

Caregiving during COVID in Manitoba: Report of Survey Findings (2021)

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“The need for caring is much greater during the pandemic even though the ability to provide it is worse.”

Who did this research and why?

In late 2020, University of Manitoba researchers Laura Funk (Sociology), Jamie Penner (Nursing), and graduate student researchers Lisette Dansereau and Kaitlyn Kuryk came together to launch an online survey of Manitoba’s family/friend caregivers to explore the impacts of the COVID-19 pandemic on their caregiving circumstances and well-being.

The last large-scale survey of a broad range of family caregivers in Manitoba occurred in 2012; 311 caregivers responded (Funk, 2012). The most frequently mentioned ‘biggest struggle’ was with system navigation and obtaining information to help access existing programs and services for the care recipient. Caregivers wanted to be able to trust the workers and professionals that were involved in the care of their friend/family member. “Strengthening existing health and social services” was a recommended government priority (Funk, 2012). Additionally, 43.5% reported needing either ‘a lot’ or ‘quite a bit’ more help managing the impact of care provision on their own mental or emotional well-being (Funk, 2012).

Surveys specifically documenting the impacts of the COVID-19 pandemic on caregivers have occurred in other provinces such as Alberta, Quebec, and British Columbia. Although there has been provincial variation during the pandemic both in terms of available supports for caregivers and changes in access to personal care homes (PCH) and other congregate living settings, there were notable similarities in some of the surveys conducted so far.

The Alberta survey (Anderson & Parmar, 2020), conducted during the summer of 2020, found that family caregivers supporting someone at home were left feeling disconnected and overwhelmed, while those caring for residents of long-term care (LTC) facilities were separated and unable to provide care. Seventy-eight per cent of these caregivers reported feeling anxiety and 85% reported loneliness, while 36% of those living in the same home reported adding 40 or more hours of additional care per week.

The Québec survey (Regroupement des aidants naturels du Québec, 2020), also conducted during the summer of 2020, found personal expenses for care rose for 20% of caregivers, and one in four felt overwhelmed. The demands of care during the early stages of the pandemic had negative impacts on employed caregivers, with 31% no longer working for fear of transmitting the virus to the person they cared for, and 22% not going to work because of a lack of available home care workers to provide the necessary support.

The British Columbia survey (Family Caregivers of British Columbia, 2021) conducted in December 2020 concluded that “what was hard got harder” (p. 2) due to COVID-related disruptions in routines and services, leaving caregivers to fill in the gaps. Anxiety increased for about 20% of caregivers, while over 40% reported declining physical health, and over 50% reported worse mental health. Similar to the situation in Alberta, British Columbia caregivers reported increasing the amount of care they were

providing; 45% noted that provincial home care services in B.C. had been reduced or suspended altogether. As in Québec, one in four B.C. caregivers reported experiencing financial hardship, and 82% had to spend more on food, PPE (personal protective equipment) and cleaning products, technology, and on purchasing private care support or medical services.

Information about the effects of the pandemic on family caregivers in Manitoba has thus far been lacking. Manitoba is home to Canada's first Caregiver Recognition Act (2011), but in 2017 the provincial-level Caregiver Advisory Committee was ended. Supports for caregivers available in this province include resources for caregivers of older adults (through the non-profit Age and Opportunity organization) and persons living with dementia (through the Alzheimer Society of Manitoba), the Primary Caregiver Tax Credit, and services such as respite available through publicly funded home care. Manitoba entered the pandemic with a publicly funded and delivered home care program, and a relatively high proportion of not-for-profit residential care facilities (Funk, 2020); arguably, however, caregiver supports were underdeveloped, especially for those caring for persons with mental illness (VIRGO, 2018; Marier, 2021). Moreover, not only did the pandemic lead to pauses and cancellations of many supportive care services and programs (including those directly and indirectly assisting caregivers), but caregivers' abilities to visit and support friends and family members living in congregate settings (group homes, personal care homes, assisted living) were curtailed.

Many of these disruptions continued for prolonged periods. As such, in early 2021, we launched this survey of Manitoba's family/friend caregivers, to explore the effects of the pandemic on caregiver circumstances and well-being.

How was the survey implemented?

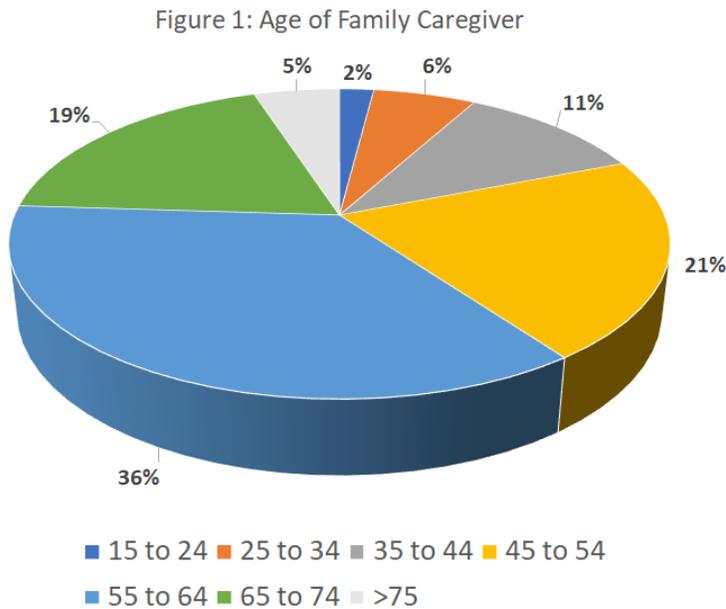
For the purposes of our study, a caregiver was defined as anyone providing emotional, physical, or practical support for a family member or friend of any age, requiring help due to a chronic condition, disability, drug/alcohol dependency, mental illness, cognitive impairment, terminal or serious illness, frailty, or aging. Survey questions were modelled after or adapted from those used in the Alberta and Quebec surveys with modifications and additions for the Manitoba context. The full survey is available upon request from the authors.

Participants were recruited through social media (Facebook, Instagram, Twitter), radio, community news websites, the Centre on Aging newsletter, and email invitations sent out through health-related organizations such as the Stroke Recovery Association and Alzheimer's Society. Recruitment occurred between December 2020 and March 2021. Participants were asked about their caregiving experience prior to the pandemic (before March 2020) and during the pandemic (after March 2020). Participants needed to be over the age of 15 and reside in Manitoba. The survey was conducted using the Qualtrics online platform. Because this is a non-probability sample, caution is needed when generalizing the results more broadly.

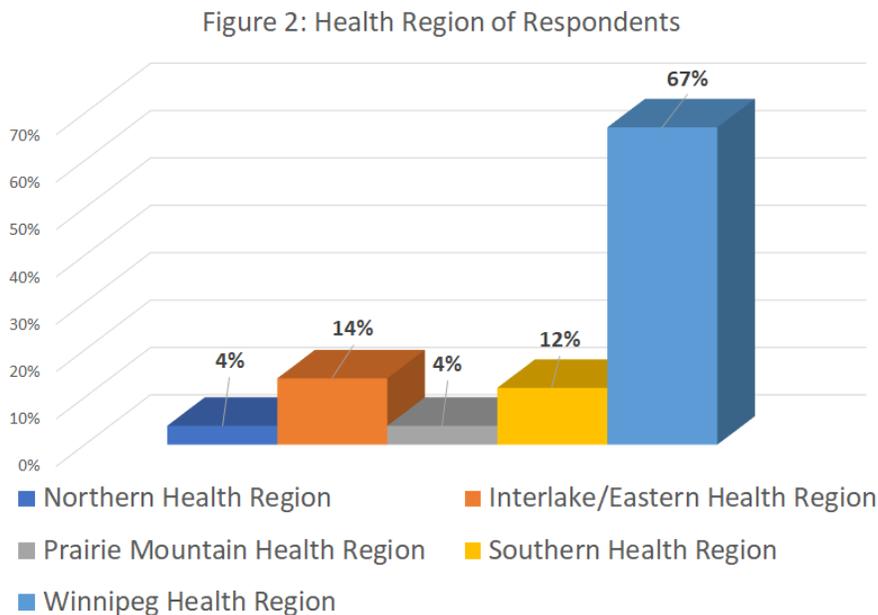
Ethics approval was received through the University of Manitoba.

