

Culturally Responsive Supports for Metis Elders and Metis Family Caregivers*

Elizabeth J. Cooper,¹ Julianne Sanguins,^{2,3} Verena Menec,³ Audrey Frances Chartrand,² Sheila Carter,² and S. Michelle Driedger^{3†}

RÉSUMÉ

Malgré une attention académique considérable au rôle de la famille des soignants avec la population générale, peu de recherches ont été menées avec les familles autochtones. Cette étude qualitative vise à combler cette lacune en se concentrant sur l'expérience des soignants Metis, fournir des soins aux adultes Metis plus âgés. Des groupes de discussions et des entrevues ont été menés avec des aidants familiaux Metis (n = 79), aînés Metis (n = 11), et soignants officiels (n = 8). Bien qu'il existe de parallèles considérables dans les expériences des soins identifiés dans cette étude sur les Metis avec celles déjà documentées dans la littérature, il existe néanmoins des différences importantes pour la prestation des soins culturellement adaptés aux aînés Metis.

ABSTRACT

Despite considerable academic attention to the role of family caregivers within the general population, little research has been conducted with Indigenous families. This qualitative study aims to fill that gap by focusing on the experiences of Metis caregivers providing care for older Metis adults. Focus groups and interviews were conducted with Metis family caregivers (n = 79), Metis Elders (n = 11) and formal caregivers (n = 8). Although there are considerable parallels in the caregiving experiences identified in this Metis study with those already documented in the literature, there are nonetheless important differences for providing culturally responsive care to Metis seniors.

REZUMAY

Malgré tot li zitchud ki lon fayt dan li zikol ipi li universiti powr l'rol di famiyl caregiver dan la populasyon general, il a paw gro d'itchud ki la iti fayt powr li famiyl Michif. L'ichud y va emplyr l'ispaws par konsantri a li ziksperians di Michif caregivers ki sa ayd a li plu vvu Michif. Li growp di djiskusyon ipi li interviews itay kondwi avek li caregivers di famiyl Michif (n = 79), li vvu Michif (n = 11), ipi li caregiver formal (n = 8). Mem ki la enmas di shos pareyl dan l'experyans di caregivers indentchifyi dan li leson di Michif avek suslaw dija ikri dan la literachur, il a kanmem tot li djiferens importan powr prodjwir li swin adapti a la kulture powr li vvu Michif.

¹ Health Sciences, University of the Fraser Valley, Chilliwack, BC

² Manitoba Metis Federation, Winnipeg, BC

³ Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, BC

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Note: Michif, like many Indigenous languages, is an oral language. Among the Metis, even within Manitoba, there are different dialects of spoken Michif. In order to preserve the language, Metis citizens have made efforts to document the language in written form. The Michif represented in this abstract comes from the Michif French as spoken by most Michif people of St. Laurent, Manitoba. Although there may be similarities with other Michif dialects when spoken orally, there are likely considerable differences in spelling and syntax.

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La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Julianne Sanguins, R.N., Ph.D.
Research Program Manager, Manitoba Metis Federation Health & Wellness Department
Assistant Professor, University of Manitoba Department of Health Sciences
150 Henry Avenue
Winnipeg MB R3B 0J7
(jsanguins@mmf.mb.ca; Julianne.Sanguins@umanitoba.ca)

Introduction

Metis citizens are an important, and often overlooked, population within Indigenous research in Canada (Furgal, Garvin, & Jardine, 2010). In 2016, about 600,000 individuals self-identified as Metis in Canada (Statistics Canada, 2017), which represents about a third of the total Indigenous population. The Metis population, like that of First Nations and Inuit as a whole, is younger than the general population and it is also aging. Whereas individuals aged 65 or older constituted 6.6 per cent of the Metis population in 2011, the proportion rose to 8.7 per cent in 2016 (Statistics Canada, 2013, 2017, 2018). As people age, there is a need to ensure that relevant supports are in place to assist both individuals and communities. Consistent with community-based participatory research, this study arose from priorities identified by the Metis community in response to an earlier project undertaken by the Manitoba Metis Federation Health and Wellness Department (MMF-HWD) that examined the aging experiences of Metis (Sanguins et al., 2013). In that MMF-HWD-led study, it was identified that many older Metis in Manitoba relied on family caregivers to meet their daily physical and emotional needs necessitating further research to better understand the experiences and support requirements of Metis family caregivers and the Metis Elders for whom they care.

The MMF-HWD, in partnership with researchers at the University of Manitoba, undertook a study to explore the needs of Metis citizens, many of whom are seniors themselves, caring for friends and family who are aging, and who want to age in place. The primary goal of our study was to identify current supports, as well as needs and expectations of unpaid Metis caregivers, caring for Metis seniors in Manitoba. This article reports on the unique experiences of Metis citizens caring for aging family members and highlights aspects raised by study participants about the need for culturally responsive care. Within this article, we use the term Elders and seniors as appropriate. We acknowledge that *Elders* denotes a respected position within a community, and is not purely a designation based on age. Within a community, some individuals are viewed as the respected Elders, called on for the purposes of ceremony, for sharing their wisdom, and for

providing guidance. However, within individual families, the older members of that family are the respected Elders. Moreover, as a general position of respect within a community, at large Metis gatherings, there are tables and/or rooms designated for Metis Elders, where younger Metis attend to the needs of those Elders present (e.g., serving them food at mealtime, being served first, not having to wait in lines). By contrast, the term seniors denotes the age designation used by many government programs and services to signify persons age 65 and older, although in this study we used the age 60 and older for our seniors because the Metis population pyramid is flatter at the top, and the overall life expectancy of Metis citizens is generally lower (Martens, Bartlett, et al., 2010).

