HQCA
Health Quality Council of Alberta

THE IMPACT ON UNPAID INFORMAL CAREGIVERS WHO SUPPORT THEIR LOVED ONES AGING IN PLACE

The experiences of family members who provide support to cognitively unwell seniors that receive home care services

It's not what I expected I would be doing… I thought when I hit this age. I'd be relaxing a little bit. and hopefully still healthy and active… at that time. my loved one was doing really well. and you don't anticipate that you're going to have to spend time caring for your loved one. And so. it's impacted my life. I married my loved one for better or worse. so be it. I'm the person that has to be there. And the buddies are there. too. but I'm the one that lives with my loved one and sees the little nuances. **I'm not an individual anymore. I'm just a caregiver, really,** plus my loved one, **and it's 24 hours a day.** defers to me all the time. right? I think the biggest challenges for myself is trying to make all the schedules work… Before you can say or do anything. you've got to whip out the calendar and see where everybody's going to fit and work. So. I think the longer we can stay in our home. probably the better. as far as feeling well and feeling good about yourself…

ABOUT
the Health Quality Council of Alberta (HQCA)

The HQCA is a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans as legislated in the *Health Quality Council of Alberta Act*. It gathers and analyzes information, monitors the healthcare system, and collaborates with Alberta Health, Alberta Health Services, health professions, academia, and other stakeholders to drive actionable improvements.

ACKNOWLEDGEMENTS

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Dr. Trevor Theman, HQCA Board Chair

FOREWORD

An estimated 400,000 Albertans provide ongoing, unpaid support to their aging loved ones. These informal caregivers allow hundreds of thousands of people to remain in their homes. Unfortunately, too often, the contributions of informal caregivers to the healthcare system go unrecognized.

As the Health Quality Council of Alberta (HQCA) learned through our engagement with families and members of the healthcare community in recent years, there is an appetite to learn more about the role informal caregivers play and how their needs can be better met.

Informal caregivers are vital to the long-term sustainability of Albertans aging in the right place.

This report, *The impact on unpaid informal caregivers who support their loved ones aging in place*, shines a light on the experiences of the informal caregivers who provide care to cognitively unwell seniors who receive home care services. It highlights the support they provide, and identifies their challenges. We would like to thank the 29 caregivers who shared their personal, and often heart-breaking, experiences with us. Through these interviews we understand better both the rewards and the toll of being a caregiver.

As you'll learn from this report, there is often an imbalance in the relationship between clients, home care staff and operations, and informal caregivers. While the client may be well supported, the caregiver is not. And while many caregivers are motivated and feel fulfilled by caring for their loved one, they have needs that are unmet, affecting their quality of life and, inevitably, the quality of care they provide their loved one. If we do not appropriately support caregivers, they risk becoming users of the healthcare system themselves.

Caregivers are vital to the long-term sustainability of Albertans aging in the right place. We hope this report generates acknowledgment of caregivers' roles and consideration as to how they can be better supported. If we address caregivers' needs, we will not only avoid considerable health system expenditures in the future, but, more importantly, we will help seniors remain safely where they want to be, in their homes with their loved ones.

In closing, we would like to thank the home care clients who also participated in this project and the individuals who led this important work. It is important that the caregivers' voice is heard by everyone working with seniors aging in place.

Trevor W.

Dr. Trevor Theman, HQCA Board Chair
Edmonton, Alberta

Informal caregiver:
family member, partner, friend, or neighbour who provides **care without pay.**

400,000

The estimated number of informal caregivers helping seniors remain at home.

BACKGROUND | A look at the role of and toll on unpaid informal caregivers

Home care depends on informal caregivers

In Alberta, there are an estimated 500,000 informal caregivers.[1] Through its own information gathering, the HQCA conservatively estimates that at least 400,000 informal caregivers are looking after seniors in Alberta. Informal caregivers (referred to as caregivers throughout the report) provide a variety of supports, including transportation, housework, medical and personal care, and emotional support to their loved one.[2] These caregivers provide a minimum of 10 hours of unpaid care per week;[3] that is about four million hours of care per week in Alberta, or over 200 million per year. This informal care is not paid for or funded by the province's healthcare system; however it enables their loved ones to continue living at home. These often-unrecognized healthcare partners save Canada's health system approximately $25 billion annually.[4] In Alberta that would be about $60 million per week or about $3 billion a year. Informal caregivers – defined as family, partners, friends or neighbours who provide care without pay[5] – will become even more important in the years ahead.

Alberta's population of seniors (aged 65 or older) is growing. Today, seniors make up about 12 per cent of our population;[6] that is over 500,000 seniors in Alberta in 2018. It is projected that by 2031, one in five Albertans, or 20 per cent, will be a senior and that the majority will choose to live in their private home.[7] Although seniors wish to remain living independently at home, they may need formal support to do so. One support available is the home care program that provides professional (such as assessment of health status, rehabilitation, and medication administration) and personal care services (such as personal hygiene, dressing, toileting, mobilization and transferring, and assistance with dining, oral care and medications).[8] However, home care is not a 24-hour service, and the number of hours of care are limited. Caregivers often fill in the unmet care needs; it is estimated that a caregiver often fulfills 70-75 per cent of the care.[9]

Providing caregiving support has a personal cost – even more so for caregivers who provide support to someone who is cognitively unwell and/or behaviourally challenging,[10,11,12] who feel unsupported by friends and family, cohabit with the care receiver who is aged 65 years or older, and/or contribute 32 or more hours of care per week.[13,14] This personal cost can lead to caregiver burnout and distress, and as a result they are more likely to place their loved one in congregate care sooner.[11,15,16] In addition, caregivers are also at risk of social isolation, poor health outcomes, and depression.[2,17,18] Other studies urge that focus be given to caregivers before they also become healthcare system users.[14,19,20]

Estimated number of support **hours** provided by **400,000 caregivers** in Alberta per year.

200M+

Projected healthcare **savings** per year when caregivers help loved ones **remain at home.**

Caregiver burnout: the sum of tasks and responsibilities culminating in physical, emotional, and mental exhaustion – leading to feeling **tired, guilty, stressed, anxious, or angry.**[1]

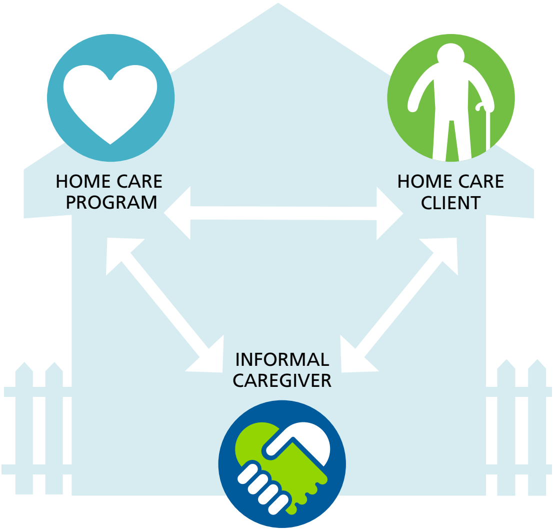
One study found that early placement into congregate care (long term care, supportive living) is more costly to the healthcare system than supporting caregivers.[21] Specifically, the cost of early admission to long term care is three to six times more than providing caregivers with four hours of respite each week and a $200 benefit per month. Another study estimated the cost of long term care is about double the cost of home care services.[22] Therefore, it's important to understand the role of and toll on our province's caregivers to ensure there are supports in place for these valuable care partners. Furthermore, strengthening support for caregivers may also lead to health system savings.

