Issue Note

Supports and interventions used in OECD countries to integrate unpaid caregivers into long-term care settings and those aging in place

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Executive Summary

As the number of older adults increases in Canada, there is a need to enhance the extent of support, recognition, and engagement of unpaid caregivers given their role and contributions as partners in providing care. This will involve potential changes within the long-term care (LTC) sector, for healthcare professional practice, and with implications for government policy. This will necessitate policy changes in the unpaid and formal care sector, and wider health and social care sector.

This paper addresses the following question: How have other countries, similar to the Canadian context, integrated essential unpaid caregivers into (1) long-term residential care and (2) care for those 'aging in place?' What were the key learnings and how can these practices be best applied to Canada?

The literature on the integration of unpaid caregivers is concentrated on hospital and LTC settings and is scant for unpaid caregivers caring in the community or for those who are 'aging in place' although in Canada, this is where the majority of older adults are living, and where the majority of unpaid caregivers are involved in providing care. In this paper, we consider the available evidence on integrating caregivers in the LTC setting. In general, caregiver research in post-acute LTC settings lags behind the research on caregiving in acute settings, likely because the need to discharge patients leads to a necessary transfer of caregiving from professional caregivers to the patient's informal or unpaid caregivers. There is much that can be learned from caregiving research in acute settings with some major differences including the longer length of stay and the need for end-of-life planning for LTC residents.

This report presents examples in many Organisation for Economic Co-operation and Development (OECD) countries that provide interventions to support the integration of unpaid caregivers, including the US, Germany, England, Spain, the Netherlands, Ireland, Finland, Hungary, Australia, Austria, and Canada. The majority of these initiatives involve financial supports, respite care, education/training, and COVID-19 specific supports (access to personal protective equipment (PPE), priority to receive vaccines, and testing). Interventions mainly fell into two categories: those that help to recognize unpaid caregivers as essential caregivers and those that support caregiver-staff partnerships.

We provide the following key considerations for policy and practice regarding strategies to integrate unpaid caregivers into LTC facilities/homes and those 'aging in place,' based on the literature and information provided by key informants:

Key consideration 1: A whole-systems approach to LTC is foundational. Recognize that the conceptualization of what constitutes the LTC system needs to expand to include unpaid caregivers, where there is a balanced mix and proper coordination of health care, social care, formal and informal (including unpaid) services. At a system level, efforts must be made to integrate or at least coordinate the formal and informal sectors that provide health and social care services.

Key consideration 2: Understand the barriers hindering integration of unpaid caregiving into the long-term care and support system. Understand the barriers that limit the integration of unpaid caregivers such as lack of skills, poor communication, limited time for interaction and coordinating support, and identify targeted improvements within Canada's provinces and territories. There is no 'one-size-fits all' solution, particularly when different structural divides exist in different places, which disincentivizes interaction between unpaid and formal care, health, and social care, and between home-based LTC and institutionalized LTC. Change and improvement should be tailored to the various contexts across Canada.

Key consideration 3: Designate one key advocate to be part of the care and support team and embed them in a family-council structure. Identify and designate a family or friend advocate who is providing support and integrate them as part of the care team. Create a family council and give them a seat at the table when decisions are being made. In Ontario, family councils have a legislative basis and

during the pandemic it was reinforced by experts that “caregivers and families must be part of the discussions around the pandemic response and involved in developing the broader vision of the Ontario Health Teams.” [1] It is important to empower caregivers and enable clear caregiving roles.

Key consideration 4: Take into account the considerable economic burden borne by unpaid caregivers. Strategies for integrating unpaid caregivers should consider the financial impact on carers’ other paid work, pensions, and overall financial stability. Other countries have implemented pension credits that recognize the time and work involved in caregiving. [2,3]

Key consideration 5: Integrating and supporting unpaid caregivers requires separate strategies. When considering designing or implementing policies and programs, keep in mind the difference between interventions that ‘support’ caregivers verses interventions that ‘integrate’ unpaid caregivers in institutional LTC settings or those ‘aging in place.’

Key consideration 6: Caring for not only residents but caregivers as well – the ‘caring for you, caring for me’ relationship. There is a tendency worldwide to consider unpaid caregivers a convenient resource rather than a group with specific needs of their own, particularly as many are older adults themselves who also may be managing their own health conditions. [4] Recognize that the ‘LTC system’ includes not only residents as clients but their unpaid caregivers – individuals, family, and friends who provide unpaid care but who may also be clients needing formal services to meet their own needs for support. For example, programs could increase adult day program access, increase home support, and increase capacity at respite beds. In this way, caregivers are well supported and able to take a break from caring.

Upcoming research on integration of unpaid caregivers into LTC and those ‘aging in place’

- A review of research that has been funded and currently in progress includes three main foci: pandemic impact on caregivers, support needs for caregivers, and policy reform.
- Longitudinal research on unpaid caregivers’ roles and support needs in settings like long-term care and home care is available through EU-funded initiatives like SHARE, PERISCOPE, RESPOND, and Eurocarers.
- Using lessons learned from international COVID-19 policy responses, research groups in the UK are working to produce policy guidance to inform social care system recovery and reform.
- In Canada, researchers from York University are working on the Re-imagining Long-term Residential Care (RELTC) project focusing on local and international best practices to guide the integration and meaningful engagement of unpaid carers (families) in the planning and organization of care for long-term care residents. The research is still in progress, and it is unclear when the results will be published.

See Appendix 3 for more information on upcoming research in this area including a list of current research groups or programs of research to watch.

Introduction

On *National Caregivers Day* – every first Tuesday of April – Canadians recognize those who are caring for others. One in four Canadians aged 15 and older are unpaid caregivers – the majority in ages 45 to 64 (67%), followed by ages 65 and older (24%), and young adults ages 25 to 34 (17%) in Canada. [4]

Unpaid caregivers are typically spouses, children, other family members, friends, or other non-kin who provide "unpaid and ongoing care or social support to a family member, neighbour, or friend who is in need as a result of physical, cognitive, or mental health conditions." [5–7]

In financial terms, the contributions of this group to health and social care are substantial. In the US, the estimated value of unpaid caregivers' support is about $648 billion in care. [18] In Canada, this figure is $24 to $31 billion annually, [9,10] and in Finland it is estimated that the health care system saves $3.4 billion per year on formal paid professional caregivers. [7]

In Canadian long-term care (LTC) homes/facilities, 96% of long-term care residents have an unpaid caregiver who performs up to 30% of the care[11]. The majority of seniors (92% in 2011) in Canada are aging at home or 'in place,' where caregivers provide about 75% of care. [9,12] In 2018, about 40% of caregivers reported spending 1 to 3 hours per week on caregiving duties, and 21% reported spending 20 or more hours. [13] In Europe, there has been a shift to prefer keeping older adults at home for as long as possible. According to Adlers et al., "the trend of aging-in-place seems to be partly driven by technological advancements, changing preferences and culture, and partly changes in health policy." [14]

Unpaid caregivers typically provide the following type of care and services for care-recipients, often in addition to full-time work and childcare: [15,7,11,15–17]

- transportation
- groceries
- household work and home maintenance
- scheduling appointments/coordinating care
- managing legal obligations and finances
- assisting with medical treatments and accompanying medical appointments
- physical/personal care (feeding, bathing, and dressing) and emotional support
- cognitive stimulation
- assistance in decision-making
- reporting or managing medical treatment or medicine side effects

