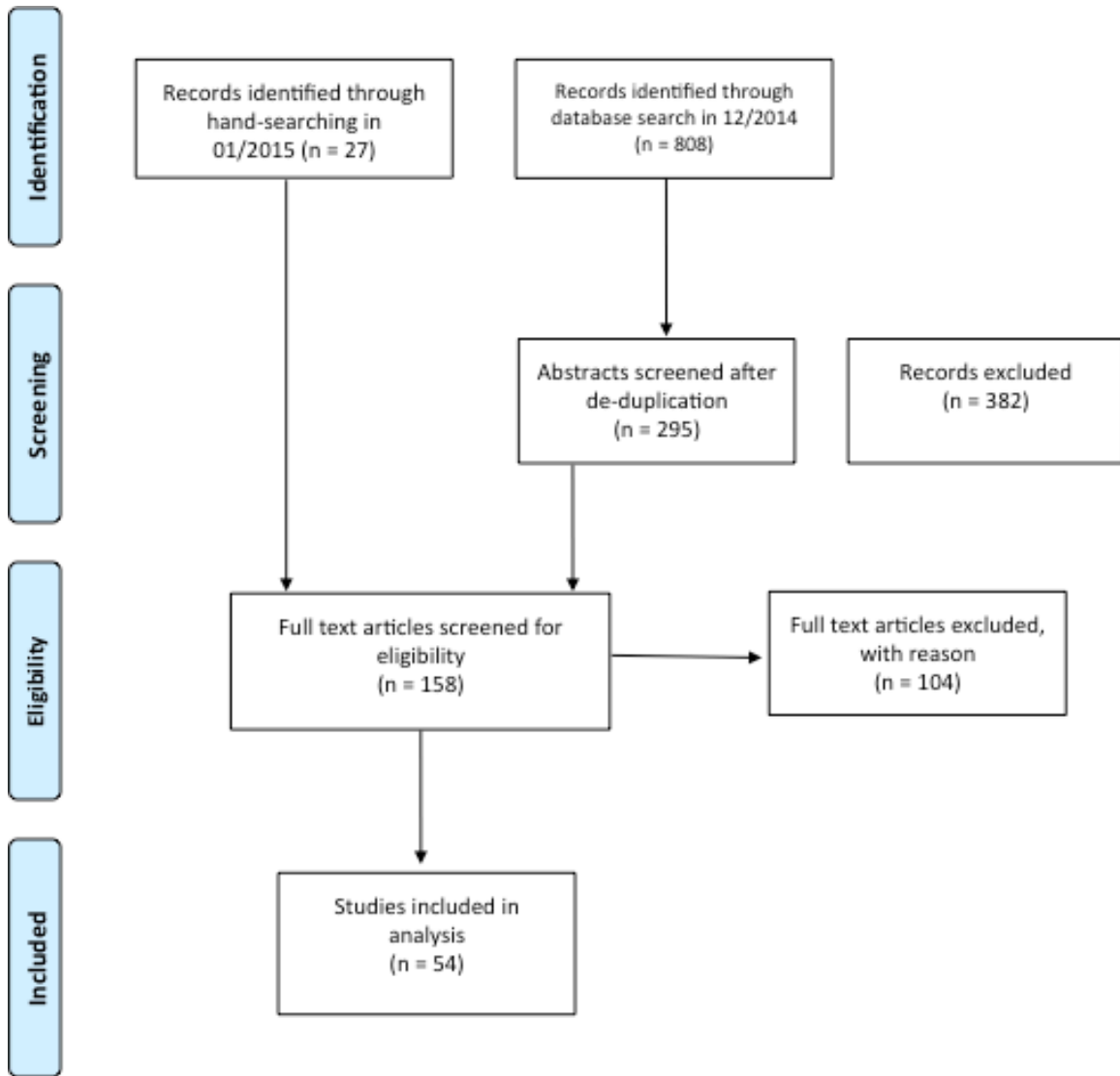


Figure 3.1: Detailed search strategy OVID (Medline) platform² & search terms

Step	Searches
1	Health Literacy/og [Organization & Administration]
2	limit 1 to humans
3	(health literate adj3 (organi?ation* or care or healthcare or hospital* or service* or policy or policies or system or systems)).ti,ab.
4	(health literacy adj3 (organi?ation* or care or healthcare or hospital* or service* or policy or policies or system or systems)).ti,ab.
5	Organizations/
6	Models, Organizational/
7	Delivery of Health Care/
8	Health Policy/
9	Policy Making/
10	Organizational Culture/
11	quality of health care/
12	5 or 6 or 7 or 8 or 9 or 10 or 11
13	Health Literacy/
14	12 and 13
15	Patient Participation/mt [Methods]
16	Patient Participation/td [Trends]
17	Patient engagement/td [Trends]
18	Health Communication/mt [Methods]
19	12 or 15 or 16 or 17 or 18
20	13 and 19
21	1 or 3 or 4 or 20

Search terms used:

care
 delivery of health care
 health
 health communication
 health literacy
 health policy
 healthcare
 hospital*
 literacy
 literate

² Above search modified for Pubmed, EMBASE and PsycINFO

models, organizational
organization*
organizational culture
organizations
patient engagement
patient participation
policies
policy
policy making
quality of health care
service*
system
systems