Supporting clients and their informal caregivers is a provincial and federal priority

In 2017, the Government of Canada announced an injection of $11 billion into home care and mental health over the next 10 years.[23] The funding, for each province and territory, was to be used for priority areas identified in the Common Statement of Principles for Shared Health Priorities.[24] One of these priority areas was to improve access to home and community care, while reducing the reliance and impact to acute care or congregate care.[25] The home care program is delivered by provincial, territorial, and some municipal governments.[26]

In 2018, the Health Quality Council of Alberta (HQCA) engaged stakeholders accountable for home care services in Alberta, to understand what information would assist their decisions regarding home care policies and funding. Participants included representatives from Alberta Health (AH), Alberta Health Services (AHS), and privately contracted home care provider organizations. Top of mind in these discussions were policies and priorities related to Aging in the Right Place,[27] the Alberta Dementia Strategy,[28] the $11 billion allocated for home care and mental health, as well as Canadian Institute of Health Information (CIHI) indicators. Stakeholders identified a need to better understand whether home care enables clients to live at home, and how to support clients and their caregivers to ensure both remain living in their chosen communities as long as possible. Of particular interest were home care clients who were cognitively unwell and their caregivers, as these clients often require more support and resources. In synthesizing the literature and the findings of this project, the HQCA views quality home care as a co-produced program by interdependent partners collaborating to co-create and co-deliver care – illustrated in **Figure 1**.

Figure 1: Interdependencies between the home care client, informal caregiver, and the home care program



Home care clients rely on home care and informal caregivers to remain at home. Caregivers, in turn, rely on home care to relieve some of their burden. Meanwhile, home care depends on informal caregivers because it's not a 24-hour service.

About this report

The intention of this report is to highlight and make visible to Alberta's health system leaders the experiences of informal caregivers and their valuable partnership with the home care sector. Despite the large number of caregivers and what the literature tells us about their critical role in our health system, there is little known about their experiences. To capture this population's voice, the HQCA conducted interviews with caregivers and their loved ones to better understand their challenges, and to identify ways our healthcare system can support clients and their caregivers to live safely at home longer.

Two types of interviews were conducted. The first interview involved speaking with clients and their caregiver together about the clients' experiences with home care. A follow-up interview took place with only the caregiver regarding their experiences with caregiving. A total of 54 face-to-face in-depth interviews were completed with 29 caregivers and 27 home care clients who were cognitively unwell,[i] in both rural and urban geographic locations across Alberta, between September and November 2018. More information about the methodology used for the caregiver interviews is available in the **Appendix.**

This report documents the role caregivers play and provides a sense of the magnitude of their contribution to the healthcare system.

This report documents the role caregivers play and provides a sense of the magnitude of their contribution to the healthcare system. The findings emphasize that in order to truly support aging in place, the healthcare system needs to recognize and support the interdependencies between the home care client, caregiver, and the home care program. Caregivers are often discussed within the context of the support they provide to their loved one, as opposed to being considered individuals with their own needs. In the following pages, we summarize what we heard from caregivers and include quotes from participants and fictional stories, constructed from real experiences.

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[i] Defined by the HQCA during cognitive testing of the *2015 Alberta Home Care Client Experience Survey*, and includes a cognitive performance score of 0 or 1.

Frankie & Jim *A fictional story based on actual experiences*

Frankie and Jim have been married for 45 years and have lived in the same community for the past 20 years. Two years ago, Frankie began to notice changes in Jim's memory, particularly when he began to forget to turn off the stove when cooking. One evening, he became disoriented and didn't know where he was. Concerned, Frankie brought Jim to the emergency department, where he was admitted and diagnosed with dementia. After, they were referred to home care to provide support to keep Jim living at home.

When home care was initially arranged, Jim was still fairly independent and could bathe and dress himself. The case manager recommended that Jim attend a day program once per week. Jim enjoys these sessions and the exercises help improve his short-term memory. Frankie also benefits because she gets a few hours to herself when she can take care of chores or grocery shop.

However, Jim's needs have increased. Frankie is finding it difficult to keep up with these needs while also taking care of their house, vehicle, driving Jim to and from medical appointments and the day program, and constantly monitoring him. She feels she is working from morning to night with no breaks. She is also losing sleep because she worries Jim might wander from their home at night.

Frankie feels her anxieties about Jim's health and the amount of work she does to support him on a day-to-day basis are taking a toll. She used to be a social person, but finds herself increasingly needed at home. She used to go to the gym, and curl one evening a week with Jim and another couple, but has quit these activities altogether. She feels this has attributed to weight gain and lowered her energy levels. It causes her too much anxiety to leave Jim alone for more than an hour at a time. Friends who used to come by are dropping off because it's getting harder to communicate with Jim. Their three children all live far away making it difficult to get their help.

Frankie is worried about her ability to continue to support her husband. While she values having this time with Jim, she feels trapped. She wonders what life would be like if she didn't have to provide this support, but feels guilty for thinking this, as she made a vow of "for better or for worse."

While the case manager is looking into getting Jim support with his personal care needs twice a week, Frankie knows this will only help a little, and won't enable her to get out to spend time on her own. Also, Jim doesn't want extra help and has told Frankie he won't let a stranger bathe him. This has resulted in arguments between the two. To make matters more difficult, Frankie's eldest daughter constantly argues that Jim should live in long term care. Frankie is doing her best to focus on the positives, but she's running out of steam and her frustrations are mounting. She's hoping with their case manager's help, she can continue to keep Jim living at home. But she also realizes that if she doesn't get more help soon, they'll have to consider long term care.

"I don't feel comfortable leaving that long, just in case. In the beginning it was – I could leave for a day and not feel worried about it… But now, no. I don't feel comfortable about leaving the whole day."

Caregivers' experiences providing support to their loved one

In general, caregivers want to be able to live at home with their loved one, and are motivated to make this possible. Aging in place is therefore just as important to caregivers as it is to clients.[29] However, as Frankie and Jim's story and the HQCA's interviews with other caregivers reveal, the amount of work caregivers take on to make this happen is substantial and the personal cost high.

Who are the caregivers?

There were 29 caregivers who took part in the interviews, ranging in age from 50 to 93 years old. Most were a spouse (20) and nine were a child or child-in-law. Most were women (17 of 29), and were retired (only nine of 29 were employed). On average, they reported spending 115 hours per week providing their loved one with care, with this ranging from 14 hours per week to 24 hours per day.

Some became caregivers over time as their loved one's health gradually declined, while others unexpectedly took on the role due to a sudden change in health.

> *"It's not what I expected I would be doing . . . I thought when I hit [this age], I'd be relaxing a little bit, and hopefully still healthy and active . . . you don't anticipate that you're going to have to spend time caring for your [loved one]."*

Caregivers have different motivations for taking on this role.[30,31,32] Most said they do it in order to continue to live at home with their loved one. Another common motivator is feelings of marital or familial obligation. Spouses feel they must honour their vow of "for better or for worse" and children feel a responsibility to their parents. For some, they are fulfilling this role strictly out of obligation, and would not be doing it otherwise. Others do it out of love and affection.

Participant Demographics

What does their work as a caregiver entail?

For many clients, home care is only provided a few hours per week. Therefore, the bulk of client care that is not, or cannot, be provided by home care, is dependent upon the caregiver to complete. In addition, the types of support caregivers provide extend beyond the scope of home care. **Table 1** provides a summary of the support they provide, most of which is consistent with what is described in the literature.[2,9,10]

Table 1: Summary of types of support caregivers provide

Activities of daily living and instrumental activities of daily living	*Hygiene, dressing, toileting, feeding, ambulating, transportation, shopping, house cleaning, yard work, laundry, finances, and medications.*
Ensure client safety	*Purchase and install safety equipment; ensure client is never alone; access, install, and maintain safety equipment; remove obstacles.*
Prepare for home care visit	*Ensure front door is unlocked; be available to instruct new staff; put out fresh towels and clothes.*
Provide emotional and social support	*Be encouraging; entertain and visit with client; support client independence.*
Monitor and manage client health and wellness	*Monitor changes in client health; provide medical support (e.g., bandage wounds).*
Manage self-managed care	*Hire and manage staff; payroll; set expectations.*
Activities	*Take client to activities and on outings; purchase activities the client will enjoy; take client to cultural events.*
Information and documentation	*Personal directive; seek information about client disease/illness; research available funding grants to recoup costs.*
Plan and schedule	*Medical appointments; in-home healthcare; private respite.*
Advocate	*Changes to medications; for additional hours of care.*
Place of residence	*Ensure home accommodates client needs (e.g., downsizing).*

"The time we get to spend together. I guess would probably be the most positive thing about supporting my loved one. I mean it makes me feel good to know that I'm helping my loved one out."

What are the challenges of caregiving?

