THE EXPERIENCES OF BLACK CANADIANS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS: A REPORT

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EXECUTIVE SUMMARY

Introduction

This report discusses the experiences of Black care recipients (CRs) living with dementia and their care partners (CPs) residing in the Greater Toronto and Hamilton Area (GTHA). This study explores the intersection of race and dementia, while focusing on mobility and the COVID-19 pandemic.

Methodology

A purposive sampling method was used to recruit 24 participants: 12 CRs and their CPs. Data collection involved 24 one-on-one interviews, analyzed using NVivo software.

Key Findings

Beliefs, Perceptions, and Attitudes regarding Dementia

1. Immunity belief: Some CRs initially believed they were immune to dementia, leading to denial of their diagnosis.
2. Link with old age: Dementia was sometimes perceived as a natural consequence of aging.
3. Stigma: Stigma surrounding dementia, focusing on the interrelation between race and disability.

Experiences with Dementia

1. The impact of dementia:
    a. Impact on identity: Dementia affected CRs' sense of self and identity.
    b. Impact on their mood: CRs reported feeling sadder since the dementia diagnosis.
    c. Impact on independence: CRs, who were previously independent, increasingly became dependent on their CPs.
    d. Impact on cognition: Memory loss was the most discussed change since their dementia diagnosis.
    e. Impact on their social lives: CRs became increasingly introverted.
2. Mobility Challenges: Both indoor and outdoor mobility were impacted. Some similarities were found between them (getting lost, using assistive devices), while each has its unique characteristics.

3. Impact of COVID-19 on CRs: Some CRs reported that the quarantine had been beneficial to them, while others claimed the opposite. A third group, however, explained that they have experienced feeling quarantined since their dementia diagnosis (meaning that they were not impacted by the restrictions imposed due to COVID-19.)

Care Partner Experiences

1. Impact on CPs: Caregiving led to important changes in CPs' routines, employment, and social lives.
2. Bonding: Caregiving often strengthened the bond between CPs and CRs.
3. External support: Relatives of both CRs and CPs served as support for some CPs, while others reported feeling isolated.
4. COVID-19 Effects: The pandemic had a positive impact on the bond between CPs and CRs. However, the quarantine was perceived as restrictive. Other CPs, however, claimed that the COVID-19 pandemic had not impacted their role.

Supports and Community Activities

- Coping Strategies: CRs developed various strategies to cope with memory loss and other symptoms.
- Service Competence: Cultural competence in healthcare services was sometimes found in dementia care. However, instances of racial discrimination were also reported.
- Community Involvement: COVID-19 limited CRs' participation in community activities.

Recommendations

- Dementia Education: Raising awareness about dementia in Black communities to improve understanding and support.
- Kinder Treatment: Emphasizing compassionate care for both CRs and CPs, especially when discussing health care practitioners.
- Accessibility: Enhancing access to dementia-focused services and programs.
- Intergenerational Programming: Promoting activities that involve multiple generations to support CRs.
- Cultural Competence: Ensuring healthcare providers understand and respect the cultural backgrounds of Black CRs.

Conclusion

The study explores the impact of dementia on Black CRs and their CPs. It discusses how the COVID-19 pandemic had a neutral, positive, or negative effect in both groups. CRs' mobility is also discussed in depth.

To give voice to their experiences may significantly improve the well-being of Black Canadians living with dementia and their caregivers.

Knowledge Translation Plan

The research team plans to disseminate the findings through workshops, presentations, short videos, and academic publications. This will ensure that the insights gained from this study reach a wide audience, including Black Canadians living with dementia, their CPs, community organizations, and researchers.

INTRODUCTION

The purpose of this study is to understand the experiences of Black care recipients (CR) living with dementia and their care partners (CP), who reside in the Greater Toronto and Hamilton Area (GTHA), paying special attention to their experiences regarding mobility during the COVID-19 pandemic. Mobility is an important feature of healthy ageing and a lack of mobility and cognitive impairment can lead to decreased quality of life, increased social isolation, and accessibility barriers to social spaces (Bell et al, 2018. As mobility can decrease as dementia progresses (Bell et al., 2018). such a deficit can translate into a need for assistive devices. Lack of mobility can also lead to accessibility barriers to social spaces, increasing social isolation. The latter will be explored in this report in the context of the COVID-19 pandemic quarantine, and it's impacts on people living with dementia and their CPs.

The purpose of this study is to understand the mobility experiences of Black Older Adults living with dementia, and their CP during the COVID-19 pandemic in the Greater Toronto and Hamilton area (GTHA).

The objectives of the study were:

- To examine the **beliefs, perceptions, and attitudes** that Black people living with dementia in the GTHA hold about the illness, including how **mobility** impacts these beliefs, perceptions, and attitudes.
- To learn about the **experiences** that diverse Black people have living with dementia, including how the illness has impacted determinants to **mobility**, especially within the context of the **COVID-19 pandemic**.
- To gain an understanding of the **community activities and services** Black people living with dementia utilize to enhance their health and well being, and how the determinants of mobility shape their experiences and access, and how COVI-19 has impacted this.
- To understand the experiences of CPs of Black people with dementia, including **any barriers or challenges to accessing care** and how the determinants of mobility and COVID-19 have impacted this.
- To use the data from objectives 1-4 to **create a knowledge translation product or resource** that will help inform future interventions that will restore, maintain, and promote mobility among Black Canadians living with dementia by addressing any structural barriers and gaps they face.

BACKGROUND

As one of the most pressing health challenges facing societies world wide, (Wang et al, 2022) attempts have been made to support and improve the lives of people living with dementia. The Public Health Agency of Canada (2019) released the National Dementia Guidelines which included a focus on inclusive approaches to dementia care for underrepresented communities. It was not specific to a particular community but, rather, was more generalizable in its approach to inclusivity of marginalized communities. This inclusive approach meant that the unique experiences, social location, and conditions of Black populations were not considered and its impact on the dementia journey". This attention to the Black community is significant when current research has revealed considerable unequal experiences and conditions with regards to dementia in the Black community, including the following below:

- Earlier onset of dementia in Black populations than White populations in the UK (Berwald et al., 2016).
- Fear, shame, and stigma associated with mental illness and dementia are barriers to help-seeking in Black communities, as well as factors that contribute to Black populations accessing services at later stages of cognitive impairment (Berwald, et al., 2016; Tuerk & Sauer, 2015).
- Black populations also experience higher exposure to risk factors for dementia including: physical inactivity, hypertension, food accessibility, and high rates of comorbid diseases, leading to a higher number of potentially preventable dementia cases in Black populations (Alzheimer Society of Canada, 2024).

Caregiving duties also have unique characteristics, including:

- Close-knit family structures with multigenerational households, a culture of intra-family reliance, and responses to the experience of racial discrimination in African American communities lead to the tradition of informal family care in African American families (Samson et al., 2016).
- Black Nova Scotians who care for loved ones with dementia at home often struggle to find the support and services they need (Smith, 2021).
- Neither Nova Scotians service providers nor CPs knew what to expect in the first few months after the COVID outbreak, leaving them stranded and unable to make decisions that would best facilitate dementia care (Smith, 2021).

This information, along with gaps in the availability of culturally responsive and culturally safe dementia care and supports (Iroanyah et al., 2021), highlights the the need to address these knowledge gaps. This study will contribute to the literature on experiences of dementia in Black communities through exploring the intersections of race, dementia, and mobility.

METHODOLOGY

The study outlined in this report used an interpretive, narrative approach (Polkinghorne, 1988, 1995) to collect and analyze the data. This qualitative approach involves data collection methods that enable participants to articulate, define and give meaning to their experiences. Within Polkinghorne's narrative methodology, humans are recognized as self-interpreting beings and their interpretation of phenomena is embodied in social, cultural and linguistic practices. Polkinghorne (1988) observes that narratives are the "primary scheme by means of which human existence is rendered meaningful" (p. 11). Therefore, narrative inquiry is not a mere retelling or description of an individual's story, but a dynamic process of interpretation that alters and contributes to the meaning of the story. The importance of individual experience to reality is a key characteristic of an interpretive approach to narrative inquiry. Individuals come to know themselves and others through stories and storytelling. Narrative knowing is a type of meaning that draws together events and actions and notes the contributions that they make to a particular outcome (Polkinghorne, 1988). Human experience is organized along a temporal dimension. Thus, attention to the past, present and future is a key feature of narrative inquiry and temporality an essential component of narrative theory.

