SCIENTIFIC WATCH BULLETIN

Caregiving as considered by Quebec researchers

JULY 2022 TO SEPTEMBER 2023

Observatoire
québécois de la
proche aidance

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1. INTRODUCTION

This document provides an analytical overview of the articles on caregiving or caregivers published by Quebec researchers between July 2022 and September 2023.

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

Analysis of the articles identified three main themes[a]:

Caregivers' experience of care and services

Caregivers' quality of life

Caregivers' relational experience

For each of these themes, the main research findings and implications for practice are discussed in the following sections. The conclusion focuses on the need for future research as identified in the articles reviewed.

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[a] It's possible for an article to address more than one theme. In this case, only the main theme is used.

En partenariat avec :
Québec

Credits

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2. SCIENTIFIC MONITORING HIGHLIGHTS

An overview of the articles

(N=60)

97 %

96.7% of articles are in **English** (58) and two are in French (2).

+1/2

More than half the articles describe studies based on a **qualitative methodology** (55%).

+1/3

In more than a third of the articles, the caregivers were **parents** of children who has one or more incapacities (36.7%).

37 % / 33 %

The incapacities most frequently discussed in the articles are **neurodevelopmental disorders**[b] (36.7%) and **aging**[c] (33.3%).

72 %

In the majority of articles, the study took place in **Canada** (71.7%).

1/2

One-half of the articles dealt with caregivers as a whole, **without singling out any particular group** of caregivers (50%).

1/3

Although all the articles deal with caregivers, a third of them do not contain one of the following terms: “*proches aidants*”, “caregiver”, “informal carer”, “carer”, etc. (30%).

Psychology (19), **medicine** (15), and **nursing** (13) are the disciplines in which the articles in this report most frequently appear[d].

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

[c] This category includes neurological disorders related to aging (e.g., Alzheimer’s, dementia, etc.), as well as incapacities related to aging in general.

[d] The identification of the different areas of research is based on the authors’ respective affiliations. Several academic fields may be associated with an article.

Key findings

- The experience of care and services is the most recurrent theme (56.6%), followed by quality of life (31.7%) and the relational experience of caregivers (6.7%).
- Caregiver’s experience of care and services:
  - *Promoting access to quality advice from peers*[1,2,3,4,5,6] *and providing access to a resource individual who supports caregivers in coordinating care and services are two proposed practices to help caregivers navigate care and services*[3,4,7,8].
  - *Collaborative approaches between the caregiver and the person being cared for increase the caregiver’s confidence in making decisions related to care and service planning. This same collaborative approach must also be deployed between professionals and caregivers*[9,10,11,12].
- Quality of life:
  - *The lack of adequate psychosocial services and support for caregivers is associated with a deterioration in their mental health (e.g., anxiety, stress, depression, etc.)*[13,14].
  - *Caregivers have support needs that differ from those of the person being cared for*[15,16,17,18].
- Relational experience of caregivers:
  - *The start of a caregiving journey is accompanied by a redefinition of the relationship dynamic between the caregiver and the care receiver*[19,20,21,22].
  - *Interpersonal difficulties between the caregiver and the care receiver for may arise from a misunderstanding of the reality experienced by one of the members of the dyad*[19,20,21].
- Implications for future research:
  - *Several authors argue that future research should bring together a more diverse sample of caregivers and put more emphasis on their perspective*[12,13,14,18,23,24].
  - *The analytical data-gathering tools used to capture the experiences of caregivers are often the same as those used for the care receiver. As a result, they do not reflect their specific reality*[13,15,22].

3. CAREGIVERS' EXPERIENCE OF CARE AND SERVICES

The majority of articles reviewed focus on caregivers' experience of care and services (56.7%). The articles grouped under this topic address the interaction of caregivers with the care and service network and system, most of which are Canadian. These articles highlight the perspectives of caregivers, professionals, and care receivers.

