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## Issue Note

# Impact of Restrictive Public Health Measures on Long-Term Care Residents, Family, and Staff

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## Executive summary

At the beginning of the pandemic, a disproportionate number of residents in long-term care (LTC) were dying from COVID-19 in Canada[51] and it had a devastating impact. Mortality rates in long-term care homes were as high as 64% [54], compared to pre-pandemic annual mortality rates of between 27% and 52% [55,56,57].

The different waves of the COVID-19 pandemic brought the imposition, lifting, and in some cases, re-imposition of restrictive public health measures in long-term care homes (or nursing homes). Such measures included visitor restrictions, restrictions on staff and resident movements, and pausing of recreational activities. The question of effectiveness – whether measures were effective in reducing the transmission of COVID-19 – is beyond the scope of this Issue Note. This paper describes the impacts of restrictive measures on nursing home residents, families, and staff, and seeks to answer the following question:

**What is the impact of the COVID-19 restrictive public health measures on the residents of long-term care homes, their family, and long-term care home staff, in terms of psychosocial, caregiving, and financial challenges?**

Key findings on the impacts of restrictive public health measures in nursing homes are as follows:

- **Impact on residents: this includes acute loneliness, depression, mood and behaviour issues, and worsened signs and symptoms of dementia.** Many of these existed prior to the pandemic and were worsened due to restrictive measures. Residents with cognitive impairment and dementia were rarely studied, hence less is known about the impacts on this group except the acknowledgement that there was a significant increase in psychotropic medication use during the pandemic.
- **Impact on families and friends as caregivers: this includes psychological impacts and impacts relating to the disruption in their caregiving roles.** Families experience double trauma in that they are affected by the impacts on their loved ones and suffer their own psychological pain as well. Seen as vital to the wellbeing of residents, the informal care and support they provided, when absent due to restrictions, was acutely felt by residents (who suffered decline in terms of wellbeing) and staff (who were left without the additional help families provided).
- **Impact on staff: long-term care staff also experienced psychological impacts and impacts relating to changes in their role, care processes, and increased workloads.** Psychological impacts differed from family members in that staff had unique anxieties relating to being the enforcers of restrictive policies, being blamed for bringing in and spreading COVID-19 and being demoralized by negative media coverage of nursing homes compared to the heroic recognition given to hospital workers.
- **Impact on safety and rights: there is a need for balance, proactive planning, and mitigation of risks.** Due to significant impacts, there is a need to 'find a balance' between safety and rights [33,34] and many agree that measures that increase isolation must be accompanied by mitigation measures or proactive preparation to augment staffing and work processes to accommodate the measures. There is a need for a balanced approach; one that both prevents the introduction of COVID-19 into nursing homes, but which also allows family to provide much-needed contact, support, and care to residents. The opinion in most papers reviewed in this paper is that blanket visitor bans should be avoided.
- **Impact of vaccinations on cases and deaths: there is a need to focus more on infection control than restrictive measures.** With evidence emerging on the successful impact of vaccination on long-term care cases and deaths, a relatively greater emphasis could be put on the use of infection control rather than restrictive measures, focusing instead on masking, physical distancing, and hand hygiene [47]. However, the recent trauma of nursing home infections and deaths,

may hold back nursing homes and families from fully implementing and enjoying less restrictive measures, even when they are able to do this. Already, the media is reporting that many are 'vaccinated and still lonely and locked inside' [48].

## Limitations

- Relevant information may have been missed given that the search and report were completed within a short timeframe.
- We did not assess the quality of the evidence.
- Given the state of the evidence, some of the information and key considerations are based on anecdotal evidence and are matters of expert opinion and not evidence.
- Only English-language resources were consulted.

