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Perceptions of healthcare professionals regarding home-based pediatric cancer care provided in French: A qualitative descriptive study

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ABSTRACT

Goal: *This study aims to explore how healthcare professionals perceive home-based pediatric cancer care provided in French.*

Methodology: *A qualitative descriptive study was conducted using semi-directed individual interviews of 22 healthcare professionals. A thematic analysis of the transcribed interviews was carried out independently by two members of the research team.*

Findings: *Pediatric cancer care is readily available in French in Quebec, but access to French-language services in Ontario is limited. The possible causes and effects of this lack of access and potential solutions are discussed in this paper.*

Conclusion: *The perceptions compiled in this study should be taken into account to help provide quality home-based pediatric cancer care in French.*

Keywords: healthcare delivery, oncology, pediatric, home-based care, French language

INTRODUCTION

Canada is a bilingual country whose official languages are English and French. Francophones living in a minority language environment in Ontario are an understudied population despite significant health-related disparities and inequalities due to language (Bouchard et al., 2009). Ontario has the largest Francophone minority population in Canada (Office of the Commissioner of Official Languages/Commissariat aux langues officielles, 2018). According to 2016 Canadian census figures, 490,720 people in Ontario (3.7%) reported that French is their mother tongue (Statistics Canada/Statistique Canada, 2016a). Considering that less than half of Franco-Ontarians say they are able to speak to Anglophone healthcare providers in French, the issue of access to French-language healthcare services is of paramount importance (Forgues et al., 2014; Gagnon-Arpin et al., 2014). Most of the Francophone population in Ontario is concentrated in the eastern part of the province, with 25.2% living in the Ottawa area (Statistics Canada/Statistique Canada, 2016b).

Pediatric oncology care can disrupt the lives and financial stability of families with a child who has been diagnosed with cancer (van Warmerdam et al., 2020; Warner et al., 2015). Therapeutic progress and changes in the healthcare system mean that children with cancer are now spending more time at home. This change in environment has resulted in increased levels of satisfaction among parents and improved quality of life for both children and parents (Duran et al., 2020; Lippert et al., 2017). Home-based pediatric cancer care is essential to the comprehensive and effective treatment of the disease for both English- and French-speaking children in Canada.

The Children's Hospital of Eastern Ontario (CHEO) in Ottawa, home to a minority Francophone community, serves children 18 years of age and under and their families living in Nunavut, northern and eastern Ontario, and western Quebec (the Outaouais region). CHEO recently implemented a program to have certain types of pediatric cancer care delivered to children in the comfort of their own home by community healthcare professionals. Home-based nursing care includes services related to nasogastric tube feeding, the administration of medication via subcutaneous injection and central venous catheters. Physiotherapy, occupational therapy, psychology and social work are also on the list of care and services that are provided in a home setting. Like other Canadian home-based pediatric cancer care programs (Lippert et al., 2017), the program delivered and coordinated by CHEO holds a great deal of promise.

To take into account the issues related to the delivery of health care and services to Francophone communities, provide high-quality pediatric cancer care in French and lay the foundations for best practices in this domain, the perceptions of those who play a direct role in home-based pediatric cancer care for Francophone children need to be considered.

Goal of the study

This study aims to explore the perceptions of healthcare professionals regarding home-based pediatric cancer care provided in French.

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METHODOLOGY

Study designs

A qualitative descriptive study was carried out in 2019.

Study setting

The study was conducted with the support of the CHEO Division of Hematology/Oncology, the Medical Day Unit (hematology and oncology outpatient clinic) in Ottawa, Ontario. The CHEO Division of Hematology/Oncology works closely with community organizations in two Canadian provinces (Ontario and Quebec) to provide home-based cancer care and services to children and their families. Support related to nasogastric tube feeding, the administration of medication via subcutaneous injection, and central venous catheters is delivered by home care nurses. Physiotherapy, occupational therapy, psychology, and social work services are also available in a home setting. Chemotherapy, on the other hand, is provided solely at the hospital through the CHEO Hematology and Oncology Program or the Medical Day Unit.