Two sub-themes have been identified in the caregivers' experience of care and services:

- **Navigating care and services**
- **Decision-making**

Care and service experience (n=34)

An overview of the articles

57 %

The majority of articles monitored focus on the **care and service experience** of caregivers (56.7%).

47 %

Almost half (47.1%) of the articles on this topic focus on the **dyad between the caregiver and the care receiver**.

2/3

Two-thirds of the articles focus on age-related incapacities (32.4%) or on neurodevelopmental disorders (29.4%).

85 %

For the majority of articles, the research took place in **Canada** (85.3%).

59 % / 41 %

58.8% of articles used a **qualitative** methodology (interviews) and 41.2% adopted a **quantitative** methodology (surveys).

32 % / 26 %

Articles from our study that are most frequently related to this theme are found in the fields of **nursing** (32.4%) and **medicine** (26.4%).

Navigation of care and services in numbers (n=18)

An overview of the articles

1/2 | In half the articles (50%), the caregivers were **parents** of children, and in 66.7% of these articles, the child's incapacity was a neurodevelopmental disorder.

72 % | 72.2% of the articles employed a **qualitative** methodology (interviews).

89 % | 88.8% of the articles that fall under this theme focus on the navigation of caregivers within the **Canadian care and services network**, with 56.3% focusing on the Quebec network in particular.

3.1 Navigating care and services

A caregiver's navigation of care and services refers to the process of guiding, coordinating, supporting, and advocating for the health and social services network's resources, usually for the care receiver.

The articles reviewed identified several **obstacles** and **facilitators** affecting access to care and services.

Obstacles

- Two articles note that because of the characteristics of the care receiver or of their caregivers, some people are simply **not eligible** for certain care or services[3,7].

> ▸ *For example, in the Rivard et al. article, the authors note that caretakers have to turn to private network services when a child has a non-severe neurodevelopmental disorder because the public network prioritizes children with more severe neurodevelopmental disorders[7].*

- **The lack of information continuity between professionals** has also been identified as an obstacle in accessing care and services for caretakers[25,26].

> ▸ *For example, in the case of parents of children with autism, parent caregivers are obliged to play an active role in transmitting information and coordinating the various interventions and services received by their family once a diagnosis has been made[27].*

- **Certain types of caregivers, such as those of immigrants or that are immigrants themselves**, find it more difficult to navigate the care and service environment[28,29]. A lack of knowledge about the system[29], a lack of interpretation services[29] and experienced discrimination[28] are some of the obstacles mentioned.

> ▸ *Furthermore, two articles report a false belief that in immigrant families, people are systematically supported by their families and therefore require fewer services or professional care. The members of an immigrant family may be living outside the country or in precarious economic circumstances that prevent them from taking on caregiving responsibilities, even though cultural norms may encourage the family to participate in care and support[28,29].*

- Finally, two studies show that the restrictive health measures and various lockdowns put in place between 2020 and 2021 in response to **the COVID-19 pandemic** have created **additional difficulties** for caregivers in **accessing care and services**[30,31]. The demand for the support and care that caregivers provide to the people they help has increased over this period.

> ▸ *In addition, the closure of most respite services and health restrictions limiting access to informal support networks (friends, family, colleagues, etc.) have increased their responsibilities[30].*
>
> ▸ *In addition, one article states that the various restrictions in long-term care settings have contributed to a breakdown in the trust that caregivers have in these institutions. This mistrust still has repercussions today[31].*

Facilitators

- **Access to quality advice from peers** is a frequently mentioned facilitator for improving the navigation of care and services[1,2,3,4,5,6].

> ▸ *Information sharing between caregivers (support groups, helplines, informal networks, etc.) enables the exchange of key information about the process of accessing care and services, as well as the development of skills for asserting their rights and those of the person they are caring for[1,2,5,6].*

- Finally, a **dynamic partnership between the caregiver, the care receiver, and the professionals** facilitates access to care and services[32,33,34].