## Future research and knowledge gaps

Future research is necessary to ascertain the following:

- Impacts on nursing home residents who have dementia, since majority of qualitative studies survey residents *without* dementia.
- Impacts of restrictions on nursing home staff who are predominantly women from minority groups for whom there are known associations with high job turnover, low wages, as well as a lack of institutional and societal support.
- Cultural influences on how restrictive measures are perceived across different groups – for instance, some Asian cultures more readily accept restrictive measures in nursing homes.
- Understanding the financial impacts of restrictions on caregivers and staff with respect to, for example, foregone income, precarious employment arrangements, and reduced financial support – topics that have received limited investigation to date.
- Whether mental health outcomes improve for residents from the use of remote communication technology, which is seen as an alternative for in-person visits. Direct resident surveys on satisfaction and impact of these technologies on their mental health are rare.
- Impact of restrictions other than visiting restrictions – which are understudied. This includes impacts on restricted movement and transportation (which can affect access to health care and services), and restricted resident activities (including recreational activities and common dining).
- The impact of ageism in the design and implementation of restrictive measures in nursing homes. Ageism is seen by some experts as the supporting belief system which has encouraged the devaluing of older adults, maintained the underinvestment of nursing homes, and informed the design of restrictive measures.

## Introduction

Long-term care homes in Canada and elsewhere broadly followed, or were encouraged to follow, guidance from the World Health Organization and their governments to use restrictive public health measures in the early waves of the COVID-19 pandemic. The recommendations included visiting restrictions, physical distancing, isolation, and restriction of movement or transportation[1]. This paper seeks to answer the following question:

**What is the impact of the COVID-19 restrictive public health measures on the residents of long-term care homes, their family, and long-term care home staff, in terms of psychosocial, caregiving, and financial challenges?**

At the beginning of the pandemic, a disproportionate number of residents in long-term care (LTC) were dying from COVID-19 in Canada[51] and it had a devastating impact. Mortality rates in long-term care homes were as high as 64% [54], compared to pre-pandemic annual mortality rates of between 27% and 52% [55,56,57].

In hindsight, given high morbidity and mortality, public health measures may have been initially overly prescriptive. Some experts saw these as a reactive response: an 'overcompensation' for poor planning by imposing 'overly restrictive reactive policies' [2]. Yet we know from historical outbreaks of other infections that restrictive measures can contribute to negative outcomes for patients, families, and caregivers despite their original intent to keep everyone safe[3].

The question of effectiveness – whether measures were effective in reducing transmission of SARS-CoV-2 – is beyond the scope of this Issue note, which focuses on the psychosocial, caregiving, and financial impacts of measures. However, it is noted that the relaxation of restrictions, specifically visiting restrictions in the Netherlands, Germany, and Hong Kong did not result in additional infections, providing infection control measures were in place. [46,52,53]

Furthermore, a rapid review preprint from British Columbia noted that visitors were not the most common vectors for infections; in most outbreaks (76%), the first COVID-19 case was a staff member and in 22% of outbreaks, a resident was the first case and there was only one outbreak where the confirmed first case was a visitor[25]. However, there are anecdotal reports of care home managers attributing infections to visitors prior to introducing restrictions.[10]

Of all the restrictive measures introduced at the outset, restrictions related to visitor policies for residents in LTC were the most criticized for the subsequent harmful effects. The implementation of visitor restrictions was seen as fast and indiscriminate, particularly in the early waves. Recommendations were to restrict and to avoid access to visitors as much as possible in long-term care [1]. The rationale was that visitors were believed to be the potential vectors for introducing infection into the homes and transmitting it back into the wider community [4,5].

However, as the pandemic evolved, restrictive policies were modified and made more flexible, as anecdotal, and scientific evidence emerged on harmful effects, pointing to a need to balance applying restrictive measures to control person-to-person transmission of COVID-19 and minimize hospitalizations and death with consequences and risks to health from the measures themselves. This led to the design and introduction of risk-mitigation initiatives. In anticipation of these negative impacts, advocacy and professional organizations issued guidance to help decision-making and the design of protocols [6].

## Methods

The following databases and sources were searched for evidence pertaining to the impact of restrictive public health measures in long-term care homes, up to September 13, 2021: PubMed's curated COVID-19 literature hub LitCovid, Trip Database, World Health Organization's Global literature on coronavirus

disease, Cochrane, PROSPERO International prospective registry of systematic reviews, Centre for Reviews and Dissemination (UK), COVID-END, CIHI-COVID collection, Long-Term Care Responses to COVID-19 database, Centre for Evidence-Based Medicine, Epistemonikos, Agency for Healthcare Research & Quality Evidence-Based Reports, Evidence Synthesis Network, Google Scholar, and Canadian Foundation for Healthcare Improvement database. A search for grey literature was also conducted.