Framing and Positioning

The Red River Settlement, located in Manitoba and the location where much of this research is situated, is widely recognized as the birthplace of the Metis nation. As such, the Manitoba Metis Federation (MMF) is one of the most established governance structures for Metis citizens within Canada. The MMF strives to develop and maintain its capacity to act collectively to promote, protect, and advance the political, social, and economic interests of Metis in Manitoba. The MMF negotiates with provincial and federal governments to access funding to provide a wide range of programs and services for its Citizens (Manitoba Metis Federation, 2018a). Through this mandate, the MMF works towards meeting the needs of Metis citizens in the province and providing a voice within national forums, such as discussions with the Metis Nation of Canada, the provincial government, and the federal government. The governance structure was established in 1967 as a corporation while formally negotiating for recognition as a self-governing body for Manitoba Metis with the government of Canada. The MMF received its first historic nation-to-nation funding transfer in September 2018 when the government of Canada, as part of its efforts towards reconciliation with the Manitoba Metis nation, formally recognized the MMF as the legal self-government for Metis citizens in Manitoba (Manitoba Metis Federation, 2018b).

Within the MMF, the Health and Wellness Department (MMF-HWD) plays a leadership role in its vision of “A Well Metis Community” by developing and using knowledge that is based in Metis culture, is holistic in perspective as advanced through the Metis Life Promotion Framework, and advances health capacity (Manitoba Metis Federation, 2019). Metis identity is grounded in the contextualization of the historical, cultural, and political experiences of individuals and the Metis Nation (Bartlett, 1995; Bartlett, 2007; Bartlett, Sanguins, Carter, Hoepfner, & Mehta, 2010). The MMF use of the Metis Life Promotion Framework (MLPF) promotes Metis ways of knowing. Structured around eight key wellness areas – nature, identity, development, relationships, supports, networks, environment, and governance – the framework provides important epistemological insight into the nuanced realities that encompass Metis identity and Metis determinants of wellness. This framework highlights the need to consider the different roles and functions that people play at different moments, how people support one another, how governance is enacted, and how health and well-being can be achieved.

Since its establishment in 2005, the MMF-HWD has strived to exemplify excellence in health research and serve as the Metis Health Knowledge Authority in Manitoba. One of the primary goals of the MMF-HWD is to enhance MMF capacity to lead extraordinary and concurrent interventions to assure improvements in Metis health status and health care program and service use that are in line with the provincial health system. The MMF is also the leader among Metis governing members in producing and using health and social information to produce evidence that can support the development of interventions for Metis populations across Canada, and has provided leadership in quantitative and qualitative research over the past 10 years (Bartlett, 2007; Bartlett et al., 2010; Sanguins et al., 2013). The research projects undertaken by the MMF provide a model to assist other governing members in producing work that is relevant within their context and that can improve the health of their citizens.

Metis Identity

The history of Metis peoples is long, complex, and under-recognized within Canadian research, programming, and policies. Metis citizens are constitutionally defined as Aboriginal people within Canada (Daniels, 1979) and are recognized as a unique nation with their own language, traditions, and culture that emerged initially through the blend of Indigenous and European settler traditions of their ancestors, who have roots in the Metis Nation (part of Ontario, Manitoba, Saskatchewan, Alberta, part of British Columbia, and part of the Northwest Territories) (Government of

Canada, 1982). Like other Indigenous populations, Metis have experienced and continue to experience the legacy of colonial policies that disrupt their ways of knowing and being. Many Metis people have hidden their identity, often in partial response to mitigate potential discrimination associated with being visibly Indigenous (Adams, 1989; Campbell, 1973; LaRocque, 2010).

During the 19th and 20th century, Metis were forced off traditional Metis territories and created homes on land, often adjacent to reserves and settlements, that had been surveyed and reserved for highway development. These homes were often precarious dwellings and residents did not have fixed addresses (Bell, 1999; Dkastelein, 2017). Living on this Crown land designated as road allowance is what led to the Metis being referred to as *road allowance people*, reflecting their highly precarious existence as being neither accepted in white settlements nor allowed to live on reserves (Dollinger & Fee, 2017). Historically, many Metis children did not attend school. This was largely related to the lack of formal residential addresses necessary for school registration. Those children who did have access to schools attended residential or day schools; the experiences at these schools were often negative and did not foster an environment for learning (Legacy of Hope Foundation, 2014; Truth and Reconciliation Commission of Canada, 2015a). With the expansion of highways, farmlands, and ensuing destruction of homes, many people were left without adequate housing which, in some cases, remains a problem even today. The MMF has had programs at different points in time to create housing for Metis citizens or to assist Metis citizens to maintain housing needs such as the provision of firewood to help heat homes, but due to changes in funding by federal and provincial governments, sustaining these programs has proven difficult. From the past to the present, Metis people have sustained themselves and their families through hunting, trapping, and the sale of crafts.

