THE EXPERIENCES OF INFORMAL AND FAMILY CAREGIVERS IN QUEBEC WHO BELONG TO AN ETHNOCULTURAL MINORITY GROUP

SUMMARY

Marie-Ève Samson
Josiane Le Gall
Kettly Pinchinat Jean-Charles
Miria Presnielle Kouka
Anaïs El Amraoui
Andréanne Guindon
Janique Johnson-Lafleur

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SHERPA
UNIVERSITY INSTITUTE

Integrated Health
and Social Services
University Network
for West-Central Montreal
Québec

Within Quebec society, a broad discussion on the contributions of informal and family caregivers led in October 2020 to the adoption of the Act to Recognize and Support Caregivers (Bill 56). Six months later, a National Policy for Caregivers and a five-year government action plan were introduced.

- Act to Recognize and Support Caregivers (LPPA)
- Plan d'action gouvernemental pour les personnes proches aidantes 2021-2026 (PAG-PPA, available in French only)

As part of measure 30 of the PAG-PPA, the Institut universitaire SHERPA (IU SHERPA) of the CIUSSS du Centre-Ouest-de-l'Île-de-Montréal was commissioned to conduct a study aimed at "studying the situations and specific needs of caregivers who belong to an English-speaking or ethnocultural minority group, with a view to defining courses of action to better support them." To this end, the specific objectives of the study conducted by IU SHERPA were as follows:

1. Understand how these caregivers perceive their role in relation to the care recipient, and how this role fits into their life path, their family history (whether or not it involves migration), and their social network;
2. Document their expectations, needs, and challenges ;
3. Document their experiences in terms of facilitating factors and obstacles to accessing and using existing resources and services.

This research project was twofold. First, a literature review was conducted. Second, semi-structured individual interviews were conducted with 37 informal and family caregivers who belong to an English-speaking or ethnocultural minority group (PAGEMA caregivers), in accordance with our mandate to cover these populations jointly, despite their often differing circumstances and experiences. The results of these two components can be found in the final report.

- **Final Report** – Les expériences de personnes appartenant à un groupe ethnoculturel minoritaire qui prennent soin d'un·e proche au Québec (French only)

This summary[1] highlights the report's main findings. It presents a brief portrait of PAGEMA caregivers as well as some trends from the literature regarding this population. It also highlights the main findings of the interviews that were conducted as part of the project and the resulting recommendations.

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[1] To make this summary more concise, we have omitted most of the sources and references on which this project is based. The complete list of references is available in the project's final report.

TABLE DES MATIÈRES

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minoritaire qui prennent soin d'un·e proche au Québec
Author: Marie-Ève Samson, Josiane Le Gall, Kettly Pinchinat Jean-Charles, Miria Presnielle Kouka, Anaïs El Amraoui, Andréanne Guindon, Janique Johnson-Lafleur
Translation: Michelle Daniel
Graphic design and layout: Andréanne Boisjoli

"Caregiver" as defined by the Ministère de la Santé et des Services sociaux

"Any person who provides support to one or more members of his or her immediate circle who has or have a temporary or permanent physical, psychological, psychosocial or other incapacity, regardless of their age or living environment, and with whom the person shares an emotional bond as a family member or otherwise. The support is continuous or occasional, and short- or long-term, and is provided on a non-professional basis and in a free, enlightened and revocable manner in order, among other things, to promote the care receiver's recovery and the preservation and improvement of his or her quality of life at home or in other living environments." (According to the Act to Recognize and Support Caregivers)

Individuals from ethnocultural minority groups

Individuals who share, to varying degrees, collective traits based on their ethnic origin, culture, language, and/or religion. They may have been born in Quebec, or be immigrants, refugees, or asylum seekers. They may also be racialized, have at least one immigrant parent or grandparent, and be Francophone, Anglophone, or allophone, with French, English, or another language as their second language[2].

PAGEMA caregivers

In French, this stands for "Personnes proches aidantes appartenant à un groupe ethnoculturel minoritaire et/ou de langue anglaise" (caregivers from an ethnocultural minority group and/or English-speaking background).[3]

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[2] The term "ethnocultural groups," rather than "ethnocultural communities" or "cultural communities," is preferred here to distance the analysis from a perspective that tends to essentialize culture by portraying it as a homogeneous and static entity. The minority status of these groups must also be understood from a sociological rather than a demographic perspective—that is, it is defined through their interactions with the majority group, namely Quebecers of French-Canadian origin.
For a more detailed explanation of the term, as well as considerations regarding its use, see the final report (page 2).

[3] *Ibid.*

A PORTRAIT OF PAGEMA CAREGIVERS

Limited statistical data is currently available on PAGEMA caregivers in Quebec or Canada[4]. However, there is some general data on people who are immigrants, born to immigrant parents or grandparents, racialized, or English-speaking. The sociodemographic characteristics and information on their living and health conditions drawn from this data offer potentially relevant insights about PAGEMA caregivers. Indeed, according to this information, people who belong to an ethnocultural minority group are more likely to experience socioeconomic insecurity than the broader Quebec population. Moreover, in many cases, different dimensions of social and health inequalities intersect, further compounding vulnerabilities..

Some sociodemographic characteristics of individuals from ethnocultural minority groups

The following table summarizes available data on the sociodemographic characteristics of people who belong to an ethnocultural minority group, based on the most recent Quebec census, which, in 2021, had a population of 8.5 million. Note that these characteristics are not mutually exclusive. For example, an immigrant may be both allophone and have a precarious status, or racialized and English-speaking.