Search terms and inclusion criteria can be found in Appendix 1, as well as details about the type of study or review, the subgroup studied, and the types of restrictive measures covered. More information about the included papers can be found in Appendix 2.

**Interviews**: researchers with expertise in long-term care were also interviewed to provide views on the current state of the evidence on this topic. These 'key informants' were selected based on relevant research output and availability for interview given the short timeframe to produce this paper. See Appendix 3 for details on the key informants interviewed.

## Limitations

- Relevant information may have been missed given that the search and report were completed within a short timeframe.
- We did not assess the quality of the evidence.
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- Only English-language resources were consulted.

## Findings

Findings will be presented in three sections, according to the population group affected, related to the impact on residents, family members, and staff.

### 1. Impact on residents

Psychological impact on residents was described in four major dimensions: 1) Acute loneliness[9,10,11,12,13,14] which can be an exacerbation of pre-existing loneliness[15,16] ; 2) Depression which can be an exacerbation of pre-existing depression[4,9,10,11,14,17,18]; 3) Mood and behaviour issues including anxiety, agitation, irritability, and aggression [4,9,10,11,14,17,18,19]; and 4) Worsened signs and symptoms of dementia[18].

One expert commented in reference to the state of LTC residents during the pandemic: "they were not themselves anymore" [38]. Most of the papers included in this review attributed the above impacts to a single measure: restrictive visiting policies. The impact of such policies affected residents directly, and some experts believe an ageist philosophy underpins the initial blanket visitor bans, since we would 'never do to children what we did to the older adults' [38]. Comparing the measure to similar visitor restrictions during the SARS outbreak in 2002, experts noted that proactive planning was put in place to mitigate the expected risks and harms to paediatric patients [38].

The impact of visiting policies also affected family members directly, with many taking offence at the term 'visitors' which devalues their paramount role in the lives of their loved one. Impacts on family members are discussed in the next section.

Compared to the four major dimensions (i.e. the impacts relating to loneliness, depression, mood/behaviour, and dementia) addressed in multiple papers, the following issues were addressed mostly by single studies and commentaries. Thus, these can be considered relatively understudied impacts:

- **Loss of independence and mobility** [4,18]
- **Physical health** including worsening of health conditions, with increased physical pain and symptoms, deterioration of nutritional and hydration status, weight loss [11,18,20,21,22,23,24]
- **Increased fear** including of staff wearing masks, and fear of death [4,12]
- **Increased use of psychotropic medication**, particularly for residents living with dementia [2,25,26,37]. In British Columbia, for example, the use of psychotropic medications was found to have increased due to the pandemic by 7%, a significant increase attributed to visiting restrictions. Experts mourned this undoing of efforts to correct the pendulum swing from overuse of psychotropics among nursing home residents, as the British Columbia Seniors Advocate remarked, "COVID wiped out all the gains" [27].
- **Delirium.** Reports from LTC homes in Italy suggest that as many as 50% of LTC residents experienced hypokinetic delirium superimposed on dementia (for example, residents refused food and had difficulty getting out of bed) attributed to public health restrictions [28].
- **Reduced cognitive ability** [2,11,17]
- **Communication challenges and ability to make decisions** or to have family acts as substitute decision-makers [29].
- **Dissatisfaction and frustration** with the living situation[11]. Commentaries and anecdotal evidence from advocacy organizations describe how quantity of life was prioritized over quality of life, physical health over psychological wellbeing, and mortality over morbidity[15], and when asked, residents in one survey were less fearful about contracting COVID-19 then perhaps expected, with 41% "not worried at all" and another 33% only "a little worried" [27].
- **Financial impact**. One study found that decreased financial support impacted older adults most [30].
- **Increased risk of mortality** not due to COVID-19, including the belief that some have 'just given up and died because they were not able to bear the stress and loneliness'[12].
- **Disproportionate impacts on marginalized residents.** Little evidence exists on the impact of restrictive measures on residents whose primary language is not spoken by staff; these residents had less ability to understand the situation and were less able to use alternatives such as social media, telephone, or video-conferencing[18].