Who participated in the survey?

A total of 187 family/friend caregivers residing in Manitoba participated in the survey (an additional 37 persons did not meet eligibility criteria).



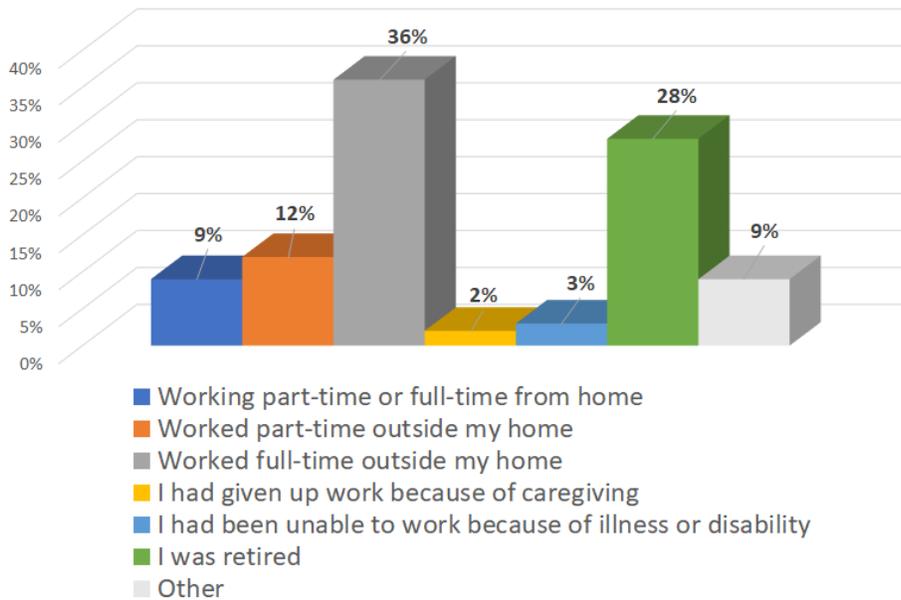
Approximately 85% of respondents identified as female. In addition, 60% were 55 years of age or older (further details about age distribution are included in Figure 1). A limitation of the survey was that we did not collect data on ethnicity or indigeneity.



Most (67%) of respondents reported living in the Winnipeg Health Region (Figure 2).

Over half (57%) of caregivers were working prior to the pandemic, most of them full time (Figure 3).

Figure 3: Employment situation prior to pandemic



However, it is important to note that the typical 'portrait' of a caregiver as a daughter, son, or spouse of a certain age or employment status, can obscure the complexity of who many caregivers are and what some of them are dealing with. For instance, open-ended comments from respondents who indicated 'other' to the employment question

reported working part-time outside of the home while simultaneously attending university full-time, or that they were retired or 'semi-retired' while working part-time outside of the home. Some indicated that, prior to the pandemic, they had scaled back their paid work responsibilities due to caregiving or were self-employed but limited in their paid work by caregiving and personal disability. Still others commented on needing to juggle work, parenting, school, and the responsibilities of caring for aging parents. The realities of caregiving are complex and multi-faceted.

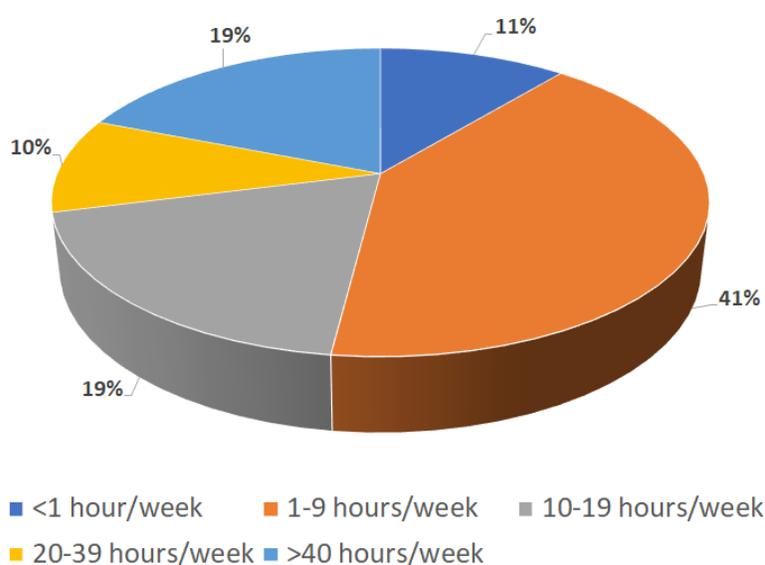
What did caregiving look like prior to the pandemic?

Respondents were asked questions about the person they were caring for, including this person's living arrangements, functional independence, and the reasons they needed support. The findings indicate that 76% of respondents were caring for one or more older persons, 20% were caring for one or more younger adults with disabilities or chronic conditions, and 4% were caring for one or more disabled or ill children. Twenty-two per cent of respondents further noted that the person they were caring for could not be left alone at all.

In terms of living situations, 34% of respondents were supporting people who lived in the same household as themselves or in the home of another family member (5%), 36% were assisting persons who lived in their own separate residence, and 25% were helping persons living in supportive accommodations such as a group home, assisted living residence, or personal care home (PCH).

Fifty-four per cent of respondents indicated that prior to the pandemic (before March 2020), the person they were caring for was receiving publicly or privately funded formal health or social services, such as home care, day programs or supportive accommodation. Of these, 20% reported this person was receiving more than 40 hours a week of support, 31% between 11 to 40 hours a week, and 49% at 10 hours or less per week.

Figure 4: Time spent providing care before the pandemic



In terms of their time spent providing care prior to the pandemic (Figure 4), about half of respondents (52%) reported providing less than 10 hours of care a week, and 29% were helping for over 20 hours a week.

Over half of respondents (53%) reported that they were not caring alone, however, and 80% of these indicated that another friend, family member or

neighbour helped with up to 10 hours of additional support per week.

Prior to the pandemic, only 1 in 4 caregivers reported ever being asked about their own support needs by health care professionals.

Caregivers may require formal supports to address their own needs,¹ such as respite services² to give them a short break, and counselling or support groups. However, even before the onset of the pandemic, only one in four of the survey respondents reported ever being asked about their own support needs by health care professionals. Fewer than one in four (22%) reported themselves receiving any kind of formal support services - of these, 46% received less than one hour per week and 38% received between one and 10 hours a week.

¹ This can include needs related to both providing care and maintaining their own health and well-being.

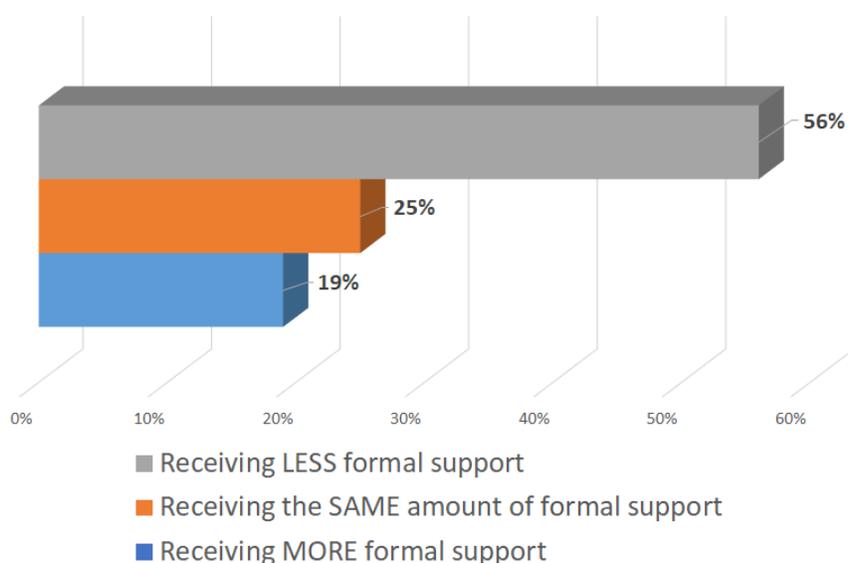
² Respite care can occur in the home, at day programs, or in residential care settings that offer overnight stays.