Unpaid caregivers support the LTC system directly by providing services that are typically done by paid professional LTC staff, and indirectly by helping to keep seniors out of LTC facilities/homes and instead aging in their own homes. [18,19] Paid LTC professionals and governments recognized the importance of unpaid caregivers when the COVID-19 pandemic accentuated the importance of their role after LTC facilities/homes and supportive programs 'shut their doors' to protect residents. [2]

Although research has shown that many unpaid caregivers feel that caregiving is rewarding[20], the lack of support for caregivers themselves has been related to lower life satisfaction, additional stress, and negative impacts on mental health, especially for those who also work outside the home and have family obligations. [4,10,20] Many face modifying their work, homelife, and finances to provide unpaid care, and feel negative health, emotional, and financial effects. [4,10,20] In Canada, "more than one million employed people aged 45-64 provide [unpaid caregiving] to seniors with long-term conditions or disabilities…,"[5] an age where unpaid caregivers may be caring for children and parents at the same time. [4]

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[2] A CanCOVID report, Impact of Restrictive Public Health Measures on Long-term Care Residents, Family and Staff, outlines the visitor policies that were put in place in LTC during the pandemic and discusses the role of unpaid or family caregivers and the degree to which they were considered an integral part of care to residents.

Financial support for unpaid caregivers may be the "[biggest] sources of stress," followed by balancing other paid work. [10] In 2018, approximately one third of Canadian unpaid caregivers indicated that they would have liked to have received financial and governmental support for the care they were providing in addition to the support they were receiving:[21] 68% would have liked to have received financial support, government assistance, and tax credits, 40% would have liked home care or additional support with tasks, 39% would have liked information or advice, and 36% would have liked help from medical professionals. [22] In Canada, unpaid caregivers spent $1.4 billion dollars out-of-pocket to care for people with dementia in 2016. [23] Further, women are disproportionately affected as they make up the majority of unpaid caregivers. In 2018, Canadian women made up a larger share of caregivers spending 20 or more hours per week on caregiving tasks compared to men (64% and 36% respectively), and they tended to provide care that required they be completed on a regular schedule and performed the more 'time consuming' tasks compared to men who tended to performe transportation and house maintenance tasks. [22]

In Europe, women make up about 60% of informal caregivers and do more hours of unpaid caregiving per week compared to men. [2] Similarly, in Ontario, 62% of unpaid caregivers are female. [10] Many often are forced to reduce their paid (non-caregiver) work hours, take time off, take a leave of absence, take a less demanding job, or not work at all,[5,20] without any compensation for their caregiving services.

The Canadian older adult population is increasing; by 2030, it is estimated that one in four adults will be seniors, a 57% increase from the total number of Canadian seniors in 2012. [24] By 2036, it is estimated that the number of Canadians ages 65 and older will be 10.5 million. [25] As such, there is a need for the LTC sector, health professionals, and governmental policies to better support, recognize, engage, and involve unpaid caregivers. [7] This will involve potential changes within the long-term care sector for health care professional practices, and will likely have implications for government policies. These changes could also help to minimize the costs and burdens related to their role and contributions.

Question

This report seeks to answer the following: how have other countries, similar to the Canadian context, integrated essential caregivers (families, friends and volunteers?) into long-term residential care and those 'aging in place?' What were the key learnings, and how can these practices be best applied to the Canadian context?

Box 1: Definitions

'Aging in place': having the health and social supports and services you need to live safely and independently in your home or your community for as long as you wish and are able. [18,19]

Essential care partners: individuals who provide "physical, psychological and emotional support, as deemed important by the patient, [and can] include support in decision-making, care coordination and continuity of care." [26]

General visitor: "neither a family caregiver nor an essential support worker and is visiting primarily for social reasons". [17]

Integrated care: "coherent set of methods and models on the funding, and the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors." [27]

Long-term care: according to Health Canada **"**long-term care facilities provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care, including professional health services, personal care, and services such as meals, laundry, and housekeeping.

Long-term facilities-based care is not publicly insured under the Canada Health Act. It is governed by provincial and territorial legislation". [28]

Unpaid caregivers: typically spouses, children, other relatives, friends, or other non-kin who provide "unpaid and ongoing care or social support to a family member, neighbour or friend who is in need as a result of physical, cognitive or mental health conditions." [5–7]

Methods

In this review, we summarized the results of studies involving qualitative and quantitative data and conducted telephone interviews with key informants in the LTC sector in Canada and abroad. We focused on OECD countries that have introduced policies or measures that aim to either support or integrate unpaid caregivers within the long-term care sector. Using a hierarchical approach, we conducted literature searches in selected databases prioritizing systematic reviews, guidelines, and evidence synthesis that focused on interventions to support, and ways to integrate, unpaid caregivers (appendix 1). We then conducted a search in Google Scholar for grey literature including country reports, policy papers, and government documents for information on policies and measures implemented for supports/integration of unpaid caregivers. There was limited evidence in the literature from OECD countries about their strategies for support and integration of unpaid caregivers. To complement the existing literature, we conducted virtual interviews with experts on caregiving and LTC in Canada and other OECD countries. (Appendix 2).

In the literature there are various terms associated with unpaid caregivers, including 'informal caregivers' (typically used in Europe), and 'family/friend caregivers.' Some argue that the term 'informal caregivers' does not accurately represent – but instead undervalues – the essential care provided by family and friends. [29] For this reason, the term 'unpaid caregiver' and 'family/friend caregiver' will be used in this paper to represent those who "provide care primarily because of a *personal relationship*…[as they are] usually next of kin (spouses, children, or other relatives) but may sometimes be friends or neighbors." [29,30]

Limitations

- Relevant information may have been missed given that the search and this report were completed within a short timeframe.
- We used our best judgment regarding the quality of evidence and not a formal system for rating quality of evidence.
- Given the state of the evidence, we based key considerations on expert opinion as per the key informants consulted for this report.
- We consulted only English-language resources.

Findings

The literature on the integration of unpaid caregivers is concentrated on the hospital and LTC settings and there have been relatively few studies focused on unpaid caregivers in the community or supporting those who are 'aging in place.' In Canada, however, this is where the majority of seniors are living, and where unpaid caregivers are caring. In 2018, 78% of 6,258,500 seniors in Canada lived in a private home owned by a member of their household. [31] More than one-quarter (26%) of seniors lived alone in 2016. As Canada experiences peak population aging over the next two decades, the share of the population that lives alone is likely to continue to increase simply due to the fact that living alone is more predominant among seniors. [32] Caregiver research, particularly on involving family and friends in a resident's care in hard-to-reach communities and in alleviating the care burden on unpaid caregivers, is nascent compared

to the more recognized settings within the health system (hospital, primary care, community settings). This is because long-term care sits in a 'no man's land' straddling a hospital-like, community- and home-like care space and sits outside the formal boundaries of the health and social care sectors, and this is especially true in Canada (but not so in the UK). [33]

Although we found several supports and integration interventions across OECD countries within hospitals and LTC sectors, we found that there was a small number of interventions (such as programs, policies) that were not yet evaluated. More research and evaluation are required to understand the impacts of these interventions, and how successful they are in integrating unpaid caregivers into LTC settings and in assisting those 'aging in place.'

