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From Caregiver to Care Partner: A View From The Other Side

Centre for Elder Research
Sheridan College

Tyze Networks

From Caregiver to Care Partner
A view from the other side

Understanding the lived experience
of unpaid caregivers as it relates to
healthcare and service provider support

July 2022

Sheridan | Centre for Elder Research

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Abstract

Background

As the trend towards aging in place continues to grow, unpaid caregivers are facing challenges that include access to relevant and meaningful resources, systemic barriers to efficient two-way communication with healthcare and service organizations, navigating the healthcare system, time management, financial strain, and difficult family dynamics.

Objective

This project was designed to help Tyze Networks broaden their understanding of how unpaid caregivers, and supportive healthcare and service organizations, perceive the value of formal managed care coordination.

Methods

This project began with a comprehensive environmental scan of existing research, policies, pathways, and best practices. This was followed by an online survey targeted at Canadian and American healthcare and service organizations and unpaid caregivers of older adults. The online survey link was provided to potential participants through the Centre for Elder Research's (CER) data base, social media, and Tyze's user base. The research team then reached out to volunteers from the survey to conduct semi-structured, one-on-one virtual interviews.

Results

Four key findings were found:

1) Communicating with healthcare and other professionals was ranked as the number one challenge for the survey participants; 2) A total of 66% of unpaid caregivers reported that they provided non-healthcare related support to the care recipient; 3) Over 70% of the respondents stated a dedicated application would help them manage all or most of the care coordination; 4) Carrying out the numerous responsibilities of providing care often significantly impacts the unpaid caregivers' well-being and self-care.

Discussion

As care partners, caregivers can help by sharing information, participating in aspects of care, and helping to make decisions. They can be spokespersons, advocates, and supporters, especially if care recipients are too ill and unable to do this for themselves.

Conclusion

The implementation of a formal mechanism to communicate and coordinate care with healthcare and service organizations has the potential to relieve many of the challenges faced by informal caregivers. For these providers, caregivers can provide invaluable timely information and facilitate coordination of care services.

Introduction

In Canada, approximately one in four individuals over the age of 15 provide unpaid care for another person, and similarly, nearly a quarter of adults over the age of 65 are also unpaid caregivers.[1] A recent study showed that a key goal of family caregivers, given the difficulty of their tasks, was to seek more integrated and comprehensive knowledge of the current supports and programs available to them, with navigating the 'system' being a part of this desire.[2]

It is well-known that unpaid caregivers are facing challenges including, but not limited to, access to relevant and meaningful resources, systemic barriers to efficient two-way communication with healthcare and service organizations, navigating the healthcare system, time management, financial strain, and difficult family dynamics. Challenges meeting the myriad of demands that are often placed on unpaid caregivers have the potential to negatively affect their own mental, emotional, and physical health.[3] Studies have shown that the additional stress of the COVID-19 pandemic has only served to exacerbate those concerns.[4] Given the additional stress on unpaid caregivers during the pandemic, the desire for their roles to be recognized in policy, along with the need for improvements in communication and navigation[5], have become more urgent.

A platform that has the potential to address these needs may help alleviate some of the associated stress of unpaid caregiving. According to a recent briefing document sponsored by AMS (Associated Medical Services) Healthcare, one of the most significant potential benefits of digital health tools is that they can empower patients and caregivers, increasing their choices as they relate to the care they receive.[6] Of course, these benefits can only be observed if there is sufficient digital literacy, as well as transparency and effective communication between contributors.[6] The project in this report was designed to explore the challenges that unpaid caregivers experience and how supportive healthcare and service organizations perceive and manage their interactions with family and other unpaid caregivers.

The Sheridan Centre for Elder Research collaborated with Tyze Networks Inc., a company that provides a web-based application and corresponding app (of the same name) that enables caregivers to create a digital support system of (primarily) family members and friends to manage the care for an older adult or an individual living with a disability. This project helped Tyze broaden their understanding of how supportive healthcare and service organizations perceive and manage their interactions with family and other informal caregivers. This included exploring the value caregivers bring to these healthcare partners, the challenges of integrating caregivers into

existing systems, and identifying which pathways to better collaboration would provide the greatest value to all parties. Tyze will use this information to develop their next generation application and convey the associated benefits for potential clients.

Methodology

Environmental Scan

This project began with a comprehensive environmental scan of existing research, policies, pathways, and best practices that support the integration of unpaid caregivers into formal healthcare and service organizational systems. Reviewing over 150 resources helped to identify trends, patterns, and gaps in the unpaid caregiver landscape. These findings informed the survey questions.

Surveys

An online survey (Appendix A) targeted to Canadian and American unpaid caregivers of older adults (n=97) was deployed to collect insights into the challenges they face related to the technological, organizational, socioeconomic, and ethical elements of their roles. For the purpose of this study 'younger' unpaid caregivers were individuals up to the age of 50, and 'older' unpaid caregivers were individuals age 51 and over.

Simultaneously, an online survey (Appendix B) targeting Canadian and American healthcare and social support stakeholders (n=23) was deployed to better understand organizational challenges from service and information fragmentation, to socioeconomic challenges such as funding and sustainability of solutions to ethical challenges around autonomy and privacy of data.

Interviews

Recruiting participant volunteers from the online caregiver surveys (n=7), the research team conducted semi-structured, one-on-one unpaid caregiver interviews (Appendix C). These interviews, conducted virtually, focused on filling in the gaps from the online survey data to better understand the experiences of unpaid caregivers, the relationship between unpaid caregivers and healthcare and service organizations, and to gain more knowledge on the role of technology in the caregiving process. These interviews provided the research team with qualitative data to better understand the opinions, ideas, motivations, experiences, satisfactions, or frustrations related to the integration of unpaid caregivers into the professional care team.

The Unpaid Caregivers

The Online Survey Participants

The online survey link was provided to potential participants through the CER's data base, social media, and Tyze's user base. Participants shared their unique insights on the challenges they faced related to the technological, organizational, socioeconomic, and ethical elements of their roles. A total of 97 complete survey responses were included in this analysis.

AGE	FEMALE	MALE
21-35	13	8
36-50	30	4
51-65	22	1
66-80	10	3
81+	4	2

56% live in CANADA

44% live in USA

MARITAL STATUS

68% married
15% never married
7% widowed
4% common law
4% separated
2% divorced

Financial management and decision-making, medical decision-making, grocery shopping and/or meal preparation, as well as assistance with mobility, were the highest reported activities of daily living support provided by the unpaid caregivers (n=88).
A total of 66% of unpaid caregivers reported that social opportunities were the non-healthcare support they provided on behalf of the care recipient (n=77).

Employment status (n=97)

- employed full-time
- employed part-time
- unemployed
- self employed
- retired
- manage household
- unpaid absence

0% 20% 40% 60%

Who helps to provide care (n=88)

- I am the only care provider
- family member(s)
- friend(s)
- in-home health care professionals
- respite providers
- healthcare professionals in congregate living
- not applicable
- other

