Language Related Difficulties Experienced by Caregivers of English-Speaking Seniors in Quebec

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Abstract
Little research has examined communication problems between speakers of official minority languages (patients or caregivers) and health care providers. The objective of this research was to identify the types of issues experienced by English-speaking caregivers of seniors in Quebec, as they interact with French-speaking health care providers. The majority of the caregivers interviewed indicated that they were satisfied with physicians’ interaction with the seniors they cared for. However, problems included health care providers who do not or who refuse to speak English, hospice personnel with insufficient English, anxiety about speaking to personnel in French, traveling to receive services in English, acting as an informal interpreter, receiving written documents in French, scheduling appointments through French-only phone systems or receptionists, and discrimination. The main finding is that in Quebec, language asymmetry might create additional stresses for an English-speaking caregiver, who is already likely to be stressed because of their caregiver role.

Keywords
diversity & multiculturalism, education, social sciences, medical sociology, sociology, social sciences, caregivers, health communication, communication studies, communication, sociology of health & illness

Introduction
This research originated in part with the observation in a report on the status of English-speaking seniors in Quebec, which indicated that there are relatively fewer English-speaking informal caregivers in Quebec, compared with the number of French-speaking caregivers (Commissioner of Official Languages, 2013, p. 23). A report by the Quebec Community Groups Network (QCGN, 2016) added that many English-speaking seniors in a caregiving role felt that their care activities limited their opportunities (p. 10). These observations led to a more general question about the experience of English-speaking caregivers of seniors in Quebec. Although this question may seem to be limited to a particular geographic area and language group, it is likely pertinent with respect to many caregivers who are members of a minority language community. This article seeks to summarize the scientific literature that provides evidence of the communication difficulties that patients and caregivers may experience and to provide new empirical evidence of the nature of the language related difficulties experienced by caregivers in a specific minority language group.

In the literature review, I will first refer to research that investigates the quality of communication between health care providers and patients. Many of the communication issues that are documented could extend to caregivers as well. Researchers have also studied the communication issues that may arise when there is language asymmetry between a health care provider and the patient or caregiver, and this situation may also contribute to communication problems. As well, it is useful to note certain general difficulties that caregivers often experience. The subject of research, communication difficulties experienced by English-speaking caregivers in Quebec, is related to each of these three research areas, so it is useful to summarize key observations from each before presenting the specific results from the empirical study. Finally, some background information is provided concerning health services and the situation of the English-speaking minority in Quebec that provides useful context for the observations.

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**The Quality of Communication Between Health Care Providers and Patients or Caregivers**

It is generally accepted that effective communication between patients and health care providers is essential for efficient and effective care (for example, Probst & Imhof, 2016). A number of studies indicate that effective communication does not always occur and that communication difficulties might occur between patients and health care providers. In a review of articles about the communication skills of palliative care physicians, Visser et al. (2014) found that physicians working in the intensive care unit often lacked appropriate communication training, skills, and attitudes, and that this could hinder communication. As well, in a survey study of 50 patient–physician dyads, Coran et al. (2013) found that physicians tended to underestimate patients’ pain and overestimate patient education and patients’ understanding of diagnosis and treatment explanations. Popa-Velea and Purcărea (2014) note that deficient physician communication skills and patient factors can impact the communication between physicians and patients and that training in communication can have a positive impact. This research suggests that communication problems can arise between patients and health care providers, even when the providers and patients have the same mother tongue. Such communication problems could extend to caregivers as well.

**Language Asymmetry and Communication Issues**

It is not surprising then that other researchers have identified communication difficulties that occur when there is language asymmetry between a patient and a health care provider (physician, nurse, pharmacist, social worker, etc.; Dilworth et al., 2009; Probst & Imhof, 2016; Regan Freeman, 2015). Language asymmetry (also called language discordance or a language barrier) occurs when the first language of the patient and health care provider are different. The degree of asymmetry will vary according to the general familiarity with the language that is used, and knowledge of the particular vocabulary used in the exchange. Communication could still proceed, to some degree, if the health care provider or patient reverts to a common language, or if an informal or trained interpreter is used. In some situations, little oral language might be used, as when there is recourse to gestures or drawings. However, the risk of poor communication and misunderstanding is likely to increase (Roberts, 2009).

Deficient communication or misunderstanding is more likely to occur with language asymmetry (Ferguson & Candib, 2002; Rocque et al., 2019). Medical errors or infections might also result (Flores, 2006; Roberts, 2009; Tang et al., 2015; Wasserman et al., 2014). Certain medical domains, such as mental health, could also be more sensitive to asymmetry (Bauer & Alegría, 2010). When there is language asymmetry, patients are more reluctant to ask questions about their care or about mental health (Green et al., 2005). In a systematic review of the effect of professional interpreters, Karlner et al. (2012) found that the use of professional interpreters improved the level of clinical care. This is indirect evidence that suggests that uncorrected language asymmetry may lead to communication problems that can affect the care of the patient. Although these findings concern language asymmetry between health care providers and patients, they are likely indicative of similar potential deficiencies in communication between providers and caregivers.

