SCIENTIFIC WATCH BULLETIN 2025

Caregiving as considered by Quebec researchers

Observatoire
québécois de la
proche aidance

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The Observatory's third Scientific Watch Bulletin presents an analytical review of the studies on caregiving and caregivers published by Quebec-based researchers between January 1 and December 31, 2025.

The aim of the bulletin is to identify the themes, key findings, trends and practices emerging from the scientific literature in Quebec, and use this knowledge to inform decision-making and action by policy-makers, professionals, and members of the scientific community in Quebec, across Canada and internationally.

Four main themes emerged from the analysis:[1]

- **Caregiver involvement in care and service delivery**
- **Quality of life in the caregiving dyad**
- **Care and service navigation**
- **The relational experience in caregiving**

For each theme, the main findings and implications for practice are presented. Before examining the themes in detail, we will look at the highlights from this year's review and compare them with the findings from previous editions. Our conclusion will focus on the future research needs identified through the review.

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[1] The studies consulted frequently addressed multiple themes. In such cases, only the main theme was considered.

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1 HIGHLIGHTS

A total of

49 articles

were reviewed in 2025.

82 %

Most studies (81.6%) **were conducted in Canada**, with the majority of these (67.5%) taking place in Quebec.

41 %

Twenty of the 49 articles (40.8%) focused on **parent caregivers**.

18

The conditions most frequently addressed were associated with **aging**[2] (11 articles), followed by **cancer** and **neurodevelopmental disorders**[3] (7 articles each).

64 %

While all of the publications reviewed addressed caregiving, nearly two-thirds (63.3%) did not use such terms as proches aidants, caregiver, informal carer or carer.

43 %

Caregivers were **the primary or secondary focus in equal proportions of studies (42.9% each)**, and 12.8% examined caregiving from a dyadic perspective (i.e., the caregiver–care recipient relationship).

The most frequently represented disciplines were **nursing sciences** (15 articles), **medicine** (12 articles) and **psychology** (10 articles).[4]

2

Although the review focused on Quebec-based researchers, only two of the publications were in French.

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[2] This category includes neurological disorders such as Alzheimer's and dementia as well as more general age-related incapacities.

[3] These disorders include autism spectrum disorder, intellectual disability, cerebral palsy and epilepsy.

[4] The identification of the different areas of research is based on the authors' respective affiliations. Note that multiple academic fields may be associated with one article.

KEY FINDINGS

Caregiver involvement in care and service delivery was the most frequently addressed theme (55.1%), followed by quality of life (32.7%), care and service navigation (6.1%), and the relational experience in caregiving (6.1%).

IN THE LITERATURE, CAREGIVER INVOLVEMENT IN CARE AND SERVICE DELIVERY COULD TAKE THE FOLLOWING FORMS

- Support provided to the care recipient (1, 2, 3, 4, 5, 6, 7).
- Information sharing and communication (1, 3, 8, 9, 10, 11, 12, 13).
- Shared decision-making (5, 8, 13, 14, 15).
- Several studies advocate for a **genuine partnership model based on shared decision-making**, in which professionals co-develop intervention goals with the caregivers rather than imposing standardized objectives (8, 10, 16, 17).

QUALITY OF LIFE IN THE CAREGIVING DYAD

- Several studies highlight the key role of **support from family and friends in shaping care recipient quality of life** (18, 19, 20, 21).
- **Improved care and service coordination** (22, 23, 24, 25), **access to psychosocial services** (21, 23, 24, 26, 27, 28, 29), **access to information** (23, 24, 30), **community support** (23, 24, 31) and supportive institutional policies (25, 32) are identified as factors that may enhance caregiver quality of life.

CARE AND SERVICE NAVIGATION

- In many cases, **no formal pathway exists to structure caregiver navigation of care and services** (33, 34, 35).
- **Peer support** is consistently identified in the literature **as instrumental in facilitating caregivers'** navigation of care and service systems (33, 34, 35).

THE RELATIONAL EXPERIENCE

- All studies on this theme focus on **parent caregivers** of a child with one or more incapacities.
- For these parents, entry into caregiving may mark the **start of a conflictual family and marital dynamic** (36, 37).
- The literature emphasizes that supporting parent caregivers cannot be limited to their caregiving role toward their child: **support for their couple relationship** is also essential (24, 36, 38).

2 COMPARISON WITH PREVIOUS BULLETINS

The 2025 Scientific Watch Bulletin is the Observatory's third. This section compares its findings with those of the 2022–2023 and 2023–2024 editions.