Population with at least one parent born outside Canada

	Proportion (%)
Immigrant population	14,6 %
“Visible minority” population	16 %
Population with at least one parent born outside of Canada	10,6 %

Data from the 2021 Quebec census, Statistics Canada

- 16.7% of immigrants arrived in Quebec within the past five years;
- 14.5% of immigrants were admitted under “refugee or similar status”;
- Immigrants are overrepresented in the Quebec workforce and tend to be younger than the rest of the population.

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[4] In addition, from one study to the next, existing data define PAGEMA caregivers using different terms and do not necessarily group the same individuals together within this category. e groupe.

A few facts about linguistic minorities in Quebec

According to the 2016 census,[i] 1.4 million Quebecers express themselves primarily in a language other than French, which does not necessarily mean they are unable to converse in French to some extent.

English speakers represent between 13.8% and 14.9% of Quebec's total population [ii]. This proportion varies according to whether the definition of English speaker is based on mother tongue, the language spoken at home, or the use of English as the language spoken in dealings with public services .

- Note that immigrants are over-represented among the English-speaking population. One third of Quebec's English-speaking population are immigrants (33.6%), compared to 8.8% of the French-speaking population[iii].
- In addition, 35.9% of English speakers identify as "visible minorities," compared to 12.0% of French speakers in Quebec[iv].

According to the 2016 census data, the proportion of allophones varies between 7% and 13% of people who live in Quebec[v].

- This proportion is higher among recent immigrants[vi].
- However, approximately 1% of Quebecers are unable to converse in English or French[vii] . Among immigrants, this proportion is higher for certain potentially more vulnerable sub-groups, such as the elderly ou les personnes en demande d'asile[viii].

According to the 2016 census, 1.4 million Quebecers express themselves primarily in a language other than French, which does not necessarily mean they are unable to converse in French to some extent.

Some data on the living and health conditions of these populations

Overall, **immigrants, refugees, asylum seekers,** and **people with precarious status** are more likely to face challenges in meeting their primary needs (housing, education, food security, etc.)[ix].

- They live with more unmet health care needs.
- They are more likely to experience professional deskilling.
- They have a lower average salary than the rest of the population.
- They were more affected by job loss during the pandemic

Similar findings were observed among **racialized individuals**[x], who are also disproportionately affected by discrimination[xi]. This has been shown to have an effect on their mental health: these individuals are twice as likely (34%) to report “fair or poor” mental health as others (14%)[xii].

Although regional differences exist, **English-speaking Quebecers** generally face more precarious living conditions, characterized by income inequality and a higher unemployment rate compared to the French-speaking population[xiii]. They are also less likely to have access to medical coverage, and find it difficult to benefit from interpreting services or to obtain services in English in the public health care system. They are also less likely to have access to medical coverage and often struggle to access interpreting services or obtain services in English within the public health care system.

Allophones (36%) are more likely to experience psychological distress than their Francophone (28.3%) and Anglophone (25.3%) counterparts[xiv].

PAGEMA CAREGIVERS IN QUEBEC

Various statistical studies show that the proportion of caregivers in immigrant populations varies between 16.3% and 41.3%[xv]. Thus, according to the studies, this proportion may, at first sight, seem lower than that of the non-immigrant population (this is notably the case of ISQ, 2024). However, the difference could be attributable to the methodology used to reach this population in surveys, to the fact that immigrants live far from their extended families and therefore have smaller support networks, to the fact that they are less likely to identify as caregivers, and to the fact that they are a younger population, rather than suggesting that caregivers are less numerous among the immigrant population of Quebec[xvi].

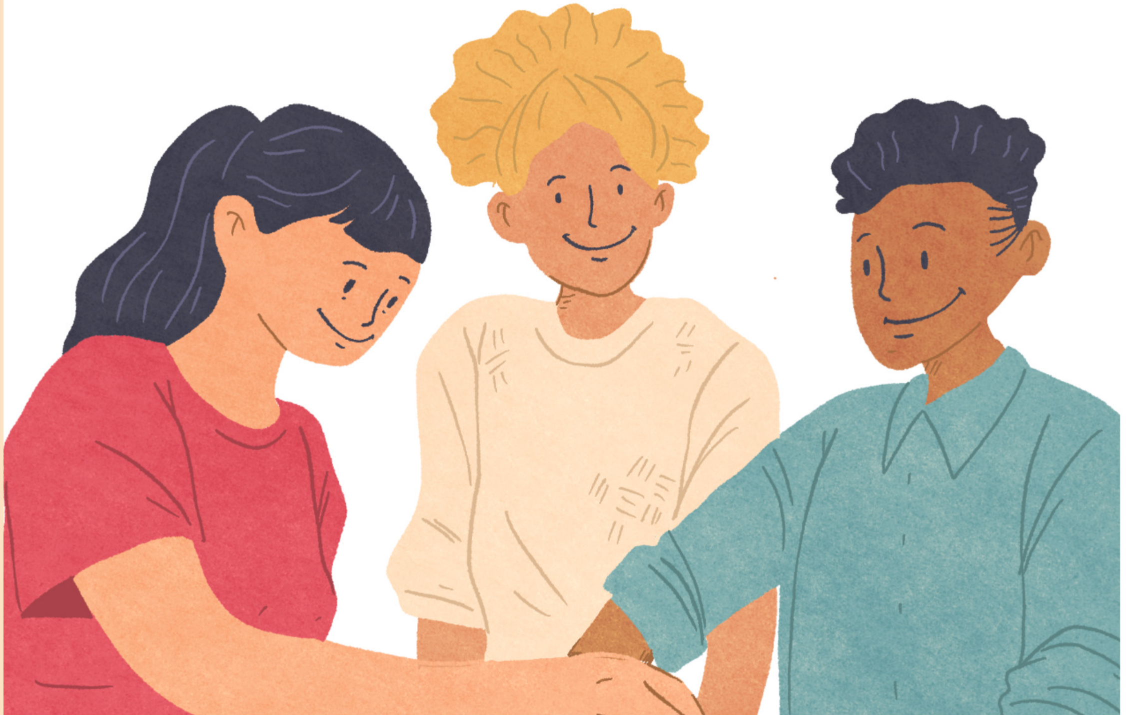
A more recent Canadian study[xvii] reveals that:

- 1 in 4 caregivers is racialized;
- 1 in 5 caregivers was born outside of Canada.