**The Experience of the Caregiver**

I am using the term “caregiver” to indicate an informal caregiver or family caregiver. It is useful to note various research projects that have investigated the general experience of the caregiver and, in particular, the stress and negative dimensions of this experience. For example, in a systematic review of research into caregivers and stress, the authors concluded that caregivers of people with dementia experienced chronic stress (Allen et al., 2017). In another review, Roth et al. (2015) examined both research that documents caregiver burden and articles that found that caregivers might experience positive health benefits from informal caregiving. In Canada, Turcotte (2012) used Statistics Canada data from questionnaires to provide a portrait of caregivers and also noted several health and economic consequences of being a caregiver. He found that 21% of caregivers reported feeling depressed and that those who cared for a parent or child reported more health and psychological problems.

Several qualitative studies have also examined the stresses and issues associated with caregiving. Witham et al. (2018) highlight various challenges and communication difficulties met by caregivers of people with cancer and dementia. Similarly, Ebrahimi et al. (2018) identify the difficulties and stresses experienced by caregivers of adults with mental illness, in a context where caregivers and health professionals use the same language. LaValley (2018) also underlines the difficulties caregivers can experience when communicating with health professionals. A qualitative study of the interaction between nurses and caregivers (Ward-Griffin, 2001) found that the relationship could be characterized as one of uncertainty and tension.

Although various studies have reported on the consequences of language asymmetry between health care providers and patients, little analysis is available with respect to asymmetry between providers and caregivers. In a qualitative study of nine Hispanic caregivers in the United States, Lucke et al. (2013) concluded that language was one barrier to the access of services and health care resources, which in turn influenced the quality of life and often the health of the family caregiver. A Hispanic participant in this study also pointed to the difficulty they had with paperwork in English that was provided by health services. These findings suggest areas that are likely to be deficient in an asymmetric language context.
Another qualitative study observed the communication between a Hispanic patient, a Hispanic caregiver, and an English-speaking occupational therapist (Martinez & Leland, 2015). Although only one group of three was studied, the detailed observations and themes that emerged are pertinent here. The occupational therapist indicated that the language asymmetry made it more difficult for her to explain her clinical reasoning, establish treatment priorities with the patient, and monitor the patient’s adjustment to life with a spinal cord injury. For her part, the caregiver wanted to ask many questions, but due to the language barrier, the caregiver asked for information from people other than the occupational therapist. The study also noted the occasional use of ad hoc interpreters, although both the patient and therapists identified problems with this arrangement. The authors concluded that, in this case study, language discordance emerged as a primary barrier to patient-centered care.

Background Information on the Language Context of Québec

As noted above, the scientific literature on caregivers emphasizes that caregiving can be a particularly stressful responsibility, which contributed to the research question of how English-speaking caregivers may be affected by the language context in Quebec. Before presenting the method and results, it would first be useful to provide some background information on this context, for those who are not familiar with it. The majority of the population in Quebec (and the majority of health care providers) speak French as their first official language, and English speakers are a minority group. Based on the 2016 Canadian Census, 71% of the Quebec population only speak French at home (Lepage, 2017).

For the Canadian (federal) government, English speakers in Quebec are an official language minority, as are French speakers outside of Quebec. In Quebec, French is the official language, although certain health services provided by the provincial government can be obtained in certain places in French and English. Some support is provided by the federal government to improve health services in the official minority language to both official language groups across the country. Still, it is important to understand that health services in Quebec fall under the Quebec (provincial) jurisdiction. Health services are officially available in English when specified through historical rights granted to specific organizations (for example, some hospitals), and/or in a government approved “access program.” In practice, a limited number of hospitals and organizations (designated institutions) have a formal offer of services in both French and English, and these are mainly concentrated in the center of Montreal or the West Island of Montreal. The point worth underlining is that government support of health services in English in Quebec is significant, compared with regions or countries with little institutional recognition of the health and language needs of minority language groups. However, as we shall see, this support has its limits.

Francophone health providers can be more or less fluent in English. Francophones in Quebec have English courses, beginning in public school and continuing through to preuniversity college (Cegep), where English courses are obligatory. Similarly, although the study of French is now obligatory for English-speaking students in high school and preuniversity English colleges in Quebec, the caregivers we interviewed may have received little schooling in French, and several likely did not continue their study of French after high school. In general, 60% of English-speaking male seniors (defined here as 65 years of age or more) in Quebec report that they are able to carry on a conversation in French, whereas 50% of females indicate this (analysis of combined 2005/2010 CHSSN-CROP survey data by the author).

The Present Study

Although a growing body of research is available on communication problems between physicians and patients, the effects of language asymmetry, and the difficulties experienced by caregivers (e.g., Allen et al., 2017; Ebrahimi et al., 2018; Roth et al., 2015; Turcotte, 2012; Witham et al., 2018), little is known about the situation of English-speaking caregivers in Quebec. The research question was whether a situation of language asymmetry could lead English-speaking caregivers to experience additional types of problems, and to identify what these were. The experiences of these caregivers are also likely to be indicative of those of English-speaking patients in Quebec. I would argue that the research is pertinent not only for English speakers in Quebec, but also for many minority language groups around the world.

