

CAREGIVING TRAJECTORIES OF CAREGIVERS BELONGING TO AN ETHNOCULTURAL MINORITY

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How to use this fact sheet: This fact sheet is intended as a tool for reflection to help service providers better understand the complexity of PAGEMA people's caregiving trajectories and offer practical strategies to help them adapt their services.

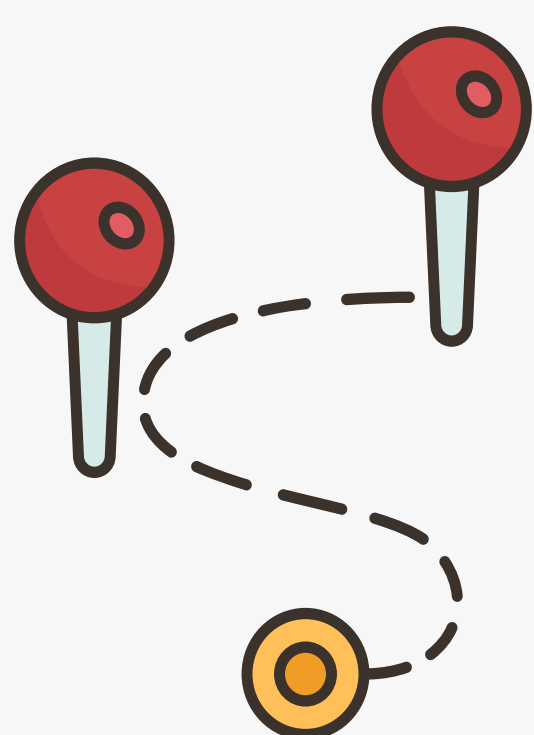
It is based on an analysis of data from the study "The Experiences of Informal and Family Caregivers from Ethnocultural Minority Groups in Quebec."

[Read the full research report \(French only\).](#)

CAREGIVING TRAJECTORIES

PAGEMA [1] people's caregiving trajectories are varied and depend on many factors including the nature of the care recipient's health condition, the social and family context of both the caregiver and the care recipient, the form and duration of care, and the resources available.

In the case of PAGEMA caregivers specifically, additional individual, structural, and contextual factors shape caregiving trajectories, such as the presence or absence of a support network in Quebec, immigration status, ability to communicate in French, and socioeconomic conditions.



PAGEMA caregivers are not a homogeneous group, and their caregiving experiences are complex and diverse. To understand their needs, the impact of caring for a loved one, the difficulties they encounter, and their access to health and social services, it is important to examine their life course [2] and, if applicable, their migration trajectory.

[1] 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).

[2] By life course, we mean the key milestones that shape a person's identity, particularly in the personal, professional, relational, and family spheres.

KEY ELEMENTS TO CONSIDER

Over the course of the care trajectory, PAGEMA **caregivers' availability to provide care** may change:

- PAGEMA caregivers may experience **difficulties or changes in their personal lives** (e.g., moving, job loss or change, birth, illness, death, etc.) that affect their ability to be involved in caring for their loved one.
- In cases of **recent immigration**, caring for a loved one may hinder or complicate their integration into Quebec society.
- For many PAGEMA caregivers, the **absence of a social support network** significantly complicates their care trajectory (e.g., increased financial insecurity, inability to get respite).
- A PAGEMA caregiver may **care for several people** on their own, and in some cases, a care recipient may be supported by multiple individuals.

According to our research



PAGEMA caregivers often do not identify as caregivers. They primarily present themselves as the spouse, sister, brother, mother, father, child, grandchild, or friend of the care recipient. This finding influences their ability to seek out services and support for themselves.



Immigrant or racialized women who care for a child with special needs are particularly likely to be separated, single parents, or alone in caring for their child. As a result, they are less able to learn French or work.

A FEW PRACTICAL SUGGESTIONS FOR INTERVENTION

As a service provider, adopting a preventive approach, demonstrating flexibility, and listening actively are considered good practices when working with PAGEMA caregivers. Here are some other practical ideas:



Help the PAGEMA caregiver recognize themselves as a caregiver (according to the Quebec government's definition) and inform them of their rights and of the services available to them.

If applicable, ask about the context, including the general reasons that led them or their loved one(s) to come to Quebec, as well as the major milestones in their caregiving trajectory and life course that may influence their experience.

Identify one's own unconscious biases.

Ask the PAGEMA caregiver what their needs are and help them identify them.

Refer the PAGEMA caregiver to relevant services and support them in the administrative steps required to obtain them.

Ask the PAGEMA caregiver who they can rely on in their role as a caregiver.

Ask the PAGEMA caregiver if they are experiencing any difficulties, particularly financial ones or those related to finding and keeping a job.

Assess the PAGEMA caregiver's understanding of services, their command of the language, and ensure they can comprehend the information provided.

AN EXAMPLE THAT ILLUSTRATES THE COMPLEXITY OF THE CAREGIVING TRAJECTORIES OF PAGEMA CAREGIVERS

The story of Julian and his mother

Julian, who is in his fifties, took care of his mother, who had a cardiac condition. Since her recent death, he has felt exhausted and overwhelmed by his end-of-life caregiving experience.

Julian's parents are of Chinese descent and originally from Indonesia. They immigrated to Quebec for economic reasons over fifty years ago. Julian was born in Quebec, considers himself a racialized person, and was educated in English. His French is adequate for everyday interactions, but not for discussing sensitive or complex topics. He has always lived with his parents in Montreal's West Island area. After his father's death, he moved to Yamaska [3] with his mother, as he could no longer afford their Montreal apartment on his own. He has a sister who lives in Longueuil with her family. Julian provided most of the caregiving for his mother.

