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Aller au sommaire du numéro

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Résumé de l'article

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Challenges Faced by Bilingual Stroke Survivors in the Healthcare System: Unique Considerations

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Abstract

The experiences of multilingual patients communicating with unilingual healthcare providers have been largely unexplored. The aim of this study was to investigate the experiences of bilingual stroke patients within the Canadian healthcare context. A secondary analysis was completed with data from a multiple case study of the experiences of seven, low-income bilingual Francophone stroke survivors living in a predominately English area. Data included semi-structured interviews, chart reviews and language proficiency assessments. Results demonstrated that bilingual survivors experience unique challenges, including limited French health vocabulary, use of non-standard French, and generally low health literacy levels in both languages. Participants with aphasia often used English and French interchangeably, leading to the potential for miscommunication when providers were not bilingual. The study highlights the importance of having bilingual healthcare providers when bilingual stroke survivors have communication or cognitive limitations.

Résumé

Peu d'études ont porté sur les expériences de communication entre des patients multilingues et des professionnels de la santé unilingues. Cette étude explore les expériences vécues dans le système de santé canadien par des patients bilingues qui ont subi un accident vasculaire cérébral (AVC). Une analyse secondaire a été réalisée des données d'une étude de cas multiples menée auprès de sept victimes d'AVC francophones bilingues vivant dans une région majoritairement anglophone. Les données proviennent d'entrevues semi-structurées, de l'examen de dossiers médicaux et d'évaluations des compétences linguistiques. Les résultats démontrent que ces survivants bilingues d'un AVC font face à des défis particuliers, dont un vocabulaire français limité relatif à la santé, l'utilisation d'un français non standard et un niveau de littéracie généralement pauvre dans les deux langues. Les participants atteints d'aphasie utilisaient souvent le français et l'anglais de façon interchangeable, ce qui donnait lieu parfois à des erreurs de communication avec les professionnels unilingues. Cette étude souligne l'importance d'utiliser des professionnels bilingues lorsque des patients bilingues qui ont subi un AVC ont des difficultés de communication ou des limites cognitives.

Language barriers can influence the safety and quality of care of Canadians from all minority language groups, including those from official language communities (de Moissac & Bowen, 2018). In Canada, the use of the two official languages, French and English, is uneven across the country, with an English minority group in the province of Quebec, where French is the majority language, and French language minority groups in the other provinces and territories. In Ontario, although an individual has the right to receive provincial government services in French in designated areas, the law does not require healthcare agencies in these areas to provide services in French, unless they have been categorized as bilingual service providers by the government (Government of Ontario, 2016). French minority language groups are therefore more likely to experience language discordant encounters within the healthcare system. In fact, 40% of Francophones in Ontario reported experiencing difficulties accessing services in their preferred official language (Gagnon-Arpin, Bouchard, Leis, & Bélanger, 2014).

Patient-provider language issues can influence processes and outcomes for many medical conditions, including stroke, which occurs when blood flow to areas of the brain is impeded and cell death results (Heart and Stroke Foundation, 2017). This cell damage can cause mild to severe impairments that impact everyday activities like working and driving. Aphasia is a common communication impairment that affects approximately one in three stroke survivors. It can limit a stroke survivor's ability to read, write and talk with or understand others (Heart and Stroke Foundation, 2017) and can further exacerbate existing communication problems caused by language discordance.

Language discordance, which occurs when the healthcare professional and the patient are not proficient in the same language, can cause challenges during all phases of stroke care. During post-stroke rehabilitation, language discordance can affect a therapist's ability to assess function, help stroke survivors identify rehabilitation goals and provide emotional support (Taylor & Jones, 2014). It can create comprehension challenges around treatment and prevention options following stroke (Cruz-Flores *et al*., 2011) and contribute to problems accessing and organizing post-discharge community services (Mold, Wolfe, & McKevitt, 2006; Yeung *et al*., 2015).

In the Canadian francophone minority context, without a guarantee that French language services will be available when needed, those who are French-English bilingual may be at an advantage when receiving services in English. However, there is a high risk of communication breakdown if healthcare providers overestimate bilingual patient second language proficiency (Bowen, 2015). Health service delivery may be compromised if service is only provided in the patient's second language.