## 2. Impact on family members

Family caregivers are the most studied population group in terms of impacts of restrictive measures in nursing homes, among the included papers. There is solid evidence in the literature on the association between family involvement and the quality of life of nursing home residents, and the vital part that family members play in the nursing home. For this reason, experts call for the establishment of family councils in every nursing home (as per the Ontario model) to be required in other provinces [37].

Family members were acutely affected by nursing home restrictions. Their immediate anxiety often centred on the resident, particularly the resident's psychological stress, care, and daily activity [4,32]. Family members also suffered impacts of their own. As 'invisible labour', family members often provided direct care and support to residents, and with the loss of this labour, came added pressure on nursing homes, which may already have been short-staffed prior to the COVID-19 pandemic [38]. The impacts felt by family members described in the included papers were psychological impacts and impacts related to caregiving.

<u>Psychological impacts</u>

- Loss of companionship[18].
- Loss of caregiving role[18].
- Complicated grief and feelings of failure [38]:
    - Grief from not being able to visit a resident who was palliative or who passed away during the pandemic [4,25] and women were the main group that died and could not express their will during the last week of life – only 13% of relatives were present during time of death [4].
    - Grief from deterioration of resident causing them to lose recognition of relatives [18].

- Worry, anxiety, uncertainty over restrictions, and the changing care environment [11].
- Need for information from care providers [11].
- Guilt and shame from admitting one's older parents into a nursing home just before the COVID-19 pandemic [38].
- Impacts are worse for family members of residents living with dementia. Seventy percent of residents in nursing homes have dementia [39] and family members of people living with dementia are 79% more likely to report poor mental health in the last month compared to non-caregivers [40].

Impacts relating to caregiving

Caregivers and families felt dissatisfied with care due to restrictions [4], felt that there was insufficient support from nursing home staff to be able to properly act as caregivers[4], and furthermore, family members felt a thwarted ability to provide care and support, or to act as substitute decision-makers for the resident [21,22,23,24]. Findings from the included papers related to other impacts were limited but included:

- **Quality of life of family caregivers.** Family caregivers had a low self-reported quality of life, decline in mood, daily living activities, and cognition, akin to the 'second patient concept' in hospital settings [11]. Experts note the stoppage of activities meant that only bed-and-body were provided, and many ate alone daily [37].
- **Financial impacts.** Mentioned in only one paper is the need for policies that support family members in balancing work and caregiving responsibilities through, for example, direct payments to caregivers[4].
- **Impact on family or friend caregivers of marginalized residents.** Family caregivers, and indeed friend caregivers (since not all are related by blood) help ensure that all residents receive culturally safe and appropriate care, especially for LGBTQ2S+ and Indigenous residents and/or those with language barriers. No studies noted these, although one guidance document did address this [33].
- **Anxiety of possible abuse or neglect.** Family members and unpaid carers worried about how their relatives were treated without their ability to monitor the situation. This included potential dehydration, starvation, neglect, and abuse [2,11,35,36,37,38].

Just as family are often referred to as the 'second patient' in acute settings, experts highlight the need to care for family caregivers in nursing home settings [41].

### 3. Impact of restrictive measures on staff

Psychological impacts

- Emotional stress from having to enforce restrictive measures and having to navigate angry responses that the restrictions were unjust [18].
    - One paper reported that enforcing restrictive measures was impossible and staff were unable to isolate residents who, for example, walked with purpose or wandered, and the challenges with trying to adhere to changing guidance from different sources [35,42].
    - Nursing home physicians perceived restrictive visiting policies as not their decision, yet they were held responsible for their implementation. Moral distress was intense when caring for residents with limited life expectancy as physicians struggled to make clinical assessments to allow for exceptions. These dilemmas had profound emotional impact on the physicians [34].
- Emotional burden and vicarious trauma from caring for residents facing significant isolation, illness, and death, and having to take on additional roles usually expected of family members [18, 19].
- Nursing home physicians described feelings of guilt, insecurity, and frustration, and felt they provided suboptimal care to the residents. Some described waking up in the middle of the night, worrying. Physicians used phrases as "Devil's bargain," "unacceptable," "poignant," "inhuman," and "unjustified" to describe some of the dilemmas they encountered [34].
- Appreciated as essential but feared (as a vector) and blamed for the pandemic.
    - Care home workers were deemed to be performing an essential service and therefore required to continue working. However, they were also blamed since movement of care home staff between their communities and the nursing home was believed to present the greatest risk of

