

Holistic Experiences of Indigenous Carer-Employees in Southern Ontario

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Abstract

This qualitative study uses Indigenous ethical protocols and the Medicine Wheel as a guiding framework for deductive coding to examine the mental, physical, emotional, and spiritual care provided by ten Indigenous Carer-Employees (CEs) living and working in Ontario. CEs are individuals who work in paid employment while providing unpaid care to family, friends, and/or relatives with physical, mental and/or cognitive disability or challenges. The paper adopts a holistic perspective by acknowledging the Medicine Wheel's four aspects—spiritual, emotional, mental, and physical well-being—to understand the nature of care provided by these CEs to their loved ones from an Indigenous perspective. This care manifests in a plethora of ways, including the importance of aiding loved ones with intellectual tasks, the need to provide physical labour, the importance of providing a safe emotional space for loved ones, and the role of helping with spirituality in the caregiving practice. The role of the workplace, including policies, experiences, and the differences between Indigenous and non-Indigenous employers, is also explored through inductive thematic analysis. This paper contributes to the growing literature on CEs and contemporary Indigenous caregiving. It provides suggestions for future scholarship to elevate the voices of Indigenous CEs, the importance of Carer-Friendly Workplace Policies, and the necessity to consider participant positionality in all research, particularly in research involving Indigenous participants, where the impacts of colonialism continue to pervade into many aspects of daily life.

Indigenization Statement

Dr. Bharati Sethi is a female racialized second-generation immigrant. She has engaged in transnational care throughout her life. As a community-engaged researcher, Dr. Sethi has collaborated with racialized populations, including immigrants and refugees and Indigenous Peoples, for over a decade. She uses her lived experiences as a racialized immigrant to challenge the status quo and strengthen research and knowledge systems.

Jacob van Haaften is a cisgender male settler of Dutch descent. He recently completed a MA in Indigenous Studies at Trent University in collaboration with Curve Lake First Nation and focused on connection with land and nature. Jacob has spent the past several years unlearning and relearning through his formal education and personal life, particularly about what it means to live in relationships defined by mutual flourishing. He is deeply committed to engaging

respectfully with communities and promoting their knowledge on their terms. As it pertains to the current paper, Jacob was deeply honoured to hear and share some of the stories captured by the research assistant (RA) conducting interviews. Jacob hopes that his extensive consultation with Indigenous literatures, his MA research journey with Curve Lake, and his reflective work on this paper have resulted in a representative, respectful, and reciprocal retelling of the stories shared by the research participants.

Introduction

Caregiving is a practice undertaken by individuals across intersecting identities. Providing support and caregiving are central components of many Indigenous societies and ways of being (e.g., Hammond et al., 2022; Johnston et al., 2012; Kelley et al., 2018). A multifaceted concept, caregiving involves identifying and accommodating the needs of others, actions that draw on personal strength (Hochschild, 1983; Thomas, 1993). Carer-employees (CEs) are individuals who engage in both paid employment and unpaid caregiving for family members or loved ones (Sethi et al., 2022). While the literature base on CEs is growing, much more research is needed to fully understand how balancing paid work and unpaid caregiving affects individuals, how their caregiving manifests, and what supports are needed for CEs (Sethi et al., 2022). There is also a paucity of research on the experiences of Indigenous CEs. This paper explores the experiences of Indigenous (First Nation, Inuit, and Métis) CEs in Southern Ontario, identifies how caregiving manifests, and what role the workplace plays in the lives of these Indigenous CEs. To provide a holistic view of CE's caregiving experiences, the Medicine Wheel is employed in theory and praxis. Specifically, the Medicine Wheel is incorporated as a grounding framework upon which the experiences of Indigenous CEs can be explored and as a methodological tool for deductive coding.

Literature Review

Indigenous Carer-Employees in Canada

Interactions within the workplace play a substantial role in CE experiences with caregiving. Previous scholarship suggests that Carer-Friendly Workplace Policies (CFWPs), such as family leave or flexible working arrangements, can help reduce the pressures of balancing paid work and unpaid caregiving responsibilities (Ireson et al., 2016). Overall, larger organizations with human resource departments are more likely to offer CFWPs than smaller businesses (Vuksan et al., 2012). Notably, Indigenous organizations or businesses operated by Indigenous Peoples or communities are more likely to offer policies designed for caregivers and are more likely to extend support to their employees (Jewell et al., 2022). A lack of CFWPs leads employees to make decisions regarding prioritizing their paid work or their unpaid caregiving. Some CEs suffer work-related consequences as they struggle to balance paid work and family responsibilities (Peters & Wilson, 2017).

The aging population in Canada will continue to drive the need for loved ones to take on the roles of caregivers, leading to an increase in the number of CEs. Moreover, the population of Indigenous Peoples in Canada is growing at a rate four times faster than the general population (Statistics Canada, 2022). However, Indigenous populations have lower access to health services than settler Canadians, increasing the need for family and community support in times of poor health. The combination of interconnected historical, social, and economic factors makes the lived experiences of Indigenous CEs necessary to inform effective social and policy decisions.

Significant scholarship exists demonstrating that CEs suffer from mental health concerns and financial challenges balancing their paid work and unpaid caregiving (e.g., Holzapfel et al., 2016; O'Sullivan, 2015; Steiner, 2017). Indigenous Peoples in Canada also suffer

disproportionately from chronic illnesses and age-related illnesses, which are the result of the ongoing forces of colonialism and erasure (Reading, 2018). Unfortunately, the disproportionate rates of chronic illnesses in Indigenous populations are compounded by the comparative lack of services available in Indigenous communities. This can lead individuals to seek care and support outside of the community, where care may be culturally unresponsive or unsafe (e.g., DeCourtney et al., 2004; Habjan et al., 2012). A better understanding of caregiving perspectives from Indigenous Peoples may contribute to the further development of culturally responsive caregiving programs and policies in workplaces that account for and accommodate the complex needs of Indigenous carer employees. We addressed this gap in the literature by elevating the experiences of Indigenous CEs in this study.