Method

Semistructured interviews were carried out with English caregivers of English-speaking seniors living in Quebec (more about this below). An interview schedule was prepared and included questions about their relationship to the person they cared for, the health issues of this person, their caretaking activities, whether they accompanied the person to medical appointments, and support received from family, friends, or groups. These questions were intended to stimulate memories of their care-giving activities. Care was taken to avoid leading questions which could suggest that problems necessarily arose from interaction with French-speaking health care providers. In addition to these general questions, others explored the caregiver’s self-assessed proficiency in French as well as that of the person cared for, the language in which communication took place with health care providers, interactions in French, and any difficult situations that occurred with medical personnel. Follow-up questions inquired about how the person felt in these situations. Participants were also asked about care instructions they might have received (and the language for this), if they had received written communication in French or English from a
health care provider and about services that could be of use to them or other recommendations they had.

Since the objective was to identify and better understand the types of issues that could arise, an effort was made to recruit participants in geographic areas that were outside an area where there was a relatively dense population of English speakers (i.e., the center of Montreal and the West Island of Montreal), and in health regions where health services were less likely to be available in English. Participants were sought from English community groups within a 3-hour drive from Montreal in three regions that had programs for English seniors. The author knew about the existence of these groups through participation in events organized by the Community Health and Social Services Network (CHSSN) for organizations that provide health services to English speakers in Quebec. In particular, the project was presented to a seniors group in the eastern part of Montreal (an area where there are relatively few English speakers), and three caregivers agreed to participate. An additional two persons were recruited from another seniors group located at a distance of a 1-hour drive north of Montreal.

A second recruitment strategy was to contact people who were acquaintances of the researcher or research assistant, or were acquaintances of the initial participants. Nine other caregivers were recruited in this way, all of whom lived in an area south of Montreal. One lived a half-hour drive from Montreal, another was at a distance of an hour drive, and seven lived near Sherbrooke (a 2-hour drive from Montreal).

Three of the participants elected to participate in the interview at a location other than their home. Two informants who were caring for their parents elected to have their spouses present, and these people also provided comments on occasion. In one case, an elderly woman spoke of her care of her husband, but her daughter was also present during the interview. Although the interviews were arranged with a single person, when there were two participants in the interview, given the tacit preference to have the interview proceed in this way, this was accepted by the researcher. Occasionally, participants would talk about their own encounters with health care providers, and this information was noted as such but not excluded.

In terms of the characteristics of the caregivers, all but two of the caregivers were 65 years of age or more (the two exceptions appeared to be in their late 50s and cared for someone over 65). Most of the participants cared for a spouse, although three of them cared for an older parent. All couples were heterosexual. One elderly woman cared for an older sister who was living with her (and quite advanced in age), and one woman in her 80s cared for a female friend who was in a long-term care institution. Four of the caregivers were male, and cared for their spouse. The spouses of three of the caregivers had passed away in the last few years. Prior to the interviews, I was somewhat concerned about the ability of these caregivers to recall care events, but this concern dissipated when they provided detailed accounts of their activities and of various interactions with health care providers.

The caregivers’ self-assessed level of French ranged from none (rarely) to good, although all noted some limitations (this will be discussed in more detail). All of the participants in the research had at least some interaction with French-speaking health care providers.

Interviews were conducted in English. Half of the interviews were conducted by the male author (who lives in Montreal) and half by a female research assistant (herself a senior) who lived near Sherbrooke.

Interviews were recorded, transcribed verbatim, checked by the author, and entered into Atlas.ti. An initial analysis characterized, for example, whether interactions with particular personnel were in English or French and indications of how the participant reacted to speaking to a health care provider in French. This line of analysis was abandoned, although the verification of the transcripts and the temporary coding did allow me to become quite familiar with what the participants said. Instead, I decided to provide a general presentation of the types of problems that were encountered (this can be considered to be a sort of thematic analysis; see e.g., Braun & Clarke, 2013). A “problem” was gradually defined as a challenging situation or interaction in relation to which participants usually provided indications that they had been bothered or upset (examples will be provided of this).

For some events noted here, even if the participant showed few signs of being upset, the author believes that at least some people would be bothered or angry, if a similar event happened to them (an example will be given). Quotations are provided, so that the reader can also assess the reaction of the research participant to a situation. The presentation here is not a complete content analysis of the interviews, since the participants also talked about many of the daily caretaking activities and general difficulties they experienced. These are not reported here because they are not the central subject of the article and because they have already received at least some attention by other researchers (for example, Wilson et al., 2014).

An ethics committee at Bishop’s University (Quebec) examined the procedures and provided ethics approval for the project. Participants provided written informed consent.

