

CAREGIVERS OF LONG-TERM CARE RESIDENTS IN THE CONTEXT OF COVID-19: CURRENT KNOWLEDGE, INSPIRING PRACTICES AND RECOMMENDATIONS

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About the Centre for Research and Expertise in Social Gerontology

The Centre for Research and Expertise in Social Gerontology (CREGÉS) brings together researchers, research-practitioners, students and collaborators from practice settings around the same mission: to improve services and professional practices for older adults. This mission is pursued by the development of social research, the development, testing and validation of Leading-edge practices, the social services and health intervention and technology assessment unit (ÉTMISSE) and through teaching and knowledge transfer activities.

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This document was prepared in response to concerns raised by community representatives and caregivers regarding the practices and procedures that directly affected caregivers during the first wave of COVID-19. By virtue of its expertise in the area of caregiving, CREGÉS shares these concerns and initiated this report with recommendations to address them.

The objective of this document is to review the scientific and grey literature on the needs of caregivers of residents in long-term care settings¹ and to suggest possible courses of action to the managers of these facilities and decision-makers in the health and social services network in order to meet these needs. In order to be able to support caregivers as quickly as possible, we have opted for a rapid response methodology. Finally, given the rapid evolution of knowledge during the COVID-19 pandemic, it is important to note that the findings presented are taken from documents available on October 1, 2020.

1. BACKGROUND AND CONTEXT

COVID-19 has been sweeping the world for several months now. Older adults, particularly those living in long-term care (LTC) settings¹, such as the Centres d'hébergement et de soins de longue durée (CHSLDs) in Quebec, have been severely affected. Data from the Institut national de la santé publique du Québec (INSPQ) attests to this. By June 1, 2020, 3,637 of the 5,206 deaths in the province had occurred in a CHSLD, or nearly 70% ^[1]. As demonstrated by the high percentage of deaths that occurred in these settings, the first wave of the pandemic highlighted many gaps ^[2-4]. Among these were the chronic lack of financial, human (e.g., staff shortages, retention issues) and material resources (e.g., older buildings, shortage of personal protective equipment) as well as inadequate preparation to deal with numerous additional obstacles appearing during pandemic ^[5,6]. The under-investment in long-term care, which is reflected in these gaps may be explained in part by ageism, which perceives older people, especially those with high dependency needs, as a burden on society rather than as citizens ^[6].

These gaps may have unintentionally lead to neglect of residents and their caregivers, but they have also led to many concerns among caregivers about the quality and adequacy of care and the treatment of residents ^[7-9].

Despite the variance in the spread of COVID-19 in LTC settings, the first wave of the pandemic saw the implementation of directives restricting the presence of caregivers in all long-term care settings ^[10], without prior consultation with key stakeholders. Although these directives were established as emergency measures to protect residents, they adversely affected them and their caregivers ^[6,11]. These directives have also been widely criticized by LTC residents and their representatives and have received extensive media coverage ^[2,3,12].

1 The term LTC settings refers to living and housing environments providing long-term care, whether public or private. This generic term was chosen to represent the diversity of this type of settings, designated by different terminologies worldwide (e.g., CHSLD in Quebec, EHPAD in France, Long-term care facilities/homes in English-speaking contexts), on which the findings are based.

Within the context of this document, the term caregiver refers to “any person who, on a continuous or occasional basis, provides significant support to a family member who has a temporary or permanent disability and with whom they share an emotional bond, whether or not the person is a family member. The support is offered on a non-professional basis, in an informal setting and without regard to the age, living environment or nature of the disability of the family member, whether physical, psychological, psychosocial or other. It may take various forms, such as transportation, assistance with personal care and housework, emotional support or care arrangements” (free translation) ^[13]. This document focuses only on caregivers of LTC residents. Within the context of this document, we consider that a caregiver can be a person employed by the resident and/or their family/friend, if they are designated as significant.

Despite the government’s intention² to establish a partnership of care between health and social services personnel and caregivers ^[13-15], in practice, caregivers are rarely treated as real partners in care. However, caregivers are essential both for the quality of life of residents and for the proper functioning of the Quebec health and social services system. They provide up to 85% of the care for older adults in all living environments and if they were remunerated for this care, it would cost the Quebec government approximately ten billion dollars per year³ ^[153]. However, they were forced to abandon their role with older adults following the implementation of visiting restrictions for a period of time. Caregivers support residents physically, psychologically and emotionally, and their presence during this crucial early period could have made a difference in mitigating the tragic outcomes that occurred during the first wave ^[5,16]. Although caregivers have been reintegrated into LTC settings, there still exist significant gaps in collaboration and communication between LTC settings and caregivers.

Finally, the various responses and reactions to the pandemic by LTC settings have also had an important impact on the physical, psychological and emotional health of caregivers. Thus, in addition to exacerbating caregiver’s emotional and informational needs, the various responses and reactions have created new needs, notably in terms of communication. In order to respond to these concerns and to better support caregivers in the context of a second wave, it is imperative to understand the effects brought about by the pandemic on caregivers, their needs, and the various practices to address them.

2 The importance of recognizing the help or support provided by caregivers was already stated in the 1985 policy of the Ministry of Social Affairs, « Un nouvel âge à partager : résumé de la politique du ministère des affaires sociales à l’égard des personnes âgées ». The outline of a care partnership is presented in the 2003 policy: « Chez soi, le premier choix : la politique de soutien à domicile » ^[14]. This approach is then confirmed in the 2012 policy : « Vieillir et vivre ensemble, chez soi, dans sa communauté au Québec » ^[15] and reiterated in Bill 56 : « Loi visant à reconnaître et à soutenir les personnes proches aidantes et modifiant diverses dispositions législatives » ^[13].

3 This number is calculated based on the average number of hours of care provided to older adults by caregivers per week (10 hours), in all living environments, the average hourly wage of a home support worker (\$24.94) and the total number of caregivers over 45 years of age in Quebec (728,000) in 2007. The total cost would likely be higher today given wage increases and the expected increase in the number of caregivers.

Thus this document has three objectives:

1. To establish a baseline of the current knowledge on the needs⁴ of caregivers of residents in LTC settings during the pandemic, and on the principal gaps in the response of the LTC settings

Note: *The objective is to provide an overview of the key gaps and needs of caregivers in the context of a pandemic. The challenges faced by LTC settings and their responses have varied considerably. Thus, the findings from the international literature may not apply to all situations experienced by LTC settings.*

2. To identify inspiring practices⁵ that can be implemented to address the needs of these caregivers and the key gaps in LTC settings

Note: *The objective is to identify all of the inspiring practices from the literature reviewed, although it is possible that some LTC settings may have already implemented certain practices during or following the first wave.*

3. To propose recommendations to managers of LTC settings and decision-makers of the Quebec health and social services network (RSSS)

This document is intended for managers of LTC settings and decision-makers in the health and social services network in order to enhance the practices put in place to meet the needs of caregivers of LTC residents in the context of COVID-19.