0% 20% 40% 60%
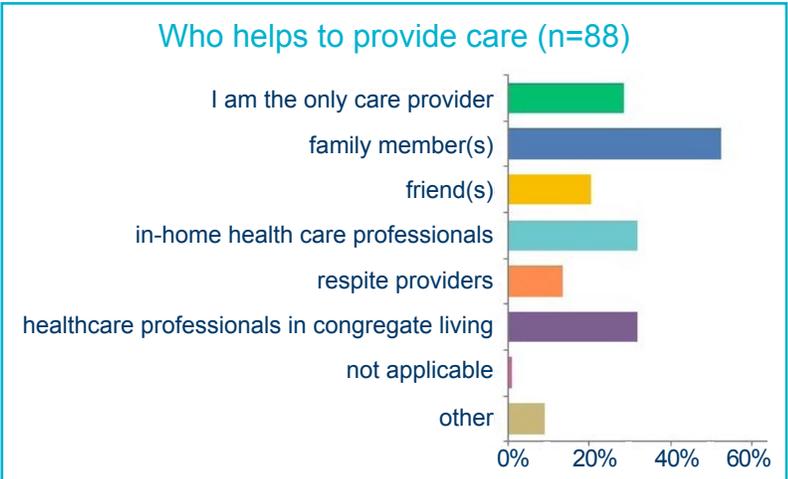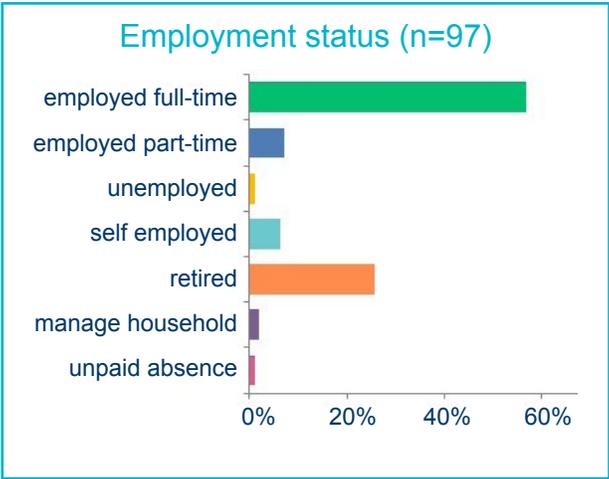
Advocating for the care recipient by serving as a link between the care recipient and healthcare and service organizations, contributing to the patient/family decision-making process and speaking up when problems go unnoticed or when family cannot or will not address them was jointly reported as the most common roles unpaid caregivers provided at 87%. The second most frequently reported roles were, at 77%, personal supervision, providing companionship and general supervision (n=86).

Length of time providing care (n=87)

Legend:
- less than 3 years
- 4 - 6 months
- 7 - 12 months
- 1 - 3 years
- 4 - 5 years
- more than 5 years
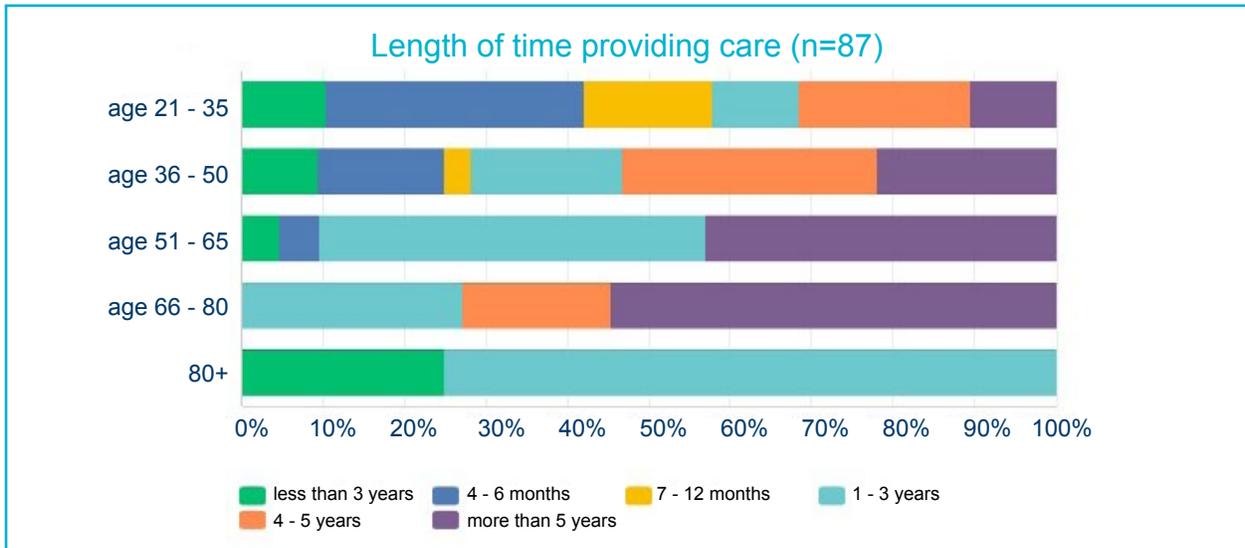
Relationship to Care Recipient (n=83)

Sixty-six percent of the unpaid caregivers were caring for their parent, 18% for a spouse, 10% for a friend, 4% for a child, 1% for a sibling, and 1% for a niece/nephew/grandchild.

The Interview Participants

The online survey participants who volunteered (n=7) to also take part in the interviews, five female and two male, answered all of the questions posed to them during the virtual interviews which lasted approximately one hour. They all resided in Canada, with three residing in a rural area and four in an urban or suburban area. All of the unpaid caregivers interviewed had substantial experience providing care for a family member, and in some cases, a history of caring for more than one family member at different times in their lives. Most recently, they were the primary care providers. One of the caregivers had been providing care for 43 years, while another described themselves as a "serial caregiver" having provided support to their father, child, mother and most recently their partner. What became evident during the interviews is that individuals are often called upon to be unpaid caregivers more than once in their lifetime.

"I have been what I might describe as a serial caregiver all of my adult life."

The situations that respondents identified at the onset of becoming an unpaid caregiver differed based on the stage of life. Often these situations highlighted a sudden, unexpected event while others experienced a slow decline in the care recipient. Each participant provided a wealth of information drawing on their lived experiences as unpaid caregivers, highlighting that, while the characteristics of one's personal caregiving journey differs, there appears to be a commonality to the challenges unpaid caregivers face to providing care.

"I kind of got thrown into it."

The Care Recipients

According to the online survey completed by the unpaid caregivers (n=88), the majority of the care recipients were between the ages of 66-80 at 41%, with the second largest cohort being over 81 years of age at 35%, and the third being between the ages of 51-65 at 15%. The gender of the care recipients was reported to be 59 female and 27 male (n=86).

The majority (60%) of care recipients live in the same home as the unpaid caregivers, while 22% live in a different home from the unpaid caregiver, 12% live in long-term care, and 6% live in a retirement home.

Types of support the unpaid caregiver provided for the care recipient (n=88)
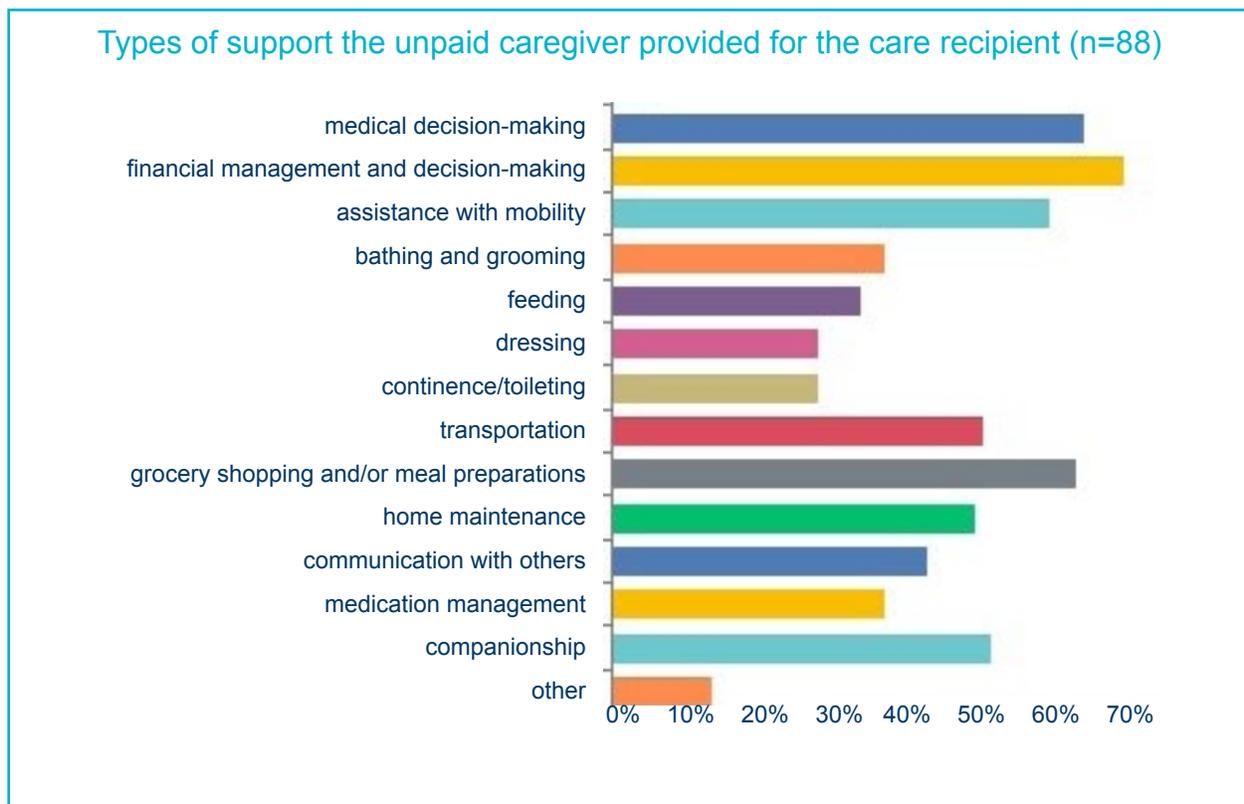
All seven interview participants were caring for close family members, with six of the participants living in the same home as the care recipient. The care recipients were spouses, parents, and in one case, a child. Providing insight into the emotional attachments, shared history and unique experiences between family unpaid caregivers and care recipients allowed for a better understanding of the care recipients as a heterogeneous group whose needs go well beyond the physical care they receive. The participants helped us better understand how the relationship between the unpaid caregiver and the care recipient impacted and informed the unpaid caregivers support.