The proportion of bilingual Canadians is increasing and is particularly high among people whose first language is French. Fifty-six percent of Francophone Canadians consider

themselves bilingual (Statistics Canada, 2017). However, it is important to note that while bilingualism is typically reported as present or absent, it is actually a complex construct capturing a variety of differing language experiences and proficiencies (Luk & Bialystok, 2013), making measurement and definitive categorization difficult (Fielding, 2015). The experiences of bilingual individuals, therefore, may vary considerably.

The objective of this study was to describe the experiences of bilingual stroke survivors receiving post-stroke health services in the context of a minority language situation.

Method

We used a descriptive qualitative approach (Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016) to investigate the unique challenges of bilingual stroke survivors who were receiving post-stroke health services in one area of Ontario, Canada. A secondary analysis of data collected using a qualitative multiple case study design drawing from Stake's approach to case studies (2006) was carried out. In the primary analysis, we investigated the impact of both income and official language minority status on return to valued activities after stroke (Sauvé-Schenk, Egan, Dubouloz-Wilner & Kristjansson, 2019).

The cases in the original study were eight low-income Francophone stroke survivors recruited from two outpatient rehabilitation services in Eastern Ontario. Potential participants were identified through rehabilitation health professionals. Recruitment criteria included being Francophone according to the definition of Statistics Canada (either having French as mother tongue or first official language spoken) (Statistics Canada, 2010), living below Statistics Canada's low income cut-off (Statistics Canada, 2015), being over the age of 18, and living in the community. Data collection was approved by local research ethics boards and every participant provided written consent. Seven of the eight cases who self-identified as French-English bilingual formed the participants for this study. The eighth case was excluded as she spoke French but not English.

The data for the primary analysis were collected from each participating stroke survivor in three sessions over a period of approximately 8-10 months. The sessions each lasted between one and three hours and were conducted in the official language of choice of the interviewee. During the interviews, four participants spoke mainly in French and used English vocabulary and expressions throughout. One participant spoke mainly in English and used French vocabulary and expressions. Two participants who were experiencing severe expressive aphasia communicated in English and French interchangeably and received assistance in the form of supported communication during the interviews. Supported communication is a series of techniques used by the interviewer to converse effectively with an individual who is experiencing aphasia. Techniques include writing down key words, using

gestures, and rephrasing (Kagan, 1998). For this secondary analysis, the sources of data were three semi-structured interviews with each stroke survivor, one semi-structured interview with each care partner, medical chart reviews, and stroke survivor self-assessments of French and English language proficiency.

The interviews were designed to better understand the influence of low income and Francophone minority status on the experience of returning to valued activities after stroke. In this secondary analysis, we focused on responses participants gave to questions on language. Specifically, participants were asked to discuss their language identity, background of language acquisition and perception of the influence of language on their general post-stroke recovery. They were also asked to describe the impact of language on their experience of stroke-related healthcare services along the continuum of care, from admission to acute care in hospital, to participation in rehabilitation and community services. Each stroke survivor also identified a care partner who could be interviewed. These care partners all consented to taking part in the study and reported on their perception of the stroke survivor's experience receiving healthcare and of the influence of language on returning to valued activities.

The questionnaire proposed by Gonzalez-Reigosa in 1976 (Vallerand & Halliwell, 1983) was used by participants to self-rate their ability to speak, understand conversations, read, and write in both French and English. Each ability is rated from 1 (very little) to 4 (perfectly). A score of at least 12/16 in both French and English qualifies as bilingualism.

Healthcare provider chart notes from acute care, rehabilitation and outpatient services were also reviewed using a pre-established form. Data related to language, specifically the stroke survivor's reported language preference, language of services provided, and team members' entries related to language or communication with the stroke survivor, was extracted.