Indigenous Perspectives on Caregiving

This research included voices from several Indigenous Nations from across Ontario.

However, this study is not representative of all Indigenous Peoples' perspectives on caregiving or all Indigenous CEs experiences living in Ontario. Likewise, it is beyond the scope of this paper to explore the entirety of the literature based on Indigenous perspectives of caregiving.

Therefore, the scholarship explored here is done in the context of the Nation in which the research was conducted or from which the knowledge stems. However, discussions of the Medicine Wheel are also explored, and in this context, similarities are drawn between distinct, nation-specific cultural teachings. Specifically, the Medicine Wheel is used to outline examples of mental, physical, emotional, and spiritual caregiving in existing literature. It is also employed as a coding tool to deductively code interview transcripts of the participants' experiences.

There is a substantial need in the academy to better understand how different Indigenous nations perceive and partake in caregiving (Ward et al., 2023). This is due to the incredible diversity of cultures, teachings, and knowledge held by individuals and nations. However, the complexities of providing support for this diversity of cultures and Indigenous nations are exacerbated by the lasting impacts of colonialism (Reading, 2018) as well as modern manifestations of colonial attitudes that worsen the existing social and economic disparities faced by many Indigenous nations (Wispelwey et al., 2023).

While the effects of colonialism continue to impact Indigenous nations, many nations continue to maintain robust, culturally driven models of caregiving. For example, in some Indigenous nations, caregiving is a time of learning for the caregiver. Specifically, in some Mi'kmaq and Anishinaabe communities, caring for a loved one provides the intimacy needed to pass on important teachings (Johnston et al., 2012; Kelley et al., 2018). Hammond et al. (2022) argue that in some Mohawk (Kanien'kehá:ka, Haudenosaunee) communities, caregiving is "a central practice of reclaiming cultural identity from colonial systems of healthcare" (p. 82). More broadly, Indigenous communities place focus on mental, physical, emotional, and spiritual caregiving (Habjan et al., 2012)

These elements of caregiving are captured through the Medicine Wheel, a teaching and cultural tool. One teaching of the Medicine Wheel is of a holistic concept of health, integrating the four interconnected dimensions of human existence: physical, mental, emotional, and spiritual (Mashford-Pringle & Shawanda, 2023). While little research documents this teaching in the context of caregiving, there are examples in the literature exploring how each of these components of caregiving manifests in Indigenous and non-Indigenous populations. Habjan et al. (2012) suggest that, in Indigenous communities, health is "perceived holistically and includes

physical, mental, emotional, spiritual ... aspects of life," and that this can be captured through the "Medicine Wheel [which] is an important representation of this holistic approach to wellness" (p. 210).

Mental caregiving may take the form of assistance with intellectual tasks that may now, for whatever reason, be difficult for the care recipient. For example, individuals with dementia may find it more difficult to remember appointments or to take medication and helping with this type of task may be considered mental caregiving. Physical caregiving may manifest through support with physical needs, such as providing transportation or cooking (Ward et al., 2023). Emotional caregiving may involve helping a care recipient to express their emotions and provide reassurance and comfort (Amin & Ingman, 2014; Brijnath, 2009). Finally, spiritual caregiving may take the form of engaging in specific spiritual practices, such as smudging (Abdi et al., 2019; Mullin et al., 2001).

Methodology

Theoretical Perspective

For this research, we endeavoured to follow the Anishinaabe concept of Mino Bimaadiziwn to keep our theoretical perspectives grounded in the importance of the work conducted and how it may benefit Indigenous CEs. Although it is a complex teaching that is beyond the scope of this paper to explore, a basic English translation of Mino Bimaadiziwin is living in a good way (Bédard, 2009; Debassige, 2010). Mino Bimaadiziwin is a theoretical outlook and practical teaching for living in a good way. It involves thinking and acting in ways that promote flourishing—particularly mutual flourishing—as the teaching suggests that all true flourishing is mutual. In this research, this meant appraising research efforts, including data collection, data analysis, and manuscript writing, to ensure that the project benefits the

participants and other Indigenous CEs. To accomplish this, we continually reflected on the goals of this research project: To elevate the voices of Indigenous CEs and promote their lived experiences and needs. In doing so, we have maintained the integrity of this project and ensured that the participants' voices are authentically represented.

Participants

The participants for this project were recruited based on a purposive snowball sampling technique (Palinkas et al., 2015), leveraging the existing contacts of the first author, who has established a robust research network in Ontario. While no prior relationships existed between the researchers and the participants, Indigenous protocols for engagement with participants specific to each of their communities/Indigenous nations were followed and upheld through collaboration with stakeholders in the community. The first author used these networks to promote the research in Ontario and ensure a culturally safe, reciprocal, and ethical research with Indigenous Peoples. The first author also formed a Research Advisory Committee (RAC) consisting of key stakeholders, including Indigenous scholars. The first author and the RA engaged the RAC members throughout the research process, from research design to dissemination. RAC members distributed the research flyers to their networks and also provided the names of key contacts to the RA. The first author and RA finalized the interview guide in collaboration with the RAC members. Based on the RAC committee's recommendation, the RA offered each participant medicine bundles before the interview. The RA shared the study findings (including artwork) with the RAC members. The first author also collaborated with the RAC members in exploring avenues for knowledge dissemination.