infection. Family members were anxious and would lash out and blame staff when their resident family members became sick or died. Thus, staff members putting their own health in jeopardy were criticized instead of supported[12].

- Staff described the demoralizing impact of negative media coverage of nursing homes compared to the heroic public recognition given to hospital staff [19].

Impacts on staff roles and care provision

The literature highlighted that working in long-term care homes is challenging for the following reasons:

- Guidance from authorities were at times confusing or contradictory [19]. Experts note that some staff have developed 'severe mistrust of government' [38].
- Lack of organizational communication and teamwork hampered ability to work under challenging circumstances [19].
- Little time for and minimal training, leaving staff ill-prepared to deal with the new working environment, and forcing them to design workarounds[12], left staff feeling as though they were 'run off their feet' [38].
- Staff absenteeism was observed, 'an exodus of staff'[38], with some homes struggling with staffing at 'skeletal' levels [38], possibly due to fear of contracting the virus and transmitting to a loved one, or from inadequate personal protective equipment (PPE) supplies[7], or from moral distress [38].
- Difficulty in balancing quality of care with protective measures. Seventy percent of nursing home residents have dementia [39] and these required assistance of multiple staff members compared to community-dwelling people living with dementia [42].
- Worsening of workload, and stress and burnout issues were experienced even before the pandemic.
- Many regular family visitors who were providing unpaid, essential care to care home residents before the pandemic were now unable to [10,26,37], resulting in a greater care burden on staff. Family caregivers of people living with dementia typically provide 20+ hours of care per week and many long-term care staff lack training in providing quality dementia care [39].
- Managing safe visits takes additional time and resources [26].
- Staffing shortages resulted in increased workloads and burnout [18,19,35].
- Associated with this is the lack of ability to recover and rest. Due to widespread staff shortages, staff would not have the opportunity to use leave entitlements if they had them [7].
- Stress from relying on 'crisis standards' including extending the use and re-use of personal protective equipment [19].
- Increased workload from having to update family members of residents and to arrange contact using virtual platforms [43].

Financial

- There was minimal coverage in the included papers on financial impacts to staff, even though it is a well-known fact that many staff have low wages and limited benefits [20]. High levels of dissatisfaction and anxiety in nursing home staff existed even before the pandemic, with many nursing home staff working multiple jobs and up to 20% worried about food security [7]. As one expert put it, 'there is a financial cost' and we need to 'compensate' the workers [38].
- In a study conducted in the UK, 43% of managers described staff shortages and 30% of care homes still depended on staff who worked across sites. There were no papers which studied the impact of single-site restrictions on staff although there was commentary on understanding why staff worked in multiple locations: 73% did so because of financial reasons [49]. One commentary noted residents lost their favourite staff members when staff were forced to choose to stay working with one of multiple employers [38].
- Some homes put non-essential staff members on 'temporary lay-off' to reduce the number of people entering the premises[12].
- As staff were believed to be vectors of transmission, some care homes offered to have their staff sleep in, or to transport them to and from home in private vehicles in order to reduce the risk of infection through traveling on public transport. For workers wanting to avoid public transport, the extra costs of alternative transport would be borne by them if their care home did not provide monetary support[12].

Evidence on staff impacts is largely based on qualitative surveys and case studies. In the grey literature, there is some coverage on staff impact from restrictions. The sparse coverage of financial impact is particularly noteworthy.

Equity issues are relevant since a large proportion of staff are minority women, for whom there are known associations with high job turnover, low wages, meager benefits, lack of institutional support and societal support, and limited autonomy [20]. These present additional challenges on top of a difficult job of balancing their own well-being and safety, the well-being and safety of residents, whilst maintaining a robust response to viral transmission [20]. Future research on the impact on staff who are predominantly women from minority groups would be beneficial.