RECRUITMENT

Purposive sampling was utilized, which ensured the inclusion of diverse Black people living with dementia (diversity based on culture, citizenship status, gender identity, sexual orientation, age, disability, income, and socio-economic status). The following strategies were used to recruit participants:

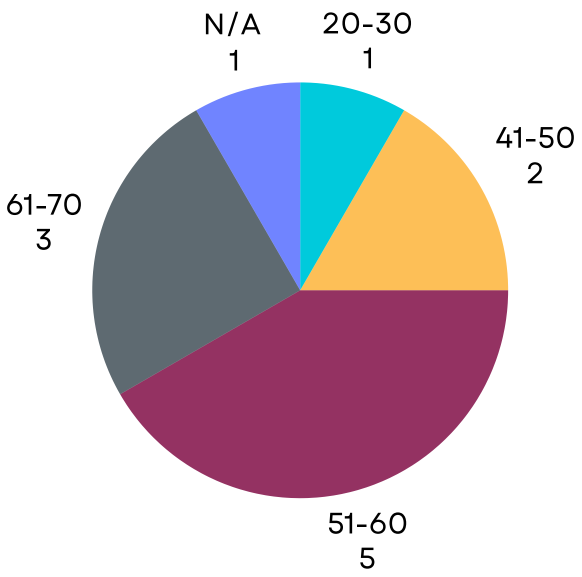
- Community outreach was conducted by the research team to Black serving community organizations in the GTHA.
- The recruitment poster was submitted to the research portal of the Alzheimer Society of Canada.
- The recruitment poster was shared on social media and disseminated by email to community organizations.
- The recruitment poster was also shared by the research team members to their networks.

SAMPLE

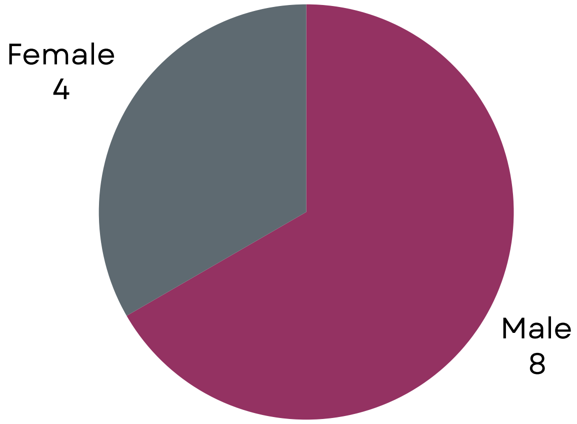
A total of 24 participants were recruited using a dyad approach: 12 Black care recipients (CRs) living in the GTHA with dementia and their 12 care partners (CPs), whether they be a family member, a friend, or a CP from an agency.

CRs

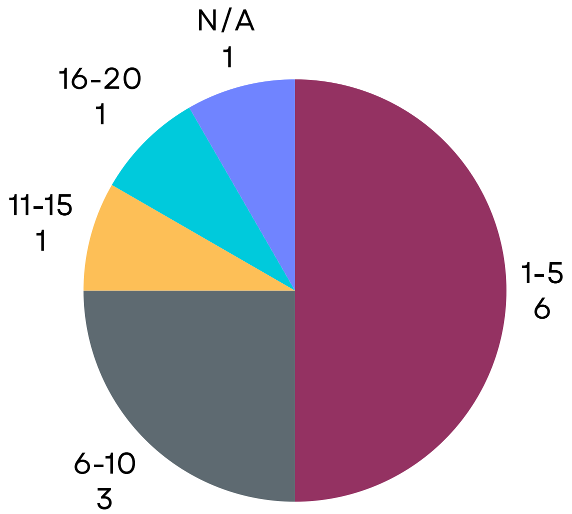
AGE



GENDER

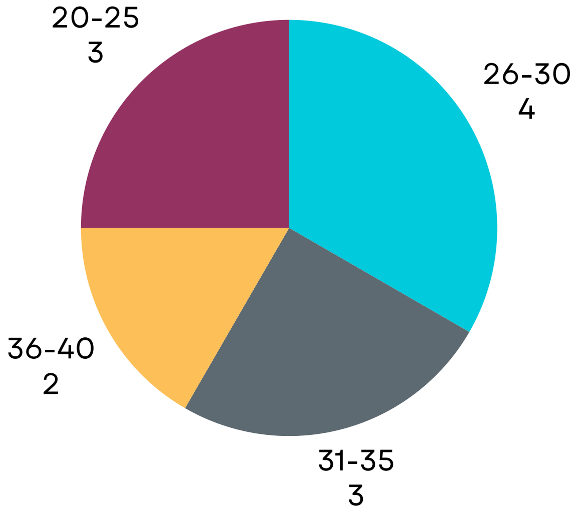


YEARS SINCE DIAGNOSIS



CPs

AGE



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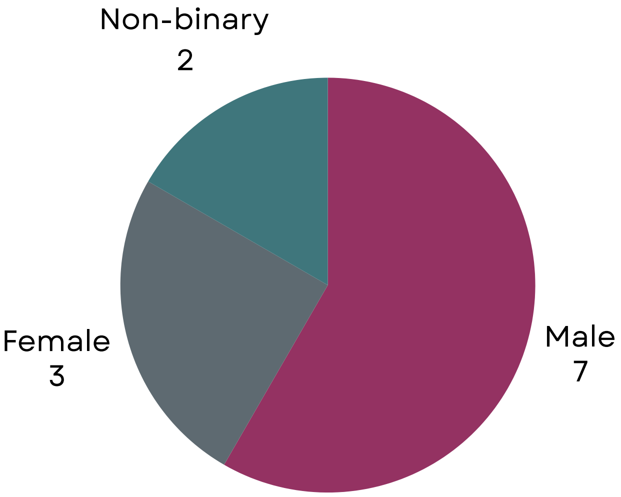
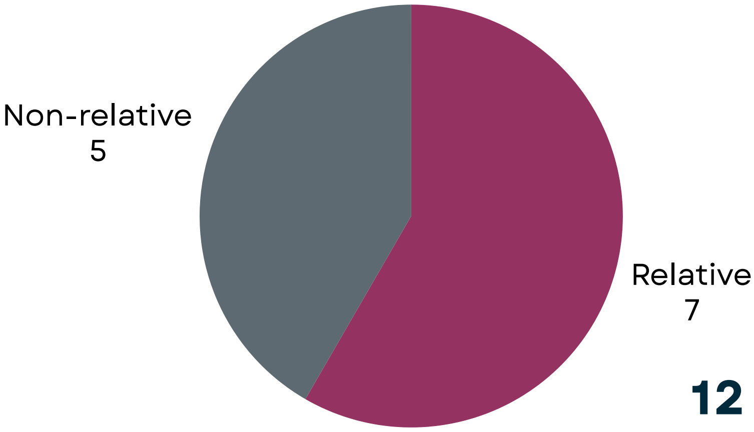


RELATIONSHIP WITH CR



DATA COLLECTION

Data collection included 24 individual interviews conducted by Co-Principal Investigators Dr. Waldrn and Dr. Kapiriri using non-standardized interview guides - one developed for the CRs and one developed for the CPs. The interviews were conducted over Zoom, digitally recorded, transcribed verbatim, and analyzed using NVivo qualitative software. The interviews with the CRs focused on:

- The supports, services, and activities they use to enhance their health and well-being, especially in the context of COVID.
- Their perceptions, beliefs and attitudes about dementia. Their lived experiences with dementia, including how COVID-19 has impacted those experiences.
- Their participation and behaviours related to physical activity, nutrition and diet, sleep, and social interactions, including the impacts of COVID.

The interviews with their CPs focused on:

- Their experiences providing care to the CR, including the impacts of COVID.
- The care they provide that seeks to enhance the emotional, cognitive, social, and physical well-being of the CRs.
- Their experiences accessing services and supports for the CR, including the impacts of COVID.
- Any challenges or barriers they faced accessing supports and services for themselves and the person living with dementia, including the impacts of COVID.

DATA ANALYSIS

We used NVivo qualitative software to organize data into themes and categories (deductive thematic analysis). Such categories were guided by the research question and central themes found in the interview guides and transcriptions. A codebook was created to follow this process.

FINDINGS

1. Beliefs, perceptions, and attitudes about dementia
2. Experiences with dementia
3. Supports and community activities
4. Experiences of CPs

1

BELIEFS, PERCEPTIONS, AND ATTITUDES ABOUT DEMENTIA

A BELIEFS ABOUT IMMUNITY

B LINK BETWEEN OLD AGE AND DEMENTIA

C ATTITUDES: DEMENTIA AND STIGMA

BELIEFS ABOUT IMMUNITY

Prior to being diagnosed, some CRs held the belief that they were 'immune' to dementia, indicating they did not think dementia would affect them.

> **CR8: "I kept on pushing that there's nothing wrong with me. That there's nothing like dementia. It's not real. It's just an illusion. Just something people believe. And it's... You have to say what you believe is what works for you. So, I did not want to believe it was real until I was diagnosed, and I saw everything the doctor said about dementia was what was really happening to me. So, I just realized that it's actually real."**
>
> **CR11: "I mean I didn't believe it. I still don't believe it, you know. But there are times when I know at a certain point I just black out because I don't remember a lot of what happened for a few moments of my life. So, I'm just forced to believe that, okay, this is actually what it is."**

Some CRs only accepted the dementia diagnosis after looking for a second opinion.