Caregivers take on many tasks, and with these come challenges and personal impacts. These challenges, and the impacts of caregiving discussed later, underscore that caregivers need more support. If they continue to be unsupported, they may burn out and no longer be able to perform this role. This is problematic, particularly because the home care program is reliant on caregivers to take on a substantive portion of the care.[9]

Challenge: The work itself

The responsibilities involved in caregiving in addition to balancing employment, managing a household, and the caregiver's own health and wellbeing can be overwhelming. The demanding nature of these responsibilities was described in several studies and echoed in what the HQCA heard from caregivers.[17,31] Some caregivers feel they are working from dawn to dusk, and even their sleep is interrupted to help their loved one at night. For many caregivers, life is pre-planned and arranged around the needs of their loved one. From the moment they wake up, caregivers are on duty. They keep track of schedules, make preparations for home care, provide care, clean the house, make meals, and drive to appointments.

> *"I think the biggest challenges for myself is trying to make all the schedules work . . . Before you can say or do anything, you've got to whip out the calendar and see where everybody's going to fit and work."*

The need to be constantly available is a huge burden and compromises their freedom to do what they'd like to do. If they want to attend an event, it needs to be planned well in advance to ensure the loved one has the proper supports in place. In addition, many spoke of giving up evening and weekend activities, because they feel home care support is confined to business hours.

Another challenge is taking on tasks they are not always comfortable with and are outside of traditional gender roles. The latter finding is supported in previous studies.[30,33] When gender roles are reversed and female caregivers take on traditionally male dominated tasks like outdoor maintenance, and men take on traditionally female dominated tasks, like housekeeping and shopping, these tasks can be overwhelming. As a result, a few caregivers experience resentment at having to do them, particularly if they also receive criticism from their loved one if they don't do it 'right'.

> *"It was me that handled the house before, and [my loved one] did all the stuff outside and the vehicles. Now I've got it all to do, and sometimes it's overwhelming."*

Challenge: Relational conflict

Many feel the quality of their relationship with their loved one has declined since taking on the role of caregiver. Some feel like their role has become paternalistic, putting them in the position of the 'bad guy' nudging their loved one to accept help with tasks important to their health and wellbeing. Sometimes, they feel they are not always appreciated by their loved one for the work they are doing, and at times, even taken for granted. Arguments and disagreements arise as both became more easily frustrated.

Additionally, several spouses spoke of loss of intimacy and romantic love towards their partner due to the changed nature of the relationship of caregiver and client, and/or because the client is no longer the same person they once knew. These changes in relational dynamics align with those observed in other studies.[17,18,30]

"It's a challenge sometimes not to snap back. I tried to not do it. sometimes I do. I'm human."

Challenge: Cognitive and physical impairment of the client

One challenge in caregiving is related to their loved one's impairments and limitations. Dealing with emotionally fragile states, memory loss, and limited physical and communication abilities often causes frustration. On a personal level, caregivers may also be struggling to adjust to these changes in their loved one and to their relationship. Some find it hard to rein in their own emotions, particularly when their loved one refuses support.

Another challenge for a caregiver is understanding their loved one's illness and its progression. Caregivers do not feel they know enough about how to manage changes in their loved one's physical capability, behaviour, and memory function; this is similar to other study findings.[31,34] Related to not understanding their loved ones illness, they do not feel skilled enough to identify changes to the client's health.

> *"I have to rein [my loved one] in, because [they] still think [they] can do everything . . . But that means that I have to be [their] bodyguard sort of thing, which sometimes is just exhausting, and I'm not capable."*

Caregivers are also concerned for the safety of their loved one. Cognitive and physical impairments require that they cannot be left alone for extended periods as they might experience injury or cause an accident such as leaving the stove on.

Challenge: Asking for and getting help

Even though help may be available, such as through family or friends, it can be hard to ask for help. Caregivers do not want to feel they are a burden. Sometimes this is a matter of pride, or a matter of protecting their loved one's dignity. For some who did ask for help, they found that initially, help was abundant, but over time this support waned.

This leads to a related issue, which is lack of support, particularly from family, which further contributes to feeling isolated, overwhelmed, and stressed.

> *"I hate to ask for help. But if it's offered . . . Then it's okay, you know? But asking for help is the hardest thing to do."*

"I'm the person that has to be there. And the buddies are there, too, but I'm the one that lives with my loved one and sees the little nuances, plus my loved one defers to me all the time, right?"

What are the impacts on caregivers?

Caregiving has an impact, with most caregivers feeling that there is a negative personal toll.

Impact: Reduces free time, self-care, and independence

One of the biggest impacts of caregiving is loss of free time. This is necessary for independence from the client and to take care of themselves; which is consistent with the literature findings.[17,30] Many caregivers feel their loved one is completely dependent upon them and feel guilty leaving them. Sometimes, this is because they feel they know their loved one best, making them the best person to meet their loved one's needs. For others, they feel they cannot leave their loved one alone, unless there is someone to watch them.

Some limit their time away as a result, or have stopped engaging in activities altogether. As a result, some feel socially isolated. Among those who did take part in activities, some feel resentment from their loved one. Caregivers who do not have time for themselves feel trapped, whereas those who are able to leave and take part in activities are happier. The negative impact of caregiving on the caregiver's social life has been identified in other findings.[17,30,34]

> *"I mean, you can't even sit in the bathtub, unless you want to do it when [my loved one] is sleeping, you know? There's just so many things you can't do on the spur of the moment that I always was able to do . . . That's what I miss . . . just to be me and not have to think about somebody else all the time."*

Impact: Mental health

Words like "mentally exhausted," "hemmed in," "trapped," "overwhelmed," "worn out," "no joy in life," and "depressed" were used to describe the impact of caregiving. Caregivers experience stress that is sometimes overwhelming, making it difficult to cope, and these experiences are also reported in other studies.[2,15,35] They worry about their capacity to continue in this role, what the health trajectory of their loved one is going to be like, and whether their loved one will be able to continue to live at home. One caregiver said they are burnt out and no longer wanted to continue to support their loved one.

> *"I was really feeling like I was drowning in this hole. I was not handling being the 24/7 caregiver."*

Impact: Physical health

Caregivers experience loss of sleep, either because they are constantly interrupted to assist with care tasks like toileting, or because they worry about their loved one. Several others mentioned that caregiving takes a physical toll in that they neglect to eat well or exercise regularly. While several are encouraged by their physician to engage in exercise to improve their own health, they feel too tired or guilty taking time away from their loved one to engage in any form of self-care. Impacts to caregivers' physical health are also noted in other studies.[2,17,31]

> *"I keep paying my monthly membership [to the gym], but I don't go . . . I do worry that my health, my physical health is not enough of a priority."*

Impact: Employment and work

> *"I probably would still be working if . . . I've had lots of calls that I could have went back, but it doesn't work at all. [My loved one would] have to be in care for me to work, and what's the point?"*

Some caregivers work part time while others balance fulltime work with caregiving, which means they work most hours of the day. This is challenging particularly when work conflicts with caregiving, for example, providing transportation to a medical appointment. Several rely on home care to check in on their loved one during the day to give them peace of mind and deliver key services like medications. While this worked for some, others said it was not feasible to continue to work and be a caregiver, particularly when their loved one requires around-the-clock care. As there is not enough support, they had to give up their employment. This was difficult for those who found enjoyment and meaning in employment. What we heard about the impact of caregiving on people's work life is consistent with what has been heard in other studies.[2,17,30]

Impact: Identity

> *"I'm not an individual anymore. I'm just a caregiver, really, and it's 24 hours a day."*

Similar to other findings,[18] many caregivers no longer feel they are an individual independent of their loved one. Instead, their primary identity is as a 'caregiver.' Some also mentioned they felt they needed to change who they are to better adapt to the needs of their loved one – for example, by giving up volunteer positions in their community or their career. Because their identity has become so interdependent with the client, their ability to take care of their own needs, including their mental and physical health, is compromised.

The positive experiences of caregiving

The positive experiences of providing care to a loved one shed light on why this work is important and meaningful for caregivers and what motivates them to continue to do this work, despite its challenges.