The RA recruited all the participants. The participants were all above the age of 18, were engaged in paid employment and provided unpaid care for loved ones and identified as

Indigenous living in Ontario. There were participants representing Anishinaabe, Haudenosaunee (Oneida), Mi'kmaq, Inuit, Lenape, and other Indigenous nations. A total of ten participants were recruited (six female, three male, and one two spirit).

Ethics

This research followed both university-level and Indigenous ethical procedures to ensure a safe and comfortable environment for participants to share their stories. In terms of university ethics, the research was approved by the McMaster University Research Ethics Board (MREB # 4881, July 24th, 2018) and King's University College Research Ethics Review Committee (June 21st, 2019). The participants provided informed consent through Qualtrics, and this was confirmed before the commencement of interviews. The participants were also informed of their right to withdraw from the study without consequences. Before publication, the participants selected pseudonyms to ensure anonymity. The RA also made available to the participants a comprehensive resource list of community supports, if participants experienced any distress during or after the interview. Finally, participants were offered a \$35 honorarium for their participation in the study.

This project also implemented special protocols to provide cultural safety for the Indigenous participants. Specifically, the participants were sent tobacco and medicine bundles prior to their interviews. The participants were then given the opportunity to begin the interview with a ceremony of their choosing. The tobacco was provided as a gesture of thankfulness in addition to the honorarium.

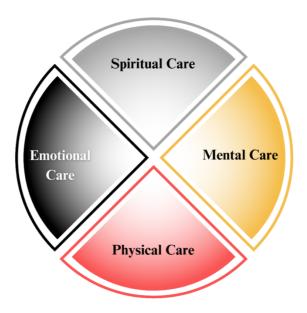
Data Collection

The participants engaged in individual interviews over Zoom, lasting 60-90 minutes. The interviews followed a conversational style that focused on establishing a relationship with the participants. The interviews were also culturally informed (Charmaz, 2006) and followed best practices for data analysis with Indigenous participants, including providing medicines to participants, beginning the interviews with introductions, and ensuring that the interviews followed a story-style conversation.

Indigenous Methods for Data Analysis: Medicine Wheel Coding

The Medicine Wheel is a teaching, research, and cultural tool used by many Indigenous Nations across Turtle Island (North America; Mashford-Pringle & Shawanda, 2023). The Medicine Wheel is represented by a circle divided into four quadrants (Figure 1). Each quadrant corresponds to various teachings and knowledge. For this research, we have implemented one teaching common to Medicine Wheels from many Indigenous Nations. Specifically, the four quadrants represent the different fundamental aspects of caregiving, including mental, physical, emotional, and spiritual caregiving. Other scholars have implemented the Medicine Wheel as a tool for data analysis, specifically for deductive coding of qualitative data (Mashford-Pringle & Shawanda, 2023). This type of coding involves the mapping of quotes to established coding frameworks (Blum et al., 2019; Clarke & Braun, 2013). This technique is particularly useful in research projects where robust theoretical frameworks already exist, such as the Medicine Wheel. Deductive thematic analysis is also beneficial in situations where there is potential to skew data (Mackieson et al., 2018).

Figure 1: Forms of Caregiving



In this project, as the authors are not Indigenous and do not belong to the communities of the participants, it is possible that our own biases and assumptions of what constitutes caregiving could have affected our abilities to develop a comprehensive list of codes. For example, there is no current definition for mental caregiving in the literature. In this paper, we divide other concepts of caregiving (e.g., practical caregiving) into base components mapped onto the medicine wheel. The goal of labelling caregiving as "mental" is not to remove autonomy from care recipients. Instead, it reflects the strengths the caregiver must draw on. Notably, the data for this project was collected by an RA who identified as Indigenous.

It is crucial to note that there is not "one" Medicine Wheel. While the basic concept of the Medicine Wheel is common among many Indigenous nations, there exist significant differences in the teachings between communities and nations. In this study, some participants identified with several different Indigenous nations. Individual Indigenous nations (e.g., First Nations, Inuit communities), as well as larger nations (e.g., Anishinaabe Confederacy), have

different Medicine Wheel teachings (Mashford-Pringle & Shawanda, 2023). These unique teachings also include the specific structural formatting of the Medicine Wheel. For example, some communities and Nations consider the Eastern quadrant to represent the mental aspect of being, whereas others believe this quadrant represents the spiritual aspects of being. However, for this project, we had to present the Medicine Wheel in one of its representations. We selected an Anishinaabe Medicine Wheel for data analysis as the data analysis process took place in Mississauga Anishinaabe territory. Beginning in the Eastern quadrant and progressing clockwise, the aspects of caregiving are mental, physical, emotional, and spiritual.

As this research was also interested in the experiences of CEs, we have included a fifth theme in the thematic analysis: the role of the workplace. Subthemes within this theme, however, were coded based on Braun and Clarke's (2006) guidelines for thematic analysis and, therefore, followed a more inductive approach. That is, the authors familiarized themselves with the data and developed initial codes. Quotations were then grouped into these codes. The final organization of the data into the codes was reviewed and agreed upon by each author and other members of the research team. All coding was conducted using NVivo 14.

Results

The deductive thematic analysis below explores the mental, physical, emotional, and spiritual aspects of caregiving in the lives of the participants of this study. It also explores the role of the workplace, a prominent theme within the transcripts.