2. SUMMARY OF THE METHODOLOGY

This literature review draws from both the scientific literature⁶ and relevant grey literature⁷. Documents come from various data sources: Medline, Psycinfo, Google Scholar, Google (websites). The team searched data sources using pre-determined combinations of keywords related three categories (caregivers, residential and long-term care settings, COVID-19) as well as a pre-established list of older adult and caregiver-related organizations. To complete this process, several additional documents recommended by experts and team members have been added. In total, 180 documents were retained and analyzed. For more details concerning the methodology, refer to appendix 1.

4 In this document, this term refers to the elements necessary for caregivers to maintain good physical, psychological and emotional health.

5 This term refers to both the guiding principles and the interventions that can be put in place to meet the needs of caregivers. Inspiring practice refers to practices that, based on information gathered from individuals, informal observations, or ongoing evaluations, appear to have positive effects on health and well-being.

6 Documents that have undergone a peer-review process that guarantees a certain scientific quality.

7 Documents that have not undergone a peer review process.

3. KEY GAPS IN LONG-TERM CARE SETTINGS RELATED TO CAREGIVERS AND THEIR RESPONSE TO THE PANDEMIC AND INSPIRING PRACTICES

The pandemic has exacerbated many of the challenges previously present in the LTC settings ^[17,18], which were already weakened by a chronic lack of financial, material and human resources ^[16,19-24]. In this difficult context, these settings faced significant challenges that shaped their own responses to protect residents, who were vulnerable to infection by COVID-19. Staff shortages ^[22,25-27], staff mobility ^[20] and lack of access to protective equipment ^[22] are among the specific challenges that influenced decisions to limit the involvement of caregivers (restrictions on visits, lack of communication).

The literature reviewed identified seven gaps affecting LTC settings' response to caregivers. These gaps explain, at least in part, the many needs outlined below. However, the literature also offers many inspiring practices that can be implemented in LTC settings to fill these gaps.

3.1 Gaps in communication with caregivers by LTC settings

During the first wave, the literature shows significant communication gaps between LTC settings and caregivers regarding the changing situation within the care setting, the guidelines and protocols being followed, and the residents' health status ^[16,28-30]. This gap in communication has been exacerbated by:

- Staff shortages ^[21,22,25-27]: this is one of the most significant gaps in LTC settings that worsened during the pandemic. The pandemic amplified shortages by creating new tasks for staff or increasing their workload ^[5,7,16] while having fewer staff available due to exhaustion or COVID-19 infections⁸.
- The lack of time slots outside of regular work hours that would allow caregivers to communicate with both the LTC setting and directly with the resident ^[39].

This communication gap creates a need for information concerning:

- The physical and mental health status of the resident ^[24,29,40-46]
- The measures implemented by the LTC settings to control and fight against COVID-19 ^[30]
- Dissemination of public health information on COVID-19 ^[47-49]

8 Several practices can be put in place to remedy the shortage of personnel, such as developing attraction and retention strategies in professions in demand by using various means such as improving working conditions (full time, salary increase, insurance, management attentive to employees' needs) ^[31-38].

There are several inspiring practices to address the communication gap between LTC settings and caregivers.

1. Establish minimum guidelines for LTC settings' communication with caregivers [28,39,44,48,50,51]. For example:
 - Mandatory weekly direct communication with a designated caregiver regarding the resident's status (telephone, personal email)
 - Mandatory weekly communication about life in the LTC setting (newsletter, post on social networks)
 - Example: "Baycrest" bulletin, monthly newsletter with news, initiatives and activities put in place within the setting [52]
2. Automate communication with caregivers (use of voice message, website or a social network platform such as a Facebook LTC status update page) [28,48,53]
3. Use of existing structures in place prior to the pandemic:
 - Resident or user committees can facilitate the sharing and circulation of information to caregivers [54]
4. Use various tools to improve communication with caregivers (e.g., standardizing both the type of information to be transmitted, and the techniques of information transfer):
 - "Quick 10 – COVID-19 Long-Term Care home update checklist" [55]: checklist of relevant information to be communicated to caregivers
 - "Huddle tool": e-learning module on how to use a particular tool to better communicate with caregivers [56]
5. Employ a psychosocial professional (e.g., social worker) to act as an intermediary communicator with caregivers.
 - Specially trained to respond to crisis situations and in active listening, psychosocial professionals promote better communication with caregivers and can be a valuable support to them, in addition to rest of the care team, to mitigate strain in times of pandemic [33].
6. Provide caregivers with information pamphlets and documents regarding the guidelines and procedures to be followed when visiting LTC settings:
 - Several documents and information pamphlets are already available:
 - "Information sheet for informal caregivers and visitors whose loved one is institutionalized - Coronavirus (COVID-19)" [57]
 - "Informal and family caregivers and visitors to facilities during the coronavirus disease (COVID-19) pandemic" [58]

3.2 Issues concerning technology in LTC settings

Visit restrictions during the pandemic have resulted in greater use of technology to facilitate communication with caregivers, or between caregivers and residents. However, the literature identifies two gaps related to technology in LTC settings.

3.2.1 Lack of technological communication tools

LTC settings lack technological tools used for communication ^[8,39,59]. Some inspiring practices can be put in place to address this gap.

1. Implement a government plan for access to tablets and computers in LTC settings (similar to what is being implemented in schools) ^[60]
2. Establish a fundraising campaign throughout each LTC setting (e.g., through GoFundMe or social networks) if the lack of financial resources is a factor ^[61]
3. Start a donation campaign of used laptop computers, tablets, smartphones from employees, caregivers and visitors ^[62]
4. Implement a schedule for the use of the tools available to residents ^[61]

3.2.2 Lack of technology literacy amongst residents and staff

In addition to a lack of available technological tools, LTC settings have also faced a lack of knowledge about the use of these tools on the part of residents and staff ^[63]. Several inspiring practices exist to fill this gap.

1. Add staff dedicated specifically for technology support ^[61]
2. Assign a staff member (not a front-line worker) as a point of contact for the residents to support them in the use of technological tools (starting applications, assistance during calls): "Buddy program" set up at St. Ann's Community in Rochester (USA) ^[61]
3. Use volunteers to assist residents in the use of communication technologies ^[60]
4. Prepare residents in the use of technological tools (computers, tablets, smartphones, or applications) or adapt technological assistance to the resident's literacy level (e.g., resident living with Alzheimer's disease or a dementia type illness) ^[64]

3.3 Absence of consultation with caregivers and the delivery of a balanced response

LTC setting responses were often characterized by:

- Lack of consultation with caregivers when implementing visit restrictions and procedures demonstrating a lack of a genuine partnership of care ^[21,44,65]
- Lack of a balanced response that takes into account the human and ethical dimensions, and one that considers the balance between the risk of infection and the risks related to social isolation (e.g., in the application of visit restrictions) ^[27,30]

Some inspiring practices can foster a more adequate response to the pandemic by developing collaboration with caregivers.