Results

The Caregivers’ Experience of Language Asymmetry During Health care Encounters

Although there is research literature that suggests that having a mother tongue that is a minority language can have negative impacts on the patient (e.g., Bowen, 2001; Irvine et al., 2006), the majority of the caregivers we interviewed indicated that they were satisfied with the interaction and/or care that physicians provided to the seniors that they were caring for, even if the physicians were not native English speakers. This is a general observation that should be emphasized. For example, a man who had cared for his wife, noted: “we
always had English doctors, other than what came here, and normally they spoke English, we had no difficulty.” Even when one of the doctors spoke Spanish as her mother tongue, the man was thankful for this physician:

. . . there’s another doctor, she’s 45 years old her name is A. She’s with the CLSC [author: a provincial health clinic], she’s from Cuba, her English is not worth a damn, but she’s a wonderful, wonderful girl.

For this man, the doctor’s care and other communication skills were more important than her ability to communicate in his first language. Other caregivers made similar positive comments about their interaction with physicians.

Even when participants expressed satisfaction and gratitude toward physicians, they could also indicate concern about interacting with a French-speaking physician. At a different time in the interview, the same man cited above who was caring for his wife, also commented about his own care:

When I had my stints put in 10 years ago, they start talking to me in French and I said hey I prefer you didn’t. If you’re talking to me do it in English so there’s no mix-up because you’re playing around with something a little important.

In this case, it was the man who was anxious about what doctors were saying to him in French. He wanted to be sure he understood what the doctors were saying, which was certainly understandable, given the context of heart surgery. There was no miscommunication per se, but the man was clearly indicating his concern that he did not want any risk of miscommunication.

It is useful to consider another participant’s concern about the language abilities of their physician:

The family doctor is in St. Jean, he is bilingual, perfectly bilingual. That’s why we never changed. We went to somebody in Hemmingford, but his English was so so, and if you can’t tell somebody in French where and what hurts, it’s very hard to get a treatment that’s appropriate (woman who cared for her husband).

This quotation indicates that the couple remained with a physician in St. Jean, apparently a native French speaker, but who was at ease in English (“perfectly bilingual”). They had tried out a physician who was closer to them but stopped going to see this physician. They appeared to be concerned about potential poor quality of care by this physician due to language asymmetry. The consequence, however, was that they had to travel farther to see a physician who spoke fluent English. This additional travel could be characterized as a problem that stemmed from language preference and low local availability of services in English.

Another type of situation concerned family meetings with French-speaking physicians about how to care for a parent. A daughter who was facilitating care for her mother recalled:

Caregiver: in order to do the biopsy she had to be off blood thinners for two weeks, and so there was, there was times in that whole conversation when I didn’t understand what was being said, but my sister did, and, and (another family member) did, so I, I was getting the jist of the conversation, but not clear enough you know . . . so uh, I would intervene and I’d say whoa whoa what was that, and so my sister would tell me in English and the doctor would start talking in English again.

In this situation, the daughter clearly wanted to be an active and informed participant in the discussion about her mother, but was not sure that she understood the information that was being given in French to her siblings. Although the physician did speak English, the physician would sometimes revert to French. The caretaker indicated that she had to repeatedly assert a need to have the information in English. It is possible that the physician was not conscious of the disadvantage (or loss of understanding) that one member of the family felt because of his or her use of French, or not fully aware of how his or her practice of reverting to French was having a negative impact on a daughter who felt that she had a right to participate in the decision making about her mother.

The quotation above also points to the practice of having family members act as informal interpreters. The physician had not arranged to have one for this meeting (interpreters are theoretically available in hospitals but have to be requested and a delay is likely to follow; Briand-Lamarche & Guériton, 2017). Also, a different caregiver recalled:

Caregiver: Really, when we go to the doctors for instance, I translate what the doctor says to him and vice versa. Interviewer: Does the doctor ever talk to him in English? Caregiver: Some doctors can, some cannot . . . and some use a little bit of what they have, you know a word or two. It depends which doctor. Like his GP [the physician] right now is really a francophone with very little English, so, I work as translator there and she [the physician] says the odd word in English sometimes or a phrase but that’s it. (Caregiver of her husband, who has Parkinson’s disease)

In this situation, the physician (in a private clinic) most likely does not have access to an interpreter, and the caregiver took on this role with certain physicians. This would of course be in addition to trying to remember and communicate to the physician any specific symptoms or issues that her husband did not mention. It is worthwhile pointing out here that various authors warn against the use of informal interpreters (e.g., Briand-Lamarche & Guériton, 2017).

Another type of interpretation situation was mentioned by a research participant:

Caregiver: (Laughs). It’s not, try getting ahold of Dr. S and you’ll find out it’s complicated.
Interviewer: Okay, so what do you do when you try to get ahold of them?

[... exchange here about the extension numbers in the hospital]

Caregiver: Then they'll start talking French, and I'm lost right there.

Interviewer: So, what do you do?

Caregiver: Well, I worked a day and a half on that one. So, I went up to see Mrs. D [a neighbor] and I said “can I use your French for a little while, she said “yes.” She knew all about it, because her doctor is at the same place my doctor is.

Interviewer: So, she can speak French.

Caregiver: Yes, she [the neighbor] is French.

Interviewer: Okay, and she will, she might leave the message for you.