Figure 3.2: PRISMA Flow Diagram

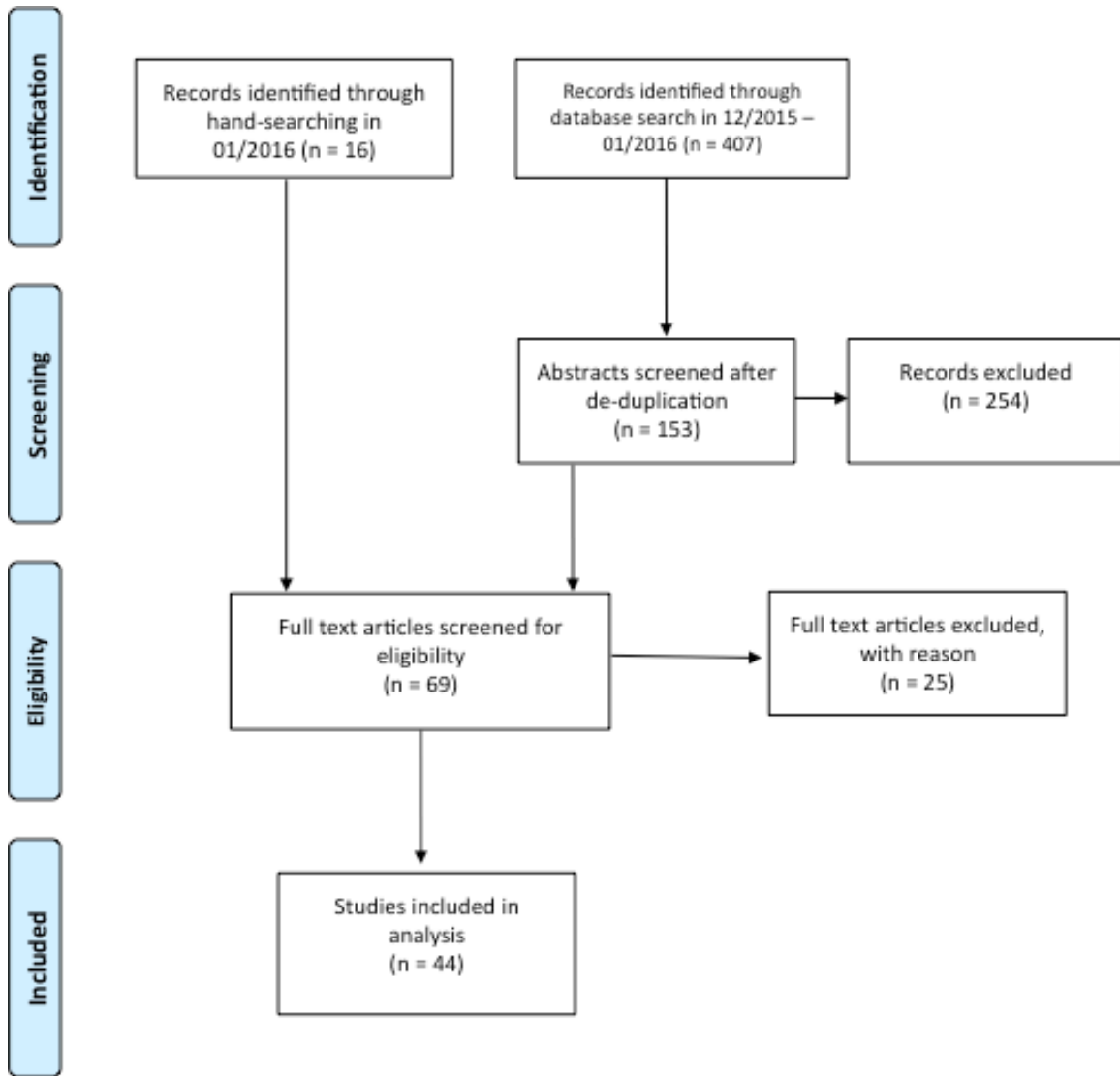


Figure 3.3: Conceptual map of theories and operational frameworks of OHL

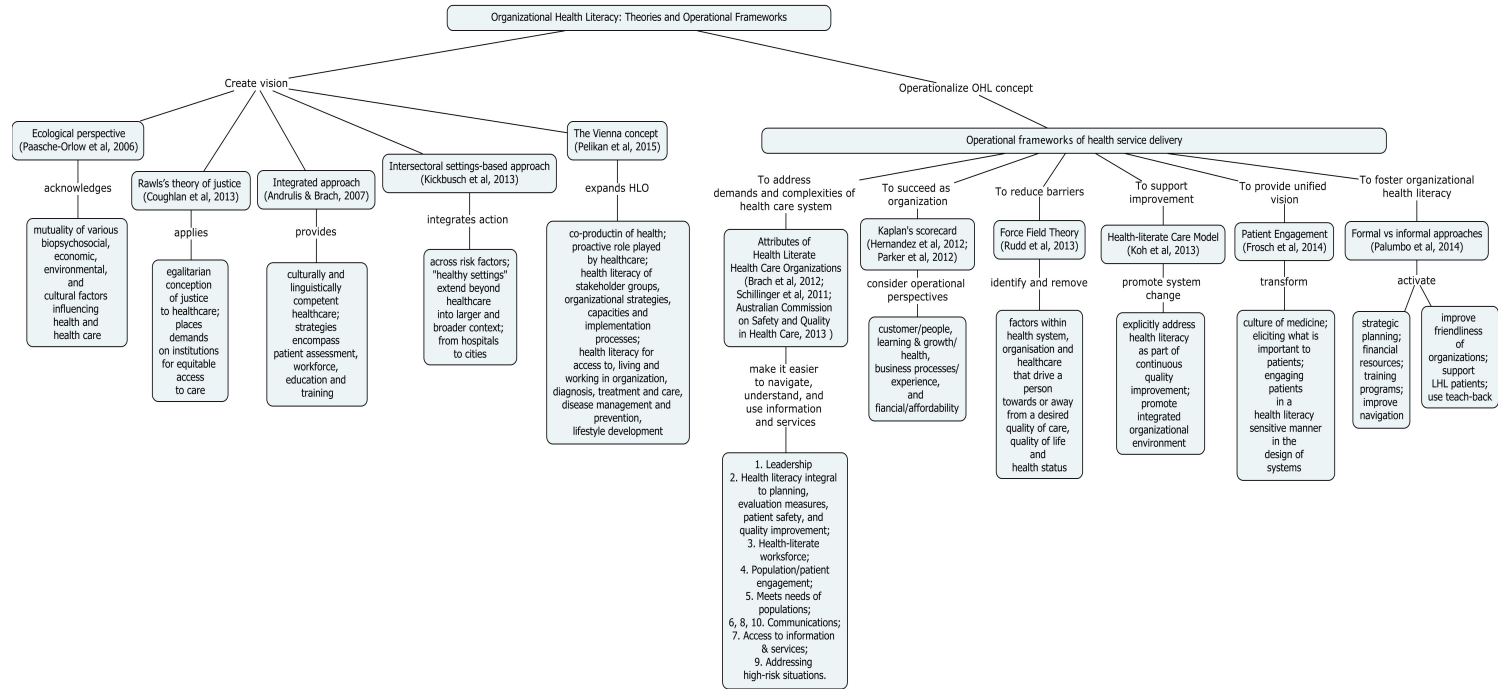


Figure 4.1: Process of designation for an active offer of health services in French

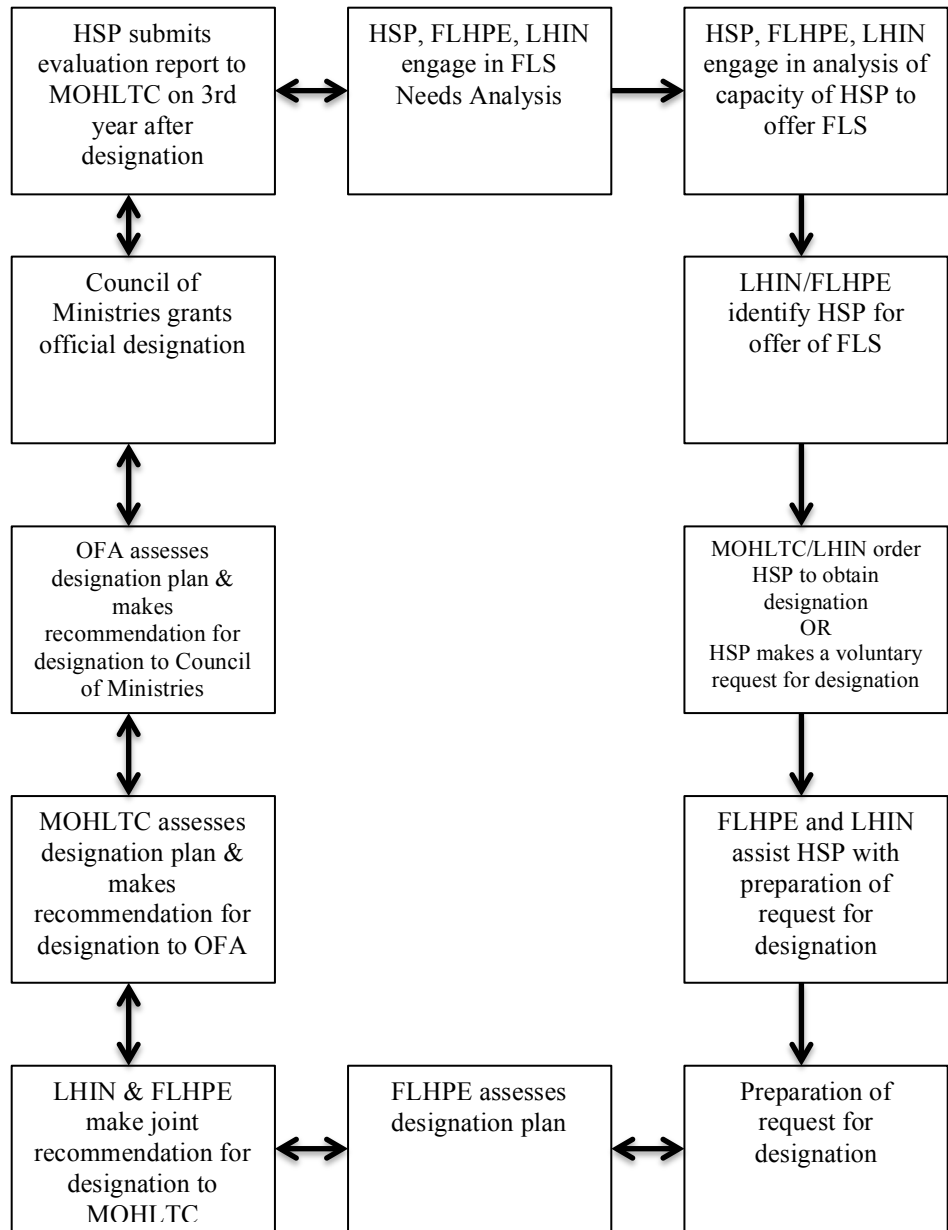
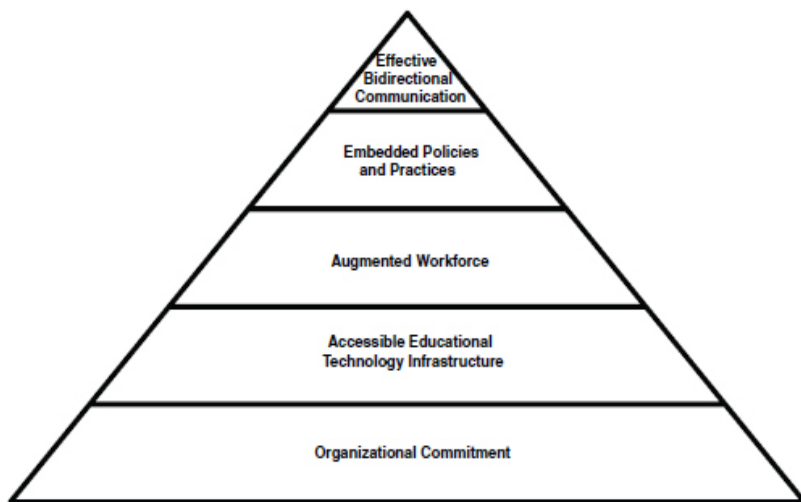