1. Build partnerships with caregivers by including them in the decision-making continuum related to the pandemic (e.g., visit restriction policies, protective measures for residents) ^[3,32,36,66-68]
 - Include resident or user committees in discussions regarding protective measures and their impact on the lives of residents and their caregivers
 - Organize consultations and invite caregivers to share their opinions on the measures put in place and their possible impacts
 - Conduct a preliminary evaluation by surveying caregivers concerning the impacts of protection measures prior to putting them in place
2. Share information and inspiring practices across LTC settings, notably through the creation of partnerships to support caregivers and creating a concerted response to managing the pandemic ^[26,60,69,70]. Various programs exist already, for example:
 - "Programme SLD+" ^[71]: The program includes a community of practice, webinars and assessment tools related to preparedness, prevention, personnel, pandemic response plan and mobilization capacity, care planning with and without COVID-19, and family presence.
 - "Multiphase Emergency Response" ^[72]: An intervention that enables a partnership between LTC settings and hospitals to establish a coherent continuum of care, an important asset in times of pandemic.

3.4 Lack of access to protective equipment for caregivers

Faced with a lack of personal protective equipment for its personnel, the LTC settings provided limited access to such equipment for caregivers ^[49,73]. Unfortunately, no inspiring practices emerged from the documents analyzed. However, many of the documents mentioned the importance of ensuring access to protective equipment for caregivers ^[31,73-76]. This practice is already in place in the Quebec health and social services network (RSSS).

4. EFFECTS OF RESPONSES BY LTC SETTINGS ON THE NEEDS OF CAREGIVERS AND INSPIRING PRACTICES

Affected by the major gaps in LTC settings, caregivers have many interrelated needs in terms of emotional/psychological, communication and involvement with residents, training, administrative support, and grief in times of COVID-19. Thus, in addition to creating new needs, the pandemic and the various responses to it exacerbated the pre-existing needs of caregivers of LTC residents [47,49,77]. This section presents the diverse needs of these caregivers and identifies the many inspiring practices that can be implemented by the LTC settings that subsequently can have a positive impact in support of caregivers.

4.1 Emotional/psychological needs of caregivers and inspiring practices

Caregivers experienced an increase in psychological distress and increased levels of stress and anxiety [53,78,79]. Consequently, pandemic responses by the government and LTC settings intensified caregivers' emotional and psychological needs. This has had adverse effects on the mental health and well-being of caregivers. While some of these effects can be countered by implementing situation-specific inspiring practices, the implementation of more comprehensive strategies, can mitigate all of these effects.

4.1.1 Effects on caregivers from Government and the LTC settings responses to the pandemic

According to the reviewed literature, the pandemic and responses to it by government and LTC settings have resulted in five adverse effects on the well-being of caregivers.

4.1.1.1 *A reduction in personal social contact*

The physical distancing measures and the prohibition on social gatherings as well as the reduction, or even absence, of social contacts has caused a decrease in the social support (family/friend) received by some caregivers, which in turn leads to an increased feeling of isolation and loneliness [7,21,49,67].

4.1.1.2 *The creation of a form of loss of identity*

Caregiving can create a sense of satisfaction, purpose and meaning in the lives of caregivers [5,47] who risk losing these positive aspects to focus more on their worry for the resident.

4.1.1.3 *The creation of a feeling of injustice*

The arrival of volunteers in the LTC settings during the first wave was seen as unjust by caregivers, who were prohibited from visiting, while individuals they considered less qualified were solicited to provide care.

4.1.1.4 *Increasing caregiver burden combined with a decline/erosion of support services*

Responses to the pandemic combined with a decrease in caregiver support services due to the lockdown of Quebec society resulted in an increase in caregiver burden, which was already considerable pre-pandemic [9,47,49,73,78,80,81]. The increased burden was particularly significant for:

- Caregivers that have taken the care receiver into their home during the pandemic [47,82,83]
- Caregivers who have had to care for several people (e.g. older adults and children at home as a result of school and child care closures) [47,49,67]

4.1.1.5 *The presence of a sense of fear/anxiety*

The pandemic and the responses to it have created a sense of fear and anxiety among caregivers:

- **Concerning the quantity and quality of care provided** to the resident by LTC settings (fear of a lack of care and a decline in its quality due to exceptional circumstances) [7-9]:
 - A situation worsened with the arrival of volunteers from the Quebec *Je Contribue* platform and insufficient communication on the part of LTC settings, resulted in a loss of trust toward the settings [9,41].
- **Concerning the worsening/decline of the resident's health status:** worry about the suffering and isolation of residents [7-9,41,49,73,84]
 - As a reminder, caregivers are partners in care [44,85] that are essential to the effective functioning and maintenance of the health status of the residents [21,28]. Their absence resulted in LTC settings experiencing increased vulnerability [16].
- **Concerning the COVID-19 infection:**
 - Fear that the resident may become infected [41,47,49,81,83,86]: a situation worsened by the insufficient communication from LTC settings [29] and the catastrophic situation reported by the media on a daily basis [28].
 - Worry about being infected themselves and no longer being able to provide care for the resident [7,49,87] as many caregivers are older adults themselves [47,81].
- **Facing the future given the uncertainty of the situation** [9]: caregivers are worried about the future, particularly with regard to their ability to continue to care for the person, their employment prospects and the increase in their financial uncertainty [7,9,47,49,67,80-82].

4.1.2 **Inspiring practices**

These five adverse effects of the pandemic strongly contributed to an increase in emotional and psychological needs and an increased need for support services (e.g., peer support, psychosocial support, psychological support) [49,88,89]. These negative effects on the emotional and psychological health of caregivers can be mitigated through the implementation of more comprehensive inspiring practices. The implementation of more situation-specific inspiring practices may also address the increased burden of caregivers and their feelings of fear and anxiety.

4.1.2.1 *Comprehensive inspiring practices*

To address the five adverse effects of the pandemic and maintain the emotional and psychological health of caregivers, LTC settings can implement two inspiring practices.

1. To address the five adverse effects of the pandemic and maintain the emotional and psychological health of caregivers, LTC settings can implement two inspiring practices.
 - Ideally free of charge ^[87] and provided by a person qualified to do so (e.g., psychosocial professionals) ^[33]
 - Several tools can guide the psychosocial professional in the type of intervention to be implemented, for example: « Repères d'intervention psychosociale en contexte de pandémie » – Benchmarks for Psychosocial Intervention in the Context of a Pandemic (free translation) is a guide to help psychosocial professionals identify the most appropriate type of intervention in the context of a pandemic ^[90].
 - Several options exist:
 - Telephone support helpline ^[87]
 - Online consultation service ^[87]: Online psychosocial or psychological interventions are effective for caregivers of people living with Alzheimer's or other dementias ^[88]
 - Online support groups ^[7]
 - "Virtual Alzheimer cafe" ^[49,91] : personnel-moderated Zoom meeting among caregivers of people with Alzheimer's or other dementias.
 - In addition to the emotional, psychosocial and psychological interventions, LTC settings can provide a list of available resources and information pamphlets:
 - "Public Health Recommendations for Informal Caregivers" ^[92]
 - « Votre proche habite en centre d'hébergement – feuillet d'information pour les proches aidants »: Your loved one lives in a nursing home - information sheet for informal caregivers (free translation) ^[93]
2. Recognize the contribution of caregivers by expressing gratitude, reassuring and encouraging them ^[67]
 - Example: Visible recognition using badges, see the "Caregiver ID" project ^[94]

4.1.2.2 *Inspiring practices that can specifically address the increasing caregiver burden*

It is possible to contribute to reducing caregiver burden by implementing this specific inspiring practice.