Caregiver: Well, she knew what I was calling for, well I had a broken blood vessel in my arm. (woman who was talking as a caregiver, and about a health problem she had)

To summarize this excerpt, the caregiver felt that the best way to communicate with her physician about her own health problem was to visit a neighbor to ask them to call her physician in the hospital, and to leave a message. In effect, she decided to find an informal interpreter. Luckily, the caregiver could ask this favor of someone nearby, and she apparently was not concerned about keeping the health problem confidential. In Quebec, as elsewhere, patients have the right to keep health issues confidential. At the same time, the need to find an interpreter also points to a deficiency in the phone and reception services at the hospital. This situation was not unique, and other research participants recounted similar experiences with telephone and reception systems that did not provide for interaction in English.

The excerpt above also provides an opportunity to discuss in more detail the notion of a language related “problem.” The research participant did not say outright that she had experienced a problem, nor did she have a change of tone in her voice that could suggest outrage (which did happen at times during interviews). Still, important clues are provided when she says, “try getting ahold of Dr. S and you’ll find out it’s complicated” and “Well, I worked a day and a half on that one.” The words “it’s complicated” suggests some irritation with the situation. As well, the way to make an appointment with the physician was not obvious to her and she had to think for a period of time about how to work around the deficient telephone communications. The episode clearly remained in the memory of the caregiver. As well, although the participant did not mention being upset by the loss of confidentiality, and the neighbor did not appear to be annoyed by the participant’s request for help, it was nevertheless a request for a favor, along with the creation of a “social debt” with the neighbor. Although a francophone in Quebec could also have difficulties arranging an appointment with a physician, it is rare that this would arise because of language ability (although perhaps for some people with a hearing disability). For these reasons, I would argue that the situation did represent a problem for this caregiver.

Several research participants were fairly fluent in French, but many of them also noted that their level of proficiency decreased in a medical setting. For example, a man who had just recounted a telephone conversation with French hospital personnel, commented:

Interviewer: What’s your level of proficiency in French?

Caregiver: General conversation, I would say 80 to 90 percent, if it comes to anything more technical like, scientific or medical or bureaucratic discussions, it drops down to around 60. (Male caregiver of spouse)

This perceived decrease in competency in French when medical expressions were used, helps us to understand why participants could be anxious about interacting with medical personnel in French.

A case of discrimination was also reported. In the 1990s, a man had accompanied his wife to an appointment in a hospital.

Interviewer: How do you know that?

Caregiver: Because I, we heard him behind the curtain telling his resident that he wasn’t going to waste government money on a poor, unemployed, overweight Anglophone woman.

Elsewhere in the interview, the man had mentioned that 20 years earlier, his and his wife’s proficiency in French was not very good and that they were not able to make themselves understood in the hospital. Given this, the specialist might have thought that he was out of earshot or that what he was saying would not be understood by the couple. Even though the appointment was 20 years ago, the specialist’s comments clearly stuck in the caregiver’s mind. This could have been in part because his wife went on to develop cancer, which had a major impact on both of them. This was the only situation of discrimination partly related to language that was reported by the caregivers who were interviewed for this study. It is worthwhile noting a similar and recent public report of a French-speaking physician in a Montreal hospital who refused to examine an English-speaking Polish man (Fidelman, 2018), which suggests that the quotation above does not refer to a unique case. Other evidence of language related discrimination in a health
setting is also found in a study of Latinos in South Carolina (Breland & Ellis, 2015).

Most of the caregivers indicated coming into contact with other health care providers who were not physicians, and they sometimes experienced difficulties with them. A daughter who had to call an ambulance for her mother who had fallen down recalled:

But we haven’t had difficulty with language it’s just that one ambulance driver who refused to speak English he said he didn’t understand English . . . what would have happened if neither of them would have spoken English? It was as bad as being in Turkey and not having somebody who spoke the language at all you know?

The ambulance driver’s partner ended up speaking English with her, but this situation clearly upset her. Here, it is possible that the initial difficulty in communicating with the ambulance attendants increased the stress she experienced related to her fallen mother.

With respect to nurses, some participants were satisfied with their ability to speak English, whereas others were not. A man caring for his mother in Laval (north of Montreal) recalled:

“. . . at first we thought [it] would be a problem because the CLSC milieu over here is basically catering to a French population; but even there, they sent over nurses and support people and they all spoke English.

Another caregiver indicated that a nurse’s English was not very good but that they were still able to communicate: “some of the nurses don’t speak too much English, but I can show you papers there she’s gotten me that, this last nurse and she doesn’t talk too much English but we get along.”

Still another caregiver stated:

The nurses in the prep area were, again I was there to translate for them when we checked into the day surgery office you know, got the card, got him in, his instructions, these women could not speak English with him. They were pleasant you know, they tried to make little sign language and, you know how people do they’ll, try to get communication. They were very sweet people and they were very nice and weren’t mean or nasty to him or anything, but there was no way he could have dealt with them in his language. (Caregiver of a husband who had Parkinson’s Disease)

Although this caregiver indicates that the interaction was acceptable (“they were pleasant”), she was interpreting information or instructions for her husband. This implies communication work on her part. She also felt she had to stay with her husband so that the interactions went smoothly (“no way he could have dealt with them in his language”).