> **CR1: "I personally feel that I was diagnosed by a health professional. So, I was certain that they would have messed it up. Because even when I was told I had dementia, I had doubts. I was in doubt. I was like, what, dementia, it can't be. Maybe there's a mistake somewhere. But then I had to go for a second check-up at a different hospital, and then I was fully convinced."**

LINK BETWEEN OLD AGE AND DEMENTIA

Several CRs mentioned their belief that old age inevitably leads to dementia, viewing it as a natural part of aging rather than a pathological condition.

> **CR8: “Dementia is something that mostly happens to people who are at old age.”**
>
> **CR5: “I would describe it as some sort of mental health illness that older adults tend to experience.”**

This idea is consistent with the belief that dementia does not impact young people. A 27-year-old CR explains the following:

> **CR2: “Yeah, like I never thought I could be diagnosed with something big like dementia at such a young age. It certainly came as a shock to me.”**

ATTITUDES: DEMENTIA AND STIGMA

Some participants discussed the stigma surrounding dementia, noting negative societal attitudes towards the condition. CRs recognized that there were changes in other people's behaviours due to this stigma.

> **CR3: “I can't really recall exactly what happened, so... But I will try to tell you all I can remember. I remember that I was showing symptoms of dementia. It was mostly memory loss. At that time, it was both short-term and long-term memory loss. So, the people around me, they were not feeling comfortable.”**

Being Black and having dementia is experienced as intersectional discrimination; stigma towards race and disability happen simultaneously.

> **CR2: “Because they (Black people with dementia) might be experiencing a bit more…a bit more challenges compared to like White people living with dementia. Yeah.”**

The belief that dementia is a natural part of aging may coexist with the denial that people experience when they receive a dementia diagnosis. This contradiction arises because the actual diagnosis of dementia can still be deeply unsettling.

Such denial is frequently influenced by societal prejudices surrounding dementia. This stigma can exacerbate feelings of fear and sadness for those diagnosed.

2

EXPERIENCES WITH DEMENTIA

A THE IMPACT OF DEMENTIA

B THE IMPACT OF DEMENTIA ON MOBILITY

C THE IMPACT OF COVID-19

THE IMPACT OF DEMENTIA

This sub-theme explores the changes in perception that CRs identified in themselves due to their dementia diagnosis.

In this sense, the CRs were aware of their change in feelings towards their own personality and identity.

> **CR2: "Like how can I say? I can say that for me, like living with dementia at such a young age, I think it's like a constant battle against invisible things. That you feel like your identity, all of your identity and independence is being taken away."**
>
> **CR11: "Just forgetting my whole personality, forgetting who I am. And, you know, I just don't know what's going on in my life for a moment until I get drawn back or until someone brings…someone snaps…you know, someone just juggles me back to reality, or, you know, I just come back to reality on my own, and stuff like that. So it wasn't nice."**

Dementia impacted their mood as well, as many CRs reported feelings of profound sadness and depression comorbidity.

> **CR7: "Okay, personally, if I think of my…if I think of my condition, what comes to mind is the loneliness, the mood swings, the loss of memory. At times it comes with depression. And then I don't… There are cases where I might have a sleeping disorder. And then might feel irritated."**
>
> **CR2: "Some symptoms, like feeling like you don't want to like engage in activities, or maybe you lack sleep, you know, those are some symptoms that you can mistake for things like depression or some other mental diseases, you know."**

Before the diagnosis, the CR participants were completely independent. This independence decreased as dementia progressed.

> **CR3: "Like I said, my life changed from being an independent person I'd always been to, you know, I'm dependent on other people."**

> **CR1: “And, my condition got worse, that I could not do things the right way. I could not brush myself. There were times when my condition would get so severe that I couldn’t take my meds alone.”**

As the CPs assisted with tasks such as medication and hygiene, the CRs’ dependency gradually increased.

> **CR2: “(..). I had to make some significant adjustments in my life. Like accepting the need for a caregiver. You know, like to have someone to look after you. I think that's kind of a humbling experience to feel like you rely on someone else for your daily needs that were like something that I could just do myself, you know. So, I think that was something that changed in my life. Because my caregiver became like the person who assists me with everything, from maintaining myself, and ensuring that I didn't forget to take my medications, you know. Yeah. Like I had to learn to like let go of my pride and like accept help. Yeah. So, I would say that’s like one of the things that's changed.”**
>
> **CR9: “At least now I know I'm having this problem. So I need to seek assistance. So I won't be living the same way I was living before. It’s now I’m under care. And the people around me understand that at particular moments I need to be washed or be taken care of, or being asked whether this or that. My daily routine is changed. I don't have to do some things on my own. Yeah, it’s a lot of change. So some things I must ask for help.”**

The most discussed impact of dementia was related to cognition: CRs experienced progressive memory loss. They also recalled forgetting about their loved ones, directions, and conversations, among other issues.

> **CR11: “How has my life changed? Right now the only person I recognize is [my partner]. There are times when he tells me that I told him to leave the house, that I don't know who he is. And he tells me sometimes it breaks his heart to see me in that condition, you know.”**
>
> **CP1: “There were times she would say a thing and would not remember what she said. There were times she made some actions that she wouldn't remember.”**

CRs often recalled pieces of information they had previously forgotten.

> **CR2: “So I’d say every day is like a reminder, you know, to cherish the present for us. You know, like small things, small victories, you know, like remembering someone's name. Because now as I go to like the hospital, I find people with more severe cases of dementia than me. People who were even to the point where they don't remember those who love them. So, you know, so when you get such experiences, maybe you had forgotten someone who you loved, and you had forgotten like their name. Like when you remember it, you know, that's a small victory for us, and that's something you can cherish.”**

The impact of dementia on CRs social life is determined by their cognitive impairment and introversion. The former includes difficulties in holding conversations.

> **CR7: “At times I might not be able to communicate fluently with someone. I have this difficulty most times. Especially if I'm in a public place, I always have this problem.”**
>
> **CR6: “A lot of things have changed. Like in relation to some of my friends. Some of my family members, too. They might like... It gets to the negative side. I might forget some things they try to ask him to get.”**

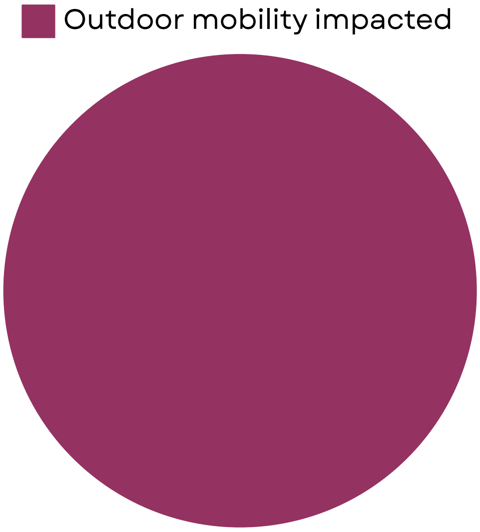
The CP perceived that their CR became less extroverted.

> **CP2: “Yeah, he was a very, very outgoing person. Like I said… Sorry, I didn’t mention this. He is a very outgoing person. Very friendly. Like I would say he was very extrovert. Yeah, he was an extrovert more so. Yeah.”**
>
> **CP1: “There were times she just needed to be all to herself. Whereas earlier, she used to be a very cheerful person, a chatty person. But ever since she was diagnosed, there were times she just needed to stay on her own, not talk to somebody. None of that.”**

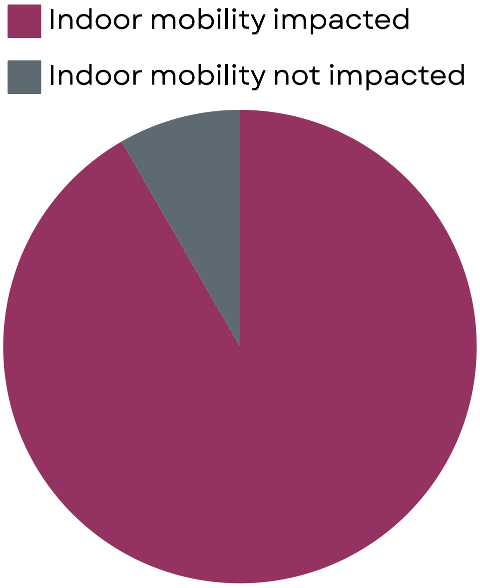
The impact of dementia on CRs also extended to different aspects of their mood, cognition, and functionality. Their memory loss obstructed their routines, while in some cases new introverted behaviors were suspected to be connected to mood swings that they experienced. CPs tried to compensate for these challenges by helping them with their activities and by providing company.

