2nd ANNUAL SCIENTIFIC WATCH BULLETIN

Observatoire québécois de la proche aidance

Caregiving as considered by Quebec researchers

OCTOBER 2023 TO DECEMBER 2024

The Observatory's second annual Scientific Watch Bulletin provides an analytical overview of the articles on caregiving and caregivers published by Quebec researchers between October 2023 and December 2024.

The goal of this initiative is to identify the themes, observations, trends and practices emerging from the scientific literature in Quebec with a view to informing action and decision-making by policy-makers, professionals, and members of the scientific community in Quebec, Canada and internationally.

The analysis identified four key themes:[a]

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

The main research findings and implications for practice related to each theme will be discussed in the sections that follow. Before delving into the theme in question, we will present highlights from the review and compare them with the findings from the previous bulletin. Our conclusion will focus on the future research needs that emerged from the review.

TABLE OF CONTENTS

---

[a] Articles frequently addressed multiple themes. In such cases, only the main theme was considered.

En partenariat avec :
Québec

Credits

WRITTEN BY

Camille Girard-Marcil, MSc
Research professional

REVIEW, VALIDATION AND DISCUSSION

Observatory team

Florence Potvin, MSc
Research professional

Margaux Reiss, MSc
Team Leader, project officer for the Knowledge Production and Monitoring pillar

Mélanie M. Gagnon, PhD
Team Manager – Head of Knowledge Transfer Services, Academic Affairs and Research Ethics

LIBRARIAN SERVICES

Rym Zakaria, Librarian

LAYOUT

Caron Communications graphiques

To cite this document:
Girard-Marcil, C. (2025). October 2023 to December 2024. 2nd Annual Scientific Watch Bulletin. Caregiving as Considered by Quebec Researchers. Quebec Observatory on Caregiving, Academic Affairs and Research Ethics, CIUSSS West-Central Montreal.

1. HIGHLIGHTS

Overview of 70 articles

53 %

The majority of the articles (72.9%) referred to research conducted in **Canada**, **mostly in Quebec**, which accounted **for 52.9%** of the total.

+ 1/2

More than half the articles focused on **caregivers in general**, without singling out any particular group (57.1%).

1/4

In 24.9% of the articles, the caregivers were **parents of a child with an incapacity**. The second group most often studied was **young caregivers** (five articles in total).

29 %

The **incapacities** most frequently discussed in the literature were linked to **ageing**[b] (28.8%), **neurodevelopmental disorders**[c] (17.1%) and **mental health** (12.9%).

37 %

Though all of the articles dealt with caregiving, more than one-third (37.1%) made no mention of such terms as *proche aidant*, *caregiver*, *informal carer* or *carer*.

47 %

47.1% of the articles treated **caregivers as a secondary focus**, 34.3% as a dyad (the relationship between the caregiver and the care recipient), and 18.6% as the primary focus.

The articles most frequently consulted were from the fields of **psychology** (21), **medicine** (19) and **nursing sciences**.[d]

65

A total of 65 articles were in English; five were in French.

---

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

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

[d] 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 common theme** (32.9%), followed by quality of life (28.6%), care and service navigation (22.9%) and the relational experience in caregiving (11.4%).

- Regarding caregiver involvement in care and service delivery:
  - *Lack of time, the requisite skills, knowledge and/or trust on the part of professionals and practitioners constituted* ***barriers to caregiver involvement*** *in care and service delivery.*[1,2,3,4,5,6]
  - *The* ***implementation of standardized, clear and accessible directives*** *fostered the systemic inclusion of caregivers in care and service delivery.*[3,6,7,8,9,10]
- Regarding quality of life:
  - *The* ***lack of psychosocial support*** *along with the* ***scarcity of available services for care recipients*** *were linked to a* ***deterioration in the mental health*** *of caregivers (e.g., manifesting as anxiety, stress, depression, etc.).*[11,12,13,14,15,16,17,18,19,20]
  - *When the* ***incapacity*** *of the person who receives the care is* ***stigmatized****, caregivers tended to isolate themselves and avoid asking for help, thereby* ***increasing their burden*** *and risking affecting their* ***mental health****.*[21,22,23,24,25]
- Regarding care and service navigation:
  - ***Navigating a complex health and social services system*** *to find the appropriate resources was* ***perceived as difficult*** *by caregivers.*[11,12,26,27,28,29]
  - *Caregivers often had to* ***prove or defend the care recipient's right to access services****,*[11,12,29,30] *an additional burden that threatened to further undermine their mental health.*[11,26]
- Regarding the relational experience:
  - ***Providing emotional and relational support*** *is also part of the caregiving experience.*[31,32,33,34]
  - ***Better supporting caregivers*** *entails adopting a comprehensive view of the relationships surrounding the dyad.*[32,35]
- Directions for future research:
  - *In caregiving research,* ***recruitment strategies must be adapted*** *to ensure the inclusion of male caregivers*[7,24,28,36,37,38] *and those from ethnocultural communities.*[2,7,34,39]

2. COMPARISON WITH THE FIRST SCIENTIFIC WATCH BULLETIN (2022-2023)

The fact that this is the Observatory's second bulletin allows us to compare its findings with the first.

Concerning the literature reviewed

- The annual update of the list added 13 Quebec researchers to the review, thus helping to expand the findings.
- This year's scientific watch includes 10 more articles than last year's. However, the period covered by the current bulletin was three months longer.
- The review process brought to light a **new theme: caregiver involvement in care and service delivery**. This theme encompasses both individual decision-making and broader caregiver participation in the health and social services system, including their role in care provision and their communication and collaboration with professionals. Most of the articles in this theme focused on documenting the barriers and facilitators to caregiver inclusion by heath care professionals. Caregiver involvement emerged as the **dominant theme of this year's review**.
- In terms of their prevalence, the other themes (care and service navigation, caregiver quality of life and the relational experience in caregiving) were similar to the findings of the first bulletin.
- This year's watch included ***more* articles on young caregivers**[e] and on **caregiving in the context of mental health**.[f]
- In terms of research location, language, methodologies and fields of study, the results of both reviews are comparable.

---

[e] No articles addressing young caregivers were in the 2022-2023 bulletin, whereas there were five in the 2023-2024 edition.

[f] Three articles concerning caregiving in a mental health context were included in the 2022-2023 bulletin; this number rose to nine in the 2023-2024 edition.