### 4. Other key considerations

Cultural perceptions of restrictions differ

Two included papers touched on cultural aspects worth noting. A Taiwanese study found that many relatives accepted and supported suspension of visit [32] and a Thai study found that residents suffered most from decreased financial support and limited freedom but had relatively *low* psychological stress [30]. These suggest that psychological distress associated with the pandemic may not be a universal phenomenon. Future research on cultural influences in how restrictive measures are perceived, and financial impacts of restrictions would be beneficial.

Impact and satisfaction of remote communication technologies are unclear

Although electronic means of communication are touted as ways to increase connection during the pandemic, one study showed that receiving COVID-19 news via social media increased risk for psychological disorders and was independently associated with post-traumatic stress and depression[30].

The use of virtual technologies such as FaceTime and Zoom offer an opportunity for social interaction during lockdown but implementation can be limited and difficult due to computer illiteracy but also workload of staff assisting the virtual interaction, with indeterminate effect on mental health outcomes [31].

## Conclusion

Restrictive public health measures, when considered necessary for protecting the public, come with consequences. Proactive and mitigating actions can help attenuate and prepare for the negative impacts of the measures [38].

It is possible to mitigate poor mental health outcomes with thoughtful intervention and ongoing evaluation.[7] A number of guidance papers describe how to mitigate restrictive public health measures [7,33] including the Inter-Agency Standing Committee (IASC)'s recommendations in *Addressing mental health and psychological aspects of COVID-10 outbreak* [44].

Other papers recommend safe on-site visiting, with options based on local levels of community transmission and designed in consultation with residents, families, staff, and health authorities [26]. The call to stop or avoid blanket visitor bans has been almost unanimous from LTC facilities, staff, and families, with one review recommending a staged, data-driven, risk-mitigated approach [26].

Virtual technologies, while valuable as ways to improve social interaction during the pandemic, remain challenging and of limited use, depending on computer literacy and staff availability to assist, and the impact of these on mental health outcomes is unclear.

The pandemic is evolving at a faster rate than the formal research process, however, one study showed it is possible to implement successful infection control measures and allow visits at the same time [46]. At a more fundamental level, expert opinion highlights the importance of rights of residents under the law, to receive visitors in their own home [45], and the need to be conscious of ageist values when designing and implementing restrictive public health measures in nursing home settings [38].

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# Appendix 1: More information on Included Papers

## Detailed information on search for academic and grey literature

In searching academic and grey literature, the following key search terms were used and inclusion criteria applied.

| Key search terms | Inclusion Criteria |
|---|---|
| "Long-term care" or "Care home" or "Nursing home"<br>"Public health measures" or "measures"<br>"Restrict*" or "restrictions"<br>"impact"<br>"review"<br>"coronavirus" and variants | Studies impact of measures<br>Studies impact on residents or families/unpaid caregivers or staff<br>Published or pre-printed in 2020 or 2021<br>English language article |

Data on review approach, study design, setting, jurisdiction, population studied, and type of impacts were extracted when reported. We summarized the results narratively due to variation in methodology in the included papers.

In total, 1,621 documents were identified, 68 were screened for relevance, and 24 included. The list of papers included are listed in Appendix 2.

### Key features of Included Papers

The 24 papers comprise the following:

- Seven are reviews (e.g. Scoping Review, Rapid Review);
- Ten are studies, mostly qualitative surveys or case studies;
- Two are policy or guidance documents; and
- Two are commentaries.

Table 1: Papers by impacted group and type of impact

| **Impacts on group in long-term care setting** | **Number of papers** |
|---|---|
| Residents | 22 |
| Families | 23 |
| Staff | 13 |
| **Type of impact** | **Number of papers** |
| Psychosocial | 23 |
| Caregiving | 23 |
| Financial | 2 |

As shown in Table 1, there is more coverage in papers of impact to residents and families, compared to staff, and more coverage of psychological and caregiving impact, compared to financial impact.