THE IMPACT OF DEMENTIA ON MOBILITY

Dementia impacted the mobility of the CRs, with many of them reporting that their ability to get around inside and outside their home had changed.



Meanwhile, most of them (n=11) claimed that their mobility changed indoors.



The impact of dementia on mobility indoors has some similar characteristics to mobility experienced outdoors with dementia, like needing assistive devices and getting lost. However, there are also distinct differences. Some characteristics exclusive to indoor mobility after the diagnosis include having limited movement and not experiencing changes in their mobility within the house. The characteristics of outdoor mobility impacted by dementia include being forced to stay inside, needing supervision, preferring to stay inside, and the inability to continue driving. These distinctions illustrate how dementia may differently affect mobility depending on the environment.

MOBILITY INSIDE THE HOUSE

The CP felt the need to monitor the CR indoors, assisting them with finding rooms.

> **CP12: “(..). So he can move freely when he is home, but sometimes he forgets where he is going to go.”**

Such attention to detail is needed because the CRs would get lost inside their own homes. CRs claimed that they would also forget about the actions to be performed inside their homes.

> **CR10: “That has changed, only in the sense that I sometimes tend to forget where I keep things. (..). And I sometimes forget places I have to go to when I'm in urgent need.”**

CRs explained that dementia had impacted not only the quantity of their mobility (in other words, the distances they were able to walk), but also the quality of their mobility (how their movement has been limited since the diagnosis).

> **CR7: “I can walk around the house. But I can't walk a long distance anymore.”**
>
> **CR3: “And sometimes when it gets worse, I can’t even move around the house.”**

The CR’s limited movement was visible to their CP.

> **CP2: “Very limited movement, actually. Very limited. He prefers sitting in one position multiple times, just trying to think, I guess. Yeah.”**

Some of the participants discussed CRs needing a device to move indoors, the walking stick being the most popular. These CRs started using a device after the diagnosis.

> **CR4: “I have a stick. I use a stick. There's also a wheelchair. But I'm not tied to the wheelchair. It's only when I am alone. I get on the wheelchair because I know I'm alone, and I would need...I may not be having any support. But for normal occasions, I use a stick, a walking stick for support.”**
>
> **CP7: “Yeah, currently he gets around the house with a walking stick. And sometimes he gets really bad. Like when his condition gets really bad, I can assist him.”**

Only one participant claimed that their mobility indoors had not changed after the diagnosis.

> **CR6: “I'm fine just walking around my home.”**
> **I: “Okay. So there's been no impact really in a big way on your body's mobility?”**
> **CR6: “No, not particularly. It doesn't affect my mobility around my home.”**

MOBILITY OUTSIDE THE HOUSE

All of the CRs acknowledged that their mobility outdoors had been impacted by dementia.

Most of the CRs used to drive before the diagnosis; however, they stopped driving because of the dementia diagnosis and their cognitive challenges. CPs took up the role of driver.

> **CP11: “Well, there was this time when he got missing, and I got scared. And I was like he wasn't going to drive anymore. So I didn't even let him see what the car... I didn't let him see what the car key looked like. He was... He didn't like it at first. You know, he was like always in a bad mood any time I’d deny him access to the car (..).”**
>
> **CR1: “And then I used to drive myself. But now I’m being restricted from driving. My caregiver drives me around.”**

The CR needed to rely on assistive devices –mainly wheelchairs– to move outdoors. Prior to their diagnosis, the participants had not needed assistive devices.

> **CP4: “She doesn't really walk well. You know, she has a stick and a chair.”**
>
> **CR12: “Well, usually... it's only when I go for a walk CP12 has to put me on a chair I think, a wheel chair so yes he does have to push or wheel me around when we go for a walk.”**

Their outdoor activity decreased; in some cases, by personal choice (not wanting to leave the house), while in other cases, the CP would prevent them from going out.

> **CR6: "Yeah, there are some activities I used to do back in the day that I don't do anymore because the dementia affects it. Like sometimes I would go to the shopping mall on Fridays right after my job. But these days I don't do that. Or if I go, I might forget some couple of things. And it like destroys my diesel. I just sent somebody else to go. Yeah."**
>
> **CR12: "Yes, yes, yes, my life probably has changed, because right now how I live… I live like I'm imprisoned."**

CR cannot leave the house alone due to the possibility of getting lost.

> **CR12: "No, literally I have to walk with CP12. CP12 has to pick me out if I'm going out. He has to drive… when I go for a walk he has to walk closer to me."**
>
> **CR4: "(..). At times where I'd go out with family, and as soon as I'm out of sight, I miss my way. I can't… I don't seem to remember anything. I miss my way. I can't even find my way back to the people who took me out of the house. So situations like this will keep arising. And I found it to be one of the embarrassing aspects of my life."**

Dementia affected mobility, causing CRs to depend on devices and supervision, both indoors and outdoors. However, their mobility dependency is notably more affected outdoors, due to the risk of getting lost when traveling or walking alone.

THE IMPACT OF COVID-19

The quarantine impacted CRs in different ways. Some positive effects involved time for growth and relaxation, while for others it was perceived as worsening their mental health and social connections.

Finally, a third group claimed that the quarantine was no different than the isolation they have experienced since their dementia diagnosis.

COVID-19 AS A BARRIER

- **Negative impact on mental health**

Participants discussed feeling worried and afraid of getting COVID-19.

> **CR5: “And I get to think of COVID and experiences that was going around at that time. It made me worry a lot.”**
>
> **CR7: “I was scared of getting COVID, and the whole information I was hearing about people being affected by COVID.”**

- **Social barrier**

The quarantine restricted the CRs’ mobility, decreasing their contact with others.

> **CR11: “I should literally say, it's one of the key factors of me, you know, limited... Or it's one of the key factors that limited my social life since I couldn't, you know, meet up with people, couldn’t talk with people. I just developed this whole social abstinence.”**
>
> **CR10: “And what I mean by less visitors, it was like I went about a few months, and the only person's face I saw was... What’s his name? Was [brother], who was my younger brother. Yeah, so those were the... That was the only face I saw. He was the one that took care of me during the COVID. And then [CP] was employed shortly after. And that's how... Those are the only people I saw.”**

POSITIVE IMPACT OF COVID-19

- **New habits**

The quarantine gave time for the CR to explore their hobbies and interests.

> **CR8: “Yes. Since I was always at home, so I just started writing (..). It's something I used to do, but just had no time. So I was always at home, nothing really to do. So I just kept on writing and writing and writing (..). I write about Black. I write about Christianity, and about the world as a whole. Just spoken words, podcast, I write. Yeah (..). I just write down how I feel about certain things, and why some things are the way they are.”**
>
> **CR6: “I learned… I learned… I learned… I learned knitting. Yeah, knitting.”**

- **Opportunity to socialize**

The CRs benefitted from their relatives, friends, and acquaintances being in quarantine, as these people had more time to connect with the participants.

> **I: “Okay. So were there things you were able to do during the pandemic when you had more time?”**
> **CR9: “Most of the family was at home (..). Yeah, I think we had a lot of fun together since most of the people were near (..). It was wonderful. Some of the moments, sometimes they come, sometimes they go. But it was such a wonderful time. We played games, we laughed. We played with the dogs. We had a good time together.”**
>
> **CG10: “(..). For the pandemic, during the pandemic, he was always doing home yoga, home workouts, and, you know, disturbing everyone with his up, down, you know. And sometimes his little nieces, when they’re around, they just spin around. You know how kids play. They spin around and jump up and down, and also make the noise of the up, up. And I think that must be what actually pushed him. You know, having fun with little ones sometimes gives great mental stability. So I think he enjoyed the fun of them around. And he kept going up, up (..).”**

- **Positive impact on mental health**

The CRs’ health improved, as they were able to rest during the quarantine.

> **CP12: “No, not really. I think his health has improved a lot in that period (..). he was technically always at home. Always pressing his phone, and I think that was mostly his peace of mind. And when people came, he had this smile, so he was always in good health.”**
>
> **CR10: “You know, that comfort, that peace, that time space made it easy for me to have, I think, speed. According to them, you get a speed recovery. Or at least that free time alone where you had to stay with less environmental distractions and noise and everything was actually worth it.”**

NO IMPACT OF COVID-19

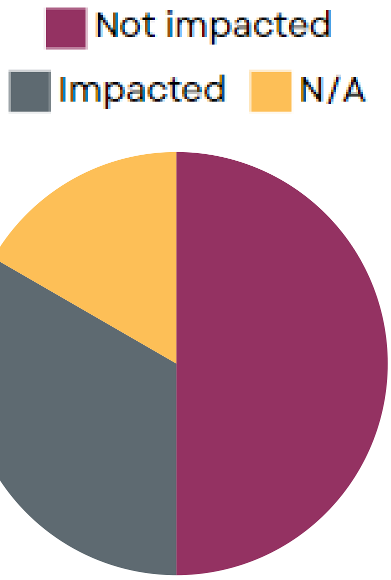
Some participants explained that their health and routines had not changed during the quarantine.