Concerning the findings from the articles

- With regard to **caregiver involvement in care and service delivery**, most of the articles concerned decision-making in a context of palliative care.[38, 40, 41, 42]

> ▸ ***The reluctance of professionals to discuss palliative and end-of-life care*** *with patients and their caregivers was a finding common to both reviews.*[9, 41, 42, 43, 44]

- Numerous articles in both reviews underscored how the lack of services for people in need of care along with the general scarcity of psychosocial support services risked affecting **caregiver quality of life.**[11, 13, 14, 15, 16, 17, 18, 19, 20, 42]

> ▸ *The articles from this year's review offered new insights on caregiver quality of life by addressing issues like stigma*[21, 22, 23, 24, 25] *and recognition.*[21, 24, 36]

- With regard to **care and service navigation**, the same two avenues for action emerged in both reviews:

  - ***Assigning a dedicated resource*** *to support families throughout their caregiving journey, assist with transitions and help coordinate care and services.*[11,12,14,42,45]
  - ***Ensuring rapid access to diagnostic and support services*** *at the outset of the caregiving journey to facilitate the navigation process for caregivers.*[15,42,46]

- As with the previous bulletin, articles focused on the **relational experience in caregiving** explored marital relations within the dyad and how these affected the experience of caregiving.[33,34,35,42,47,48]

- Regarding **directions for future research**, both reviews offered the same observation:

  - *Future research should consider a more diverse sample, particularly with regard to ethnocultural communities.*[27,34,39,42] *However, this year's articles also highlighted the lack of representation of male caregivers.*[7,24,28,36,37,38]
  - *Greater emphasis should be placed on incorporating caregivers' perspectives into scientific research.*[19,29,42,49,50,51,52,53,54]

- This year's articles also went into more depth in their discussion of methods for including caregivers in research.[51,52,54]

3. CAREGIVER INVOLVEMENT IN CARE AND SERVICE DELIVERY

This theme refers to the involvement of family members, friends or other significant individuals in the care and support of service users within the health and social services system. It includes caregiver participation in care, services and decision-making; communication and collaboration between caregivers and professionals; specialized training to support caregivers in their role; and systematic consideration of their needs.

- Many articles discussed the importance of incorporating caregiver input into the care and service continuum.[3,4,6,7,9,55,56]

> - *Caregivers are **less apt to undergo physical or mental stress if they feel validated and included** in the care and services provided to the service user.*[7,39]
> - *Caregiver presence also positively affected the health outcomes of the service user.*[5,6]
>
>   *For example, one article on the caregiver presence in intensive care settings found that having their caregiver nearby gave the user a feeling of comfort, thereby lowering their agitation, irritability and anxiety.*[6]
> - ***Including caregivers in the care process made them more apt to accept interventions and improved their feelings of competency.***[39,56]
> - *Caregivers are generally those who have the most knowledge about the user's medical history and the progress of their incapacity. They are therefore well positioned to **act as key partners in a health system that can be fragmented** and difficult to navigate.*[8]

Caregiver involvement in care and service delivery, in numbers

– An overview of 23 articles

33 %	**Caregiver involvement** in care and service delivery was the **most recurrent theme** in the articles reviewed (32.9%).
1/2	Close to half (43.5%) of the articles concerned caregiver involvement in **palliative, long-term or home-based care**.
1/2	While all of the articles focused on caregiving, over half (52.2%) made no mention of the terms *proche aidant*, *caregiver*, *informal carer* or *carer*, preferring terms like *family*, *famille* and *proches* instead.

- Family involvement is a recognized and widely accepted practice in health care. However, this year's review identified several lingering barriers to the involvement of caregivers in the provision of care and services.[12,45,57]

  - ***Insufficient knowledge and know-how*** *about how to include them along with mistrust of the caregiver's abilities discouraged professionals from more actively involving caregivers.*[1,2,3]
  - *Facing time and resource shortages,* ***professionals felt their priority had to be the service user*** *and noted that their already heavy workload left them with little time for collaborating with caregivers.*
  - *The* ***organizational culture*** *within the healthcare system led to an* ***unequal recognition of the contributions from both professionals and caregivers.***[3,4,8]

    For instance, in an article on the role of caregivers in long-term care facilities in British Columbia, Wu et al. (2024) found that family carers felt devalued, rejected, unheard and unsupported by professionals.[8]

- Taking caregiver choices and preferences into account is a crucial factor in their involvement. These decisions may include care planning (e.g., end-of-life care), choosing medical treatments, organizing home care services, and selecting the living environment or care setting, as well as various aspects of daily life.

- The articles reviewed indicated that **involving caregivers in decisions about care and services not only improved the caregiver's quality of life, but also that of the person they cared for.**[7,40,55]

- The majority of the studies dealt with decision-making in a palliative care context.[9,38,40,41,43,44]

  - ***Health and social services professionals often hesitate to discuss palliative and end-of-life care*** *with service users and their caregivers.*[9,41,43,44] *This reluctance may arise from a fear of exacerbating the family's distress.*[9]
  - *However,* ***caregivers who lack the opportunity to discuss their loved one's condition, prognosis and treatment frequently struggle with the decision-making process****, feeling uncertain about the illness and possibly also unprepared for the loved one's death.*[38,57]

    Conversely, an article on the caregivers of individuals who received medical assistance in dying found that being actively involved in choosing the date and organizing the medically assisted death tended to help with the grieving process.[38]
  - *Caregiver availability (or the lack thereof) is a key factor in the decision to remain at home.*[10,50,58]

    Cherba et al. (2023) questioned the notion of "choice," citing disparities in home care services. For example, individuals without access to caregivers or those unable to afford care services were less likely to want to remain at home. The article also emphasized ***the essential role of family/friend caregivers in the quality of end-of-life care.***[50]

- Numerous articles examined the impact of COVID-19 on decision-making in the context of end-of-life care.[9,10,43,50]

  - *Preferences concerning dying at home, in the ICU or in a palliative care ward remained unchanged from the pre-COVID era. However, after the pandemic, Canadian adults were significantly less apt to want to* ***die in a long-term care facility****.*[10,50]
  - ***COVID-19*** *and the associated infection control measures (e.g., visitor restrictions)* ***were found to have eroded the trust between families and long-term care staff****. Trust between caregivers and professionals is crucial for enabling caregiver participation in decision-making.*[8,43]

Palliative care in Canada: what does public policy say?

One article conducted a critical analysis of the public policy narratives — municipal, provincial, and federal government reports, policies, statements and websites — that surrounded dying at home in Canada.[59] The authors shared certain findings with regard to caregiving:

- In home care, the contribution of family members is seen as inherent and unquestioned due to embedded assumptions that all individuals at the end of life have access to caregiver support.[59]
- Family caregivers and their needs are sometimes “lumped in” and made almost indistinguishable from the dying person. Phrases like “patients/family caregivers” frequently recur in government and policy texts.[59]
- Little acknowledgement is made of potential disagreements in the decision-making processes between family caregivers and the person they care for.[59]
- Caregivers’ needs are often framed in instrumental terms. Ensuring that the carer received support was viewed as essential only insofar as it allowed them to continue providing care.[59]

3.1 Implications for practice

The articles on caregiver involvement also proposed practices and interventions that had the potential to improve the integration of caregivers into the care process:

- Focusing on the **collaboration between the caregiver and the person they supported would promote their inclusion** and let them gain confidence in their decision-making.[5, 6, 9, 38, 43]
- Establishing **standardized, clear and accessible guidelines would help systematize the inclusion** of caregivers in the care plan.[2, 5, 6, 7, 8, 9, 10]
- Developing a **questionnaire** for professionals in different services **aimed at measuring caregiver involvement** would allow managers to set guidelines in areas of need.[1]
- **Improving working conditions and staff-to-user ratios** would afford professionals more time to include caregivers in the care plan.[4]
- Training programs for health care personnel could **operationalize and assess the skills related to caregiver involvement**.[5, 8]
- **The role of each member of the interdisciplinary team should be clarified.**[9]

▸ *For example, Punia et al. (2024) highlighted the direct impact of hierarchical structures in long-term care facilities, noting that nurses’ uncertainty about their authority was a barrier to their engaging with caregivers about end-of-life care.*[9]

4. CAREGIVER QUALITY OF LIFE

The articles in this category assessed caregiver quality of life through such wellness indicators as mental health, stress, social isolation and burden of care. Articles that focused on what caregivers needed to improve their quality of life were also included.