Table 2: Heavy coverage of impact of visiting policies, and relatively little coverage on other restrictive measures

| **Type of restrictive measure studied** | **Number of papers** |
|---|---|
| Restrictive visiting policies | 24 |
| Restricting staff who work in long-term care homes to work at only one site | 2 |
| Restricting resident activities and interactions in the nursing home | 2 |
| Isolation measures and cohorting | 1 |
| Restricting transporting of residents to and from acute settings | 1 |

Nearly all papers were focused on restrictive visiting policies, with very few covering the impacts of isolation measures and cohorting [7], and restricting transportation of residents to and from hospital for medical care [8].

## Brief overview of the nature and commentary on the evidence retrieved

Although formal assessment of quality was not possible given the tight timeframe for producing this Note, some observations are made here on the quality and limitations of included papers.

Most of the included papers that focused on impact on residents were based on data not from residents directly but from staff or caregivers' perceptions of the impact on residents. Experts attribute this to the inaccessibility of the patient during the pandemic but also the difficulty in surveying and interviewing people living in nursing homes [37].

Although 70% of residents in nursing homes have dementia[39], and despite evidence that a greater proportion of carers of people with dementia report negative feelings than carers of people with other care needs [50], studies containing resident participants surveyed only residents *without* cognitive impairment, which means there is an under-representation of the majority of residents.

There is evidence that people living with dementia in nursing homes experience a particularly harsher impact of measures, such as some not understanding why their family no longer come to see them. A report by *The COVID-19 and Dementia Task Force* focused on end-of-life issues in the context of the pandemic recommended that end-of-life planning in the context of COVID-19 needs to be bolstered for the benefit of residents living with dementia, their families, and staff [58].

There is a need for more studies on people living with dementia in nursing homes to gauge majority resident impact. By surveying only residents without cognitive impairment, studies focus on the minority subgroup in nursing homes: those who do respond and are able to act as participants or subjects will be those who are able to do more for themselves in terms of personal care, grooming and feeding, and more likely to have and use a personal phone and to use video-calling such as Zoom or FaceTime [25].

Survey methodologies are also biased by employing the internet, phone, or paper-based surveys. These are also limited to those communicating with their loved one in the dominant language (English). This means that there is an under-representation of caregivers who do not communicate in English and who cannot access the internet or phone or post office.

There were seven reviews out of the 24 included papers. Reviews of studies (i.e. Scoping reviews or Rapid reviews) note that the main limitation was the small number of studies, small samples, and the lack of ability to generalize findings. However, the fact that psychosocial issues consistently appear as impacts on residents, families, and staff alike, is noteworthy.

There were ten studies out of the 24 included papers. These comprised mostly of qualitative surveys and case reports, with few quantitative methodologies such as the use of cognitive, functional, and depression scores [17]. Again, psychosocial issues consistently appear as impacts on residents, families, and staff alike.

## Appendix 2: List of papers included

| No. | Type of Evidence | Authors, Countries covered | Resource | Year |
|---|---|---|---|---|
| 1. | Scoping Review | Bethell et al, Multiple countries | Social Connection in Long-Term Care Homes: A Scoping Review of Published Research on the Mental Health Impacts and Potential Strategies During COVID-19 | 2021 |
| 2. | Scoping review | Shamik et al, Multiple countries | Nursing homes during the COVID-19 pandemic: a scoping review of challenges and responses | 2021 |
| 3. | Scoping review | Veiga-Seijo, Rachel, Multiple countries | Strategies and actions to enable meaningful family connections in nursing homes during the COVID-19: A Scoping Review | 2021 |
| 4. | Rapid Review | Comas-Herrera, Multiple countries | Rapid review of the evidence on impacts of visiting policies in care homes during the COVID-19 pandemic | 2020 |
| 5. | Rapid review | Lorenz-Dant and Comas-Herrera | The impacts of COVID-19 on unpaid carers of adults with long-term care needs and measures to address these impacts: a rapid review of evidence up to November 2020 | 2021 |
| 6. | Review | Low et al, Multiple countries | Safe visiting at care homes during COVID-19: A review of international guidelines and emerging practices during the COVID-19 pandemic | 2021 |
| 7. | Review | Hugelius et al, Multiple countries | Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review | 2021 |
| 8. | Review | Suarez-Gonzalez | Detrimental effects of confinement and isolation on the cognitive and psychological health of people living with dementia during COVID-19: emerging evidence | 2020 |
| 9. | Study using nationally represented data | Hua, Cassandra | Coronavirus Disease 19 (COVID-19) Restrictions and loneliness among residents in long-term care communities: Data from the National Health and Aging Trends Study | 2021 |
| 10. | Study | Sizoo et al, The Netherlands | Dilemmas With Restrictive Visiting Policies in Dutch Nursing Homes During the COVID-19 Pandemic: A Qualitative Analysis of an Open-Ended Questionnaire With Elderly Care Physicians | 2020 |
| 11. | Study | Anand et al, Multiple European countries | The covid-19 pandemic and care homes for older people in Europe - deaths, damage and violations of human rights | 2021 |
| 12. | Study | Srifuengfung et al, Thailand | Impact of the COVID-19 pandemic on older adults living in long-term care centers in Thailand, and risk factors for post-traumatic stress, depression, and anxiety | 2021 |
| 13. | Study | Pereiro et al, Spain | Impact of the COVID-19 Lockdown on a Long-Term Care Facility: The Role of Social Contact | 2021 |