Other studies indicate that there is in fact no significant difference between the number of immigrant and non-immigrant caregivers[xviii].

According to two reports conducted for the Community Health and Social Services Network on access to health and social services for the English-speaking population of Quebec, 17% of those surveyed provided unpaid care to a vulnerable or dependent person in 2019[xix]. Of the English-speaking respondents who care for a loved one in Quebec, 23.6% speak English only[xx].

Certain circumstances and experiences are particularly associated with PAGEMA caregivers, notably when they have to act as informal interpreters for their loved ones, or when the family network is small.



THE NEEDS AND CHALLENGES FACED BY PAGEMA CAREGIVERS WHEN ACCESSING AND USING SERVICES

PAGEMA caregivers do not typically see themselves as caregivers. In the reviewed literature, the forms of support offered by PAGEMA caregivers are, in many respects, similar to those found among caregivers in the general population. This support includes financial aid, administrative assistance, accompaniment to medical appointments, help with household chores, transportation, assistance with personal hygiene, medication administration, emotional support, etc. .

However, certain circumstances and experiences are particularly associated with PAGEMA caregivers, notably when they have to act as informal interpreters for their loved ones, or when the family network is small. The transnational aspect of caregiving, i.e., caring for a loved one abroad or receiving support from relatives who don't live in Quebec, is also a key factor that influences the experiences of PAGEMA caregivers and their ability to support their loved ones.

Caregivers generally have difficulty articulating their needs without mentioning those of their loved ones and often even tend to put the needs of their loved ones first. However, identifying and assessing the needs of caregivers is crucial, as denying them could be considered a form of mistreatment. The needs of PAGEMA caregivers are numerous and similar to those of all caregivers, but they are often complicated by other experiences related to belonging to an ethnocultural minority group. The literature emphasizes the need for:

1. services for those being cared for and better access to information and referral;
2. culturally adapted services for PAGEMA caregivers and care recipients;
3. financial support and measures to combat social inequalities;
4. respite;
5. psychosocial and listening services.

Caring for a loved one is sometimes seen as "normal" or "natural" in certain ethnocultural groups (as stated by health care workers and the caregivers themselves). A number of studies, however, caution against familialist approaches and emphasize that underuse of services is more a constraint than a choice, given contextual and structural obstacles. The results of our study support this conclusion.

KEY RESEARCH FINDINGS

37 PAGEMA caregivers were interviewed individually about their caregiving experiences.

These included **30** women and **7** men.

These individuals had **varied profiles**, in terms of **age**, **status in Quebec** (recent immigrant, long-term immigrant, refugee, Quebec-born to immigrant parents and grandparents, or English-speaking with no recent immigration history), the **number of people they care for**, their **relationship with the care recipient**s, and the **condition of care recipients**.

> A detailed overview of their profiles is included in the final report, and a few tables providing the sociodemographic profiles of the participants are appended to the summary.

It is important to note, however, that among these participants, all the unemployed individual **(n = 8)** mainly immigrants and/or racialized.

All those living below the low-income threshold were also women **(n = 9)**, mostly racialized and/or immigrants. Half of these women were single or divorced, and two thirds were caring for at least one child with special needs, sometimes in addition to an aging parent.

MEANINGS ATTRIBUTED TO THE CAREGIVING EXPERIENCE

The participants mentioned various ways of seeing their role and motivations for providing care to family members and friends in need of support. At the outset, many of them explained their involvement with their loved ones on the basis of their identity or vocation, the nature of their relationship, or their emotional closeness to the person, which is consistent with the findings of several studies.

Caregiving as an identity marker or vocation

Some participants stated that caring for others is part of their personality or identity, or that it is a calling. Others consider themselves best suited to offer this type of support, notably because of their professional experience in health care or caregiving, but also sometimes because of their proximity to the care recipient. Their involvement may also stem from a commitment to advocating for a more equitable society.

The caregiver-care recipient relationship and the sense of duty or responsibility

The vast majority of participants said they take care of their loved ones because of their relationship to them, i.e., simply because the care recipient is their child, parent, or spouse. Most perceive their caregiving role as “natural” or “normal” and as a duty toward their loved ones. Because of the familial ties with their loved one, many do not initially identify as caregivers, whether they are caring for a child or a parent.

> ***«So I just tend to say (laughs) that I was a good son! In the traditional view of what a family is, I fulfilled my role and responsibilities as a good son within the family.» – Naroeun (free translation)***

Caring for a loved one: between duty and affection

Many PAGEMA caregivers expressed their motivation for caring for their loved ones in terms of “duty” or “responsibility.” Some caregivers associate this view of their caregiving role with their ethnocultural background, while others see it as rooted in their family values, without connection to culture or religion. In all cases, participants stressed that the well-being of the care recipient is at the heart of their motivation to support them, despite the many impacts associated with the care relationship, and the sacrifices it entails.