The review identified various factors liable to influence caregiver quality of life.

- The general **lack of psychosocial support** as well as of **services for care recipients** were linked to a deterioration in the mental health of caregivers (e.g., anxiety, stress, depression).[11,12,13,14,15,16,17,18,19,20]
- **Strengthening caregivers' sense of competency** tended to reduce their stress and improve their quality of life.[17,60,61]
- Some articles touched on the **impact of care-related responsibilities on other areas of the caregiver's life**.

> ▸ *For example, a restricted ability to participate in social and leisure activities or spend time on work or studies negatively affected their overall quality of life.*[22,25,62,63]

Caregiver quality of life, in numbers

– An overview of 20 articles

2nd	Caregiver quality of life was the **second most common theme** in the articles reviewed (28.6%).
35 %	Over one-third (35%) of the articles dealt with the **parents of special-needs children**.
1/2	Close to half (45%) of the articles in this category were in the field of psychology.

- In cases of **stigmatized disability**, caregivers tended to isolate themselves and avoid asking for help, a situation that added to their burden and negatively impacted their **mental health**.[21,22,23,24,25]

> ▸ *One article on the caregivers of adults with substance dependencies noted that their levels of distress tended to be higher than among other caregiver groups. This was partially ascribed to the fact that substance use, unlike a physical disability, is perceived as a personal choice, and thus subject to greater judgment.*[24]

4.1 Implications for practice

The articles also considered the practices and interventions that could help improve caregiver quality of life.

- **Psychosocial screening** to determine caregivers' mental health needs would be useful in terms of **guiding them toward the appropriate resources.**[15,19,37,61,64] Psychosocial follow-up should also be available to support families that are more socioeconomically vulnerable.[15]
- **Recognition has certain benefits for caregiver quality of life** in terms of potentially reducing stigma and promoting access to services for both the caregiver and the person they care for.[21,24,36]
- **Professional support plays a key role in caregiver quality of life.**[19,46,61,65] In their interventions with service users, professionals can be proactive by also paying attention to how care-related responsibilities are affecting the user's caregiver(s).[65]
- **Technology can facilitate caregiver access to support services.**[20,36]

  ▸ *One article assessed the effectiveness of a mental health literacy and self-care website intended for the young carers of a parent with a mental health disorder. Designed in conjunction with its target users, the website was shown to have a positive impact, specifically in terms of how its interactivity, user-friendliness and anonymity encouraged users to seek help.*[36]

Flexibility: central to respite innovations

Respite is crucial to caregiver quality of life, since it helps lower the risk of burnout and improve everyday life.[14,20,66]

One article assessed the development and implementation of a web-based "on demand" respite request platform in Guadeloupe, which allowed caregivers to book at-home respite time slots with a professional service.[20]

A key takeaway was the need for greater flexibility:

- Caregivers' use of the platform highlighted the need for respite outside of office hours (e.g., on weekends) as well as for both short- and long-term respite periods. The authors also recommended adding overnight slots.[20]
- The online platform also enabled a certain flexibility: its user-friendliness and ease of navigation made it possible to reach individuals with low digital literacy.[20]

5. CARE AND SERVICE NAVIGATION

Care and service navigation refers to the processes surrounding guidance, coordination, transition, support and advocacy in relation to accessing health and social services resources, typically by caregivers on behalf of the person they care for.

Navigating the health and social services system is perceived as complex by caregivers and hinders their access to services.[12,27,29] These difficulties can be attributed to different factors:

- **Inadequate organization** of health and social services as well as **service discontinuity**.[1,12,29,45,55]
- **Low cross-sectoral collaboration** among professionals.[12]
- **Poor communication** between caregivers and professionals.[67,68]
- **Insufficient information** made available to caregivers.[27,46,49]

> ▸ *For example, Rivard and Mello (2024) found that lack of awareness about autism risked creating additional barriers to seeking services, particularly when the pathways to accessing those services were unclear.*[46]

The articles reviewed also found that navigational complexity served to increase the burden on caregivers.[27,28,29] Indeed, over and above their care-related tasks, caregivers often had to **advocate for the user's rights and their eligibility for care and services.**[11,12,29,30]

If access difficulties and the lack of consistency in the health system negatively impacted care provision to the service user,[15,68,69] the **additional burden** this imposed could also **negatively impact caregiver mental health.**[11,26]

Care and service navigation, in numbers

– An overview of 16 articles

3rd	Care and service navigation was the **third most common** theme in the reviewed articles (22.9%).
+1/2	In more than half of the articles reviewed (56.3%), the disability of the person being cared for was **related to ageing.**
1/2	Half of the articles (50%) used a qualitative methodology (interviews).
81 %/ 63 %	81.3% of the articles in this category focused on navigating the Canadian health care system, with 62.5% specifically in Quebec.

> ▸ *In an article on the services for children with autism, the authors observed that the child's mother tended to interact with service providers more than the father. Indeed, many mothers elected to leave their jobs to focus full-time on navigating the available services. However, the article underscored that, while families with stay-at-home moms may benefit from better quality services, the mother's mental health also deteriorated more rapidly than that of mothers who continued to work.*[26]

Care and service navigation: the international context

While the majority of articles that touched on care and service navigation studied the Quebec or Canadian health system, one article compared access to dementia diagnostic services in four countries (Australia, Canada, Netherlands and Poland).[27]

- More similarities than differences were observed between the countries. **Navigating complex health care systems was perceived as difficult by the caregivers in all four nations**.[27]

Some articles discussed the barriers to care and service navigation:

- **Lack of knowledge** about the health care system and a limited ability to defend the interests of the person needing care (e.g., due to low literacy, financial insecurity, etc.).[12]
- **Navigation was more difficult for caregivers who were immigrants, were from ethnocultural communities or whose mother tongue was other than English or French.** Communications with professionals and the ability to advocate for patient rights were less effective. Language barriers, discrimination and the perception among professionals that the needs of these groups were somehow less legitimate were the primary contributing factors to the difficulty.[26,46]
- Regarding autism, the more the caregivers attempted to diversify the services they sought, the more complicated became the task of navigating between them.[46]
- The care recipient's situation could also complicate navigation.[26,46]

- ▸ *For instance, an article documenting post-diagnostic service pathways for autistic children in Quebec reported that parents experienced greater difficulty navigating care and services when their child was a girl. One explanation for this was that the child's needs were perceived as greater by the parents than by professionals, due to the gendered perception that autism is more prevalent in boys. A further complicating factor in system navigation was that the modes of service delivery for autistic children with low-to-moderate support needs tended to be less clearly defined.*[46]

5.1 Implications for practice

The articles on care and service navigation also proposed actions and interventions for helping improve health system access for both caregivers and those they cared for.

- Creating a **service pathway** to ensure consistency between the different services.[49,68]
- Assigning a **resource person to monitor families through the care continuum**, thereby facilitating care and service coordination throughout health transitions.[11,12,14,45]
- **Making rapid access to diagnostic and support services available** at the start of the care pathway.[15,46]
- **Establishing online clinical services (telehealth, telerehabilitation)** to provide greater flexibility.[56]
- **Centralizing and making accessible information** about care and services.[15,46]

▸ *For example, some authors recommended developing a guide containing key information about service changes to help the parents of children with intellectual disabilities better navigate the transition to adulthood.*[15]

6. THE RELATIONAL EXPERIENCE IN CAREGIVING

The articles grouped under this theme examined the relational aspects to caregiving, particularly how support activities impacted relationships within the dyad and in the family caregiving support system as a whole.