> **CR3: “No, it didn't impact my mental health. I was quite okay. Nothing really changed.”**
>
> **I: “Okay. So is there a way that the pandemic affected [CR]'s health?”**
> **CP10: “No, it just. No. No. I think that's when he tried flawlessly, and we had less need for physical check-up in that period because, you know, there was no cause for alarm. Everything was just easy.”**

Half (n=6) of the CR participants claimed that COVID-19 had not impacted them, as they had been already confined/isolated since their dementia diagnosis. In this sense, the pandemic was experienced in a similar way than their dementia care.

> **CR2: “No, I’d say, no, it didn’t. It was pretty much the same because personally, I was getting used to... I was starting to get used to like living indoors mostly because of my situation, and not like going out a lot. Like to avoid maybe getting lost or accidents, or something like that. So I’d say no.”**

> **CR1: “Certainly after my diagnosis was exactly the same time I had during COVID. I was always indoors. I didn't really have anywhere to go, aside going for check-ups.”**
> **I: “Where would you have wanted to go which was restricted because of the pandemic?”**
> **CR1: “I wouldn't say it's because of the pandemic. I would say it’s mostly because of my condition.”**



The impact of COVID-19 on people with dementia varied greatly depending on the participant. While some of them suffered from isolation due to the quarantine, others’ social interactions improved. In a similar way, while some people became stressed due to the thought of getting sick, some participants relaxed. However, the first step in exploring whether the impact of COVID-19 was negative or positive on CRs is to acknowledge if these participants were impacted by the pandemic at all. As previously stated, some of them had already felt quarantined since their dementia diagnosis.

3

EXPERIENCES OF CPS

- A IMPACT OF CAREGIVING ON CPS
- B CAREGIVING AS A BONDING EXPERIENCE
- C RELATIVES AS EXTERNAL SUPPORT
- D CPS WITHOUT SUPPORT
- E COVID-19 EXPERIENCE AS A CP

EXPERIENCES OF CPS

CP (CP) may be providing care formally or informally. The latter means “unpaid family members, or friends or neighbours rather than formally trained or paid carers” (Wiles, 2003, p.1). Both types of CPs participated in this research: 58.3% (n=7) of the CPs are relatives of their CR, while 41.7 % (n=5) are formal workers. Some of the informal CPs explain that they took up this role as a way of ‘giving back’ or returning a favor:

> **CP7: “Okay. So [CR] is my uncle. And after he was diagnosed, he didn't really have anyone around to take care of him. And it became very difficult for him to cope on his own. So I volunteered to, you know, start taking care of him, because before then, he has always been of support to me, and he has really been helpful. So I've been taking care of him for about eight years now.”**

Most of the following subthemes are shared by both formal and informal CPs, with the exception of 'impact of caregiving on CP,' which specifically concerns informal CPs.

IMPACT OF CAREGIVING ON CP

Being a full-time CP led to changes in their routines, employment, and social life, impacting all aspects of their lives

> **CP2: “Yeah, [CR], at the time he was getting dementia, he had some bit of withdrawal symptom. So we thought that it would be best to, you know, come back and take care of him. So with that happening, I tried to… Where I was working, I explained to them the situation, and they got a better understanding of it, and they agreed to allow me work remotely because I'm just in the department of IT. So sometimes some support doesn't really need me to be there physically. I only go there once in a while when I'm really, really needed. Yeah.”**
>
> **CP11: ”But then, okay, to answer your question, I had to adjust. You know, this is a personal decision, but I had to adjust myself, my work time. And I had to limit my social life. Because I had [partner] as my number one priority. So I just needed to always be there for him. So if I was to go out on anything, any occasion, I'll have to take him with me. But then I also had to limit other, you know, occasions so that I don't have to go unless it's necessary. I had to talk to my boss at work, and I could work from home. It’s made everything a lot easier. I don't have to go out now.”**

CAREGIVING AS A BONDING EXPERIENCE

The CPs explained that their role helped strengthen their bond with the CR, whether they were formal employees or relatives of people with dementia.

> **CP11: “So it's basically just me. I just do most of the things. So I like it. I like it because it's making me a little more intimate with him. I realized that we really didn't talk much. We talked like... I don't know if you know what I mean (..). We’re just a little bit more connected than before since I happen to always see him, watch him. You know, there are times when I look at him, and I just smile. And, you know, I just as it goes.”**
>
> **CP1: “Okay, I'm working for her. I was employed to work for her when her health became critical. So I came to work for her. But we are more like family now. But I worked for her over the years. Though I knew her earlier before I started working for her.”**

RELATIVES AS EXTERNAL SUPPORT

CRs are supported by their own and their CP’s relatives.

> **CG10: “Well, just if there was anything I needed, I asked his younger brother.”**
>
> **CG12: “I reached out to everyone who was interested. My parents, then his siblings -that's my uncles-”**

CPS WITHOUT SUPPORT

Some CPs stressed the lack of support they felt from their relatives when taking care of people with dementia.

> **Hamilton workshop participant 3: “I also think you're pretty much isolated looking after your mother as… We were the only ones, and not having anyone else to pick up a little bit of slack (..). It would have been good in our situation to have had other family members that may have been able to come in and… but you know, with a lot of people, like we were talking about a lot of the family… don't want to and they just hide from it or they just don't have the ability to be able to step up?“**

COVID-19 EXPERIENCE AS A CP

Just as it did with CRs, the impact of COVID-19 on CPs showed discrepancies. While some of them explained that the pandemic had no impact on their job (‘no modifications’), others discussed the positive (‘enhanced bond’) or negative (‘restrictive experience’) implications of COVID-19, which impacted their role.

ENHANCED BOND

COVID-19 was perceived as an opportunity for the bond between the CP and the CR to grow stronger. In this sense, it seems like the closeness caused by caregiving was enhanced by the pandemic.

> **CP11: “I wouldn't say… If I was to say impacted, I should say, yeah, the impact was it enhanced my relationship, and it also enhanced the amount of attention I give to him.”**
>
> **I: “Okay. How did the pandemic change being a CP for you?”**
> **CP2: “Okay, I think it brought us more together. I would say the bond is much greater right now. Yeah. Because I'm taking care of someone, yes, who I love and who I care for. Yeah.”**

NO MODIFICATIONS

COVID was perceived as having no impact on the participants’ caregiving.

> **ICR2: “(the quarantine) was pretty much the same because personally, I was getting used to…I was starting to get used to like living indoors mostly because of my situation, and not like going out a lot. Like to avoid maybe getting lost or accidents, or something like that.”**
>
> **CR6: “(the quarantine was a bit lonely and… It was a bit lonely, but I could go through it because I was… I was kind of… I was kind of used to it. But it was okay. It's okay.”**

RESTRICTIVE EXPERIENCE

As a way to prevent the CR from getting COVID-19, CPs restricted their own behaviours, both regarding locations (by trying not to leave the house) and personal contact (they distanced themselves from the person with dementia as a precaution).

> **CP1: “The pandemic, the only thing it changed about my caregiving was that we were restricted to staying at home. We didn't do a lot of outside activities. So that was just… At first, it was a bit difficult because there were times that we were tired of staying at home.”**
>
> **I: “Okay. Did being a CP during the pandemic affect your ability to provide care for her in other ways?**
> **CP3: I think generally it affected the way I provided care for her because, you know, the care that I was providing at that period, I would describe it as inadequate, you know, because there was a lot of distancing and, you know, precautions which you had to take because it was a COVID period.”**
> **I: “Yes. So there was more distance from you.”**

The caregiving experiences are similar for formal and informal CPs: both bond with their CRs, need external support from relatives, and perform similar roles (for example, they all help with activities of daily living and driving). However, the COVID-19 impact on their work cannot be generalized. Some of them found the pandemic helpful; others, restrictive, while a few did not perceive any changes at all.

4 SUPPORTS AND COMMUNITY ACTIVITIES

- A SUPPORTS AND STRATEGIES
- B COMMUNITY ACTIVITIES
- C ACCESS TO CARE
- D FINANCIAL BARRIERS

SUPPORTS AND STRATEGIES

Strategies and supports that improve CRs' lives are discussed here. Competences regarding services are also found in this section.

COPING STRATEGIES

CRs devised their own strategies to cope with the dementia symptoms; they also discussed the benefits of therapy.

- Strategies:

CRs compensated their memory impairment with strategies to recall information:

> **CR6: "Sometimes I take notes or put stickers in order to remind myself. "**
>
> **CR8: "But right now I'm used to it. Because you see, I can handle it to some extent. Sometimes if I want to maybe do something, I will just write it down so that maybe in case I forget. Because I know I will forget. But the only problem with that, maybe I will forget where I dropped it. But I normally keep it where I will see it."**

- Therapy

CRs discussed the benefits of therapy for people with dementia.