Although it is known that Metis citizens within Manitoba have increased rates of chronic diseases and lower life expectancy than other Manitobans (Martens, Bartlett et al., 2010), there continues to be a gap in the literature about Metis health and well-being. This is especially true of older adults. Being able to address inequities that the Metis peoples face in access to supports and services is an important step towards improving the health and well-being of all citizens. Whereas the federal government provides and operates health services for First Nations and Inuit, federal supports are not formally allotted to Metis citizens in Manitoba, despite their Canadian constitutional identification as Indigenous people (Boyer, 2003; Government of Canada, 1982). With minor exceptions

(Cook, 2003), Metis health services are provided by the province of Manitoba in the same manner as general population Manitobans (Haworth-Brockman, Bent, & Havelock, 2009). Individual Metis nations are independent self-governing political entities that act as a political voice for citizens of the Metis nation within their provincial or territorial jurisdiction. Historically, they have not received funds to develop or deliver specific health services.

In recent history, Canada has seen a general push towards the provision of more culturally relevant services and supports for Indigenous peoples in Canada, spurred on largely by community momentum. This includes conscious efforts to create safe spaces. Safe space, as used by us here, recognizes that spaces and experiences are mediated by cultural perspectives. As a result, people working to create and maintain safe spaces need to respond to these experiences in respectful ways (Bin-Sallik, 2003; Gay, 2000; Sundar, Todd, Danseco, Kelly, & Cuning, 2012; The Education Alliance Brown University, 2008). Founded on the principles of New Zealand's Treaty of Waitangi, cultural safety aims to destabilize power relations in a health system, such that what is "safe" is defined by the care recipient (Richardson & Williams, 2007).

Community momentum for raised visibility in change has been happening through advocacy movements such as Idle No More (www.idlenomore.ca); the Truth and Reconciliation Report, spanning over a thousand pages (Truth and Reconciliation Commission of Canada, 2015a), and the calls to action that resulted from the Truth and Reconciliation Commission (Truth and Reconciliation Commission of Canada, 2015b). This grassroots drive has helped mobilize other stakeholders to begin examining the role that they can play to improve relationships between all Indigenous nations within Canada. Although some of these movements have been largely First Nations focused and/or where Metis have not been formally acknowledged, many individual Metis activists have been involved, as these initiatives represent a larger raised consciousness aimed at drawing attention to the inequalities and systemic harms that have been experienced by Canada's Indigenous peoples. The first step towards reconciliation is when a space for dialogue is created (Emberley, 2015; Episkenew, 2009). Metis experiences and needs continue to be underrepresented, hidden and ignored in research, programming, and policy. In part, this may be a reflection of the unbounded nature of many Metis communities (Cooper & Driedger, 2018), but it also speaks loudly to the historical challenges Metis have faced as they have fought to maintain their autonomy within the political discourse of Canada (Andersen, 2014; Larocque, 2010).

Family Caregivers

Although the majority of care is provided to family members (parents or parents-in-law, grandparents, siblings, or extended family), care recipients also include close friends and neighbors (Sinha, 2013; Turcotte, 2013). Caregivers provide a variety of supports to family and friends, including transportation to go shopping, to participate in social events, or to attend medical appointments. Caregivers also help with activities of daily living, such as preparing meals, cleaning, and laundry. Furthermore, family caregivers provide emotional support, such as checking on a family member or friend to make sure they are doing well (Sinha, 2013). The time spent in caregiving can be substantial. On average, family caregivers have been found to spend four hours per week caring for their parents (Turcotte, 2013). As care recipients age and their care needs increase, family caregiving also increases, often supplemented with formal care services (Cranswick & Thomas, 2005). However, family caregivers continue to play an important role in supporting family or friends, even when individuals are admitted to a care facility. Upwards of 40 per cent of seniors living in a care facility continue to receive support from family members and friends, such as assistance with care coordination (Cranswick & Dosman, 2008).

Changing demographics within rural and remote communities as younger family members relocate to urban environments for employment results in fewer people available to provide care than in previous generations (Bartlett et al., 2012; Buchignani & Armstrong-Esther, 1999). Although there have been calls to improve services in remote and rural locations, this gap continues to widen, leaving many seniors without access to basic medical needs and formal support systems (Allec, 2005; Health Council of Canada, 2013), and creating an even stronger reliance on family supports to meet current needs. Many of the factors associated with formal caregiving apply to both Indigenous and other Canadians; nonetheless, understanding the unique financial, cultural, social, and active living needs of Metis Elders is important, especially as we work as a nation towards reconciliation and fulfilling the commitments identified in the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2007).

Although caregiving is often rewarding, family caregivers experience substantial caregiving burdens. Negative consequences of caregiving include psychological distress, fatigue, anxiety, and sleep problems (Ringer, Hazzan, Agarwal, Mutsaers, & Papaioannou, 2017; Turcotte, 2013). There is also a considerable economic burden, as caregiving can lead to exiting the labor force prematurely, restricting work hours and work absences

(Keating, Fast, Lero, Lucas, & Eales, 2014), as well as substantial out-of-pocket costs borne by the caregiver (Keating et al., 2014).