- Relations within the dyad as well as **the nature of the caregiver's role tended to change as the condition of the care recipient evolved.**[35,47,48]

  - *For example, a heavy burden of care could both erode the initial relationship and leave the caregiver with a lost sense of identity when their loved one died.*[47]

- The relationship between the caregiver and the person they care for is not centred solely around physical support. **Providing emotional and relational support are just as integral to the role.**[31,32,33,34,70]

  - *For example, an article on LGBTQ+ individuals with intellectual disabilities in Quebec highlighted the need to affirm the care recipient's sexual and gender identity and raise awareness, particularly among family members, regarding the lived experiences of this population as a means of improving the support they received.*[31]
  - *Kuhlmann et al. (2024) emphasized the importance of emotional support among the caregivers of people with dementia due to the stigma associated with the condition.*[33]

The relational experience in caregiving, in numbers

– An overview of 8 articles

11 %	The relational experience in caregiving was the least common theme in the articles reviewed (11.4%).
7	Seven of the articles were based on qualitative research (interviews); only one used quantitative methods (survey).
63 %	While all of the articles under this theme dealt with caregiving, the majority (62.5%) used no terms like *proche aidant*, *caregiver*, *informal carer*, *carer*, etc.

Caregiver self-identification in a conjugal context

One book chapter presenting accounts from older married caregivers highlighted the central role of the relational experience in their ability or inclination to self-identify as such.[35]

- The subtle and gradual nature of support within a conjugal relationship can make it difficult for the person providing the care to recognize their role as that of a "caregiver" since such support is generally seen as a normal part of marriage.[35]
- Self-recognition happens when individuals begin to feel that they are more than just a spouse, believing that the support they provide daily goes beyond their initial marital duties. This dynamic typically evolves as the illness progresses.[35]
- For some individuals, the burden of care eventually overwhelms the marital relationship. The caregiver role then takes precedence within the couple, overshadowing the role of spouse.[35]
- Lastly, some individuals will never see themselves as caregivers. For many, the term is too evocative of clinical services, failing to capture the subjective experience of being in a partnership — i.e., where support is a symbol of reciprocity and loyalty. For these individuals, the tension between the roles of spouse and caregiver remains irreconcilable.[35]

6.1 Implications for practice

The articles focused on the relational experience also reflected on the practices and interventions that could be implemented.

- Several articles highlighted that, in order to better support caregivers, **a broader view of the relationships *surrounding* the dyad was essential**, as opposed to focusing solely on the carer/care recipient relationship.[31,34,35]

> ▸ *For instance, one article on the parents of children with cancer pointed to a need for professionals to help couples develop strategies for adapting to their changing relationship, the better to strengthen their resilience and confidence as caregivers.*[34]

7. DIRECTIONS FOR FUTURE RESEARCH

Certain needs for future research emerged from this year’s Scientific Watch, as summarized in the two main findings below:

1. **Recruitment strategies needed to be adapted to account for male caregivers**[4,14,29,36,37,38] **and those from ethnocultural communities** in caregiving research.[9,14,34,39]
2. **Greater emphasis should be placed on caregiver perspectives in the scientific studies about them.**[19,29,49,50,51,52,53,54,71] Taking caregivers into account not only stood to improve their quality of life, but also enhance the programs and interventions aimed at them.[29]

Three articles suggested action steps to optimize caregiver participation in research.[51,52,54]

- The caregiver/researcher relationship is key to helping caregivers feel confident during the research process. **The dialogue must be open from the outset to avoid creating an imbalance in power dynamics.**[51,52]
- Planning that ensures flexible terms of participation is crucial. **Participating in research should not add to the caregiving burden nor contribute to caregiver burnout.**[51,54]
- Researchers should use accessible language, **avoiding excessive acronyms, technical jargon or complex terminology**.[51]
- Providing **regular updates and summaries helps clarify the topics being discussed**, fostering trust and encouraging caregivers to speak out during meetings.[51,52]

Appendix 1: Methodology

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

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

Data collection

The Observatory had previously compiled a list of 66 Quebec researchers[g] whose work focused primarily on caregiving.[h] The list is updated annually, with 13 new names added over the past year. Based on this list, a librarian conducted a literature search based on the researchers' first and last names in two databases (Google Scholar and PubMed.

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 researchers.
- Published between October 1, 2023 and December 31, 2024.[i]
- Address the topic of caregiving in the findings, considerations for practice or proposed future research needs.
- Published in a scientific or professional journal.[j]
- Written in English or French.

Publication selection process

Once duplicates were removed, the search yielded 381 publications. An initial screening for relevance (i.e., by reading the titles and abstracts) resulted in a preselection of 154 articles. Each of these was then fully reviewed for compliance with the selection criteria, resulting in a final selection of 70 articles.

Document analysis

To facilitate document analysis, the papers were organized using Zotero. Broad analytical categories were first developed by the Observatory. Next, labels were created and applied to the articles based on their characteristics. Classification was updated with this year's scientific watch.

---

[g] Allard Émilie; Beauchet Olivier; Beaudet Line; Blain-Moraes Stefanie; Bogossian Aline; Bottari Carolina; Bourbonnais Anne; Bravo Gina; Brotman Shari; Carbonneau Hélène; Champaign Manon; Chenard Josée; Courcy Isabelle; Couture Mélanie; Daneau Stéphanie; Demers Louise; des Rivières-Pigeon Catherine; Dubé Véronique; Ducharme Francine Carole; Éthier Sophie; Fortin Gabrielle; Fournier Anne; Gervais Christine; Gascon Hubert; Girard Dominique; Goldfarb Michael; Laquerre Marie-Emmanuelle; Lampert Sylvie; Lach Lucyna; Lefebvre Hélène; Le Dorze Guylaine; Levert Marie-Josée; Lemelin Carmen; 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; Rivard Mélina; Rochette Annie; Rousseau Myriam; Sussman Tamara; Sultan Serge; Thombs Brett; Ummel Deborah; Van Pevenage Isabelle; Vedel Isabelle; Vezina Jean; Viau-Quesnel Charles; Villatte Aude; Jutras Sylvie; Khanassov Vladimir.

[h] 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.

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

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

ARTICLE CLASSIFICATION IN ZOTERO

CATEGORY	LABEL
Field of study	Psychology Public health Nursing sciences Gerontology Pediatrics Medicine Geriatrics Oncology Social work Occupational therapy Sociology Epidemiology Public policy Psychiatry Rehabilitation Physiotherapy Communication Economics Psychoeducation
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

CATEGORY	LABEL
Care setting	Long-term care facility Home Hospital
Caregiver type	Parents of children with an incapacity Partner/spouse Ethnocultural community member Rural inhabitant Children of a parent with an incapacity
Caregiving focus	Secondary subject Main subject Dyad (the caregiver/care recipient relationship)
Use of terms like *personne proche aidante, 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 Belgique 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 of 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.
- Caregiver quality of life.
- Care and service navigation.
- The relational experience in caregiving.