Figure 4.2: Framework for attributes of health literate health care organizations.



Source: (Schillinger & Keller, 2011)

Tables

Table 2.1: Research foci and themes for research and quality improvement

Patient-engagement capable healthcare systems:		Health-literate service redesign:	
Area of research and improvement	Rationale/Research questions	Area of research and improvement	Rationale/Research questions
1. Care interface (e.g., making appointments, follow ups etc.).	<p>Language is a problem for many minority patients when making an appointment, during the appointment, and with the follow-up instructions (Britigan et al., 2009). Bouchard et al recommend that healthcare services should be actively offered in minority languages, signage and documentation should exist in both English and a minority language to promote equality and the use of minority languages in healthcare (Bouchard et al., 2010).</p> <p>Research question(s): What care interfaces have been tried with patients from linguistic minority groups and what is the evidence of their effectiveness?</p>	1. Culturally adopting, tailoring EBTs	<p>Evidence Based Treatments (EBTs) are developed and tested in non-minority populations, which makes EBTs not always appropriate for all patients (Ramos & Alegria, 2014). Guidelines for cultural adaptations and studies detailing the adaptation process are lacking. Some suggest standardizing treatment protocols to reduce disparities that may arise from differences in patients' level of health literacy (Fang, Machtinger, Wang, & Schillinger, 2006).</p> <p>Research question(s): Can standardizing EBTs assure their applicability with linguistic minority patients? Does cultural adaption of EBTs show clinical superiority to their standardization?</p>
2. Care navigation	<p>Research shows that individuals with low health literacy have difficulty navigating the healthcare system (Gazmararian et al., 1999; Wang et al., 2013). Recommendations have been made to introduce “care navigators” offering orientation and translation/interpretation services to minority patients and particularly older adults to ease care</p>	2. Patient–provider communication	<p>When the patient's first language is not the prevalent language of the healthcare system, patient-provider communication becomes problematic. Cultural discordance acts as an obstacle to patient-provider communication by introducing conflicting beliefs, perceptions and expectations regarding care and low health literacy all negatively impact information</p>

Patient-engagement capable healthcare systems:		Health-literate service redesign:	
	<p>navigation process (Bouchard et al., 2010).</p> <p>Research question(s): What do we know about practices related to "care navigation" and their application with patients belonging to linguistic minority groups?</p>		<p>exchanges (Fry-Bowers, Maliski, Lewis, Macabasco-O'Connell, & DiMatteo, 2014). Bouchard et al recommend the development, evaluation and adaptation of communication tools and decision aids in minority language (Bouchard et al., 2010).</p> <p>Research question(s): What practices or strategies in patient-provider communications have shown to be effective with linguistic minority patients and might be considered as best practices?</p>
3. Development of decision aids	<p>Low health literacy can be problematic to understand forms, signs, and instructions encountered in healthcare system (Lora et al., 2011). Trupin et al recommend providing low literacy decision aid tools to promote shared decision-making and treatment decisions that align with patient preferences (Trupin, Barton, Evans-Young, Imboden, & Gross, 2012). Bouchard et al recommend development of cue or flash cards (available on Internet and also in healthcare settings) containing frequently used medical terms and their plain language definitions (Bouchard et al., 2010) .</p> <p>Research question(s): What evidence-based decision aids can be used with linguistic minority patients? What best practices could be recommended for use in health-literate systems of care?</p>	3. Treatment adherence/compliance	<p>To effectively adhere to complex regimens typically associated with chronic disease management, patients must have a clear understanding of the instructions provided and basic understanding of the importance of these regimens for chronic diseases and the severity of complications if regimens are not followed (Servellen et al., 2003).</p> <p>Research question(s): What is the evidence about the effectiveness of treatment adherence/compliance methods used with linguistic minority patients?</p>

Patient-engagement capable healthcare systems:		Health-literate service redesign:	
4. Shared decision-making	<p>Linguistic minority patients commonly lack adequate information and support to make an informed healthcare decision (Trupin et al., 2012). Fang et al (2006) discuss the phenomenon of <i>undertreatment</i> or withholding of therapy among eligible minority and elderly patients due to barriers to communication with providers and lack of comprehension.</p> <p>Research question(s): How can shared decision-making involving linguistic minority patients be supported within the healthcare system?</p>	4. Short visits with providers	<p>The pressures of today's healthcare environments make it difficult for physicians to spend an extended period of time with their patient, which affects the establishment of a trusting patient-provider relationship, patient education, and the quality of patient care. Medical encounters are limited to 15-20 min per patient/addressing one two issues at a time (Fang et al., 2006; Poureslami & Rootman, 2007).</p> <p>Research question(s): How could the structure and process of a medical encounter change and improve to accommodate complex needs of linguistic minority patients?</p>
5. Cross-cultural training of healthcare professionals	<p>Many have suggested that cross-cultural training of healthcare professionals would help improve the quality of care and also eliminate persistent racial and ethnic disparities (Poureslami & Rootman, 2007). In the context of linguistic minorities, Bouchard et al (2010) recommend that healthcare providers be made aware of language rights of their minority patients, their healthcare experiences and cultural differences.</p> <p>Research question(s): What cross-cultural training shows best results and is most beneficial to what kind of healthcare providers?</p>		