Caregivers were more critical of nurses in managerial positions (Head Nurses) who did not, or would not speak English. For example, a female caregiver who visited an English-speaking woman in a long-term care institution recalled:

Caregiver: Well I had difficulty with the Head Nurse, because she doesn’t speak English, so I have to talk my best French to her, but I can’t always express myself the way I want to.
Interviewer: Is there anyone in the hospital she could call on?
Caregiver: Yes she’s supposed to but she doesn’t.

In this regard, other research has found that, in Quebec, fewer nurses than physicians speak English (Bouchard & Desmeules, 2013). The quotation above also corroborates a previous one that indicates that personnel do not always request the help of other English-speaking health care providers or official interpreters. The caregiver’s statement “she’s supposed to” indicates that she thinks there are policies and resources to allow for interpretation (and this could be true). This caregiver was annoyed that a person in a management position did not use these resources. It seemed that the caregiver felt that the head nurse should make the effort to try to find an interpreter. There may also have been some surprise on the caregiver’s part that a person in a management position appeared unable to speak English.

Another personnel group that was mentioned in the interviews was home and hospice support workers. One of the caregivers suspected that poor English skills on the part of a hospice worker contributed to the degradation of a care situation. The wife of a man with Alzheimer’s disease recounted how her caregiving activities had escalated beyond her capabilities.

Caregiver: I had half hour naps, 1 hour naps, but not much more in a row. He was up constantly.
Interviewer: During the night?
Caregiver: Night, day, it didn’t make a difference.
Interviewer: And you were running [a demanding home business] at the same time.
Caregiver: I was exhausted. I really was exhausted. So the respite care, for those 3 days. She [a hospice worker] was English, he [another hospice worker] was not. But during the night, he was up all the time, he [the male hospice worker] was taking care of that. So his English, if that played a role, I don’t know, I wasn’t there. He spoke some, but I don’t know how well he spoke. And then since they couldn’t handle him any longer I picked him up.

A longer stay in the hospice had been planned (to allow the wife to rest) but her respite was interrupted when the hospice asked her to pick up her husband. In the excerpt above, the wife wonders if the lack of English on the part of the male hospice worker contributed to the premature interruption of her respite. This quotation allows me to underline the potential seriousness of language asymmetry and to question the
effectiveness of the English language skills of the hospice worker.

A few people recalled having asked for homecare workers who spoke English, sometimes with success, sometimes without.

She [a social worker] knows, I’ve told her that I don’t want a sitter unless she speaks English. But I guess when they, probably not all of us have somebody that they could send that speaks English. Because it’s a very French district. (Female caregiver of elderly sister in East Montreal)

Here, the caregiver indicated that when offered the services of a sitter (who may have been a volunteer), she considered these to be of no use unless the person spoke English. The role of a sitter seems to be to provide respite to the caregiver, and perhaps also to provide some cognitive stimulation to the loved one by engaging in conversation with that person. The caregiver’s comments suggested that both of these functions suffered when a homecare worker was not at ease in English, calling into question the value of the aid provided by someone who was not fluent in English. It seemed that public agencies that provided homecare workers generally tried to provide English-speaking workers when asked, although the participants noted that they sometimes received personnel who were not at ease in English.

Another dimension of communication between health care providers and caretakers involves written language, for example, in documentation about potential services, prescriptions for the loved one, and instructions on how to carry out certain care activities. This aspect is of interest because the understanding of written health information or instructions is one important form of health literacy. One of the caregivers remembered having received printed information about services for caregivers:

Caregiver: This is in French.
Interviewer: You read French.
Caregiver: I can read enough to get the sense of what they want. But since it’s French and since I don’t have much time, I usually don’t make the effort to go through. English is faster, I can skim. . . some of it was in English, most of it, some was in French. (Caregiver of a husband with dementia)

Here, it is useful to remember that this caregiver was extremely busy, and given the extra effort required to read French, gave the information provided in French little attention.

Even after his mother had lived in a francophone residence for several months, a son and his wife had some outstanding concerns about the ability of personnel to interact with his mother in English:

Wife of son: And there was three of them at the time and it took a few minutes before an official nurse came by and she was somewhat bilingual, and she was trying to calm my mother-in-law down because she was very upset cause . . .
Son of elderly mother: The other woman had fallen.
Wife of son: Cause the other woman had fallen, yeah, so I mean that was the only time there was a serious matter, and if it had been your mother, it would have been more complicated but it wasn’t, so take a deep breath and go on you know.

In this quotation, the wife (of the caregiver son) seems to be expressing anxiety about what could happen if her husband’s mother had an emergency and was not able to communicate very well with the personnel.