The Organizations

Individuals who work for healthcare or service organizations (n=23) completed an online survey highlighting the work they do with unpaid caregivers. Participants reported that 'aging-related services are the main focus of their organization' as always 44%, very often 39%, and sometimes 17% .

The participants were equally divided into working for healthcare and service organizations with 43% (n=21) providing both types of services. Of the 19 respondents who indicated their role, 47% were management/administration, 47% front line staff, 16% front line staff medical, and 5% support staff.

Types of healthcare organizations (n=12)

Types of service organizations (n=19)

Engagement with unpaid caregivers (n=22)
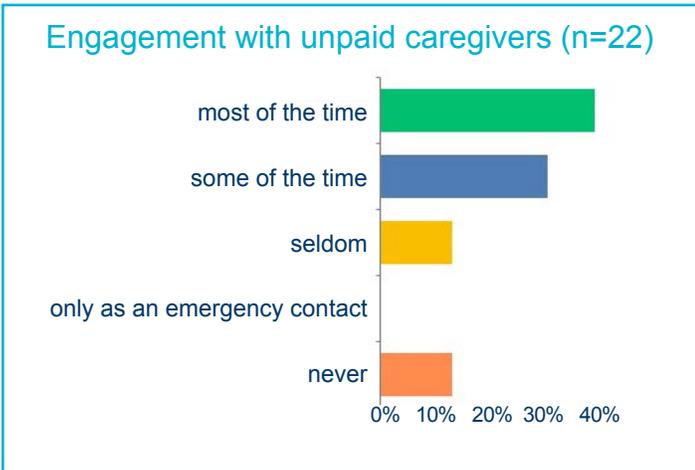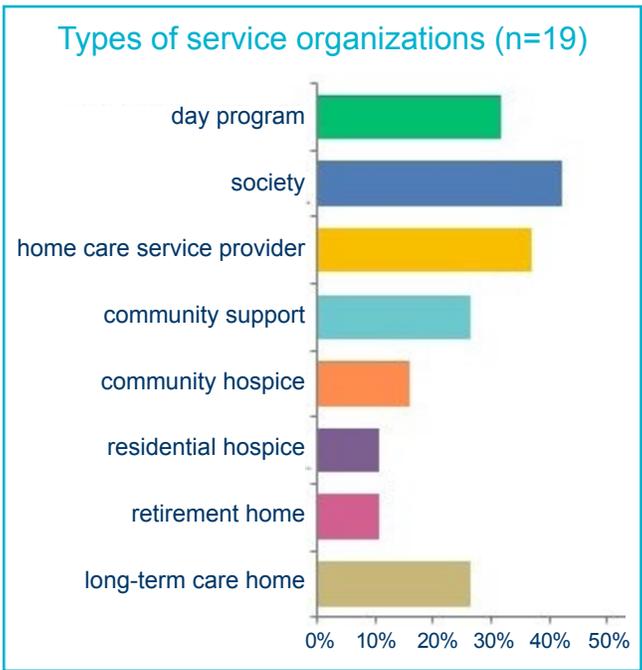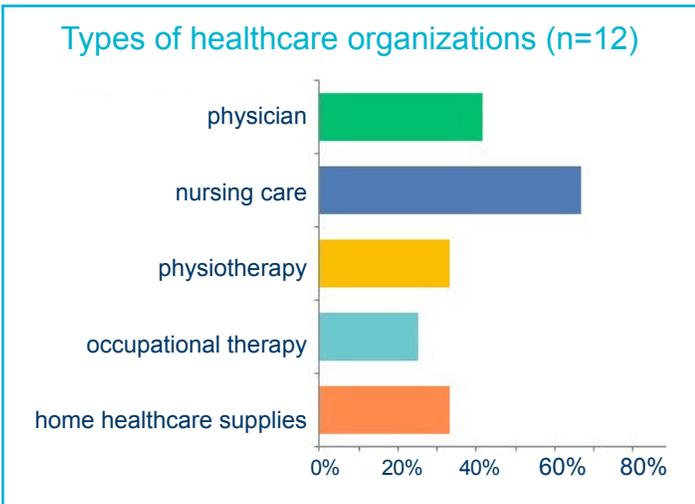
Themes

The following themes combine results from both the online survey respondents and the virtual interviewees.

WELL-BEING OF UNPAID CAREGIVERS

Carrying out the numerous responsibilities of providing care often significantly impacts the unpaid caregivers' well-being and ability to provide self-care. The interview participants were very knowledgeable and adept when creating the systems and structure of a care plan for the care recipient but did not appear to take into consideration their own needs in the planning process. What became apparent during the interviews was their deep desire to provide the best care possible for their family member, sometimes at the expense of their own well-being.

"I was not going to go ahead with the surgery because the recovery time and the rehabilitation was about six months and I wouldn't be able to care for her during that period."

"I don't really think I could think of anything...it was just non-stop. There wasn't really an opportunity to think about what personal time I had."

Many unpaid caregivers perform numerous roles within their family structure in addition to working outside the home. Fifty-seven percent of survey respondents (n=97) reported that they were employed full-time. Over 90% live in a home that they own (n=94). Balancing their time between competing commitments and tasks often becomes a considerable struggle for the unpaid caregiver.

When the interview participants were asked, "What would make you feel more comfortable taking time for yourself?", the responses included financial support, ability to ensure the care recipient is okay, finding someone to be a friend to the care recipient who didn't feel like a caregiver, ability to sleep or go out with peace of mind, having someone take care of the dog or deliver food during an emergency situation, help with the

housekeeping, overnight respite opportunities, and someone available on a 24-hour basis. Most of the caregivers shared that as the primary caregiver there were no readily reliable resources or immediate supports to cover the daily tasks of providing care. Consequently, unpaid caregivers may be hesitant to take time for themselves.

"But at times, when you have even a few hours to be away, they still occupy your mind and I keep on thinking of what could happen if I'm not around."

When the survey participants (n=80) were asked, "What do you wish you knew when you became a caregiver?", 37% responded, 'how to find support for yourself'. When asked the same question, one participant shared, "How to prevent my personal exhaustion serving as an essential caregiver as I deal with multiple health issues of my own."