Three articles did not fall into any of the aforementioned themes; rather, they focused solely on caregiver participation in scientific research.[51,52,54] For this reason, they were included in the section on directions for future research.

Certain articles touched on multiple themes; however, in these cases, only their main subject 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 implementation of new knowledge in the work of practitioners).
- Future research needs (gaps identified in the study's methodology, results or conclusions)
- Key themes (topics, fields or main issues addressed).

Limitations

The methodology applied 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 only) used to conduct the literature search. This choice may also have disadvantaged articles published in French, as the databases in question 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, and some researchers may have been omitted.

Lastly, it is important to note that the articles reviewed were published between October 2023 and December 2024. More recent articles may well offer new knowledge or insights that could complement the observations presented in this bulletin.

References

---

[1] **Piché, G., Villatte, A., Fournier-Marceau, M., Clément, M.-È., Morin, M.-H., Maybery, D., Reupert, A., Richard-Devantoy, S., Cyr-Villeneuve, C., & Lemieux, A. (2024).** Psychometric proprieties of the French Version of the Family-Focused Mental Health Practice Questionnaire (FFMHPQ). *European Review of Applied Psychology, 74*(3), 100969. https://doi.org/10.1016/j.erap.2023.100969

---

[2] **Piché, G., Villatte, A., Clément, M.-È., Morin, M.-H., Maybery, D., Reupert, A., Richard-Devantoy, S., & Fournier-Marceau, M. (2024).** Predictors of family-focused practices among mental health workers in Quebec. *Frontiers in Psychiatry, 15*. https://doi.org/10.3389/fpsyt.2024.1380001

---

[3] **Lavoie, P., Arbour, C., Garneau, A. B., Côté, J., Crétaz, M., Denault, A., Gosselin, É., Lapierre, A., Mailhot, T., & Tessier, V. (2024)**. A dimensional analysis of experienced intensive care unit nurses' clinical decision-making for bleeding after cardiac surgery. *Nursing in Critical Care, 29*(5), 1119–1131. https://doi.org/10.1111/nicc.13116

---

[4] **Serrano, D., Sussman, T., Kaasalanien, S., Wickson-Griffiths, A., Thompson, G., Hunter, P. V., MacIntosh, H. B., & Brazil, K. (2024).** A Parallel Process of Staff–Family Distress in Long-Term Care: A Challenge to Collaboration. SAGE *Open Nursing, 10*, 23779608241306404. https://doi.org/10.1177/23779608241306403

---

[5] **Solomon, J., & Goldfarb, M. (2023).** Family engagement in care for medical trainees and early career clinicians. *BMC Medical Education, 23*(1), 811. https://doi.org/10.1186/s12909-023-04792-2

---

[6] **Duong, J., Wang, G., Lean, G., Slobod, D., & Goldfarb, M. (2024).** Family-centered interventions and patient outcomes in the adult intensive care unit: A systematic review of randomized controlled trials. *Journal of Critical Care, 83*, 154829. https://doi.org/10.1016/j.jcrc.2024.154829

---

[7] **Lemay-Compagnat, A., Cetin-Sahin, D., Rojas-Rozo, L., Arsenault-Lapierre, G., Couturier, Y., Bergman, H., Vedel, I., & COVID-ROSA Research Team. (2024).** Formulating recommendations to improve care for persons living with dementia: deliberative dialogues with multiple stakeholders in the province of Quebec, Canada. *BMC Health Services Research, 24*(1), 1461. https://doi.org/10.1186/s12913-024-11565-0

---

[8] **Wu, S. A., Kervin, L., Cooke, H. A., Puurveen, G., Bourbonnais, A., & Baumbusch, J. (2024).** The golden ticket: gaining in-person access to relatives in long-term care homes during the Covid-19 pandemic. *Journal of Long-Term Care, 2024*, 62–76. https://journal.ilpnetwork.org/

---

[9] **Punia, H., Kaasalainen, S., Ploeg, J., Strachan, P., & Sussman, T. (2024).** Exploring the Role of Nurses in Advance Care Planning Within Long-Term Care Homes: A Qualitative Study. *SAGE Open Nursing, 10,* 23779608241249336. https://doi.org/10.1177/23779608241249335

---

[10] **Funk, L. M., Mackenzie, C. S., Rapaport, L.-E., Cherba, M., Cohen, S. R., Krawczyk, M., Rounce, A., & Stajduhar, K. I. (2024).** How the COVID-19 pandemic shaped Canadians' preferences for setting of dying: Comparison of two panel surveys. *Healthcare Management Forum*, 08404704241297037. https://doi.org/10.1177/08404704241297037

---

[11] **Dionne, É., Haggerty, J., Scott, C. M., Doucet, S., Stewart, T., Quesnel-Vallée, A., Montelpare, W., Urquhart, R., Sutherland, J. M., & Couturier, Y. (2023, October 2).** *Toward Comprehensive Care Integration in Canada: Delphi Process Findings from Researchers, Clinicians, Patients and Decision Makers. | EBSCOhost*. https://openurl.ebsco.com/contentitem/doi:10.12927%2Fhcpol.2023.27181?sid=ebsco:plink:crawler&id=ebsco:doi:10.12927%2Fhcpol.2023.27181

---

[12] **Cetin-Sahin, D., Ilali, M., Lemay-Compagnat, A., Arsenault-Lapierre, G., Bolster-Foucault, C., Quesnel-Vallée, A., & Vedel, I. (2024).** A comprehensive experience-based framework of actionable priorities to enhance Canada's health and social care system: discussions with older persons, clinicians, managers, and decision-makers using nominal group technique. *BMC Geriatrics, 24*(1), 976. https://doi.org/10.1186/s12877-024-05561-6

[13] **Yous, M.-L., Coker, E., Hunter, P. V., Fisher, K. A., Sue, J. L., Nicula, M., Kazmie, N., Orsini, T., Sussman, T., Thompson, G., & Kaasalainen, S. (2024).** Acceptability and preliminary effects of the volunteer-supported Meaningful Moments program to engage older adults with advanced dementia on a hospital-based specialized dementia care unit: a mixed methods study. *BMC Geriatrics, 24*(1), 593. https://doi.org/10.1186/s12877-024-05194-9

[14] **Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2024).** Action priorities to facilitate planning of the transition to adulthood of young people with profound intellectual disability. *International Journal of Developmental Disabilities, 0*(0), 1–14. https://doi.org/10.1080/20473869.2024.2327777

[15] **Heslon, K., Hanson, J. H., & Ogourtsova, T. (2024).** Mental health in children with disabilities and their families: red flags, services' impact, facilitators, barriers, and proposed solutions. *Frontiers in Rehabilitation Sciences, 5*. https://doi.org/10.3389/fresc.2024.1347412

[16] **Bouthillier, M.-E., Farmer, Y., Ramirez, C. C., Downar, J., Frolic, A., Dahine, J., Opatrny, L., Poirier, D., Bravo, G., L'Espérance, A., Payot, A., Tanuseputro, P., Rousseau, L.-M., Dumez, V., Descôteaux, A., Dallaire, C., Laporte, K., & Gaucher, N. O. (2024).** Public perspectives on COVID-19 triage protocols for access to critical care in extreme pandemic context. *PLOS ONE, 19*(12), e0314460. https://doi.org/10.1371/journal.pone.0314460