Mental

For the participants, mental caregiving often manifested through providing aid with tasks that are intellectually demanding. For example, Kay has been her mother's (97 years old)

primary caregiver since her mother was diagnosed with cancer at 83 years of age. As part of her caregiving, Kay has helped her loved one "pay her bills" and "ended up getting a joint account to make it easier for me to pay her bills to help with her financial management." Kay ensures that her loved one can focus on other topics and rest assured that her finances are taken care of. This example of mental caregiving was similarly expressed by other participants. It appears that helping with the intellectual tasks involved in finances is a common feature of mental caregiving. For example, Northern Light took emergency leave from work to take care of his father's sudden illness. His father was admitted to the hospital and needed dialysis. His father passed away within two weeks of staying in the hospital. Northern Light spent the time before his father's death supporting him in preparing his finances: "We talked about ... assets and finances ... At that time, we had gone to the Band Office, filled out forms and had witnesses to verify those forms for ...his assets, his property, ... and we went to the bank and pushed that forward ... the financial aspect." Another participant discussed how mental caregiving can manifest in practice. Pam tries "to help [her loved one] understand legal documents" and helped "to sort out legal papers or medical notes." Likewise, Kay tries to help her loved one stay on schedule with her medications. Northern Light discussed his frustration regarding the health care system. He felt that his father was not receiving culturally responsive care. As he noted: "He (my father) just felt that he wasn't being heard by the nurses and nobody quite understood the pain he was going through."

John provides his loved ones with intellectual stimulation through sharing teachings and other educational opportunities. As John's mother had alcohol-related issues, he took care of his siblings aged 9 to 17 years, as well as cooking dinner for the family. He provided caregiving while going to school and working three jobs. However, he is "concerned for them for education

on the reserve" and wishes he could do more. A big part of John's caregiving for his loved ones and his community involves passing on teachings and cultural knowledge.

Physical

Each of the participants discussed some form of physical caregiving. These generally revolved around helping with physical tasks that are no longer easy or possible for their loved ones. Kay would "drive her mother to appointments. I would take her to the hospital when she would have to have procedures done." Similarly, one of the ways that Glenda provided care for her dad (in his 80s) and her sister (in her 60s) was by bringing her loved ones food. Moreover, Glenda helped ease her loved one's pain by providing safe doses of pain medications through enjoyable foods: "I made mom some THC brownies and cookies and even melted some on some popcorn."

As the oldest child, Isabella provided care to her aging parents. Her father had to attend a lot of medical appointments after his cancer diagnosis. She also takes care of her disabled aunt, who is also her godmother. After one of her aunt's children died by suicide, Isabella ensured that her aunt had access to healthy food. She discussed the importance of contributing to a loved one's healthy eating, sharing, "I cook supper at home, then I go take her some food."

Other participants aided their loved ones with physical tasks. John helps with home maintenance and making sure that his family has groceries." After Jay's mother lost her sight due to an illness, Jay helped her with laundry and other physical labour: "I help lift stuff for her, lift the heavy stuff for her and take care of all that." Kat helps his aging mother with household chores, "cleaning and doing those kinds of things for her." One participant spoke of a difficult time for her community:

...prior to COVID, we would have healers come in from all over the place. There was someone who would come in from the States, and they would refer to him as a traditional healer. A lot of our clients who would come in to see him were more physical. He would provide medicines and more things for your physical needs (Alexis).

During the COVID-19 pandemic, travel and visitation limitations placed an extra burden on caregivers as they now attempted to provide some of the care traditional healers had provided before.

Emotional

Emotional caregiving took several forms in the participants' lives. Northern Light discussed the role some caregivers play as emotional support and advocates in the health system:

I got to be with him (dad) for the last three days and stayed with him for those three days. And in those three days, he mentioned that nobody quite understands what it is that he's going through. [He] asked me to help him and to be by his side and to advocate for him in the hospital.

Northern Light also discussed how he sees his fundamental role as a caregiver, of "being that soft place to land. And being the number one supporter." John also expressed his feelings about being that "soft place to land" when discussing a particularly hard but meaningful exchange between him and his grandmother:

Yeah, my grandma's scary. Recently, after my younger cousin passed away in December, she has been very vulnerable. She broke down. I hate seeing my grandma cry. It's the worst experience of my life. And it's very, it's very rare that she ever cries, but she's very, she's a very strong woman. She just basically said, "I can't lose another one of you guys," and stuff like that. And it was really sad to see.

Alexis does not physically live with her father (74 years old). But after her father had a stroke, she checked on him regularly from afar through phone calls. Her father also experienced depression, which was emotionally difficult for Alexis. She commented on a sense of role reversal, reflecting: "That's your dad, and he's strong, and he takes care of you and stuff. So, the

roles are just super reversed." Taking care of her dad from afar was emotionally very difficult for Alexis:

Even though I can't really be with him, because we live far away, but [paused for a deep breath] I don't know, he's just - he's alone. And that sucks. And it's like you just want to be there for them. But then, like, they're old, they're already very vulnerable.

Pam provided care for her mother and her other relatives, including her aunt, who is in her 80s. She spoke briefly about how difficult it has been for her to provide emotional caregiving based on her past and intergenerational legacies in her family. Reflecting on her mother, Pam recounts: "I know that she has experienced a lot of her own emotional abusive stuff from her husband ... So, I'm trying to help her work through that too."

Spiritual

We as Anishinaabe people have a really strong connection to spirit ... certain things happen in those final days, and you have to be open to it, you know? You have to feel it, you know? They're there and you're going to get their message, you're going to hear them and you're certainly going to feel that energy, that energy around you, it's a lot of strong ancestors around (Northern Light).

Northern Light explained that in his culture, there is a strong belief that ancestors arrive from the spirit world to help guide loved ones who are near death. He suggested that part of a caregiver's role is to be open to that spiritual experience and to help facilitate a loved one's journey. Similarly, Isabella tried to get her aunt engaged in a 'letting go' ceremony. However, even after 10 years since losing a child, her aunt did not want to do the ceremony,

Kay practices smudging. Likewise, Glenda expressed the importance of cultural, spiritual practices: "Even in my caregiving, I lay down my tobacco ... I smudge; I do all that." While some aspects of spiritual caregiving are innate, some forms of spiritual caregiving require a certain knowledge base. Isabella explained this well:

... that spirit lives with you, as long as you're alive and even if you don't know about your culture ... you have this sense of feeling that you're awakening your spirit ... That's what I'm so thankful for because about three years ago, I started going to ceremonies and that really made me who the person I am today ... So I go to my elders, I go sit with them. I let them know, I want to learn this. They're more than happy to share what they know.