The primary analysis strategy, which drew from the works of Stake (1994, 1995, 2006), used two levels of case analysis: intra and inter case. The works of Patton (2015) and Miles, Huberman and Saldaña (2014) influenced the coding and aggregation strategies. The secondary analysis, also influenced by Miles *et al*. (2014), began with a re-examination of the language-related codes and categories from the primary study. These existing codes and categories were re-aggregated for best fit with the research question. Larger themes related to the role and influence of language and bilingualism were then identified. These themes contributed to a better understanding of the participants' language experiences within the healthcare system. The information gleaned from the assessment of patient bilingualism and medical chart reviews were then directly interpreted and integrated into this analysis, with special attention given to whether the data confirmed or contradicted information from the

interviews and identified themes. Analyses of the data were carried out by the first author and peer-reviewed by the co-authors.

Results

Participant Characteristics

The seven participants were between the approximate ages of 30 and 80 at the time of the first interview. Three were women and four were men. At the time of the study, one participant reported being fully recovered, while the others reported varying levels of functional impairments. Five participants experienced aphasia, and two of these participants had severe aphasia and required supported communication to complete the interviews. Five participants lived alone; one participant had no permanent address and lived with various family members in rotation. One participant lived in a retirement home and received assistance, including personal care and meals.

Following their stroke, the participants received health services in multiple settings. All were initially admitted to acute care hospitals, six then participated in inpatient rehabilitation programs and all received outpatient rehabilitation services.

All seven participants were considered Francophone based on the Statistics Canada (2010) definition and self-identified as French-English bilingual, five of them having French as their mother tongue. The other two had Creole as their mother tongue, French as their second language and English as their third. The participants learned their second languages at different ages. For the remainder of the article, the term bilingual will be used to designate French-English bilingualism.

While all participants described themselves as bilingual, only five of these seven stroke survivors scored as bilingual on the scale developed by Gonzalez-Reigosa. Laurent self-identified as bilingual, but his reading and writing abilities in French scored too low to meet the criteria for bilingualism. He explained that he had not completed grade eight because of a learning disability and perceived that this strongly limited his general language skills, particularly in French. Sylvain also did not meet the bilingualism criteria. He scored his abilities in French lower than his skills in English and reported that his main limitation was French vocabulary and grammar.

Table 1 provides details of participant education, language proficiencies and language acquisition backgrounds.

Table 1

Linguistic and Communication Characteristics of the Stroke Survivors

Pseudonym	Cultural background	Education	Languages and language acquisition background (approximate)	Bilingualism self-assessment scores (Vallerand and Halliwell, 1983)		Supported communication needs
Charlotte	Canadian	High school	Bilingual (French and English), French mother tongue	French 14/16 :	Understanding 4/4 Expression 4/4 Writing 3/4 Reading 3/4	No
			Learned English in school in adolescence.	English 12/16 :	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	
Paul	Haitian	College	Bilingual (French and English), Creole mother tongue, French first official language	French 15.5/16 :	Understanding 3.5/4 Expression 4/4 Writing 4/4 Reading 4/4	No
			Learned French and English in school in Haiti.	English 12/16 :	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	
Jackie	Canadian	High school	Bilingual (French and English), French mother tongue	French 12/16 :	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	Yes
			Learned English as a youth.	English 16/16 :	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	
Laurent	Canadian	Primary school – with learning disabilities	Bilingual (French and English), French mother tongue	French 7/16 :	Understanding 1/4 Expression 4/4 Writing 1/4 Reading 1/4	No
			Learned English as a child.	English 8/16 :	Understanding 3/4 Expression 4/4 Writing 1/4 Reading 0/4	

Josée	Canadian	University	Bilingual (French and English), French mother tongue Learned English as a child.	French 15/16 : English 16/16 :	Understanding 4/4 Expression 4/4 Writing 3/4 Reading 4/4 Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	Yes
Sylvain	Canadian	College	Bilingual (French and English), French mother tongue. Learned English as a child.	French 11/16 : English 16/16 :	Understanding 3/4 Expression 3/4 Writing 2/4 Reading 3/4 Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	No
Daniel	Haitian	College, some university courses	Bilingual (French and English), Creole mother tongue, French first official language Learned French and English in school in Haiti.	French 16/16 : English 16/16 :	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4 Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	Partial

Analysis of the data resulted in four major emerging themes: preferred language for services, aphasia and bilingualism, language insecurity and low health literacy. These themes are outlined below using quotations from the experiences described by the stroke survivors and care partners. Quotations that were originally in French were translated into English by the first author for inclusion in this article. All participant names are pseudonyms.