How satisfied are you that you have enough time and energy to take care of yourself? (n=80)
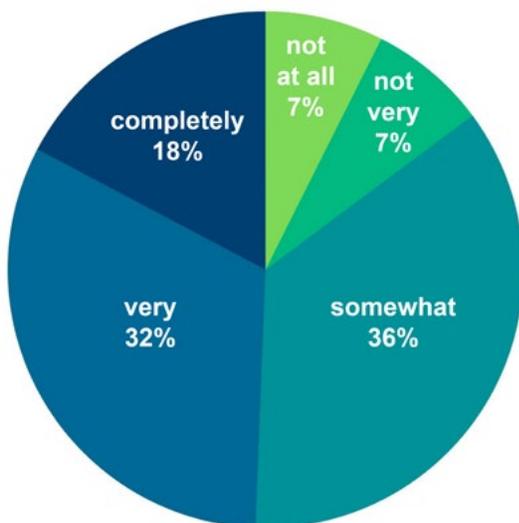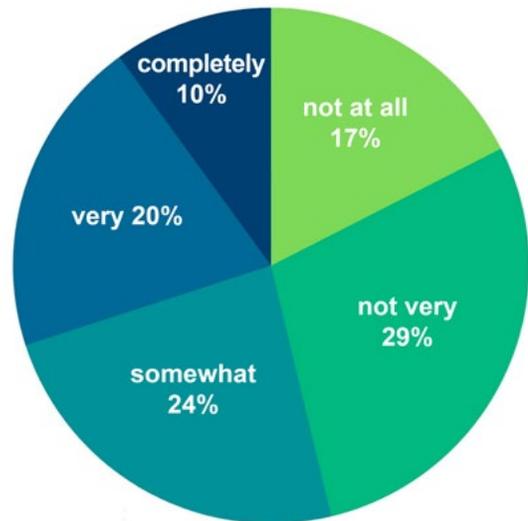
completely 10%
not at all 17%
very 20%
not very 29%
somewhat 24%

How satisfied are you that you have family or friends to support you when you feel lonely or isolated? (n=81)

not at all 7%
not very 7%
completely 18%
very 32%
somewhat 36%

CHALLENGES TO CARE PROVISION

"I often don't think that healthcare agencies really care or understand what unpaid caregivers are. I think some care and compassion, and some empathy (should) come with that."

Communication

'Communicating with healthcare and other professionals' was ranked the number one challenge for the survey participants at 35% (n=81). Insights from the interview participants also revealed that there are systemic barriers to effective and efficient two-way communication between healthcare and other professionals coupled with inefficient and time-consuming organizational processes. Some of the interview participants were hesitant to seek out existing programs and services because of previous unsuccessful attempts trying to navigate the healthcare system. The interview participants also disclosed that they often felt disregarded during these interactions and that healthcare providers appear to not take into consideration the emotional attachment and unique experiences that exist between the unpaid caregiver and care recipient.

"Everyone just seems too overworked."

Resources

The interview participants acknowledged that while some resources were easily accessible, there are also critical care areas where reliable resources are not easily found. The inaccessible and unreliable information was often reported as being about the care recipient's specific health condition. When one caregiver reached out to a large support organization for information on their care recipient's medical condition, they eventually gave up when no one responded to their numerous requests for resources. When asked, "What do you wish you knew when you became a caregiver?", the number one survey choice at 71% (n=80) was where to find information on what specific skills you might need to care for someone with this diagnosis.

On the other hand, hospitals and nurses in particular were often cited as providing 'great' support when the care recipient was staying in the hospital. However, once the individual was back home, there was reported to be an immediate disconnect to those support services and resources. When asked, "What would be helpful to you as a caregiver?", one respondent replied, "Navigating bureaucracy and finding resources to support recovery and rehab at home."

"I get most of my information about resources from other family caregivers."

Communication and Resource Challenges

Unpaid caregivers often experience challenges accessing relevant resources and services along with barriers to efficient two-way communication with service providers.

"The communications between healthcare systems is dreadful."

'Communicating with healthcare and other professionals' ranked as the **#1 challenge** for unpaid caregivers

What do you wish you knew when you became a caregiver?

71% Where to find information on what specific skills you might need to care for someone with this diagnosis

46% How to identify resources, both personal and in the community

44% How to obtain information from the specialist or geriatrician, if necessary, of your care recipient's health condition

As a caregiver, how often do you encounter the access to resources and eligibility for services challenges or situations listed below?

DAILY	WEEKLY	MONTHLY
15% housing	**22%** housing	**19%** housing
17% healthcare	**28%** healthcare	**22%** healthcare
19% respite	**24%** respite	**19%** respite
18% social services	**18%** social services	**19%** social services
17% community services	**29%** community services	**17%** community services
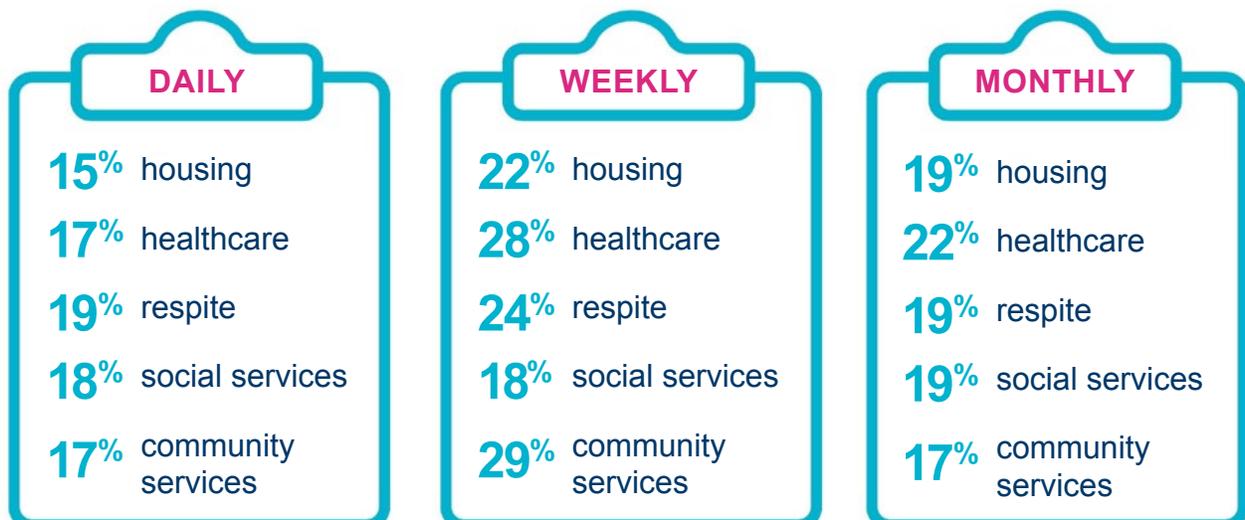
CHALLENGES TO CARE PROVISION

Family Dynamics

The majority of the survey respondents (66%) were caring for a parent, with the next most common care recipient being spouses at 18% (n=83). When asked, "Who helps you to provide care?", the most common response was family members at 52% (n=88). Being a primary caregiver often necessitates negotiating mutual collaboration between family members, themselves, and the care recipient. When asked, "As a caregiver, how often do you encounter the family challenges or situations below?", the data revealed that, the older the caregiver, the less likely they were to encounter lack of cooperation by the care recipient, balancing the needs of healthy and sick family members, lack of support from other family members, and conflicts about care. However, the older caregivers did report a similar rate of care recipient behavioural issues to the younger caregivers.

Financial

Insights from the interviews showed that often there was little or no financial support to help with the cost of medications, home care, and medical equipment. Paradoxically, the demands of caregiving have led some of the participants to take a leave of absence from work or make the move from full-time to part-time work. When asked, "What type of support do you currently provide for the care recipient's activities of daily living?", (n=88) financial management (e.g. Power of Attorney for Property) was the number one response at 70%. When asked, "What could the government do to make the role of a caregiver better?", (n=81) 37% of recipients ranked 'more financial support to cover my costs' as their number one choice.

"Qualification to some services and aids are not scaled and have unreachable criteria to make use of. It seems you need to be 'living in a van down by a river' to get assistance."

Household Chores

"Vacuuming, dusting, cleaning, and laundry. That would be a big, big help. You take four things, even two things, away from caregivers to lighten their load."