> ▸ *Good communication improves the care pathway for caregivers, especially when the health of the care receiver deteriorates or when there is a change in the type of care provided or in the care and service environment[4].*

Practical implications

The articles on care and service navigation also look at practices and interventions that have the potential to improve access to the care and service system for caregivers and their person cared for.

- Four articles suggest the use of a resource person whose role would be to follow families throughout their journey to facilitate smooth transitions and coordination between services or care[3,4,7,8].
- In a similar light, two articles consider that rapid access to diagnostic and support services at the start of the care and service journey would improve the navigation process for caregivers[1,7].
- Three articles propose the creation of culturally appropriate and safe care and service environments for immigrant caregivers[1,28,29].

> ▸ *In an article by Boulé and Rivard (2023) on immigrant caregivers of children with autism spectrum disorders, the authors argue that professionals have a role to play in maintaining a relationship of trust between caregivers and the care and service system. Professionals must take a sympathetic interest in their culture, their specific challenges, and their immigration history[1].*

3.2 Decision-making

Decision-making is the second sub-theme identified in the articles on caregivers' experience of care and services. It refers to the process by which caregivers make decisions about the care and services to be provided to the person they support. This includes care planning (e.g. end-of-life care), the choice of medical treatments, the organization of domestic help services, the choice of residential or care and service environment, and other aspects of daily life.

- The results of the articles show that some caregivers are **reluctant to make decisions** about the end-of-life care and services to be provided[9,35,36].

> ▸ *This reluctance may be the result of a belief (whether founded or not) that the individual does not have the skills required to support the care receiver within the home environment[36].*
>
> ▸ *Sometimes, the fact that the caregivers do not have a well-developed support network is a factor that drives them to prefer that the care receiver reside in a long-term care environment[36].*

Decision-making (n=16)

An overview of the articles

1/2 | In half of the articles (8), the incapacity of the care receiver is linked to **aging**.

38 % | 37.5% of articles deal with decision-making in **palliative care**.

- Caregivers may also be **reluctant to discuss end-of-life care planning** with their person cared for[11].

> ▸ *In the article by Vellani, S., et al (2022), the authors observe that caregivers are reluctant to openly discuss end-of-life care because they want to avoid subjecting their care receiver to adverse emotions[11].*

- **Among professionals** in long-term care facilities, **discussions** regarding palliative care are **relatively rare**[10].

> ▸ *For caregivers, not being able to discuss end-of-life decisions openly with professionals leads to stress, guilt, and questioning of decisions taken[10].*
>
> ▸ *Consideration of the caregiver's preferred option, the involvement of other family members in the decision-making process, and a lower burden of care are factors associated with greater support for the decision taken[37,38].*

Medical assistance in dying

- Bravo et al (2022) looked at **caregivers' perceptions of medical aid in dying**[39].

> ▸ *The authors report that the vast majority of caregivers are in favor of medical aid in dying[39].*
>
> ▸ *There is no evidence that the burden and the unmet support needs of caregivers influence their attitude toward early requests for medical assistance in dying[39].*

- Stacey et al (2023) report that one of the most common decisions made by Canadians during the **first year of the pandemic** was to **move** a family member **into** or **out** of long-term care[38].

> ▸ *During this period, the difficulty of talking to professionals was exacerbated by health restrictions. As a result, most caregivers had to make their decisions alone, leading to stress and regret when it came to decision-making[38].*

Practical implications

The articles on decision-making also look at practices and interventions that can help caregivers in their decision-making process.

- In planning care and services, approaches based on the collaboration between the caregiver and the care receiver are ways of giving caregivers confidence in their decision-making[8,9,10,11].

> ▸ *This collaborative approach must also be deployed between caregivers and professionals*[40,41,42].
>
> > ▹ *Professionals must be in constant dialogue with the caregiver and the care receiver[43] and not assume that all people wish to receive care or services in the same way[9,44].*

- Some articles agree that decisions about care or services should take into account the needs of caregivers[9,37,38].