> ***“I appreciate every moment with her, and everything I do for her, I do with a lot of love.” – Hayda (free translation)***

Our study shows that each caregiving journey is unique, and is part of the wider life path of the people interviewed, including, but not limited to, their migratory background. The results also challenge familialist perspectives and the idea that participants' involvement in caregiving is solely motivated by a voluntary choice, whether cultural or religious. It is thus reductive to consider belonging to a minority ethnocultural group as the main factor that determines a person's decision to care for their loved ones. Indeed, the participants' accounts reveal tensions in their motivations. PAGEMA caregivers are also, to varying degrees, compelled to take on this role, notably due to the following factors:

- The absence or non-involvement of an extended support network in Quebec
- Migration experiences, immigration status, and reasons for immigration;
- Precarious employment conditions or limited income.

> ***"I just think I had no choice but to do it, because nobody else was doing it. […]" – Linda***

> ***"Oh, I forgot a detail. […] Dad [referring to her partner and the father of her children] commuted to Montreal every day from Monday to Thursday. […] That's right, Dad wasn't around. […] That's it; it was hard. […] It's especially important to say this because [in our country], it's hard to find a job […] At the time, we'd been here for 4 years. […] So we were stressed for sure because we didn't know where we were going; we didn't know what would happen. […] We didn't know how long it would take Dad to find [another] job." – Marie (free translation)***

The participants' comments thus concur with several of the studies consulted, which highlight the constraints associated with the decision to provide care for a loved one.

CAREGIVERS' SOCIAL NETWORKS

An analysis of our data shows that while family and social network composition vary significantly among PAGEMA caregivers, most have small social networks—a finding that aligns with existing literature on the subject. Certain factors, such as recent arrival in Canada or being far from family members who stayed in their country of origin may explain the small size of these networks.

> ***"When my [oldest child] was in the public school, I cannot help [my oldest child] a lot, because I have my [youngest child], I have to survive, so I don't have time to follow [my oldest child]. So, I only followed the teachers, and it was not enough. [It is] my mistake, because I haven't integrated into society yet. When the parent cannot integrate the society, how can the children do it?" – Lisa***

For others, the challenge of balancing caregiving responsibilities with their social lives reduces opportunities to develop new friendships.

Types of networks

Small networks

- PAGEMA caregivers and their care recipients generally have small social networks, consisting mainly of a few close family members (siblings, spouses, children, parents, etc.) or a few close friends.
- PAGEMA caregivers who care for children or adults have a smaller network than those who care for elderly people, who generally have a wider support network.
- Single mothers, unmarried individuals, and immigrants are at greater risk of isolation.

Varying geographical configurations

- The first type of network is characterized by close geographical proximity, i.e., families who live under the same roof or in the same city. While cohabitation facilitates caregiving, it may also isolate the PAGEMA caregiver and restrict their opportunities to build a social network.
- In a second, more common type of network, family members are spread out in different locations, whether in Quebec, another Canadian province, or abroad. Many family ties remain strong despite the distance.
- Some participants travel regularly to provide care for loved ones outside of Quebec, while others are taking steps to bring their loved ones to Quebec.

Insufficient support

- The limited size of social networks reduces access to additional support resources.
- Most of the people interviewed rely on a small circle of close friends and family members for regular help—one or two people at most.
- Many participants expressed a deep longing for a larger support network.

Forms of support

Support from their network primarily takes the form of material and practical help (household chores, transportation assistance, management of administrative tasks, informational support, etc.). The pooling of financial resources within the family is uncommon among the interviewees.

For those with a social network, emotional support is an important form of assistance, enabling them to share their concerns and experiences, find comfort, and receive advice and information. The division of responsibilities also varies according to the caregiving context. Networks, tasks, and forms of support differ depending on the type of relationship PAGEMA caregivers have with their care recipients.

For PAGEMA caregivers, geographical distance from their network is a major challenge. Relatives outside Quebec can offer important support, particularly on an emotional level, but they cannot provide the day-to-day assistance that would provide respite to PAGEMA caregivers.

> ***« The main difficulty is that I don't have any close family here [...] when they were diagnosed, I would have liked to have my mom next to me [...] If I had a niece, a sister here, I would have benefited from more respite. » – Eva (free translation)***

Support that evolves over time

The need for support fluctuates and depends on the following factors:

- The health of the care recipient;
- The personal and professional responsibilities of other family members;
- The emergence of conflicts within the network;
- The PAGEMA caregiver's health status;
- New people in the network who require support;
- New people in the network who can provide support to the care recipient or the PAGEMA caregiver.

This requires continually reassessing the networks and support available to PAGEMA caregivers, without assuming that any given configuration will endure over time.

THE IMPACT OF CAREGIVING ON PAGEMA CAREGIVERS

The interviewees gain personal fulfillment and satisfaction from the time they invest and the sacrifices they make.

Positive effects

Stronger bonds

- Between the PAGEMA caregiver and their care recipient(s), but also between the various people providing care;
- Spending more time together (a newfound closeness);
- New supportive connections;
- Small moments of joy and companionship with their loved one.

> ***"Being able to have a relationship with my mother where I can accompany her […] I think it's beautiful to have reached this moment in life." – Jacqueline (free translation)***

Personal fulfillment and validation

- A feeling of accomplishment, pride, importance, and usefulness
- A sense of changing something in the loved one's experience and easing the situation

> ***"And through all the hardships, through all the pain and all that, it's beautiful, really, you know. It's beautiful to be able to care like this. I really do feel that this pain is beautiful." – Antoine***

Learning opportunities

- Acquiring new skills, such as managing care and time, coordinating medical treatments, and handling administrative tasks;
- Deepening one's understanding of the disease;
- Having an opportunity to deepen self-knowledge, better understand one's strengths and limitations, and cultivate qualities such as patience and respect.

Personal transformation

- Reflections on life, relationships, and health;
- Redefinition of priorities;
- Professional career changes..

> ***"But I don't think he realizes how much having him as impacted the person that I am and the things that I want to pursue. […] I don't think he knows how much he's added to my life." – Sebastian***

However, our results especially stress the adverse effects of caregiving on various aspects of the participants' lives.