Positive: Personal development

For some, being a caregiver offers personal satisfaction or growth; it is rewarding to meet the needs of a loved one and know they are capable of caring for them at home. Some also mentioned they always enjoyed helping others, and this is simply a natural extension of their personality. Caregiving provides purpose and meaning, as many are retired and feel this work enables them to be productive with their time. The insights shared by the interviewees align with previous study findings.[2,17,32]

> *"What could be more rewarding than helping your [loved one], right, especially when [they've] done so much for all of us, for everybody?"*

Positive: Relationship with their loved one

For some, the primary benefit of fulfilling this role is that they are able to develop a closer relationship with their loved one. Whether they are a spouse or a child, being able to spend more time with them in the same home is comforting. Some feel that this role provides an opportunity to give back to their loved one such as children caring for a parent. These positive feelings are echoed in other studies.[17,30,32]

Caregivers also found appreciation from their loved one motivating. Many clients recognize their caregiver as being instrumental to enabling them to live at home and caregivers in turn are aware of this appreciation.

> *"Oddly enough, the last [number of] months have been the happiest of my life. As close as I've ever been with my [loved one], we've become closer."*

Positive: Living at home

Many caregivers appreciate being able to live in their own home, where they are most comfortable. They worry they will need to move into congregate care with their loved one if they require additional help.

What enables caregivers to continue in this role?

Having access to support and utilizing coping strategies enabled caregivers to continue to provide their loved one with care.

Enabler: Having supports

The supports most available to caregivers are family and friends. As outlined in other studies, relational supports are essential in helping reduce the demands placed on caregivers.[31] Family and friends provide respite hours, transportation, household and home maintenance support, social and emotional support, and advice and information. Caregivers also rely on home care to fulfill some of their loved ones' care needs and remove this burden from them.

When caregivers could afford it, some also invested in private services, most often for housekeeping or homemaking services (e.g., cleaning, vacuuming, and cooking), respite hours (typically evening or overnight hours), services from other providers such as optometrist visits, and in-home grooming services. These services are unavailable through home care or exceeded home care's capacity (e.g., having overnight respite).

> *"I feel very supported by all my family members. We all keep a very close eye on each other, to make sure we're all doing okay. If somebody needs to step away for a little while, we're good with that part."*

"It relieves me, because I know my loved one is safe in there with someone, who has knowledge and knows how to handle people. That's the best part of that for me."

Enabler: Coping strategies

Many described using personal coping strategies to handle stress, recognizing this is important self-care that enables them to continue to provide their loved one with support.

> *"It's good for me [to volunteer], because I get out, I meet people, I enjoy being with people."*

Coping methods are unique to the individual and may include:

- Participating in enjoyed activities, such as shopping, crafts, or esthetician services
- Exercise
- Paid employment or volunteering
- Spending time away from the client for a brief period of time such as going for a walk
- Maintaining a positive attitude – focusing on what is good and having hope
- Religion – reading scripture or attending church
- Sleep more and taking naps
- Talking with somebody like a friend or relative who is not the client
- Pets
- Becoming informed about client illness/disease through support groups, Internet research
- Professional services: massage therapy, reflexology, psychologist

Many of these coping methods are consistent with those identified in other studies.[15,17,30]

Engaging in these coping methods requires time and not everyone had this luxury. Therefore, not all coping methods are accessible to all, and some caregivers admitted they did not employ any strategies to cope at all. In addition to lack of time, other barriers to utilizing coping methods included feeling low in energy, stressed, guilty, or lacking motivation.

What could prevent caregivers from continuing their role?

> *"Well, as long as I stay healthy. That's the main secret. If something happens to me, then we're both up the creek without a paddle."*

Throughout the interviews, caregivers expressed concerns with not being able to continue in this role if the client's health declined and required 24-hour support, or if their own health declined and they were unable to take care of their loved one. While most caregivers feel confident that they would be able to continue in this role, some feel overwhelmed and question whether aging at home is appropriate moving forward. Similar to other studies, some caregivers considered placing their loved one in congregate care because their increasing needs are becoming unmanageable.[15,16,36] Several feel their quality of life would improve if they were no longer a caregiver. Despite wanting to make this transition, they experience barriers. One is financial – spouses cannot afford to maintain both their current residence and pay for their loved one's congregate care. Or, their loved one is unwilling to make this transition. Overall, most caregivers feel that if they were not able to take care of their loved one any longer, their next option is congregate care.

The more depended upon and restricted the caregiver feels, the less happy they seemed to be.

Summary

While most caregivers are motivated to continue to care for their loved one at home, and experience positive benefits in taking up this role, they also experience challenges. This work is time-consuming, demanding, and difficult. It takes a toll physically, socially, mentally, and on employment. While some are coping and managing fine, others admit they are not.

Having someone dependent on them leads to feeling stressed, overwhelmed, and that they have no time to themselves. In general, the degree to which their loved one is dependent on the caregiver and the degree to which the caregiver feels supported by others and able to spend time apart from their loved one impacts how satisfied they are in this role and whether they feel more positively or negatively about it. The more depended upon and restricted the caregiver feels, the less happy they seemed to be.

"We get tired, and sometimes it's really frustrating, because you feel kind of hemmed in and you can't really – you just need to let loose and you can't, because I had to keep my loved one safe, because my loved one has always been a bit of a risk taker."

Emmett & Vivian *A fictional story based on actual experiences*

When Emmett married Vivian 15 years ago, Emmett was aware of Vivian's chronic medical condition that would cause her physical health to deteriorate. Over time, Vivian has lost most of her physical independence, which has been difficult on their relationship. Vivian has struggled to accept these changes, and Emmett is not always understanding of how she is feeling, and finds himself getting frustrated with her when she is upset. When this happens, Emmett finds they argue more. He does his best to cope with these feelings by going for a walk or exercising on his stationary bike.

As Vivian became less able to complete activities of daily living, her family physician recommended home care. Vivian now receives three home care visits per day to help her into and out of bed, with bathing, dressing, and toileting. While Emmett is grateful for the amount of help available, he also feels it is disruptive and invasive, as his home no longer feels private. Staff regularly change, making it feel like there are always strangers in their home. It also involves intervention from Emmett, as it is important to Emmett that he is present at each visit because staff are not always familiar with how to best meet Vivian's needs. For example, sometimes they don't know how to safely transfer her from her chair to bed so he needs to be present to supervise and provide direction. Most, however, are well trained, knowledgeable, and do their jobs efficiently, which they are both grateful for. He also finds staff are willing to listen when he corrects them without getting upset or defensive.

Emmett helps Vivian to the best of his ability, but his own health is declining and Emmett worries about what will happen in the future as Vivian's needs increase. If he can no longer go grocery shopping or cook meals, would home care be able to provide support with these tasks? He does not know what home care can and cannot provide beyond what they are already doing. Emmett feels there may come a time when he will be told to consider long term care. Vivian is very opposed to this option and any discussion about it has resulted in arguments. Emmett knows they are very reliant on home care to support Vivian living at home. Without home care, they would not be able to manage.

Similarly, Emmett really appreciates the gift of time home care has given him. Several years ago, their case manager talked with Emmett and suggested he would benefit from respite hours so that he could have time to himself. As Emmett enjoys volunteering at a local pet shelter, but worried about leaving his wife alone in case she fell, he gladly took up this offer. He's come to realize that time apart, even for short periods, is helping him to stay motivated to help his wife. When he doesn't leave to volunteer, however, he wishes he could have time alone in their apartment – something he never gets unless Vivian goes for a medical appointment. He thinks Vivian would like to go on an outing, such as shopping or to view scenery, for a change of pace so she is not always stuck with just him. She doesn't go out and has become socially isolated. Her only social calls are with home care staff and family.

Ultimately, Emmett recognizes that at some point they are going to have to move into congregate care as their needs increase. He imagines their greatest needs in the future will be help with household tasks like cooking, which might not be within the purview of home care. It would be helpful, in preparing for their future, if he could know more about the scope of home care so he and Vivian can gradually adjust.

> "There's just some times that I'd like to just be at home by myself. You never get that."

How does home care support caregivers?