It is important to engage with Elders and other knowledge holders to provide the best possible spiritual care. Jay suggested that everyone should strive for this goal: "Well if you're a caregiver, you should be able to care for everybody, not just all one person you know. You should help out anybody and everybody you can that's in need."

Role of the Workplace

The role of the workplace featured prominently in the conversations with participants.

Discussions about workplace roles focus on three subthemes: Carer-Friendly Workplace

Policies (CFWPs); Participants' Workplace Experiences; and CFWPs in Indigenous versus Non-Indigenous Workplaces.

Carer-Friendly Workplace Policies (CFWPs)

Overall, the participants were largely unaware of any specific policies related to caregiving in their workplaces. Alexis was aware of compassionate care leave at her organization. However, she did not know the specifics about the policy. Likewise, Kay had some understanding of how her workplace protects and supports caregivers:

I think it would be different if I were full-time. There are more policies and procedures if you're a full-time, permanent employee. But there is way less if you are part-time on contract ... but at the same time, I have a lot of support from my direct supervisor.

Kay does feel supported by her supervisor, but she is unaware of any policies meant to support part-time employees who are also caregivers.

Kay most emphatically stated that there are no policies at her workplace that apply to her as a caregiver, yet Alexis was aware of compassionate care leave at her organization. However, most participants were unaware of what supports may or may not exist, suggesting that, if they do exist, the policies are not widely discussed. Donna felt, however, that "I think I would like to see ... a policy or something written up in workplaces. I think that's a really good idea." This sentiment was common among the participants: They were unaware of policies, but felt it would be great if they existed.

Participant's Workplace Experiences

The participants' experiences in the workplace relating to their roles as caregivers were mixed. Some participants reported only positive experiences, whereas others had fewer positive stories. John recalled:

My brother was in the hospital. He had a super high fever once and I was at work ... I just told them I was like, I gotta go ... my brother needs me. So, you know, you need to figure something out. And, yeah, they were not accommodating. I got in a lot of trouble. Like I said, I was working three jobs. I didn't care. [If] you've got to fire me, then fire me.

In his current position, John found more support: "Right now, it's super easy. Like if I need to take some time or whatever, pushing back deadlines is not a big deal." Kay also reported positive experiences in her current position:

I think that communicating with my employer has really helped because they're totally aware of my circumstances and my responsibilities at home and are open to being flexible, like I can be flexible with my schedule. Or if I have to go to appointments or things like that, then it works well.

Kay attributes this partly to talking with her employer about what is happening in her life.

However, her employer was accommodating after hearing about her circumstances, unlike

John's previous employer. Similarly, Northern Light suggested that having a conversation with

his employer helped set the stage for accommodations and support:

I let her know that my father was really ill, he's in the hospital, he's asking for me and I don't really know what's all happening, but everything seems to be shutting down on him, so I need to go, and I need to go tomorrow ... She had no problems with me leaving that afternoon at lunch time when I talked to her. It seemed like it wasn't an issue."

CFWPs in the Indigenous versus Non-Indigenous Workplaces

This theme compares the provision or lack of CFWPs in Indigenous workplaces that are owned or operated by Indigenous Peoples and/or are located on reserves. Alexis believed that working in an Indigenous organization provides Indigenous employees with significant benefits:

I work in an Indigenous-led organization, so we have all that that knowledge and all those same values and morals within the workplace. So, it's pretty cool like, if I'm struggling, I could talk to anybody. We'd all smudge together. If I need support with my dad, like people would help and it's okay too—it's okay to be vulnerable at work, so I think, like not working in a Westernized place is super helpful when you're trying to juggle stuff like this.

Reflecting on his employer, John suggested that "I think they would definitely be accommodating. I feel like it's because they're also Indigenous." Likewise, Donna shared that

I've worked for other organizations that are not as understanding, and they're non-Indigenous. They don't look at family and stuff like that the way we look at family, um, so I've noticed that they need to learn kind of that those parts of people's lives are just as important or if not more important.

Overall, the participants agreed that working in an Indigenous organization provides benefits for Indigenous CEs. One notable exception to this was Northern Light. He felt that his bosses, Indigenous or otherwise, had always been accommodating to his needs as a CE.

Discussion

Medicine Wheel Discussion

The participants in this study discussed several ways in which they provide mental, physical, emotional, and/or spiritual care to their loved ones. These findings are consistent with

scholarship on family caregiving (e.g., Holland, 2022; Kurtgöz & Edis, 2023) and scant literature on carer-employees (e.g., Rottenberg et al., 2023; Sethi, 2022; Sethi et al., 2022; Vuskan et al., 2012). For example, Holland (2022) describes the types of labour involved in "knowing, doing, and negotiating" care at home (p. 1).

The use of the Medicine Wheel for data analysis has provided insight into how practical tasks may draw on different types of caregiving strengths. For example, while taking care of a loved one's finances and cleaning their house are both forms of practical caregiving, they draw on distinct strengths from the caregivers. Many of the physical and emotional aspects of caregiving help loved ones to stay at home, a concept described as 'Aging in Place.' This may also be described as a "practical" or essential form of "health work" (Holland, 2022, p. 1).