1. Support caregivers in the decision-making process regarding the resident (e.g., decisions related to where they live, care planning, place of death):
 - Propose decision-aid tools ^[95]

- Example of a decision-making support tool concerning the person's place of residence: "During the COVID-19 pandemic, should I go to live elsewhere or stay in my retirement/assisted living home?" [96]
- Other tools related to care planning are explained in section 4.3.
- Organize meetings with caregivers using decision-aids tools [95]

4.1.2.3 *Inspiring practices that can specifically address the caregivers' feelings of fear and worry*

Several inspiring practices can be implemented by LTC settings to help alleviate feelings of fear/worry.

1. Reassure caregivers on staff training (social networks communication, institutional accreditation process) [26,31,97]
 - Consider the possibility of setting up communities of practice for staff from different institutions in order to broaden the scope of their skills (COVID-19 measures) [98]
2. Reassure caregivers regarding the physical and mental stimulation of their loved ones by communicating on the various activities put in place (use of social networks).
 - Several options for activities respecting socially distancing can be implemented in LTC settings, for example:
 - "Alternative activity therapy": Stimulation of people with dementia with activity kits to be completed [49]
 - « Projet Liratoutâge » [99]: reading aloud for older adults available online
3. Provide an open and friendly environment for residents in order to maintain their relationships with caregivers and prevent decline in residents' health statuses [34,39,91].
 - Display photos, drawings, objects reminiscent of the family/friends [91]
 - Meaningful music playlists for residents and their families/friends [91]
4. Help reduce fear and worry that the resident may be infected by increasing communication about the infection control and prevention measures implemented by the LTC setting:
 - Use videos capsules to illustrate to caregivers how it is being done in the facility (application of COVID-19 control and prevention measures): Sayre Christian Village, Lexington (USA) [61]
 - Implement webinars to inform the caregivers of the various regulations and measures to combat COVID-19 that have been put in place and allow caregivers to ask questions: RiverSpring Health, Riverdale (USA) [61]
5. In the event that an older person needs to integrate into a LTC setting during the pandemic, reassure caregivers and future residents by planning for the integration of this new resident.

- "Family Transition Program" ^[100]: Implementation of a transition plan between home and the LTC setting with the intervention of a third party to support the caregivers and the future resident. This includes a pre-admission visit to the LTC setting to become familiar with the setting and the team.

4.2 Communication needs between caregivers and residents and inspiring practices

In order to avoid deleterious effects on their mental health that amplify emotional/psychological needs, caregivers, like residents, need to communicate with each other.

For caregivers, the absence of contact or regular communication with the resident ^[3,25,27,42,45,46] results in:

- An increase in feelings of guilt regarding the relocation of the person to a LTC setting: increase in feelings that they have abandoned the person being cared for ^[21,67]
- A sense of worry ^[7-9,41,49,73,84]

Several inspiring practices are proposed in the reviewed literature to address this issue.

1. While respecting the latitude of the LTC setting, limit restrictions on caregiver visits through a variety of measures that:
 - Differentiate caregivers from visitors by considering them as partners in care ^[30,65,66,68,68,78,101,102]
 - Support the development of meaningful relationships between staff and caregivers ^[102]
 - Implement collaborative meetings (e.g., resident follow-up meetings including caregivers once a month) or activities (e.g., resident's birthday party) between staff and caregivers in order to develop trust and mutual respect ^[103]
 - ▶ During the pandemic, these meetings/activities can be held online.
 - Recognition of the caregiver's expertise in the resident's history and well-being ^[104]
 - There are several effective tools to implement this concept
 - "Better Together": guide divided into three phases (evaluation of the current situation, formulation of guidelines and practices to be followed in order to include family and friends, implementation, development and long-term follow-up) in order to create a real partnership between the staff and the support network.⁹
 - "Partners in care" ^[105]: toolkit for LTC settings to identify caregivers and the mutual commitments that a partnership of care involves
 - « Proche-aidant partenaire : Travailler en collaboration avec l'expert dans la gestion des symptômes comportementaux et psychologiques de la démence à domicile » - Caregiver partner: Working in collaboration with the expert to manage behavioural and psychological symptoms of dementia at home (free translation): presentation highlighting the importance of implementing the care partner principle and its foundations ^[106]

⁹ Although this tool was created for the hospital setting, it can be adapted for LTC settings.

- "Visitors Tool: Key Considerations for Long-Term Care Homes" ^[101]: tools in the form of questions that LTC settings need to ask themselves in order to allow for the gradual and safe reintegration of caregivers as partners in care
 - Implement a caregiver designation process developed with all concerned parties (staff, residents and caregivers) ^[85]
 - Note:** *this process may result in the designation of a caregiver hired by families, but not employed by the LTC setting (private caregiver¹⁰), if this is the wish of the relatives and the resident.*
 - Identify caregivers explicitly
 - Caregiver ID : recognition of the caregiver by a badge or card ^[94,107]
 - Establishment of a registry of caregivers entering a LTC setting, containing their contact information, to facilitate contact with them in the event of an outbreak or potential contact with COVID-19 ^[76]
 - Establish a specific visit plan for each resident ^[16,30]
 - Ideally, the plan should reflect the needs of residents and caregivers and therefore developed in collaboration with them ^[16,30].
 - The plan must be equitable and tailored to each resident. The same model does not fit everyone (no "one size fits all") ^[16,30].
2. If caregivers are prohibited entry in the LTC settings, it is necessary, at a minimum, to plan for their absence ^[108,109]:
- Available tools: « À vos marques, prêts, planifiez - pour l'absence des partenaires de soins » - On your marks, get set, plan - for the absence of care partners (free translation) ^[108,109]. This is an information sheet that LTC settings can have caregivers complete in order to meet the needs of the resident despite the absence of the caregiver. The tool includes personal information (preferred name, culture, language, address and phone number of the caregiver, daily routine) and medical information (medications, medical devices).
3. Facilitate communication between residents and caregivers ^[66,108,110] by implementing communication practices that include :
- In-person communication with social distancing: It is important for caregivers and residents alike to see each other in person and there are several options, for example:
 - Window greeting¹¹ ^[91]
 - Drive-in visit using the car honk or singing to make the activity more festive ^[91]: The Hebrew Home in Riverdale (USA) or Elm Terrace Gardens in Lansdale (USA) ^[61]
 - Use of Plexiglas partitions outdoors to allow for visits without masks, which are important for people with cognitive loss or hearing disabilities ^[64]
 - Creation of living room cabins separated by a Plexiglas: Netherlands ^[112]

10 This term refers to people hired and paid privately by residents or their relatives to meet the needs of the resident. These caregivers offer non-professional assistance in the sense that they are not hired as health and social services personnel.