This section summarizes the types of support home care provides to caregivers, both directly and indirectly, as well as how home care could better support caregivers. As Emmett and Vivian's story highlights, caregivers rely upon home care to meet the needs of their loved one. For many caregivers this support reduces the burden of care tasks that would otherwise fall to them to provide. Some also receive direct supports, like respite through home care, and consider this time invaluable. These supports enable caregivers to continue in their role as caregiver, supporting aging in place.

Home care support

Caregivers are at ease knowing that professionally trained staff are responsible for fulfilling care tasks that meet the needs of their loved one, relieving this burden of care. Furthermore, caregivers take comfort that their loved one is being looked after while they are not at home.

> *"I'm at work, so to know that somebody's here helping [my loved one] is certainly peace of mind."*

Caregivers also turn to home care staff for advice, to ask questions, seek information, and to encourage clients who are resistant to accepting help.

On the other hand, caregiver distress increased when staff did not arrive on time, or were rushed when providing care because then the caregiver had to complete the tasks themselves, which in turn took away from their own free time. Also, the consistency of staff is important because the caregivers spend time to train new staff, which increased the caregiver's workload.

In-home respite

> *"They can give you more time, and that sort of thing, but maybe I'd just like to be at home reading a book, you know?"*

In-home respite involves home care staff spending a number of consecutive hours providing services such as personal care and companionship. Caregivers often use this time to complete tasks outside of the home such as grocery shopping or to socialize with friends. However, caregiver concerns with respite are that it is often not enough time. It is usually limited to a few hours once or twice per week, and some caregivers find that they are rushing to leave and then rushing to return home. Another concern is inflexibility in that caregivers would like the option of leaving or staying during the respite visit. Some caregivers feel obligated to leave their home during this time, otherwise they continue to take care of their loved one or find themselves playing host to the staff. An added concern is that if unplanned respite hours are needed, they are not guaranteed to be available. Overall, respite hours are highly valued, but caregivers feel they would benefit from having more access and more frequent hours of respite.

Adult day programs

> *"Well, it's wonderful [to have access to a day program]. Even if I only get an hour, I'm happy…"*

Adult day programs provide clients with a range of services to optimize their physical, spiritual, social, and emotional functioning.[37] Some of the clients interviewed attend an adult day program and find it invaluable to engage with other seniors and take part in physical and cognitive exercises. As another benefit, day programs provide a type of respite for caregivers, affording them the opportunity to spend time on their own.

However, day programs are typically limited to once or twice per week, are not available on holidays, and often require the caregiver to transport their loved one to and from the site. For those who live in rural areas, this form of respite is not always accessible to everyone.

Caregivers' unmet needs

This report highlights that caregiving comes with its own challenges, as well as rewards. Throughout the interviews, caregivers expressed a desire to continue to provide their loved one with support, and do their best to remain motivated, healthy, and energized. However, they also talked about barriers that can inhibit this, and some caregivers feel they need additional supports.

Unmet need: Respite

> *"In the ideal world, it would be somebody that would free me up in the evening…"*

What caregivers crave most is time for themselves, independent of their loved one. Instead, many feel their needs, interests, and desires come second to their loved one's needs. On the other hand, there is an expectation that caregivers engage in self-care for the benefit of being able to continue to care for their loved one, not necessarily for their own wellbeing. However, without any formal supports available, self-care has ironically added to caregiver burden. Interestingly, a focus group study found caregivers felt their caregiving work and their own support needs were invisible to the healthcare system and to healthcare providers.[38] While many studies have found that caregivers' biggest support need is respite[16,19,34,39] the focus group study argues it is common for caregivers to be turned down under the subtext that the healthcare system is too overburdened to provide this support.

Respite services offered through home care provide relief for some caregivers, but it is often not enough. Evening, weekend, and consecutive days are often unavailable, preventing caregivers from attending social engagements or traveling. They also want time alone in their own home. Caregivers would like it if home care could take their loved one on an outing, which would provide them with time alone, while offering their loved one a change of scenery as well as the opportunity to socialize.

Overall, additional hours of respite through home care would be beneficial and would give caregivers time to themselves while providing them with peace of mind that their loved one is safe and cared for.

Unmet need: Clarity of scope of home care services

Many caregivers are unaware of the range of assistance or services they can access through home care. They lack knowledge of what is and is not within scope, and feel it would help to get a better understanding of what services are available to them. Several caregivers interviewed would like more information on what services are available long-term based on the projected trajectory of their loved one's illness. This information allows them to plan and have realistic expectations of home care moving forward. Moreover, when caregivers and their loved ones are not provided with information about the types of services available through home care, this adds to their burden as they spend time researching information. This sentiment is echoed in other studies.[14,17]

> *"I'd like to know more about what, specifically, home care can provide . . . Then I think we would have a much clearer conversation with home care, a much better understanding of the near future, my [family member] and I could have a greater feeling of comfort, that all of [our loved one's] needs are being met."*

Unmet need: Support with day-to-day household tasks

> *"I don't know if it's reasonable to expect for home care to just provide friendship or companionship, or to provide cleaning services . . . those are things, I think, that for me, certainly, would make a difference."*

Many feel support with day-to-day household tasks would relieve some of the burden of care. In particular, support with house cleaning, home maintenance, yard work, and cooking. While some can afford these services from private organizations, others cannot. They acknowledged these tasks fall beyond the scope of home care, but feel that it would be beneficial if home care could recommend reputable services or supplement the cost of these tasks. Ultimately, it is felt relief from upkeep of their home will enable them to remain in their home longer, especially as the caregiver's own health declines and they became less able to complete this work. This too is consistent with what has been heard in other studies.[16,40]

Unmet need: Information and social support about specific illnesses and diseases

> *"My concern, my principle concern, is that lack of knowledge will mean I overlook something serious, and my [loved one] will pay for my failure."*

As the health of their loved ones decline, caregivers want more information about the medical condition. They felt it was particularly overwhelming to understand all of the information provided to them when their loved one was first diagnosed. They would prefer to have access to continuous information and support, and to be able to ask questions as their loved one's health declines. In addition, some would like to connect with other caregivers whose loved ones have the same medical condition, to hear about their experiences and learn how to overcome challenges. This concern has been identified elsewhere with the observation being that healthcare, specifically between community services and home care, operates in silos and does not share information across services or healthcare sectors, making it challenging for caregivers to navigate the healthcare system to advocate for their loved one.[19,31,39] Further, without information, caregivers find it difficult to manage their loved one's illness.[34]

Unmet need: Transportation

> *"For me, the transportation – it would be very helpful, so that we don't have to take time off work and reschedule. It's a stressor."*

A number of caregivers are the primary transportation for their loved one, particularly to medical appointments. However, some are concerned about their ability to drive as they age or are uncomfortable driving when road conditions are poor. Alternatives are not always available. Some communities, especially in rural locations, do not have public transit available or it is not mobility accessible. As a result, caregivers feel it would be helpful for home care to offer transportation services, including companion services when their loved ones require support at their appointments. Transportation is identified as a need of home care clients in prior work.[41]

To support clients aging in the right place, it’s important to explore whether transitions into congregate care can be avoided with additional supports.

Summary

Home care directly and indirectly provides caregivers with support, but this support is not always enough, and caregivers have needs that are going unmet, which in turn impacts the quality of life for the caregiver and the quality of care for the client. Specifically, caregivers’ biggest needs are more time to themselves, more support with maintaining their homes, and information about how to better support their loved one moving forward. Many caregivers feel that home care could provide them with more support in these areas. For those who feel unsupported, be it lack of support from home care or their own social support networks, they are considering congregate care. To support clients aging in the right place, it’s important to explore whether transitions into congregate care can be avoided with additional supports, when it is safe and appropriate for both the client and caregiver.

"I worry sometimes now, as I'm getting older, if I'm going to be able to keep up and continue doing it for my loved one, because as my loved one progresses, I do as well."

Cameron & Barb *A fictional story based on actual experiences*

A year ago, Cameron's family doctor referred him to home care to treat a persistent wound. A home care office was in touch within several days, and the case manager came to their home shortly after. She checked Cameron's wound, and advised that a nurse would be coming in regularly until the wound healed. Both Barb and Cameron were pleased they would not need to drive to a wound care clinic – which they had found very time consuming.