Preferred Language of Service

Participants did not necessarily prefer to receive their health services in their mother tongue or first official language. For Sylvain, Charlotte and Laurent, the choice of language of service appeared to be based on their perceived proficiency and comfort with the language, including being confident that they had sufficient vocabulary to manage the topic of conversation or to understand the tasks to be completed.

Sylvain wanted to receive services in his second language while in hospital, because he felt that he lacked the French vocabulary necessary for optimal communication. “Blood pressure in French? I don’t know what that [word] is.” He also reported particular difficulties

with written material in French, such as health forms. "You need a French-English dictionary to understand what they are saying!"

Charlotte and Laurent requested, and received, services in both English and French depending on the assessments or treatment tasks at hand. The medical chart indicated that Charlotte self-identified as Francophone, but requested many of her services in English, in particular cognitive assessments and evaluations from speech-language pathologists. Charlotte stated that French was a complicated language and she felt she might understand and express herself better in English. She stated that she felt more comfortable with English vocabulary because that was the language she predominantly used in her job at the time of the stroke. "Right after my stroke, because I was working in English, English was easier for me than French. I have always found that French … it takes 15 words to say the same thing as in English."

Laurent's medical chart also indicated that he self-identified as a French-speaker. Laurent stated being happy to interact with the healthcare staff in French during general assessments and treatments. As Charlotte, he also requested that cognitive assessments be completed in English because he felt he would perform better in that language. Laurent described an incident that took place several weeks after his stroke when he was invited back to the hospital for cognitive assessments. Laurent had been assigned a French speaking professional, but he requested to complete the evaluation in English. He reported that this individual had difficulties administering the assessments in English, and he felt that this might have had a negative impact on his evaluation. "I asked them [to do the assessment] in English and, you see, again I am going to turn this around—they were the ones who were having difficulties [speaking English]. I found that they were not giving the assessment as well in English as they were giving it in French."

Daniel and Paul both had French as their first official language. They indicated that they did not ask for a particular language of service and that they were not explicitly offered services in both official languages in all settings along the continuum of care. Unless they specifically asked for French services, they received services in English by default. Daniel and Paul both stated that, although they would have preferred receiving services in French, neither felt at a disadvantage in terms of their ability to understand or express themselves in English.

Aphasia and Bilingualism

Charlotte, Daniel, Sylvain, Jackie and Josée experienced aphasia following their stroke. For these individuals, speech-language therapy provided in both French and English, rather than in just one language or the other, allowed them to communicate more proficiently. In the early weeks of their stroke recovery, the medical charts indicated that Charlotte's

abilities in English were stronger than in French, whereas Sylvain and Daniel were both stronger in French than in English. They all eventually regained their communication skills in both languages.

Josée and Jackie experienced specific aphasia-related challenges. Due to the severity of their impairments, they unconsciously used French and English interchangeably as if they were one language. As a result, both Jackie and Josée required services in both languages from providers who were themselves French-English bilingual and could effortlessly move between the two languages. Josée's mother, Denise, explained how being bilingual was a challenge for providers, because Josée was unaware of what language she was speaking:

Denise: Because she is so bilingual, she doesn't even know in what language you are speaking to her.

Interviewer: So, is it important that the service provider can speak both [languages]?

Denise: It is important that when she starts speaking French, the other person understands what she is talking about, you know?

While Josée's family was bilingual, Jackie's care partners only spoke English. Jackie's interchangeable use of both English and French created challenges when communicating with her care partners and also with service providers who did not speak both official languages. Jackie's care partner, Marilyn, explained that "she speaks as much English as French right now, which is limiting." She also described a recent meeting with unilingual homecare service providers who had difficulties assessing her needs. "[The community services] care coordinator says to her 'do you have any pain?' and she says [in French] 'there, there, there …'".