Sample

The subjects included in this study were healthcare professionals who 1) were Anglophones or Francophones; 2) worked with the CHEO Hematology and Oncology Program or a community organization providing home-based healthcare in the Ottawa area; and 3) were providers or coordinators of home-based pediatric cancer care for Francophone children.

Data collection

The study was approved by the research ethics boards at CHEO (Protocole 18/70X) and the University of Ottawa (Protocole H-08-18-823). A data sharing contract was signed by CHEO and the University of Ottawa. Informed consent was obtained from all study participants.

Semi-directed individual interviews were conducted in person and by telephone with the participants recruited for the study. The interviews lasted approximately 30 minutes and were recorded using an audio recorder and subsequently transcribed. The interview guide was tested with a healthcare professional who met the eligibility criteria for the study, but who was not part of the sample. None of the questions was modified following this test. The interview guide included questions such as the following (translated here into English): What do you think about the home-based cancer care provided to Francophone patients and their families? Do you think Francophone patients and their families receive all their home-based cancer care and services in French? What do you think are the obstacles to accessing home-based cancer care in French?

Data analysis

The demographic data for this study were analyzed using descriptive statistics. JC, RB, CG, SC and EBH analyzed the transcriptions of the interviews of the study participants (n = 22). The inductive thematic analysis of the transcribed interviews was inspired by Braun & Clarke (2006). JC, RB, CG, SC and EBH read each transcription three times to obtain a general idea of their content. They then each coded the transcription line by line, working independently. Coding decisions were made based on previously analyzed data using the constant comparative method (Lincoln & Guba, 1985). JC and CG subsequently met to analyze the data in depth and decide how to group codes into themes and subthemes based on the relationship between the codes and the units. JC and CG also came to a consensus on the final coding scheme. Where there were differences of opinion, LJ intervened to find a mutually acceptable solution. All of the analytical decisions were logged during meetings.

FINDINGS

Sample characteristics

The study was based on interviews of 22 healthcare professionals working with CHEO or a community organization providing health care to Francophone families. Participants were primarily female (90.9%), Anglophone (90.9%) and between 30 and 50 years of age (77.3%). It came as little surprise that the majority of participants were Anglophone, given that they were recruited in Ottawa and eastern Ontario, where the Francophone communities are a minority. Many of the participants were registered nurses, licensed practical nurses and oncologists (45.4%). Other healthcare professionals who took part in the study included physiotherapists, a physician's assistant, a child life specialist, a social worker, an occupational therapist and a psychologist. On average, participants had 12.5 years of experience in pediatric cancer care at CHEO (77.3%) or in a home setting (22.7%).

Themes

The perceptions of participants regarding home-based pediatric cancer care provided in French could be grouped into two distinct themes: 1) access to home-based cancer care in French; and 2) healthcare professionals' unfamiliarity with the needs of Francophone cancer patients and their families.

Access to home-based cancer care in French

One of the participants indicated that *"it is important that they receive their care [home-based pediatric cancer care] in their own language, because families should be comfortable having someone who can answer questions"* (Healthcare Professional #01, translated). The healthcare professionals interviewed talked about the mechanisms in place that take into account the preferred language of cancer patients and their families. As one of the study participants indicated: *"So on our referral form, when we request home care and it goes to our home care team, we do have a check box for English or French services"* (Healthcare Professional #02). As a result, Francophone families can receive their written educational materials in French. However, this does not necessarily guarantee that the home-based cancer care and services they are given will similarly be in French. In fact, when the language needs of patients and families were documented and discussed, several healthcare professionals acknowledged that the system was not able to provide home-based care in French in Ontario given the shortage of Francophone and bilingual nurses in the community system: *"We do lack nurses speaking French in the community, there has been a lack of French speaking nurses, though we try our best"* (Healthcare Professional #04); *"Where here at [the*

hospital] there's such a big pool French-speaking of bilingual nurses that you'd probably be able to meet that need. But perhaps not so much out in the community, because they have a smaller pool" (Healthcare Professional #03).