> **CR4: "My experience doing therapy was improved…improving because I felt better. I became better. Things have changed. Like there were times where I was… There were times where it was like it seems like the therapist was the only one that could understand what I was going through - trying to fix herself in my shoes."**

> **CR9: “I just like the way how sometimes they bring about this... How do they call it? Like counselling. Yeah, like a speech therapist, something like that, where you just, you know, sometimes we will talk. Especially at this age, you might be wanting to offload some things off your head. Or maybe have a chit-chat. They can give you... You may also have your thoughts about this or that. I like how they give the counselling speech. It helps you meditate. Just like a good therapy. It's good. I would recommend for that.”**

SERVICES:

Competence in services may be related to dementia knowledge or cultural sensitivity.
Incompetence was usually associated with racial discrimination, and it was perceived as detrimental to the treatment of dementia.

- Cultural competence

Cultural competence was defined as “healthcare providers are being respectful of Black people’s race, culture, gender identity, sexual orientation, and age,” as described by the principal investigators of this study. Most CPs described their CRs’ medical professionals as culturally competent. The same number of CRs considered them competent. Such a competence was often associated with the medical professionals having the same or a similar racial background as them.

> **CR12: “maybe maybe, but CP12 has been a good care person, because he tends to always... he sees me and he respects me. He's always there when I need. He's able to just understand what I need. I think he has a good sense of judgment and he's also a Black person like me, so technically, I would say my cultural support... that’s what you are asking right?”**

> **I: “And how about their cross-cultural sensitivity, do you feel they are culturally sensitive?”**
> **CP2: “The doctors, medical personnel, actually, they just treat him like fairly equally, like any other person.”**
> **I: “Okay. How about the others?”**
> **CP2: “Sorry?”**
> **I: “You specified that the medical doctor treats him like the others. How about the other CP, care providers?”**
> **CP2: “Yeah, I would say for me, as much as I've observed, I think it's quite the same. People love him. They just treat him fairly. Yeah, no discrimination or anything so far.”**

- Cultural incompetence

A third of CRs (33.3 %) stated that they received culturally incompetent treatment from health professionals. The same number of CPs also expressed that their CR’s health providers were not culturally competent.

> **CP10: “Because he's had people… He has had White doctors, and he also has a Latino doctor. So I've watched their treatment session with him. And the White sometimes are a little bit extreme. But what can I say? I’m not a medical personnel. But they’re a little bit extreme. So somehow some people might call it racism, racial activity.”**
>
> **CR8: “Or will say some of them were caring. Most of them were caring. But some of them had this… I don't… I don't really remember but I know that some of them, one of them could be should I say rude or discriminative? I don't know what word to use. But most of them were caring.”**

- Dementia-related competence

Professionals who treated CRs with patience and calmness were perceived as competent.

> **CR12: “I can understand they always want to be just like you right now. They always try to converse with me in a very friendly way and I think they are always patient to know because sometimes I could sit aimlessly looking at the wall or somewhere because I have forgotten something and I really need to see that thing you know? and their patience is always good for me to have enough time to remember and then I can give them my answer.”**
>
> **CR4: “I sometimes have those relieved experience, relieved mindset because the doctor is bound to give me some moral support and health support.”**

- CPs’ basic dementia knowledge

Some CP participants did not have in-depth knowledge about dementia (they did not recognize the type of dementia their CR had, for example).

> **I: “Okay. And what type of dementia does [CR1] have?”**
> **CP1: “What type of?”**
> **I: “Of dementia. Do you know the type of dementia she has?”**
> **CP1: “What I really know is loss of memory. Like she tends to forget a lot. That's the type.”**
>
> **I: “What type of dementia does she have?”**
> **CP8: “Dementia in general.”**

COMMUNITY ACTIVITIES

Some (n=5) CR participants were involved with their community prior to COVID. For some of them, it was difficult to recall the type of activities they were involved in. However, they highlighted the social component of such activities.

> **CR10: “There was this thing I remember, but that was quite a long time ago. It was something about... I’m getting it, I’m getting it. Something about save. It was save your... Save your need or... It was something about where people literally just had to work. You know, try to find people on the street, try to see how they can feed them maybe once or twice a day, you know, to get... I'm trying to remember the name of how it went. It's been like 10 years or so since I did any kind of community outreach or something. So it was more like we got food, and we happened to give people on the streets who actually needed them. Because... It's something we did twice in a week. Yeah, it was something we did twice in a week. And I think I participated in that for about for about six months or so. Five to six months, I'm not mistaken, yeah, I participated in that.”**
>
> **CR11: “Yeah, I just love... I love hanging around kids. You know, I’d sometime go to the park, or I could visit an orphanage. Or I could just, you know, come out and do something with the (..). neighbor’s kids, and just catch my fill, and then back inside.”**

CRs discussed the impact of COVID-19 on community activities, as it involved restriction.

> **I: “Okay. So community activities, I mean like maybe social gatherings, going to church.”**
> **CR8: “I go to church, yes (..). We weren't allowed to go outside. So I would say some churches didn't hold. And my church happened to be one of them. But we held some fellowship in our houses. So it affected me going to church. But sometimes I held fellowship with my family at home.”**
>
> **CR6: “(..). after the pandemic, it kind of...my rate of participating in community activities reduced.”**

ACCESS TO CARE

In the same sense, medical appointments were affected by the quarantine. COVID-19 caused a medical barrier, as it was difficult to have a frequent and close relationship with health professionals.

> **CP6: “We had to wait for an appointment. Not like today when you can wake up and just say you're headed out to see the physician.”**
>
> **CR4: “It's affected me at some point because my doctor had limited time of seeing people. And it became a difficult situation for me. I was always... I tried my best to protect myself due to the rules that was given. I mean the whole mask and everything, it was uncomfortable for me. But I still had to. So I found it difficult to access my doctor because he had limited time to do the things he was supposed to do. There was no time at all. The little time my doctor would use in helping and assisting me would be limited and very small. There was always this barrier. Because even with the little time, we were never close. There was this huge distance. That didn't really make me connected and feel encouraged. I didn't really get the services of encouragement. I didn't really get the support I wanted.”**

The solution to this medical barrier were virtual appointments, which were perceived as beneficial to some participants.

> **CP3: “You know, actually you couldn’t go out based on the lockdown. So appointments were online.”**
>
> **I: “Okay. So you're saying that instead of going to the hospital, they changed to virtual meetings?”**
> **CR2: “Yeah, they suggested that because it was too risky to like travel physical... I mean public transport. Like because of COVID. So the doctor suggested that. And I found it like a good idea.”**

FINANCIAL BARRIERS

Financial challenges in Black populations were discussed as preventing them from accessing services targeted at people with dementia, like long-term care homes.

> **Toronto workshop: “We need supports, we need money. We talked about financial ability to pay for PSW's, to pay for nursing care, to pay for these workers to come in and support us when we're in the black.”**

RECOMMENDATIONS

1. Education about dementia
2. Kinder treatment
3. Intergenerational programming
4. More accessibility
5. Similar background

EDUCATION ABOUT DEMENTIA

Participants discussed the importance of dementia awareness in general, and in Black communities in particular. Regarding the former, CRs explain that prior knowledge about dementia helps with coping. Regarding the latter, the importance of Black CR advocates was mentioned:

> **CR2: “So, yeah, I think the Black people living with dementia should like use the experience to raise awareness about it, and advocate for like greater support and understanding in society to like avoid those people. To like make sure like the way racism is fought for. Like making sure that like it's over, and making sure everyone is treated equally, you know. So, yeah, I think people with dementia should like advocate for things like that to make people in the society to understand dementia a bit better. Yeah.”**
>
> **CR9: “I think it is very important for people who have such illnesses to know earlier. If they're having a problem, it makes it easier for you to live with the people around you. At least they can understand you, and the way you react or behave around them. So I think it's very important. Yeah.”**

KINDER TREATMENT

CRs expressed the importance of CPs and health providers providing kinder and more sensitive treatment to people with dementia. A CP stressed the importance of CPs being treated with more sympathy.

> **CP12: “For social support, I can't say, but if I use my head I can literally just say that anyone who gives encouragement or help, maybe in the form of food stamps or I don't know... anything you can do to support someone who's caring for someone with dementia, or anything you to give support to people with dementia please, do it. It's not easy.”**

This need for support may allude to CP burnout.