The challenges of delivering care and managing household work like meal planning, laundry, and cleaning were a common concern for all the interview participants. Some of the participants wondered if Personal Support Workers (PSW) are able to help with these tasks if the care recipient was, for example, not in need of a bath that day as originally scheduled. Support, no matter how small, with daily household tasks was one of the ways the caregivers felt they could alleviate some of the stressors and demands of caregiving.

Family Dynamics

Unpaid caregivers often experience challenges negotiating mutual collaboration between family members, themselves, and the care recipient.

"I have outstanding emotional support from our two adult children but one lives at a distance and the other has extensive responsibilities with a high pressure career."

"Most of the conflict comes from former caregivers and siblings who have a lot to say but not much help to give."

52% of unpaid caregivers **receive help providing care from family members**

12% of unpaid caregivers are 'completely satisfied' that they **have family or friends to support them when they need assistance**

As a caregiver, how often do you encounter the family challenges or situations listed below?

DAILY
18% conflicts about care

21% lack of support from other family members

23% balancing the needs of healthy and sick family members

19% interpersonal conflicts

WEEKLY
24% conflicts about care

28% lack of support from other family members

30% balancing the needs of healthy and sick family members

33% interpersonal conflicts

MONTHLY
20% conflicts about care

14% lack of support from other family members

16% balancing the needs of healthy and sick family members

6% interpersonal conflicts

HEALTHCARE AND SERVICE ORGANIZATION INTERACTIONS WITH UNPAID CAREGIVERS

"We are here and you are not alone."

When asked "What could healthcare organizations do better to help you stay informed and support your role as a caregiver?", the respondents' (n=81) top two responses at 28% were, 'instructions to help me care for the care recipient' and 'better information exchange between the various healthcare providers.' When asked the same question about service organizations, the respondents (n=79) listed 'better communication' as the top choice (45%), with the second being 'less expensive' at 27%.

Individuals from healthcare (n=6) and service organizations (n=2) both indicated that unpaid caregivers play a significant role in the social and emotional support of the care recipient with 80% stating that staff members encourage unpaid caregivers to 'participate in the care and treatment decision making' (n=12). Most organizations (87%) indicated that working with unpaid caregivers as members of the healthcare team was also clearly addressed in their organization's policy (n=12).

Individuals working for healthcare organizations reported 'always introducing the unpaid caregiver/s to the staff' at a rate of 50%, whereas service organization employees reported at a rate of 67% (n=15). However, healthcare workers reported that their organization explains 'how an unpaid caregiver/s may also actively participate in providing care' at a rate of 50%, with service organizations reporting a rate of 33% (n=15).

When asked, "What do you perceive to be the advantages of engaging with unpaid caregivers?" both the healthcare and service organization respondents (n=12) recognized and empathized with the important role caregivers play in their comments. Respondents from both types of organizations expressed that the unpaid caregivers know the client best and are therefore able to provide valuable information to the organization. There appeared to be few disadvantages or challenges when engaging with unpaid caregivers from an organizational perspective. Of the comments that were shared, most stressed the need for families to designate one person for staff to work with to avoid discrepancies between the different family members' care provision goals.

We asked the employees of healthcare and service organizations if, 'there is anything you or your organization wish more unpaid caregivers knew/understood about your organization' (n=11). The majority replied no, but several of the responses expressed empathy for the unpaid caregivers. One respondent expressed the critical importance of social connectivity and engagement as a human right. Another respondent shared the significant impact hospice can have in helping to improve the care recipients experience with illness and the end of life.

Healthcare and Service Organization Interactions

Individuals working for healthcare and service organizations often recognize the advantages of collaborating with unpaid caregivers to support person- and family-centred care, however, organizations do not appear to provide the formal processes and policies to support staff engagement with unpaid caregivers.

"They know the client best, their nuances, likes/dislikes which helps in creating a care plan for the client."

Does your organization introduce the unpaid caregivers to the staff?

healthcare organizations
50%always

service organizations
67%always

Does your organization explain how an unpaid caregivers may also actively participate in providing care?

healthcare organizations
50%always

service organizations
33%always

How often do you include unpaid caregivers in your care planning?

healthcare organizations
50%always

service organizations
33%always

TECHNOLOGY ADOPTION

When asked, "Would a dedicated application to help you and your family manage all or most of the care coordination would be helpful?", 75% of the online survey respondents (n=79) replied yes, with 5% saying no, and 20% not sure.

Of the respondents that answered yes to the question above (n=66) 70% felt that 'a way to communicate (ask questions) directly with the healthcare, social and community service people' was the most important feature the application could offer. Closely followed at 68% was 'a way to share information with family and other support members.' The third most popular feature being 'a way to schedule and manage all appointments' at 59%. The survey participants also noted that the filing of medical records and documents and a way to update the care recipients' health status would be helpful.

The interview participants typically developed a mix of manual and digital systems that they relied on to monitor, record, and track the changes and needs of the care recipients. Implementing manual logs and integrating technology such as emails, text messaging, WhatsApp messenger, and phone calls were some of the methods used to communicate with family members. Participants seemed to be pleased with the current system they had developed themselves.

When asked to describe their comfort level with technology during the interviews, all the respondents (n=7), self-reported as adept. However, when asked, "What exactly would a dedicated application to help you and your family manage care coordination look like and what would it do?", three of the participants expressed no interest in such an app citing that they were happy with their existing messaging platforms, had no family close by to share the in-person care with, or believed that other family members would not be able to navigate the technology. These three respondents appeared to be resistant to changing their current caregiving system by applying a new technology. The remaining four participants expressed interest in a dedicated application to help them find resources, consolidate scheduling and activities, plan meals, schedule appointments, find someone to take the care recipient to appointments, coordinate socialization opportunities, and connect with hospitals, pharmacies, and physicians for medical coordination. There appears to be two distinct types of caregivers, those who show no interest at all in integrating applications into their care system, and those who see the value of incorporating a dedicated application to help them perform their caregiving duties more efficiently and effectively.

Technology Adoption

Many of the challenges unpaid caregivers face may be addressed by accessing the support of a dedicated application designed to help manage care coordination and communication.

Would a dedicated application to help you and your family manage all or most of the care coordination be helpful?

age:	yes:
21-35	100%
36-50	81%
51-65	50%
66-80	60%
80+	70%
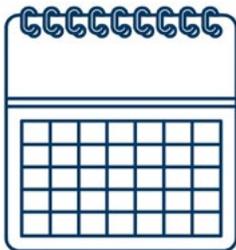
"The filing of medical records and documents."

"Update the health status of the care recipient."

If yes, the most important features would be:

70% 'a way to communicate directly with the healthcare, social and community service people'

68% 'a way to share information with family and other support members'

59% 'a way to schedule and manage all appointments'

Discussion

The unpaid caregivers who participated in this study often struggled to meet the demands of caregiving, leaving little or no time for their own needs or respite opportunities. In addition to providing for the care recipient's physical and medical needs, they often took on the role of supporting the social, emotional, and financial needs of the care recipient. The responses suggest that the responsibility often falls on the primary unpaid caregiver to ensure other family members and friends are kept up to date on the care recipients' condition.

To efficiently manage these competing demands to the best of their ability, the unpaid caregivers who participated in the interviews created their own customized care plan for the care recipient to help them monitor health, coordinate support services, provide social opportunities, stay informed, inform others, and maintain medical records. However, numerous responses indicated that coordinating these individual systems to communicate and share information with healthcare and service organizations posed a challenge. 'Communicating with healthcare and other professionals' was ranked the number one challenge for the survey participants. Although most of the individuals working for organizations recognize the importance of the unpaid caregivers' role in care provision, and most of the organizations indicated that working with unpaid caregivers as members of the healthcare team was clearly addressed in their organization's policy, there did not appear to be a formal method of communication and resource sharing. This disconnect appears to create barriers to efficient two-way communication between the unpaid caregiver and organizations, thus impacting the caregivers ability to manage their time effectively and receive resources and support in a timely manner.