To make matters worse, there also seems to be a lack of French-speaking nurses specializing in pediatric oncology working in the community: "*You know, maybe they are French speaking but not comfortable with peds, or cancer"* (Healthcare Professional #02). This further exacerbates the obstacles to providing home-based cancer care in French.

As indicated previously, the home-based cancer care program is also offered in Quebec, given that CHEO's territory extends to the Outaouais region. This segment of the program is provided primarily in French, the language spoken by most people in Quebec. A number of participants said they believed that, in Quebec, Francophone patients and their families did not have any difficulty receiving their home-based care in French, in that "*Because their home care is provided back home in Quebec, a francophone, francophone, francophone province, I would imagine that it would all be done in French"* (Healthcare Professional #05).

Healthcare professionals made use of a range of strategies to address the lack of access to French-language cancer care services in the community. Knowing in advance that it would be impossible to meet the language needs of Francophone patients and their families in some cases, one of the healthcare professionals had this to say: "*If we know ahead of time if they don't have any French nurses, like they'll come [to the outpatient clinic]"* (Healthcare Professional #04), where there are more Francophone and bilingual nurses than in the home-based program. They also mentioned that home-based interpreting services are available, but they did not indicate that they had used these services when working with Francophone patients and their families. They did specify, however, that "*When a family member speaks both languages, we ask them to translate"* (Healthcare Professional #08). The healthcare professionals also explained that Franco-Ontarian patients *"whether or not they have a Francophone nurse, they would be able to manage with an English-speaking nurse"* (Healthcare Professional #20). The impact of this lack of access to home-based cancer care and services in French for Francophone patients and families was touched on by the study subjects. One of the healthcare professionals interviewed spoke about their concerns about the privacy of Francophone patients, saying:

> *"I had a patient a couple of weeks ago who was admitted and we're trialing right now a screening tool for suicidal risk in cancer patients, and none of the nurses were Francophone when she had screened positive, and so she was basically forced to answer questions through the translation of her mum about her suicidal ideation"* (Healthcare Professional #21)

Unfamiliarity with the needs and realities of Francophone patients

The healthcare professionals interviewed stated that they had not received any complaints from Francophone patients or their families with regard to the home-based cancer care received. As one of them pointed out, "*I haven't heard anything different from French families versus English families as far as like if there was like language issues or anything like that as far as care service"* (Healthcare Professional #02). Another explained, "*honestly, of all the families on my cases, I've never heard anyone coming back to me and saying, "I couldn't get a French nurse"* (Healthcare Professional #20). A few of the interviewees repeatedly expressed their uncertainty and ignorance as to the access Francophone cancer patients and their families had to Francophone and bilingual nurses, saying for example, "*I know we have like other families of other languages where I definitely see them having issues 'cause they need like, when they come to see us, they each have a translator. But, I don't know about the Francophone"* (Healthcare Professional #22) or "*I'm not really sure the degree of how bilingual the nurses who work in home care. I haven't heard anything about this"* (Healthcare Professional #11). A number of the healthcare professionals indicated that they assumed Franco-Ontarian families were all bilingual. One of the comments to this effect was: "*In Ontario, it's rare that I have uniquely French speaking families"* (Healthcare Professional #17). Another of the participants said that "*all the Francophone families, they'll have some level of English. Not all of them"* (Healthcare Professional #22). Two of their co-workers used phrases like *"francophones, francophones, francophones"* or "*francophones, francophones"* to describe families who did not speak or understand any English (Healthcare Professionals #05 and #16).