Broadly speaking, the support provided to caregivers has been shown to be insufficient. In a study conducted in British Columbia, caregivers felt that they were left to fend for themselves, with inadequate help from the formal care system for services such as information and referral, and respite services. They also felt that there are insufficient supports to help caregivers maintain their own health, which left them feeling that unrealistic expectations were placed on them in terms of how they managed competing priorities, including the capacity to engage in effective self-care (Lilly, Robinson, Holtzman, & Bottorff, 2012).

Although family caregiving has been a key area of research in the field of aging for decades, to date, there is a dearth of academic literature about caregiving in Metis communities, including how to provide care and support to Metis people – both for those providing and those receiving family care. For Metis Elders, aging well in place often requires additional supports beyond those needed by the general population. Indigenous senior populations are more likely to live even further below the poverty line than low-income seniors in the general population, have less access to formal health care services, and are more likely to have chronic diseases and other conditions (Rosenberg et al., 2009). Many older Metis citizens also live in rural or remote communities, which means they face the additional challenges associated with living in these areas, including lack of services and inadequate infrastructure such as indoor plumbing or electricity. For other people, the high cost of electricity or gas/oil heat, combined with poor insulation, means that people rely on wood as a heat source (Bartlett et al., 2012).

Methods

Interviews and focus groups to explore experiences caring for Metis Elders/seniors, with a focus on family caregivers, were conducted and analyzed by researchers from the MMF-HWD and the University of Manitoba. The study received ethics approval from the University of Manitoba's Health Research Ethics Board (H2014:178).

Participants, Sampling, and Recruitment

Participants were recruited to participate in focus groups (family caregivers and Metis Elders) and individual interviews (formal caregivers and Metis Elders). Recruitment criteria for family caregivers included older than 19 years of age, self-identification as Metis,

and the provision (current or past) of unpaid care to one or more Metis Elders/seniors. Formal caregivers (paid caregivers) had to have worked for one of the Regional Health Authorities and provided services for Metis seniors to be eligible. Metis Elders self-identified as receiving care from a Metis citizen. It was not required that their family caregiver also participate in the study. The MMF divides the province into 7 regions which are further divided into 134 locals. Each level of organization provides different supports to its citizens. Participants were recruited from across all regions. Additional recruitment was conducted at the MMF Annual General Assembly, attended by more than 3,000 Metis citizens from across the province, and through ads aired on a local radio station during a Metis-specific radio show on two occasions.

Data Collection

Interviews with Metis Elders and formal caregivers, and focus groups with Metis Elders/seniors and Metis family caregivers, were conducted between 2014 and 2015. Focus groups were divided evenly between urban and rural locations, with seven focus groups in each category, for a total of 14 focus groups. Interviews were conducted over the phone or in person, as per the preference of study participants. As a method, focus groups are particularly useful in situations where there is an interest in learning how participants discuss and describe their experiences in a social setting (Krueger, 1988), and they can be effective in community-based research contexts (Daley et al., 2010). As family caregiving is often disproportionately borne by a single individual, providing a group context for family caregivers to hear the stories of others was believed by the MMF to offer important benefits and group support to Metis participants.

Authors Cooper, Driedger, and Sanguins were involved in data collection, with the assistance of a staff person from the MMF. The focus group and interview guides were semi-structured (interview and focus group guides available upon request) and based upon the domains of the Metis Life Promotion Framework. Questions addressed favourite memories people had about their experiences growing up; from where people developed caregiving skills; what kinds of tasks are completed by formal and family caregivers; rewarding and challenging experiences with family caregiving; services available to seniors within their communities; and self-care practices.

Data Analysis

All interviews were digitally audio-recorded, transcribed verbatim, audio-verified against the recordings, and edited to correct any errors. As a decolonizing

approach for Metis-specific data, the research team analyzed the data using the collective consensual data analytic procedure (CCDAP). CCDAP is well suited to qualitative analysis in Metis health research (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007) as it affords input into the analysis process by Metis and Metis allies to assist in the expression of the social, historical, and political contexts that shape a Metis experience. This is an important step as it is necessary to keep the experiences of Metis participants connected to broader historical contexts (colonialism, racism, marginalization).

The CCDAP process involves compiling all of the interview transcripts, where quotes are printed on index cards. A first index card is selected, read, and placed under a generic symbol (e.g., ○, ◇, *, @) on the wall. After the first card is selected and placed under a symbol, the next randomly selected card is compared to see if it is (dis)similar to the first. The process continues until all team members are satisfied with the card placements and the clusters are given broader theme labels according to the information they convey. The entire team deliberately tries to disprove emerging conclusions, to explore discrepant data, and to propose alternative explanations. This classification technique helps to minimize bias in interpretation because the research team members, throughout the collective process, actively discuss and revise the ideal location and grouping of random index cards of key phrases. The process provides a space and a place for each member to contribute to the discussion of emerging ideas and to add contextualizing information. Moreover, because this project was led by the MMF-HWD, senior leadership participated in these CCDAP processes. The benefit this brings is that all study results were considered by MMF team members in terms of what available services or supports provided by the MMF could be extended in different areas based on identified caregiver needs.

For reasons of confidentiality, participant quotations illustrating findings do not identify participants' geographic location or gender. Our sample is drawn from a relatively small population, and participants were promised anonymity. When selecting quotations, we have attempted to incorporate those that are representative of multiple participants while, at the same time, including unique insights given the heterogeneity of experiences.