Many of the unpaid caregivers in this study shared that the creation of a dedicated application that formally supports unpaid caregivers may help them to alleviate some of the time consuming and frustrating interactions that they regularly experience when interacting with organizations and family. However, it is important to note that not all the unpaid caregivers were immediately drawn to the idea of using technology to support their caregiving duties. Insights provided by the interviews suggest that they may be more inclined to use a dedicated application if they felt that the technology was easy to use and able to enhance their existing individualized care plan. Another desirable feature would be the ability to enable and connect family members who are not close in proximity but still able to provide support.

Conclusions

There is an opportunity for healthcare and service organizations to formally integrate the unpaid caregiver into their processes and policies to facilitate a more collaborative approach to client care provision. A dedicated application that facilitates an efficient and effective way for primary unpaid caregivers to communicate with healthcare and service organizations and family, has the potential to mitigate some of the common challenges unpaid caregivers experience when trying to access resources, communicate with healthcare and service providers, navigate the healthcare system, manage their time, and cope with difficult family dynamics. Meaningful communication between organizations and unpaid caregivers would also serve to strengthen a person-centred approach to care. The integration of a dedicated application has the potential to enhance the quality of care for the care recipient and to improve the well-being of the unpaid caregiver.

Limitations

The participants in this study were recruited, and communicated with, using email and the Internet. Therefore, potential participants who do not use or have access to technology were excluded from participation.

A small data set participated in the organizations survey and none of the healthcare or service organization online survey participants were able to take part in an interview. This is likely because the study was completed during the COVID-19 global pandemic, rendering most healthcare and service organization staff too overworked to participate. The individuals that did participate in the organizational survey are more likely to complete a survey about unpaid caregivers if they engage with them in their roles at work.

References

[1]Arriagada, P. (2020). "The experiences and needs of older caregivers in Canada". Insights on Canadian Society. November. *Statistics Canada Catalogue* no. 75-006-X. https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00007-eng.htm

[2]Leslie, M., Gray, R.P., Eales, J. et al. (2020). The care capacity goals of family carers and the role of technology in achieving them. *BMC Geriatrics* 20, 52. https://doi.org/10.1186/s12877-020-1455-x

[3]Shaffer, K. M., Chow, P. I., Cohn, W. F., Ingersoll, K. S., & Ritterband, L. M. (2018). Informal Caregivers' Use of Internet-Based Health Resources: An Analysis of the Health Information National Trends Survey. *JMIR Aging*, 1(2), e11051. https://doi.org/10.2196/11051 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6715019/

[4]Beach, S. R., Schulz, R., Donovan, H., Rosland, A. (2021). Family Caregiving During the COVID-19 Pandemic, *The Gerontologist*, Volume 61, Issue 5, August 2021, Pages 650–660, https://doi.org/10.1093/geront/gnab049

[5]Parmar, J., Anderson, S., Dobbs, B., Tian, P., Charles, L., Triscott, J., Stickney-Lee, J., Brémault-Phillips, S., Sereda, S., & Poole, L. (2021). Neglected Needs of Family Caregivers during the COVID-19 Pandemic and What They Need Now: A Qualitative Study. *Diseases.* (Basel, Switzerland), 9(4), 70. https://doi.org/10.3390/diseases9040070

[6]McCradden, M. (2020). *Empowering Patients and Caregivers to Engage with Digital Health: A Briefing Document.* Toronto, ON: AMS Healthcare.

Appendix A

Unpaid Caregiver Online Survey

First, we would like to know a little about you.

1. Where do you live?
❑ Canada   ❑ USA   ❑ Other

2. What is your age?
❑ Under 20   ❑ 21-35   ❑ 36-50   ❑ 51-65   ❑ 66-80   ❑ Over 80

3. How would you describe your gender?
❑ Female   ❑ Male   ❑ Prefer not to say   ❑ Identify as:

4. What is your ancestry?
❑ First Nations, Inuit, Métis
❑ Black (Examples: Afro-Caribbean, African-Canadian, African)
❑ White (Examples: English, Greek, Italian, Russian)
❑ Latin American (Examples: Brazilian, Colombian, Cuban, Mexican)
❑ Arab, Middle Eastern, West Asian (Examples: Afghan, Armenian, Lebanese, Iranian)
❑ South Asian, Indo-Caribbean (Examples: Indian, Pakistani, Sri Lankan)
❑ Southeast Asian (Examples: Filipino, Vietnamese, Cambodian, Thai)
❑ East Asian (Examples: Chinese, Korean, Japanese, Taiwanese)
❑ Other (please specify)

5. How well can you communicate in English?
❑ Very well   ❑ Well   ❑ Moderately   ❑ Poorly

6. What is your marital status?
❑ Married   ❑ Never married   ❑ Separated   ❑ Divorced   ❑ Common-law   ❑ Widowed
❑ Other (please specify)

7. What is your employment status?
❑ Employed full time   ❑ Employed part time   ❑ Unemployed   ❑ Self employed   ❑ Retired
❑ Manage household   ❑ Other (please specify)

8. What is your annual household income?
❑ Less than $10,000   ❑ $10,000 to $24,999   ❑ $25,000 to $49,999   ❑ $50,000 to $74,999
❑ $75,000 to $99,999   ❑ $100,000 to $149,999   ❑ $150,000 and greater   ❑ Prefer not to answer

9. What is your living situation?
❑ Live in a home I own   ❑ Live in a rental home   ❑ Live in a retirement community
❑ Live in a long-term care home   ❑ Other (please specify)

Now, we would like to know more about your care recipient.

10. What is their age?
❑ Under 20   ❑ 21-35   ❑ 36-50   ❑ 51-65   ❑ 66-80   ❑ Over 81

11. What is their gender?
❑ Female   ❑ Male   ❑ Prefer not to say   ❑ Prefer to describe as:

12. What is their relationship to you?
❑ Parent   ❑ Spouse   ❑ Sibling   ❑ Child   ❑ Niece/nephew/grandchild   ❑ Friend
❑ Other (please specify)

13. What is their ancestry? (select all that apply)
❑ First Nations, Inuit, Métis
❑ Black (Examples: Afro-Caribbean, African-Canadian, African)
❑ White (Examples: English, Greek, Italian, Russian)
❑ Latin American (Examples: Brazilian, Colombian, Cuban, Mexican)
❑ Arab, Middle Eastern, West Asian (Examples: Afghan, Armenian, Lebanese, Iranian)
❑ South Asian, Indo-Caribbean (Examples: Indian, Pakistani, Sri Lankan)
❑ Southeast Asian (Examples: Filipino, Vietnamese, Cambodian, Thai)
❑ East Asian (Examples: Chinese, Korean, Japanese, Taiwanese)
❑ Other (please specify)

14. What is their English language fluency?
❑ Very good   ❑ Good   ❑ Moderate   ❑ Poor

15. Where does the care recipient live?
❑ Live in a different home from me   ❑ Live in the same home as me   ❑ Live in a retirement community
❑ Live in a long-term care home   ❑ Other (please specify)

16. How long have you been providing care for this recipient?
❑ Less than 3 months   ❑ 4 - 6 months   ❑ 7 - 12 months   ❑ 1 - 3 years   ❑ 4 - 5 years
❑ More than 5 years

17. What type of support do you currently provide for the care recipient's activities of daily living?
(Check all that apply)
❑ I do not provide any support
❑ Medical decision-making (e.g. Power of Attorney for Personal Care)
❑ Financial management and decision-making (e.g. Power of Attorney for Property)
❑ Assistance with mobility (e.g., moving from one position to another)
❑ Bathing and grooming
❑ Feeding
❑ Dressing
❑ Continence/toileting
❑ Transportation
❑ Grocery shopping and/or meal preparation
❑ Home maintenance
❑ Communication with others
❑ Medication management
❑ Companionship
❑ Other (please specify)

18. How often do you provide in-person support? (Check all that apply)
❑ Never   ❑ 24 hours per day   ❑ Every day for a few hours   ❑ A few days per week
❑ A few hours a week   ❑ Other (please specify)

19. Who helps you to provide care? (Check all that apply)
❑ I am the only care provider
❑ Family member(s)
❑ Friend(s)
❑ In-home health care professionals
❑ Respite providers
❑ Health care professionals in a congregate living setting (e.g. long-term care home)
❑ Not applicable
❑ Other (please specify)

20. What other role(s) as a caregiver do you fulfill? (Check all that apply.)
❑ Advocacy: Serve as the link between care recipient and healthcare, social and community systems, contribute to the patient/family decision-making process and speak up when problems go unnoticed or when family can't or won't address them.
❑ Translation: When the care recipient and professional don't speak a common language.
❑ Personal supervision: Providing companionship and general supervision.
❑ Emotional support: Being a stable companion and supporter in all matters personal, health-related and emotional.
❑ Back-up care (or respite) services: Providing other caregivers a break.
❑ Health monitoring: Following a care plan and noticing any changes in the individual's health, recording and reporting any changes.
❑ Coordination of support: Scheduling appointments.
❑ Other (please specify)

21. What non health care related support do you access as a caregiver on behalf of the care recipient?
❑ Support groups   ❑ Social opportunities   ❑ Events - educational
❑ Financial   ❑ Formal exercise   ❑ Formal diet and nutritional

22. What other services not mentioned above would be helpful to you as a caregiver?

23. Do you experience any barriers to receiving the support mentioned above?

24. Please feel free to share any additional comments or details about your caregiver relationship and the services you access.