We summarized the findings under strategies that contribute 'supports' for unpaid caregivers, and interventions that promote the 'integration' of unpaid caregivers in both LTC settings and the care of those 'aging in place.' Supports include money, guidance, education, tools, and technology, that assist unpaid caregivers with the care they are providing to their care recipient. In this report, we consider integration to encompass initiatives or actions to include unpaid caregivers within care teams where their care is recognized as essential. This stems from the integrated care model which is a "coherent set of methods and models on the funding, the administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment, and collaboration within and between the cure and care sectors." [27]

Comparing formal verses unpaid care: A typology of European LTC regimes

Table 1 illustrates that Nordic countries tend to emphasize professional solutions to meet LTC needs, hence high levels of formal care. In countries such as Denmark and the Netherlands, less than half their populations consider family-provided care ideal for a parent with LTC needs. In contrast, other countries prize family-provided care: in Eastern and Southern European countries (Poland, Portugal, Spain), filial obligations are the cultural driver for high levels of unpaid care. The typology reflects cultural values that influence expectation of roles and responsibilities; cultural values are dynamic and form the underlying paradigms of each country's LTC regime.

Given that Canada is a country with high levels of unpaid caregiving (96% long-term care residents have an unpaid caregiver that performs up to 30% of the care[11] and unpaid caregivers provide at least 70% of care to those 'aging in place' or living in the community)[9], Canada is probably a country that can be classified as reliant on family/informal-based care as per the typology below, meaning that families (or friends) have a larger role in the care of older adults.

In some countries, policy interventions have tipped the balance of informal/formal care provision. The experience in Italy is noteworthy here: since 2002, the migrant workforce for LTC was legalized and the 'non-formal' workers are now considered part of the formal care provision system. [34] In contrast, in countries with low formal care provision – such as Spain and Portugal, large numbers of informal care workers provide care, often illegally, and act as substitutes for family or professional carers, and 'black markets' for such services exist in countries such as Romania, Russia, and Ukraine. [34]

Table 1: Typology of European long-term care regimes - unpaid vs. formal care[35]

Type	**Unpaid (Informal) care**	**Formal (Professional) Care**
Family-based *Spain, Portugal, Ireland, Greece*	Medium	Low
Public-Nordic *Sweden, Denmark, Netherlands*	Low	High

Standard-care mix *Germany, Austria, France, Italy, UK*	Medium/Low	Medium
Transition *Hungary, Poland, Czech Republic, Slovakia*	High	Medium/Low

Adapted from: Typology of European long-term care regimes

Supports: Interventions to support unpaid caregivers

The main interventions/policies supporting unpaid caregivers among OECD countries were financial supports, guidance/education/training (including virtual care supports), and COVID-19 specific supports. In response to the COVID-19 pandemic, Sweden did not provide additional supports for unpaid caregivers during the COVID-19 pandemic. [36]

Financial supports[36]

In a systematic review on unpaid caregivers who are caring for those with dementia, the greatest impact on the economic cost of dementia was found to be an indirect cost borne by caregivers since the majority had to stop working in order to be a caregiver. [37,38]

Cash-for-care benefits provided in some jurisdictions to support those who are aging at home are "direct public transfers paid to LTC recipients or their caregivers to support care at home where it is provided by professional health care workers or by family or friends… these cash benefits give more control over how care is organized and provided, and hence more autonomy." [39] For Canada, the goal of financial supports should be to "maximize care recipient's autonomy, address unmet LTC needs" and ensure that women (who are mostly caregivers) are supported with "measures [that] strengthen job-protected leave legislation and supplementing Canada Pension Plan contributions for caregivers." [39] In Canada, financial benefits for caregivers include:

- **Employment Insurance Compassionate Care Benefits.** This provides care benefits up to six months for those who need to take time off of work to provide care to someone who is very ill and risk of dying within six months. [40]
- **Employment Insurance Family Caregiver Benefit for Adults.** Adults who need to take a leave of absence from work to take care of an adult family member who is critically ill or injured, can receive EI benefits for up to 15 weeks. [40]

Despite the existence of these short-term supports, there is variation across Canada with respect to employer benefits and pensions in relation to caregiving. The Government of Canada website provides guidance and information for caregivers. [40]

The OECD countries listed in Table 1 have implemented programs/policies that aim to provide monetary support for unpaid caregivers, to recognize their work and reduce associated costs. These can be distilled into three types of financial supports: (1) those that are provided directly to the caregiver; (2) those that are provided to the care recipient to pay for caregiving; and (3) those that help to protect an unpaid caregiver's paid non-caregiving job affected by their caregiving role. Table 2 provides examples of financial supports in these three domains and examples of polices and interventions implemented by OECD countries.

Table 2: Types of financial supports and examples from OECD countries

Type of financial support	Countries where implemented	Examples
Financial supports provided directly to the caregiver	US, Germany, Ireland, Spain, Finland, Hungary	• Cash-for-care benefits as part of public insurance plans (Germany & the Netherlands). [39] • Carers Allowance that provides repayment of care during the COVID-19 pandemic for those with low incomes, with additional payments if the carer lost their job .[36] (Ireland) • Self-directed Medicaid funds, financial support programs or tax credits in some US States. [41] (US) • "Mortgage debt moratorium" offering support for caregivers with mortgages. [36] (Spain) • Employing family or unpaid caregivers directly and paying them a salary to compensate for loss of work or reduced work hours or costs associated with their care (Scandinavian countries) – these benefits are to help keep the aging population at home for as long as possible. [7] • Social Security Caregiver Credit Act is a social security credit added to a person's total career earnings for caregivers who spend 80 hours per month caring. [41] (US) • Credit for Caring Act is a US bill that would provide up to $5,000 federal tax credit for those working and also providing unpaid caregiving. [41] (US)
Financial support provided to the care recipient who can pay for their caregiving needs	US, Germany, Sweden, the Netherlands	• Money provided monthly through stipends for those who require caregiving. [36] (US and Germany) • Cash-for-Care schemes. [7] (England, Sweden, the Netherlands) • Medicaid Self-Directed Program allows care recipients to hire family members as carers. [41] (US)
Policies that protect caregiver's jobs that are affected by their caregiving role	US, Germany, England, Spain, the Netherlands	• Providing unpaid caregivers with the right to request a leave of absence, and maintain 80% of their income (England), and reduce employment (Germany). [36] • Provide access to interest-free loans to cover costs from caregiving duties. [36] (Germany) • Caregivers that receive cash benefits for their unpaid caregiving are protected by a work contract and can access social security benefits. [7,14] (the Netherlands) • Paid emergency leave of absence: short-term (few days for death or sudden illness, and up to 10 days per year with 70% of earnings), and long-term unpaid leaves. [7] (the Netherlands) • Family Medical Leave Act provides up to 12 weeks of unpaid job-protected time off work to care for a person in need of care with a serious health condition. [41] (US)

		• Caregivers Alberta and MatchWork have created a new platform that aims to help unpaid caregivers find flexible work opportunities so that they can find work that is meaningful and that allows them to juggle caregiving. [42] (Canada)

Respite care

Respite care programs provide unpaid carers with breaks from caregiving (i.e., in-home care, adult day services, and overnight care). The main goal of respite care is to help with reducing stress and burden from caregiving and is effective at supporting caregivers' employment in combination with other services. [7,43] In many OECD countries, respite care is not usually subsidized, and if it is, there are funding limits, such as in Germany and Austria. [7]