> ▸ *To ensure informed and sustainable decision-making, the support needs of caregivers must be met, particularly with regard to in-home care[9].*

- In conclusion, the wider public needs to be made fully aware of the options available for palliative care, in order to help caregivers make the right decisions[44].

> ▸ *Funk et al (2023) argue that journalists, professionals, and stakeholders must play their part in sharing information[45].*

4. CAREGIVERS' QUALITY OF LIFE

The articles included under this theme assess the quality of life of caregivers using indicators related to the well-being of this group (e.g. mental health, stress, social isolation, burden). Articles looking at the needs of caregivers in order to improve their quality of life are also included.

The articles in this review have identified factors that can influence caregivers' quality of life.

- Two articles have identified the **degree of autonomy of the care receiver** as an important factor in the quality of life of caregivers[17,46]. The autonomy referred to in the articles can be as much about carrying out daily tasks as it is about social relations.

> ▸ *For example, in Patel et al (2022), the authors note that the higher the level of social autonomy of a child with an autism spectrum disorder, the lower the level of parental stress[17].*

- Increasing **caregivers' sense of competency** reduces their stress and improves their quality of life[47,48].

> ▸ *Training to improve the skills of caregivers in caring for their loved ones is an effective way of reducing their stress[47].*
>
> ▸ *However, this training does not replace a specialized support service[47].*

- Feeling a lack of control over a caregiving situation increases the risk of emotional distress and adversely affects caregivers' quality of life[14,49]. Lack of control among caregivers can manifest itself as not having control over the decisions made or not feeling able to adequately support the care receiver[49].

Quality of life (n=19)

An overview of the articles

32 %

Quality of life for caregivers was the second most common theme in the articles reviewed (31.7%).

47 %

Nearly half the articles under this theme dealt with people with **neurodevelopmental disorders** (47.4%).

53 %

52.6% of articles dealt with **parents** of children with special needs.

The majority of articles under this theme come from the fields of **psychology** (8) and **medicine** (6).

- According to some authors, the lack of psychosocial services and support can affect caregivers' quality of life, particularly because it is associated with a deterioration of their mental health[5,12,13].

- Peer support and the establishment of informal support networks play an important role in caregivers' quality of life[5,13,50].

> ▸ *Sharing experiences is a useful way of feeling less isolated, creating meaning in the face of a difficult situation, and helping to develop a form of resilience[50].*

- A scoping review[e] of studies evaluating services for parents of children with neurodevelopmental disorders indicates that the child's well-being influences the parents' well-being and vice versa[50].

> ▸ *However, some studies have shown that the well-being of parents has a greater influence on that of their children than the other way round[51].*

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[e] The aim of a scoping review is to present an overview of the literature dealing with a generally broad subject of study.

- As mentioned in two articles from the review, a heavier support burden assumed by caregivers is likely to have a negative impact on their quality of life[14,52].
- The quality of life of caregivers was affected by the health restrictions and lockdowns linked to COVID-19 in 2020 and 2021[13,16,53].
- Parent caregivers experienced isolation or anxiety and felt overwhelmed by the pandemic and the lack of alternative measures to support families and children in response to the restrictions[13,16].

▸ ***Many parent caregivers reported that one of their greatest needs that went unmet during the COVID-19 pandemic was the inability to access respite services due to health restrictions[13,16].***

▸ ***Mothers largely found themselves with additional caregiving responsibilities in addition to other demands related to their work and care/support during the pandemic (e.g. domestic work[f] and homeschooling)[16].***

> ▹ *This additional burden led to a more pronounced deterioration in anxiety in women than in men during the pandemic[53].*

Practical implications

The articles on quality of life also look at ways of improving the quality of life of caregivers.

- Although the quality of life of caregivers may depend on the care and services that the person cared for receives, several articles state that caregivers also need support that is specifically adapted to their needs[13,15,16,17,18].
- In terms of support, several articles stress the importance of not considering caregivers as a homogenous group[24,30,54]. The needs of caregivers depend on their profile.