> **CR10: “Well, that's what I was trying to explain before you asked me based on culture and society. I said people should technically… I mean anybody in charge of taking care of people with dementia, whatever colour these people with dementia are, should be able to take good care of them patiently, or with love. (..). You know, just try to make it easy and… Try to make life easy for people with dementia. Not having to make them feel that their condition can’t be cured, and their condition will only worsen. You know, just instead of giving them a bad omen or negative whatever, just make them feel like they’re at home, let them feel comfortable, let them feel friendly, and feel everything.”**

MORE ACCESSIBILITY

Participants discussed the importance of more accessible dementia-focused services and programs.

> **CP9: “I think more of like a peer support system. Like where they can meet…people meet in person or people meet virtually. Or even a group. Maybe, I don't know, a Facebook group or a WhatsApp group to connect with so that one can relate with others facing the same condition.”**
> **I: “Okay. And any other recommendations like for health services? Do you have any thoughts there?”**
> **CP9: “Basically making them more accessible. Yeah.”**
> **I: “In what way?”**
> **CP9: “Like I don't need to call friends to like refer me to a good doctor who is good with dementia patients. I think if I need to have the service, I just need to like go there or just make a call without having to like go through so many steps.”**

> **CR5: “In some situations, if possible, a health care provider that supports people with dementia. So there should be more like a section or a specific environment (..). although these are in the specialist hospital. But then hospitals or clinics in rural areas and suburbs should have this. Even if it's to groups of people, just a group of people, they should have some sort of mini groups that could take charge of conditions within that area you come within this local environment. So say a certain community has a good number of elderlies with dementia. (..). So it would help the experience. Because for me, I was really...I really needed to speak with some sort of specialist. And I didn't know where or how to go about this.”**

The importance of dementia resources being accessible to people with dementia is crucial for the community. It was noted that participants expressed a preference for professionals to come into community to visit and share knowledge in familiar places for people with dementia instead of the latter finding resources themselves.

> **Toronto workshop participant 2: “I (care worker) have personally suggested that we as professionals go out to the communities.”**

Participants agreed that churches are a great place to educate Black older adults on dementia.

> **Toronto workshop participant: “And approaching the churches and community groups, because a lot of old people go to church and are part of their church community.”**

INTERGENERATIONAL PROGRAMMING

Intergenerational activities were highlighted as beneficial for individuals with dementia.

> **Toronto workshop participant 1: “Do more initiatives that are intergenerational... the way children do their dance and stuff (..)., I don't know how it affects, but I'm sure all seniors benefit from the exposure to your youth and staff. So if those programs can maybe work together. And you know perform, not plays or dance or different things or the youth volunteer to help the elderly people cater to them.”**

SIMILAR BACKGROUND

Cultural competence was associated with professionals having a similar cultural background. Participants discussed the importance of Black professionals providing care to Black CRs.

> **CP10: “No, just the fact that they should be taken care of by people who actually understand their cultural background. I mean if any White person wants to take on the role, I'm not saying he or she should not be given the chance. But until they are certain these White people understand the cultural background of the Black, or this White person is interested in taking or taking charge of the person, I don't feel they should give that role to any White person. I still stand by that.”**
>
> **CP9: “I think possibly if... Like if there’s that option... Because for us, maybe we’ve got the right people. For some, they don’t necessarily get the right people. They’ll get someone who will not be. So when you go to a health facility, if you can choose who attends to you. Like from a certain race, who you would feel comfortable from. Or even maybe let's say the person is from... Because nowadays, they're the Black community is so much pronounced that they will want to have someone relate more with them. You see, that option of choosing is important. Yeah.”**

CRs interacted with health services and, to a lesser extent, with their communities, both of which were affected by COVID-19. The quality of these health services was evaluated based on their cultural competence and expertise in dementia care. Patients often felt these aspects were lacking. Consequently, greater dementia awareness in society and more accessibility to services were suggested. They also recommended that healthcare professionals should be more compassionate and share a similar cultural background with patients.

CONCLUSION

CR participants' lives were severely impacted by dementia. It restricted not only their cognition and physical ability, but it also impacted their sense of self.

Their cognitive and physical challenges affected their independence, requiring CRs to rely on their CPs for assistance with activities of daily living. Cognition was often discussed regarding their memory loss, directly decreasing their sense of belonging in social circles. Meanwhile, physical challenges were experienced as changes in mobility. Outdoor mobility appeared to be the first area affected, followed by indoor mobility. Participants required support, including devices and assistance from CPs, to navigate their everyday lives without getting lost or injured.

Dementia also impacted their mood negatively, which, for some CRs, deepened during the quarantine. Others had a contrary experience, since the quarantine served as a time to relax and explore new hobbies. However, the most surprising finding was that a third group claimed that the quarantine did not feel different to their everyday life since their dementia diagnosis. This situation speaks of the urgent need to provide more and better services to people with dementia, tailored to their cultural backgrounds, so they may be given more resources to lead more fulfilling lives. As a participant said, "(..). having dementia is not the end of the world" (RC1).

CPs are needed companions for CRs. Most of them were their relatives, which reflects findings by Samson et al (2016) about the tradition of Black families being more likely to provide care to a family member with dementia. These CPs had to readjust their routines to provide appropriate care, and their roles involved compensating for the cognitive and physical challenges that the CRs had identified in themselves. In this sense, CPs played an important role in providing CRs with support around mobility and their performance of activities of daily living.

This report aimed to give voice to the Black people living with dementia and their care partners, which is why it is important to conclude this section with their reflections on dementia awareness in the Black population:

> **CR2: “I could say that people…Black people living with dementia… I’d say like living with dementia is like…is hard. It's a struggle, you know. You have to be resilient sometimes, and be strong because like people… different people treat you differently. There are some people like who observe your situation, and like misunderstand you for who you are. There are other people who isolate you. So I’d say every day is like a reminder, you know, to cherish the present for us. You know, like small things, small victories, you know, like remembering someone's name. Because now as I go to like the hospital, I find people with more severe cases of dementia than me. People who were even to the point where they don't remember those who love them. So, you know, so when you get such experiences, maybe you had forgotten someone who you loved, and you had forgotten like their name… Like, when you remember it, you know, that's a small victory for us, and that's something you can cherish (..).”**

KNOWLEDGE TRANSLATION PLAN

The knowledge translation plan for this study is focusing on creating diverse resources to share our findings with diverse audiences: Black people living with dementia, CPs, our Advisory Committee, the Alzheimer Society of Canada, community organizations, our participants, and researchers/academics. We are taking the following steps to share our findings with these diverse individuals and organizations:

- We delivered a workshop in Toronto and a workshop in Hamilton, which were attended by research team members, individuals from organizations, community members interested in learning about dementia, and study participants. These events had two goals: to share study findings, and to hear attendees' suggestions about the kinds of knowledge translation resources the research team should develop.
- A knowledge translation resource in the form of a series of short videos related to the study topic will be developed and shared with diverse audiences.
- A community presentation on the findings from this study will be delivered by the research team and Advisory Committee members to individuals and organizations in the GTHA. In the spirit of co-creation with study participants, they will be invited to deliver a presentation to organizations in the GTHA.
- The research team and the research assistant will deliver a presentation on the findings to one or more conferences that will target academic audiences.
- The final study report will be shared with the study participants, the Alzheimer Society of Canada, the Advisory Committee members, other organizations, researchers/academics and the general public through email, websites, social media and post.
- The research team will publish articles in journals focused on dementia, aging, and gerontology.