There are directly funded home care programs that serve a small portion of home care clients in Canada and are designed to target specific population groups. That figure is 40 percent in Newfoundland and Labrador, 20% in New Brunswick, and 10% in the rest of the Canadian provinces who access directly funded home care programs. [44]

The *Lifespan Respite Care Program* and the *National Family Caregiver Support Program* in the US provides grants to US states to assist with respite care but also assists with accessing services, counselling, support groups, and caregiver training. [41] The *Department of Health's National Carers' Strategy Demonstrator Sites* programme in the UK included a total of 12 sites that provided carers with breaks from caring, and found that caregivers felt they had more time for themselves and had positive outcomes for their health and wellbeing compared to those who did not use this service to have a break. [43] In British Columbia Canada, the B.C. Home and Community Care program offers three ways to provide caregivers with breaks: the adult day programs, home support where professionals support with caregiving tasks, and the residential care respite where the care-recipient can temporarily stay in residential care for one to two weeks. [12]

Guidance/education/training

OECD countries including Australia, Austria, England, Ireland, the Netherlands, Spain, and the US provided guidance and educational supports to unpaid caregivers during the COVID-19 pandemic. Guidance and education in these countries were delivered through information on websites including lists of supports available in their country or town, phone services, and physical copies of booklets and guidelines available at Town Halls. [36] Most resources were meant for unpaid caregivers, for example, providing a list of meaningful activities for those caring for someone with dementia, hygiene standards, and what to do if the person in need of care develops symptoms of COVID-19. [36] In Canada, there are general guidance documents, not specific to unpaid caregivers, that provide information on how to care for someone who may have been exposed to COVID-19. [45]

Other forms of educational materials were directed towards physicians, including guidelines for general practitioners (GPs) to help support unpaid caregivers and provide management services for those 'aging in place' who develop COVID-19 symptoms. Additionally, the US created guidelines for hospitals to record patient caregiver names in health records for caregiver identification and to communicate important information to caregivers (more about this will be discussed in the following section on integration of unpaid caregivers). There are also volunteer programs that leverage peer-to-peer support. The Finnish Expert Caregiver program leverages the skills of past caregivers to help train current caregivers. A study evaluating the program noted that former caregivers felt it was a positive experience giving them a "sense of belonging" to help current caregivers. [46]

Tools & technology; virtual care supports

Prior to the COVID-19 pandemic, Sweden provided online and technical supports including e-care, e-health, peer support and e-learning, to educate unpaid caregivers about caregiving. They also provide support groups and centres dedicated to support carers.[7] The *Caregiver Support Line* in British Columbia Canada is a service that provides support and advice to informal caregivers.[12] There are also one-on-one caregiver consults that the Family Caregivers of BC offers to caregivers especially those who are caring for those with complex needs.[12] The *CHATS Caregiver Support & Education Program* supports caregivers through consultations and counselling, support groups, workshops, information, and referral services.[47]

Due to the public health restrictions imposed by the COVID-19 pandemic, the use and development of virtual care supports, and the use of technology were essential for unpaid caregivers to support their care-recipient. Smart phones, personal computers, and social media were used to keep in touch with family members, relatives, and friends, to take care of finances, to obtain information about current pandemic events, and to keep in touch with carer/patient organizations. [3] The US, England, Australia, Austria, Finland, Germany, Ireland, and Spain provided funding to existing helplines that offered advice for unpaid caregivers and virtual peer support for older adults who were socially isolated, created private Facebook groups managed by health care professionals, social workers, and volunteers for advice and resources, and provided online carer training programs for unpaid caregivers. [36]

For unpaid caregivers caring for those with dementia, informational platforms increased caregiver knowledge about dementia and improve their quality of life. Some of the web-based platforms and technologies for those with dementia include the Internet-Based Savvy Caregiver Program, Caring For You, Caring for Me, the STAR-Caregivers program, the SCORE Program, the Tele-Savvy program, and the WeCareAdvisor program. [48]

COVID-19 benefits, testing and vaccines

During the pandemic, countries including Australia, England, USA, and the Netherlands, implemented support measures specific to the COVID-19 pandemic, including giving unpaid caregivers priority status for vaccines (Australia, England, USA), allowing them to access testing if they felt any symptoms (England, the Netherlands), and provided access to free PPE if the caregiver was supporting a vulnerable person experiencing symptoms of COVID-19 and required care (the Netherlands). [36,49] Interestingly, Ireland implemented a National Helpline with telephone or video call services with nurses or advisors for those who are caring for a person with dementia. [36] Although in Canada, unpaid carers were eligible to obtain the Canada Emergency Response Benefit (CERB) from March 2020 to September 2020, and then the Canada Recovery Caregiving Benefit (CRCB), that gives income support to employed and self-employed individuals who are unable to work because they must care for a child under the age of 12 or a family member who needs supervised care and applies only if: “if their school, regular program or facility is closed or unavailable to them due to COVID-19, or because they are sick, self-isolating, or at risk of serious health complications due to COVID-19.” [50] However, in British Columbia the government doubled the 2020 fund for family caregivers to $1 million in their emergency COVID-19 response plan. [49]

In general, even when restrictions are put in place and there is a COVID-19 outbreak, nursing homes are recommended to allow family caregivers in the home one at a time and access both indoor and outdoor areas with some conditions met to protect the care recipient. [51] They undergo screening and testing requirements, wear proper PPE, and are educated on how to properly wear PPE.

Integration: where do unpaid caregivers currently fit in the social and health care systems?

In providing support for a care recipient, unpaid caregivers often straddle the divide between the social care system and the health care system. [34] Typically, family and friends contribute a mix of health care support as well as social care work, whereas volunteers in long-term care settings might primarily perform

social care work such as socialization and recreational activity support. Figure 1 below illustrates the formal-informal divide as well as the health-social care divide. Any efforts towards integration must concurrently consider the integration across formal caregiving and unpaid caregiving as well as health and social care divides.

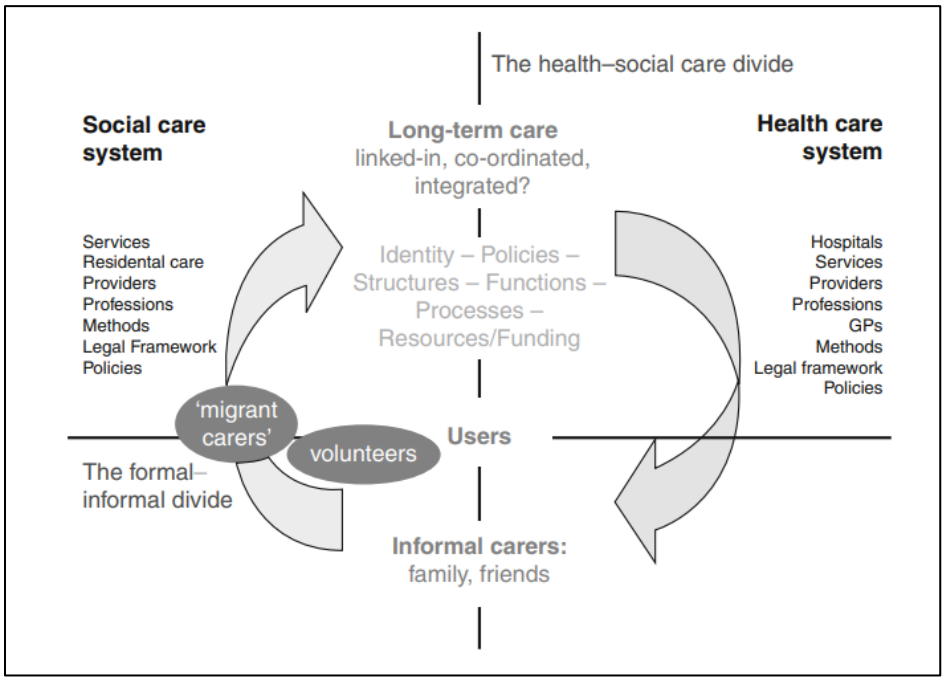

Figure 1: Integrated long-term care and unpaid (or informal) caregivers[34]