What happened to existing supports during the pandemic?

The majority (56%) of respondents indicated that the care recipient was receiving fewer formal support services after the onset of the pandemic, while 25% reported no change, and 19% reported an increase in formal services (Figure 5). Of those reporting a reduction in services, this was primarily due to general cutbacks and paused or suspended services.

“I would be called to say I was on my own with Dad.”

Figure 5: Changes to formal services since start of pandemic



In an open-ended follow-up to this question, several respondents emphasized the withdrawal of services imposed by health and social systems due to program shutdowns or healthcare workers being reassigned to work in other settings. For example, one respondent caring for their father with the support of publicly delivered home care

explained that the care aides were being redeployed to address needs in PCHs and hospitals, resulting in no-shows for scheduled home care services. Others described service cutbacks or shutdowns of programs (especially day programs and respite programs), a greater reliance on telephone rather than in-person support, or that home care aides were not allowed into assisted living buildings. To a lesser extent, other respondents indicated that they or the care recipient stopped or reduced various services due to the risk of contracting COVID-19 from workers and/or in respite settings, while a few explained that they asked the person they were caring for to move in with them to minimize contact with others.

“We were horrified to have heard that [home care] workers at the onset were NOT being advised by [the regional health authority] admin as to which clients had Covid... This played a major part in our decision to suspend my wife’s home care... we simply didn’t want the disease ‘walking in through our front door’.”

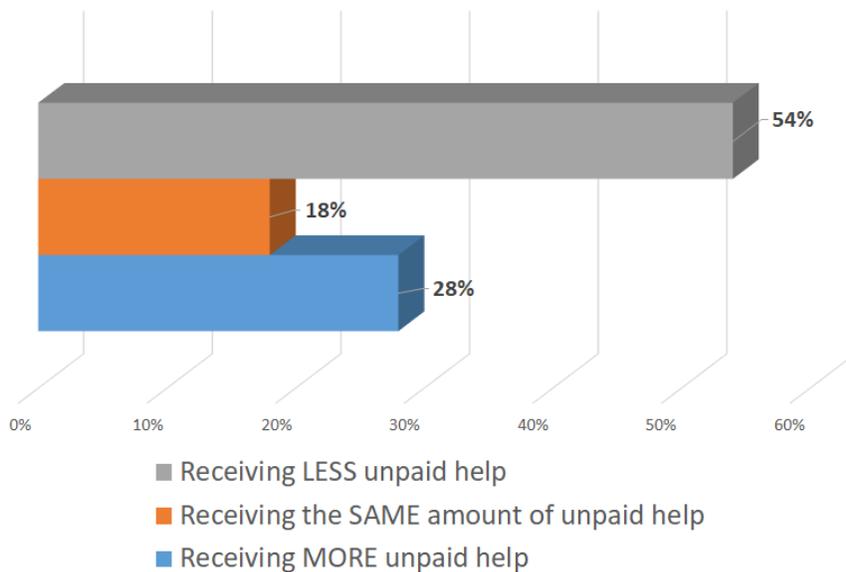
There were fewer comments from respondents who had indicated the care recipient was receiving the same (25%) or more (19%) formal services. Some families/friends filled the gap caused by reductions in public services by purchasing from private sources, while others explained the care recipient was on a trajectory of receiving enhanced support due to increasing needs over time (e.g., some respondents noted care transitions had occurred, such as a move from supportive housing to a PCH).

However, even those receiving the same or more formal services noted the effects of the pandemic on the quality of those services. One respondent remarked that the care aides “always seem to be so rushed and in a hurry to leave” and others indicated that services were generally less reliable, most notably for home care. Some respondents supporting a person living in a PCH expressed that staffing shortages were

eroding care quality, which was further diminished by their own inability to visit due to restrictions. Many respondents particularly noted declines in social and emotional care, describing a great deal of distress over restrictive visitation policies. Common phrases described the experience as “awful”, “devastating”, “traumatic”, and “torture.”

“Physically there is no change to [the] support or care provided, [but] mentally or emotionally I feel she is getting less. There is less interaction with residents, no activities, [and] less cognitive stimulation. This is the key role I played prior to COVID-19.”

Figure 6: Changes in informal help since start of pandemic



Despite the need to maintain care supports, caregivers expressed being hesitant to ask for additional resources. As one respondent described, “It is difficult to consider asking for more support during a pandemic. I feel fortunate just to not have had our services cut.”

Among respondents already receiving unpaid help from other family, friends, and neighbours before the

pandemic, more than half (54%) were receiving fewer of these supports after the pandemic began, while 28% were receiving more of this help (Figure 6). Only 18% reported no change.

Comments from respondents reporting reductions in unpaid support from other family/friends indicate that this was due to a combination of public health restrictions and personal concerns about risk. Public

“My siblings are not able to be around my Mom since we are concerned about passing something on to her. We have limited exposure to everyone for my Mom. Prior to COVID my Mom would go to different homes for support and companionship. This is no longer happening.”

health restrictions included limiting in-home visits to one person per household, which in turn limited the amount of support possible from friends, neighbours, and other family members. Visitor and essential caregiver restrictions were likewise implemented in institutional settings. Personal concerns (of the care recipients and/or those providing care) centered around risk of infection from exposure to others. Respondents also referred to travel restrictions for out-of-province family members who would otherwise visit and provide some help. A few

comments indicated that reductions in family/friend support reflected a change in the care setting of the recipient, thereby reducing the need for additional supports (e.g., moving from home to a long-term care facility).

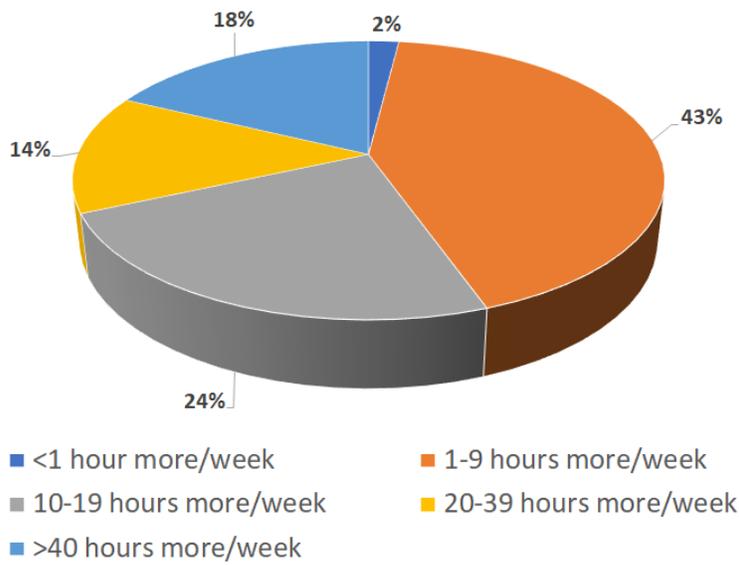
In contrast, some respondents reported an *increase in unpaid help from others* during the pandemic, such as neighbours contributing in socially distanced ways (dropping off food, shoveling, running errands and shopping). Occasionally, caregivers mentioned having more help from other family members who had lost their job due to COVID. In other cases, increased support reflected responses to declining health and increasing needs in the person receiving care. Some respondents further indicated that the loss of formal services meant that informal networks were the only option for filling gaps. For instance, one respondent who worked in the health care sector wrote that it was “absolutely impossible to provide all the support on my own” and she had to rely on others. Yet unpaid supports from other family/friends may not completely fill the gaps, as indicated by a respondent who wrote that she had previously provided all of the support needed by the care recipient, but due to COVID she had to work full time in essential paid work. The care recipient’s unmet needs for help in this case were only partially met by other family members and paid housekeepers.

Notably, 91% of respondents caring for someone residing in a congregate living or residential care setting (n=58) reported having been affected by visitation policies in these settings during the pandemic; the varied impacts of these restrictions will be reviewed in subsequent sections.

How did these changes impact the work of family caregiving?

As discussed earlier, prior to the pandemic, approximately ½ of our respondents reported caring for 10 hours or more on a weekly basis, with about 20% providing more than 40 hours of care per week.