Caregiving has significant economic, professional, and personal consequences for the majority of caregivers, and can also hinder the integration of immigrants in Quebec.

Adverse effects

Professional life and career opportunities

- Having to quit a job, reduce working hours, or retire early;

> ***" If I want to be a good caregiver, I can't work full time, so automatically I face financial constraints, and automatically I am in a more precarious situation " – Judith (free translation)***

- Having to take a more precarious job or one below their qualifications for greater flexibility or fewer responsibilities in order to make ends meet. This loss of professional skills can worsen the deskilling resulting from migration;
- Being repeatedly absent from work, struggling with punctuality, and experiencing decreased productivity;
- Fearing consequences if the situation is revealed to one's employer (i.e., losing one's job, missing out on career advancement opportunities, or being perceived negatively).

> ***"It's interfering with work, for sure. I have had to take more time off and I am falling behind. [...] it means that I have to work evenings or weekends, just random times to get things done" – Ezza***

Finances

- Significant loss of income and financial instability. These losses are sometimes compensated for by a family member (often the father or spouse), sometimes they force people (e.g., single mothers) to resort to social assistance;

> ***"At my age, I might have about $20 in my pension funds" – Joy (free translation)***

- Inability to obtain certain financial benefits or tax credits;
- Limited access to certain social benefits (insurance, pension plan, paid leave, etc.) for people required to work part-time.

> ***"Last year, I qualified for unemployment benefits, for example, but this year [...] I was short by 36 hours. Again, there's nothing in the system to help people like us — there's really nothing there [...]" – Judith (free translation)***

- Indirect costs (e.g., transportation, food, medical equipment, medications, specialized services).

Caregiving has significant economic, professional, and personal consequences for the majority of caregivers, and can also hinder the integration of immigrants in Quebec.

Social and personal activities

- Significant reduction in free time, difficulty balancing social and family life with caregiving activities
- Weakening of certain marital, parental, or extended family relationships
- Pressure on the children in the family to participate in support activities

> ***“I could never have anything intimate in my life because for me, caregiving always came first.” – Joy (free translation)***

> ***“I believe the hardest thing for a healthy caregiver who is capable of doing things is precisely not doing them, because you feel like you’re in a prison.” – Alina (free translation)***

Physical health and well-being

- Fatigue, lack of time to look after one's health and do personal activities

> ***"I barely have time to take a shower" – Myriam (free translation)***

> ***"I don't know what I like to do anymore" – Linda (free translation)***

- Burnout, increased stress, anxiety, hypervigilance, and depressive symptoms;

> ***"I feel like my mind is constantly caught up in it" – Jeanne (free translation)***

> ***"I feel overwhelmed all the time." – Marie (free translation)***

- Risk of physical injury, abuse, etc.

Integration

- Difficulty or impossibility of completing francization courses due to caregiving responsibilities;
- Difficulty or impossibility of joining the workforce and establishing social connections;
- Renunciation of certain immigration-related dreams (the ideal of a new life in the host country is shattered).

PAGEMA CAREGIVERS’ USE OF EXISTING RESOURCES AND SERVICES

Resources used by PAGEMA caregivers

When it comes to accessing services, many PAGEMA caregivers express appreciation for the support and resources available through public and community networks. Immigrant caregivers, in particular, highlight the quality of services available in Quebec, acknowledging that they may not have had access to similar resources elsewhere, especially in their country of origin. As a result, PAGEMA caregivers also access various resources and services outside their social networks.

Resources and services used by PAGEMA caregivers

- **Ethnocultural and support organizations for immigrants and English-speaking communities**
- **Religious institutions and leaders**
- **Organizations that serve caregivers and/or care recipients**
- **Private-sector health and social services**
- **Public-sector health and social services**
- **Respite services**
- **Tax credits and financial benefits**

Factors that facilitate the PAGEMA caregiving experience

Some key facilitating factors are essential for PAGEMA caregivers because they enhance their ability to care for their loved ones and make it easier for them to access resources and services. These factors help lighten their burden and prevent burnout.

> *“Time has a way of taking care of things; there’s no use worrying about what’s beyond our control. Having faith sets energies in motion in the universe, drawing good things back to us” – Saleh (free translation)*

Regarding the overall caregiving experience

Services that are adapted to meet the specific cultural and linguistic needs of PAGEMA caregivers. These services should be flexible and adaptable.

Sufficient **financial resources** to mitigate the financial impact of caregiving or to allow them to avoid financial insecurity.

A **flexible job** that allows PAGEMA caregivers to take time off for caregiving or to adjust their working hours if necessary.

Faith, when present, can provide a refuge for certain PAGEMA caregivers. When practised in a community setting, it also helps create social bonds and reduce isolation.

Regarding access to and use of services and resources

The **assistance of a trusted professional** from the health and social services network or the community sector who takes the time to listen to and understand individuals' needs, offering compassionate and personalized guidance.

> *"This is a situation you cannot continue with, because as I see you, you're going to collapse — you are the pillar of your family, and if you fall, the whole family will fall. So I'm thinking, you have no resources, no family here, it's hard for you — we need to help you." – Eva's child's caseworker (free translation)*

Knowledge of the health and social services network, or the presence of a contact within that network, can help individuals navigate the system, understand services, and know their rights. It can also facilitate access to culturally sensitive services.

> *"We had a friend who works at a CLSC, and she helped us find someone who could speak our mother tongue." – Anh Dao (free translation)*

The financial option of turning to the private sector, particularly in the absence of adapted services, when waiting times for public services are too long, or when people are not eligible for services.