REGARDING THE LITERATURE REVIEWED

This year's watch (49 articles) included fewer studies than the two previous editions (60 and 70 studies, respectively). However, the 2025 review period is three months shorter.

Despite the more limited corpus, **a higher proportion of studies were primarily focused on caregiving**[5], indicating a strong interest in better understanding caregivers' lived experiences independently of the care recipients' situations.

For a second consecutive year, **caregiver involvement in care and service delivery emerged as the most frequently addressed theme**.

LAs a theme, care and service navigation decreased considerably compared to previous years.[6]

A greater number of articles focused on parent caregivers than in previous years.[7]

In 2025, a higher proportion of studies made no mention of terms such as proches aidants, caregiver, informal carer or carer[8]. This may be partly explained by **the increased proportion of studies on parent caregivers**. Terminology related to caregiving remains more strongly associated with aging contexts, whereas studies focusing on parent caregivers of a dependent child tend to use family-related terms instead.

REGARDING THE FINDINGS

Compared to the previous review (39), **fewer articles focused on caregiver involvement in palliative care**, as the scope broadened to encompass a wider range of caregiving contexts (e.g., cardiac, intensive and pediatric care).

As in the two previous bulletins (39, 40), the impact of caregiving burden on caregivers' quality of life was highlighted in the literature.

- In this year's review, **some studies highlighted the importance of support from family and friends for care recipients' quality of life** (18, 19, 20, 21).

For a third consecutive review, **care and service navigation emerged as a major barrier for caregivers**, regardless of the type of incapacity or care context (39, 40).

In 2025, all studies on this theme identified **peer support** as an essential lever for **sharing caregiving experiences** and facilitating **access to relevant resources** (33, 34, 35).

As highlighted in last year's bulletin, supporting caregivers effectively entails taking a **broader view of the relationships surrounding the dyad, rather than focusing solely on the caregiver–care recipient relationship**.

- Studies focused in particular on parent caregivers emphasized the **importance of supporting their couple relationship** (36, 37, 38).

The need for a more diverse sample in caregiver research is consistently identified as a future research priority across all three bulletins.

- This year, emphasis was placed on **including caregivers with lower socioeconomic status** (6, 19, 25).

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[5] In 2025, 42.9% of the articles treated caregiving as their primary focus, compared to 25% in 2022–2023 and 18.6% in 2023–2024.

[6] In 2025, 6.1% of the articles focused on care and service navigation, compared to 30% in 2022–2023 and 22.9% in 2023–2024.

[7] In 2025, 40.8% of the articles focused on parent caregivers, compared to 36.7% in 2022–2023 and 24.9% in 2023–2024.

[8] In 2025, 63.3% of the articles contained none of these terms, compared to 30% in 2022–2023 and 37.1% in 2023–2024.

3 CAREGIVER INVOLVEMENT IN CARE AND SERVICE DELIVERY

Articles on this theme examined the involvement of family members, friends and other significant persons in supporting users of Quebec's health and social services system (RSSS). "Caregiver involvement" refers to participation in care and service delivery, shared decision-making processes, caregiver–professional communications and collaboration, and training initiatives designed to support caregivers in their roles. Some studies also considered the extent to which caregiver needs are taken into account within the RSSS.

Caregiver involvement in care and services: key figures

27	**Twenty-seven (55.1%) of the articles reviewed focused on this theme.**
55 %	Caregiver involvement in care and service delivery was the most frequently addressed theme in this year's review, accounting for over half of the studies.
37 %	Of these, 37% concern **caregiver involvement in hospital or intensive care settings**, while 29.6% focus on **support for aging individuals**, including older adults with neurocognitive disorders.

The literature describes caregiver involvement in care and services in various ways, including **assistance with daily care, information sharing and communication, and participation in shared decision-making**.

Several studies describe caregiver involvement in terms of **caregiver presence and support** during appointments or within care settings.

The presence of family members or friends often **reassures the care recipient, alleviates the workload for professionals** — particularly when caregivers take on tasks such as assisting with feeding — and **promotes better adherence to treatment plans** through the provision of emotional and practical support (1, 2, 3, 4, 5, 6, 7, 41). Caregiver presence is particularly important in settings such as long-term care facilities (5).

One study examined the impact of caregiver absence on long-term care (LTC) homes in Ontario during COVID-19-related public health restrictions.