Before the case manager left, she asked how they were managing in their home, and Barb, not having been asked that question in some time, became emotional, and explained that she was finding that a back injury was causing her a lot of pain. Cameron needed assistance getting his compression stockings on and she was finding it very hard on her back to help him. To help Barb and Cameron, the case manager offered home care support every morning to help Cameron with his compression stockings.

Following this initial assessment, AHS nurses came to manage Cameron's wound. They were professional and pleasant, always greeting Cameron and Barb when they came to their home. The nurses showed Barb how to change the bandages in between visits, and which bandages worked best. Within a few weeks, Cameron's wound healed and the nurses' visits ended.

Through an AHS contracted organization, personal care staff also began visiting daily to help Cameron with his compression stockings. Cameron was seen by one of the same three staff on rotation. His favourite staff member, Trevor, has a good sense of humour and talks with Cameron about hockey – which Cameron is very passionate about. The other two staff are just as nice, but Cameron really finds he looks forward to visits with Trevor. Barb is confident in each staff member's ability. They are all knowledgeable and do not snag his skin when they roll up the stocking. As a result she doesn't feel the need to supervise; instead, she takes this time (between 9:00 and 9:30 a.m. - they're usually always on time) to have a cup of coffee and do a crossword puzzle.

Recently, Cameron confided in Trevor that he's worried that Barb feels she cannot leave to go to her yoga classes anymore because she's concerned he will fall when he gets out of his chair to go to the bathroom. Cameron's been unsteady since his stroke two years ago, and had a fall (without injury) the week before. Trevor spoke with the case manager about Cameron's concern, requesting that she reassess Cameron and Barb's needs. In response, the case manager visited and asked Barb how she was doing. Barb explained that she realizes she needs to exercise for her own health – her doctor is worried about recent weight gain, but feels she cannot leave Cameron alone. Hearing Barb and Cameron's concerns, the case manager offered respite hours that cover the length of time it takes for Barb to go to yoga classes twice per week.

Now, the same staff who help Cameron with compression stockings come in for an extended time period twice per week. This makes Cameron happy, because he gets more time to talk with Trevor about hockey. Barb is happier and feels her back pain is getting better with each class. She is also eating better and slowly losing weight. Both Barb and Cameron are grateful that home care is so willing to help. They are confident that with home care's support, they can continue to live at home for as long as they are able, which is their goal.

"This program that my loved one is on, it's really helping them. That's helping me."

Interview insights

Home care is made up of interdependent relationships between the home care program and the client, the home care program and the informal caregiver, and the informal caregiver and the client. The goal of home care is to keep clients living at home for as long as it is safe and appropriate. The home care program however, is not a 24-hour service, and is reliant on caregivers (where there are caregivers available) to meet the day-to-day needs of clients.[9] Clients rely on the home care program and specifically on unpaid informal caregivers to be able to remain at home. Caregivers, in turn, rely on home care to relieve some of the burden of client care and provide them with respite.

For some, these interdependencies are functioning well. This is highlighted in Cameron and Barb's story, which reflects the most positive experiences that surfaced in interviews with caregivers. However, most caregivers interviewed do not feel supported enough. Some do not have the energy, motivation, or time to engage in self-care activities that would enable them to cope with the challenges of caregiving. While many were managing with support, such as from family and friends, and/or utilizing coping mechanisms, most wished for more support and time for themselves.

These findings suggest there is an imbalance in the relationship between clients, the home care program, and caregivers, where the client may be well supported, but the caregiver is not. As a result, many caregivers experienced negative impacts related to their caregiving role. Unsupported caregivers are at risk to experience burnout, distress and social isolation and may transition from providing care to needing care. Therefore it is important to understand the role of and toll on caregivers and to ensure there are supports in place for these valuable partners.

"I didn't have the impression in the process that the focus was on what we needed. It was what does [my loved one] need specifically, what can the family accomplish, and then what can they add to that process?"

Actions for improvement

The HQCA sees opportunities for healthcare system leaders to take action on this report. Below are some of the ways informal caregivers can be better supported to help Albertans age in the right place.

Recognize caregivers' role

The crucial role of caregivers in the client's healthcare team cannot be understated; they are a critical element to our healthcare system. Home care hours are limited. Caregivers often fill in the unmet care needs; it is estimated that a caregiver often fulfills 70-75 per cent of the care.[9] For Alberta, the approximate 400,000 caregivers who look after seniors provide, at a minimum, four million hours of unpaid care per week. The benefits of this support is that it enables the caregivers' loved ones to continue living at home and it saves Alberta's healthcare system an estimated $3 billion a year. Providing unpaid caregiving support has a personal cost.

"I know there's always costs involved in doing that kind of thing, but anything they can develop that helps people be able to stay together and stay in their home, because in the long run, it's going to be beneficial to the healthcare system. That's my feeling, anyway."

Ask caregivers about their needs

A previous Canadian study argued that the healthcare system is quick to assume caregivers are willing and capable participants in the care of their loved one.[19] Furthermore, caregivers' needs are not fully understood, as their needs are not regularly and proactively assessed. In Alberta, as part of the annual Resident Assessment Instrument-Home Care (RAI-HC) assessment, the case manager is required to capture responses to three questions about the caregiver that are known to be correlated with caregiver distress and burnout. These three questions are:

1) Whether the caregiver is satisfied with the amount of family support they have.
2) Whether the caregiver feels in distress.
3) If the caregiver feels they cannot continue to provide care.

Of the caregivers interviewed for this report, in their most recent assessment, only six had responses to some, but not all, of the questions. This may indicate that case managers are not systematically asking caregivers about their needs and what can be done to better support them. Further, the caregiver who expressed feeling burnt out had no responses to each of these questions. A criticism of the RAI-HC assessment is that it is designed to capture when caregivers are already at the point of distress and unable to continue in caregiving activities, and at risk of becoming or have become healthcare system users themselves.[38] This is a reactionary approach, where resources are only allocated to support caregivers after they have already been struggling for some time. The HQCA agrees with suggestions that a formal assessment tool for caregivers needs to be in place.[38]

Consider caregivers' unmet needs and determine how best to support them

In addition to reviewing responses to the RAI-HC, caregivers were asked during their interview whether they had been asked about their needs by the case manager. While some confirmed they had been asked, and that the case manager identified opportunities to better support them, most could not recall being asked about their needs. Some felt that this might be inappropriate, because they believe it is home care's role to support the client, not provide support for them.

Caregivers may experience burnout and distress and be unable to continue in their roles if their needs are not met. Home care can support a positive overall client experience which ensures clients' needs are being met in a safe and appropriate manner, and indirectly reduces the burden of care for caregivers. Supporting caregivers and helping them to alleviate their burdens and stress would also reduce considerable health system expenditures in the future by ensuring that caregivers don't themselves become users of the healthcare system. Therefore, recognizing caregivers' important role and addressing the many challenges and impacts that come with caring for their loved ones is key to the long-term sustainability of clients aging in the right place.

"My loved one is what it's all about, to start off with, but there's still me, too."

APPENDIX

Method

This study involved interviews with caregivers in rural and urban locations across Alberta. A contact at select home care offices in each AHS zone confirmed the contact information for eligible caregivers. Eligible caregivers were those who lived with a home care client that met the following criteria: was a long-term supportive and/or maintenance client, receiving weekly services, aged 65 and older, and cognitively unwell (defined as a Cognitive Performance Score of 2 or 3 to ensure they are able to meaningfully engage in an hour-long conversation). To protect the anonymity of caregivers and clients, home care offices are not named in this report.

Caregivers were recruited by the HQCA with a letter that explained the purpose of the study and the risks and benefits of participation (see **Figure 2** on P. 27). This letter detailed that participation involved two interviews. The first was a dyad interview where both the client and caregiver took part together (clients were invited to participate in a separate letter). The focus of this conversation was clients' experiences with home care services, and the results of these interviews are available in the *HQCA Alberta Home Care Client Experience Survey Report*. Second, a follow-up interview with just the caregiver took place (although they could include the client if they chose) about the caregivers' experiences with providing support to their loved one. These interviews are the focus of this report. Caregivers were also invited to take part in a photo elicitation activity, which is described in greater detail below. After agreeing to participate, the client or caregiver contacted one of two primary interviewers at the HQCA to arrange for an interview.