Patient-engagement capable healthcare systems:		Health-literate service redesign:	
6. Patient activation	<p>Some discuss the necessity of preparing both the system and the patients to actively participate in care and creating an informed and activated patient (Penaranda, Diaz, Noriega, & Shokar, 2012; Rooks, Wiltshire, Elder, BeLue, & Gary, 2012; Servellen et al., 2003; Shaw, Armin, Torres, Orzech, & Vivian, 2012).</p> <p>Research question(s): What evidence do we have to judge the effectiveness of patient activation practices? What patient activation practices are relevant for and applicable with patients from linguistic minority groups?</p>		

Table 3.1: Descriptive characteristics of OHL guides

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Rudd & Anderson	2006	USA	To assist leadership and staff to consider health literacy environment of healthcare facilities	Hospitals or health centers	Approach for analyzing health literacy related barriers to healthcare access and navigation and an action plan	1. Navigation; 2. Print Communication; 3. Oral Exchange; 4. Technology; 5. Policies & Protocols	Y
The Joint Commission	2007	USA	To improve health literacy, reduce communications-related errors, and better support the interests of patients and providers of care	Healthcare delivery organizations	Recommendations for improving communications	1. Make communications organizational priority to protect safety of patients; 2. Address patients' communication needs across continuum of care	N
Jacobson (A Pharmacy Health Literacy Assessment Tool User's Guide)	2007	USA	To capture critical perspectives about pharmacy health literacy as a step for quality improvement in organizations that serve individuals with limited health literacy	Outpatient pharmacies of large, urban, public hospitals	Pharmacy health literacy assessment	1. A Pharmacy Assessment Tour; 2. A survey for pharmacy staff; 3. A guide for focus groups with pharmacy patients	Y

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Peters, 2008 (Health Literacy Audit)	2008	Canada	Identify patients' health literacy needs, reaffirm practices done well, give suggestions for improving health information	Healthcare delivery organizations	Checklists to help health organizations and providers choose more literacy-friendly methods of communicating with patients	1. Advertising; 2. Health facility setting; 3. Admission procedures; 4. Appointments; 5. Discharge procedures; 7. Patient education; 8. English as an Additional Language and Cultural Sensitivity; 9. Clear print materials; 10. Staff and volunteer training	Y
Deasy et al, 2009 (Literacy Audit for Healthcare Settings)	2009	Ireland	To address literacy issues in healthcare settings	Healthcare delivery organizations	Assessment and best practice guidelines for implementation	1. Literacy awareness; 2. Navigation - finding your way around; 3. Print materials; 4. Visuals; 5. Verbal communication; 6. Websites and kiosks; 7. Health literacy summary sheet	Y
Emory University and America's Health Insurance Plans	2010	USA	To evaluate the health literacy friendliness of health insurance plans	Healthcare organizations that have health insurance plans	Self-assessment tool helps identify areas in need of improvement to enhance health literacy at organisational level	1. Printed Member Information; 2. Web Navigation; 3. Member Services/Verbal Communication; 4. Forms; 5. Nurse Call Line 6. Member Case/Disease Management	N

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Rudd et al., 2010 (The Health Literacy Environment Activity Packet First Impressions & Walking Interview)	2010	USA	To address physical navigation as part of the creation of the Health Literacy Environment of a Healthcare Facility	Hospitals and health centers	Assessment of physical navigation to and within the healthcare organization	First impressions [phone call, website review, and walk to facility's entrance]; Walking interview [navigation, observation, reflections, use of signs, feedback].	N
DeWalt, 2010 (Health Literacy Universal Precautions Toolkit)	2010	USA	To provide step-by-step guidance and tools for assessing your practice and making changes so you connect with patients of all literacy levels	Primary care practices	Assessment and implementation strategies to make changes to connect with patients of all health literacy levels	1. Spoken Communication; 2. Written Communication; 3. Self-Management and Empowerment; 4. Supportive Systems	NR
Strickland (A Health Literacy Tool Kit for Healthcare Providers: Improving Communication with Clients)	2011	Canada	To provide practical tools, applications and resources for communication with clients and encourage integration of user-friendly modules into training curriculum of healthcare providers	Healthcare delivery and social services organizations	Practical tools, applications and resources for communication with clients	1. Introduction to Health Literacy; 2. Communicating with Your Clients; 3. Plain Language and Clear Design	NR
Ten Attributes of Health Literate Health	2012	USA	To describe 10 attributes of health literate healthcare	Healthcare delivery organization	Assessment and implementation strategies to	1. Leadership; 2. Integration of health literacy; 3. Workforce; 4. Public/patient	N

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Care Organizations			organizations	s	become a health literate organization	engagement; 5. Needs of populations; 6. Communication with providers; 7. Access; 8. Health information; 9. Care transitions; 10. Communication about payment.	
Thomacos & Zazryn (Enliven Organisational Health Literacy Self-assessment Resource)	2013	Australia	To provide health and social service organisations with a self-assessment tool to guide and inform their development as health literate organisations	Health and social service organisations	Assessment and implementation strategies to become a health literate organization	1. Leadership; 2. Integration of HL; 3. Workforce; 4. Public/patient engagement; 5. Needs of populations; 6. Communication with providers; 7. Access; 8. Health information; 9. Care transitions; 10. Communication about payment.	Y
Dodson et al. (Health literacy toolkit for low- and middle-income countries)	2014	WHO	To assist organizations and governments to incorporate health literacy responses into practice, service delivery systems, and policy	Health systems in low- and middle-income countries	Information sheets and recommendations for action to assess health literacy needs of communities and strengthen health systems	Promotes the Ophelia approach to optimizing HL based on the identification of community HL needs, and the development and testing of potential solutions.	N

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Abrams et al. (Building Health Literate Organizations: A Guidebook to Achieving Organizational Change)	2014	USA	To help organizations of any size become health literate healthcare organizations	Healthcare delivery organizations	A change package to transform care environment, culture, policies and procedures to delivery health-literate care in a health-literate organization	1.Engaging leadership; 2.Preparing the workforce; 3.The care environment; 4.Involving populations served; 5.Verbal communication; 6.Reader-friendly materials; 7.Case study	N
Brega et al. (Health Literacy Universal Precautions Toolkit Second Edition)	2015	USA	To support primary care practices in addressing shortages in health literacy.	Primary care practices	A change package to reduce the complexity of healthcare, increase patient understanding of health information, and enhance support for patients of all health literacy levels.	1. Spoken Communication; 2. Written Communication; 3. Self-Management and Empowerment; 4. Supportive Systems	N
Cifuentes et al. (Implementing the AHRQ Health Literacy Universal Precautions Toolkit:	2015	USA	To offer implementation advice based on experiences of 12 primary care practices from the Demonstration of Health Literacy Universal Precautions	Primary care practices	A companion to the AHRQ Health Literacy Universal Precautions Toolkit	1. Spoken Communication; 2. Written Communication; 3. Self-Management and Empowerment; 4. Supportive Systems	N