The findings of our study contribute to the role of caregivers in maintaining cultural knowledge. For example, as noted in the results, John felt that a large part of his role as a caregiver is to help ensure the protection and survival of vital cultural knowledge. This extended beyond his loved ones to his community. However, it also describes a potentially unique component of his caregiving experiences. Substantial scholarship has focused on emotional caregiving and what it entails. In fact, Hochschild's (1983) and Thomas's (1993) definitions of care include the necessary emotional strength of the caregiver. Other scholars have also highlighted the importance of emotional caregiving (e.g., Hawken et al., 2018; Pakenham et al., 2006). Notably, Pam suggested that it is particularly difficult for her to provide emotional care because of the history of emotional abuse in her family. Indigenous Peoples in Canada are more likely to be victims of abuse than settlers (Government of Canada, Department of Justice, 2019). Indigenous women, in particular, are much more likely to suffer violence than other populations in Canada, with some scholars suggesting that acts of domestic violence are representative of the

perpetuation of abuse cycles beginning with colonial actions such as residential schools (Ogden & Tutty, 2023).

Spiritual caregiving, a topic that has become more prominent in recent literature (e.g., Nissen et al., 2021; Zhang et al., 2024), is important to many Indigenous cultures (Fleming & Ledogar, 2008). This spiritual component was also an important part of the participants' caregiving roles. The participants discussed the innate nature of spirituality and the link between spirituality and caregiving. Likewise, they discussed the importance of specific spiritual customs in times of caregiving. There have long been limitations on Indigenous healing and spiritual practices in caregiving environments such as hospitals, retirement homes, or hospices (Redvers et al., 2019). However, this is improving as smudging is now permitted in certain locations (e.g., Ambtman-Smith et al., 2024).

Overall, the use of the Medicine Wheel for coding greatly increased the depth of the themes. Understanding that caregiving involves mental, physical, emotional, and spiritual elements provided insights into how existing categorizations of caregiving types (e.g., practical) may be insufficient. Likewise, framing spiritual caregiving as a central component of the role of CEs also promoted a more holistic understanding of what it means to be an Indigenous caregiver.

Role of the Workplace

The participants reported mixed experiences in their workplaces in the context of their roles as CEs. Very few were aware of CFWPs, designed to support caregivers (Ireson et al., 2016). The knowledge and use of CFWPs have been found to greatly improve the lives of CEs (Wang et al., 2018). CFWPs also help the employer as they lead to positive workplace outcomes, including worker satisfaction and reduced unexpected absenteeism (Lorenz et al., 2021). There is an increased need for carer-friendly workplace policies because a growing number of people are

providing unpaid care alongside their paid employment. Evidence suggests that a lack of CFWPs can lead to negative outcomes for both employees and employers if not supported (Ireson et al., 2016; Patterson & Williams, 2025).

Most of the participants felt that it was beneficial to work for an Indigenous organization in terms of caregiving. The Canadian Council of Aboriginal Businesses (CCAB) and Indspire (2020) found that Indigenous employees report more positive experiences when employed by Indigenous organizations than non-Indigenous organizations. Further, CCAB and Indspire (2020) noted that Indigenous employees working for Indigenous employers were more likely to report that their work contributes to the overall Indigenous community. In conjunction with the findings from this study, CCAB and Indspire suggest that Indigenous employers, overall, are more attuned to their employees' and their communities' needs. Reflecting on the results of the Medicine Wheel analysis, non-Indigenous workplaces may consider how their CFWPs address the mental, physical, emotional, and spiritual needs of their CEs.

Limitations

This study employed a purposeful sampling technique. However, it could have benefited from interviewing a larger sample. Furthermore, although this research is framed as understanding "Indigenous" CEs experiences, the sample does not represent the entirety of Indigenous nations or identities in Ontario. Therefore, the benefits of this research may be limited to the Indigenous Nations represented in the study. Finally, the Medicine Wheel implemented in this research for deductive coding is not representative of the complexity of Medicine Wheel teachings. The Medicine Wheel is a multifaceted and multidimensional tool that extends far beyond how it was implemented in this paper (Mashford-Pringle & Shawanda,

2023). Although the sample for this study was small, this paper represents—to our knowledge—the first academic use of the Medicine Wheel to code types of caregiving.

Future Directions

This research has highlighted several potential future directions. The use of the Medicine Wheel in this project, while not representative of the true complexity of Medicine Wheel teachings, did highlight important points about how caregiving is understood and perceived amongst Indigenous CEs. Furthermore, discussions around Indigenous CEs experiences of providing family caregiving from afar or 'virtual care' to understand the barriers they experience and support them in their caregiving roles. The rates of abuse are higher in Indigenous populations as compared to non-Indigenous populations. The relationship between the history of abuse and how it impacts caregiving is important to explore in future research. The continuing effects of colonialism should be considered in the context of caregiving research. Future research should also explore the outcomes of caregiving in spaces where traditional spiritual and cultural practices are encouraged.

Finally, more research is needed to understand perceived differences between how Indigenous and non-Indigenous employers accommodate their CEs. Such research would contribute to retaining Indigenous employees in traditional Western employment, as Indigenous organizations often use Indigenous knowledge integration to promote cultural preservation and empower employees.

Conclusion

This paper contributes to scant scholarship on the mental, physical, emotional, and spiritual caregiving that Indigenous CEs provide their loved ones. The paper also discusses the

role the workplace plays in the lives of Indigenous CEs and supports the idea that CEs working for Indigenous organizations are happy as their caregiving needs are accommodated. However, more work in this area is needed. As spiritual care is important for Indigenous CEs, health care practitioners must work with family caregivers to meet these needs.