Barriers to accessing and using services and resources

PAGEMA caregivers' access to and use of services and resources is often hindered by a range of barriers. These barriers—whether individual, relational, or systemic—limit their ability to obtain adequate support. As a result, some caregivers turn to alternative solutions—such as the private sector or services in their country of origin—while others become increasingly isolated and remain without services despite their needs.

Different conceptions of illness or disability, when present, may influence (and limit) requests for help—especially if certain aspects of the care recipient's condition are considered taboo.

A lack of information about the care recipient's condition and the services available to both PAGEMA caregivers and care recipients.

> ***"I don't know anything about the healthcare 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 [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***

Difficulty expressing themselves on complex subjects in French complicates communication, increases the burden on PAGEMA caregivers, and can lead to negative consequences for both them and care recipients (e.g., discomfort, frustration, treatment errors, etc.). Some people have been refused services in English or have not had access to interpreting services.

> ***"We are meeting quite a few people who don't speak any English. And they usually explain:"Parlez-vous un petit peu de français ?", "Oui, juste un petit peu." And then, they proceed to speak French"– Jay***

Difficulty communicating effectively with health care staff and establishing trust - especially when expressing needs, understanding technical language, and deciphering treatment plans and other information. Some PAGEMA caregivers also report a lack of empathy and listening from health care staff, which sometimes makes them feel uncomfortable asking questions or requesting additional services.

Experiences of stigmatization, discrimination, or racism based on ethnocultural origin, language, illness, or disability. While some forms of discrimination are direct, others are more subtle yet equally insidious. They undermine the trust that PAGEMA caregivers have in public services and their staff. Some caregivers have even reported being refused services on this basis.

> ***"The way we were perceived and received [...] it was a sign that we were seen as different patients [and caregivers], special patients, patients who might potentially ask for something unpredictable or hard to define." – Naroeun (free translation)***

Difficulty being heard and acknowledged by health care staff. Many PAGEMA caregivers feel they must fight to have their viewpoints considered and encounter a lack of empathy and attentive listening. They report that their words or opinions are questioned. Such situations have sometimes led to serious consequences for care recipients and distress for PAGEMA caregivers.

Difficulty in having their needs recognized as PAGEMA caregivers. This was particularly emphasized by several mothers who, after expressing symptoms of depression or exhaustion in the hope of obtaining psychosocial support, instead found themselves under the supervision of the CLSC or DPJ to monitor their child's well-being.

The difficulties encountered by PAGEMA caregivers in accessing and using services are not primarily caused by individual differences or personal preferences. Although certain caregivers expressed slightly different conceptions of illness or disability, these divergences do not appear to be irreconcilable with the manner in which Quebec’s system of health and social services defines or approaches these issues. **The obstacles documented in this study were predominantly structural, and many were linked to the organization of Quebec’s health and social services network, as well as to the allocation of resources and services**.

A lack of adapted services. PAGEMA caregivers express dissatisfaction with the overall insufficiency of services and their inflexibility. They stress the need for services that are more culturally and linguistically sensitive, in order to offer better adapted and more effective support. Adapted services are particularly difficult to access for individuals living outside major urban centres, especially when they require services in English (or in another language besides French). Many PAGEMA caregivers and care recipients are forced to decline the assistance offered, preferring to forgo poorly adapted services that could exacerbate certain caregiving situations.

> ***“They can’t justify transferring a patient if they can give the services there. I’m like but “if you can’t give it to him in English and he’s getting frustrated and then you don’t even understand when he’s having pain?’ “ – Tania***

Overly restrictive access criteria. Specific considerations—particularly those linked to certain migratory statuses—are not taken into account for PAGEMA caregivers. Many caregivers also face administrative challenges in securing benefits and compensation. Moreover, besides the complexity of the process, many caregivers have not accumulated enough work hours, their loved one does not match the typical profile, or the loved one’s condition is not deemed severe enough. Furthermore, eligibility criteria do not always consider that a PAGEMA caregiver may be caring for multiple individuals simultaneously.

> ***“[...] I also had to fight for the supplement for a disabled child because they don’t fit neatly into the category — they’re always kind of on the side.” – Sabrina (free translation)***

Difficulty navigating the health and social services network. PAGEMA caregivers are often unfamiliar with the organization of the health care system and the manner in which services are deployed. Many do not know where to begin when seeking a specific service.

> ***“I have another social worker [since I moved]… but I barely ever see her. [My child] needs glasses, and it seems that social assistance doesn’t cover them… I don’t even know where to bring the paperwork so they can tell me where to get glasses”. – Maria (free translation)***

Issues with service continuity, particularly due to turnover and staff shortages within the health and social services network, a lack of interpreters, and underfunding of services (i.e., services that disappear without notice). In areas far from urban centres, the distance to services further complicates matters. Many PAGEMA caregivers struggle to sustain services throughout the care process, especially when adjustments are needed due to changes in the care recipient’s health or when they relocate.

THE NEEDS AND SERVICE EXPECTATIONS OF PAGEMA CAREGIVERS

The needs of PAGEMA caregivers, whether clearly expressed or more subtly evoked, are multi-faceted and complex. They sometimes overlap or are even intertwined with the needs of care recipients, making it difficult to distinguish them individually. These needs are directly linked to the adverse effects of caregiving and to obstacles in accessing available resources and services. Meeting the needs of care recipients would therefore help address many of the issues raised by PAGEMA caregivers.

Informational, logistical, and administrative needs

Information obtained ahead of critical moments on caregivers' rights, available services and access procedures, the risks and challenges of caregiving, the functioning of the health and social services network, language accessibility of services, financial assistance, and the nature of their loved one's health condition. **Simplified administrative procedures and support for navigating services**.

Financial needs and improved working conditions

Simplified eligibility criteria for accessing benefits, tax credits, and employment insurance benefits.