11 This type of visit has been practiced by several caregivers in Quebec but was not a practice organized by CHSLDs ^[111].

- "Hug Booth": Plastic wall with plastic arms allowing to individuals to embrace: Netherlands ^[112] and Freeburg Care Center (Illinois, USA) ^[113]
- Remote "conversational" communication: If it is not possible for caregivers and residents to communicate otherwise, a conversational type of remote communication can be put in place.
 - Several supports are available:
 - Residential phone line and handwritten letters: the use of tools already familiar to residents and caregivers is a facilitating element ^[114].
 - Video calls (e.g, Messenger, Whatsapp) ^[115,116]: residents would prefer video calls, but they are seldom used because they are not accustomed to using them ^[117].
 - ▶ « Communication proches aidants (COMPAs) »: COMPAs is an application developed to promote communication with people living with dementia or with all other barriers to communication with caregivers or professionals ^[118].
 - ▶ "10 Tips for Meaningful Video Calls" is a document containing tips to enable a satisfactory video call between family members and the resident ^[52].
 - ▶ Use of voice-activated devices (Alexa, Google Home) to use videoconferencing applications without the need for complex user engagement ^[24].
 - To assist LTC settings in setting up virtual tours, there is a "COVID-19 Virtual Visits Toolkit" ^[62]: this toolkit includes several communication application usage sheets (Facebook, Zoom, Skype) as well as a tip sheet for setting up virtual tours (how to deal with the many problems related to residents' access or use of these devices).
- Remote "desynchronized exchange" communication
 - Exchanging photos and videos through social media ^[61]: At the Presbyterian Homes & Services in Roseville (USA) residents and caregivers posted photos and videos of encouragement and love on social networks ^[61].

4.3 Needs regarding the involvement of caregivers with the resident and inspiring practices

The involvement of caregivers in LTC settings' care planning for residents is often unsatisfactory and oscillates between a lack of involvement and rapid and abrupt involvement (e.g., level of care) with regard to decisions concerning the resident, particularly when the resident's health status deteriorates (advance care planning) ^[3,19,22,24,29,45,46,97,114,116,119,120]. To avoid the negative impacts associated with this relative involvement, several inspiring practices can be put in place.

1. Put in place an advance care planning strategy ^[80] by using ways to:
 - Plan and discuss care in advance ^[121]
 - Encouraging discussions about advance care planning in families ^[48,67,122]
 - Several tools are available, for example:
 - "COVID-19 Conversation Guide for Long-Term Care" ^[123]: a conversation guide allowing a discussion on care planning between caregivers, the resident and staff
 - "COVID-19 Communication and Care Planning Tool": tools for decision-making and specific involvement in the age of COVID-19 ^[42]

- « Niveaux de soins - niveaux d'interventions médicales (NIM) : parlons-en dans le contexte de la pandémie COVID-19 »¹²: Levels of Care - Levels of Medical Intervention (LOC): Let's talk about it in the context of the COVID-19 pandemic (free translation) ^[124]. A conversation support toolkit containing conversation guides for expressing goals of care that may lead to levels of care.

2. Facilitate dialogue between staff and caregivers using technology ^[82]

- Use of telehealth to facilitate discussions regarding the resident with caregivers ^[67,119]

4.4 Training needs and inspiring practices

The pandemic has greatly affected the availability of training for caregivers, whereas these services are necessary in facing new challenges in this very particular context of COVID-19. Already a significant need prior to the pandemic, these needs during COVID-19 have increased and concern:

- Proper use of protective equipment (masks, visors, gloves, etc.) ^[25,27]
- Prevention and protection measures to fight against the transmission of the virus ^[25,47]
- Use of technology ^[63,64]

However, LTC settings can reinforce the training available to caregivers regarding protective equipment, protection and prevention measures by implementing some inspiring practices ^[73,74,76,110].

1. Adequately train staff in these procedures so that they can in turn educate caregivers on best practices ^[74]

- For example, « Projet ECHO »: Tele-mentoring program for professionals to share best practices and trainings ^[98]

2. Offer online training or provide existing resources to caregivers

- Various platforms are available:
 - Virtual reality: "Embodied Labs" is a site offering training courses for caregivers through virtual reality ^[63]
 - Video capsules: "Personal Protective Equipment for Family Caregivers" ^[125] is a video presentation explaining the proper use of protective equipment for caregivers

3. Provide checklists regarding prevention and protection measures (hand hygiene, respiratory etiquette) and the use of protective equipment for caregivers

- For example, « Aide-mémoire à l'intention du proche aidant », a checklist for caregivers ^[126]

12 This document is intended for caregivers and community residents but is adaptable for residents in LTC settings.

4.5 Needs for administrative support and inspiring practices

The pandemic generated a great deal of dissatisfaction, which subsequently led to a strong desire for support and administrative assistance regarding the complaint process or other recourses [30,65]. LTC settings can put in place various inspiring practices.

1. Put in place mechanisms to assist caregivers to file complaints or provide rapid feedback that will be promptly reviewed in the LTC setting [30,65].
 - Consider the creation of COVID-19 specific appeal processes within LTC settings allowing for rapid decision-making (e.g., regarding the interpretation of visit restriction guidelines) [65].
2. Clearly communicate the steps to be taken by caregivers and the resources available to support them:
 - Example of a resource: « Centre d'assistance et d'accompagnement aux plaintes » [127]. This resource accompanies caregivers or residents in their complaints process (information, guide, support during the process).

4.6 Needs related to the bereavement experience during COVID-19 and inspiring practices

Death due to COVID-19 or during COVID-19 is accompanied by unique challenges (suffering, absence at the time of death, limitations of in-person funeral rituals) that can complicate the grieving process [80,97]. This risk creates a need for bereavement support services:

- Spiritual support [89]
- Bereavement follow-up care [81,116]
- Support for funeral services [116] and especially their adaptation to the particular context

LTC settings have a role to play in addressing this situation. Several inspiring practices can be put in place.

1. Allow caregivers to be present during the end-of-life¹³ [39,116,129]
2. Offer bereavement follow-up services by qualified and trained individuals (psychosocial professionals) [80,116] or guide the caregivers towards these resources
 - Evaluate caregivers' needs and propose an appropriate response by considering the factors that can influence their bereavement experience: "Cartography of Factors Influencing Caregivers' Experiences of Loss", is a tool to help professionals identify caregivers in need of more targeted interventions by identifying factors that can be either resources or obstacles to the grieving process [130].

13 While most LTC settings have allowed caregivers to spend the last moments of the resident's life with them, this is not the case for all of them [128].