In addition, any efforts towards integration should keep in mind financial, mental, and social effects on unpaid caregivers, especially those who are caring for those 'aging in place.' In the effort to integrate unpaid and formal care, intentionally and unintentionally the burden of care can shift to unpaid caregivers. Therefore, any efforts towards integration should be mindful of the mental, physical, and economic effects on unpaid caregivers especially those caring for adults who are 'aging in place.' Hidden cost burdens arise which impact the economic, mental health, and physical wellbeing of unpaid caregivers. Sweden, which has put in place reductions in institutionalized care and experienced cutbacks in LTC services, has seen negative consequences as families and caregivers expanded to fill the gaps in service and placements. [52,53] This includes placing more responsibilities on families and caregivers to help their care recipient navigate the health and social care systems, leading to increases in people quitting their jobs or reducing their working hours to provide care, as well as decreases in quality and efficiency in LTC, and decreases in job satisfaction by LTC workers. [54]

Integration: How are OECD countries integrating unpaid caregivers?

In this section, we present a summary of a set of recommendations identified in the literature and/or as expressed by our key informants during interviews. We also highlight interventions, policies, and programs that aim to better integrate unpaid caregivers and their effectiveness/impact on unpaid caregivers, although, to our knowledge, many of these policies/programs/interventions have yet to be evaluated and/or the results have yet to be published. We grouped these interventions into two main areas: 1) interventions that help recognize unpaid caregivers as essential care partners; and 2) interventions that support the creation of caregiver-staff partnerships.

When considering ways (or interventions) to integrate unpaid caregivers into LTC, the Healthcare Excellence Canada advisory panel,[55] and other groups,[1,5,51,56,57] have recommended that to "reintegrate caregivers as essential care partners" the strategies (or interventions) should be guided by these seven principles:

1. Recognize unpaid caregivers as essential care partners. [1,5,51,55–57] View unpaid caregivers as essential to the health and social wellbeing of care-recipients. Distinguish unpaid caregivers from visitors as they provide more than just a social visit and ensure a foundation of patient and family-partnered care.

2. Give caregivers a "seat at the table" when making decisions and developing policies. Create a family council and give them a seat on the table when programs or decisions are being made and ensure that they are part of the decision-making process. In Ontario, "caregivers and families must be part of the discussions around the pandemic response and involved in developing the broader vision of the Ontario Health Teams." [1]

3. Provide caregivers with an avenue to appeal decisions that they do not agree with. Establish a rapid appeal process, to allow caregivers to appeal decisions made by LTC facilities/homes or other policies related to the care-recipient if they feel they are not justified. For example, if LTC facilities/homes were to restrict visitation, this rapid appeal process would provide unpaid caregivers with an avenue to appeal this decision if they do not agree. [55–57]

4. Provide tailored support interventions for unpaid caregivers. This includes addressing the economic security of unpaid caregivers[5], and providing education, training, and tools to support their caregiving.

5. Consider the needs of people who face specific risks without the presence of family caregivers as essential partners in care. [55]

6. Take a comprehensive, balanced approach to assessing risk. [55]

7. Increase research evidence to guide decisions regarding family caregiver presence as essential partners in care. [55,56]

The barriers to integrating unpaid caregivers into LTC and health teams have been summarized as follows[58]:

- Identifying the caregiver – the name and contact information is not consistently recorded in health records, or many caregivers do not self-identify as caregivers.
- Communicating and sharing important information related to caregiving. Many caregivers do not have the medical background or training required to provide care, and they require information and training to perform their caregiving responsibilities.
- Clinical providers have limited time and resources to interact with family members.
- Trust and cultural barriers that make it difficult to interact with family caregivers.

1. Integration: intervention to help recognize unpaid caregivers as essential caregivers

Caregiver-centred care is care that is focused on building a "collaborative working relationship between families and health and community care professionals, with professionals supporting [unpaid caregivers]." This type of care distinguishes the caregiver from a visitor – it respectfully acknowledges that the term visitor does not accurately represent the role of unpaid caregivers. [15] Instead, they are recognized as

members of the care team, and require information, training, care, and support to continue caring for the care recipient. [15]

The following are ways that unpaid caregivers can be recognized for their essential care and be distinguished from visitors:

- Have care recipients in LTC choose their own unpaid caregivers (at least two) and have this documented in the LTC resident's records and care plan. [51]
- Legislation implemented in most US states—*Caregiver, Advise, Record, Enable (CARE) Act*— "requires hospitals to record the name of the family caregivers for a patient in hospital records, to consult with caregivers when a patient is to be discharged from the hospital, and to provide instructions about medical tasks that the caregivers will need to assume after a patient's release." [58]
- If visitation restrictions are implemented in the future, allow designated caregivers to co-habit with the care recipient in LTC homes, especially for care-recipients who are mentally and physically impacted by restrictions. [15]
- In recognition of the importance of providing supports for unpaid caregivers, the US federal government created the *Recognize, Assist, Include, Support and Engage (RAISE)* Family Caregivers Act which is a "council of diverse informants who were charged with developing a national strategy and plan to support family caregivers." [58,59]
- The European Care Strategy is a long-term care initiative focused on supporting "men and women in finding best care and best life balance" that will help LTC better recognize unpaid carers and acknowledge their work. [2,60]

2. Integration: interventions that support caregiver-staff partnerships

The creation of family-staff partnerships is essential to better communication between caregivers and health care staff, to build trust, and, ultimately, to work together to provide the best possible care for those in need. This type of care is grounded in mutually beneficial partnerships among health care providers, patients, families, and caregivers. [26]

In the Netherlands, increasing better collaboration between family caregivers of those with dementia and staff in nursing homes involves[61]:

- "communication: A way of having contact or interaction with staff, either formal or informal"; [61]
- "trust and dependency: feeling highly responsible for a relative while being dependent on staff care provision and deciding whether to trust staff by monitoring and creating a personal connection"; [61] and
- "involvement: being involved in relative's daily life by means of looking after the relative and keeping control over relatives' daily life by visiting and caring for the relative." [61]

The following is a list of interventions that we have identified to help integrate unpaid caregivers through creating meaningful partnerships:

- *Veterans Affairs (VA) Campaign for Inclusive Care,* established in January 2020, is a US program that targets health care providers. Their aim is to identify caregivers, reduce trust and cultural barriers, and reduce time limitations and competing demands faced by health care staff. The program trains health care providers to best integrate unpaid caregivers into care coordination. The program aims to make it a practice for providers to include unpaid caregivers into the care and coordination of the patient. [58,62]

- *Family Involvement in Care Program* designed in the US "negotiates and establishes partnerships and cooperative role behaviours between family caregivers of cognitively impaired residents and nursing home staff members." [16] The program was comprised of education sessions, and the development of a partnership agreement between families and staff and held monthly catch-up

meetings. This program was shown to strengthen partnerships between caregivers and nursing home staff compared to those facilities that did not implement the program.[16] However, it was also found that staff faced increased stress and role strain, and decreased satisfaction with care. [57]

- *Partners in Caregiving Program* designed in 1998 was to "intervene not only on the part of family members, but also to engage staff and administrators to effectively change facility policies." [16] The program involves training in communication and listening, and group discussions for nurses, nursing assistants and family members, which reduced caregiver and staff conflict in nursing homes for about six months. [16] This program saw small improvements in integrating unpaid caregivers, but unpaid caregivers and staff expressed that they would recommend this program to others. [57]

- *Walcheren Integrated Care Model*, implemented in the Netherlands prior to the COVID-19 pandemic, was "promising but modest" and supported that integrated care can benefit unpaid caregivers. [6] After undergoing evaluation, the model did reduce the "subjective burden" of unpaid caregivers meaning that they experienced "fewer problems and more support and satisfaction." [6] However, it did increase the amount of household tasks that the unpaid caregiver assumed. Box 2 summarizes the characteristics of the model.

- Educational sessions and informational resources (pamphlets, brochures) for health care staff to improve family-staff interactions and also for family members, to improve their knowledge and emotional support. [57]

- *Family Intervention: This US Telephone Tracking – Nursing Home (FITT-NH)* aims at "improving family members' adjustment following residents' nursing home admission including emotional support, directing them to appropriate resources and teaching them strategies to cope with ongoing problems related to nursing home placement." [57]

- *Chronic Grief Management Intervention* is a US program for unpaid caregivers that provides education to those who are caring for those with dementia and teaches communication and conflict resolution with staff, and grief management. [57]

  Taking Care of Myself Program empowers Canadian unpaid caregivers to better communicate with staff by expressing their views and also helping them have better visits with those who have dementia. [57]

- Providing more formal care services for care-recipients, reduces the amount of unpaid caregiving. A review showed positive relationships between the use of formal care and employment including higher probability of being employed. [43] In the UK, the 2014 Care Act recognizes the importance of providing formal care services for care recipients to support the employment of unpaid caregivers. [43]

Box 2: Walcheren Integrated Care Model[6]

This model is focused on frail elderly individuals 'aging in place' or living in their own homes or an assisted living facility, and informal caregivers. The model provides a comprehensive assessment of the identified frail elderly and the unpaid caregiver to determine the needs of the elderly person, and the needs of the unpaid caregiver and a care plan is formulated. A case manager assists with the following available to unpaid caregivers:

- Respite care services for temporary relief

- Coordinate care
- Education and training
- Group counselling and emotional support

Conclusion

To conclude, we provide the following key considerations when thinking about integrating unpaid caregivers into LTC facilities/homes and those 'aging in place' based on the literature and information gathered by key informants:

Key consideration 1: A whole-systems approach to LTC is foundational. Recognize that the conceptualization of what constitutes the LTC system needs to expand to include unpaid caregivers, where there is a balanced mix and proper coordination of health care, social care, formal and informal (including unpaid) services. At a system-level, efforts must be made to integrate or at least coordinate the formal and informal sectors that provide health and social care services.

Key consideration 2: Understand the barriers hindering integration of unpaid caregiving into the long-term care and support system. Understand the barriers that limit the integration of unpaid caregivers such as lack of skills, poor communication, limited time for interaction and coordinating support, and identify targeted improvements within Canada's provinces and territories. There is no 'one-size-fits all' solution particularly when different structural divides exist in different places, which disincentivize interaction between unpaid and formal care, health and social care, and between home-based LTC and institutionalized LTC. Change and improvement should be tailored to the various contexts across Canada.

Key consideration 3: Designate one key advocate to be part of the care and support team and embed them in a family-council structure. Identify and designate a family or friend advocate who is providing support and integrate them as part of the care team. Create a family council and give them a seat at the table when decisions are being made. For example, in Ontario, family councils have a legislative basis and during the pandemic it was reinforced by experts that "caregivers and families must be part of the discussions around the pandemic response and involved in developing the broader vision of the Ontario Health Teams." [1] This has also been emphasized by the BC Seniors Advocate in 2020 which stated that the "Ministry of Health work with the Office of the Seniors Advocate to establish a Long-Term Care & Assisted Living Resident and Family Council Association." [63] Empower caregivers and enable clear caregiving roles.

Key consideration 4: Take into account the considerable economic burden borne by unpaid caregivers. Strategies for integrating unpaid caregivers should consider the financial impact on carers' other paid work, pensions, and overall financial stability. Other countries have implemented pension credits that recognize the time and work involved in caregiving. [2,3]

Key consideration 5: Integrating and supporting unpaid caregivers requires separate strategies. When considering designing or implementing policies and programs, keep in mind the difference between interventions that 'support' caregivers verses interventions that 'integrate' unpaid caregivers in institutional LTC settings or those 'aging in place.'

Key consideration 6: Caring for not only residents but caregivers as well – the 'caring for you, caring for me' relationship. There is a tendency worldwide to consider unpaid caregivers a convenient resource rather than a group with specific needs of their own. Recognize that the 'LTC system' includes not only residents as clients but their unpaid caregivers – individuals, family, and friends who provide unpaid care but who may also be clients needing formal services to meet their own needs for support. For example, programs could increase adult day program access, increase home support, and increase capacity at respite beds. In this way, caregivers are well supported and able to take a break from caring.

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Appendix 1: Search terms

Table 3: Search results

Database	Search Terms/ Strings	Search Yield(n)	Screened (n/type of evidence)	Included (n)
WHO COVID-19 Global Literature	tw:((tw:(long-term care)) OR (tw:(residential facilities)) OR (tw:(nursing home)) AND (tw:(caregivers))	114	114	10
	tw:((tw:(long-term care)) OR (tw:(residential facilities)) OR (tw:(nursing home)) AND (tw:(informal carers))	97	97	11
Epistemonikos	(long-term care OR residential care OR nursing home) AND (family caregiving OR informal carers OR unpaid carers)	3	3	/
	(long-term care OR residential care OR nursing home) AND (family engagement OR informal OR unpaid)	89	89	1
TRIP	Keyword search: family, long-term care, covid	578	95 screened Systematic /Scoping Reviews)	/
Health Systems Evidence Database	Keyword search: informal carers, long-term care	26	26	/
LitCOVID	long-term care OR long-term home OR residential facilities OR nursing home AND unpaid carers	35	35	3
Google Scholar	Search terms including long-term care, long-term home, residential facilities, nursing home, unpaid carers, family engagement, family inclusion, informal care	Approximately 2,000	First few pages for each search yield	20