DISCUSSION

The findings of this study show that Franco-Ontarians who are living in a minority language environment do not have easy access to home-based pediatric cancer care in French, as opposed to Francophone families in Quebec, where the majority of the population is French-speaking. A shortage of Francophone and bilingual healthcare professionals specializing in pediatric oncology may explain this disparity in terms of home-based care of this type in French. The study also sheds light on the fact that healthcare professionals are unaware of the actual status of home-based pediatric cancer care and services received by Francophone patients and their families. Moreover, it highlights that many healthcare professionals are under the impression that all Franco-Ontarians are fluent in English.

Lack of access to healthcare services in French

The lack of access to French-language healthcare services in Ontario is nothing new. The situation predates the adoption of the *French Language Services Act* (Government of Ontario/Gouvernement de l'Ontario, 2016). However, this study shows that the problem remains unresolved, in this case as it applies to home-based pediatric cancer care in French.

Causes

In this study, the preferred language of patients and families receiving home-based pediatric cancer care was indicated via a checkbox on the program intake form. It is strongly recommended to promptly determine patients' language fluency in order to help refer them to the appropriate care and

Francophone or bilingual healthcare professionals (de Moissac et al., 2020). However, Francophone families living in a minority language environment, in Ontario in this case, do not necessarily have access to care in French. Furthermore, the healthcare professionals interviewed in this study indicated that they were uncertain as to the care received by Francophone patients, since there does not seem to be a process in place to assess home-based pediatric cancer care provided in French. The onus for evaluating access to and the quality of the care and services provided to patients and families in minority Francophone communities is on healthcare organizations and, potentially, on healthcare coordinators. In situations where patients' preferred language is taken into consideration, some patients, families, and healthcare professionals acknowledge that the system is ill equipped to provide services in French, due to the lack of Francophone and bilingual healthcare professionals. Healthcare organizations must therefore adopt specific strategies to recruit and retain Francophone and bilingual healthcare professionals. These strategies may include 1) hiring healthcare professionals who are not bilingual but who are incentivized to become bilingual to be granted permanent employment status; 2) recruiting healthcare professionals from communities where Francophones are the majority (Quebec, France, Africa, etc.); and 3) providing ongoing language training to bilingual healthcare professionals already on staff (Savard et al., 2017).

Francophones living in a minority language environment tend to attribute the lack of access to health care to the shortage of French-speaking healthcare professionals (Gagnon-Arpin et al., 2014). This study revealed that, not only is there a lack of pediatric oncology nurses working in a community setting, but also that precious few of them speak French. As indicated in a paper by Chartrand et al. (2019), French is considered to be an optional asset when hiring new staff members, e.g., nurses to provide home-based care and services to pediatric cancer patients and their families. Other studies do indeed show that most employers prioritize clinical skills over linguistic competencies in their hiring criteria (Aucoin, 2018).

There are also other reasons that may contribute to the lack of availability of home-based pediatric cancer care in French. The healthcare professionals interviewed said that Franco-Ontarian families are bilingual, meaning that they speak and understand English. This would make providing healthcare services in French unnecessary. However, although some of these patients do indeed speak English, it does not mean they are fully comfortable expressing themselves or receiving care in this language (Drolet et al., 2017). Study participants also indicated that they had never received any complaints from families about the lack of French-language services. As a result, many of these healthcare professionals are of the opinion that, if nobody asks to be served in French, there is no issue with providing home-based care in English (Forgues et al., 2014; Villard, 2018). These beliefs run counter to the realities experienced by Francophone families living in a minority language environment, which in turn undermines the safety and the quality of care provided to patients (van Kemenade & Forest, 2019; Villard, 2018). It is widely understood that Francophones living in a majority-English community are not comfortable making demands for French-language services (Forgues et al., 2014). It is possible that these families simply stop asking to be served in French and come to terms with the fact that the care provided will be in English when a French-language alternative is unavailable (van Kemenade & Forest, 2019). The lack of requests and complaints with regard to French-language services contributes to the perception that there is no demand for these services and therefore no issues to be resolved (van Kemenade & Forest, 2019).