- The authors found **restricted visitation had significant negative impacts on the well-being of both LTC residents and their care partners** (5).
- For residents, the profound social isolation and erosion of peer and familial bonds resulting from these measures could lead to depressive symptoms. The absence of care partners also increased the risk that residents' needs would go unmet or be inadequately communicated to staff, given that caregivers often play an advocacy role (5).
- For caregivers, having to witness the decline of their loved ones from a distance proved particularly traumatic, not least due to the sense of powerlessness many reported (5).
- Overall, the consequences associated with caregiver absence, as documented in the study, **highlight the importance of caregiver presence and involvement for LTC residents** (5).
- However, the authors also observed **a broader devaluation of relational care and marginalization of caregiver involvement in long-term care settings**, as infection prevention measures often took precedence over the mental and physical well-being of both residents and caregivers (5).

Various studies also highlighted **information sharing and communication between caregivers and health professionals** as key components of caregiver involvement in care and services (1, 4, 9, 11, 12, 13, 42).

Communication helps tailor care and services to the care recipient's needs and is thereby crucial to caregiver involvement, as it supports **shared and informed decision-making** (3, 8, 10, 11, 17, 41, 42).

Information sharing is part of a two-way dynamic between caregivers and health professionals.

- First, professionals may share information about a care recipient's health with their family and friends. Being informed of the diagnosis and health status of the person who receives care is a critical first step to caregiver involvement. Following this, ongoing information sharing is essential to allow caregivers to adapt their support in response to changing needs (1, 11, 12, 13).
- Second, caregivers also serve as key sources of information for professionals, thereby helping to better identify the care recipient's needs (4). Family and friends are often well positioned to provide information on their loved one's health, needs and preferences.

In situations where care recipients are unable to make their own decisions — for example, in contexts of palliative care, end-of-life care or neurocognitive disorders — **communication and information sharing become even more critical to ensuring sound decision-making** (8, 10, 15, 42, 43, 44, 45).

- Some studies indicate that **health professionals are just as apt as caregivers and the general public to lack knowledge of advance care planning**, including palliative and end-of-life care (42, 44, 45).
    - For example, one study assessed general knowledge of end-of-life care in Quebec. Among respondents in favour of medical assistance in dying (MAiD), which is legal in Canada, the majority were unable to provide an accurate definition, often conflating end-of-life practices with patient-initiated treatment refusal or interruption. Approximately 39% of respondents incorrectly associated continuous palliative sedation with MAiD, while 34% incorrectly indicated that the described intervention was illegal (44).
    - The study suggests that the gaps in knowledge about end-of-life practices may hinder informed decision-making by caregivers and care recipients (44).

For caregivers to feel truly involved and valued in care and service delivery, shared decision-making is essential, as it recognizes and reinforces their expertise. Nonetheless, this dimension of caregiver involvement is frequently overlooked within the health and social services system (5, 8, 13, 14, 15, 41). **Challenges in caregiver involvement in care and service delivery** relate to two aspects in particular: **the role of health professionals**, and **institutional support.**

Role of health professionals in caregiver involvement:

- Attitudes toward patients' families and friends, as well as perceptions of their knowledge, sense of competence and confidence, are key determinants in caregiver involvement in care and services (1, 46, 47).
- A shift in professional attitudes is needed to foster a **more collaborative approach with caregivers, so that their expertise is recognized** and considered alongside that of health professionals (13).

Such a collaborative approach can contribute to improved well-being for both care recipients and their caregivers. Studies on this topic emphasize that **recognizing caregivers as care partners is essential to care quality**, and should not be sidelined or deprioritized (5, 8, 13, 15).

Despite professionals' best intentions, several studies suggest that their efforts to involve caregivers are often constrained by **insufficient institutional support** and by their own uncertainties about how and when to do so (1, 11, 12, 42, 48):

- **Policies and practices related to caregiver involvement** vary considerably across services and settings, complicating the task for health professionals (1, 3, 42, 48).
- In one study, the authors conducted a discourse analysis of guidelines issued by major cardiovascular societies in North America and Europe. **Family involvement was the least frequently addressed dimension in the cardiology guidelines issued for health professionals**, and this absence has direct implications for clinical practice (3).
- **Professionals' availability and capacity, particularly in relation to workload**, are key factors influencing caregiver involvement. Many professionals reported feeling overburdened and lacking the time required to meaningfully involve caregivers in their practice (1, 11).