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References

- Abdi, A., Soufinia, A., Borji, M., & Tarjoman, A. (2019). The effect of religion intervention on life satisfaction and depression in elderly with heart failure. *Journal of Religion and Health*, 58(3), 823–832. https://doi.org/10.1007/s10943-018-0727-7
- Ambtman-Smith, V. N., Crawford, A., D'Hondt, J., Lindstone, W., Linklater, R., Longboat, D., & Richmond, C. (2024). Incorporating First Nations, Inuit and Métis traditional healing spaces within a hospital context: A place-based study of three unique spaces within Canada's oldest and largest mental health hospital. *International Journal of Environmental Research and Public Health*, 21(3), 282. https://doi.org/10.3390/ijerph21030282
- Amin, I., & Ingman, S. (2014). Eldercare in the transnational setting: Insights from Bangladeshi transnational families in the United States. *Journal of Cross-Cultural Gerontology*, 29(3), 315–328. https://doi.org/10.1007/s10823-014-9236-7
- Bédard, R. E. M.-K. (2009). Role Models: An Anishinaabe-kwe Perspective. *Canadian Woman Studies*, *26*(3), 190–192. https://www.proquest.com/docview/217444108?sourcetype=Scholarly%20Journals
- Blum, E. R., Stenfors, T., & Palmgren, P. J. (2019). Benefits of massive open online course (MOOC) participation: Qualitative synthesis (preprint). *Journal of Medical Internet Research*, 22(7), e17318. https://doi.org/10.2196/17318
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. http://dx.doi.org/10.1191/1478088706qp063oa
- Brijnath, B. (2009). Familial bonds and boarding passes: Understanding caregiving in a transnational context. *Identities*, 16(1), 83–101. https://doi.org/10.1080/10702890802605836
- Canadian Council for Aboriginal Business & Indspire. (2020). *Insights into Indigenous post-secondary graduates' experiences in the Canadian workforce*. https://indspire.ca/wp-content/uploads/2020/09/CCAB-Indspire-AODA_English3_FINAL-SEP3.pdf
- Charmaz, K. (2006). Grounded theory. In J. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 81–110). Sage.
- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *Psychologist*, 26(2), 120-123.
- Debassige, B. (2010). Re-conceptualizing anishinaabe mino-bimaadiziwin (the good life) as research methodology: A spirit-centered way in anishinaabe research. *Canadian Journal of Native Education*, 33(1), 11–28. https://www.proquest.com/docview/864885139?pq-origsite=gscholar&fromopenview=true
- DeCourtney, C. A., Jones, K., Merriman, M. P., Heavener, N., & Branch, P. K. (2004). Establishing a Culturally Sensitive Palliative Care Program in Rural Alaska Native American Communities. *Journal of Palliative Medicine*, *6*(3), 501–510. https://doi.org/10.1089/109662103322144871
- Fleming, J., & Ledogar, R. J. (2008). Resilience, an evolving concept: A review of literature relevant to Aboriginal research. *Pimatisiwin*, 6(2), 7–23.
- Government of Canada, Department of Justice. (2019). *Indigenous overrepresentation in the criminal justice system*. JustFacts. https://www.justice.gc.ca/eng/rp-pr/jr/jf-pf/2019/may01.html

- Habjan, S., Prince, H., & Kelley, M. L. (2012). Caregiving for Elders in First Nations communities: Social system perspective on barriers and challenges. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, 31(2), 209–222. https://doi.org/10.1017/s071498081200013x
- Hammond, C., Thomas, R., & Rice, C. (2022). Widening the circle of care: Digital stories of community-based caregiving in a Mohawk First Nation. *International Journal of Indigenous Health*, 17(2), 82-95. https://doi.org/10.32799/ijih.v17i2.36513
- Hawken, T., Turner-Cobb, J., & Barnett, J. (2018). Coping and adjustment in caregivers: A systematic review. *Health Psychology Open*, *5*(2), 205510291881065. https://doi.org/10.1177/2055102918810659
- Hochschild, A. R. (1983). *The Managed Heart: Commercialization of Human Feeling*. University of California Press.
- Holland, M. R. (2022). More than chores: The invisible health work of family caregivers in rural New Brunswick, Canada. *Health & Place*, 73, 102726. https://doi.org/10.1016/j.healthplace.2021.102726
- Holzapfel, D., Adelson, A., & McUlsky, J. (2016). What workplaces can do to support employee caregivers. *Generations*, 39(4), 96–100. https://www.proquest.com/scholarly-journals/what-workplaces-can-do-support-employee/docview/1764312603/se-2
- Ireson, R., Sethi, B., & Williams, A. (2016). Availability of caregiver-friendly workplace policies (CFWPs): An international scoping review. *Health & Social Care in the Community*, 26(1), e1–e14. https://doi.org/10.1111/hsc.12347
- Jewell, E., Doucet, A., Falk, J., & Hilston, K. (2022). "Looking after our own is what we do": Urban Ontario Indigenous perspectives on juggling paid work and unpaid care work for adult family members. *Wellbeing, Space and Society*, *3*, 100102. https://doi.org/10.1016/j.wss.2022.100102
- Johnston, G., Vukic, A., & Parker, S. (2012). Cultural understanding in the provision of supportive and palliative care: Perspectives in relation to an indigenous population. *BMJ Supportive & Palliative Care*, 3(1), 61–68. https://doi.org/10.1136/bmjspcare-2011-000122
- Kelley, M. L., Prince, H., Nadin, S., Brazil, K., Crow, M., Hanson, G., Maki, L., Monture, L., Mushquash, C. J., O'Brien, V., & Smith, J. (2018). Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. *Annals of Palliative Medicine*, 7(S2), S52–S72. https://doi.org/10.21037/apm.2018.03.06
- Kurtgöz, A., & Edis, E. K. (2023). Spiritual care from the perspective of family caregivers and nurses in palliative care: A qualitative study. *BMC Palliative Care*, 22(1), 161. https://doi.org/10.1186/s12904-023-01286-2
- Lorenz, F., Whittaker, L., Tazzeo, J., & Williams, A. (2021). Availability of caregiver-friendly workplace policies: An international scoping review follow-up study. *International Journal of Workplace Health Management*, *14*(4), 459–476. https://doi.org/10.1108/ijwhm-10-2019-0136
- Mackieson, P., Shlonsky, A., & Connolly, M. (2018). Increasing rigor and reducing bias in qualitative research: A document analysis of parliamentary debates using applied thematic analysis. *Qualitative Social Work*, *18*(6), 147332501878699. https://doi.org/10.1177/1473325018786996