Figure 7: More hours of care provided since pandemic



Sixty per cent of respondents indicated they were providing more care following the onset of COVID-19 in Manitoba, followed by 22% who reported no change, and 18% who reported providing less care. Of those reporting increases in care provision, over half of these persons (55%) were providing 10 or more additional hours of support per week. This includes 37% of caregivers

providing up to 39 additional hours per week, and 18% providing at least 40 hours of additional care per week (Figure 7).

Respondents described pauses in formal services such as home care or respite as the main reason that they were providing more care when supporting someone at home. As previously discussed, the withdrawal of services was related to public health restrictions or personal concerns over being exposed to COVID-19. As one caregiver commented, “[there are] limited people I trust to be ‘safe’ to do respite”. In either case, caregivers were often left to shoulder increased amounts of care responsibilities with little,

“[There is] no respite now, so no breaks at all for months on end.”

if any, support. One respondent caring for a person living with them expressed, “...it is always difficult to find respite staff, COVID has made this harder.”

Some caregivers resorted to purchasing support services, which meant incurring additional out-of-pocket expenses.

One respondent, for instance, noted that they hired external services to help with cleaning, meals and visiting, adding “all the restrictions have made my caring for her a lot more difficult.”

Providing social and emotional support fell largely on caregivers when those they were caring for were isolated in their homes due to public health restrictions and concerns about COVID. As one respondent explained, “I am the one designated caregiver allowed to visit, so they miss seeing other people and are so dependent upon my visits and supports so they do not go out in the community.” The same was often true for those supporting residents of congregate care settings.

“It is constant and unexpected, unpredictable anytime, so our plans can change at any moment. This has been stressful, on top of ordinary stresses before COVID, as well as providing a lot more social visits and emotional boosts than otherwise, in person visits by other people would have helped.”

Sometimes, families and caregivers implemented significant changes to daily routines to reduce the risk of COVID transmission to the care recipient.³ This often then increased caregiving demands. One respondent described how she kept her child at home full-time (facilitating virtual schooling), so as to reduce the risk that her co-resident father might contract COVID: “This full-time childcare is in addition to the care that I provide for my father, and the direct result of my father being in the home with us.”

Although we asked respondents to answer the survey questions considering the person they provide the *most* care for, caregivers may be caring for more than one individual, shaping their overall experiences. For instance, one respondent described the complex nature of her caregiving role after the onset of the pandemic:

“My father attended a day program and clients could access this one day to 5 days/week. Prior to March 2020, he attended 3-4 days per week. When Covid-19 was declared a pandemic, he stopped attending; the program shut down for a time before opening again allowing up to half the clients at any given time. I was responsible for my father’s transportation, medical appointments, and emotional support. My husband and I were the responders to lifeline emergency calls and needed to attend to falls. I was the one called when my father needed 911 attention always followed by ER visits and /or admission to hospital. While my father was hospitalized, I was responsible for my mother’s well-being as she continued to live in their condo. She has multiple comorbidities along with untreated anxiety. She requires ongoing emotional support, which has increased since my father’s death (in May 2020). My caregiving responsibilities have shifted from my father to my mother. I see her daily.”

³ Of those respondents who were caring for someone living in supportive accommodations of some kind, 35% indicated that they had considered bringing the person home because of the COVID-19 pandemic. It is not known how many followed through with bringing the care recipient home, but many caregivers clearly had reservations about safely keeping the person they were supporting in a congregate care setting.

Of the 18% of caregivers in our survey that reported spending less time providing care, by far the most common reason was because they were supporting a person living in a PCH, assisted living residence, group home or hospice closed to external visitors or support persons.

Caregivers affected by visitation restrictions described several additional challenges and concerns. For example, when residents of congregate living settings were unable to leave due to public health orders, some caregivers took on increased responsibility for shopping, errands, and paying bills. Many caregivers also spent more time connecting with the care recipient by phone or video call to provide emotional and social support and monitor their well-being⁴.

The amount of time caregivers spent providing direct care or support varied along with fluctuations in public health orders and site-specific rules and conditions within PCH/assisted living/group homes. These included, for example, situations where visitors might be limited to one or two designated persons and/or restrictions were made on the numbers of weekly visits.

“Visits were 30 minutes once a week. Outside. Distanced. Not private. Then virtual visits once a week for 30 minutes. Not private. I could not see the condition of her room. I could not really talk to her as there was always someone nearby.”

“I am allowed to visit with an essential visitor pass. No one else from the family is allowed to go in. I am spending more time there helping and dealing with mental health issues like anxiety and depression in my parents.”

In some cases, suitable spaces were not available for visiting – outdoor visits, for instance, did not work well for some respondents and their family member/friend, as hearing impairments or dementia combined with unsuitable (e.g., noisy) spaces lacking privacy. Even “window visits,” which were allowed at some facilities, were not possible for residents without accessible windows, or when family members had hearing impairments.

⁴ However, even connecting in this way was not always possible. As one respondent explained, they were “only able to video chat once a week for half hour. Mother is not able to use a phone [without assistance] and is also hearing impaired.”

One respondent explained that they were only allowed to visit the person they were supporting for ‘essential’, or ‘emergency’ situations and they were ‘challenged [by staff] if we are coming for non-medical reasons.’ The respondent concluded by elaborating on what this felt like for them personally:

“You are faced with a moral consideration of do you go in under a pretense, or after-hours when there is no monitoring - or obey the rules. Both have serious consequences. Terrible feeling to wait until another break down to be allowed to go visit instead of doing someone proactive and preventative.”

A few respondents commented how being unable to visit was made more difficult, confusing, or frustrating in the context of poor communication from facilities or mixed or frequently changing public messages on rules and policies. This could be, for instance, specific to a particular facility or type of facility (e.g., “supportive housing does not know what regulations it needs to follow and [there] has been no clear direction for the management”) or more broadly (e.g., “mixed messages from our government on rules and what was the ‘responsible’ course of action”).

Restrictions were also an issue for those who were caregiving from a distance. While living in another province, one respondent’s father died in March of 2020 and she was trying to help her mother through bereavement. “The public health travel restrictions for out of province travel are making this experience almost unbearable because as I understand it, I cannot go and see her. Her health is deteriorating (started smoking again, alcohol consumption is increased) and it seems like there is nothing I can do.”

“Even a simple thing like changing his address became more complicated and much more time consuming. Purchasing clothing and shoes and other items challenging without being able to get into the facility and try things on or take him anywhere. Covid has definitely increased my stress in just dealing with the day-to-day things as I am very cautious...I am the only caregiver for my father and need to stay healthy.”

Whether caring for someone at home, in a facility, or from a distance, caregivers faced increased challenges related to communicating with healthcare providers and coordinating resources to address the needs of the care recipient and monitor their wellbeing. Caregivers expressed grave concern for care recipients and a heightened sense of needing to monitor care environments, particularly with respect to the adherence to public health orders (masks, distancing) by others – including formal care workers and to a lesser extent, other family members/friends. Moreover, caregivers felt added pressure to protect themselves from COVID to safeguard the care recipient.

How did these changes affect care recipients?

In open-ended comments, the overwhelming majority of respondents expressed considerable concern that changes to formal services and other network supports during the pandemic had a negative impact⁵ on the well-being of the care recipient. These concerns often related to cutbacks in formal services, but respondents wrote even more frequently about the general effects of physical and social distancing, as well as additional restrictions for those living in congregate care settings as described earlier.

It's been awful. My Mom has declined rapidly. She is isolated, depressed, and fearful.

Visitor restrictions were particularly difficult when caregivers had concerns about declining quality of care in a congregate setting (especially PCHs and hospitals), and when the care recipient was living with dementia or mental health challenges. Residents in PCHs in some cases were denied access to in-home social activities, and during outbreaks could be confined to their rooms. One respondent explained

"Losing their recreation works negatively impacted all residents. Not being able to go outside has left the residents depressed and lonely."

that she could not visit her father for three months: "When I was allowed to see him, he was a different person...very little communication with me and didn't seem to care if I was there or not. He had lost much interest, and I tried to explain to him what had happened, but think he felt like he had been 'forgotten.'"

Another respondent was unable to be with her mother who had been hospitalized: "Given her diminished cognitive capacity and inability to provide an accurate history to clinicians, this was very worrisome, as plans were being made about her care based on incorrect information." Other caregivers shared how visitor restrictions kept them from being with their family members at the end of their life.