- Various possible formats
 - By phone
 - Online counseling sessions ^[80]
 - Provide a list of available resources and coping with grief tip-sheets (explanation of possible grief reactions and actions) ^[131]:
 - « Guide pour les personnes endeuillées en période de pandémie »: a guide for people suffering from a loss during the pandemic (free translation) ^[132]
 - "I am in bereavement for one or more people who lost their lives in the pandemic" ^[133]
 - « COVID-19 – La proche aidance et le deuil en temps de pandémie » : information on caregiving and bereavement during the pandemic ^[134]
 - « Conseils aux personnes endeuillées » : Bereavement counseling tips (free translation) ^[135]
 - During these interventions, encourage caregivers to make use of their social network:
 - For example, encourage them to make video calls with their family and friends during this difficult time ^[38]
3. To offer support in the planning and organization of the funeral process ^[116]
 4. Train staff on the palliative and end-of-life care approach, its integration into their practice, as well as the means at their disposal in order to better support caregivers ^[97,136]
 5. Put in place, or encourage caregivers to put in place a commemoration plan with rituals that respect distancing guidelines ^[48], for example:
 - Rituels funéraires en ligne ^[80,132]
 - Mémorial disponible en ligne ^[38]
 - Rituels de deuil collectifs, par exemple : « Tricots en mémoire », création d'un foulard collectif géant à la mémoire des personnes qui sont disparues dans le quartier Sud-Ouest-Verdun (Montréal) ^[137].

5. RECOMMENDATIONS

Despite some degree of variability, a review of the available literature highlights some general trends in terms of gaps and responses to the pandemic. This analysis also reveals that caregivers have many needs, exacerbated or generated by the pandemic. Finally, the literature offers multiple inspiring practices to address the situation and assist LTC settings in their desire to better support caregivers.

Nevertheless, it can be difficult to specify which of the many practices identified should be prioritized and implemented. In order to help LTC settings managers and decision-makers in health and social services network improve the practices implemented to meet the needs of caregivers in a pandemic context, the working group consulted five experts to develop detailed recommendations.

While being aware that these recommendations require financial, material and human resources, their implementation would make it possible to avoid the negative consequences that were observed during the first wave in the LTC settings. They could be the subject of a discussion with the health and social service authorities in order to determine the resources required for their implementation. In addition, although the implementation of these recommendations would improve the situation during the COVID-19 pandemic, they could also be beneficial in dealing with other health emergencies (e.g., flu outbreaks, gastroenteritis). Finally, the implementation of several of these recommendations can be maintained in the usual context, which could result in positive impacts in the longer term and could be a vector for improving the situation for caregivers of LTC residents.

1. Strengthen the recognition of caregivers as essential care partners by allowing designated caregivers access at all times to the LTC setting and by establishing a partnership between staff and caregivers

a. Enable caregivers to have access to the LTC setting at all times

- ▶ Designate a minimum of 2 caregivers per resident, who are authorized to be in the LTC setting under health regulations
 - Implement a policy for the collaborative designation of caregivers by including the resident, family/ friends and staff in the decision-making process
 - Note: this process may result in the designation of a caregiver hired by relatives and/or the resident (private caregiver), but not employed by LTC settings, if this is the choice of the relatives and/or the resident.*
 - Permit a change in this designation if the caregivers are no longer willing or able to care for the resident
- ▶ Create a list of designated caregivers specific to the context of visit restrictions and communicate it to staff¹⁴
- ▶ Identify caregivers with an identification badge so that they are recognizable and acknowledged by all ("Caregiver ID" ^[94])
- ▶ Prepare caregivers in the proper use of personal protective equipment and infection control measures (prevention and protection measures).
- ▶ Regularly test designated caregivers moving through the LTC facility (rapid antigenic tests may be used ^[138])

b. Develop a partnership between staff and caregivers

- ▶ Provide caregivers with access to designated areas for breaks and meals
- ▶ Involve designated caregivers in care planning and decision-making processes regarding the resident, while respecting the rules of confidentiality
- ▶ Prepare staff on how to set up an effective partnership with caregivers involving:
 - Knowledge of the definition of a partnership: a partnership is a collaborative relationship between two or more people based on trust, equality and mutual understanding, to achieve a specific goal
 - Knowledge of the realities experienced by caregivers
 - Improving communication with caregivers

Available resources: "Caregiver ID" ^[94] , "Partners in Care" ^[105] , "Better Together : A Change Package" ^[139] , « Proche-aidant partenaire » ^[106]

¹⁴ This list could also be used in the event of an outbreak of other illnesses resulting in visit restrictions such as influenza or gastroenteritis.

2. Designate a person responsible for communication¹⁵ with caregivers within the LTC setting¹⁶

- ▶ Establish minimum communication guidelines in collaboration with the caregivers and the residents
 - Communication between LTC settings and caregivers
 - Information about the LTC setting in general: situation, rules, activities carried out, staff training
 - Information about the resident: physical, psychological and emotional health, activities performed, progress
 - Communication between the resident and the caregivers
- ▶ Establish, in collaboration with the caregivers, the technological means to be used to communicate
 - If necessary, assist residents in the use of communications technology
 - Direct caregivers to the resources available to support them
 - For the transmission of information about the LTC setting in general, it is possible to set up several modes of communication at the same time in order to reach a maximum of caregivers. Examples : automated message on voice mail, publication on social networks, newsletter

Available resources: Tablet "Grandpad" ^[140], "COMPas" ^[118], "Baycrest bulletin" ^[52]

3. Establish partnerships with resources that support caregivers (e.g., CISSS/ CIUSSS programs and services, community organizations)

- ▶ Make a psychosocial professional available for caregivers as a pivot person/responder
 - Reachable by various technological means (telephone, e-mail, social networks)
 - Possible activities:
 - Support for administrative procedures (ex: procedures related to death, complaints, access to various external support services)
 - Psychosocial interventions
 - Bereavement Follow-up Services
- ▶ Organize support activities using communication technologies
 - Support Group
 - Psychosocial interventions
- ▶ Inform caregivers about available support services
 - Organize information sessions on the various support activities
 - Provide a list of support services and resource

Available resources: "Public Health Recommendations for Informal Caregivers" ^[92], « Votre proche habite en centre d'hébergement – feuillet d'information pour les proches aidants » ^[93]

15 This person is responsible for LTC settings communication with caregivers and communication between residents and caregivers.

16 This recommendation is useful in the context of visit restrictions as well as for caregivers unable to visit the LTC settings (e.g., due to illness, employment).