- Mashford-Pringle, A., & Shawanda, A. (2023). Using the Medicine Wheel as theory, conceptual framework, analysis, and evaluation tool in health research. *SSM Qualitative Research in Health*, *3*, 100251. https://doi.org/10.1016/j.ssmqr.2023.100251
- Mullin, J., Lee, L., Hertwig, S., & Silverthorne, G. (2001). A native smudging ceremony: A young native patient in palliative care teaches his caregivers a lesson in spirituality and cultural diversity. *The Canadian Nurse*, 97(9), 20-22.
- Nissen, R. D., Viftrup, D. T., & Hvidt, N. C. (2021). The process of spiritual care. *Frontiers in Psychology*, 12, 674453. https://doi.org/10.3389/fpsyg.2021.674453
- Ogden, C., & Tutty, L. M. (2023). My parents, my grandparents went through residential school, and all this abuse has come from it: Examining intimate partner violence against Canadian Indigenous women in the context of colonialism. *Journal of Interpersonal Violence*, 38(23-24), 12185-12209. https://doi.org/10.1177/08862605231192580
- O'Sullivan, A. (2015). Pulled from all sides: The sandwich generation at work. *WORK: A Journal of Prevention, Assessment & Rehabilitation*, 50(3), 491–494. https://doi.org/10.3233/WOR-141959
- Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology*, 51(2), 113–126. https://doi.org/10.1037/0090-5550.51.2.113
- Palinkas, L., Horwitz, S., Green, C., Wisdom, J., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y
- Patterson, A., & Williams, A. (2025). Achieving a caregiver-friendly workplace standard for Canadian carer-workers: An ex ante evaluation of potential uptake. *Evaluation and Program Planning*, 111, 102582. https://doi.org/10.1016/j.evalprogplan.2025.102582
- Peters, I., & Wilson, K. (2017). The business case for employers supporting carers: Reflecting on a UK model. *International Journal of Care and Caring*, *1*(3), 415–420. https://doi.org/10.1332/239788217x15018369385347
- Reading, C. (2018). Structural determinants of Aboriginal Peoples' health. In M. Greenwood, S. de Leeuw, & N. M. Lindsay (Eds.), *Determinants of Indigenous Peoples' Health* (pp. 3–17). Canadian Scholar's Press.
- Redvers, N., Marianayagam, J., & Blondin, B. (2019). Improving access to Indigenous medicine for patients in hospital-based settings: a challenge for health systems in northern Canada. *International Journal of Circumpolar Health*, 78(2), 1589208. https://doi.org/10.1080/22423982.2019.1589208
- Rottenberg, S., Sethi, B., & Williams, A. (2023). Transnational caring in times of COVID-19: The experiences of visible minority immigrant carer-employees. *Wellbeing, Space and Society*, *4*, 100129. https://doi.org/10.1016/j.wss.2023.100129
- Sethi, B. (2022). Negotiating culture, geographical distance, and employment: The lived experiences of European transnational carer employees. *Wellbeing, Space and Society, 3*, 100083. https://doi.org/10.1016/j.wss.2022.100083
- Sethi, B., Williams, A., & Leung, J. L. S. (2022). Caregiving across international borders: A systematic review of literature on transnational CEs. *Journal of Cross-Cultural Gerontology*, *37*(4), 427–461. https://doi.org/10.1007/s10823-022-09468-w

- Statistics Canada. (2022). *Indigenous Peoples and communities*. Government of Canada. https://www.rcaanc-cirnac.gc.ca/eng/1100100013785/1529102490303
- Steiner, A. M., & Fletcher, P. C. (2017). Sandwich generation caregiving: A complex and dynamic role. *Journal of Adult Development*, 24(2), 133–143. https://doi.org/10.1007/s10804-016-9252-7
- Thomas, C. (1993). De-Constructing concepts of care. *Sociology*, *27*(4), 649–669. https://doi.org/10.1177/0038038593027004006
- Vuksan, M., Williams, A., & Crooks, V. (2012). Family friendly policies: Accommodating endof-life caregivers in workplaces. *International Journal of Workplace Health Management*, 5(1), 4–14. https://doi.org/10.1108/17538351211215357
- Wang, L., Williams, A., & Kitchen, P. (2018). Health of caregiver-employees in Canada. *International Journal of Workplace Health Management*, 11(6), 382–394. https://doi.org/10.1108/ijwhm-04-2018-0043
- Ward, A., Buffalo, L., McDonald, C., L'Heureux, T., Charles, L., Pollard, C., Tian, P. G., Anderson, S., & Parmar, J. (2023). Three perspectives on the experience of support for family caregivers in First Nations communities. *Diseases*, *11*(1), 47. https://doi.org/10.3390/diseases11010047
- Wispelwey, B., Tanous, O., Asi, Y. M., Hammoudeh, W., & Mills, D. (2023). Because its power remains naturalized: introducing the settler colonial determinants of health. *Frontiers in Public Health*, 11, 1137428. https://doi.org/10.3389/fpubh.2023.1137428
- Zhang, G., Zhang, Q., & Li, F. (2024). The impact of spiritual care on the psychological health and quality of life of adults with heart failure: A systematic review of randomized trials. *Frontiers in Medicine*, 11, 1334920. https://doi.org/10.3389/fmed.2024.1334920