

First Nations Family Caregivers: Time to Build a Better Support System

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Background

One in four Canadians are family caregivers [FCGs]. We define FCGs (carers, care-partners) as any person, such as a family member, chosen family, friend, or neighbor who takes on a generally unpaid caring role providing emotional, physical, or practical support in response to mental or physical illness, disability, or frailty.

In the Cree language, a caregiver/healer is Onatahwihwew and the business of a caregiver taking care of is Onakahtohkewin.

Delivery of Aboriginal health services and continuing care is complex. Minister Mark Miller's 2020 and the 2018 report of the Standing Committee on Indigenous and Northern Affairs noted that the "complicated and ambiguous framework" of overlapping responsibilities and current policies shared between federal and provincial governments, different ministries and departments, First Nations leadership, organizations, communities, and third-party service providers make it challenging for Aboriginal people to access the services they need.

Although not voluminous, the extant literature reports Canadian Indigenous caregivers have difficulty accessing the services and supports they need to care.

The complex First Nations Health and Continuing Care delivery systems are also challenging for the healthcare providers who work with Aboriginal people and their families.

However, there is a dearth of knowledge about First Nations from the perspectives of both family caregivers and the health and community providers.

Objectives

Report on the experiences of First Nations family caregivers, health and community providers and leaders on support and care for family caregivers in two First Nations Communities.

Methods

We employed a qualitative, collaborative participatory action research methodology. We drew on Etuaptmumk, the Mi'kmaw understanding of being in the world is the gift of multiple perspectives. The Etuaptmumk view is that Indigenous and non-Indigenous views can be seen as complementary with researchers from both viewpoints considered as allies. This approach seeks to re-center Indigenous knowledge and concerns within knowledge construction. Western knowledge is not rejected, rather it is seen as partial, a colonists' record that needs to be balanced and re-situated within Indigenous histories and worldviews.

Data Collection: Individual interviews conducted by a First Nations Nurse from May to August 2022.

Data Analysis: Braun and Clarke Thematic Analysis

Participants

1. Family caregivers (n=6),
2. Health and community providers (n=14)
3. Healthcare and community leaders (n=6)

- All were over 21 years of age & 2 were over 65 years of age.
- Family caregivers all identified as First Nations.
- Providers identified as First Nations, Canadian, Caucasian.

Findings: Themes

Overarching Theme "Hierarchy of challenge"

Aboriginal FCGs, health providers, and healthcare leadership were all coping with siloed and complex community, healthcare, policy, and funding systems.

Six Themes capture the challenges faced by FCGs:

1. "Caregiving is a demanding job": "No one in a sense is taking care of them";
2. Difficult navigation: "I am unable to access that";
3. Delayed assessments and treatment "And I don't know how they're being missed
4. Disconnected health records: "It's kind of on you to follow up";
5. Racism, "It's treated differently"; and,
6. Social determinants of health, "A lot of these factors have been developing for the longest time".

Theme 1: Caregiving is a demanding job, "No one in a sense is taking care of them"

I guess the caregivers in this community face a lot of struggles, one maybe being a lack of resources, even racism. And then another thing is they tend to do everything alone. And I think a lot of times that comes from, I guess, us having to have a person who is disabled, whether there were physical, emotional, psychological disabilities. We raised them without having to resort to anybody's assistance. The caregivers in this community today really need assistance. Some of them can't get it here [Name of Health Centre] for example, if they're raising a disabled child. [Community Provider]

So the biggest factors in my life are the lack of sleep and the finances because of the cost of living is making it hard to get through the month. Because I also have my grandchildren to take care of as well. [Caregiver]

Because they're caregivers, their tendency in my view, is to overlook their own personal health because of the tasks they take on in urgent situations. They take on events or activities or incidents that can be very traumatic and are taken on by the caregiver with no one, in a sense, taking care of them. So there is a need I see to support caregivers every which way possible. [Leader]

Theme 3: Delayed assessments and treatment "And I don't know how they're being missed"

There's a gap where there's people that have these illnesses and they're not being tracked. They're being missed. And I don't know how they're being missed, especially if they come from a huge facility, say the [Name] of cancer facility or whatever hospital. Yeah they are getting missed. [Caregiver]

Peoples, number one, are always expecting to be treated differently or to be treated like they're being a bother for wanting to make sure that their person that they're caring for or themselves or their child or whoever, that when they're accessing that service, they feel like you're going to have to defend something. You feel like you're going to have a whole list of really great things to defend. And it's almost like you're validating why you're there, seeking the support, and seeking the assistance. And you can't just have one reason. It's like we have to have a whole bunch. [Senior Leader]

So we get a lot of requests for things like FASD assessments or children with special needs, where I have concerns about developmental assessments and developmental pediatrics, and there's a lot of delay and trouble getting those assessments in a timely manner. Mostly x-ray and lab and whatever is pretty straightforward. It's mostly diagnostics, like where you're diagnosing somebody with a syndrome where you need the advice of a specialist. It's not something that I can, like do an x-ray and say, "This is the problem." It's somebody who has that specialized knowledge. I can tell that it's not normal, but it's outside the scope of family medicine and then it's like trying to connect them to the appropriate resources. [Health Provider]

Theme 4: Disconnected health records: "It's kind of on you to follow up"

No, our records aren't connected. So even Alberta Health Services, we have different health care management. So, we have Phantom, we have Meditech, we have Netcare. All of those things are actually going into Connect Care and then there will be one system. But for FNIB, we have something called CHIP or C-DOM for a communicable disease management. So FNIB is a bit connected to system, but not really. So CHIP, we can extract information from Netcare. So let's say if one of our clients goes into an Alberta Health Services Clinic to get immunized, the nurse enters it into Meditech. Well now, before it didn't go to Netcare, but now it's going to Netcare because of COVID. We need those records. And now in CHIP, we have that option of extracting Netcare's immunization record and merging it into our CHIPS records. So, we do have a bit of that connection, but we don't have any connection to Phantom, Meditech, or even ConnectCare at this point. [Healthcare Leader]

We do not have access to our own health records, nor is it in our possession at our own health centers. Everybody else has our records. We need those back. [Caregiver]

Right now, we have access to Netcare, but there's not really a formal communication system between Alberta Health Services and the band or the health centers. If you sent the patient out, it's kind of on you to follow up and check Netcare to see what happened to them when they went out. No one will really call you unless it's quite urgent, like, "I'm sending this patient back. We amputated their leg. You probably need to see them tomorrow." They don't really let us know. They're quite busy. Again, they're also short staffed. Limited staffing is probably the big thing, but we don't really have much communication. [Health Provider]

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Conclusions

This study provides evidence that First Nations Family Caregivers needs to care and to maintain their own wellbeing is not top of mind in policy or programs in these First Nations Communities. As we advocate for supports for Canadian Family Caregivers, we need to ensure that Indigenous Family Caregivers are also recognized in policy and programs. There should be a department that explicitly ensures that FCGs are considered.

Selected References

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