Health System Problems Related to Language

Up until this point, I have presented problems associated with interactions between caregivers and health care providers who were not at ease in English, but another type of problem was implicit in several comments, which I will call systemic problems (similar to “organizational issues,” as used by Irvine et al., 2006). If I remain with the example of the couple who were the caregivers of the man’s mother, they pointed to another problem that they had experienced when placing the mother in a residence. The man’s brother lived in a neighboring city which had residences where English was common, but the caregiver indicated that his English-speaking mother could not be placed in that city in a reasonable timeframe because it was a different health region. The caregiver indicated that this would have required considerable paperwork and would have created a delay. The consequence of this was that, given the procedures and the time lag, the caregiver decided to spend time and energy to try to find a suitable residence near himself and was put in a position of trying to evaluate by himself the extent to which personnel at various residences could speak English. I suggest that the paperwork, delay associated with a regional transfer, and subsequent efforts deployed to evaluate local residences in order to receive a service in English, are indicative of a systemic problem.

A previous example was also given of caregivers who received written documentation in French. The caregiver could understandably have difficulty comprehending the documentation in French, and the person providing the documentation did not appear to anticipate this. From a systemic viewpoint, the managers responsible for the documentation contribute to this situation because they did not ensure the translation and distribution of information in English. Similarly, I previously provided a quotation about a woman who was unable to make an appointment by telephone in French and decided to ask a neighbor for help. An additional interpretation can be given to the quotation: it points to unilingual telephone systems (and reception personnel) which create communication problems for caregivers and patients.
Telephone systems and reception personnel are the artifacts of organizations (clinics and hospitals) and managers who install the systems or hire the personnel. Similarly, ambulance attendants who cannot speak adequate English are more likely if clear policies about this are not established or if proper language screening is not carried out at the time of hiring. The formulation and application of pertinent and effective policies can be considered to be a responsibility of the health system, and certain deficiencies constitute systemic problems.

Discussion

The majority of the caregivers interviewed indicated that they were satisfied with the interaction and/or care that physicians provided to the seniors that they were caring for, even if the physicians were not native English speakers. However, some problems were mentioned in relation to the caregivers’ interaction with physicians, and more frequently with other health care providers. Critical comments were made by caregivers who spoke about health care providers who refused or were unable to speak English, or about the lack of English skills on the part of some home or residence (long-term housing) support personnel. Some caregivers indicated anxiety about speaking to health care providers in French. Other problems identified included traveling further than French speakers in order to receive health services in their first language, needing to insist that interaction takes place in English, acting as an informal interpreter, having to find an informal English to French interpreter, and foregoing the right to confidentiality about health problems, asserting a need to have information in English, receiving written information in French about care procedures or services, trying to arrange appointments through phone systems or receptionists that were unilingual French, outright discrimination based on language, and receiving personnel in the home who were not able to provide full support to a loved one because of insufficient English language skills. The main finding is that, in comparison with French-speaking caregivers, a situation of language asymmetry may create additional problems, stresses, and frustrations in the life of an English-speaking caregiver in Quebec, who is already likely to be stressed because of their caregiver role (e.g., Allen et al., 2017; Ebrahimi et al., 2018; Roth et al., 2015; Turcotte, 2012; Witham et al., 2018). The specific problems identified here expand beyond the issues identified in previous research into communication between physicians and patients, healthcare and language asymmetry, and caregiving.

The participants in the research sometimes provided informal interpretation services. This is a practice in Quebec that has been identified and investigated by other researchers (e.g., Briand-Lamarche & Guérîton, 2017). The persistence of the practice suggests that health care coordinators and managers may not fully appreciate the effort that such a service requires and the associated inconvenience for caregivers and risks to patients. Interpretation by caregivers would not be as frequent if hospitals and other health organizations had adequate services and reduced the effort health care providers have to make to obtain professional interpreters. The nature of the problem is not solely that caregivers have to provide interpretation but also that managers in an organization may not recognize the gravity of the issue and may not ensure the availability of a sufficient number of interpreters. Similarly, hiring managers in a variety of organizations may not ensure that staff are bilingual, or that information distributed to patients or caregivers is available in English. As well, the choice of unilingual French telephone systems and receptionists can be attributed to managers in an organization. These are examples of what I have called systemic problems. Such a label suggests a viewpoint that is infrequent in the literature associated with this research area.

Although several studies have examined communication problems between patients and physicians in particular (e.g., Armas et al., 2017), very few have examined communication problems between caregivers and the range of health personnel with whom caregivers interact. As well, although the relative health status of members of official minority language groups in Canada has been studied (e.g., Bouchard & Desmeules, 2013), very few have provided empirical investigations of the communication by health care providers with minority language groups.

The observations provided here suggest that studies of communication in the health sector should expand beyond physicians and their interaction with patients, to include other health care providers and caregivers. Similarly, deeper understanding is needed of the interaction of health care providers with minority language groups. Comments in the interviews also highlighted potential situations of interest for additional research, such as family meetings in a francophone institution concerning the care of a seriously ill patient who does not speak French. The situation of elderly English speakers who are hospitalized in a francophone hospital or placed in a francophone residence or CHSLD (long-term care institution) is also likely to be of interest, as they may experience social isolation.