Recruitment and interviewing took place between September and November of 2018. In total, 27 clients and 29 caregivers took part in semi-structured interviews about their experiences. **Table 2** details the demographics of participating caregivers.

Table 2: Demographics of participating caregivers

ZONE AND GEOGRAPHY		NUMBER OF CAREGIVERS INTERVIEWED	AVERAGE AGE	GENDER (%FEMALE)	RELATIONSHIP TO CLIENT (% SPOUSE VS. CHILD OR CHILD-IN LAW)	EDUCATION (% COMPLETED SOME/ALL POST SECONDARY DEGREE OR DIPLOMA VS. GRADE 12)	EMPLOYMENT STATUS (% RETIRED VS. EMPLOYED)
Calgary (N=5)	Rural	3	74	80% (N=4)	80% (N=4)	80% (N=4)	80% (N=4)
	Urban	2					
Central (N=5)	Rural	3	77	40% (N=2)	80% (N=4)	80% (N=4)	100% (N=5)
	Urban	2					
Edmonton (N=5)	Rural	0	65	80% (N=4)	40% (N=2)	100% (N=4)	60% (N=3)
	Urban	5					
North (N=6)	Rural	2	71	33% (N=2)	83% (N=5)	50% (N=3)	33% (N=2)
	Urban	4					
South (N=8)	Rural	3	69	63% (N=5)	63% (N=5)	63% (N=5)	75% (N=6)
	Urban	5					
		29	71	59%	69%	69%	69%

Method – continued

To ensure voluntary participation, clients and caregivers were required to give their individual informed consent to participate before the start of an interview. Both interviews were conducted consecutively in the client and caregiver’s home. On average, the informal caregiver interview took 46 minutes to complete. Most interviews were audio recorded, with the consent of the informal caregiver. In a few cases, notes were taken instead of an audio recording. Audio recordings were transcribed with assured anonymity and analyzed for themes by two analysts to ensure validity of the findings.

Caregiver one-on-one interviews and photo elicitation

One-on-one interviews with caregivers about their experiences with supporting the client were conducted. While caregivers were encouraged to engage in this conversation independent of the client to enable them the opportunity to express their honest opinion, many chose to be interviewed with their loved one present. The interview guide (see **Figure 3** on P. 30) was informed by key questions identified by the HQCA’s 2018 stakeholder engagement sessions with stakeholders accountable for home care in Alberta. These included three questions:

1) What are the experiences of Albertans who provide informal care to cognitively unwell clients?
2) What enables caregivers to continue to support clients to live at home?
3) What are the barriers to continuing to support clients to live at home?

Questions were also informed by literature on the topic of caregiving and caregiver distress.

Three caregivers also chose to take part in an optional photo elicitation activity. Elicitation techniques are utilized in qualitative research to gain a more in-depth understanding of a topic, particularly when working with vulnerable populations or discussing sensitive topics, because it offers an alternate form of expression.[42] When they agreed to take part in this activity, they were provided with information and instructions (see **Figure 4** on P. 31), and their verbal consent was taken. Over the course of one week, and prior to their interview, caregivers were instructed to take photos using their own camera of things which were important to them about helping their loved one. In general, this technique was found to enable deeper reflection during conversation with these participants.

Ethics protocol

Prior to beginning this project a review was conducted using the A Project Ethics Community Consensus Initiative (ARECCI) tool, as well as a second-opinion review through ARECCI. As part of the informed consent process each eligible participant was provided with a letter that detailed the purpose of the project, risks and benefits to their participation, steps that would be taken to protect their confidentiality and anonymity, and how the HQCA would be using the information provided.

Figure 2: Invitation to participate - informal caregiver

If you live in Calgary, Southern or Central Alberta contact:

Sonja Smith, Lead
210, 811 – 14th Street NW
Calgary, Alberta T2N 2A4

If you live in Edmonton or Northern Alberta contact:

Rinda LaBranche, Lead
210, 811 – 14th Street NW
Calgary, Alberta T2N 2A4

About the Health Quality Council of Alberta

These interviews are sponsored and conducted by the Health Quality Council of Alberta (HQCA). The HQCA is **a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans.**

The HQCA is independent of Alberta Health Services, and does not oversee or provide care to Albertans, including those who receive home care.

Under provincial legislation, the HQCA has a role to survey Albertans on their experiences with the quality of health services they receive. More information about the HQCA mandate can be found on our website: http://hqca.ca/about/our-mandate/

How did the Health Quality Council of Alberta get my information?

Any information the HQCA collects is subject to Alberta laws and requires the HQCA to protect this information. The two pieces of legislation that guide the HQCA are the Freedom of Information and Protection of Privacy Act.

Why are we doing this?

The purpose of these interviews is to better understand clients' and families' experiences with home care. Through listening to Albertans like you, the HQCA hopes to provide information that will help identify things that can be done better and things that are already of high quality. The hope is to make a difference to people receiving care, and to their families.

Why have I been invited to participate?

You have been invited to take part in two interviews because you are over the age of 18 and live with someone who is 65 years of age or older and receives home care services, and because you provide support to them. The HQCA wants to speak with Albertans like you so we can better understand what your experiences are like, including what motivates you and what your needs are to continue to provide this support.

What will I be asked to do?

To participate, you and your family member – who receives home care services – have to both agree to take part. You and your family member are invited to take part in one interview together. You are also invited to take part in a separate interview with just you. Each interview should take approximately 90 minutes. You can also choose to take part in an optional photo activity.

The first interview will take place in-person with **both you and your family member, the person receiving home care services, together.** This interview will help the HQCA learn about your family member's experiences with home care, including what they like about the home care services they receive, and what they think could be better. Your input will be beneficial because you may remember details your family member might not.

Figure 2: Invitation to participate - informal caregiver – continued

The second interview will take place **with just you**, in a way that is convenient for you (in person, by phone, or Skype). This interview will help the HQCA learn about your experiences providing your family member with support. You can choose to have your family member present for this interview, but we recommend it be just you so that you can feel free to give your honest opinion.

You are also invited to take part in an **optional photo activity**. This will involve taking photos for seven days with a camera you own (e.g., digital or camera phone), or selecting photos you have already created, or that already exist (e.g., photos on the internet, a painting, or in magazines) of things that are important to you about helping your family member. The reason we are asking you to complete this activity is because research has found that taking pictures of things and talking about them can help us think in different ways than simply talking can. This activity can take place any time before your second interview. Your photos will be printed so that we can discuss them at the time of your second interview. These photos will be analyzed with the information you share during your interview. If you would like to take part in the photo activity, let Sonja or Rinda know, and they will provide you with more information.

Voluntary participation

Taking part is entirely up to you. If you do not want to take part you do not have to, and you do not have to give a reason. You can also refuse to answer any questions you do not feel comfortable with at any point in the interview. If you agree to take part now and later change your mind you can do that at any time without giving a reason. The care and support your family member receives will not be affected in any way if you do or do not choose to take part.

Benefits

Talking with you will help us to better understand your experience of supporting a family member who receives home care services, and to learn about what is working well and where there are opportunities to improve home care services.

If you choose to take part, you will be given $50 by cheque for your participation in each interview, to a total of $100. You will not receive additional compensation for participation in the photo activity. If you choose to end your participation at any time, you will still be compensated for your contribution.

Risks

There are no known risks associated with this type of interview. All information about you will be kept completely confidential. Interviews are a common way of finding out about people's experiences. If at any time anything we talk about is upsetting to you, we can take as many breaks as you need, change the subject, or stop the discussion.

Confidentiality and Anonymity

All information about you or anyone else that you speak about during your interviews will be kept completely confidential. Results from this project may be used in reports, presentations, or in publications that the HQCA will create about what it is like to receive home care in Alberta. No names or identifying details will be included.

It is important for you to know that the HQCA cannot guarantee your anonymity when we are at your home if you are expecting a visit from home care staff. For example, a staff member may see an interviewer in your home if they arrive during the time of the interview to provide scheduled care. If possible, you can arrange to have an interviewer come to your home when home care staff are not scheduled to come to your home.