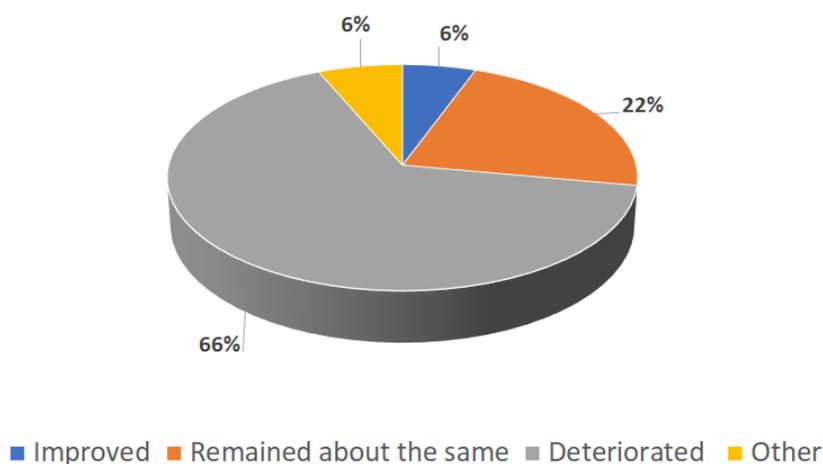
"I watched my father die on FaceTime, in the parking lot (of the facility). I let my sister and mother be there with my dad at the end."

Another respondent was caring for someone living with mental illness who was residing in a group home. During COVID lockdown the group home did not allow this person to attend an appointment for a monthly pharmaceutical injection, resulting in psychosis. The care recipient would call the respondent up to 40

⁵ Albeit very few, there were some positive impacts identified by family caregivers in this survey, particularly those caring for children. For example, one respondent caring for a child that was not attending school during the provincially mandated lockdown acknowledged the child had fewer colds than usual. Another respondent caring for a child that was being home-schooled described the pros and cons to their situation, noting "He has actually had less anxiety and outbursts due to feeling less pressure at therapies and school. However, all the pressure is on me to keep him still engaged and learning while we are stuck inside."

times a day. A family member who was a nurse was initially approved to provide the injection on-site, but this was later also prohibited by the home. After considerable advocacy, eventually the respondent was allowed to take this person home to live with them to ensure they got their injections.

Figure 8: During the COVID-19 pandemic, the health of the person you provide the MOST care for has:



As seen in Figure 8, approximately 66% of respondents believed that the health⁶ of the person they were caring for deteriorated over the course of the pandemic, while at the same time 41% of respondents reported avoiding taking them to a doctor⁷ because of concerns about COVID.

In open-ended responses about the negative impacts of the pandemic on care recipients, the most commonly expressed concerns were about the deterioration of the mental and emotional well-being of care recipients, including loneliness, depression, and anxiety. These were most often tied to a lack of social interaction. As one respondent wrote: “The lock down has had a very negative effect on the person I provide care for, in that the reduced interaction and reduced mental stimulation has I believe greatly accelerated their mental deterioration.” Indeed, there were

“It is very difficult for a person who has dementia to be confined to a room for months at a time ...serious mental health decline.”

frequent concerns about cognitive decline due to lack of social and mental stimulation, particularly for care recipients with dementia. For example, one respondent believed the pandemic caused a sharp worsening of their parent’s dementia. Another respondent emphasized potential difficulties for persons living with dementia, such as being

unable to fully understand the reasons for pandemic restrictions or why workers would show up to the home wearing PPE.

⁶ For this question, health was defined broadly as “e.g., more depressed, worried, forgetful or frail”.

⁷ It is also possible that respondents viewed the issues experienced by some care recipients as emotional and social in nature rather than something that could be addressed through medical or clinical intervention.

Physical effects due to the pandemic were also described by respondents as stemming from the loss of access to recreation programs, the physical manifestations of emotional challenges, social disconnection, and isolation, and unhealthy coping strategies. A few comments indicated that observed health declines were an expected part of the progression of a particular disease or condition, while others indicated that they believed the person had deteriorated more quickly because of the pandemic restrictions.

“[I had] very limited contact and can see that my father declined somewhat without regular support from me; telephone support not adequate.”

Some respondents wrote that the effects of the COVID-19 pandemic on health care services resulted in medical errors and other problems, negatively affecting a care recipient’s physical health. One respondent believed the lack of an appropriate specialist follow-up, a rushed hospital discharge and post-surgery complications that were not promptly addressed contributed to her husband’s deterioration and pain, adding: “COVID-19 has caused a lot of people in the same boat as this person to be lost in the dust to the medical system.” (For a more in-depth story of a ‘broken system,’ see Appendix A).

“It was devastating. My father suffered from depression prior to being admitted to a personal care home late in 2019. After his admission, he became severely depressed and requested MAID [medical assistance in dying] ...he was often in great distress, which was only alleviated by visits from myself and my mother. When visits were cancelled or restricted, my father had very little relief from his suffering. Having to watch him in agony and be so powerless to help him was torture.”

Another respondent was concerned about the reliance on phone assessments during the pandemic to monitor chronic progressive illnesses, such as multiple sclerosis, stating: “I don't think that the deterioration by the disease can be properly measured on the phone.” Other home-based caregivers wrote that further health deterioration might result in PCH placement, exacerbating their concern about risk.

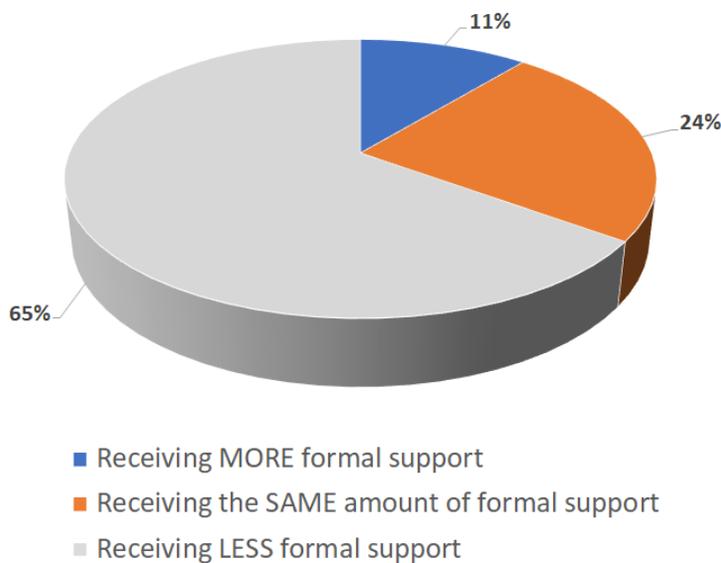
What did caregivers say about the impact of all of this on themselves?

The nature of caregiving changed during the pandemic, and pre-existing challenges with navigating health and social care systems were intensified. Many respondents expressed feeling let down by the system as they were “left on their own” to do more but with fewer resources.

Comments often reiterated that fewer supports were due to cutbacks or pauses to services received by the client, reflecting how services for clients (e.g., home care) also support caregivers. However, formal supports specific to addressing caregivers' own needs were also impacted. As mentioned previously, fewer than one in four participants (22%) were receiving any formal caregiver-specific supports prior to the pandemic, and of these, 65% reported a reduction in support because of the pandemic (Figure 9).

"I found that there is no help or even support from the government or my workplace in trying to manage this. It is overwhelming and just seems to be my problem..."

Figure 9: Changes to the amount of formal caregiver support



As noted earlier, some caregivers wrote specifically about pauses or cancellation of caregiver-targeted services such as respite, noting that there had been, for example, “no respite for months now.” For some, lack of trust and fear of contagion again appeared to motivate them to avoid accessing available services. Respondents also had less access to counselling services and support groups.

Services that remained available involved virtual appointments such as sessions over Zoom, but many commented that “Zoom just doesn’t work” and “[you] can’t connect with another person properly, can’t meet new people”. One respondent further stated, “[I] haven’t been prioritizing my own health during the pandemic as I don’t feel like I have the time and mental space for more than what I am already doing.” Another wrote that they could no longer afford counselling after the loss of their paid work position due to the pandemic.