Now we would like to know a bit about the challenges you face as a caregiver.

25. What do you wish you knew when you became a caregiver? (Check all that apply)
❑ The need to identify myself as a caregiver.
❑ How to obtain information from the specialist or geriatrician if necessary of your care recipient's health condition.
❑ Where to find information on what specific skills you might need to care for someone with this diagnosis (Caring for someone with Frontotemporal dementia, for example, is different from caring for someone with chronic heart disease).
❑ How to discuss finances and the care recipients wishes.
❑ The need for legal paperwork (e.g., Powers of Attorney, Advance Directives).
❑ How to bring family and friends together to discuss care.
❑ How to keep family and friends up to date on the current situation.
❑ How to identify resources, both personal and in the community.
❑ How to find support for yourself.
❑ Other (please specify)

26. As a caregiver, how often do you encounter the care decision challenges or situations below?
❑ Daily   ❑ Weekly   ❑ Monthly   ❑ Multiple times a year   ❑ Have not encountered this yet
When is the right time for various services?
When should I consider transition to a long-term care home?
When is the right time to consider end of life planning?

27. As a caregiver, how often do you encounter the access to resources and eligibility for services challenges or situations below?
❑ Housing   ❑ Health care   ❑ Social services   ❑ Community services
❑ Respite   ❑ Other (please specify)

28. As a caregiver, how often do you encounter the family challenges or situations below?
❑ Daily   ❑ Weekly   ❑ Monthly   ❑ Multiple times per year   ❑ Have not encountered this yet
Conflicts about care
Lack of support from other family members
Balancing needs of healthy and sick family members
Behavioral issues
Interpersonal conflicts
Lack of cooperation by care recipient
Other (please specify)

29. As a caregiver, how often do you encounter the advocacy for care challenges or situations below?
❑ Daily   ❑ Weekly   ❑ Monthly   ❑ Multiple times per year   ❑ Have not encountered this yet
Interface with service systems
Coordinating systems

Now we would like to know about your interactions with the formal systems of care.

30. Which health care services have you interacted with directly? (Please select all that apply)
❑ Family physician   ❑ Specialist   ❑ Nurse   ❑ Outpatient clinic   ❑ Dentist
❑ Hospital (emergency)   ❑ Other (please specify)

31. Which community services have you interacted with directly? (please select all that apply)
❑ Seniors/recreation centres   ❑ Volunteer programs   ❑ Food support services
❑ Other (please specify)

Please think about the interactions the care recipient and you as a caregiver have had with physicians, nurses, personal support workers (psws), other registered health care professionals, social and community services.

For each question you will be asked to choose a number between 1 and 5 to indicate how satisfied you are with that aspect of care; the higher the number, the more satisfied you are. For example, if you choose option #1 "Not at all satisfied", you will be indicating that this aspect of care you or the recipient received did not meet any of your expectations. At the other end of the scale, your choice of option #5 "Completely satisfied" will indicate that this aspect of the care you received met or exceeded your expectations.

32. Relationship with health care provider.
(A health care provider can be your family physician, a specialist, hospital, clinic, etc.)
1 Not at all   2 Not very   3 Somewhat   4 Very   5 Completely
❑ How satisfied are you with knowing who the doctor(s) are that are in charge of your care recipient?
❑ How satisfied are you with the level of information exchange with the health care providers who supported your care recipient? (Family physician, specialist, hospital, medical imaging, pharmacy, etc.)
❑ How satisfied are you with your role in decision-making for the recipient's medical care?

33. Relationship with social service provider. (A social service provider can be personal care such as a psw, medical insurance plans, government services, etc.)
1 Not at all   2 Not very   3 Somewhat   4 Very   5 Completely
❑ How satisfied are you knowing the social services available to you in your area?
❑ How satisfied are you with the level of information exchange with the social services providers who support your care recipient? (health or medical insurance, government services, etc.)
❑ How satisfied are you interacting with social services on behalf of your care recipient?
Other (please specify)

34. Relationship with community service provider. (A community service provider can be a transportation service, personal care such as a psw, medical insurance plans, government services, etc.)
1 Not at all   2 Not very   3 Somewhat   4 Very   5 Completely
❑ How satisfied are you knowing the community services available to you in your area?
❑ How satisfied are you with the level of information exchange with the community service providers who support your care recipient? (health or medical insurance, government services, etc.)
❑ How satisfied are you interacting with the community service providers on behalf of your care recipient?
❑ How satisfied are you that you have enough time and energy to take care of yourself?
❑ How satisfied are you that you have family or friends to support you when you need assistance?
❑ How satisfied are you that you have family or friends to support you when you feel lonely or isolated?

Finally, we would like to know what can be done to make your role as a caregiver easier.
Coordinating care may be particularly challenging for caregivers providing support to older adults. The spectrum of formal support options available to care recipients and caregivers may be broad, complex, and disorganized, with different access points and eligibility criteria. Access to information about options for care, such as respite services, adult day centres, support groups, nutrition, transportation services, and financial aid, may be one of the major unmet needs of unpaid caregivers.

35. What are your biggest challenges as a caregiver? (Rank in order of importance - 1 being the biggest challenge. If you do not experience a listed challenge click on NA not applicable.)
❑ Difficulty getting information about available resources.
❑ Communicating with health care and other professionals.
❑ Cost of medications, home care, etc.
❑ Managing the time needed for my personal and family needs along with caregiving demands.
❑ Getting help from other family members.

36. What could health care organizations do better to help you stay informed and support your role as a caregiver? (Rank in order of importance - 1 being the biggest challenge. If you do not experience a listed challenge click on NA not applicable.)
❑ Include me in medication and other health related decisions.
❑ Instructions to help me care for the care recipient.
❑ Better information exchange between the various health care providers
(hospital, family, physician, specialists, nurse practitioners, etc.)
❑ Access to notes or summaries from visits.

37. What could social service organizations do better to help you stay informed and support your role as a caregiver? (Rank in order of importance - 1 being the biggest challenge. If you do not experience a listed challenge click on NA not applicable.)
❑ Better communications   ❑ Less expensive   ❑ Provide schedule of activities and events.

38. What could community service organizations do better to help you stay informed and support your role as a caregiver?

39. What could the government do to make the role of a caregiver better? (Rank in order of importance - 1 being the biggest challenge. If you do not experience a listed challenge click on NA not applicable.)
❑ Support if the caregiving demands a reduction in hours or having to quit my job.
❑ More financial support to cover my costs.
❑ A comprehensive list of available services and how to access them.
❑ Formalize the role of caregivers in delivery of health care services, long-term care homes, etc.

40. Would a dedicated application to help you and your family manage all or most of the care coordination be helpful?

Appendix B

Healthcare and Service Organizations Online Survey

First, we would like to know about you and your organization.