Results

Sample Characteristics

In this study, 79 family caregivers participated in focus groups, eight formal caregivers were interviewed, and 12 seniors participated in either focus groups or interviews.

Most family focus group participants were between 60 and 69 years of age, with 16 per cent over the age of 70. While there were no gender recruitment criteria, 86 per cent of family caregiver study participants were women. Of those providing care for family and friends, 35 per cent reported that they were the only caregivers. Although equal numbers of urban and rural focus groups were conducted, there were fewer participants in the urban focus groups (40% of participants), with only one male participant recruited from within an urban community. Of the seniors who participated in the study, three people (one man and two women) participated in a focus group, and eight people (one man and seven women) participated in individual interviews.

Themes

Our presentation of results relates to Metis identity, values, and culture as central components of culturally responsive care as described by participants. Participants highlighted a Metis culture of caring, and recognized the need to have tools in place to help people age, and care for aging family members in a culturally responsive manner. These connect closely to the wellness areas present in the Metis Life Promotion Framework – nature, identity, development, relationship, network, supports, environment, and governance.

Metis Identity and Values: Culture, Language, and Caring

Focus group and interview participants often situated their experiences with caregiving within a Metis cultural context. Metis identity featured prominently within the data, although it was not always discussed explicitly. Some of the discussion was clear about tangible cultural traditions and symbols, such as having Metis fiddlers coming to perform for seniors' programs or having a Metis flag hanging in bedrooms of residents in care facilities and the pride that this instilled in their identity, combined with the challenges of such overt self-identification as Metis. Others discussed intangible cultural experiences, such as how they learned about their Metis identity, identification of Metis spaces, and the challenges that come with learning about historical impacts of colonialism, such as the loss of language. Although there was a hopefulness associated with many of these comments, a sense of melancholy was ever present with comments made such as "I have a little Metis flag in my room, but nobody has ever come and said 'oh, you know, you're Metis, so am I.'" (Metis Elder).

When it came to discussing from where informal caregiving was learned, Metis identity did feature

prominently, particularly within inter-generational family contexts. Historically, many Metis families were large and community connections were strong. Care-giving was learned by doing. It was modelled within the family, and even young children were involved in caregiving practices.

I can remember, I think from as little as from the age of four where I was being asked to do things for other people. And so I think it's just a part of who we are. (Metis family caregiver)

So that's what I think Metis people learn informally from their parents and because you saw such large families, you would also be learning it from your older brothers and sisters. I think caring for your brothers and sisters as children is teaching you to be an informal caregiver for a parent later on in life – the helping thing where everybody helped. (Metis Elder)

And I up and left and I went home and I stayed home. I was over there for a month and I moved and everything, just to take care of my mom. Because she brought us here, she did everything for us, so now it's our turn to take care of her. (Metis family caregiver)

Focus group participants discussed how the expectation within the family household was that people would share with one another and care for one another. This, participants explained, created a culture of caregiving within Metis families.

And I always said to my sisters because I'm the youngest ... We never had running water, and we used to have a big tub and we'd all bathe in it. And I said, "I have to bathe last, why?" They had the nerve to tell me that I was the dirtiest. [Laughter] But I mean, that's how we shared and that's how we learned. Sunday night was bath night and Wednesday night was bath night. Like, that's what we did. And that's how I looked after my mom was, you know, one night you have a shower and the next night you have a sponge wash and the next night you have a shower and we were just taught that way. (Metis Elder)

Because we've grown up in families where there's been a grandmother, a grandfather, and your mom and dad and you. And you just, well, okay, when grandpa or granny got sick or whatever, the kid looked after gram, granny, and grandpa. Like my dad. He never married until he was 35. So he was – he was there for my grandparents. And so we just grew up knowing that, okay when granny or grandpa got sick you knew okay, you'd go to the store for granny, you'd pick up the things and then ... you just grew up like that from maybe seven or eight ... all because you saw dad do that first for granny and grandpa. (Metis family caregiver)

While Metis family caregivers indicated that it was an expectation that they accepted that they would provide care, many discussed the challenges of meeting this expectation now that the family structure had changed so much from when their parents or their grandparents were the caregivers. In particular, this played out in being part of a sandwich generation and the challenge this creates for individuals working in paid capacities.

In today's culture particularly, with Metis people, is to have both the parents working to make ends meet. So if you have both adults in the family working, and you have children, or even if you don't have children – you don't have any time left to be the caregiver, because by the time you get home, get your supper, do your chores ... whereas before, when the wife was a stay-at-home mom, she would have the time to get the work and chores done, so the time in the evening would be there to go and help the elderly auntie, or the mom and the dad. (Metis family caregiver)

The importance of language was often discussed. Language serves many purposes. It shapes an understanding of the world. It connects people, and for many of our participants, it was highlighted as a tool that may also be used to maintain autonomy. The process of colonialism has included the destruction of supports to maintain Indigenous languages. Consequently, Metis participants who focused on the importance of language highlight the need for culturally relevant supports and services. The loss of language, unlike some of the other markers of colonialism, is relatively easy to contextualize. Requiring supports and services provided within Indigenous languages is a marker of the broader recognition of culturally relevant approaches to caregiving.