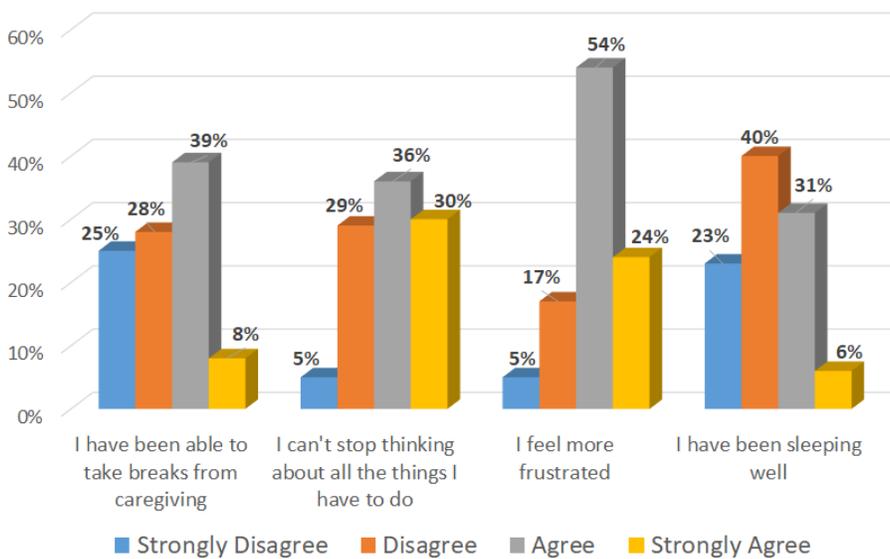
Notably, the few respondents (11%) that were receiving more formal services during the pandemic were moderately more likely⁸ to report stronger feelings of overall wellness.

“The pandemic has affected my support system i.e., family and friends being able to come into our home to help out. I do have some homecare respite, but it is limited.”

Caregivers also shared how reductions in support from their own family and friend networks (as noted earlier) had a negative impact on them. For instance, one respondent commented, “my sisters live out of province and have not been able to travel here to provide some respite for me. He recently fell and broke his hip. Normally they would have come post-surgery/hospitalization to help in his care. I am worn out after 12 years of doing this.”

Our survey questions asked caregivers to reflect on how they felt before the pandemic, and how they were feeling at the time of their response. In answer to these questions about their own well-being, the majority (78%) of respondents reported feeling more frustrated since the pandemic began, 67% indicated they could not stop thinking about all the things they have to do, 63% were not sleeping well, and just over half (53%) reported being unable to take breaks from caregiving (Figure 10).

Figure 10: How are you feeling since the pandemic began?

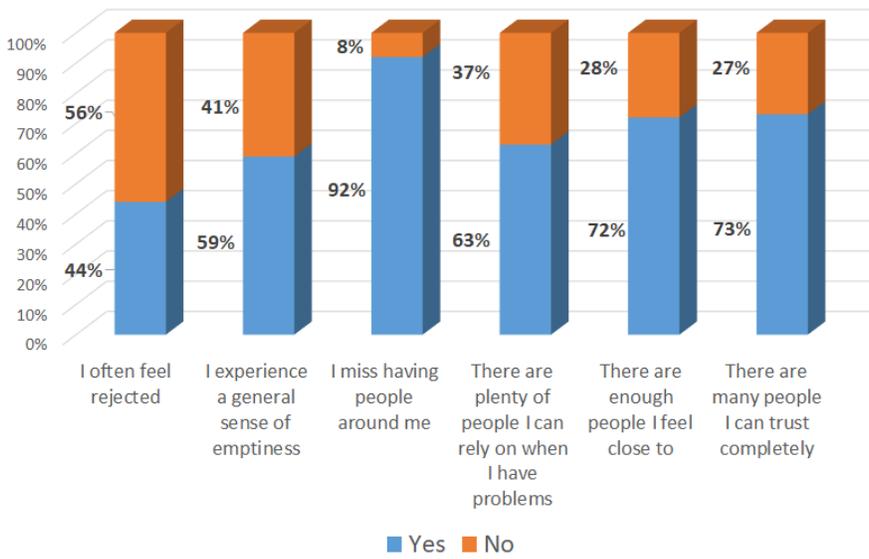


“I’m feeling imprisoned in my own home with very little support ... I pray the end of Covid comes soon... Covid made things worse a hundred-fold!”

Respondents also reported an increase in feeling rejected, empty, missing people, anguished, nervous, and concerned. In addition, feelings associated with wellness - having people to rely on, feel close to, and trust, feeling comfortable, at ease, and good - decreased overall for respondents during the pandemic (Figures 11 and 12).

⁸ R=0.357; p<0.5

Figure 11: How do you feel right now?

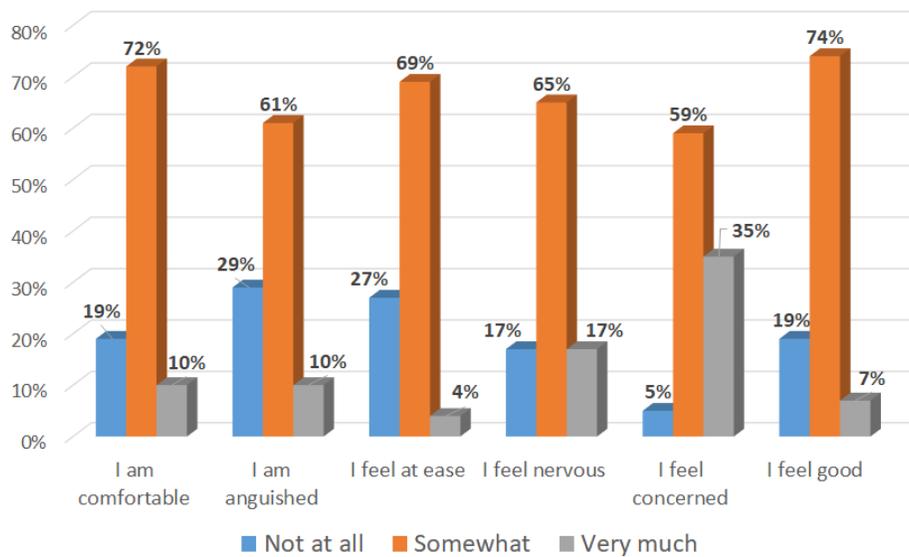


Written comments from respondents also revealed that many were feeling more guilt, stress, helplessness, and worry in the context of the pandemic. For instance, one respondent conveyed how she was the primary caregiver for her father in a PCH and felt pressure as being the only designated family member allowed into the facility. “I try and get up to see my dad any (extra) time I have, but some days I

am just too tired, and there is a lot of guilt/anxiety with that.” Another respondent whose family member was hospitalized but they were unable to visit stated: “it’s making me insane with worry.”

Reports of exhaustion and feeling overwhelmed are woven throughout the open-ended responses to almost all our survey questions. For example, one respondent wrote about the work involved in trying to manage their emotions: “I try not to lose my shit.” Another caregiver commented on the combined emotional, mental and physical effects of being unable to visit their dying parent in a PCH: “It caused

Figure 12: How do you feel right now?



terrible anxiety, as well as shame, self-doubt, difficulty concentrating, acid reflux and sleep disruption...this entire experience has been traumatic for me.”

Over half of respondents (57%) specifically reported a deterioration in their mental health since the COVID restrictions began in March 2020.

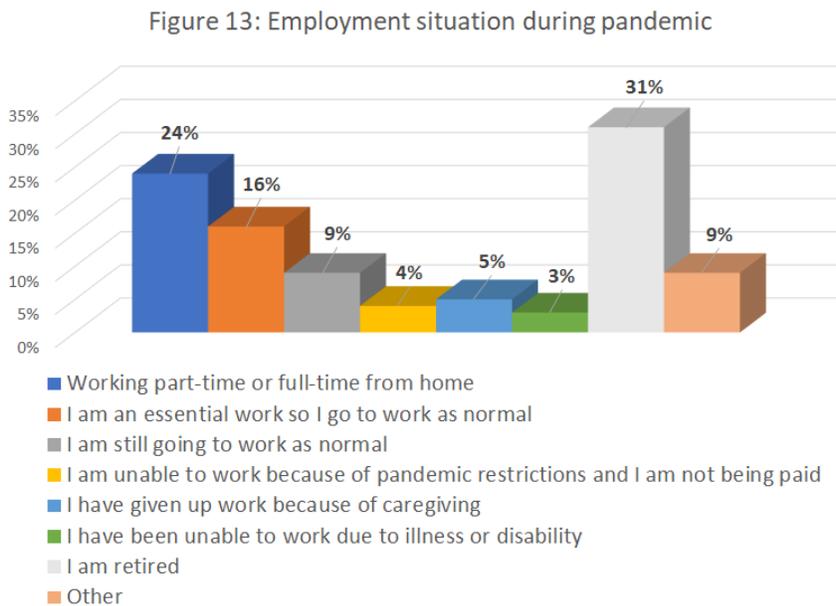
“The level of worry has drastically increased – [I] feel like I'm permanently 'on call' to provide support.”