Professional attitudes: a barrier to involving fathers in care and service delivery?

One study examined the practical and clinical experiences of nurses working with fathers who care for a child with one or more incapacities. The findings highlight the role of gendered perceptions in caregiver involvement (46):

- **Nurses tended to maintain a traditional understanding of the father's role, often viewing fathers as passive participants**. As a result, they were inclined to focus their attention and care on the mother and the child, thereby limiting the father's opportunities to develop caregiving skills and reducing their interest in participating and engaging in their child's care (46).
- When fathers did not spontaneously express a desire to learn or be involved, **nurses reported feeling uncomfortable and appeared uncertain about how to interact with them**. They were unable to explore fathers' perceptions of their role or encourage greater involvement (46).
- The authors argue that **promoting and supporting father involvement is an effective strategy for achieving a more equitable distribution** of family responsibilities and reducing gender-based inequalities (46).
- By proactively and directly asking fathers how they would like to be involved in their child's care, nurses can help foster their participation in care and service delivery (46).

3.1 IMPLICATIONS FOR PRACTICE

Various actions and interventions to foster caregiver involvement in care and services were proposed in the literature.

Several studies suggest that **digital tools** such as informational websites, online training and virtual appointments could facilitate caregiver involvement (2, 5, 49):

- One study on caregiver involvement in intensive care proposed the use of **virtual meetings and visits** (2).
- Setting up an online communication channel can **give family members and friends more direct and flexible access** to health professionals, thereby enhancing caregiver involvement (2).
- Digital tools are not a one-size-fits-all solution. Access to technology and levels of digital literacy are not equal among caregivers, highlighting the need for tailored support in using these technologies (49).

Some studies identify practices for fostering shared decision-making among all parties involved, including caregivers:

- **Multidisciplinary team participation is central to shared decision-making**. The authors of one study propose developing a centralized platform bringing together all clinicians involved in patient's care, along with patients and families, to create a shared space for communication and information exchange regarding diagnosis and treatment (50).
- Several studies promote an approach to foster genuine partnerships, in which **professionals support shared decision-making by co-developing care goals with caregivers** rather than imposing standardized objectives (8, 10, 16, 17).

Lastly, studies under this theme highlight the benefits of caregiver involvement for patients, professionals and the caregivers themselves. However, some also **emphasize the need for caution to avoid overburdening families and caregivers** (1, 6, 8):

- To balance information-sharing against the risk of overburdening families already under strain, professionals must assess each family's capacity to cope with stress (8).
- Along with flexible services, supportive relationships between professionals and caregivers are key to ensuring that increased involvement does not inadvertently add to the caregivers' burden (8).

4 QUALITY OF LIFE IN THE CAREGIVING DYAD

The articles under this theme explored quality of life within the caregiving context, using indicators related to well-being (e.g., mental health, stress, social isolation, burden). This theme includes studies examining caregivers' needs to improve their quality of life, as well as those focused on the impact of caregiving on care recipients' quality of life.

Quality of life in the caregiving dyad: key figures

16	**Sixteen (32.7%) of the articles reviewed focused on this theme.**
33 %	Quality of life in the dyad was the second most frequently addressed theme in the review, accounting for close to one-third of the studies.
1/2	Half of the studies focused on parent caregivers of children with neurodevelopmental disorders or cancer.
31 %	Psychology was the main disciplinary field in approximately one-third of the studies (31.3%).

udies indirectly addressing caregiver quality of life highlighted how **support from family and friends was a key factor in determining quality of life** for the person supported by the caregiver (18, 19, 20, 21).

Other studies directly examined caregiver quality of life, such as the **stress experienced by parents of children with disabilities**. These parents may experience s**ignificant psychological distress** and are at higher risk of symptoms like chronic stress, anxiety, depression and physical health issues, compared to the parents of children without disabilities or developmental conditions (22, 24, 26, 51).

One study on quality of life among parents of recently diagnosed autistic children identified multiple contributing factors to parental stress (24):

- Emotions linked to the diagnosis
- Uncertainty about the future
- The child's behaviour
- Parental mental health
- Insufficient professional support
- Difficulty navigating services
- Changes to family routine
- Lack of personal time
- Marital conflict or tension

Studying while supporting a loved one: resilience among young caregivers

The burden associated with caregiving tasks may affect multiple spheres of a caregiver's life, and therefore their quality of life.