1. What is your job title?

2. What is your role within the organization?
❑ Administration/Management ❑ Front-line staff (non-medical) ❑ Front-line staff (medical)
❑ Support staff ❑ Other (please specify)

3. In your role, do you currently engage directly with unpaid caregivers?
❑ Most of the time ❑ Some of the time ❑ Seldom ❑ Only as an emergency contact
❑ Never ❑ Other (please specify)

4. How would you describe your organization?
❑ Health care organization ❑ Service organization
❑ We provide both healthcare and services ❑ Other (please specify)

5. If you said 'healthcare', please indicate the type/s of health care organization (check all that apply).
❑ Physician care (family physician, geriatric physician, specialist, medical centre, etc.)
❑ Nursing care (assistance in taking medications, changing bandages and cleaning wounds,
recovery from an injury or health problem, health checks)
❑ Physiotherapy (help for back pain, mobility problems, blood circulation, pain relief and relaxation)
❑ Occupational therapy (physical therapy services to make day-to-day activities easier and make
it easier to move around in the home)
❑ Home health care supplies (including dressings, walking aids, braces, cushions)
❑ Other (please specify)

6. If you said 'service' please indicate the type of service organization (check all that apply).
❑ Day program (social, fitness and other healthy activities)
❑ Society (organization with a focus on supporting individuals with specific physical or cognitive
disabilities e.g. Alzheimer Society, AODA, CNIB)
❑ Home care service provider (companionship, assistance with activities of daily living)
❑ Community support (meal/food delivery, respite, transportation)
❑ Community hospice (provide support for in-home end-of-life care)
❑ Residential hospice (where end-of-life care is provided in a home-like environment for those who can
no longer stay in their own homes)
❑ Retirement home ❑ Long-term care home ❑ Other (please specify)

7. Are aging-related services the main focus of your organization?
❑ Always ❑ Very often ❑ Sometimes ❑ Rarely ❑ Never

Now we'd like to know more about your organization's interactions with unpaid caregivers.

8. Does the organization introduce the unpaid caregiver(s) to the staff?
❑ Always ❑ Very often ❑ Sometimes ❑ Rarely ❑ Never

9. If you answered always, very often or sometimes to question 8, does the organization explain how
an unpaid caregiver(s) may also actively participate in providing care?
❑ Always ❑ Very often ❑ Sometimes ❑ Rarely ❑ Never

10. Do staff members who support patients/clients, but are not the 'lead' for that individual, know how
to reach the unpaid caregiver(s)?
❑ Yes (for all of our clients) ❑ Yes (for some of our clients) ❑ No (for all of our clients)

11. Do you provide a primary contact within your organization for the unpaid caregiver(s) to communicate with?
❑ Yes   ❑ No   ❑ Sometimes (please explain)

12. Within your organization, how would unpaid caregivers communicate with your staff on the following topics?
❑ formally with a written/documented process   ❑ informally by reaching out to a staff member
❑ not applicable
Any updates or changes about the care recipient (physical, behavioural, emotional, social)
Serious updates or concerns for the care recipient's wellbeing
Concerns with care
When something "just doesn't feel right"

13. How often do you include unpaid caregivers in your care planning?
❑ Always   ❑ Very often   ❑ Sometimes   ❑ Rarely   ❑ Never

14. During care provision, how often do you communicate with an unpaid caregiver?
❑ Regularly   ❑ Occasionally   ❑ Seldom   ❑ Never

15. What does your organization consider key items to share with unpaid caregivers?

16. Do you inform and request that the unpaid caregiver(s) are present when important decisions are being made?
❑ Yes   ❑ No   ❑ Sometimes (please explain)

17. Do staff members encourage unpaid caregivers to: (click all that apply)
❑ Participate in the care and treatment decision-making?
❑ Participate in planning transitions/discharge?
❑ Participate in planning end of life care?
❑ Be a second set of eyes and ears for the care recipient?
❑ Ask questions and take notes?
❑ Encourage the care recipient to participate in decision-making to the extent they choose?
❑ Enlist help from staff members to support them in care and decision-making?
❑ Ready themselves for the transition to home or community care e.g. before you leave the hospital?
❑ Make sure questions have been answered i.e. what will be needed after a transition (medications, treatment, equipment, follow-up appointments) and what changes, if any, in the care recipients condition should be reported to healthcare providers?

18. Where can the following information be found within your organization? (if multiple options per row apply, please describe in more detail in the comment box below')
❑ Brochures   ❑ Written policies   ❑ Staff practices   ❑ Documentation systems/records   ❑ Website
Encouragement for care recipients to name who would like to be involved in their care and decision making?
Encouragement for care recipients to define how their chosen unpaid caregivers will be involved in care and decision making?
Information about where and when in your organization an unpaid caregiver can be involved?
Distinctions between unpaid caregivers AND visitors (i.e. friends, colleagues, distant relatives).
❑ If multiple options apply, please describe here:

19. Is the necessity of working with care recipients and their unpaid caregivers, as members of the healthcare team, clearly addressed in: (check all that apply)
❑ The organization's policy   ❑ Orientation/training for clinicians   ❑ Orientation/training for other staff
❑ In service and continuing education for clinicians   ❑ In service and continuing education for other staff

20. Do care recipients and unpaid caregivers contribute to the organization's family and caregiver inclusion policy? ❑ Yes   ❑ No   ❑ Comment:

Now we'd like to hear your personal thoughts/perspectives as a participant in this broad ecosystem of supportive healthcare.

21. What do you perceive as the advantages of engaging with unpaid caregivers?

22. What do you perceive as the disadvantages or challenges of engaging with unpaid caregivers?

23. What role do you believe unpaid caregivers play in the well-being of the care recipient?
(check all that apply)
❑ Social and emotional support
❑ Scheduling doctor's visits
❑ Organizing daily routine
❑ Keeping track of medications
❑ Providing care
❑ Updating health care providers and family members
❑ Ensuring that staff recommendations are followed
❑ Other (please specify)

24. Does your organization believe that integrating caregivers into the health team is very important for the wellbeing of the care recipient?
❑ Very important
❑ Important
❑ Fairly important
❑ Slightly important
❑ Not important
❑ Comment:

25. How satisfied are you with your organization's current communication system with unpaid caregivers?
❑ Very satisfied
❑ Satisfied
❑ Neutral
❑ Unsatisfied
❑ Very unsatisfied
❑ Comment:

26. What types of information can unpaid caregivers provide to your organization to improve your services?
(check all that apply)
❑ Daily challenges
❑ Access to resources
❑ Transportation challenges
❑ Family structure
❑ Home environment
❑ Successes and challenges in caregiving
❑ Other (please specify)

27. Is there anything you or your organization wish more unpaid caregivers knew/understood about your organization?

28. Is there anything else you would like to add?

Appendix C

Unpaid Caregiver Virtual Interview Script

1. Do you currently live in a rural, urban or suburban area?

2. How would you describe your comfort level with technology?

3. Tell us about the beginning of your caregiving journey. How did you become a caregiver? Did your caregiving responsibilities increase slowly or was it a sudden incident?

4. What types and kinds of information and resources are most useful to you as a caregiver?

5. What would be the most helpful information a family physician could share?

6. Are you able to knowledgeably make a care plan? What is the biggest barrier?

7. How do you manage scheduling and sharing information with other unpaid caregivers?

8. How do you keep track of the care recipients health records and financial documentation?

9. Are you ever confused about the jargon of healthcare?

10. What systems and processes do you think would help facilitate shared family decision making and support? What types of support would be the most helpful from other family members?

11. What is the one task that you would delegate to help you better manage your personal time?

12. What would make you feel more comfortable taking time for yourself?

13. What exactly would a dedicated application to help you and your family manage care coordination look like? What would it do?

14. Is there anything you would like to add?

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About Us
The Sheridan Centre for Elder Research, founded in 2003, conducts applied research in the field of aging by leveraging creative multidisciplinary partnerships to examine innovative ways to enhance the well-being of older adults and the environments that support them and their families.

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Tyze Networks is a private, secure, and practical, web-based application that enables caregivers to create, connect, communicate, and coordinate a care team. It leverages the concept of a networked model of care, an integrated social media model, and secure cloud computing to help people and organizations manage care for others.

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