A similar number of respondents (52%) reported a deterioration in their physical health over the course of the pandemic.

Despite negative effects on their mental and physical health, 43% of respondents indicated that they avoided going to the doctor, often citing that they did not have time to tend to their own health needs. Many caregivers also described this choice as an effort to protect themselves and the care recipient from potentially being exposed to the virus. As one caregiver noted, "...[I] fear that if I get ill (covid or other illness) there is really no one to provide care (grocery shopping, pharmacy pickups, banking, etc.)."

"Just trying to keep up with everything which led me to becoming physically sick from the stress because there weren't enough supports in place."

Caregiving responsibilities had an impact on other aspects of caregivers' lives as well. Socially, many caregivers felt isolated, with 74% reporting they missed having people around them. One caregiver described, "[Our] caring role for an elderly parent has trumped most other social connection. [We were] previously involved with childcare for our grandchildren and a part time job as a substitute. It has been difficult to negotiate these roles and we miss the connection with our grandchildren."



Many caregivers also described the tension between the increased demands of caregiving and paid employment. As noted earlier, over half (57%) of caregivers were working prior to the pandemic, most of them full time. Almost one year later, most (48%) continued to work in paid employment, but a greater proportion were working at home (a jump of 15%) while 40% reported continuing to

go to work outside the home as previously (Figure 13). Seven respondents (5%) reported having given up work because of their caregiving responsibilities, and six (4%) reported being unable to work because of pandemic restrictions.

One respondent explained that her adult child lived in a group home apartment setting where support workers were not being sent in and was experiencing violence from her roommate: "I had to leave work in the middle of my day to attend to this...So many zoom meetings to discuss [the] situation - having to take additional time off work...which is very stressful."

Financial stressors were also a reality for many caregivers. Financial strain was sometimes a result of stopping work due to increased caregiving responsibilities or the need to protect vulnerable care-recipients. As one respondent noted, “Due to my dual caregiver role, I have had to take unpaid leave from my job and the financial hit to the family is real. It is disappointing that there are no income supports in place for people who are virtual schooling (with medical documentation) their children to keep other high-risk people in the home safer.”

For other caregivers, there were added out-of-pocket expenses entailed in trying to fill formal service gaps. One respondent explained that during the pandemic they had been paying privately for a respite worker “who comes only to my mother’s home and doesn’t care for multiple seniors...the pandemic has resulted in a significant financial cost for care.”

Caregiving during COVID had a tremendous impact on the family caregivers in this survey. Most respondents expressed a sense of stress, burnout, being overwhelmed, and unable to continue as is. As one respondent described, “We cannot continue this way. It has been extremely difficult and not healthy for any of us.”

“I wonder how much longer I’m going to be able to do this mentally exhausting role.”

Also evident, but to a far lesser extent, a few respondents elaborated on some positive aspects of their caregiving role. One respondent, whose family was helping a neighbour, noted: “It was good for my family to have someone else to focus on these past months and not be so worried about our own situation.” Another caregiver reflected on the personal growth they experienced as a caregiver, “the care I am able to give, helped me to grow as a person and provided me with more self-respect.”

There was also a sense of relief in some respondents’ comments, during times that the province was seeing the easing of restrictions. As one respondent wrote, “I am now able to provide care for my mother finally. As a caregiver I was denied this for the majority of 2020. I am now able to provide care.” Another caregiver shared a similar sentiment: “Restrictions easing and cases going down definitely makes me feel better about going and being a caregiver.”

However, time and again throughout this survey, caregivers explicitly expressed needing more support but feeling uncertain about when and if they might receive it. Moreover, caregivers expressed significant concerns about the potential long-term effects of service and program ‘pauses’ seen during COVID.

“This pandemic has been very draining on caregivers and there has been little support from healthcare providers. We are all just holding on and hoping for a break, but not really sure what that looks like at this point.”

Summary and Discussion

Reflections on the survey sample

Prior to the pandemic, the caregivers who responded to our survey were *caring for one or more family/friends often with very little support*. Forty-seven per cent of caregivers reported providing care without additional support from informal networks, and only 54% reported that care recipients were themselves accessing formal supports and services (i.e., which would indirectly support caregivers). This may reflect that a) caregivers needed more support but were not receiving it; or that b) the persons receiving support had relatively low needs and additional supports for caregivers were not needed; or c) their role as caregiver was secondary (that is, supportive to a main caregiver) rather than as a primary/main caregiver. Only one in four respondents (22%) were receiving any caregiver-specific supports prior to the pandemic, and similarly only one in four reported being ever asked about their own needs by health care professionals. Importantly, this may reflect the fact that many people who responded to the survey were not providing intensive levels of care prior to COVID (e.g., 52% reported helping less than 10 hours of care a week). The sample may also under-represent higher-intensity caregivers, since those with higher caregiving loads may have been less likely to volunteer to complete our survey during the pandemic.

Twenty-nine per cent of respondents reported providing over 20 hours a week of care prior to the pandemic, however. This is a level of care associated with higher levels of perceived strain and negative outcomes for caregiver wellbeing (Funk, 2021). Although we do not know for certain, findings from the 2012 Caregiver Consultations (Funk, 2012) suggest that many of these caregivers, and those they were supporting, may not have been receiving enough formal supports and services even before the pandemic.

Reflections on Covid-related changes and concerns

Sixty per cent of respondents *took on more care responsibilities* during the pandemic, whether due to COVID-related service pauses for the care recipient, pandemic restrictions, staffing disruptions, or to a lesser extent, families' fear of contagion. At the same time, among the 22% of respondents who were receiving any formal caregiver-specific supports (counselling, respite) prior to the pandemic, 65% reported a reduction in these supports during the pandemic. Some families filled the gap with out-of-pocket purchase of private service (some taking on considerable financial strain to do so), and others relied on their informal networks, which unfortunately were also less available due to the pandemic.

Regardless of whether or not they reported providing more care, we learned through respondent comments of pandemic-related *shifts in the nature of what caregivers were doing, and their sense of difficulty*. In particular, caregivers of those in congregate living were more likely to report providing less care while the nature of what they were doing shifted and their experience of caregiving became more difficult, particularly in terms of worry and anxiety. Indeed, our findings highlight the impact of visitation restrictions on caregivers to persons in congregate residential settings, exacerbated by concerns about

eroding quality of care and confusion and frustration arising from poor, mixed or frequently shifting communication from facilities or government.

Caregivers cited *increased challenges related to communicating with healthcare providers, navigating health and social care systems, and coordinating resources* to address the needs of the care recipient and monitor their wellbeing. Such challenges existed prior to the pandemic (Funk, 2012), but appear to have been aggravated due to rapid and ongoing changes across the health care system, including system-wide responses to infection rates and rates of hospitalization, public health orders, staffing concerns and so on.

Some unique challenges specific to COVID-19 include caregivers' *heightened sense of needing to monitor formal care services*, including formal care settings and the adherence of workers and others to public health orders. Caregivers were also feeling added *pressure to protect themselves from COVID* to safeguard the care recipient, with some also worrying that they were putting themselves at additional risk by doing errands for the care recipient.

"I believe that public health restrictions in general were brought in much too late in the fall of 2020. With significant community transmission, poor contact tracing, the impending circulation of new SARS-Cov-2 variants, the slow rollout of vaccines, and tinkering with public health restrictions contrary to evidence, the burden on myself as individual to protect myself and my mother is that much greater."