One study examined how the carer role shaped the educational experiences of 438 post-secondary students in Quebec. Student caregivers were compared to two other groups: young people with a sick relative but without caregiving responsibilities; and young people without a sick relative (25).

- The study highlights that, while student caregivers demonstrated levels of academic commitment and social adjustment comparable to their peers, **they experienced greater emotional strain and less linear educational pathways** (e.g., delays, interruptions, etc.) (25).
- These difficulties can be attributed to the cumulative burden of holding the roles of student and caregiver simultaneously. Time, energy and attention, already limited, are repeatedly redirected toward caregiving responsibilities, leaving less time for studies. Student caregivers may consequently experience frustration, guilt, fatigue and mental overload, in addition to ongoing concerns about their loved one (25).
- This dual burden — caregiving and schooling — creates tensions that affect emotional well-being and academic functioning, even if **student caregivers are demonstrably resilient enough to maintain levels of academic engagement comparable to their peers** (25).

These findings point to the need for institutional recognition of the specific needs of young caregivers and the implementation of adapted support in higher education (25).

- The authors recommend **creating a formalized pathway, coordinated by a designated resource, to enable time-limited academic accommodations during periods of increased caregiving demand** without affecting students' academic progress (e.g., assignment deadline flexibility, access to asynchronous course components, course load adjustments) (25).

4.1 IMPLICATIONS FOR PRACTICE

The literature highlighted various interventions that could improve quality of life for caregivers and care recipients, including:

IMPROVED CARE AND SERVICE COORDINATION (22, 23, 24, 25)

- One study on parent caregivers of autistic children underscored the key role of continuous care — e.g., availability of professionals during crises, telephone support, multidisciplinary team coordination — in reducing family anxiety levels and strengthening caregivers' confidence in their own abilities (24).
- Other authors advocate for more flexible and adaptive models of professional support (21, 22, 23, 25).

ACCESS TO PSYCHOSOCIAL SERVICES (21, 23, 24, 26, 27, 28, 29)

Some studies assessed the contribution of support groups to caregiver well-being (23, 24, 28, 29). Feeling understood and validated, as well as sharing resources with others who have experienced similar situations, emerge as key benefits of support groups (23, 24, 28, 29).

- One study on mothers of autistic children involved the implementation and evaluation of support groups hosted on Facebook (28).
- Participants described these groups as safe spaces where they could break free of their isolation and express themselves without fear of judgment. The asynchronous format was also appreciated, since it allowed them to interact at times that suited their availability (28).

ACCESS TO INFORMATION (23, 24, 30)

As many authors point out, having access to information about the care recipient's health status, their care trajectory, and the caregiving role itself can help reduce caregiver stress (23, 24, 30).

COMMUNITY SUPPORT (23, 24, 31)

Various studies underscore the important role of community organizations that offer caregivers support such as respite services (23, 24, 51).

One study went further, examining how informal community-based care networks supported elderly racialized individuals in Montreal during the COVID-19 pandemic (31).

- The authors show that, in a context of gaps in formal support systems — particularly pronounced for racialized populations — **caregivers and care recipients created informal mutual aid networks within their communities** to ensure the well-being of their most vulnerable members during the crisis (31).
- **These networks became essential support systems, helping to maintain the quality of life of racialized older adults** under challenging circumstances (31).
- The authors note that **community-based care is often overlooked** in the caregiving literature, despite being a long-standing feature of many racialized communities in Montreal. Most studies focus primarily on the caregiving dyad without fully accounting for broader support networks (31).

INSTITUTIONAL POLICY (25, 32)

Two studies argue that interventions to improve caregiver quality of life must be supported by institutional-level policy (25, 32).

- These authors call for formal organizational support for caregivers in the workplace and educational settings (e.g., paid caregiving leave, flexible scheduling and other accommodations) (25, 32).

5 CARE AND SERVICE NAVIGATION

The articles under this theme examine processes of navigation, coordination, transition, support and advocacy undertaken by caregivers in accessing health and social services, generally on behalf of the care recipient.

Care and service navigation: key figures

3	**Three of the articles reviewed focused on this theme.**
6 %	Though a significant issue for caregivers, care and service navigation was one of the least frequently addressed themes in the literature reviewed, accounting for just 6.1% of all articles, a figure on par with the theme of relational experiences.
3/3	All studies on this theme focus on parent caregivers: two examine children with neurodevelopmental disorders, and one focuses on children diagnosed with cancer.
100 %	The articles fall primarily within the field of psychology.