About three years ago, Julian had a car accident. Since then, he has experienced chronic migraines and has been unable to drive.

His mother's cardiac condition began around 12 years ago. Julian became actively involved in her care at that point, as her health declined and she was frequently hospitalized. He had to quit his job because his mother required extensive support in the last few years of her life. He is currently receiving social assistance.

Julian's mother had a serious cardiac condition that required her to take medication at set times each day. She had her first heart attack while awaiting surgery for a fractured femur. Despite the doctor's reservations about her ability to withstand the procedure, the operation was ultimately successful. However, his mother's return home was a nightmare for Julian. He believed his mother's condition was unstable and that she was too weak to return home. She had difficulty moving around and bathing, and was often aggressive toward Julian, who was helping care for her.

Exhausted, Julian eventually requested that his mother be admitted to a residential and long-term care centre (CHSLD). Given the circumstances, he had no choice but to accept the first available bed. He insisted that his mother's file clearly indicate the importance of her receiving her medication at set times. His mother was anxious and constantly called him to confirm that she was receiving her medication on time. Not speaking French made it difficult for her to communicate with the facility's staff, which further increased her anxiety. This situation caused distress for Julian, who was unable to visit her easily because he did not have a car to go to the CHSLD. Despite Julian's reminders, medication administration procedures were reportedly not followed, which, according to him, caused his mother to have another heart attack and be hospitalized again.

Julian tried to have her transferred to a hospital in Montreal, hoping she could receive services in English. He began to lose confidence in the care team. He also had disagreements with a doctor who questioned how his mother's medication was being administered.

The situation weighed heavily on Julian, affecting his sleep and appetite. He felt powerless and deeply misunderstood. Overwhelmed, he consulted a physician in the public health system, who prescribed antidepressants. He was then referred to a community organization for caregivers. His mother died alone in hospital a few weeks later, possibly as a result of another heart attack. Julian was never given a clear explanation of what had happened.

A few months after his mother's death, Julian's life has not returned to normal. He has not started looking for work and does not know whether he will stay in Yamaska. He does not feel close enough to his sister to talk to her about it. Nevertheless, walking and outdoor activities are helping him to regain stability. He also appreciates the emotional support services offered by the caregiver organization, where he can talk about what he is going through in his mother tongue.

[3] Fictional town in a rural area

TIMELINE OF EVENTS

Julian (caregiver)

Julian's mother (care receiver)



Although Julian is receiving services, he still hasn't returned to work. He feels lost and is struggling with his grief.



I was literally drowning when she was alive, because I was living in a state of adrenaline and... Then, she passed away and that adrenaline was still there, and I had been drowning for these past couple of months trying to get help. My doctor, she... I am supposed to get someone from the CLSC as a social worker or counsellor to help me, but I'm on a waiting list.
- Julian



[...] I just want to speak with the social worker and let him know that she refuses to go [there] because there will be no English services. And he's like: 'What more do you want? We're giving her her medicine.' [Soft laughter] I don't even know how to respond to that.
- Julian

ANALYSIS OF THE CARE TRAJECTORY

IMPACTS

Unemployed and has limited financial means
Limited support network
Without a car in a rural area
Distrust of services and staff

BARRIERS

Difficulty obtaining services in English
Difficulty establishing trust
Experiences of discrimination and stigmatization
Difficulty having his opinions on his mother's condition taken seriously
Distance from services
Lack of information about services
Difficulty accessing continuous services
Lack of intercultural awareness among service providers

NEEDS

Financial needs
Need for interpretation services
Need to be heard, recognized, and understood
Need for home care services for the care recipient
Psychosocial needs
Post-caregiving needs

FACILITATING FACTORS

Leisure activities
Presence of services for caregivers



I received \$920 from social assistance, and it was barely enough to get groceries, pay rent, and travel to see my mother while she was hospitalized and needed urgent family presence at the hospital. – Julian

SUGGESTIONS FOR INTERVENTION

On several occasions during his journey as a caregiver, Julian interacted with public health and social service providers but was only informed of his rights to services very late in the process. Access to more appropriate services for his mother—particularly with regard to language—could also have reduced Julian's burden.

What the team caring for Julian's mother, the CLSC, or a community organization could have done for Julian and his mother:

- From the first meeting, inform Julian about his rights as a caregiver and the services available to him and his mother, and provide him with adapted documentation.
- Discuss Julian's needs and the resources he can rely on from the outset of the support process.
- Offer increased support to Julian and his mother upon their return home to ensure a smoother transition.
- Proactively identify potential barriers to accessing services in English, particularly in a rural area.
- Facilitate access to interpretation services and transportation options suited to the needs of Julian and his mother.
- Take into account Julian's concerns about his mother's strict medication schedule, recognize his role as a care partner, and foster a collaborative relationship with him in managing the care plan.
- Clarify past misunderstandings and address the issues that have contributed to a loss of trust in care staff.

MORE ON THIS TOPIC

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

Complementary readings :

- Brotman, Shari, Marjorie Silverman, Hayden Boska, & Marc Molgat. 2020. Intergenerational Care in the Context of Migration: A Feminist Intersectional Life-Course Exploration of Racialized Young Adult Women's Narratives of Care. *Affilia* 36 (4): 552-70.
- Penrod, Janice, Hupcey, Judith E., Baney, Brenda L., & Loeb, Susan J. 2011. End-of-life caregiving trajectories. *Clinical nursing research*, 20(1), 7-24.

[Access additional fact sheets here](#)