More flexible and better-protected jobs to help balance work and family responsibilities and reduce the financial burden of caregiving (e.g., job loss, reduced hours).

The need for improved collaboration and communication with health care staff

Facilitated access to professional interpreting services and support in languages other than French. More systematic information sharing among professionals. PAGEMA caregivers should be held in higher regard, be listened to more attentively, and have their boundaries respected.

The need for adapted and sufficient support services that address real-life challenges

Services provided in the language of their choice, more flexible and tailored to the specific needs of those receiving help, and delivered continuously by the same providers to foster trust.

The need for validation, recognition, and psychosocial support

The creation of additional support groups and improved access to psychosocial services in the health and social services network within a reasonable time frame to combat isolation, reduce stress, help PAGEMA caregivers build new social networks, and provide more spaces for support and self-expression.

The need for respite or childcare services

More flexible and accessible services to prevent burnout and offer respite, but also to have fun, socialize, run errands, go to work, do other things, and be more than just a caregiver.

The majority of PAGEMA caregivers tend to reduce their needs to a minimum, and this seems to be part of the process of accepting their caregiving situation

> ***«It's not easy to accept, and it's not even easy to live with. Right now, my biggest worry — because I won't be around forever for [my child] — is making sure they can manage on their own. […] I've focused all my energy on that.» – Deborah (free translation)***

Several participants expressed concerns about the future. Many are reluctant to even think about what would happen if they were to pass away before their loved ones. This inability to look ahead can lead to uncertainty, which contributes to the exhaustion of PAGEMA caregivers, as documented in the literature.

> ***«I'm afraid of breaking down. I'm fully aware that I'm the pillar of the family. They need me to be okay, but I'm not okay — I'm exhausted, and sometimes my body just gives out.» – Josée (free translation)***

Many participants hope that sharing their experiences in this study will improve the situation for other caregivers from ethnocultural minority groups.

RECOMMENDATIONS

Considering the challenges and experiences uncovered by this study, along with the best practices and issues identified in the literature, nine recommendations have been formulated for the various stakeholders involved in improving living conditions and access to services for PAGEMA caregivers. These recommendations, outlined briefly below, are discussed in detail in the final report and are accompanied by concrete action steps to support their implementation[5]. These recommendations require changes at various levels within the health care system, which must be considered collectively to improve the caregiving experiences of PAGEMA caregivers in an integrated manner.

When reading these recommendations, it is important to bear in mind that PAGEMA caregivers are not a homogeneous group, and further recommendations will need to be made that are more specific to subgroups within the PAGEMA caregiver population. For professionals working with caregivers, these recommendations suggest that it is important to be well aware of the various challenges of caregiving, to pay attention to both what PAGEMA caregivers say and what they leave unsaid, and to attempt to identify services and resources that could support them in their caregiving role, even if their own specific needs are not necessarily expressed openly.

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[5] The final report also distinguishes between recommendations specific to PAGEMA caregivers and those addressed to the overall caregiver population in Quebec.

RECOMMENDATION 1: TAKE INTO ACCOUNT THE COMPLEXITY OF THE CHALLENGES FACED BY PAGEMA CAREGIVERS IN THE NEXT GOVERNMENT ACTION PLAN

Suggested actions:

- Collect province-wide statistical data on PAGEMA caregivers;
- Recognize and address their specific issues in all intersectoral actions;
- Promote an integrated care approach that focuses on the individual;
- Adopt an evolving and flexible vision of caregiving, taking into account the care recipient’s entire support network;
- Acknowledge structural and contextual constraints that influence the possibility of truly choosing to care for a loved one in a free, informed, and revocable manner.

RECOMMENDATION 2: ENSURE A SAFER ENVIRONMENT AND LEGAL PROTECTIONS FOR PAGEMA CAREGIVERS

Suggested actions:

- Strengthen protections for PAGEMA caregivers by recognizing caregiving as a prohibited ground of discrimination under the Quebec Charter of Human Rights and Freedoms;
- Ensure that certain reserved acts remain under the responsibility of health and social services professionals.

RECOMMENDATION 3: STRENGTHEN FRONT-LINE HEALTH AND SOCIAL SERVICES, WITH A PARTICULAR FOCUS ON HOME CARE

Suggested actions:

- Adapt and expand home care services while increasing their flexibility;
- Promote and broaden the range of services provided by community organizations;

- Make substantial and long-term investments in front-line services, including home care, adapted respite, and mental health services
- Improve working conditions by making them safer and increasing compensation for health care personnel

RECOMMENDATION 4: IMPROVE PAGEMA CAREGIVERS' ACCESS TO HEALTH CARE RESOURCES AND SERVICES, AS WELL AS THEIR NAVIGATION OF THE HEALTH CARE SYSTEM

Suggested actions:

- Provide support for navigating and coordinating care;
- Mandate information sharing, referrals, and regular reassessment of PAGEMA caregivers' needs, while streamlining administrative procedures for accessing services .

RECOMMENDATION 5: MAKE PUBLIC HEALTH AND SOCIAL SERVICES MORE INCLUSIVE TO ENSURE EQUITABLE SERVICE DELIVERY

Suggested actions:

- Enhance training and resources for workers on the challenges faced by PAGEMA caregivers, available resources, and intercultural intervention;
- Document and recognize the existence of structural barriers to accessing and using health and social services;
- Provide ongoing funding to community organizations that support immigrants, racialized individuals, and/or English-speaking populations offering family services;
- Take action to reduce these barriers by increasing funding for community organizations, improving access to the IFHP program, shortening the RAMQ waiting period, promoting more diverse and inclusive hiring, acknowledging the challenges of informal interpretation, and enhancing the linguistic accessibility of services and access to qualified interpreters.