Many care and service trajectories **lack a formal pathway to structure and guide caregivers** through the steps they must take (33, 34, 35). In the **absence of clear guidelines and standardized procedures, caregivers are often left to navigate a fragmented system on their own**, which can be overwhelming (33, 34, 35).

For example, one study examining the diagnostic evaluation trajectory for autistic children in Quebec found that, for most professionals and parents interviewed, **lack of service continuity was one of the main barriers to accessing resources** (33).

In particular, discontinuities between services are reflected in:

- Insufficient information sharing between service providers (33)
- A lack of collaboration among professionals (33)
- Burdensome administrative procedures (33)
- Insufficient information on procedures and the functioning of the health and social services system (33, 35).

5.1 IMPLICATIONS FOR PRACTICE

The studies on this theme identify various measures to facilitate care and service navigation.

All studies highlight **peer support** as a **key mechanism for pooling caregivers' experiences and facilitating the sharing of relevant resources**, whether through formal support groups or informal exchanges between caregivers who face similar care trajectories (33, 34, 35).

The articles also identify other potential avenues for action, including **developing training for caregivers** to help them navigate services (33, 34), **fully digitizing medical records** to facilitate their transfer between organizations and services (33), and **establishing standardized care pathways** (33).

6 THE RELATIONAL EXPERIENCE IN CAREGIVING

The articles grouped under this theme consider caregiving in relational terms, examining the impact of caregiving activities on relationships both within the dyad and in the broader caregiving support network.

The relational experience: key figures

3	**Three articles in the review focused on this theme.**
6 %	The relational experience in caregiving is one of the least frequently addressed themes in the literature reviewed, accounting for just 6.1% of articles overall, on par with care and service navigation.
100 %	All studies in this section focus on parent caregivers: one concerns children with cancer, another concerns adult children with severe multiple disabilities, and the third concerns autistic children.

All of the studies address the relational experiences of parent caregivers with their children or their spouses (36, 37, 38).

Two studies highlight **marital conflicts and tensions that may emerge following entry into caregiving** (36, 37).

- **Entry into caregiving** — whether this coincides with the diagnosis, the onset of support needs or the start of treatment — **can mark the beginning of a conflictual family climate** in some cases, and reveal or amplify pre-existing vulnerabilities within the family in others. In all cases, these tensions may lead to marital breakdown (36, 37).
- Conversely, **some couples develop strategies that foster resilience**, such as prioritizing open communication and teamwork, adapting family routines, seeking support from professional services, and jointly informing themselves about their child's condition. These approaches support **emotional adaptation** (24).

Regarding parent–child relationships, the authors of the study on autonomy in adult children with severe multiple disabilities emphasize that, **beyond the direct support provided by parents, the child's developmental trajectory is decisively influenced by parenting practices**. An educational style that promotes self-determination — i.e., by recognizing the child's preferences, abilities, interests and values — contributes significantly to their well-being into adulthood (37).

The unique relationship between mothers and their autistic children

One study conducted in Quebec examined the impact of caregiving on the mother–child dyad when the child is autistic. The authors highlight the challenges, emotional dimensions and potential evolution of this dynamic, and note differences compared to dyads where the child is not autistic (38).

The study reports that **mothers of autistic children perceived higher levels of conflict and lower closeness in their relationship with their child** compared to the mothers of non-autistic children (38). Several factors may help explain these findings:

- The communication and social interaction challenges associated with autism can make it difficult for parents of autistic children to interpret and respond sensitively to their children's needs (38).
- The quality of interactions is often perceived as lower by mothers, which may contribute to a sense of distance in the relationship (38).
- Mothers of autistic children also report higher levels of psychosocial problems, including anxiety and depression, which may influence how they perceive their relationship with their child (38).

The authors note that **the relationship is not fixed, but evolves over time** and may develop positively as the child grows older:

- As autistic children age, their social and communication skills may improve, enabling more reciprocal and rewarding interactions, which in turn can strengthen mothers' sense of closeness (38).
- **These findings highlight the importance of supporting not only the child's development, but also parental well-being and the broader relational context** (38).

6.1 IMPLICATIONS FOR PRACTICE

Supporting parent caregivers is not limited to helping them fulfil their caregiving responsibilities toward their child. **It is equally essential to consider their relational context**, including their couple relationship, sense of parental competence, and overall well-being (24, 36, 38).

- Support groups and educational programs for parents can potentially improve couple relationships, strengthen communication and promote well-being (24).