[17] **Chertkow, H., Phillips, N., Rockwood, K., Anderson, N., Andrew, M. K., Bartha, R., Beaudoin, C., Bélanger, N., Bellec, P., Belleville, S., Bergman, H., Best, S., Bethell, J., Bherer, L., Black, S., Borrie, M., Camicioli, R., Carrier, J., Cashman, N., … Wittich, W. (2024).** Impact of a national dementia research consortium: The Canadian Consortium on Neurodegeneration in Aging (CCNA). *Journal of Alzheimer's Disease, 102*(3), 535–561. https://doi.org/10.1177/13872877241290990

[18] **Mestari, Z., Rivard, M., & Mello, C. (2024).** Learning from educators: Implementation of a positive behavior support program targeting challenging behavior in children with autism. *Evaluation and Program Planning, 107*, 102491. https://doi.org/10.1016/j.evalprogplan.2024.102491

[19] **Rivard, M., Tremblay, J., Mestari, Z., Desjardins, L., Bergeron, É., & Lefebvre, C. (2024).** Survey of families' psychosocial needs in the context of pediatric cancer: a first step toward the participatory development of a group intervention. *Journal of Psychosocial Oncology*, 1–17. https://doi.org/10.1080/07347332.2024.2404570

[20] **Viens, M., Sabin, J., & Provencher, V. (2024).** ANAAÏS : répit sur demande pour les proches aidants d'aînés en Guadeloupe. *Gérontologie et société*, Ia-XVIII. https://shs.cairn.info/revue-gerontologie-et-societe-2025-0-page-Ia

[21] **Couture, M., Gauthier-Mongeon, J., Simamonika, P., Bernard, R., St-Martin, K., Lacasse, R., & Israel, S. (2024).** Practices Used in Health and Social Services for the Management of Mistreatment Situations towards Adults in a Context of Gender and Sexual Diversity: A Scoping Review. *OBM Geriatrics, 8(3)*, 1–23. https://doi.org/10.21926/obm.geriatr.2403282

[22] **Piché, G., Davidson, G., Dunkley-Smith, A., Grant, A., Yates, S., & Maybery, D. (2024).** Exploring past research to move forward: a scoping review of aims, outcomes, and recommendations in parental mental illness qualitative research. *Frontiers in Public Health, 12*. https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2024.1427432

[23] **Banaru, D., Boyd, D., Halevy, M., Oliver, A., Orsat-Parker, K., Brien, M., Krishna, D., Coutinho, F., & Ogourtsova, T. (2024).** Social capital of families of children with neurodevelopmental disabilities in South India. *Developmental Medicine & Child Neurology, n/a*(n/a). https://doi.org/10.1111/dmcn.15949

[24] **Côté, M., Morency, E.-E., Roussel, N., Ferland, F., Tremblay, J., & Blanchette-Martin, N. (2024).** What Do We Know About Informal Caregiving in the Field of Addiction?: A Scoping Review. *International Journal of Mental Health and Addiction*. https://doi.org/10.1007/s11469-024-01301-4

---

[25] **Bani Odeh, K., & Lach, L. M. (2024).** Barriers to, and facilitators of, education for children with disabilities worldwide: a descriptive review. *Frontiers in Public Health, 11*. https://doi.org/10.3389/fpubh.2023.1294849

[26] **Rivard, M., Chatenoud, C., (Caya) Chiu, C.-Y., Aldersey, H., Coulombe, P., Morin, M., Mello, C., & Magnan, C. (2024).** From Early Behavioral Intervention to School: A Systematic Evaluation of Parents' Perspectives on the Quality of the Autism Services During the Transition to Kindergarten. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-024-06594-x

[27] **Hevink, M., Linden, I., de Vugt, M., Brodaty, H., Low, L.-F., Phillipson, L., Jeon, Y.-H., Gresham, M., Doucet, S., Luke, A., Vedel, I., McAiney, C., Szcześniak, D., Błaszkiewicz, M., Rymaszewska, J., Verhey, F., & Wolfs, C. (2024).** Moving forward with dementia: an explorative cross-country qualitative study into post-diagnostic experiences. *Aging & Mental Health, 0*(0), 1–10. https://doi.org/10.1080/13607863.2024.2342968

[28] **Champagne, E., Chénard, J., Simard, C., Bonanno, M., Bogossian, A., Roberge, V., Olivier-d'Avignon, M., Ummel, D., Fortin, G., Bergeron, F., & Bonenfant, F. (2024).** Scoping Review on Transitions in the Context of Pediatric Palliative Care. *Journal of Palliative Medicine*. https://doi.org/10.1089/jpm.2023.0673

[29] **Lucchese, S., Yous, M.-L., Kruizinga, J., Vellani, S., Rivas, V. M., Tétrault, B., Holliday, P., Geoghegan, C., Just, D., Sussman, T., Ganann, R., & Kaasalainen, S. (2024).** Motivations of family advisors in engaging in research to improve a palliative approach to care for persons living with dementia: an interpretive descriptive study. *Research Involvement and Engagement, 10*(1), 94. https://doi.org/10.1186/s40900-024-00623-w

[30] **Dufour, I., Margo-Dermer, E., Hudon, C., Sirois, C., Godard-Sebillotte, C., Sourial, N., Rochette, L., Quesnel-Vallée, A., & Vedel, I. (2024).** Profiles of healthcare use of persons living with dementia: A population-based cohort study. *Geriatrics & Gerontology International, 24*(8), 789–796. https://doi.org/10.1111/ggi.14930

[31] **Milot, É., Otis, A.-S., Lavoie, K., Caouette, M., & Marthouret, B. (2024).** Navigating Unique Intersectional Experiences: LGBTQ+ Community Organisations Addressing Individuals With Intellectual Disabilities' Needs. *Journal of Applied Research in Intellectual Disabilities, 37*(6), e13308. https://doi.org/10.1111/jar.13308

[32] **Lessard, S., Oyinlola, O., & Sussman, T. (2024).** Tragedy and value of life of older persons in long-term care homes during COVID-19: a critical discourse analysis. *Ageing & Society*, 1–18. https://doi.org/10.1017/S0144686X24000217

[33] **Kuhlmann, N., Thomas, A., Incio-Serra, N., & Blain-Moraes, S. (2024).** Piece of Mind: knowledge translation performances for public engagement on Parkinson's disease and dementia. *Frontiers in Psychology, 15*. https://doi.org/10.3389/fpsyg.2024.1439362

[34] **Laplante, S., Beaulieu, N., Sultan, S., & Péloquin, K. (2024).** The Role of Attachment in Parents' Perception of the Impact of Pediatric Cancer on Their Relationship. *Science of Nursing and Health Practices / Science Infirmière et Pratiques En Santé,* 7(1), 34–50. https://doi.org/10.7202/1112375ar

[35] **Pevenage, I. V., Dupont, D., Dauphinais, C., & Bourgeois-Guérin, V. (2024).** À LA CROISÉE DES IDENTITÉS. Proche aidance et conjugalité aux âges avancés. In *Sexualités et conjugalités en contexte de vieillissement : Perspectives sociales et critiques*. Presses de l'Université du Québec. https://www.degruyter.com/document/doi/10.1515/9782760559981/html