No one involved with your family member's care will have access to what you say during the interviews.

Figure 2: Invitation to participate - informal caregiver – continued

Only Health Quality Council of Alberta (HQCA) staff who are working on this project will have access to the information you share. Any information that Sonja or Rinda collect from you, including consent forms, will be kept secured at the HQCA office and will be destroyed two years after the project is completed. Audio recordings of interviews will be destroyed within three months of when the project is completed. Transcripts and notes of interviews that do not contain any identifiable details will be stored for five years in NVivo, a secured qualitative software package used to analyse interviews, so that we can make comparisons over time. This approach is being taken for all interviews in order to protect people’s privacy. If you choose to take part in the photo activity, your photos will be kept secured and confidential. Your photos will be destroyed within three months of when the project is completed.

In accordance with the Alberta Protection for Persons in Care Act we are legally obligated to report any abuse or neglect, which we are informed about, to the appropriate authorities.

What do I need to do next?

1) You can ask Sonja or Rinda, the HQCA staff members that will be doing the interviews, any questions you may have.
2) If you and your family member choose to take part, then let Sonja or Rinda know (see contact information on the top of the first page). Sonja or Rinda will arrange a date for both interviews at a time that is convenient for you.

The first interview will be scheduled in your home, or a location that is convenient for you (Sonja and Rinda are unable to drive you anywhere).Your second interview can take place in your home, another location, by telephone, or Skype. You can decide whether to have both interviews on different days or the same day. Some possible options for scheduling both interviews are:

Option A	Both interviews, same day.	No photo activity.
Option B	Both interviews, same day.	Take/select photos before the first interview.
Option C	Time between interviews	No photo activity.
Option D	Time between interviews	Take/select photos after the first interview.

If you agree to take part, Sonja or Rinda will need you to sign a consent form, and verbally agree to take part if signed consent cannot be taken right away before each interview and before taking part in the photo activity. A consent form is a form that lets us know that you agree to take part.

With your permission, Sonja or Rinda will audio record the interviews and type them out later. This lets Sonja or Rinda give you their full attention during the interviews without having to take notes. If you would like to participate, but don’t want Sonja or Rinda to record you, please let Sonja or Rinda know and they will take notes during the interviews instead.

You can stop the interviews at any point. You do not have to give a reason. Simply tell Sonja or Rinda that you no longer want to take part.

If you would like to take part, or would like more information, please contact Sonja or Rinda who are listed on the first page of this document. If you do not contact either Sonja or Rinda, one of them may contact you to determine your interest in participating.

Figure 3: Interview guide – informal caregiver

Interview guide – follow-up with informal caregiver

Photo elicitation

- Pick the photo you like the most and the least. Why did you select these photos?
- Which photo best expresses/represents helping [name of client]? Which is most removed? Tell me about them.
- Which photo shows what is great about helping your [name of client]? And what is hard? Tell me about them.
- Is there any other photo here you would like to discuss?
- Is there a photo you would have liked to make but could not?

Overall experience

1) Tell me about how you became a support for [name of client].

Competency

2) Do you feel confident in your ability to help [name of client]?

What is great - Enablers

3) What helps you to continue to provide this help?
4) What have been some of the positive things about helping [name of client]?

What is hard - Barriers & unmet needs

5) What are the challenging parts about providing [name of client] with help?
6) What are your most important needs right now?
7) What supports do you wish you had? (Prompt: respite, community resources, emotional support, physical support, financial support)
8) What would prevent you from continuing to provide help to [name of client]?

The future

9) What do you think is working well with home care that you would not want to see changed?
10) What would you change about home care if you could change anything?

Closing

11) Is there something I've missed that you would like to discuss?
12) Is there a question you expected me to ask you that I didn't?
13) Would you like to ask me any questions?

Figure 4: Photo elicitation information and instructions

What do I do?

For 7 days, using a camera you own (e.g., cellphone or digital camera), please:

1) Make photos or select existing photos of things which are important to you, both positive and negative, about helping your loved one.
2) Send these photos to your interviewer before your next interview.

What should I exclude?

- Do not take photos of people who do not give their consent (e.g., other family members)
- Do not take photos of others in ways that would identify them (e.g., photos of their faces)
- Do not take photos of, or inside, buildings that are not your residence (e.g., a healthcare facility)
- Home care staff
- Nudity

How are these photos being used?

The reason we are asking you to complete this activity is because research has found that taking pictures of things and talking about them can help us think in different ways than simply talking can. These photos will be analysed with the information you share during the second interview, and will provide us with more context to your experiences.

I want to do this, but I don’t have a camera

You can choose instead, to select photos you have already created or, select photos that already exist (e.g., photos on the internet, a painting, or in magazines). Please ensure that these photos are publically available, and are not private photos belonging to someone else (e.g., belonging to someone’s Facebook or Instagram).

What do I do with my photos after 7 days?

If you are using your own camera, please download your photos to your computer, and save them to the encrypted memory stick provided to you by your interviewer. You will need the password the interviewer gave you to use the memory stick. Then mail the memory stick in the prepaid mailing envelope sent to you. The interviewer will print your photos and bring them to your next interview. If you need any help uploading your photos to the memory stick, please contact Sonja.

What are the risks in doing this activity?

The photos you make or select will be analyzed with what you say during your next interview. If you choose, this is as much as these photos will be used.

How will my photos be kept secure?

If you are downloading your photos from your personal camera onto the memory stick, this memory stick is encrypted and password protected, and only you and the interviewers have access to the password.

When your photos arrive at the HQCA office, they will be kept locked and secured at the HQCA office. Only the interviewers will have access. The interviewers will print your photos and keep the physical copies locked and secured. When transporting the photos to you for our next interview together, your interviewer will carry these photos in a locked briefcase.

Identifying details, like GPS data on any digital photos you take (such as on your cellphone), will be removed.

Your photos will be kept locked and secured at the HQCA office. Your photos will be destroyed within three months of project completion.

Thank you, but it’s not for me

That’s perfectly okay! We are happy to continue with our interview together, as planned, without photos.

I still have questions

Feel free to contact the lead for this project, Sonja Smith, and she will be happy to answer your questions.

Limitations

This study aimed to recruit evenly from urban and rural geographic locations across Alberta, and evenly amongst the five AHS Health Zones. However, given that the Edmonton Zone is classified entirely as an urban area, this resulted in more urban clients and caregivers represented as compared to those who reside in rural areas. In addition, more female informal caregivers and female clients participated than male. Lastly, most of the participants were Caucasian in race and identified as European or Canadian ethnicity. As a result, there may be gaps in the understanding of cognitively unwell client and caregiver's home care experiences, which could benefit from a more diverse racial, ethnic, and gender perspective. Another limitation is that these results are not representative of the population. The goal of qualitative interviewing is to reach saturation in findings, which was achieved for this study. However, it is acknowledged that the results of this work are limited to the perspective of 56 participants and there are other perspectives that might not be represented in the results of this report.

"I can go out during the day, get my loved one's lunch, that kind of thing. I cannot go out in the evening, unless I have somebody that will come here."

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"I think, as a family, we've kind of decided that, as long as we can, we'd like to keep my loved one at home. And I mean, it could all change tomorrow, could have another medical event and be gone. But for now, that's what we'd like to do. And so far, we're managing."

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If there's things that can be done that help people do that, I think that's going to be beneficial, I think, to the healthcare system in the long run... going back to home care if there's things that they can develop and I know there's always costs involved in doing that kind of thing, but anything that they can develop that helps people be able to stay together and stay in their home, because in the long run, it's going to be beneficial to the healthcare system. There's just some times that I'd like to just be at home by myself. You never get that. My loved one is what it's all about, to start off with, but there's still me, too. I don't know if it's reasonable to expect for home care to just provide friendship or companionship, or to provide cleaning services... those are things, I think, that for me, certainly, would make a difference. For me, the transportation it would be very helpful, so that we don't have to take time off work and reschedule. It's a stressor. I wouldn't say – I didn't have the impression in the process that the focus was on what we needed. It was what does my loved one need specifically, what can the family accomplish, and then what can they add to that process?

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