If you'd said "my mom wants someone that speaks Metis French or French" you know, and if there's nobody that talks French [in the facility], then they can't send their senior to live there. (Metis family caregiver)

The only thing that would – it would be great if you spoke Cree or Saulteaux or something, at least you would have somebody know that – because it's lost. [...] They [the Elders/seniors] just love that when they have someone that spoke Saulteaux to them. (Metis family caregiver)

Language is also a way to exert autonomy and control in situations where a Metis Elder may feel less empowered in a system where they may feel culturally isolated.

I think it's because of – they need someone to speak like their language. I think [it] is when they would defend themselves or speak up or whatever. (Metis family caregiver)

He used to fight with everybody. I don't know why they liked him. He used to fight the old people. He used to swear at them in Indian. He didn't know the nurse understood what he was saying and she said "You can't say that" and he said "How do you know? You don't know what I said" and she said "You know I can understand you." "No you can't." She said, "Yes I can. You said a bad word." (Metis family caregiver)

Learning about cultural identity remained an important aspect for Elders and their caregivers, particularly in their efforts to reclaim some of what was lost as a consequence of colonialism.

But the thing too is I like to sit and try to learn words from her, like, Metis words and stuff like that. And she'll talk to me and I don't understand half of it, and then she'll explain it to me and ... So, that's the good part ... and then sometimes if we're out somewhere and I'm dropping her off and I'll see her walking into her building and I'll say, "Please, God, just keep her a little bit longer so I can learn some more from her." (Metis family caregiver)

Caregiving Experiences

One of the challenges discussed by many family caregivers was the emotional challenge created by the change in roles as their loved ones needed more care. Family caregivers often struggled as they saw changes in the abilities of the people they love. Focus groups were often emotionally charged when participants discussed this. In some instances, the discussion during the focus groups made them realize that they were not alone in the challenge of navigating changing family dynamics.

The biggest thing is, you know, your mother, it's like we've switched. [...] It's just a big realization that – that now I'm the adult. (Metis family caregiver)

And yeah, with my parents it's limited. The support I give them. It's just my brother and I. We take turns. They're pretty independent still so it's not – not bad yet. But my dad's 73 and he's a stubborn Metis man. And that's him. (Metis family caregiver)

There was a point where my mom was my mom. And as years went by and she got older, it's really hard to turn around and be the person who cares for your parent. (Metis family caregiver)

Metis family caregivers did recognize that there may be a point when their Elders will require further assistance. Family caregivers noted increased challenges that take place in trying to navigate complex family relationships involved with caregiving with the changing abilities of Elders.

It's hard to always stay upbeat when you go to see them, because you have to not see their problems ... and I guess, that's a struggle for us as caregivers is to keep that happy face all the time. (Metis family caregiver)

Family caregivers discussed caregiver burden as an ongoing challenge, especially in terms of being able to manage their time to meet all of their commitments.

And you see, my biggest fight of last winter was at 8:25 p.m. Me and my baby went home from Papa's, went up the stairs right into the house, my baby turned around, two hands she took hold of me and she was literally standing on firecrackers – excited – I said "What is it, baby?" "Daddy," she said, "now we can have family time." You wouldn't believe how hard that hit my heart; I wasn't making enough time for my baby. And that hurt. It really really hurt ... but I'm looking after freezing [pipes] at Papa's house, my dad's house. (Metis family caregiver)

I remember a couple times because I'm all stressed out and I'd say or do something with mom and then I'd go back and apologize and she'd say "Don't worry, you got enough on your plate, you know, I forgive you." (Metis family caregiver)

Elders themselves recognize the challenges associated with caregiving and tried to alleviate the burnout their family support networks might potentially experience if they ask for too much help.

Oh yes, that happens too because you think "Oh, maybe they're at work or doing something or busy themselves" and I hold back from calling, which I shouldn't. I should let them know. (Metis Elder)

I don't want to be a burden and I don't want to constantly be saying "Can you do this for me. Can you do that for me?" I like to be independent as much as I can. (Metis Elder)

Community Factors

One of the most important needs that was highlighted by Metis family caregivers in all of the focus groups was improved housing, including having the necessary supports to help Metis Elders remain in their home. If housing and housing supports were improved, participants believed that quality of life for both Elders and caregivers would improve. Challenges with housing included the ability to heat the home in winter months or have a fuel source to cook food, especially for those who rely on wood-burning stoves as both a heat and cooking source. For a few rural Elders, other housing challenges included having no indoor potable water and indoor plumbing. This compromised any ability of Metis seniors to receive formal home care supports

in locations where such services were available, and where individuals could qualify for formal home care support programs but only if a home was equipped with basic plumbing and running water. This challenge and limitation adds further burdens on already stretched family caregivers to fulfill tasks that could otherwise have qualified under formal home care support programs. Equally challenging were houses without year-round road access especially in northern and remote communities that are only accessible by air in the months when there are no ice roads, and the potential challenges this created in instances of medical emergencies. In order to be able to care for Elders/seniors, especially those who want to age in place within Metis communities, supports must be in place to be able to maintain a home or to sustain oneself while living within a home.