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Practical Ideas for Primary Care Practices)			Toolkit				
French (Transforming Nursing Care Through Health Literacy ACTS)	2015	USA	To transform nursing care through health literacy ACTS educate patients and advocate for practical improvements in healthcare systems accessibility.	Nursing care	An informal practice guideline based on universal precautions and health literacy to healthy-literate nursing care	ACTSs	N
The New Zealand Ministry of Health (Health Literacy Review: A guide)	2015	New Zealand	To help carry out a health literacy review and build a health-literate organisation	Healthcare delivery organizations	A change package to conduct health literacy review and develop action plan	1. Leadership and management; 2. Consumer involvement; 3. Workforce; 4. Meeting the needs of the population; 5. Access and navigation; 6. Communication	N
Centers of Disease Control and Prevention, (Making Health Literacy Real: The Beginnings of My Organization's	ND	US	To help organizations get started in developing your own plan to change organizational and professional practices to improve health literacy	Healthcare delivery organizations	Assessment and plan of action	1. Identifying my advocates; 2. Getting buy-in; 3. Commitment to planning; 4. Honest assessment; 5. Consider barriers & solutions; 6. Developing your action plan; 7. Next steps; 8. Planning resources	N

Author/Guide	Year	Country	Objective	Healthcare sector	Focus	HLO elements included	Score
Plan for Action)							
Clinical Excellence Commission (Health Literacy Guide)	ND	Australia	To assist health services by providing practical strategies to address health literacy barriers for patients	Healthcare delivery organizations	Assessment	1.Gap Analysis; 2.Recruiting advisors; 3.Literacy and communication; 4.Numeracy; 5. Way-finding; 6.Quick start check list	N

Table 3.2: Health-literate dimensions of OHL guides

Guides	Dimensions of health-literate organizations					
	Access and navigation	Communication	Consumer involvement	Workforce	Leadership and management	Meeting needs of population
Rudd, 2006 (The Health Literacy Environment of Hospitals and Health Centers: Making your Healthcare Facility Literacy Friendly)	Access to health literacy-friendly telephone system; physical environment.	Print communication; Oral Exchange		Orientation and training in health literacy, oral exchange with patients; English for Speakers of Other Languages courses		Assistance with medical records, pharmacy, translation, etc.
The Joint Commission, 2007 (What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety)	Wayfinding (especially with consideration for patients with Limited English Proficiency)	Effectiveness of communication among caregivers;		Training to recognize and respond to patients with literacy and language needs	Create culture of safety and quality; ensure easy access to services	Improve accuracy of patient identification; medication reconciliation; self-management; care transitions; use medical interpreters
Jacobson, 2007 (A Pharmacy Health Literacy Assessment Tool User's Guide)	Promotion of services; physical environment	Print materials; clear verbal communication	Requesting feedback during assessment	Assessment of workforce		Assessment of care processes
Peters, 2008 (Health Literacy Audit)	Physical environment	Advertising; clear print materials		Staff and volunteer training (e.g., use of plain language, easy to read materials, use of readability tool)		Admission; appointments; discharge; patient education; English as an Additional Language and

Guides	Dimensions of health-literate organizations					
	Access and navigation	Communication	Consumer involvement	Workforce	Leadership and management	Meeting needs of population
						cultural sensitivity
Deasy et al, 2009 (Literacy Audit for Healthcare Settings)	Wayfinding	Print materials; Visuals; Verbal communication; Websites and kiosks		Health literacy awareness training		
Emory University and America's Health Insurance Plans, 2010 (Health Plan Organizational Assessment of Health Literacy Activities)	Web navigation	Printed information; verbal communication; forms; nurse call line; case/disease management		Training health communication (embedded in nurse call line; case/ disease management)		Nurse call line; case/ disease management
Rudd, 2010 (The Health Literacy Environment Activity Packet First Impressions & Walking Interview)	Wayfinding	Printed words, internal and external signs, plain language, translation (as part of Walking Interview)				
DeWalt, 2010 (Health Literacy Universal Precautions Toolkit)	Access to health-literate telephone system; signs, physical environment and navigation	Verbal and print communication; use of teach-back method	Use of teach-back method; follow up with patients; patients' feedback to improve self-management	Health literacy awareness training	Commit to health literacy universal precautions	Language assistance; use of teach-back; follow up with patients; "Brown Bag review" of medicines; referral for non-medical

Guides	Dimensions of health-literate organizations					
	Access and navigation	Communication	Consumer involvement	Workforce	Leadership and management	Meeting needs of population
						services
Strickland, 2011 (A Health Literacy Tool Kit for Healthcare Providers: Improving Communication with Clients)		Communicating with your clients; plain language and clear design				
Brach, 2012 (Ten Attributes of Health Literate Health Care Organizations)	Easy access to health information and services; assistance with navigation	Interpersonal communications; print, audio-visual, and social media content	Involved in design, implementation, and evaluation of health information and services	Training and involvement in monitoring progress	Make health literacy integral to mission, structure, and operations	Practices allowing to avoid stigmatization, addressing high-risk situations, medication reconciliation, innovations and technology
Thomacos & Zazryn, 2013 (Enliven Organisational Health Literacy Self-assessment Resource)	Easy access to health information and services; assistance with navigation	Interpersonal communications; print, audio-visual, and social media content	Involved in design, implementation, and evaluation of health information and services	Training and involvement in monitoring progress	Make health literacy integral to mission, structure, and operations	Practices allowing to avoid stigmatization, address high-risk situations, medication reconciliation, innovations and technology

Guides	Dimensions of health-literate organizations					
	Access and navigation	Communication	Consumer involvement	Workforce	Leadership and management	Meeting needs of population
Care Practices)	navigation					
French, 2015 (Transforming Nursing Care Through Health Literacy ACTS)	Assess health environments	Assess health materials; Use of Teach 3 or teach-back	Use of Teach 3 or teach-back; review or modification of patient educational materials	Training with peers to implement health literacy competencies training		Assess patient concerns; match relevant resources to patient knowledge gaps and needs; Use of Teach 3 or teach-back
The New Zealand Ministry of Health, 2015 (Health Literacy Review: A guide)	Assess health environment and processes; assure that consumers easily find and engage with health and related services	Identify information needs; help consumers find and engage with services	Design, development and evaluation of organisation's values, vision, structure and service delivery	Feedback about perceptions and practices relevant to health literacy; support of effective health literacy practices; health literacy training	Include health literacy in strategic and operational plans	Service delivery assures that consumers are able to participate and have their HL needs identified and met
Centers of Disease Control and Prevention, n.d. (Making Health Literacy Real: The Beginnings of My Organization's Plan for Action)	Assess physical environment	Health information forms & fact sheets; verbal communication	Identify champions, allies, workgroup members	Identify champions, allies, workgroup members;	Gain endorsement from senior leadership; "vet" health literacy improvement plan	

Guides	Dimensions of health-literate organizations					
	Access and navigation	Communication	Consumer involvement	Workforce	Leadership and management	Meeting needs of population
Clinical Excellence Commission, n.d., (Health Literacy Guide)	Wayfinding	Develop and assess patient information; improve communication, understanding and use of information; signage	Recruit consumer advisors	health literacy training for reception, admissions and hotel services		Use teach-back; assist with medications [how to take, explain new medications, etc.]