▸ ***This implies that designing services should not provide a "one-size-fits-all" approach. It is important to take into account the specific needs of caregivers when making decisions about services[24,55].***

> ▹ *A systematic review of care and services for people with dementia and their caregivers, shows that support services (e.g. respite care) are used more by caregivers living in rural areas than by those living in urban areas[56].*

- In Grandisson et al (2023), the authors identify several key elements for the development of services benefiting caregivers[57].

▸ ***Professionals responsible for designing programs must be aware of the potential negative impact of services on caregivers[57].***

▸ ***They must ensure that they do not overload families with information or recommendations but that they take the necessary time with said families[57].***

▸ ***Ultimately, access to the service needs to be as flexible as possible[57].***

- Lockdowns and health restrictions during the COVID-19 pandemic had a negative impact on caregivers' quality of life[13,16]. Some authors suggest that a holistic approach that looks at the social and relational aspects underlying the involvement of caregivers is beneficial for both their quality of life and that of the care receiver. Indeed, this approach ensures a balance between physical and mental health, and the control of infections (e.g. restrictions on visits to care environments, compliance with the two-metre distance, etc.)[53].

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[f] All the domestic tasks carried out in a household.

5. CAREGIVERS' RELATIONAL EXPERIENCE

The articles contained under this theme study the relational aspects of caregiving. They look at the impact of support activities on the relationships maintained between the members of the dyad or on the whole support system deployed within the caregiving relationship.

Becoming a caregiver means redefining the dynamics of the relationship between the caregiver and the care receiver[19,20,21,22].

- The relationship within the dyad and the role of the caregiver evolve with the care receiver's condition and wishes[19,22].

> ► ***Some care receivers want to become more independent, so the dyad has to be redefined. Others prefer for their caregiver to remain involved within the parameters they themselves have defined[19,22].***

- An article discusses how couples can adapt when the child is the care receiver[20]. Mothers, whether employed or not, tend to favor a more proactive approach to issues involving their child, while fathers tend to withdraw from family life and immerse themselves in work and recreational activities[20].

> ► ***These differences can create tensions in the relationship. According to the research, couples should have a shared understanding of the challenges they face, so that they can adopt a team approach when seeking information, sharing responsibilities, and supporting each other[20].***

Relational experience (n=4)

An overview of the articles

7 %
The **relational** experience of caregivers is the third most frequent theme in the articles (6.7%).

100 %
All the articles within this theme used a **qualitative** methodology (interviews or participative research).

1/2
Half of the articles have **psychology** as their main field of study (50%).

- Another article looks at how couples adapt when the care receiver is a life partner[19].

> ► ***The person cared for is more likely to feel a lack of empathy or support if their partner has trouble communicating their fears about the condition or their role as caregiver[19].***

- Difficulties in the relationship between the caregiver and the care receiver may result from a misunderstanding of the challenges faced by the two members of the dyad[19,20,21].

> ► ***Hendryckx et al (2023), for example, looked at the problematic behaviors of people with brain injury and the consequences for their caregiver. Caregivers may experience anger or fear in the face of impulsive or aggressive behavior, while people with brain injury may experience frustration due to their loss of control. This dynamic can create a great deal of frustration on a daily basis for both members of the dyad[21]. If the caregiver believes that they are provoking the care receiver's aggressive behavior, this may exacerbate the psychological distress or lead to the use of strategies that will aggravate the behavior[21].***

- Despite all this, caregiving can also consolidate the relationship between a caregiver and the person they are helping[19].

> ▸ *In a study of couples in which one of the partners has cancer, the authors note that an awareness of the precarious nature of life helps to strengthen the relationship between the partners and with others around them[19].*

Practical implications

The articles on relational experiences also look at practices and actions that can strengthen the relationship between a caregiver and a care receiver.

- While caregiving involves the redefinition of the relationships and dynamics uniting caregivers and care receivers, the social support of family and friends, as well as of professionals, is a key factor in the adaptation of the dyad in the context of caregiving[19,21].