4. Implement an integrated palliative care approach within the LTC setting

- ▶ Train staff to integrate this approach into their professional practices
 - These trainings should focus on the quality of life of the resident and her/his family/caregivers
 - Train the staff in psychosocial, psychological, emotional and medical support practices dedicated to residents and their families
- ▶ Implement advance care planning that includes caregivers and the resident, if possible
 - Facilitate open and honest discussions with caregivers around the prognosis and evolution of the residents' health status

Available resources: « Approche palliative intégrée : Quand et comment » [141], « L'approche palliative : Améliorer les soins pour les Canadiens atteints d'une maladie limitant l'espérance de vie » [142]

5. Establish a family/caregiver bereavement support follow-up plan and a plan of commemoration with rituals that respect the public health guidelines

- ▶ Offer bereavement support services (pre and post-death)
- ▶ Encourage families/caregivers to use their social network
- ▶ Provide a list of available resources
- ▶ Follow up with family/caregivers of the deceased within one month of death to identify those who are experiencing complex grief and may require further follow-up
 - Train staff to identify people who are at risk of complicated grief
- ▶ Implement collective mourning rituals following the death of the resident by inviting caregivers and relatives to participate
 - An Online Memorial
 - The Creation of a poem about the deceased person
 - The lighting of a candle
- ▶ Encourage caregivers to create their own mourning rituals

Available resources: « Guide pour les personnes endeuillées en période de pandémie » [132], "I am in bereavement for one or more people who lost their lives in the pandemic" [133], « COVID-19 – La proche aidance et le deuil en temps de pandémie » [134], « Conseils aux personnes endeuillées » [135], « Guide pour la réalisation de rituels collectifs de deuil à Montréal en temps de COVID-19 » [137], "Cartography of Factors Influencing Caregivers' Experiences of Loss" [130]

6. Establish additional LTC setting review visits by the responsible CISSS/CIUSSS regarding actions to support caregivers¹⁷

- ▶ Conduct at regular intervals, the review visits in accordance with the actions concerning caregivers in the LTC setting
 - Undertake this review minimally on an annual basis
 - Include in the review criteria, the actions that have been put in place to support caregivers (e.g., care partnerships)
 - Entrust the Caregiver Steering Committee to assure that these reviews are completed
- ▶ Set up an improvement plan with clear objectives and monitoring indicators
 - Conduct an ongoing follow-up of this improvement plan with LTC settings
- ▶ Establish a procedure to recognize the accomplishments of the LTC settings
 - Collaborative practices with caregivers
 - The well-being and well-treatment of residents (compliance with the Loi visant à lutter contre la maltraitance envers les aînés et toute autre personne majeure en situation de vulnérabilité and with existing institutional policies) ^[143,144]

Available resources: « visites d'évaluation de la qualité des milieux de vie » ^[145]

7. Promote direct social contact between the residents and their support network (including caregivers)

- ▶ Implement inspiring practices that allow residents and their support network to maintain direct social contact while complying with current health regulations, such as:
 - E.g., Greetings at the window, Visiting by car, Use of Plexiglas, Hugbooth

Available resources: LeadingAge brings together several inspiring practices ^[61]

¹⁷ We are aware that visits to evaluate the quality of living environments are already conducted under the supervision of the MSSS. However, these evaluations are not performed regularly and the evaluating organizations do not always have the specific knowledge of the institutions and the possibility of following up on recommendations. In addition, the evaluation criteria for these visits do not necessarily cover the dimensions proposed in this recommendation. CIUSSS could build on and improve this process.

8. Create a CISSS/CIUSSS Caregiver Steering Committee composed of caregivers and managers in each establishment (CISSS/CIUSSS)

- ▶ Ensure that the committee is composed of caregivers providing care in various settings (e.g., LTC settings, hospital, in home, and with various levels of incapacities of the person being cared for)
- ▶ Mandate this committee to establish common guiding principles for actions and to harmonize the implementation of practices by the various settings with regards to caregivers¹⁸
 - Create sub-committees, at the local level, in the LTC settings to assume responsibility for monitoring the implementation of these actions or request that existing user committees ensure the follow-up
- ▶ Consult the committee when implementing new guidelines, practices or regulations concerning quality of life in LTC settings
- ▶ Promote the steering and sub-committees to the caregivers of the various establishment (CISSS/CIUSSS)
- ▶ Set up an information campaign on the actions carried out by the steering committee
 - E.g., use of posters and social media networks, transmission of information by the staff of the establishment
- ▶ Ensure that caregivers are represented on user committees

Available resources: « Campagne de promotion sur les droits des usagers » ^[141]

6. CONCLUSION

In conclusion, in order to better respond to the different needs of caregivers, LTC settings can draw inspiration from the practices and recommendations proposed in this document. These recommendations are tools that may be useful during a pandemic or other health emergencies. Many of them can also be maintained under normal circumstances.

Thus, while this document highlights the importance of knowing the needs of caregivers and responding to them, it also demonstrates the value of developing and evaluating actions (interventions, programs, measures, services) to improve these responses. It is therefore important to pursue and encourage the development of various research projects on the needs and realities of caregivers and on best practices to support them, particularly in relation to the impact of the pandemic in LTC settings ^[16,30,65,89].

Finally, the various recommendations proposed are for consideration in the development of government actions in support of caregivers, following the adoption of Bill 56 ^[147].

18 This committee could be responsible for the follow-up and implementation of previously proposed recommendations.

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8. APPENDIX 1: METHODOLOGY

This methodology aimed to meet 3 objectives:

1. Identify the needs of caregivers of LTC residents during the COVID-19 pandemic
2. Identify the main gaps of LTC settings with respect to caregivers during the COVID-19 pandemic
3. Identify inspiring practices that can address these needs and fill key gaps in LTC settings

8.1 Literature Review

In order to meet these three objectives, three research professionals and a librarian conducted a literature review in the scientific¹⁹ and grey literature²⁰. The working group then produced a narrative synthesis of the documents. Considering the desire to quickly gather information on the subject, the unprecedented context and the limited information available, the following literature review strategies were adapted.

Three data collections were conducted:

1. Search of scientific literature in bibliographic databases (Medline, PsycInfo) (conducted on September 30, 2020)

Two databases were consulted: Ovid MEDLINE(R) ALL and APA PsycInfo. Multiple combinations of keywords regrouping two concepts were applied:

- COVID-19: (covid or coronavirus or corona virus or pandemic? or quarantine or lock?down or social distanc* or physical distanc* or containment).ab,ti., coronavirus/ or betacoronavirus/ Communicable Diseases/, Pneumonia, Viral/, SARS Virus/ or Pandemics/)
- LTC settings: ((long term or residential or intermediate or high or skilled nursing or assisted living) adj2 (care or home? or setting? or facilities or facility or institution?)). ab,ti., Long-Term Care/, Residential Facilities/, Homes for the Aged/, Nursing Homes/, Intermediate Care Facilities/, Skilled Nursing Facilities/, Assisted Living Facilities/, residential care institutions/)

A time limit was applied: 2020-2021. In total, the team found **542 documents** (including duplicates)²¹.

19 Documents that have undergone a peer-review process that guarantees a certain scientific quality.

20 Documents that have not undergone a peer review process.

21 The search identified 511 documents in Ovid MEDLINE(R) ALL and 31 in APA PsycInfo.

2. Literature review in Google Scholar (conducted on September 30, 2020)

A combination of keywords: "Long term care" covid, caregiv* was applied and two research professionals examined the 10 first pages of results. The working group then chose the retained documents following this first step based on their titles and the following criteria:

- Date of publication: 2020
- Language of the title: French or English
- The title mentions the COVID-19 pandemic in LTC settings

In total, **72 documents** (including duplicates) were found.

3. Literature review on websites of organizations related to older adults and caregivers

A search of websites of organizations related to older adults and caregivers was conducted by three research professionals from September 30 to October 1, 2020. The working group developed the list based on their expertise and based on proposals from the advisory committee. This list is detailed in Table 1. Documents were searched in the "publications" sections of the various websites or by keywords related to the three concepts: caregivers, LTC settings, COVID-19. After removing duplicates, the team identified **96 documents**.