Table 3.3: Quality improvement characteristics of OHL guides

First author/Guides	Form team	Set aims	Assess	Establish measures	Communicate, raise awareness	Develop action plan	Test changes	Track progress/Sustain efforts
Rudd, 2006 (The Health Literacy Environment of Hospitals and Health Centers: Making your Healthcare Facility Literacy Friendly)			x			x		
The Joint Commission, 2007 (What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety)		x			x	x		
Jacobson, 2007 (A Pharmacy Health Literacy Assessment Tool User's Guide)			x		x	x		
Peters, 2008 (Health Literacy Audit)			x					
Deasy et al, 2009 (Literacy Audit for Healthcare Settings)			x					x
Emory University and America's Health Insurance Plans, 2010 (Health Plan Organizational Assessment of Health Literacy Activities)			x					
Rudd, 2010 (The Health Literacy Environment Activity Packet First Impressions & Walking Interview)			x					
DeWalt, 2010 (Health Literacy	x	x	x	x	x	x	x	x

First author/Guides	Form team	Set aims	Assess	Establish measures	Communicate, raise awareness	Develop action plan	Test changes	Track progress/Sustain efforts
Universal Precautions Toolkit)								
Strickland, 2011 (A Health Literacy Tool Kit for Healthcare Providers: Improving Communication with Clients)			x					
Brach, 2012 (Ten Attributes of Health Literate Health Care Organizations)	x	x	x	x	x	x		
Thomacos & Zazryn, 2013 (Enliven Organisational Health Literacy Self-assessment Resource)	x	x	x	x	x	x		
Dodson, 2014 (Health literacy toolkit for low- and middle-income countries)			x			x		x
Abrams, 2014 (Building Health Literate Organizations: A Guidebook to Achieving Organizational Change)	x	x		x	x	x	x	x
Brega, 2015 (AHRQ Health Literacy Universal Precautions Toolkit Second Edition)	x	x	x	x	x	x	x	x
Cifuentes et al., 2015 (Implementing the AHRQ Health Literacy Universal Precautions Toolkit: Practical Ideas for Primary Care Practices)	x	x	x	x	x	x	x	x

First author/Guides	Form team	Set aims	Assess	Establish measures	Communicate, raise awareness	Develop action plan	Test changes	Track progress/Sustain efforts
French, 2015 (Transforming Nursing Care Through Health Literacy ACTS)			x			x		
The New Zealand Ministry of Health, 2015 (Health Literacy Review: A guide)	x		x	x	x	x		x
Centers of Disease Control and Prevention, n.d. (Making Health Literacy Real: The Beginnings of My Organization's Plan for Action)	x	x	x	x		x		
Clinical Excellence Commission, n.d., (Health Literacy Guide)		x	x			x	x	

Table 3.4: Key barriers to organizational health literacy

1.	Low priority of health literacy and related activities
2.	Lack of commitment to health literacy
3.	Limited or no buy-in from leadership
4.	Becoming health-literate is not perceived advantageous
5.	Lack of culture of change and innovation
6.	No change champions in the organization
7.	Not having procedures, policies, protocols supporting health-literate practice
8.	Not having enough time
9.	Lack of resources
10.	Complexity of health literacy tools and guides
11.	Ambiguity of roles among staff
12.	Lack of training in health literacy
13.	Lack of awareness about health literacy

Table 4.1: Conformity scale

Conformity requirements	Conformity, 0-100% ³											
	A ⁴	B	C	D	E	F	G	H	I	J	K	L
Organization has put in place or instituted:	A ⁴	B	C	D	E	F	G	H	I	J	K	L
Administrative regulations												
1. ... a detailed announcement about the delivery of French-language services (FLS)	0	0	5	0	0	0	0	5	0	5	0	0
2. ... a policy on planning and provision of FLS	5	0	5	5	5	5	5	5	5	5	5	5
3. ... a committee to support the planning and provision of FLS	5	5	5	5	5	5	5	5	5	5	5	5
Direct client services												
4. ... direct services, including switchboard/reception, voice mail and other systems offered in French	0	0	5	5	5	5	5	5	5	5	5	5
5. ... a procedure to help identify linguistic identity/ language of preference of clients at first contact	5	0	5	5	5	5	5	5	5	5	5	5
6. ... a plan and/or policy and procedures to prepare the workforce to engage in the provision of FLS and monitor progress	0	0	5	5	5	5	5	5	5	5	5	5
7. ... policies and procedures for receiving and addressing language assistance concerns or complaints from consumers	5	5	5	5	0	0	5	5	5	0	0	5

³Total score is obtained by adding up all individual scores per statement, where “0” means No and “5” means Yes.

⁴Letters A to L replace names of healthcare organizations.

Corporate identity and communications												
8. ... a French version of the official web site	5	5	5	5	5	5	5	5	5	5	5	5
9. ... external signage in French or French and English	5	5	5	5	5	5	5	5	5	5	5	5
10. ... registration, admission and other documents in French	5	0	5	5	5	5	5	5	5	5	5	5
11. ... a policy/procedure identifying employees that speak French by signage/ID cards that they wear and business cards	5	0	5	0	5	0	5	5	5	5	0	5
12. ... a policy and procedure to address active offer of FLS/language assistance in high-risk situations, including care transitions, communications about medicines, etc.	0	0	5	0	0	0	5	0	0	0	0	0
13. ... all publications and communications intended for public access are available in French	5	5	5	5	5	5	5	5	5	5	5	5
14. ... a procedure to allow organization to respond in French to correspondence received in French	5	0	5	5	0	5	5	5	5	5	5	5
15. ... a procedure to facilitate translation into French of documents intended for public distribution	5	5	5	5	5	5	5	5	5	5	5	5
Governance and accountability												
16. ... an integration of an active offer of FLS into planning, evaluation, safety and quality improvement	0	5	5	0	0	0	5	5	0	0	0	5
17. ... a consumer satisfaction and other surveys, and other means of obtaining feedback on services delivered, including FLS	0	0	5	5	0	0	5	5	0	0	0	0
18. ... a Francophone representation on a senior management committee or a similar high level management body	5	5	5	5	5	5	0	5	5	5	5	5
19. ... a high ranking manager responsible for delivery of FLS	5	0	5	5	5	5	5	5	5	5	5	5

20. ... an adequate representation of Francophones on the Board of Directors	5	5	5	5	5	5	5	5	5	5	5	5
Total:	70	45	100	80	70	70	90	95	80	80	70	85

Appendixes

Appendix 4.1: Data Transfer Agreement RSSF - Farmanova

DATA TRANSFER AGREEMENT

This Agreement is made this October 25, 2015 by and among

ORGANISATION

Réseau des services de santé en français de l'Est de l'Ontario /
French Language Health Services Network of Eastern Ontario
(hereinafter referred to as the “Disclosing Institution”)

-and-

PRINCIPAL INVESTIGATOR

Jean-François Pagé

Directeur de la planification/Director of Planning

(hereinafter referred to as the “Disclosing Institution Principal Investigator”)

-and-

INSTITUTION

University of Ottawa, Population Health Program
(hereinafter referred to as “Receiving Institution”)

-and-

INVESTIGATOR

Elina Farmanova

PhD Student, Population Health Program

(hereinafter referred to as “Receiving Institution Investigator”)

-and-

UNIVERSITY OF OTTAWA

3042 – 800 King Edward Avenue

Ottawa, Ontario K1N 6N5
(hereinafter referred to as “Receiving University”)

-and-

UNIVERSITY OF OTTAWA INVESTIGATOR

Elina Farmanova
PhD Student, Population Health Program
(hereinafter referred to as “Receiving University Investigator”)

(Collectively Disclosing Institution and Disclosing Institution Principal Investigator are the “Disclosing Party” and Receiving Institution, Receiving University, Receiving Institution Investigator, and Receiving University Investigator are referred to individually as a “Receiving Party” and collectively as the “Receiving Parties”)

with respect to data that Disclosing Party will provide for

“Organizational health literacy and an active offer of French-language services: a study of healthcare organizations in Ontario” (“the Study”). The Study protocol (“Protocol”) as approved by the Disclosing Party’s Research Ethics Board (“REB”) is attached hereto in Schedule “A”.

The Study will not commence until the Disclosing Party’s, Receiving Institution’s and Receiving University’s respective REBs have approved the Study Protocol.

This Agreement is made in compliance with section 44(5) of the *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3 (“PHIPA”).