A key finding conveyed in this survey is *respondents' grave concern for care recipients and the negative impact of the pandemic on these persons*, due to eroding quality of various formal services and the health care system⁹, staffing shortages and a loss of social and emotional care, as well as the general effects of physical/social distancing and isolation. Sixty-six per cent of respondents believed the health, (especially cognitive, social and emotional well-being) of the person they were caring for had deteriorated, and the open-ended comments tended to convey considerable worry and distress in this regard. For those care recipients in congregate residential settings, this was worsened by visitation restrictions. The potential for future burnout among these caregivers, and for their own personal health complications, is significant.

Reflections on the impacts on caregivers

Perhaps most importantly, we can conclude from our findings that *pandemic-related care provision compounded with increased concern and worry about care recipient well-being generated considerable*

⁹ As respondents expressed, the pandemic created new challenges related to erosion of the health care system (that may or may not be alleviated once the pandemic is over), worsened pre-existing issues, and exposed major gaps and pitfalls in our system.

levels of distress, difficult emotions, and other negative outcomes (poor sleep, exhaustion) for respondents. Fifty-seven per cent reported a deterioration in their mental health and 52% reported a deterioration in their physical health. Although some of this distress might be considered an unavoidable effect of the pandemic, it is important to note that a) unlike in Manitoba not all provincial governments scaled back public services such as home care during the pandemic; b) initially formulated visitor restriction policies in Manitoba were later amended as their unintended effects became evident; c) some provincial governments increased supports specific for caregivers during COVID-19. Moreover, participants' interpretations of and trust in governments and systems at various levels is important for their mental health and well-being.

What is striking about these survey results is that the same issues that caregivers identified nearly a decade ago (Funk, 2012) related to navigating health and social systems, accessing adequate supports, and needing much more help to manage the impact of care provision on their own health and wellbeing still exist in Manitoba today. What is more, these significant challenges have been greatly intensified during the pandemic. It is concerning and disheartening that the voices of caregivers (Funk, 2012) and other formal recommendations (such as those in the Caregiver Recognition Act) and consultations have yet to result in a meaningful response. As evidenced yet again in the current survey, this comes at a tremendous cost – to caregivers and those they are caring for. The time has come for prioritizing deliberate action to strengthen health and social care systems, and meaningfully support family caregivers in both the provision of care and maintenance of their own health and wellbeing.

Recommendations and Conclusions

Concrete recommendations and suggestions for supporting both caregivers and the persons they are caring for were provided by many respondents in response to a question at the close of the survey. Our research team summarized the most common suggestions and extended these with additional recommendations based on our analysis and interpretation of the survey findings as a whole, as well as our knowledge of the broader base of evidence on family caregiving and well-being.

- Future pandemic responses at multiple levels of government and across different types of health and social care services need to recognize the importance of social and emotional aspects of care and human connection. This includes but is not limited to policies/procedures for ensuring better access for more family members to persons living in congregate settings, residential care, and hospitals, as well as family integration into care more generally (Heyland et al., 2020).
 - Ensure sufficient staff and resources are provided to congregate care settings in order to facilitate visits and care provision by family/friends
 - Transparent and clear governance and accountability processes (e.g., not leaving visitation decisions up to facility directors; transparency around how home care case coordinators engage in decision-making with clients/families about service pauses)

- Designate palliative and end-of-life volunteer services and programs as essential services
- Empower and educate staff and volunteers to correctly follow infection-mitigation protocols (such as mask and PPE requirements, etc.). This is especially important as a concern appears to have motivated some families to voluntarily pause their services.
- Increase mental health funding and access to free counselling, to address consequences of the pandemic on the population as well as on caregivers
- Training for health care professionals and administrators on how to assess and support caregivers is vital (Parmar, Anderson et al., 2020). Family caregivers should be asked by system professionals about their own needs for supports, which should then be responded to and addressed.
- Greater awareness of and supports for the caregiving role¹⁰ should be accompanied by greater recognition of caregivers' circumstances beyond caregiving and their rights to participate more broadly in society – that is, their interests in paid work, school, leisure, and friends (Government of Manitoba, 2011; Heyland et al., 2020).
- Workplace accommodations and paid care leaves are needed to recognize and support caregivers, whether during a pandemic or otherwise.
- Access to formal programs and services for care recipients should be promptly but safely reinstated and strengthened - some respondents expressed significant concerns about potential long-term negative effects of service and program 'pauses' seen during COVID.
- Strengthen the broader health and social care system infrastructure (including access to PPE, staffing, etc.) so that Manitoba is better able to manage future waves or pandemics. These efforts should be directly informed by the Caregiver Recognition Act, the Toews report, the VIRGO report, and findings from academic research.

Because I am older and experiencing certain health issues, some brought on by the absence of Homecare, I am hoping these services for my wife can resume soon. In that respect, I/we will not really feel completely comfortable with Homecare until there are 100% assurances that these workers are fully informed as to the Covid status of their clients, AND that these workers are fully and completely outfitted with all needed PPE to ensure they are as safe as possible, AND that these workers are also tested DAILY for Covid, so as to protect not only their clients, but also themselves, their co-workers, and of course their own families.

¹⁰ In particular, some respondents emphasized a need for greater supports for and awareness of the caregiving role among those caring for persons with addictions and/or mental health issues, and recognition of the caregiving role that can continue after someone enters a personal care home.

My daughter with disabilities has had her day-to-day support programs cut, with no increase to her one-on-one support staff and restrictions on allowable support provided, so I've picked up as much that slack (without compensation) as I can. I personally feel like the funding to programs like day programs will never be the same again because we've managed without them for an entire year so 'they must not be necessary, do more with less.'

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Appendix A - A story of a broken system during COVID

One respondent described their mother pre-pandemic as physically healthy with mid-stage dementia, living in assisted living in a rural community and with good quality of life. The redeployment of facility workers by the health care system left “my mom’s home short staffed for months which led to a decline in her physical and mental health.” Their mother then broke her hip (requiring surgery), and the local hospital was experiencing a COVID outbreak. She was held in the local emergency department for 24 hours before being transported to a different rural hospital where she was held for another 12 hours before being flown to a Winnipeg urgent care facility. In Winnipeg she waited an additional 24 hours for a negative COVID test result before being admitted for surgery, which she received the following day. Knowing how stressful this would be for their mother, the respondent tried their best to help:

With each new place, and new shift of new workers I tried to do what I could for my mom by phone as code red was in place and no visitors were allowed. I did what I could from a distance, but the reality was she was on her own with no advocate to speak for her, no one to say this is her baseline, no one to say this is normal for her or not normal. Often, it would take all day of calling to connect with a nurse only to get little or no information on how my mom was doing. Each time I spoke with a new nurse I made sure they were aware of my mom’s short term memory loss.

Two days after surgery her mom fell again, and the respondent did not learn of this until 3 days later when the doctor read an x-ray. The respondent was told that chairs with safety belts were in use by patients ‘more in need’ than her mother. She was also told by nurses that they did not know how her mom was doing, or did not have time to read the chart.

When she was ready to be transferred back to her home hospital, it was not accepting patients due to the continued outbreak so I requested that she be transferred to a different rural hospital where she had recently lived for more than 50 years and more importantly, I have siblings living there and my sister would be allowed to see her daily.

Complicated further by a blizzard on the day of the transfer, her mother was left at a different hospital en route and fell again, this time hitting her head. “I was assured she was fine” but the next day her mother’s health declined greatly, at which point she was taken to yet another hospital for a CT scan, revealing a fractured skull and brain bleed. The respondent described her mother’s condition as “day by day wait and see”. She further expressed:

I believe I’m not alone, that there are many more stories just like my mom’s or even worse. COVID -19 cannot take all the blame for the misfortunes my mom has suffered. However, I do believe COVID-19 has merely exposed the healthcare system for what it was already - A Broken System that cannot provide proper patient care. Our healthcare system is understaffed. The staffing shortage is being filled with agency workers and that attempt to fix the situation comes with a whole host of negative issues. Staff are overworked, and staff are poorly managed, all these shortcomings create a breakdown of communication and collaboration with regard to proper patient care, making it impossible for our healthcare system to provide adequate and safe patient care. Honestly, our hospitals are not a safe place to be especially right now.