Table 1: list of organizations

Types of organization	Name of the organization	URL
Non-profit organizations	Association lavalloise des personnes aidantes (ALPA)	http://www.aldpa.org/
	L'Appui pour les proches aidants	https://www.lappui.org/en
	Regroupement des Aidants Naturels du Québec (RANO)	https://ranq.qc.ca/en/ https://ranq.qc.ca/communique-covid19-prochesaidants-resultats-sondage/
	Carers Canada	https://www.carerscanada.ca/
	BC careproviders Association	https://bccare.ca/
	FADOQ	https://www.fadoq.ca/ile-de-montreal/
	Regroupement québécois des résidences pour Aînés (RQRA)	https://www.rqra.qc.ca/info-pandemie
	Change Foundation	https://changefoundation.ca/
	The Ontario Caregiver Organization	https://ontariocaregiver.ca/covid-19/
Alzheimer Society Canada	https://alzheimer.ca/en/Home/Living-with-dementia/managing-through-covid-19	

Types of organization	Name of the organization	URL
Government Agencies	Conseil national des aînés	https://www.canada.ca/fr/conseil-national-aines.html
	Québec.ca	https://www.quebec.ca/sante/problemes-de-sante/a-z/coronavirus-2019/proches-aidants-en-contexte-de-pandemie-covid-19/
	Protecteur du citoyen	https://protecteurducitoyen.qc.ca/fr https://protecteurducitoyen.qc.ca/fr/enquetes/rapports-speciaux/avis-contribution-chsld
	Gouvernement du Canada / Canada.ca	https://www.canada.ca/fr/sante-publique/services/maladies/2019-nouveau-coronavirus/document-orientation/residents-etablissements-soins-longue-covid-19.html
	Ministère de la Santé et des Services sociaux	https://publications.msss.gouv.qc.ca/msss/
Research institutes and centers	Institut de recherches en politiques publiques (IRPP)	https://irpp.org/fr/
	Institut national de la recherche scientifique (INRS)	https://inrs.ca/en/
	Institut national de santé publique du Québec (INSPQ)	https://www.inspq.qc.ca/
	Institut national d'excellence en santé et services sociaux (INESSS)	https://www.inesss.qc.ca/en/home.html https://www.inesss.qc.ca/fileadmin/doc/INESSS/COVID-19/COVID-19_Socialisation_distance.pdf https://www.inesss.qc.ca/fileadmin/doc/INESSS/COVID-19/COVID-19_INESSS_Retablissement_SAPA.pdf
	Institut universitaire de gériatrie de Montréal (IUGM)	http://www.criugm.qc.ca/fr.html
	Institut Vanier de la famille	https://institutvanier.ca/
	Association canadienne pour les soins de longues durées (Canadian Association for Long-Term Care)	https://caltc.ca/
	Association canadienne de gérontologie	https://cagacg.ca/
	Centre d'apprentissage, de recherche et d'innovation en soins de longue durée	https://clri-ltc.ca/covid19/ (anglais) https://clri-ltc.ca/fr/covid19/ (français)

Types of organization	Name of the organization	URL
	Research institute for Aging	https://the-ria.ca/resources/
	Association canadienne de soins palliatifs	https://www.chpca.ca/
	Baycrest	https://www.baycrest.org/Baycrest/Coming-to-Baycrest/Patient-Visitor-Safety/COVID-19-Information
	Canadian Virtual Hospice	https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
	Policy alternatives	https://www.policyalternatives.ca/publications/reports/re-imagining-long-term-residential-care-covid-19-crisis
Others	World Health Organization	https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf?sfvrsn=6d3578af_8
	Regroupement québécois des résidences pour aînés (RQRA)	https://www.rqra.qc.ca/salle-de-presse/communiqués-de-presse
	Biblio-aidants	https://biblioaidants.ca/
	Veille informationnelle et scientifique du CCSMTL	http://veille.ccsmtl-biblio.ca/personnes-agees/proches-aidants/
	Réseau Santé.com – La référence documentaire en santé et services sociaux	https://catalogue.santecom.qc.ca/cgi-bin/koha/opac-search
	Communauté d'échanges COVID-19 (UQTR + l'Appui)	https://oraprdnt.uqtr.quebec.ca/pls/public/gscw031?owa_no_site=6278&owa_no_fiche=9&owa_bottin=
	ITcovid	https://ltccovid.org/?s=caregiver

To complete this process, several documents recommended by experts or team members were added. The working group then evaluated these documents on the basis of the title and the abstract. The documents had to meet the following selection criteria:

- Mention the needs of caregivers of LTC residents during the COVID-19 pandemic
- Mention the main gaps of LTC settings during the COVID-19 pandemic
- Describe practices that can address the needs of caregivers or key gaps in LTC settings
- Written in English or French: the document had to be written in English or French

A total of **194 documents** were selected. During the data extraction, the team eliminated some documents according to the following criteria:

- The document is not accessible in its entirety (full text)
- The document does not contain any relevant information
- The document is a duplicate

Thus, after the extraction process, **180 documents** were finally retained and analyzed.

8.2 Observations on the reviewed literature

Among the documents reviewed, few directly address the needs of caregivers of older adults living in LTC settings during COVID-19 [9,44]. Many people agree on the importance and urgency of developing specific research on this population [89] in order to effectively manage the second wave [16]. Indeed, the vast majority of the literature reviewed focuses on the challenges and needs of residents [5,7,8,18,19,64,114].

The literature on the needs of caregivers in the context of COVID-19 centres on the needs of caregivers of older adults living at home or in the home of the caregiver [47,81,83,84,148-150].

Finally, a significant number of the documents reviewed focus on the caregivers of older adults with Alzheimer's and other types of dementia. [41,43,78,82,84,87,88,151,152].

8.3 Advisory Committee

This document was read externally by five experts from the academic and community sectors. A detailed list of their titles and affiliations can be found at the beginning of the report.

The purpose of the expert consultation was twofold:

- To provide feedback on the results of the literature review and their presentations.
- Discuss priority recommendations to be included in this document

In order to achieve these two goals, the document was provided in PDF format for the experts to review and two discussion sessions were held with the working group and the various experts.

Finally, a working session was held to discuss the comments and recommendations that were made.

8.4 Methodological limitations of the document

Considering the short time frame for conducting the literature review and the necessary adaptation of the various research strategies, the document presents certain methodological limitations.

- **Time frame for collection:** The documents reviewed in this document represent only the literature available as of October 1, 2020 at the latest. Considering the timeliness of the

subject matter, other documents and studies continue to be produced. Thus, this document represents only a snapshot of the situation.

- **Comprehensiveness of Information:** The research strategies did not aim to collect comprehensive information. It is therefore possible that some information may be missing.
- **Document Quality Assessment:** No document quality assessment was conducted.
- **Few documents addressing the subject in detail:** Few specific studies on the subject have been produced. Findings are drawn from a variety of documents, often briefly addressing the subject.