The parties hereby agree as follows:

1. Definition of Data; Transfer of Data. (1) As used in this Agreement, the term "Data" means organizational level publicly available data related to the designation plan and process collected by the RSSF and is provided to the Receiving Parties for the purpose of carrying out the Study in accordance with the Study Protocol as approved by the Disclosing Party’s Research Ethics Board.⁵ (2) Disclosing Party shall collect and transfer to Receiving Parties the Data in accordance with the Protocol. Disclosing Party, acting reasonably, retains the right to refuse the transfer of the Data requested hereunder.

⁵ The disclosing party’s senior management approval replaces REB as such structure does not exist as part of FLHSN. This study is eligible for an exemption from ethical review and does not require submission to an approval from the University of Ottawa REB following Article 2.2 of the Tri-council agreement.

2. Compliance with Law. In the performance of the Study, the parties shall comply with all applicable laws, regulations, guidelines and policies (“Applicable Law”), including but not limited to PHIPA. Each party agrees to notify the other(s) of changes to Applicable Law of which the party becomes aware that may necessitate an amendment to the terms of this Agreement. The parties shall promptly and in good faith take all necessary action to ensure that the terms of the Agreement remain compliant with Applicable Law.

3. Non-Disclosure of Data. (1) Without limiting the obligation set out in Section 2, the Receiving Parties each agree that it/he/she shall, and shall require its/his/her directors, officers, employees, staff, research fellows, students, consultants, and advisors who need to know such Data for the purposes of the Study (“Study Staff”) to:

(a) maintain Data in confidence, and not disclose Data except as permitted by this Agreement.

(b) use Data solely for the purposes of the Study, in compliance with

(i) the approved Study Protocol as it may be amended from time to time, provided that amendments are approved by the Disclosing Party’s and Receiving Parties’ REBs and made known to the Disclosing Party; the approved Study Protocol is attached hereto as Schedule “A”;

(ii) Disclosing Party’s and Receiving Parties’ REB letters of approval of the Study Protocol (and if applicable any written conditions imposed by the Disclosing Party’s or Receiving Party’s REB), attached hereto in Schedule “B”. The REB applications and approvals will include notice to the REBs noted above that Study subjects had previously signed a consent form agreeing to future research of Data collected by the RSSF as approved by the Disclosing Party’s REB.

(iii) the informed consent form approved by the appropriate REB,

(iv) any other reasonable conditions or restrictions imposed by Disclosing Party relating to the use, security, disclosure, return or disposal of the Data, as set out in this Agreement.

For further clarification and so that there is no misunderstanding, the Receiving Parties each agree to use the Data provided by the Disclosing Party pursuant to this Agreement solely for the purpose of this Study, and shall not use or disclose the Data for the purpose of any sub-study, secondary study or for any other purpose whatsoever.

For further clarification and so that there is no misunderstanding, although Receiving Institution, Receiving University, Receiving Institution Investigator, and Receiving University Investigator are sometimes referred

to collectively as the “Receiving Parties” in this Agreement, each Receiving Party shall be responsible for its own actions, omissions, negligence or willful misconduct relating to this Agreement and the actions, omissions, negligence or willful misconduct of its respective directors, officers, employees, medical staff, research fellows, students, and consultants. No Receiving Party shall be liable to the Disclosing Party for any breach of this Agreement by another Receiving Party.

The Receiving Parties each agree:

(a) not to compile, link or otherwise connect any of the Data or any other information provided to the Receiving Parties pursuant to this Agreement with any other individualized data or information accessible to the Receiving Parties, except with the prior written approval of the Disclosing Party’s REB.

(b) not to use the Data to identify any patients or Study subjects whose information has been copied from the RSSF.

(c) not to transfer the Data disclosed under this Agreement to any third parties without prior written consent of the Disclosing Party and without legally obligating such third parties to comply with the terms and conditions of confidentiality and non-disclosure set out in this Agreement.

(d) to destroy the Data securely as required by the Disclosing Party’s REB approval and provide a written confirmation of the manner of destruction to Disclosing Party.

(2) Receiving Parties shall each use appropriate safeguards which are at least as stringent as those it employs to protect its own confidential information and in compliance with all applicable laws and regulations to prevent any unauthorized use or disclosure of the Data and shall within twenty-four (24) hours report to Disclosing Party any unauthorized use or disclosure of Data, or any breach of this Agreement, of which a Receiving Party becomes aware. Disclosing Party and the Disclosing Party’s Research Ethics Board shall have the right on reasonable written notice and during the normal business hours of a Receiving Party to conduct audits to verify that appropriate security safeguards are in place and to ensure the confidentiality, accuracy, security, and integrity of the Data.

4. Permitted Disclosure of Data. A Receiving Party may disclose Data

(a) to its/his/her Study Staff with a need to know who are under an obligation of confidentiality with respect to the Data and are obligated by

law or contract to maintain the confidential nature of such Data, and to regulatory authorities;

and

(b) in order to comply with applicable laws or regulations or judicial process, or with a court or regulatory order, provided that the Receiving Party gives prior written notice of such intended disclosure to the Disclosing Party and that the Receiving Party takes reasonable and lawful steps to obtain confidential treatment for such disclosure and, if possible, to minimize the extent of such disclosure.

5. Publication and Ownership. Each Receiving Party shall have the right to use the analyzed Data as part of a publication or presentation of the results of the Study. The Data provided to the Receiving Parties shall remain the property of the Disclosing Party and the Receiving Parties shall retain the right to use such Data only as described in the Study Protocol and as approved by the REB of each Party and as described in this Section 5 pertaining to publication. Each Receiving Party is free to publish or present the Data in accordance with the clause herein, provided the Receiving Party proposing such publication or presentation provides a copy of the proposed manuscript for publication, or presentation, to the Disclosing Party for review at least thirty (30) days before submission for consideration for publication. Disclosing Party's and Disclosing Party's Investigator's(s') contribution to the Study shall be acknowledged appropriately in any such publication or presentation. Any publication with the Data must meet the criteria for authorship as formulated by the International Committee of Medical Journal Editors ("ICMJE") and published in its *Uniform Requirements for Manuscripts submitted to Biomedical Journals* (NEJM 336(4):309-316, January 23, 1997). The Receiving Parties shall not publish or present any personal or personal health information about a Study subject or patient in a form that could reasonably enable a person to ascertain the identity of the Study subject or patient.

The Disclosing Party's disclosure of the Data to the Receiving Parties shall not imply or lead to the inference that the Disclosing Party endorses any reports, publications or presentations published or presented under this Section 5. Accordingly, the following statement shall be prominently included in any report, publication or presentation: "This Study is based in part on de-identified data provided by French Language Health Services Network of Eastern Ontario. The interpretation and conclusions contained herein are those of the author(s) and do not necessarily represent those of the French Language Health Services Network of Eastern Ontario."

6. Budget is attached as Schedule "C" attached hereto.⁶

⁶ The study is executed solely by the principal investigator in collaboration with FLHSN and does not require additional staff or funding.

7. Liability. Each party to this Agreement assumes liability for any costs, suits, claims or penalties on account of negligent or wrongful disclosure of personal or personal health information which may arise as a result of that party's activities, except to the extent that such costs, suits, claims or penalties arise out of the negligent or intentional acts or omissions of another party or parties.

Disclosing Institution, Receiving Institution, and Receiving University shall maintain sufficient liability coverage to cover their respective liabilities and obligations under this Agreement. Principal Investigator shall maintain membership in the Canadian Medical Protective Association (CMPA).