My mother's grandmother – or my mother's mother was – she suffered from Parkinson's. Her family took care of her. They would take turns. They would come to the house and stay with her and then one of the sisters – one of my mom's sisters and her husband moved in and she stayed with them. But it was always – it must have been a real chore. Even though everybody had their own bedroom, there was no running water, not even any electricity, coal – three coal oil lamps: one in the bedroom, one in the dining room, and one in the kitchen, you know. And imagine having to do that, especially in the wintertime. (Metis family caregiver)

Well I carry in wood but that's getting to be a problem too. I just, I have a whole pile of wood at the door and I just pick up a stick and carry it in. One stick at a time I carry it into the house. (Metis Elder/senior)

Seeing my dad, he's sitting on his bench crying, because he said that ... "Mamma deserves a better home." That really, really hurts. Age can be really aggressive though. You can do everything, take the worry off, to going helping, but there's things that we can't that really hurts. Like my dad said: "I can't haul a pail of water. I can't empty the slop pail, I can't even carry in a block of wood. You know, son," he said, "If you weren't here, I don't know where me and Mom would be." (Metis family caregiver)

Family caregivers discussed their stress and worry about what would happen if they were not available to provide care. It was suggested that their Metis Elders would not receive any supports. There is a fear that this may leave loved ones in destitute conditions.

I'm sure a lot of people could make a stew or homemade soup or if you got extra at home or a little bannock, and haul them down the road to them like we do. (Metis family caregiver)

If I wasn't there for my dad, he'd probably be sleeping in a homeless shelter. He wouldn't have enough food, he wouldn't have enough money to survive. He doesn't have enough money to pay for an apartment, utilities, a vehicle to get to and from the doctor. He'd probably be standing in line for food every day. Guaranteed. He would probably not have his medication, because I buy it. And I take care of it, and I make sure that he takes it. He wouldn't have enough money to ensure that his basic needs are met, and so he wouldn't be in any positive situation for himself at the end of the day if it wasn't for what I try to make sure he has for himself. (Metis family caregiver)

Community Supports

While family caregivers have many of the tools necessary to care for Elders/seniors within and outside of formal care facilities, they recognize that there are certain physical and financial tools that would improve the quality of care that they can provide. In addition to improved housing supports, access to care in a language of preference (e.g., Cree, Michif, French), increased numbers of formal Metis caregivers, and better access to these supports were some of the key suggestions participants offered for improving caregiving practices.

Participants talked about informal pathways used to ensure that seniors have all of the supplies that they need, including knowing where to access donated supplies, such as bath chairs.

And certain things are covered and supplied, like incontinence supplies, but a lot of stuff is not. "Oh, you should buy this \$1,200 wheelchair because they really need it." Yeah, and who has that money in their back pocket just to, you know ... We looked online for a lot of second-hand things that we could buy, but, yeah, it's difficult. (Metis family caregiver)

They noted that navigating processes such as claiming family caregiving costs on income tax, getting financial assistance to purchase items necessary to provide appropriate care, such as bathroom assistive devices, was an onerous process, and they would like to have help navigating these processes.

I think there should be more teaching, how to provide more care and what you can look into to help you out, to help your parents out. I think there should be more programs to do stuff like that because most people don't know what to do. (Metis family caregiver)

It was frustrating when you don't know where to turn to. I was lucky, the manager of the homecare system in our area was my cousin. So I knew who to turn to and where to turn to. But in the city, it's a

whole different ball game and there is one person – they should have an ombudsman office that you could call that could get you the assistance that you need. (Metis family caregiver)

When participants discussed navigating formal supports, such as health care teams, they discussed challenges faced with ensuring that Elders' needs were being met. Family caregivers want to be part of the decision-making process. Participants told us their ability to be effectively involved in the care of their senior in some cases was hampered by privacy legislation.

Or just won't share it [information]. Like they just won't share. Like the doctors just won't share. (Metis family caregiver)

There again, it's that confidentiality thing that we talked about earlier. They [paid caregivers, such as Homecare staff] are not allowed to call you. (Metis family caregiver)

Family members want to ensure that their loved ones are receiving the most appropriate and highest standard of care possible. Family caregivers also recognize that they shoulder much of the caregiving responsibilities. We heard that if the family caregiver is unclear about when medications need to be taken, or when follow-up appointments need to be scheduled, they are unable to ensure that appropriate care is in place.

You'd like to work as a team. It's a gap. (Metis family caregiver)

If care needs to be provided by people other than family members, many Elders/seniors wanted this care to be provided by Metis citizens.

Having help from the Metis, first of all, with homecare, the majority, it seems about 50 or 60% of the Homecare girls are Metis, and they provide an excellent care and they were caring individuals and personable. You can have a little visit with them and I really appreciated that. (Metis Elder/senior)

We just, sort of, had a little something extra in common than maybe they had with the other individuals ... maybe we understood one another better or thought we did [because we are both Metis]. (Metis Elder/senior)

Discussion

One of the key challenges in ensuring that Metis Elders receive culturally responsive care and that caregivers have the tools and resources available to ensure culturally responsive care can be provided falls on the legacy of existing programs and policies that privilege dominant Canadian society. The Metis Nation exists because of the political action of people (Chartrand, 2017). The Truth and Reconciliation Commission, especially the

Calls to Action, have instigated a much-needed conversation about the ongoing effects of colonial policies (Truth and Reconciliation Commission of Canada, 2015a; Truth and Reconciliation Commission of Canada, 2015b). The Daniels Decision in 2016 has further opened discussions about Metis identity, autonomy, and federal funding responsibilities (Truesdale, 2016). There is a shift occurring within Canada as people are beginning to openly consider the influence colonial practices and policies have had on Indigenous populations. As our participants discussed, many people have hidden their identity and may continue to hide their cultural identity as Metis citizens. It is through actions, such as a flag or Metis sash displayed in the room, speaking Indigenous languages – even if a language is spoken as an act of subversion between residents in a care facility – or bringing children to help care for seniors, that many Metis exercise and maintain their cultural autonomy and traditions.