7 DIRECTIONS FOR FUTURE RESEARCH

The literature reviewed highlights several priorities for future research, particularly with respect to methodological approaches.

Some authors remark that their **studies would benefit from being extended through longitudinal research** (6, 19, 25). This type of approach makes it possible to track changes over time, thereby developing a more nuanced and robust understanding of caregiving trajectories.

Numerous authors highlight the **need for more diverse samples**, particularly through greater representation of participants with **lower socioeconomic status** (25, 37), from a **wider range of residential settings** (2, 8, 11), and from **other marginalized populations** (2, 5, 23, 37, 38).

To stay informed of Scientific Watch findings

The scientific watch in caregiving involves monitoring, collecting and analyzing the most recent scientific findings in the field. **By providing up-to-the-minute insights into caregivers' changing needs and realities, it supports and informs research, action and decision-making on their behalf.**

Every three months, our team compiles the most recent scientific publications in caregiving from Quebec researchers and presents them as a list, broken down by theme.

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APPENDIX 1: METHODOLOGY

his section outlines the methodological stages involved in producing the scientific watch bulletin.

The review aimed to identify key themes, findings, trends and practices emerging from the scientific literature in Quebec, thereby offering valuable insights from the latest research in the field of caregiving.

DATA COLLECTION

The Observatory had previously compiled a list of 70 Quebec researchers whose work focused primarily on caregiving. The list is updated annually; four new names were added in the past year. This list formed the basis for a literature search in two databases (Google Scholar and PubMed) using the researchers' full names.

ARTICLE SELECTION CRITERIA

To be included in the review, articles had to meet the following criteria:

- Authored or co-authored by one or more Quebec-based researchers.[11]
- Findings applicable or transferrable to a Quebec context.
- Published between January 1 and December 31, 2025.[12]
- Address the topic of caregiving in the findings, considerations for practice or proposed future research needs.[13]
- Published in a scientific or professional journal.[14]
- Written in English or French.

PUBLICATION SELECTION PROCESS

Once duplicates were removed, the search yielded 285 publications. An initial screening for relevance (i.e., by reading the titles and abstracts) resulted in a preselection of 111 articles. Each of these was then fully reviewed for compliance with the selection criteria, resulting in a final selection of 49 articles.

DOCUMENT ANALYSIS

To facilitate document analysis, the papers were organized using Zotero. Broad analytical categories were first developed by the Observatory. Labels were then created and applied to the articles based on their characteristics. Article classification was updated against the corpus of this year's review.

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[9] Allard, Émilie; Beauchet, Olivier; Beaudet, Line; Blain-Moraes, Stefanie; Bogossian, Aline; Bottari, Carolina; Bourbonnais, Anne; Bravo, Gina; Brotman, Shari; Carbonneau, Hélène; Castro, Aimée; Champagne, Manon; Chenard, Josée; Courcy, Isabelle; Couture, Mélanie; Côté, Mélissa; Daneau, Stéphanie; Demers, Louise; des Rivières-Pigeon, Catherine; Dubé, Véronique; Ducharme, Francine Carole; Éthier, Sophie; Fortin, Gabrielle; Fournier, Anne; Gascon, Hubert; Gervais, Christine; Girard, Dominique; Goldfarb, Michael; Jutras, Sylvie; Khanassov, Vladimir; Kilpatrick, Kelley; Lach, Lucyna; Lambert, Sylvie; Landry, Marjolaine; Lanovaz, Marc J.; Lapointe, Bernard Joseph; Laquerre, Marie-Emmanuelle; Le Dorze, Guylaine; Le Gall, Josianne; Lefebvre, Hélène; Lemelin, Carmen; Levert, Marie-Josée; Légaré, France; Mailhot, Tanya; McCusker, Jane; Milot, Elise; Mongeau, Suzanne; Morin, Marie-Hélène; Ogourtsova, Tatiana; Orzeck, Pam; Piché, Geneviève; Poirier, Nathalie; Poulin, Marie-Hélène; Purden, Margaret Ann; Quesnel-Vallée, Amélie; Rennick, Janet Elizabeth; Rey, Sylvie; Rivard, Mélina; Rochette, Annie; Rousseau, Myriam; Siméon, Frantz; Sultan, Serge; Sussman, Tamara; Thombs, Brett; Ummel, Deborah; Van Pevenage, Isabelle; Vedel, Isabelle; Vezina, Jean; Viau-Quesnel, Charles; Villatte, Aude.