Linguistic Insecurity

Charlotte, Laurent and Sylvain reported that they perceived their French language to be "inferior" or "less educated" than the French language used by the healthcare professionals. This appeared to limit ease of communication and affected their willingness to ask questions and seek clarifications. Laurent indicated that he did not speak "standard" French: "I speak a French that they call slang. Slang French, you know, [that is what we spoke] where we were brought up." Laurent also spoke of feeling judged when choosing services in English: "So sometimes people look at me and say 'what's your problem? With [your French last name], and you want to speak in English?'"

Similarly, Sylvain's sister Angèle stated that her brother was unable to use "standard" French, which she reported was only for highly educated individuals: "… because that very educated, educated French, that is not him. You know?" Angèle felt this affected Sylvain's

comfort level communicating with the professionals—and, on several occasions, Angèle and her other sibling needed to get involved to help Sylvain obtain more information.

Low Health Literacy

All the participants, with the exception of Josée, demonstrated low literacy and low health literacy levels in both official languages. The healthcare providers' use of professional jargon and complex health concepts and information was problematic for these stroke survivors. It affected their understanding of stroke and its effects, recommended lifestyle changes for stroke prevention and instructions related to hospital discharge.

Laurent indicated that on several occasions he did not understand the words or terms used by the professionals. He expressed having a poor understanding of his stroke and its effects. "So the words that they use eh? The doctor gave me … I have it here … a report from when I had my stroke. You should see the words in there!" Laurent's brother, Armand, who was also bilingual, often tried to assist his brother understand the healthcare professionals' messages. Armand explained that regardless of the language spoken, there were times when Laurent clearly did not understand. Armand explained: "Ok. So let's say there is a term he didn't understand. There might have been a doctor who might have [translated it into] English to see if he understood it in English, [but] if it was a medical term, in English or even in French, it was all Chinese to him!"

Paul reported on his general difficulties understanding the professional jargon as well as the instructions he was given regarding discharge and resumption of driving. "Important message? I don't want any shortcuts. You have to say everything, and with words from the vocabulary that I know."

Charlotte stated that she often felt that the French vocabulary that professionals used was not the French that she could understand as it was far too complex. Charlotte indicated that she had not understood her stroke, and that at the time of the interviews, more than a year after her stroke, she still did not understand how the stroke happened or how to prevent a subsequent one. She stated that it was necessary for professionals to better communicate this information: "I think that it is important that the patient receive better explanations and understand exactly what happened."

Sylvain's sister felt that, whether they were in French or in English, conversations related to health would have been equally problematic for her brother: "It would not have been understood in either one or the other [language]." She specified that the concepts were too complex for Sylvain to understand.

In Paul and Laurent's medical charts, there was evidence of decreased health literacy. Specifically, the professionals questioned whether these stroke survivors had understood the

health instructions that had been provided. For example, there were several entries from the outpatient rehabilitation nutritionist questioning Paul's understanding of diabetes management even after he had participated in several education sessions provided in French.

Discussion

Despite varying backgrounds of language acquisition and circumstances of language use and different language preferences and skills, the French-English bilingual stroke survivors in this study all had communication challenges that shaped their experience of post-stroke care.

In this linguistic minority context, language of service was an important consideration for these bilingual stroke survivors who self-identified as Francophone. French language services are not always available or offered along the continuum of care (Savard, Bigney, Kubina, Savard, & Drolet, 2020) and, in many instances, the stroke survivors wanted to receive their services in their mother tongue or first official language. However, it could not be assumed that they wanted all of their services in French. Language preferences for healthcare services were dynamic. For instance, it was possible to prefer to be interviewed in French, but to request formal assessments in English.

Provider bilingualism and language flexibility were most important for the individuals recovering from aphasia and, in particular, for those with severe expressive aphasia who used French and English interchangeably without realizing it. The availability of bilingual professionals was not only appreciated by the stroke survivors, but also necessary when communication or cognitive difficulties were present.

Choice of language for services and ease of communication may have been affected by the level of comfort of the stroke survivors and their perceived ability to use "standard" French with healthcare providers. The bilingual participants used regional vernaculars and expressed themselves with a combination of French and English (Mougeon, 1995). Importantly, linguistic insecurity, or a feeling that their way of speaking French was illegitimate and a sign of poor education (LeBlanc, 2010), seemed to have played a role in the stroke survivors' reluctance to request further needed clarifications during their interactions with providers. Healthcare providers should be sensitive to how professional language is an element of social status that can create situations of marginalization (Johansson & Śliwa, 2016). By adapting their language levels to meet the stroke survivor's abilities, service providers can enhance health communication and improve quality of care.

