CAREGIVING AND ETHNOCULTURAL MINORITY GROUPS IN QUEBEC

FACILITATORS AND BARRIERS TO ACCESSING AND USING SERVICES

Authors : Anais El Amraoui, Philippe Gagnon, Marie-Ève Samson, Josiane Le Gall & Kettly Pinchinat Jean-Charles (translated by Michelle Daniel)

How to use this fact sheet: This fact sheet is a tool to raise awareness among individuals who work with informal and family caregivers to help them better understand the various factors that influence PAGEMA caregivers' access to and use of services.

It is based on an analysis of data from the study "The Experiences of Informal and Family Caregivers from Ethnocultural Minority Groups in Quebec."

Read the full research report (French Only)

WHAT IS THIS ABOUT ?

It is often difficult to distinguish between the specific needs of caregivers who belong to an ethnocultural minority group (PAGEMA caregivers) and the needs of the people they support in terms of resources and health and social services. PAGEMA caregivers also believe that when their loved ones' needs are met, they generally experience fewer difficulties.

Nevertheless, certain conditions can reduce the burden associated with caregiving and prevent or reduce burnout among PAGEMA caregivers. In the absence of these conditions, and when relational and systemic constraints are present, PAGEMA caregivers' access to and use of services may be hindered by their migration background, precarious living conditions, or experiences of discrimination.

These factors are expressed at several levels [1] :

Individual: This level includes various elements specific to individuals, such as their sociodemographic characteristics, personal and social skills, cultural norms and values, etc.

Relational: This refers to conditions related to living and care environments, support networks, local communities, etc. These are the factors that connect individuals to others.

Systemic: These factors relate to broader systems, including the organization of the health and social services network, organizational norms and cultures, and the delivery of services.

It is important not to overlook the broader context (including political, legislative, economic, social and cultural factors, etc.).

It can influence these factors and shape the experiences of PAGEMA caregivers within the public health and social services network.

---

[1] Inspired from Anctil, H. (2012). La santé et ses déterminants. Mieux comprendre pour mieux agir. Gouvernement du Québec.

DID YOU KNOW… ?

Some perspectives, particularly **familialist approaches** to care, suggest that for cultural reasons, PAGEMA caregivers prefer to care for their loved ones at home rather than using formal services, such as residential facilities for older adults.

The results of our study challenge the idea that PAGEMA caregivers' involvement is solely a voluntary decision driven by cultural preferences. The accounts of our participants are consistent with findings from several other studies that criticize familialist approaches for **overemphasizing cultural factors while downplaying the structural and situational barriers that may limit access to services and influence the decision to care for a loved one.**

RESOURCES AND SERVICES USED

Faced with the challenges of caring for a loved one, many PAGEMA caregivers seek support and turn to a range of resources and services, despite difficulties accessing them.

The following resources and services are used outside the social networks of PAGEMA caregivers:

Community organizations and caregiving associations

Organizations that serve ethnocultural minority and/or **English-speaking groups**

Non-specialized community organizations

Respite services

Religious leaders and institutions

Public services (particularly **CLSCs**)

Support groups

Private services (particularly for psychosocial support and psychotherapy services)

Services in their country of origin, which are sometimes more accessible, available, and less expensive (even when accessed from abroad)

Caregiver benefits and tax credits (federal and provincial)

* *The order of presentation is not representative of PAGEMA caregivers' use of resources and does not reflect sequence of use.*

FACTORS INFLUENCING ACCESS TO AND USE OF SERVICES

According to our data, a number of factors, which manifest differently from one person to another, have a tangible influence on the quantity and quality of care received by PAGEMA caregivers and their loved ones. These factors may combine and interact. While they primarily concern PAGEMA caregivers, they also affect the people they support. [2]

AT THE INDIVIDUAL (MICRO) LEVEL

FACILITATORS

- Good knowledge of the health and social services network and its resources
- A flexible job
- The possibility of turning to private resources and services to compensate for the absence of adapted services

BARRIERS

- Possibly a different understanding of illness or disability
- Stigmas or taboos surrounding certain types of intervention, services, or illnesses
- A lack of knowledge about the illness or condition of the person being cared for
- Difficulty recognizing themself as a caregiver and naming their needs related to this role to health and social services network staff
- A lack of understanding of the functioning of Québec's health and social services network, and of the responsibilities of certain professions
- A lack of knowledge of existing resources and services for PAGEMA caregivers and their loved ones
- Difficulty communicating in French about complex and intimate topics

For example, Zihan didn't know what occupational therapy was, as it has no equivalent in her mother tongue or country of origin:

> ***"During this time, I don't know what is ergothérapie. I have no idea. I checked: Oh, it is for movement. We don't need movement, what is that? [My child] was going already to physiotherapy. But now, I understand. After being out of the hospital, you have two branches of recovery. One is like physiotherapy, all the muscles recovering, but the other is like [for] mental sickness, it is like ergothérapie. The big thing I am proud of, [my child] and the ergothérapie, they did success, now [my child] is independent." - Zihan***

Lisa spoke about how unfamiliarity with the system affects people who are new to Quebec:

> ***"I don't know anything about the health care system in Quebec. How can I contact the CLSC? How can I know that there would be a centre that help [my child]? I had to wait for the family doctor. I had to wait… [inaudible]. I am not active, I [feel I] am also in the passive position. But [I am] the mother, I also struggle for my [child]. So I will ask, what I don't understand, I will ask for help." – Lisa***

---

[2] It should be noted that the presence of certain elements may act as facilitators, whereas their absence may pose barriers. We have presented them here based on how they were perceived and described by the PAGEMA caregivers who took part in our study.

AT THE RELATIONNAL (MESO) LEVEL

FACILITATORS

- The presence of someone in the caregiver's social circle who works in the health and social services network or the medical field
- Support from care staff in navigating services
- Strong, trusting relationships with care staff
- Facilitated access to community resources
- The presence of immigrant and racialized staff who share cultural reference points or speak their language

BARRIERS

- Difficulty establishing trust, often related to communication challenges or past experiences of inadequate care
- A perceived lack of empathy and consideration from care staff
- Isolation, exacerbated by the absence of an established social network in Quebec

PAGEMA caregivers place great importance on establishing an atmosphere of receptiveness, openness, and empathy with care staff. Establishing this kind of positive atmosphere requires time and continuity in relationships. Conversely, communication difficulties and past experiences of inadequate care are among the main sources of frustration for participants, and may lead to mistrust of services.

The limited size of many PAGEMA caregivers' social networks makes it harder for them to access additional sources of support. Most participants felt disappointed that they could only rely on a small circle of family and friends for regular help—one or two people at most. This kind of support also plays an important role in finding services.

Maria spoke about how isolated she feels in Quebec as a single mother of a child with special needs:

> ***"What I would like most is to have my mother here. Honestly, because I know that… if my mother were here, I could work, and I would feel better emotionally."***
> **- Maria**

Conversely, some PAGEMA caregivers consider themselves lucky to be able to count on a support network. Anh Dao explained that her parents were able to stay in their own home through a family contact:

> **« *[…]* "We had a friend who works at a CLSC, and she helped us find someone who could speak our mother tongue."**
> **- Anh Dao**

AT THE SYSTEMIC (MACRO) LEVEL

FACILITATORS

- Access to free care, when caregivers and the people they support are eligible
- Adequate and accessible benefits and tax credits
- Measures to help balance work, family, and caregiving responsibilities
- Permanent residency or citizenship
- A skilled, well-paid, flexible, and stable job

PAGEMA caregivers often feel that they are not a priority for services or the health and social services network, in particular because they:

- Do not feel recognized as true partners in care
- Face a large number of organizational and systemic obstacle

BARRIERS

- A general lack of services and a lack of flexibility in those available
- A lack of culturally adapted services
- Staff turnover and shortages
- A lack of interpreters or services in the caregiver's mother tongue
- Overly restrictive and complex access criteria to services and benefits for caregivers
- Difficulty in being heard and acknowledged as a legitimate representative by service providers
- Experiences of stigmatization, discrimination, or racism that undermine trust in services
- A lack of accessible information on existing resources and services as well as the rights of PAGEMA caregivers and their loved ones
- Geographical distance from adapted services
- Precarious migratory status
- Precarious socioeconomic conditions
- Inadequate or unaffordable housing
- Professional deskilling
- Living in an area with limited public transit

PAGEMA caregivers sometimes face biased attitudes that affect their caregiving experience, leave a lasting impact on their view of the health care network, and shape their future interactions with health care teams.

> ***"But for the social, the health, and the education services, it says equality [in Quebec]. But the way, the behaviour, the way of thinking, [what] I get [is] discrimination."***
> **- Lisa**

> ***"I've felt that quite a few times—when they come into the room, you can tell by their attitude, how they talk to you and all that. In some cases, it's like we're stereotypes: 'Ah, they're Arabs or…' Maybe some people have gone through stuff, heard things, so they already have that in their minds. But when they talk to you, when they get to know you, they change their minds and start to respect you. But you always have to prove yourself—that's what's hard, it doesn't happen right away."***
> ***- Saleh (free translation)***

PRACTICAL IMPLICATIONS

While some people express slightly different conceptions of illness and disability, these differences do not appear irreconcilable with how Quebec's health and social services approach these issues. **Above all, PAGEMA caregivers want access to services for their loved ones and also for themselves.**

When **services are limited**, some families may be denied access because of prejudice, without their true preferences being taken into consideration. [3] These barriers are compounded when PAGEMA caregivers support more than one person.