> ▸ ***Professionals should encourage a team approach to managing stress by helping members of the dyad openly discuss their challenges, develop a shared vision, remain flexible, and find solutions that work for both of them[19,21].***
>
> ▸ ***Relatives, meanwhile, have a duty to provide caregivers with a non-judgmental space in which to relieve their stress[20].***

6. AVENUES FOR FUTURE RESEARCH

The articles in the review highlighted a number of needs for future research. Two points stood out in a number of the articles.

- According to several authors, future studies need to bring together a more diverse population and include an intersectional perspective [g,8,9,12,18,26,31,32,33,47,60].

> ▸ ***Future research should integrate the theoretical and practical approaches of caregivers from ethnocultural communities[9], 2SLBGTQIA+ communities[20,60], indigenous communities[31,33] and from low-income backgrounds[47].***
>
> > ▹ *One study on the relational experience of caregivers of children with neurodevelopmental disorders, only included heterosexual couples. The authors noted that it would be interesting to include the perspective of homosexual couples in a future study[20].*

- The second observation is that the perspective of caregivers needs to be given greater prominence in research[13,14,15,19,21,22].

> ▸ ***The analytical data collection tools used to understand the experiences of caregivers are often the same as those used for care receivers. They are therefore not adapted to the former's specific reality[14,15,22].***
>
> > ▹ *One study on the quality of life of caregivers of brain cancer patients, for example, mentions that the same questionnaire was used to assess the health of care receivers and caregivers. As a result, concerns such as access to support and burden alleviation are not considered[14].*

- To sum up, the inclusion of caregivers in research has led to significant additions to the scientific literature as well as improvements in their well-being[14,19].

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[g] Intersectionality is an analytical method that highlights the interweaving of different systems of oppression.

Appendix 1: Methodology

This section provides an overview of the methodological stages involved in the production of this scientific watch bulletin.

This review aimed to pinpoint the themes, findings, trends as well as practices emerging from the scientific literature in Quebec, in order to provide information for those interested in learning more about the research trends in the field of caregiving.

Data collection

The Observatory team created a list of 53 Quebec researchers[h] whose research focuses mainly on caregiving[i]. From this list, a librarian conducted a search using their first and last names in two databases, namely Google Scholar and PubMed.

Criteria for selecting articles

The scientific articles included in the watch had to meet the following criteria:

- be authored or co-authored by one or more Quebec researchers;
- be published between July 1st 2022 and September 30th 2023;
- address the topic of caregiving in the results of the research, in the considerations for practice, or in the needs for future research[j];
- be published in a scientific or professional journal[k];
- be in English or in French.

Process for selecting articles

After removing duplicates, the search yielded a list of 816 publications. Following an initial sort by relevance (reading the title and abstract), 270 articles were retained. Each of these articles was fully reviewed, and 73 met the selection criteria. Subsequently, some of these publications were left out, because caregiving was not addressed in the research results, in the considerations for practice, or in the needs for future research. In the end, 60 articles made up the final corpus of the scientific watch.

Analysis of the articles

To facilitate the analysis of the documentary corpus, the articles were organized using the Zotero software. First, broad analytical categories were developed by the Observatory team. Next, labels were created and applied to the articles according to their characteristics.

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[h] Olivier Beauchet; Line Beaudet; Aline Bogossian; Caroline Bottari; Anne Bourbonnais; Gina Bravo; Shari Brotman; Hélène Carbonneau; Manon Champagne; Josée Chénard; Robin Cohen; Isabelle Courcy; Mélanie Couture; Louise Demers; Catherine Des Rivières-Pigeon; Véronique Dubé; Francine Ducharme; Sophie Éthier; Anne Fournier; Hubert Gascon; Christine Gervais; Sylvie Jutras; Vladimir Khanassov; Kelley Kilpatrick; Lucy Lach; Sylvie Lambert; Marjolaine Landry; Marc Lanovaz; Bernard Lapointe; Guylaine Le Dorze; Hélène Lefebvre; France Légaré; Marie-Josée Levert; Jane McCusker; Élise Milot; Suzanne Mongeau; Marie-Hélène Morin; Pam Orzeck; Geneviève Piché; Nathalie Poirier; Marie-Hélène Poulin; Margaret Purden; Janet Rennick; Mélina Rivard; Annie Rochette; Serge Sultan; Tamara Sussman; Brett Thombs; Isabelle Van Pevenage; Jean Vézina; Charles Viau-Quesnel; Aude Villatte.