[36] **Villatte, A., Piché, G., Habib, R., & Gariépy, J. (2023).** Evaluation of a mental-health literacy and self-care website intended for young people who have a parent with a mental illness. *Advances in Mental Health, 0*(0), 1–20. https://doi.org/10.1080/18387357.2023.2264416

[37] **Levesque, A., Ogez, D., Gravel, V., Marcil, V., Curnier, D., Rondeau, É., Sinnett, D., Péloquin, K., & Sultan, S. (2024).** Feasibility Study of Taking Back Control Together, an Intervention to Support Parents of Children with Cancer. *Journal of Clinical Psychology in Medical Settings, 31*(2), 444–454. https://doi.org/10.1007/s10880-023-09998-6

[38] **Crnich-Côté, T., Allard, É., & Marcoux, I. (2023).** Deuil et aide médicale à mourir : exploration narrative de l'expérience d'enfants d'âge adulte. *Frontières, 34*(1). https://doi.org/10.7202/1107627ar

[39] **Hallot, S., Debay, V., Foster, N., Burns, K. E. A., & Goldfarb, M. (2024).** Development and initial validation of a family activation measure for acute care. *PLOS ONE, 19*(1), e0286844. https://doi.org/10.1371/journal.pone.0286844

---

[40] **Robichaud, L.-A., Olivier-D'Avignon, M., Felipe, J., Ehrenfeld, H. F. T., Marquis, M.-A., Michon, B., Rondeau, É., Tyo-Gomez, M., Duval, M., & Sultan, S. (2024).** Processus pour le développement d'une stratégie d'évaluation de la qualité de vie en cancer avancé pédiatrique. *Psycho-Oncologie, 18*(2), 127–135. https://doi.org/10.32604/po.2024.046496

[41] **Allard, E., Dumaine, S., Sasseville, M., Gabet, M., & Duhoux, A. (2024).** Quality of palliative and end-of-life care: a qualitative study of experts' recommendations to improve indicators in Quebec (Canada). *BMC Palliative Care, 23*(1), 146. https://doi.org/10.1186/s12904-024-01474-8

[42] **Girard-Marcil, C. et Reiss, M. (2024).** Bulletin de veille scientifique. La proche aidance réfléchie par les chercheur·euse·s québécois·e·s. Juillet 2022 à septembre 2023. Observatoire québécois de la proche aidance, Direction des affaires académiques et de l'éthique de la recherche, CIUSSS du Centre-Ouest-de-l'Île-de-Montréal.

[43] **Brazil, K., Walshe, C., Doherty, J., Harding, A. J. E., Preston, N., Bavelaar, L., Cornally, N., Di Giulio, P., Gonella, S., Hartigan, I., Henderson, C., Kaasalainen, S., Loucka, M., Sussman, T., Vlckova, K., van der Steen, J. T., & mySupport Study Group. (2024).** Implementation of an Advance Care Planning Intervention in Nursing Homes: An International Multiple Case Study. *The Gerontologist, 64*(6), gnae007. https://doi.org/10.1093/geront/gnae007

[44] **Asmaou Bouba, D., Gomes Souza, L., Dofara, S. G., Guay-Bélanger, S., Gadio, S., Mochcovitch, D., Paquette, J.-S., Izumi, S. (Seiko), Archambault, P., Totten, A. M., Rivest, L.-P., & Légaré, F. (2024).** Long-Term Effects of Individual-Focused and Team-Based Training on Health Professionals' Intention to Have Serious Illness Conversations: A Cluster Randomised Trial. *Journal of CME, 13*(1), 2420475. https://doi.org/10.1080/28338073.2024.2420475

[45] **Marier, P., Joy, M., Smele, S., Zakaria, R., Beauchamp, J., Bourgeois-Guérin, V., Lupien, P.-L., & Sussman, T. (2024).** Older Adults in Administrative Quagmire: A Scoping Review of Policy and Program Coordination Across 6 Marginalized Older Adult Populations. *The Gerontologist*, gnae120. https://doi.org/10.1093/geront/gnae120

[46] **Rivard, M., Mello, C., Patel, S., Morin, M., & Morin, D. (2024).** A Window into the Use of Post-diagnostic Services for Autism and Parents' Perspective on the Quality of Early Childhood Services Trajectory in a Canadian Province. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-024-06265-x

[47] **Millette, V., & Bourgeois-Guérin, V. (2024).** « J'AI PAS 100 ANS ! » REFAIRE SA VIE APRÈS LE DÉCÈS D'UNE PARTENAIRE DE MÊME SEXE ? L'expérience de femmes de plus de 65 ans. In *Sexualités et conjugalités en contexte de vieillissement : Perspectives sociales et critiques*. Presses de l'Université du Québec. https://www.degruyter.com/document/doi/10.1515/9782760559981/html

[48] **Padley, N., Moubayed, D., Lanteigne, A., Ouimet, F., Clermont, M.-J., Fournier, A., & Racine, E. (2023).** Transition from Paediatric to adult health services: Aspirations and practices of human flourishing. *International Journal of Qualitative Studies on Health and Well-Being, 18*(1), 2278904. https://doi.org/10.1080/17482631.2023.2278904

[49] **Arsenault-Lapierre, G., Rodriguez Duarte, M. A., Rojas-Rozo, L., Jeon, Y.-H., Hevink, M., Ciułkowicz, M., Szczesniak, D., Rait, G., Robinson, L., Wilcock, J., Poole, M., McAiney, C., Doucet, S., Luke, A., Reid, A. E., & Vedel, I. (2024).** Exploring perceived helpfulness of health services in men and women with dementia and care partners: A cross-sectional analysis. *Dementia*, 14713012241289472. https://doi.org/10.1177/14713012241289471

[50] **Cherba, M., Funk, L., Scott, E., Salman, B., Rounce, A., Mackenzie, C., Stajduhar, K., Dujela, C., Krawczyk, M., & Cohen, S. R. (2023).** How initial policy responses to COVID-19 contributed to shaping dying at home preferences and care provision: key informant perspectives from Canada. BMC *Health Services Research, 23*(1), 1330. https://doi.org/10.1186/s12913-023-10340-x

[51] **Rojas-Rozo, L., Arsenault-Lapierre, G., Dumaresq, D., Trépanier, T., Lea, P., Myers Barnett, K., O'Connor, D., Fernandez Loughlin, R., Miskucza, K., Wighton, M. B., Godard-Sebillotte, C., Gruneir, A., Beuscart, J.-B., Bronskill, S. E., Sourial, N., Smith, E. E., Bethell, J., Vedel, I., The COVID ROSA Research Team, … Wilchesky, M. (2024).** Unlocking Engagement: Enhancing Participation in Research With Vulnerable Populations. *International Journal of Public Health, 69*, 1606705. https://doi.org/10.3389/ijph.2024.1606705

---

[52] **Vlckova, K., Gonella, S., Bavelaar, L., Mitchell, G., & Sussman, T. (n.d.).** Methodological and ethical challenges in designing and conducting research at the end of life: A systematic review of qualitative and textual evidence. *International Journal of Nursing Practice, n/a*(n/a), e13224. https://doi.org/10.1111/ijn.13224

[53] **A., Quesnel-Vallee, A., & Vedel, I. (2024).** Care trajectories around a first dementia diagnosis in patients with serious mental illness. *Geriatrics & Gerontology International, 24*(6), 577–586. https://doi.org/10.1111/ggi.14889