Faced with these experiences, PAGEMA caregivers feel they must **struggle against the system** to adequately support their loved ones. Mothers of children with special needs expressed their desire for psychosocial support, feeling exhausted by the amount of care they must provide for their children and the lack of services available to support them. These mothers expressed frustration that, instead of receiving the necessary support, they felt judged, as if they were not "good mothers" or were not doing enough. In many such cases, services were sent to assess the child's well-being instead of responding to the mother's expressed needs.

As such, **most of the barriers experienced by PAGEMA caregivers reflect structural and systemic challenges that go beyond the limits of their individual agency.**

Structural barriers should be understood as those arising from the organization of the health care system, intersecting with other factors, including migration experiences, racialization, and minority language status, among others.

By acting on the various structural factors that stigmatize PAGEMA caregivers in specific ways and perpetuate social inequalities, it is possible to ensure greater equity in the provision of health and social services.

Recommendations for service development:

Continue to document and recognize the existence of structural barriers to accessing and using services for people from ethnocultural minority groups in Quebec, and work to eliminate them.

Improve access to information about available services and referral processes.

Offer caregivers and care recipients stable support with navigating the health and social services network and coordinating care and services.

Adapt services, expand service offerings, and make home care services more flexible to better meet the needs of subgroups who may be more vulnerable.

---

[3] Simard, J., Grenier, Y. et Dauphinais, C. (2023). *La proche aidance en contexte de diversité ethnoculturelle au Québec, constats et recommandations.* L'Alliance des communautés culturelles pour l'égalité dans la santé et les services sociaux (ACCÉSSS); Lee, E. (2020). *Access to Health and Social Services for Racial and Ethnic Minority Family Caregivers of Older Adults: Unmet Needs, Satisfaction with Health and Social Services, and Service Use.* School of Social Work, McGill University, Montreal; Lavoie, J-P., et coll. (2007). L'État face aux solidarités familiales à l'égard des parents âgés fragilisés : substitution, soutien ou responsabilisation. Les cas français et québécois, dans *Prendre soin d'un proche âgé*, 21-83. Pratiques gérontologiques. Toulouse.

PRACTICAL IMPLICATIONS

Several courses of action

1. **Take an interest in the caregiver's context**, beyond their personal characteristics and those of the care recipient.
2. Seek to better understand the caregiver's context and the **systemic barriers** they may face, particularly those related to immigration status, languages spoken, and so on.
3. Foster **listening, empathy, and flexibility** in service delivery.
4. Remain **informed about the needs** of PAGEMA caregivers and their loved ones, and solicit feedback on the services provided.
5. Recognize that **certain conditions may discourage PAGEMA caregivers from accessing the services** and resources they are entitled to, and take action to reduce these barriers.
6. **Provide referrals** to external resources for PAGEMA caregivers and their loved ones, as needed.
7. **Collaborate with community organizations and local resources** to strengthen support networks and build trust with PAGEMA caregivers.
8. **Acquire training** in intercultural intervention approaches.
9. **Adopt an attitude of ongoing learning,** while encouraging awareness among colleagues.
10. Recognize that each individual is best positioned to **share their lived experiences**, and ensure that the necessary conditions are in place for them to do so in a safe environment.

POUR ALLER PLUS LOIN

The Experiences of Informal and Family Caregivers in Quebec Who Belong to an Ethnocultural Minority Group – Research Summary, SHERPA University Institute.

Caregiving in Canada: Challenges and opportunities shaping a national conversation, Report, Petro-Canada CareMakers Foundation.

Access To Services for Asylum Seekers in Québec, Toolkit for Health Professionals and Community Workers, from the Centre d'expertise sur le bien-être et l'état de santé physique des réfugiés et des demandeurs d'asile (CERDA) of the CIUSSS du Centre- Ouest-de-l'Île-de-Montréal.

The Health and Access to Care of Uninsured Migrants in Montreal, Valerie Ridde (2017) at the M8 Alliance Expert Meeting on Migrants' and Refugees' Health.

Complementary articles :

- Brotman, Shari, et Ilyan Ferrer. 2015. « Diversity Within Family Caregiving: Extending Definitions of "Who Counts" to Include Marginalized Communities. » *HealthcarePapers* 15 (1): 47-53.
- Brotman, Shari. 2003. « The Primacy of Family in Elder Care Discourse ». *Journal of Gerontological Social Work* 38 (3): 19-52

Access additionnal fact sheets

INSTITUT UNIVERSITAIRE SHERPA
Immigration. Diversité. Santé.

Québec
In partnership with