Consequences

Faced with the lack of access to care in French, Francophone patients often tend to adapt and agree to be served in the majority language, i.e., English (van Kemenade & Forest, 2019). Language barriers between healthcare professionals and Francophone children and families dealing with cancer undermine the quality of communication. Other studies have shown that these barriers exist for Francophones outside Quebec (de Moissac & Bowen, 2019). These barriers compromise access to and the quality of care for patients and undermine their safety (Al Shamsi et al., 2020; de Moissac & Bowen, 2019; Khan et al., 2020) since they increase risk during diagnosis, intervention and treatment (Bouchard & Desmeules, 2017). Specifically, as it pertains to home-based pediatric cancer care, language barriers can have negative repercussions on health, well-being, quality of life and patient/family satisfaction.

Solutions

The healthcare professionals and healthcare organizations that were the focus of this study reacted in different ways to the lack of Francophone nurses working in the community. In the rare cases where a healthcare coordinator knew in advance that patients and families needed to be served in French and was aware that French-language services could not be guaranteed at home, the coordinator would direct them to the outpatient clinic, where there were more Francophone and bilingual nurses on staff. However, this meant that these patients and families had to travel long distances to access cancer care and services in French, as opposed to their English-speaking counterparts (Forest, 2019). The extra travel time between home and the hospital only added to the financial strains already experienced by cancer patients and their families (Warner et al., 2015). Without access to home-based pediatric cancer care, due to a shortage of Francophone and bilingual healthcare professionals, Francophone patients and their families could not enjoy the same benefits as their Anglophone counterparts, who were able to receive care and services in the comfort of their own home. Although travelling to the hospital was intended as a solution to ensure access to pediatric cancer care in French, it instead widened the service delivery gap between French- and English-speaking patients.

According to the healthcare professionals who took part in this study, interpreting services are available to support Francophone patients and their families, although it was mentioned that nobody had actually used these services. Healthcare organizations and professionals should have access to formal translation services delivered by professional translators and

interpreters. This would be in the best interest of Francophone patients and their families (Hsieh, 2015). In this study, the healthcare professionals instead turned to informal translation sources (i.e., family members considered to be bilingual). This practice was not without its problems, however, especially with respect to patients' privacy (Bowen, 2015). Healthcare professionals should not have to call upon bilingual friends or family members to translate patient-related information (Farmanova et al., 2018). The findings of this study show that the healthcare professionals interviewed, the majority of whom are Anglophone, were the ones to decide whether or not to make use of the available resources, including interpreting services. They are also the ones who determine whether Francophone patients and their families are sufficiently fluent in English and whether they should be addressed in French, even though their language preferences are already indicated at intake. Organizational measures are essential in this regard, e.g., an assessment of home-based pediatric cancer care and services provided to Francophone patients and their families in French, as well as recipients' satisfaction. An assessment of this nature should be conducted on a regular basis by administrators in order to ensure a swift response to the findings of this study.

Limitations

Like any study, there were limitations to contend with in this paper. The most significant limitation involves the sample, which did not include any patients (children) or parents. Future studies are needed to explore the perceptions of Francophone children and parents regarding home-based pediatric cancer care in French to provide a clearer picture of the situation based on the findings and conclusions of this study. This research would shed even more light on the realities experienced by Francophone patients and their families living in a minority language environment.

CONCLUSION

Overall, the perceptions of healthcare professionals regarding the quality of home-based pediatric cancer care in French must be taken into consideration by pediatric oncology program administrators specializing in home care as well as by interdisciplinary professionals operating out of hospitals and community organizations. The perceptions and needs of Francophone patients and their families underscore the lack of access to French-language health care. By taking these perceptions into account and acting on them, administrators can help improve the quality of home-based pediatric cancer care in French and mitigate the risks associated with being "lost in translation" in a health context. Future studies should also look into the perceptions of healthcare administrators who oversee home-based pediatric cancer care provided in French, to understand better the role they play in planning and assessing the quality of care in French.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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