8. Term, Termination and Survival. This Agreement shall come into effect on the date of signature of the last party to sign this Agreement, and shall continue in effect until the completion or earlier termination of the Study. Any party may terminate this Agreement on thirty (30) days written notice to the other parties. Any notice or other document to be given under this Agreement shall be in writing and shall be deemed to have been duly given if delivered by hand or courier, or sent by first class post, registered airmail to the other parties at the addresses set out above or to such other address as the parties may designate by written notice to the others. Any such notice or other document shall be deemed to have been received by the addressee on the day of delivery if delivered by hand or by courier, or five (5) working days following the date of dispatch if sent by post. The rights and obligations set forth in sections 2, 3, 4, 5, 6, 7, 8, 9 and 10 shall survive the completion or termination of the Study.

9. Notice. Any notice or other communication required or permitted to be given by a party to the others shall be sent to the following addresses:

To Disclosing Institution:

To Disclosing Institution Principal Investigator:

To Receiving Institution:

To Receiving Institution Investigator:

To Receiving University:

To Receiving University Investigator:

10. General. (1) No party shall be entitled to assign or transfer this Agreement or the rights and obligations hereunder to any third party without the prior written approval of the other parties. (2) This Agreement including the attached Schedules represents the entire understanding between or among the parties related to the Study and supersedes all previously or contemporaneously executed agreements related to the Study. In the event that there is a conflict between the terms of this Agreement and a Schedule, the terms of the Schedule shall govern. (3) This Agreement shall not be amended, modified, varied or supplemented except in writing signed by each of the parties. (4) No failure or delay on the part of any party hereto to exercise any right or remedy under this Agreement shall be construed or operate as a waiver thereof. (5) The parties hereto are independent contractors. Nothing contained herein shall be deemed or construed to create between or among the parties hereto a partnership or joint venture or employment or principal-agent relationship. No party shall have the authority to act on behalf of any other party or to bind another party in any manner. (6) Each party hereto acknowledges that it/he/she has been advised by the others to seek independent legal advice with respect to this Agreement and that it/he/she has not relied upon any of the other parties hereto for any advice, whether legal or otherwise, with respect to this Agreement. (7) No party shall use, or authorize others to use, the name, symbols, or marks of another party hereto or its's/his's/her's staffs without prior written approval from the party whose name, symbols or marks are to be used. (8) This Agreement shall be governed by and construed in accordance with the laws of the Province of Ontario and the federal laws of Canada applicable therein.

Acknowledged and agreed by:

Disclosing Institution:
Signature:
Date:
Name and Title:

Disclosing Institution Principal Investigator:
Signature:
Date:

Receiving Institution:

Signature:
Date:
Name and Title:

Receiving Institution Investigator
Signature:
Date:

Receiving University:
Signature:
Date:
Name and Title:

Receiving University Investigator:
Signature:
Date:

Schedule "A"
A copy of the Study Protocol has been provided to the parties.

Schedule "C"
Schedule C does not apply.

Appendix 5.1: Interview guide

Interview guide Planning and implementation of an active offer of French-language services

December 11, 2015

Kingston, Ontario

Part 1: Introduction (7-10 min)

- 1.1. Introduce myself. Explain the purpose of our discussion today.
- 1.2. Begin with a 5 min talk/presentation on organizational health literacy. Familiarize your group with the concept of health-literate organizations (HLO) and universal precautions. End with drawing connections between the concept of an active offer and HLO.
- 1.3. Familiarize your participants with the focus group protocol (e.g. taking turns to speak, allowing everyone to express their opinions and respecting them, etc.) and ethical aspects of their participation in the focus group (right to withdraw, not answer questions, no personal health information or identified are collected, no names used in the publication, etc.) before proceeding to the discussion.

Part 2: Focus group discussion (35-40 min).

1. Let's begin our discussion today by exploring the definition of an "active offer" adopted within your organization. *Probes for leadership and staff perspectives.*
 - 1.1. Do you think of a specific theory, model or framework when you think about the definition of an active offer? *Probe: Many think and differentiate among clinical, financial, population health, or public health perspective when they plan on make a change like this at organizational level. What guides you to imagine the vision for the active offer of French language services?*
2. To what extent you believe the active offer is currently integrated (or not) within your organization's broader strategies and actions for quality of care and patient safety? Think of the current and what would be an ideal level of integration...
 - 2.1. *Probe for organization's effort to foster a patient-centered delivery of care to all clients/patients, equity discussed and operationalized in any way, patient engagement strategies, improvements in cultural competency of your organization, its processes and workforce.*
 - 2.2. How implementation of an active offer might or has already affected your organization? Has it, for example, resulted or you think might result in new or changed organizational values, infrastructure and other resources that make ethical and equitable practices more or less likely at your organization?
 - 2.3. *Probe: point to changes in operating procedures, care team supports, tools and strategies, patient education materials and clinic forms?*

3. What are the barriers that you have encountered so far or barriers that you anticipate would limit implementation of the active offer within your organization and beyond?
 - 3.1. *Probe: In general, some identify lack of time, resources, low priority and lack of knowledge as barriers. Do these resonate with you?*
 - 3.2. Are there barriers that are more specific to your geographic area and the delivery of care in your geographic area and your organization?
 - 3.3. Let's specify barriers specifically at leadership level, service re-design and delivery, workforce preparation, communication strategies, continuous quality improvement, etc.?

4. What do your organization's clients/patients think and tell you about your organization's plan and implementation of the active offer?
 - 4.1. *Probe: How well do you think you know the needs of your clients/patients when it comes to their experience with accessing care, navigating care, interacting with providers, adhering to regimens and medication, self-management, etc.?*
 - 4.2. *Probe: Some organizations implement what is known as "universal precautions" that allow them to assume that all their clients/patients have some difficulty accessing care, understanding information, navigating care, etc. and that allows them to standardize and simplify the care process. How do you and your organization approach this interface of knowing your clients/patients and re-designing care based on this knowledge?*

Appendix 5.2: Exit Survey

Please think about your organization at this time and assess by ticking against the scale from 1 to 6 to what extent does your organization...	Absolutely not	Very little	To some extent	About half the time	To a large extent	To a very large extent
1. ...promote French-language services through appropriate policies, organization's planning and operations, practices, and allocated resources?						
2. ...conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the needs of Francophones living in the service area.						
3. ...involve patients and consumers at large in the design and evaluation of the organisation's values, vision, structure and service delivery?						
4. ...provide easy access to health information and services and navigation assistance in French?						
5. ...provide easy-to-understand print and multimedia materials and signage in French?						
6. ...have communication standards which ensure that patients understand the necessary information?						
7. ...inform all individuals of the availability of French language services orally and in writing? (e.g. asking what language patient would like to use when registering a patient for service or at an appointment)						

Please think about your organization at this time and assess by ticking against the scale from 1 to 6 to what extent does your organization...	Absolutely not	Very little	To some extent	About half the time	To a large extent	To a very large extent
8. ...recruit, promote, and support French-speaking workforce?						
9. ...ensure the competence of Francophone providers?						
10. ...educate and train governance, leadership, and workforce in culture and language appropriate policies and practices?						
11. ...address limitations or barriers in French and ensure that the patients have truly understood everything in high-risk and critical situations, including referrals, care transitions, consent forms and communications about medicines?						
12. ...offer free French language assistance to individuals who have limited English proficiency to facilitate timely access to all health care and services?						
13. ...conduct ongoing assessments of French language related activities and integrates them into quality improvement initiatives?						
14. ...provide care and services in French that are comparable in quality to care and services provided in English?						
15. ...partner with the community to design, implement, and evaluate policies, practices, and services for cultural and linguistic appropriateness in French?						