RECOMMENDATION 6: RAISE AWARENESS OF ISSUES RELATED TO CAREGIVING AND FACILITATE THE RECOGNITION OF PAGEMA CAREGIVERS

Suggested actions:

- Raise PAGEMA caregivers' awareness of the various challenges of caregiving to support their recognition;
- Improve PAGEMA caregivers' access to information about existing services. This information should be written in accessible language and in a variety of other languages.

RECOMMENDATION 7: IMPROVE THE FINANCIAL AND MATERIAL LIVING CONDITIONS OF PAGEMA CAREGIVERS

Suggested actions:

- Acknowledge and address the potential impact of caregiving on the professional and social integration of PAGEMA caregivers;
- Recognize the potential transnational nature of caregiving;
- Broaden eligibility criteria for benefits, tax credits, and leave for PAGEMA caregivers;
- Provide caregivers with a direct allowance;
- Allow caregivers to contribute to the Quebec Pension Plan;
- Make it easier to reimburse all direct costs related to care and services.

RECOMMENDATION 8: STRENGTHEN COLLABORATION AND CAPACITY TO ACT AMONG VARIOUS PARTNERS SUPPORTING PAGEMA CAREGIVERS

Suggested actions:

- Develop training on the challenges and specific needs of PAGEMA caregivers for national and regional caregiver organizations;

- Encourage partnerships within each health and social services region;
- Invest in initiatives that address linguistic and digital divides;
- Foster improved cooperation between different levels of government.

RECOMMENDATION 9: INCREASE KNOWLEDGE OF THE CHALLENGES FACED BY PAGEMA CAREGIVERS

Suggested actions:

- Increase funding for research into the challenges faced by specific subgroups of PAGEMA caregivers who may be more vulnerable;
- Conduct research on the challenges faced by English-speaking caregivers with no recent immigration history separately from those of immigrant caregivers;
- Encourage the production of plain-language content to raise awareness of PAGEMA caregivers' challenges within the health and social services network and community organizations;
- Foster regular knowledge transfer between the research community, leaders, community organizations, and the health and social services network .

APPENDICES

APPENDIX 1 – SOCIODEMOGRAPHIC TABLES

Number of people supported	Number of participants (n = 37)	Total number of people supported
1	20	20
2	10	20
3	6	18
4 or more	1	4
Total	37	62

Table 1 : Sociodemographic tables

Relationship of caregiver to care recipient	Number (n = 62)
Child of PAGEMA caregiver (son or daughter	19
Brother, sister, brother-in-law, or sister-in-law of PAGEMA caregiver	6
Spouse of PAGEMA caregiver	5
Parent (or parent-in-law) of PAGEMA caregiver	21
Grandparent of PAGEMA caregiver	3
Other	8
Total	62

Table 2 : Relationship of caregivers to care recipients

Condition of the care recipient	Number (n = 62)
Neurocognitive disorder, neurodegenerative disease	14
Mental health condition	7
Acute illness	4
Cancer	6
Chronical disorder	8
Rare or orphan disease	4
Autism spectrum disorder, physical and intellectual impairment	11
Total	62

Table 3 : Condition of the care recipient as stated by participants

Migration status upon arrival	Number of participants (n = 24)
Economic immigrant	11
Sponsored immigrant	8
Temporary resident (work permit, study permit, visitor visa)	3
Refugee protection	2
Total	24

Table 4 : Migration status upon arrival

Summary of number of languages spoken by all participants	Number (n = 37)
Unilingual French	7
Unilingual English	1
Unilingual another language	2
Bilingual[6] French and English	8
Bilingual French and another language	6
Bilingual English and another language	2
Bilingual other languages	1
Multilingual French, English, and another language	9
Multilingual, three or more languages other than French and English	1
Total	37

Table 5 : Summary of number of languages spoken by all participants

Level of comfort communicating with health and social services in French	Number (n = 37)
Very comfortable	19
Comfortable	2
Somewhat comfortable	1
Uncomfortable	5
Very uncomfortable	10
Total	37

Table 6 : Level of comfort communicating with health and social services in French

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[6] Defined in the context of this study as the ability to speak two languages, regardless of the level of proficiency in these languages. Similarly, the “multilingual” category does not assess the level of fluency in these languages

Employment status of participants	Number of participants (n = 37)
Full-time worker	12
Part-time worker	9
Retired	6
Student	2
Unemployed	8
Total	37

Table 7 : Employment status of participants

Average household income (n = 37)	Number of people in household					Total number of participants
	1	2	3	4	5 et +	
Under $21,000		3*	1*	1*		5
$21,000 to $45,999		2*	3*		1*	6
$46,000 to $70,999		1		1*		2
$71,000 to $95,999		2	1	3		6
$96,000 to $119,999			4		1	5
$120,000 or over	1	1		1	1	4
Prefer not to answer	1	2			1	4
Not available		3	1		1	5
Total	2	14	10	6	5	37

Table 8 : Average household income according to number of people in household

Average household income	Number of care recipients				Total number of participants (n = 37)
	1	2	3	4	
Under $21,000	3	1	1		5
$21,000 to $45,999	4	1	1		6
$46,000 to $70,999	1	1			2
$71,000 to $95,999	2	3	1		6
$96,000 to $119,999	4	1			5
$120,000 or over	2	2			4
Prefer not to answer	2	1		1	4
Not available	2		3		5
Total	20	10	6	1	37

Table 9 : Average household income according to number of care recipients

APPENDIX 2 – REFERENCES FOR FURTHER READING

To simplify the presentation of the text, this summary does not include the majority of the sources and references that this project relies on. Some are highlighted here, particularly the statistics. Please refer to the final report for the full list of references.

End notes

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