I would underline that some of the participants said that the convivial attitudes or goodwill of some personnel often allowed the health care provider to mitigate limitations they had speaking English. This should be of interest to all health care providers who interact with language minority groups. The implication for hiring managers is that when hiring a health care provider who will be interacting with a language minority group(s), they should assess a candidate’s attitudes toward that minority group(s).

Conclusion

Relatively few studies have identified problems experienced by minority language caregivers or patients beyond that of health status. The research reported here concerned caretakers
in Quebec who were members of a minority language group that used a relatively well-known language, which was English. The main finding is that, in comparison with French-speaking caregivers, a situation of language asymmetry may create additional problems, stresses, and frustrations in the life of an English-speaking caregiver who is already likely to be stressed because of their caregiver role. Some of these difficulties point to deep-rooted systemic problems in the Quebec health system. These problems are undoubtedly not unique to Quebec. The problems experienced by the caregivers who were interviewed for this study are likely to be experienced in other regions and countries by both caregivers and patients who use minority languages.

Certain limitations of the research should be noted. The problems identified here do not constitute an exhaustive list nor are there any indications of the relative frequency of the difficulties identified in this research. As well, although I sought interviews from a variety of caregivers in different geographic regions, given the limited resources for the research, these took place in three regions. At the most, caregivers were at a distance of a 2-hour drive from a part of Montreal where services are generally available in English. It is possible that other types of problems might be experienced by caregivers who live in areas with less access to services in English.

Other researchers could attempt to collect other forms of appropriate data, other than through interviews. A different approach of direct observation of consultations and of hospitals/hospices/respite would likely allow a finer grained analysis of participants’ problems and interaction strategies in the context of language asymmetry, if permission could be obtained to do so. As well, a different but related type of analysis could be pursued by studying complaints submitted to health organizations by English (or other language) speakers. Still, my viewpoint is that the information provided by the participants constituted a useful condensed version of many years of experience with the health system in Quebec.

The problems I have identified occur in a context where the minority language (English) is often understood and spoken to some degree. Other additional problems could be experienced by caregivers or patients in countries or regions that use a language that is less common than English in Quebec.

I hope that health care providers will be particularly attentive to the problems and stress experienced by caregivers and patients who are more proficient in a minority language and consider the implementation of measures that may improve communication with patients and caregivers who use a minority language. The information and suggestions provided by caregivers underpins the formulation of a number of measures that could help to attenuate problems related to language asymmetry. These are friendly attitudes on the part of French-speaking health care providers and a willingness to use the English they know; sensitizing (training) of providers about appropriate attitudes when interacting with patients and caregivers for whom French is not their first language; having recourse to interpreters without penalizing the caregiver or patient or health care provider who requests the service; recognizing that patient participation in decision making means the accommodation of family members who wish to hear and discuss medical opinions in English; installing telephone systems in all organizations with an option to hear or speak English; hiring bilingual receptionists when a clinic has more than a small percentage of English-speaking patients; creating or supporting additional English caregiver groups; increasing the number of bilingual staff in French hospitals where there are English speakers in their catchment area; increasing the number of English or bilingual homecare workers; allowing patients in an ambulance to be taken to a bilingual hospital when it is only a short additional distance from a French hospital; ensuring that there is a number of “bilingual beds” available in government supported residences, CHSLDs, and short-term housing that corresponds to the percentage of English-speaking population in cities or boroughs; providing in English, written information on services and procedures; and the creation of a list of English or bilingual residences by region. The suggestion here that residence and homecare services need to be readily available in English echoes a similar conclusion by Dupuis-Bouchard et al. (2013) concerning services and outreach in French for francophone seniors in New Brunswick. The feasibility or effectiveness of these changes have not been verified and could require further policy-oriented or knowledge translation research.

In personal conversations with French speakers, I have heard French speakers voice an expectation that English-speaking residents in Quebec should learn French. Younger English speakers have tended to do this. For English-speaking seniors, I believe that is not reasonable to expect them to become functionally bilingual in the medical domain in their later years. For this reason, I have not included this option here.

For English speakers, a general observation by one of the caregivers could also be considered to be a useful recommendation for all English speakers seeking health services. The caregiver commented:

You know, a lot of it has to do with how you interact with the support personnel; we’ve noticed that quite a bit, because my brothers and I have different personalities, and when you approach them, and you try to force them to do certain things or if you’re brusk in your approach, the chances are you will get a response that mirrors that.

The caregiver was suggesting here that tact and respect will likely be helpful, whichever language is being used.

Authors’ Note

Duncan Sanderson Ph. D. is an independent researcher who carried out this research while working as a research associate at Bishop’s University, Lennoxville, Quebec.
Acknowledgments

My sincere gratitude is extended to Dr. Cheryl Gosselin at Bishop’s University who helped to secure and manage the funding for this research, and to Heather Keith who conducted interviews in the Eastern Townships. I would also like to thank the participants in the interviews, Richard Walling (Jeffery Hale Community Partners), The Townshippers, REISA, 4Korners, and Almage, for their interest and support. An editor and anonymous reviewers provided judicious comments.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research received funding from Health Canada, administered by the McGill Training and Retention of Health Professionals Project.

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