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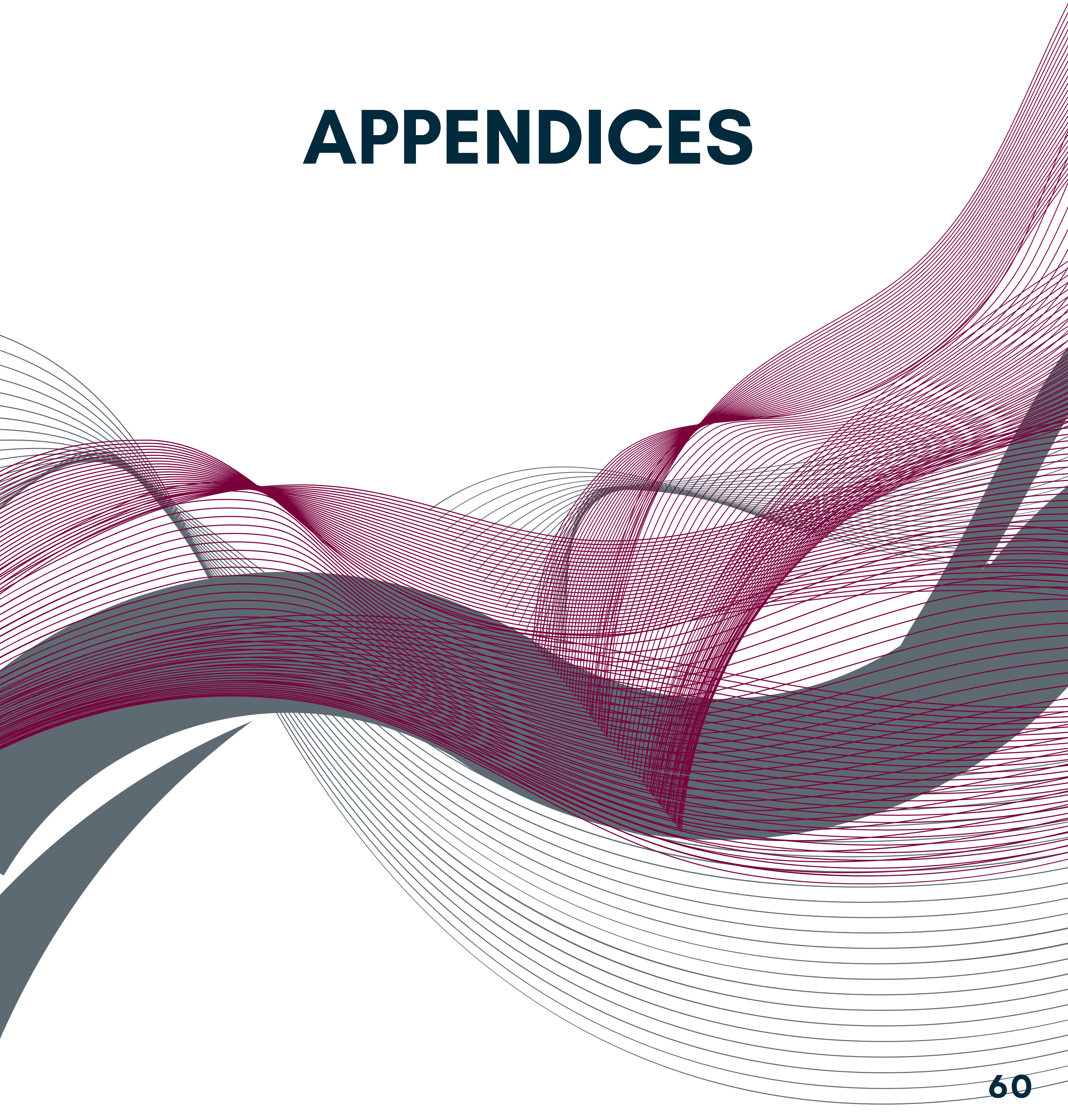
APPENDICES



WORKSHOP PHOTOS

TORONTO

HAMILTON

TORONTO

WORKSHOP QUESTIONS

During the workshops, the participants discussed their experiences regarding dementia. The questions were:

- What are the experiences of diverse Black Canadians living with dementia? (diverse based on culture, immigrant status, gender identity, sexual orientation, where they live, age, religion, disability)
- What supports do they use and what community activities do they engage in to maintain and enhance their health and well-being? (e.g. health and social services, sleep, hearing and vision, physical activity, nutrition and diet, and social interactions)
- What are the experiences of their CP in accessing services for persons living with dementia, including services such as dementia services, physicians, nurses, and other supports, especially within the context of the COVID-19 pandemic? Do CP experience any barriers in providing care to individuals living with dementia?
- What resource should the study team consider developing to do any one or more of the following:
    - Create awareness and decrease stigma around dementia in Black communities in the GTHA.
    - Inform future interventions that will restore, maintain, and promote mobility among Black Canadians living with dementia by addressing structural barriers and gaps they face that prevent them from accessing and participating in the health care system and various spaces, opportunities, and activities due to mobility and the pandemic.

NON-STANDARDIZED INTERVIEW GUIDES

Interview Guide – Person with Dementia

Greetings/Intros

- We are talking with people with dementia and their CPs to better understand dementia in Black communities. We hope to develop better supports for Black people with dementia and their CPs.
- Do you have any questions?
- Review consent forms and answer questions

Definition

- We'll be talking about dementia today, we're defining dementia as a general term for a set of symptoms that are caused by disorders affecting the brain, not just one specific condition. Dementia can include: memory loss, both short-term and long-term, difficulties with thinking, problem-solving or language that are severe enough to reduce a person's ability to perform everyday activities, and changes in mood or behaviour.

Demographic Questions

- Where were you born?
- How old are you?
- What is your gender?
- Where do you live?

Participant's Story

- Can you tell me your story of being diagnosed with dementia and how you feel about it today? (i.e. time, place, what led to you being screened for dementia?)
- How did you feel about getting assessed? How did you feel after you were diagnosed?

Beliefs, Perceptions and Attitudes

- Did you ever learn about dementia before being diagnosed?
- What comes to your mind when you think of dementia?
- If you were speaking with someone that had never heard of dementia before, how would you describe it to them?
- Did your beliefs about dementia change after your diagnosis?
- Did your life change after being diagnosed? In what ways has dementia affected your daily living?
- Have you lived or are you currently living with another health condition? And how does this compare?

Mobility

- Before being diagnosed, how did you get around outside? (Walk, drive, public transit, etc)
- Does dementia affect how you get around outside now?
- What about getting around inside your home, has that changed since your diagnosis? (Do/did you use any assistive devices before or currently, do/did you experience any pain or difficulty when being active, etc)

Access and COVID-19

- When you’re looking to maintain or improve your health, who do you reach out to?
- Before your diagnosis, how did you access health care? What were your experiences with health providers like? Did that change after you were diagnosed?
- How has COVID affected your access to health care? (social distancing, virtual appointments, vaccination status restrictions)
- Did you take part in community activities before the pandemic? If yes, which ones, and what were your experiences like?
- Have you tried to access services or supports before the pandemic (such as health and social services, sleep, hearing and vision, physical activity, nutrition and diet, and social interactions, dentists)?
- What is your experience with accessing community supports/services or activities during the pandemic? (Were services closed or virtual?)

- Were there things you were able to do during the pandemic when you had more time? (learning new skills, getting more familiar with tech)
- Do you feel that COVID protocols affected you differently because you are living with dementia? (i.e. stricter restrictions)
- How has the pandemic affected how you get around outside your home? How about inside your home?
- Has the pandemic affected your health? (mental health, ie fear or isolation; physical health, i.e. joint pain, COVID infection)
- How culturally competent are the healthcare services and other supports used by the person you are caring for? (understanding of race, culture, gender identity, etc and how these issues might affect care).
- If they are not, how can they be more culturally competent?

Concluding Remarks

- Those are all of the questions we have, do you have anything else you would us to know before we finish?
- Thank you for your time.

Interview Guide – CP

Greetings/Intros

- We are talking with people with dementia and their CPs to better understand dementia in Black communities. We hope to develop better supports for Black people with dementia and their CPs.
- Do you have any questions?
- Review consent forms and answer questions

Definition

- We'll be talking about dementia today, we're defining dementia as a general term for a set of symptoms that are caused by disorders affecting the brain, not just one specific condition. Dementia can include memory loss, both short-term and long-term, difficulties with thinking, problem-solving or language that are severe enough to reduce a person's ability to perform everyday activities, and changes in mood or behaviour.

Demographic information

What is your age?

What is your gender?

Participant's Story

- Can you start by telling me your story about how you became a CP to the person you're caring for?
- What is your relationship to the person you're caring for? (how did you meet?).
- How often do you provide care for the person you are caring for?
- What is the nature of the care you provide to the person you are caring for?

CP's Observations About the Person They are Caring For

Mobility

- Before their diagnosis, how did they get around outside? (Walk, drive, public transit, etc)
- Does dementia affect how they get around outside now?
- What about getting around inside their home, has that changed since their diagnosis? (Do/did they use any assistive devices before or currently, do/did they experience any pain or difficulty when being active, etc)

Accessing Supports

- Before their diagnosis, did you access health care together? If yes, what were their interactions with health providers like? And have they changed since their diagnosis?
- Did they use any supports/services or take part in community activities before the pandemic? If yes, which ones, and what were your experiences like?
- How has COVID affected their access to health care? (social distancing, virtual appointments, vaccination status restrictions)
- What is their experience like when accessing community supports/services or activities during the pandemic? (Were services closed or virtual?)
- How culturally competent are the healthcare services and other supports used by the person you are caring for? (understanding of race, culture, gender identity, etc and how these issues might affect care).
- If they are not, how can they be more culturally competent?

CP Access During COVID-19

- Can you describe your experience care giving before the pandemic?
- How has the pandemic changed being a CP for you?
- Were there gaps in services? If so, how did you manage them?
- Who did you reach out to for support during the pandemic? (community services, family/friends?)
- Has accessing certain spaces/services changed for you and the person you are caring for with COVID protocols?
- What kinds of decisions did you make around vaccines and masks? (What did it affect?)
- Did being a CP during the pandemic affect your ability to provide care for the person you are caring for?
- Did being a CP during the pandemic affect your ability to access services for the person you are caring for?
- How do you think the pandemic has affected **their** health? (mental health, ie fear or isolation; physical health, ie joint pain)

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