[i] Created in 2022, this list brings together Quebec researchers whose research focuses on caregiving. To compile the list, a research professional searched for keywords related to caregiving (e.g. caregiver, loved ones, family) on the grant allocation engines 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 people who received a grant for a project in the field of caregiving between 2010 and 2022 were included.

[j] Articles dealing with the concepts of family support or any type of support based on an emotional bond, without mentioning the terms "*proches aidants*", "caregivers" or "informal carers", were also included.

[k] Articles were required to be 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 Paediatrics Medicine Geriatrics Oncology Social work Occupational therapy Sociology Epidemiology Public policy Psychiatry Rehabilitation Physiotherapy
Methodology	Qualitative • Interview • Discussion group • Participative research • Photovoice • Case study • Comparative study Quantitative • Poll • Survey • Clinical trial Literature review Policy and practice note Mixed methods
Publication type	Scientific Professional
Language	French English
Type of incapacity of the care receiver	Neurodevelopmental disorders Cancer Cognitive disorders associated with aging Heart disease Other incapacities associated with aging Brain injury Mental health Transplant Immunodeficiency Juvenile arthritis Diabetes

CATEGORY	LABEL
Care environment	Long-term care Home-based care Hospital care
Caregiver type	Parents of children Partner Ethnocultural community Rural areas
The caregivers are treated as:	A secondary subject A principal subject A dyad (the article focuses on the relationship between the caregiver and the care receiver·s)
The following terms are used: “*personnes proches aidantes*”, “*proches aidants*”, “caregiver”, “informal carer” or “carer”.	Yes No
Geographical area of research	Canada • Quebec • Montreal • Ontario • British Columbia • Manitoba • New Brunswick • Saskatchewan • Newfoundland and Labrador Belgium France International
Subject matter	COVID-19 pandemic Practices and interventions

To highlight the most frequently studied trends in the articles, these were organized by theme. The themes identified had to be broad enough to include all the articles in the review, but specific enough to identify relevant categories for analysis. The three themes selected were:

- Caregivers' experience of care and services
- Caregivers' quality of life
- Caregivers' relational experience

Two articles did not fall under any of the three aforementioned themes. Both articles described the support activities provided by caregivers for people with brain injuries[58] and people with autism spectrum disorders[59] respectively. Finally, an article on the realities of people in the LGBTQ+ community who suffer from an intellectual disability[60] referred to caregiving only as a topic for future research.

Although some articles may be associated with more than one theme, only their main subject was considered. For each article, the Observatory has highlighted:

- The findings of the research (what new knowledge is derived from the research).
- The practical implications (the real-life applications of the study and the application of new knowledge in the work of practitioners).
- The needs for future research (gaps identified by the authors in the methodology, results, or findings of the study).
- The main themes (topics, fields, or main issues addressed in the article).

Methodological limitations

The methodology used may have had an impact on the selection of articles for the review.

It is possible that some articles were overlooked because the literature search was carried out using only two databases (Google Scholar and PubMed). This choice may also have disadvantaged articles published in French, as the content of these databases is predominantly in English.

The articles reviewed are limited to those written by Quebec researchers in the field of caregiving as identified by the Quebec Observatory on Caregiving (*Observatoire québécois de la proche aidance*). It is possible that this list is not exhaustive and that some researchers have been omitted from the list.

Finally, it should be noted that the review only covers articles published between July 2022 and September 2023. It is therefore possible that more recent articles will provide new insights or nuance to some of the observations made in this watch bulletin.

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