[10] Created in 2022 and updated in 2024, the list includes Quebec researchers whose focus is caregiving. To compile the list, a research professional conducted a keyword search using such caregiving terms as caregiver, proches and families on the funding platforms of the Social Sciences and Humanities Research Council of Canada (SSHRC), the Fonds de recherche du Québec (FRQ) and the Canadian Institutes of Health Research (CIHR). All individuals who received funding for a caregiving project between 2010 and 2023 were included.

[11] Quebec researchers on the list developed by the Quebec Observatory on Caregiving.

[12] The initial online publication date was used as the basis for inclusion.

[13] Articles addressing the concepts of "family support" or any form of support based on an emotional bond, and not explicitly referring to the terms proches aidants, caregivers, or informal carers, were also included.

[14] Articles were required to have been published in a scientific or professional journal. Grey literature, conference proceedings and journal editorials were excluded.

TABLE: ARTICLE CLASSIFICATION IN ZOTERO

FIELD OF STUDY	• Anthropology • Psychology • Public health • Nursing sciences • Gerontology • Pediatrics • Medicine • Geriatrics • Oncology • Social work • Ergotherapy	• Sociology • Epidemiology • Public policy • Psychiatry • Rehabilitation • Physiotherapy • Communication • Economics • Psychoeducation • Neuroscience • Philosophy

METHODOLOGY	• Qualitative
	  • Interviews
	  • Focus groups
	  • Participatory research
	  • Case studies
	  • Comparative studies
	  • Discourse analysis
		• Quantitative
		  • Surveys
		  • Studies
		  • Clinical trials
		• Literature reviews
		• Policy and practice briefs
		• Mixed-method studies

LANGUAGE	• French • English	
TYPE OF INCAPACITY	• Neurodevelopmental disorders Cancer • Age-related cognitive disorders • Heart disease • Other age-related incapacities • Cerebral trauma • Mental health • Transplant	• Immunodeficiency • Juvenile arthritis • Diabetes • Muscular pain • Disability • Palliative care • Surgery • Coma • Motor difficulties • Precariousness/ homelessness

CARE SETTING	• Long-term care • Home • Hospital	
CAREGIVER TYPE	• Parent caregivers • Partners/spouses • Caregivers from ethnocultural communities • Immigrants • Rural residents • Adult caregivers of an aging parent	
CAREGIVING FOCUS	• Secondary subject • Main subject • Dyad (caregiver/care recipient relationship)	
USE OF TERMS LIKE PERSONNE PROCHE AIDANTE, PROCHE AIDANT, CAREGIVER, INFORMAL CARER OR CARER	• Yes • No	

GEOGRAPHICAL AREA OF THE RESEARCH	• Canada
	  • Quebec
	  • Montreal
	  • Ontario
	  • British Columbia
	  • Manitoba
	  • New Brunswick
	  • Saskatchewan
	  • Newfoundland and Labrador
		• Belgium
		• France
		• International
		• India
		• Ireland
		• Czech Republic
		• Italy
		• Netherlands
		• United Kingdom

SUBJECT MATTER	• COVID-19 pandemic	• Practices and interventions

To highlight the most prominent trends, the articles were organized by theme. The themes identified had to be broad enough to encompass all the articles in the review, yet specific enough to pinpoint the relevant analytical categories. This process yielded the following four themes:

- Caregiver involvement in care and service delivery
- Quality of life in the caregiving dyad
- Care and service navigation
- The relational experience in caregiving

Certain articles touched on multiple themes; in such cases, only the primary theme was considered.

For each article, the Observatory highlighted:

- Study findings (the new knowledge derived from the research).
- Implications for practice (the study's real-world applications and the incorporation of new knowledge into clinical practice).
- Future research needs (author-identified gaps in the methodology, results or conclusions).
- Key themes (topics, fields or main issues addressed).

LIMITATIONS

The methodology used may have affected the selection of articles for the review.

Some articles may have been overlooked due to the limited number of databases (Google Scholar and PubMed) used to conduct the literature search. This choice may also have disadvantaged articles published in French, since both databases predominantly feature English-language content.

The articles reviewed were limited to those authored by Quebec-based caregiving researchers identified by the Quebec Observatory on Caregiving. This list may not be exhaustive.

Lastly, it is important to note that review focused only on publications from 2025. More recent studies may therefore offer new knowledge or insights that could complement the observations presented in this bulletin.

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Observatoire
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