[54] **Vellani, S., Yous, M.-L., Rivas, V. M., Lucchese, S., Kruizinga, J., Sussman, T., Abelson, J., Akhtar-Danesh, N., Bravo, G., Brazil, K., Ganann, R., & Kaasalainen, S. (2024).** Patient and public involvement in international research: Perspectives of a team of researchers from six countries on collaborating with people with lived experiences of dementia and end-of-life. *Health Expectations, 27*(1), e13942. https://doi.org/10.1111/hex.13942

[55] **Rivard, M., Jacques, C., Hérault, É., Mello, C., Abouzeid, N., Saulnier, G., & Boulé, M. (2024).** An innovative and collaborative method to develop a model care and service trajectory for the assessment, diagnosis, and support of children with developmental disabilities. *Evaluation and Program Planning*, 104, 102431. https://doi.org/10.1016/j.evalprogplan.2024.102431

[56] **Rivard, M., Grenier-Martin, J., Mello, C., Sanchez, C., Morin, D., Forget, J., Lefebvre, C., Mestari, Z., & Duchaine, J. (2024).** Implementing a Positive Behavior Support Program for Young Children with Autism in Public Agencies: A Social Validity Evaluation from Parents, Practitioners, and Administrators. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-024-06590-1

[57] **Simmons-Mackie, N., Kagan, A., Chan, M., Shumway, E., & Le Dorze, G. (2024).** Aphasia and acute care: a qualitative study of healthcare provider perspectives. *Aphasiology, 0*(0), 1–18. https://doi.org/10.1080/02687038.2024.2392900

[58] **Bolster-Foucault, C., Vedel, I., Busa, G., Hacker, G., Sourial, N., & Quesnel-Vallée, A. (2024).** Social inequity in ageing in place among older adults in Organisation for Economic Cooperation and Development countries: a mixed studies systematic review. *Age and Ageing, 53*(8), afae166. https://doi.org/10.1093/ageing/afae166

[59] **Scott, E., Funk, L., Cherba, M., Krawczyk, M., Rounce, A., Stajduhar, K., & Robin Cohen, S. (2023).** Naturalizing dying at home for older adults: A critical analysis of policy texts. *Canadian Public Administration, 66*(4), 533–555. https://doi.org/10.1111/capa.12546

[60] **Zukerman, N., Bottone, E., Low, M., & Ogourtsova, T. (2024).** Resilience and adolescence-transition in youth with developmental disabilities and their families: a scoping review. *Frontiers in Rehabilitation Sciences, 5*. https://doi.org/10.3389/fresc.2024.1341740

[61] **Mestari, Z., Rivard, M., & Mello, C. (2024).** Learning From Parents: Implementation of a Parent-Mediated Positive Behavior Support Program Targeting Challenging Behavior in Children With Autism. *Families in Society*, 10443894241227620. https://doi.org/10.1177/10443894241227619

[62] **Boucher, V., Jouhair, E.-M., Sirois, M.-J., Tailleur, L., Voyer, P., Mercier, É., Giguère, A., Dionne, C. E., Légaré, F., Dallaire, C., Bergeron, S., Carmichael, P.-H., & Emond, M. (2024).** The mobile seniors' clinic — an innovative transition of care for frail older adults. *BMC Geriatrics, 24*, 914. https://doi.org/10.1186/s12877-024-05490-4

[63] **Greenberg, P., O'Callaghan, L., Fournier, A.-A., Gagnon-Sanschagrin, P., Maitland, J., & Chitnis, A. (2024).** Impact of living with an adult with depressive symptoms among households in the United States. *Journal of Affective Disorders, 349*, 107–115. https://doi.org/10.1016/j.jad.2023.12.040

[64] **Arsenault-Lapierre, G., Bui, T., Godard-Sebillotte, C., Kang, N., Sourial, N., Rochette, L., Massamba, V., Quesnel-Vallée, A., & Vedel, I. (2024).** Sex Differences in Healthcare Utilization in Persons Living with Dementia Between 2000 and 2017: A Population-Based Study in Quebec, Canada. *Journal of Aging and Health*, 08982643241242512. https://doi.org/10.1177/08982643241242512

[65] **Maybery, D., Grant, A., Piché, G., Yates, S., Ruud, T., Dunkley-Smith, A., & Davidson, G. (2024).** Summarising Quantitative Outcomes in Parental Mental Illness Research. *International Journal of Mental Health Nursing, n/a*(n/a). https://doi.org/10.1111/inm.13385

---

[66] **Arsenault-Lapierre, G., Godard-Sebillotte, C., Bui, T., Sourial, N., Rochette, L., Massamba, V., Sirois, C., Kosteniuk, J., Morgan, D., Quesnel-Vallée, A., & Vedel, I. (2024).** Rural–Urban Differences in Healthcare Use in Persons With Dementia Between 2000 and 2019: A Quebec Population-Based Study. *Healthcare Policy, 19*(3), 78–95. https://doi.org/10.12927/hcpol.2024.27281

---

[67] **Couture, V., Germain, N., Côté, É., Lavoie, L., Robitaille, J., Morin, M., Chouinard, J., Couturier, Y., Légaré, F., Hardy, M.-S., Chartier, L. B., Brousseau, A.-A., Sourial, N., Mercier, É., Dallaire, C., Fleet, R., Leblanc, A., Melady, D., Roy, D., … on behalf of the Network of Canadian Emergency Researchers. (2024).** Transitions of care for older adults discharged home from the emergency department: an inductive thematic content analysis of patient comments. *BMC Geriatrics, 24*(1), 8. https://doi.org/10.1186/s12877-023-04482-0

---

[68] **Attieh, S., Kilpatrick, K., Chênevert, D., Pomey, M.-P., & Loiselle, C. G. (2024).** Measuring Team Functioning During the COVID-19 Pandemic: Perspectives of Cancer Care Team Members. *Journal of Multidisciplinary Healthcare, 17*, 2623–2633. https://doi.org/10.2147/JMDH.S448985

---

[69] **Solomon, J., Gabbay, D., & Goldfarb, M. (2024).** Virtual Patient and Family Engagement Strategies in Critical Care: A Scoping Review. *Telemedicine and E-Health, 30*(8), e2203–e2213. https://doi.org/10.1089/tmj.2024.0090

---

[70] **Azevedo, N., Le Dorze, G., Jarema, G., Alary Gauvreau, C., Ogourtsova, T., Beaulieu, S., Beaujard, C., Yvon, M., & Kehayia, E. (2023).** Understanding the experience of users of communication aids and applications through focus group discussions with people with aphasia and family members. *Frontiers in Communication, 8*. https://doi.org/10.3389/fcomm.2023.1219331

---

[71] **Hendryckx, C., Couture, M., Gosselin, N., Nalder, E., Gagnon-Roy, M., Thibault, G., & Bottari, C. (2024).** A window into the reality of families living long term with challenging behaviours after a TBI. *Neuropsychological Rehabilitation*. https://www.tandfonline.com/doi/abs/10.1080/09602011.2024.2354402

Observatoire
québécois de la
proche aidance

The mandate for the Observatory’s development, coordination and administrative support has been entrusted to the Integrated Health and Social Services University Network for West-Central Montreal (CIUSSS West-Central Montreal).

info@observatoireprocheaidance.ca