Appendix 2: Key informants interviewed

No.	Name, credentials
Canada	
1.	Dr. Amy Hsu, PhD Investigator at the Bruyère Research Institute uOttawa Brain and Mind-Bruyère Research Institute Chair in Primary Health Care in Dementia (2019-2024)
2.	Professor Colleen Flood University Research Chair in Health Law & Policy University of Ottawa
3.	Dr. James Conklin, PhD Associate Professor, Applied Human Sciences Investigator, Bruyére Research Institute Concordia University Montreal
4.	Ms. Maggie Keresteci, MA, CHE Executive Director, Canadian Association for Health Services and Policy Research
Denmark	
5.	Mrs. Louise Weikop Head of Quality and Innovation in the Municipality of Aalborg, Denmark

Appendix 3: Summary of selected upcoming research

Selected Upcoming Research – Support for Unpaid Carers and Integration into Long-Term Care

Funded research on COVID-19 and unpaid carers that is currently in progress (not a comprehensive list) covers three main foci: the impact of the pandemic on caregivers, support for caregivers and policy development or reform regarding unpaid care in long term care. Current research on the role and integration of caregivers includes quantitative and qualitative approaches to understanding the impact of the pandemic, caregiver roles and responsibilities, strategies for engagement and integration into health and social care, as well as implications for reform in policy and practice.

- In Europe, on-going longitudinal data collection on older adults and their caregivers (including informal caregivers) is conducted through EU-funded research groups like SHARE (Survey of Health, Ageing and Retirement in Europe), PERISCOPE (Pan-European Response to the impacts of COVID-19 and future pandemics and epidemics) and RESPOND (Improving the preparedness of health systems to reduce mental health and psychosocial concerns resulting from the COVID-19 pandemic). In addition, the European network representing informal carers and their organizations (Euro carers) frequently conducts research with unpaid caregivers to explore their role in long-term care and home care. We recommend these research groups' reports and online platforms as sources for recent and updated information on European unpaid caregivers' situations, demands, opportunities for action, and new research initiatives.

- In the United Kingdom, upcoming research will add to current knowledge on the impact of COVID on unpaid carers' wellbeing, experiences, and satisfaction with the social care system from the perspective of underrepresented groups like ethnic minorities, LGBTQ+ communities, and older

caregivers. In addition, the UK's LTC-COVID branch leads the research project on social care system reform using lessons learned from international COVID-19 policy responses.

- In Canada researchers from York University in Ontario have been working locally and internationally to publish sets of best practices to integrate and engage families and unpaid carers meaningfully into the planning and organization of care for long-term care home residents. In addition, the Nova Scotia Centre on Ageing's projects such as 'SALTY (Seniors-Adding Life to Years),' 'Home care pathways,' and 'Long Term Care Support Visitations During COVID-19 Pandemic' will provide insights on innovative approaches to care relationships including informal caregivers as well as the impact of caregiver support on patients' care pathways. Finally, a CIHR funded project 'Perennial Policy Issues in Directly-Funded Home Care in Canada: An Intersectional, Qualitative Study to enhance Social and Health Outcomes' led by researchers from across Canada focuses on three perennial policy issues; 1) the role of home care agencies in the directly funded home care service delivery; 2) developing directly funded options as a niche or mainstream programs; and 3) adapting directly funded options for rural contexts. [64]

Table 4: List of upcoming research or research in progress on unpaid caregivers*

Project Name	PI	Country/Province	Description	Link
Seniors-Adding Life to Years (SALTY)	Janice Keefe	Canada (British Columbia, Alberta, Ontario, and Nova Scotia)	Aim: SALTY is a four-year project which aims to add quality of life to older adults living in residential long-term care and for their caregivers, including family, friends, and volunteers who support their care. Description: SALTY's research is organized into four interrelated streams: Monitor Care Practice, Map Promising Approaches to Care Relationships, Evaluative Innovative Practice, and Examine Policy Context and the study will employ diverse and multiple methods to achieve its objectives. The SALTY team includes established and emerging researchers, decision makers, clinicians, and representatives for staff, volunteers, family, and residents. The study is being conducted in four Canadian provinces – British Columbia, Alberta, Ontario, and Nova Scotia – and its results will have relevance for other jurisdictions. Funder: Canadian Institutes of Health Research, Nova Scotia Health Research Foundation, Michael Smith Foundation for Health Research, Alzheimer Society of Canada. Start date: April 2016	https://www.msvu.ca/research-at-the-mount/research-chairs/centres-and-institutes/nova-scotia-centre-on-aging/projects/current-projects/
Home Care pathways	Janice Keefe, Susan Stevens, Michelle Lobchuk	Canada (Nova Scotia, Manitoba)	Aim: This multi-site project will generate evidence to understand how approaches to care shape the pathways of older adult home care clients with chronic and long term conditions through the home care system. Description: Project activities to include retrospective analysis of home care client assessment data, interviews with members of	https://www.msvu.ca/research-at-the-mount/research-chairs/centres-and-institutes/nova

			care constellations (clients, caregivers, workers, health care practitioners), and review of key policy documents Funder: Canadian Institutes of Health Research Start date: April 2018	-scotia-centre-on-aging/projects/current-projects/
Long Term Care Support Visitations During COVID-19 Pandemic	Janice Keefe, Stephanie Chamberlain, Melissa Andrew	Canada (Nova Scotia, Prince Edward Island)	Aim: This multi-site implementation science project will examine the barriers and enablers to support visitation programs in long-term care homes during the COVID-19 pandemic. Description: Four care homes in Nova Scotia and two care homes in Prince Edward Island are study sites. Project activities include survey of facility characteristics and review of relevant documents, interviews with care home staff, and family/friends approved as designated caregivers/partners in care. In addition, consultation with three other jurisdictions implementing similar family visitation programs will be undertaken. Funder: Canadian Institute of Health Research Start date: December 2020 Note: The project timeline was until October 2021, but it is not clear if the results have yet been published. However, a recording of a presentation can be found here: https://ltccovid.org/2021/11/09/family-visitation-programs-during-covid-19-long-term-care-restrictions-the-role-and-experience-of-staff-canada/	https://webapps.cihr-irsc.gc.ca/decisions/p/main.html?lang=en#sort=namesort%20asc&start=0&rows=20
Re-imagining Long-term Residential Care	Pat Armstrong, Donna Baines, Martha MacDonald, Hugh Armstrong, Jacqueline Choiniere, Tamara Daly, James Struthers, Albert Banerjee, Sally Chivers	International Canada, the U.S., the U.K., Sweden, Germany and Norway.	Aim: An international study of promising practices for planning and organizing long-term residential care that allow residents and their care providers to flourish and be treated with dignity and respect. Description: Umbrella hub for a series of research projects divided into four overlapping areas to deal with the complexity in long-term residential care: (1) Approaches to Care: What approaches to and what models of care support long-term care as a viable, desirable and equitable option for individuals, families and caregivers, in the process promoting and supporting a more inclusive notion of citizenship?, (2) Work Organization: What kinds of work organization and rewards are most promising in meeting the needs and balancing the rights of residents, providers, managers, families, and communities?, (3) Accountability: What are the promising practices in approaches to accountability that nurture care and inspire quality workplace relations in long-term residential facilities?, and	https://reltc.apps01.yorku.ca/