| No. | Type of Evidence | Authors, Countries covered | Resource | Year |
|---|---|---|---|---|
| 14. | Study | Freidus et al, USA | A Rapid Qualitative Appraisal of the Impact of COVID-19 on Long-term Care Communities in the United States: Perspectives from Area Aging Staff and Advocates | 2020 |
| 15. | Study | White et al, USA | Front-line Nursing Home Staff Experiences During the COVID-19 Pandemic | 2021 |
| 16. | Study | Van der Roest et al, Netherlands | The impact of COVID-19 measures on well-being of older long-term care facility residents in the Netherlands | 2020 |
| 17. | Study | McArthur et al, Canada | Evaluating the Effect of COVID-19 Pandemic Lockdown on Long-Term Care Residents' Mental Health: A Data-Driven Approach in New Brunswick | 2021 |
| 18. | Study | Canadian Institute of Health Information (CIHI), Canada | The Impact of COVID-19 on Long-Term Care in Canada: Focus on the First 6 Months | 2021 |
| 19. | Study | Rajan and Mckee | Learning From the Impacts of COVID-19 on Care Homes: A Pilot Survey | 2020 |
| 20. | Study | Office of the Seniors Advocate, British Columbia | Staying Apart to Stay Safe: The Impact of Visit Restrictions on Long-Term Care and Assisted Living Survey | 2020 |
| 21. | Guidance document | Stall et al, Canada | Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Nursing Homes to Family Caregivers and Visitors during the Coronavirus Disease 2019 Pandemic | 2020 |
| 22. | Policy review | Jacobs et al | The Impact of Covid-19 on Long-term Care Facilities in South Africa with a specific focus on Dementia Care | 2020 |
| 23. | Commentary by experts from six countries | Chu, Charlene | The Impact of COVID-19 on Social Isolation in Long-term Care Homes: Perspectives of Policies and Strategies from Six Countries | 2020 |
| 24. | Commentary from Saskatchewan, Canada | Tupper, Susan | Family Presence in Long-Term Care During the COVID-19 Pandemic: Call to Action for Policy, Practice, and Research | 2020 |

## Appendix 3: Experts interviewed

| Name, post-nominal letters | Affiliations |
|---|---|
| **Jennifer Baumbusch**, RN, PhD | Associate Professor<br>CIHR Sex & Gender Science Chair<br>The Dynamics of Caregiving in an Aging Society<br>School of Nursing<br>The University of British Columbia |
| **Charlene Chu**, RN, GNC(c), PhD | Assistant Professor<br>Lawrence S. Bloomberg Faculty of Nursing<br>University of Toronto<br><br>Cross-appointed, Institute for Life Course and Aging<br>University of Toronto<br><br>Affiliate Scientist<br>KITE-Toronto Rehabilitation Institute, University Health Network, Toronto, ON M5G 2A2<br><br>Chair, Nursing Research Interest Group<br>Registered Nurses Association of Ontario |