Even when these bilingual stroke survivors received services in their language of preference, issues with health literacy were apparent. Their ability to understand and act on information given to them about their health condition, secondary prevention (for example medication management, diet), and other instructions for recovery and return to everyday

life, was limited. Health literacy is said to extend beyond education and literacy and to be affected by a combination of socioeconomic status, culture, and language factors that may influence one's ability to understand or act on instructions of a medical or therapeutic nature (Shaw, Huebner, Armin, Orzech, & Vivian, 2009). Low health literacy leads to challenges with obtaining health information and making health-related decisions (Magasi, Durkin, Wolf, & Deutsch, 2009) and can affect several aspects of post-stroke life, including adaptation to the effects of stroke and overall wellbeing (Brunborg & Ytrehus, 2014). The stroke survivor's understanding of their health is of prime concern, and service providers adhering to patient centered-care will understand that it is their responsibility to ensure that the message has been well received. In a complex linguistic minority context, where bilingual stroke survivors have varying service needs across a continuum, health literacy may be better addressed as a system issue (Brach, 2017; Brach *et al.*, 2012)

In many countries, having limited proficiency and receiving services in English, or in the majority language, can create a variety of challenging health situations (Dilworth, Mott, & Young, 2009; Karliner *et al.*, 2012). This study shows that, whereas bilingual people whose first language is not English may be proficient in that language and may be able to manage many health situations, they may also have special language needs. Moreover, it highlights the importance of professionals using plain language in all encounters with their patients.

Limitations

Two limitations are worth mentioning. The main limitation of this study is the language context in which the study was conducted. The study took place in an area where 18% of the population self-identifies as Francophone. With relatively good availability of Francophone and bilingual providers, the area was likely better able to cater to the language needs of Francophone and bilingual stroke survivors. However, it is interesting to note that, even within this context, important issues emerged for these bilingual stroke survivors and their care partners. Second, considering the diversity in language acquisition, language proficiencies and culture of the bilingual participants, it may have been beneficial to explore the themes brought forward through this secondary analysis with more participants from each of the language profiles.

Several strategies were put in place to support the trustworthiness and rigour of the results. These include prolonged engagement with the participants, triangulation, a clear description of the analysis method and a detailed audit trail.

Future Research

Future research could focus on increasing our understanding of the experiences of bilingual individuals in other health contexts, investigating the perceptions of health service providers vis-à-vis language and the needs of bilingual stroke survivors, as well as investigating provider challenges in providing bilingual services. The health literacy of bilingual individuals, taking into account primary and secondary languages, should be further explored to inform practice. It is also important to test the effectiveness of different approaches for supporting bilingual patients, including efforts to support health literacy in discordant language and differing social positions. Finally, research should be carried out to provide a better understanding of the needs of bilingual stroke survivors within the intersectional context of immigration, and how to best address these needs.

Conclusion

In a majority English-speaking community supportive of French language services, French-English bilingual stroke survivors experienced unique issues along the continuum of stroke care. These stroke survivors required flexible language services and the ability to participate in assessments and interventions in both languages. This was particularly important for survivors with aphasia.

In this particular region of Canada, other communication challenges, including the use of jargon and *standard* French, in addition to low health literacy, appeared to have the potential to influence longer-term outcomes. The stroke survivors in this study were not all able to understand information given to them about their health condition, secondary prevention, and general service use, which may have had an impact on participation in daily life. In addition to the importance of having bilingual healthcare providers, this study suggests that it is important to have healthcare and social service professionals who can adapt their language level to the client's abilities and needs along the continuum of language between French and English, and remain sensitive to social positioning issues of language, while ensuring that health literacy is addressed. In overlooking the language support or accommodations that stroke survivors may need, and by failing to notice the influence of language as an element of social status, healthcare and social service professionals can create or perpetuate miscommunications which can lead to poorer stroke outcomes.

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