			(4) Financing and Ownership: What innovative financing and ownership models are promising in terms of ensuring equitable access to quality long-term residential care while reducing the offloading of both material and other costs onto workers, employers, families, or individuals? Funder: Social Sciences and Humanities Research Council of Canada	
Covid-19, families and long-term residential care	Pat Amstrong	Canada / Ontario	Aim: The goal of this project is to identify promising practices for family engagement now and in the future, with a view that includes but goes beyond safety to make care as good as it can be and brings joy to families, residents, and staff. Description: This project will identify principles and processes for family engagement in the post-COVID19 environment with support from partner organizations such as Family councils Network Four, Champlain Region Family Council Network; Ontario North Family Council Network Funder: Social Sciences and Humanities Research Council of Canada Start date: 2021	https://reltc.aps01.yorku.ca/covid-19-familes-and-long-term-residential-care
Changing Places, Unpaid Work in Public Spaces	Pat Amstrong	Canada (Ontario), United Kingdom, Norway, Sweden	Aim: The goal of this project is to identify and assess promising conditions of care for resident and family work as they vary among settings in Ontario, the U.K, Norway, and Sweden, and between urban and rural areas. Description: This project looks at the changes in self-care and family care work when moving from home to residential care as well as the conditions which support unpaid work that is rewarding and meaningful for families and residents. Funder: Social Sciences and Humanities Research Council of Canada Start date: 2017	https://reltc.aps01.yorku.ca/related-projects/changing-places-unpaid-work-in-public-places
Family Carers and COVID-19: A Rapid Integrated Mixed Methods Systematic Review	Monica Parry, Ann K Bjoernnes	Canada	Aim: The overall goal of this project is to develop a population-based program to improve the mental health and well-being in family carers of COVID-19. Description: Two-phase project in which Phase 1 (current proposal) is a 6-month project to summarize the published, unpublished, and grey literature related to the mental health and well-being of family carers. Results from Phase 1 will inform Phase 2, which is the development of a population-based	https://cihr-irsc.gc.ca/e/52072.html

			intervention. The logic model of the Caregiver Support Framework and research team's previous experience / expertise in synthesizing the literature will be used to identify gaps and plans for improvements. The search strategy involves a broad search of published papers describing the approaches used to improve the mental health and well-being of family carers (i.e., informal or unpaid adult family caregivers over 18 years of age caring for adults or children) during communicable disease outbreaks (e.g., SARS, Ebola, COVID-19). This information will be presented as a knowledge map (e.g., visual aid) to describe the age, sex, ethnicity, and geographical spread. Then two rapid searches of the unpublished and grey literature (e.g., guidelines, policies, websites, public health campaigns) will be conducted to determine: 1) the mood, thinking, and behaviours (including substance use) of family carers during COVID-19, and 2) how approaches are used to improve the mental health and well-being of family carers during COVID-19. The knowledge mobilization plan includes updating the first knowledge map to include unpublished and grey literature related to COVID-19. The rapid search results will be integrated into the knowledge map and applied to the Caregiver support framework to inform the phase 2 proposal (population-based intervention), public/conference presentations, and lay summaries/open access publications. Funder: Canadian Institutes of Health Research Start date: 2020	
The Impact of the COVID-19 Pandemic on Veteran Caregivers: A Mixed Methods Study to inform the VA Caregiver Support System	Lauren Penney	United States	Aim: The objectives of this study are (1) To describe both positive and negative caregiver experiences during the COVID-19 pandemic and to identify threats to long-term caregiver resiliency. (2) To provide preliminary data and debrief with VISN and national level VA stakeholders to understand how these issues are perceived and responded to at regional and national levels, and their priorities for caregiver services and research. (3) To engage Veteran caregivers in a participatory, deliberative process to identify top priorities for future research and intervention. Description: This study provides a unique opportunity to learn about an essential ally in the care of Veterans, and the ways in which the VA system can enhance their support for Veterans experiencing functional and clinical impairment. This study combines an ecological	https://reporter.nih.gov/search/nkw_TgJLukSvmhYj9rhfSw/project-details/10188706

			systems framework and the concept of 'cascading effects' from disaster research to help frame and understand the different complex short- and long-term effects caregivers may experience. This is a 15-month, multi-sited (San Antonio, Palo Alto, Miami, Salt Lake City, Durham), mixed methods study, utilizing a brief Veteran caregiver survey, semi-structured interviews with caregivers and VA stakeholders, and virtual focus groups with caregivers. Funder: National Institute of Health Start date: 2021	
Social Care Recovery & Resilience: Learning lessons from international responses to the COVID-19 pandemic in long-term care systems	Adelina Comas-Herrera	United Kingdom	Aims and objectives: Facilitate learning from the scientific evidence and relevant experiences of other countries in preventing and mitigating COVID, as well as recovering from its impacts in social care setting through co-development of a framework to provide strategic direction for how the social care sector in England can recover from, and respond to, COVID-19 (social care sector is defined as care provided in residential and community settings, by paid and unpaid carers). Description: This project will consist of synthesis of international evidence and lessons learned that are relevant to the English social care sector using scoping reviews of empirical evidence on measures that can support the social care sector in preventing and mitigating the negative impact of COVID. A situational analysis and Theory of Change (ToC) model will be used to establish a framework from which to assess the relevance of international experiences and evidence to the social care system in England. A case study approach, including document analysis and interviews, will be used to review in detail the experiences and learnings from four countries. The findings from this study will inform the development of policies and practices to support recovery and better prevent and manage future outbreaks. Funder: National Institute for Health Research Start date: January 2021	https://www.lse.ac.uk/cpec/research/scr-r
The dyadic wider impact of social care: support for older carers	Stacy Rand	United Kingdom	Objectives: This study seeks to understand the experiences of older carers and the people they care for – both individually and together. It will also look at the ways social care services	https://www.sscr.nihr.ac.uk/projects/p145/

and the people they care for (The DYAD project)			may improve the quality of life for the carer, as well as the person being cared for. Description: This work will identify the potential benefit(s) of having a wider view of the social care as supporting the person and their carer, as well as any challenges or barriers in achieving this. This will provide insights for policymaking, service development, and commissioning (including of carers' assessments). Interviews will be conducted with adults using community-based social care (e.g. home care) supported by a carer living with them, aged 65 years or over. The carer and the person who is supported will both be interviewed separately. Professionals who work in local authority social care departments and care/carers' organizations, who support or work with the care recipient as well as the carer, will also be interviewed. Funder: NIHR School for Social Care Research Start date: September 2020	
Diverse Experiences of unpaid Carers Across the caring Trajectory (DECAT)	Diane Fox	United Kingdom	Aim: The main aim of this study is to identify factors associated with carer's satisfaction with social care services and quality of life over time. Description: A mixed method design will be used to achieve the following (1) the identification of factors that contribute to changes in carers' quality of life and satisfaction with services over time; (2) exploration of the extent of the differences in quality of life and satisfaction between carers of people with mental health problems, learning disabilities or autism, dementia or other needs; (3) identification of support, services and other factors that enable carers to optimize their quality of life; and (4) understanding of the specific barriers in accessing services faced by carers from 'frequently excluded' groups (e.g. LGBTQ+ carers, or those from Ethnic Minority backgrounds) and identify ways to overcome them. Funder: National Institute of Health Research, School for Social Care Research Start date: April 2020	https://www.pssru.ac.uk/decat/homepage/

*Several descriptions were taken directly from the projects' websites. Please refer to the links provided for more information.