Maintaining cultural autonomy is a central component of addressing the impacts of colonization, which in turn improves the well-being of individuals and communities (Adelson, 2000; Allan & Smylie, 2015; Linklater, 2014). There is a legitimate fear that cultural identity negatively influences the quality of care that people receive through a history of inequitable access and service delivery (Allan & Smylie, 2015; Lux, 2016). This adds to the challenges Metis Elders/seniors and their caregivers face when trying to advocate for the best quality of life possible. The MMF has the capacity to provide some assistance to Metis Elders/seniors and advocates to the best of their abilities for their citizens; however, without access to the same services and supplies as other Indigenous people through federal programs, such as the non-insured health benefits program, Metis seniors, especially those who live in rural and remote communities, remain at a disadvantage compared to other Canadian seniors (Standing Senate Committee on Aboriginal Peoples, 2013).

Family caregiving within Canada is essential. Supports, either financial or trained personnel, are not in place to help seniors meet all of their needs without the assistance of family caregivers. Family caregivers have learned many of the necessary skills required to care for seniors, but they recognize that there are problems with navigating the health care system. With complex health needs of many seniors, Metis family caregivers may be at a disadvantage when they are not included in decision-making processes such as what medications will be given, where a senior will live, and how to recoup expenditures for income tax purposes.

Services and supports need to be in place to help maintain a semblance of normalcy for aging Metis citizens, such as the ability to go on the trap lines, cook

traditional foods, or sew using traditional materials such as animal skin. If these supports are not available, it compromises the ability for family caregivers to provide culturally responsive care. The result of historical processes and policies, such as being road allowance people and living in rural/remote communities, as raised by study participants, is that many Metis Elders/seniors do not have sufficient housing or funds saved for retirement, and many do not have the literacy skills to successfully navigate available funding programs, yet they wish to remain within their communities.

Family caregivers must find ways to improve housing supports for their aging parents, otherwise, their Elders have to live with family or move to care facilities. If aging Metis do not have family or community supports available, they risk homelessness; something that is far too common an experience for Indigenous Elders (Leach, n.d.) and which is often a direct result of colonial policies. Lack of adequate, affordable housing is a real fear faced by some study participants. Because of the exponential growth of youth within Indigenous communities, priorities for addressing housing needs of Elders remain under-researched and under-resourced (Durocher, Hammersmith, Littlejohn, & McCaslin, 2013). Family caregivers worry that if they are not around, Elders will not receive adequate care. Although many people have other family members and external family supports, this is not always the case, and it often requires other community members and extended family to ensure that Elders receive the supports they need. Family caregivers and Elders both noted the possibility of caregiver burnout, although discussion about self-care practices did not feature prominently in conversations.

Methodological Issues and Limitations

Data collection was conducted in English. Although participants did not request that the focus groups or interviews be conducted in another language, they did discuss the need for services and supports in languages other than English, hence English-only focus groups may have created barriers to participation for Metis who are more comfortable speaking one of the traditional languages (e.g., Cree-Michif, French-Michif, Cree, Oji-Cree, Saulteaux). As the information we were seeking was specifically about caring for Metis Elders, information about other populations that received family care, such as people who were younger and had disabilities or health conditions, was excluded from the transcript data, thus experiences should not be generalized to other age groups. Participants were not asked to demonstrate Metis status through the presentation of citizenship cards; consequently, it is possible

that study participants may not fall under the official definition of Metis citizenship. As the majority of recruitment was conducted through the MMF, and all family caregivers indicated some level of involvement in the Metis nation, we were comfortable in our assumption that all participants self-identified as Metis citizens.

Conclusion

Cultural responsiveness is necessary to ensure that care provided to both Metis Elders/seniors and Metis family caregivers meets their needs. It is essential that the Canadian population, especially policy and decision makers, recognize that legitimate challenges remain with the resources available to understand what the current experiences and health of Metis people are presently like. This challenge is being addressed by the Metis Nation and its citizens. While the larger constitutional and legal battles take place in the courts as to legal identity, land rights, and fiduciary responsibilities, the smaller battles are waged at home as people work to ensure that their loved one can live at home as long as possible, that there are language supports in place that allow Elders to communicate in their language, and that family caregivers also have support to meet their ongoing economic, social, and pragmatic needs.

The Metis population is growing. Increased rates of self-identification related to an increased sense of safety (verbal communication; Bartlett, 2011) and pride associated with Metis identity, changes to census data collection procedures (Andersen, 2008; Andersen, 2016), as well as higher fertility rates are largely responsible for this change in demographics (Adams, Dahl, & Peach, 2013). It is important that continued exploration of the needs of family caregivers and the Elders they support are undertaken while keeping culture as part of the discussion. This will not only allow for continued recognition of the influence colonial practices and policies have had, but also ensure that the well-being of Indigenous people is at the forefront of policy and service delivery which in turn will improve the lives of Metis citizens across the lifespan.

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