



Metis Health Knowledge Authority In Manitoba

‘There’s No Place Like Home’— The Experience of Metis Aging in Place

Winnipeg, Manitoba, Canada 2012



**Manitoba Metis Federation–Health & Wellness Department
in collaboration with the
Manitoba Metis Federation Northwest Region**

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Executive Summary

This report resulted after Metis citizens in the Manitoba Metis Federation (MMF) Northwest Region identified a need to further understand the experiences of Metis seniors aging in their communities, and to become informed about any unmet needs. Thus, the overall goal of this research was for the MMF and the University of Manitoba to develop an understanding of the experience of Metis seniors aging in place in the MMF Northwest Region. The research was carried out in four rural communities, collecting stories and experiences from focus groups with Metis seniors as well as informal and formal caregivers. Data was analyzed using the CDDAPing process, using coded cards to categorize identifiable themes. An important finding from the research was the recognition that Metis culture is alive and inherent in many rural communities; it is both sustained by, and provides a strong support for, Metis seniors. Governance, defined as having a voice to speak for yourself or having someone to speak on your behalf, was an important issue to the participants, as were many factors commonly identified in the literature. Many Metis seniors living on their own reported a need for additional support to basic home maintenance such as snow removal, grass cutting, and general upkeep of their dwellings. Due to insufficient amenities, stores, and care facilities in rural communities, access to transportation for Metis seniors who are no longer able to drive was a major barrier to aging in place. There was a clearly identified need to provide affordable and accessible transportation services for this group. While home care services were seen as a benefit to many, the current service model has many aspects that make the services inaccessible or undesirable to Metis seniors. Finally, appropriate housing was determined to be essential for Metis seniors aging in place. In many instances, upgrades to existing homes are needed and physical supports must be installed to ensure mobility in home living environments. When Metis seniors are no longer able to live on their own, independent living facilities located in or close to home communities were seen as a desirable alternative.

“Stay young at heart and if your body doesn’t do it, then you sit there and laugh about it” —Metis senior, MMF Northwest Region

Section 1: Introduction

1.1 The Manitoba Metis Federation

The Manitoba Metis Federation (MMF), founded in 1967, is the “democratic and self-governing body of the Manitoba Metis community” (www.mmf.mb.ca). The MMF strives to develop and maintain its capacity to *act collectively* to successfully 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. Within the MMF, the MMF–HWD was established in 2005. By using a Metis culture-based holistic health framework the MMF–HWD builds Metis health planning capacity, develops and implements a Metis health research agenda, and acts as a Metis health ‘expert authority’ to advise the health system.

1.2 Background of the Research Team

The Co-Principal Investigators (Co-PIs) on this study were **Dr. Judith G. Bartlett** and **Dr. Julianne Sanguins**. **Dr. Judith G. Bartlett** is an Associate Professor in the Department of Community Health Sciences in the Faculty of Medicine at the University of Manitoba, and an Adjunct Scientist with the MCHP. Dr. Bartlett holds an MD, CCFP, and an MSc in Community Health Sciences. Dr. Bartlett was Co-Principal Investigator on the *Metis Atlas* as well as PI on several projects funded by the Canadian Institutes of Health Research. She is a part-time clinician, an academic physician, and scientific director with a strong understanding of and experience in public health administration. **Dr. Julianne Sanguins** is an Assistant Professor in the University of Manitoba’s Department of Community Health Sciences. Dr. Sanguins is an RN and holds a PhD in Nursing. She is also the Research Program Manager of the MMF–HWD and was a member of the *Metis Atlas* research team. Dr. Sanguins managed all aspects of the academic needs of the study, including directly supervising research staff.

Frances Chartrand is the Director of the MMF Metis Community Liaison Services. As part of her active role on the research team Ms. Chartrand participated in study design and analysis, and facilitated entry into the communities.

Sheila Carter is Director of the MMF–HWD. Ms. Carter was a member of the *Metis Atlas* research team, the *Cancer in Metis in Manitoba* study, and the *Diabetes in Metis in Manitoba* study, providing expertise in health program and policy development. In this project, Ms. Carter was a member of the team from the project’s inception, and participated in study design and analysis.

Jennifer Temmer is the Community-Based Research Capacity Developer at the MMF–HWD and Project Coordinator. Ms. Temmer holds an MSc in Rural Planning and Development. Ms. Temmer served as Project Coordinator for the study.

Diane McKay is the Community Liaison Worker in the Northwest Region and assisted in organizational aspects of the study in the communities.

1.3 Justification for Research

Until recently, little was known about the experiences of Metis aging in place. From the *Health Status and Health Services Utilization* study (Martens, Bartlett, et al., 2010) we know that

Metis¹ live diffusely throughout the province of Manitoba. In 2011, a gap in knowledge regarding service needs for Metis citizens aging in place in rural areas of the MMF Northwest Region was identified. In order to support program and policy responses, and to best support this population, further information related to Metis aging in place in Manitoba is essential. This report provides an initial examination of this important health issue.

Funding was secured from the University of Manitoba's Network Environments for Aboriginal Health Research (NEAHR) Program. Two members of the Research Team are from MMF Northwest Region and have been involved in the project design, data collection, analysis, and dissemination.

1.4 Goal and Objectives of this Study

The overall goal of this research was for the MMF and the University of Manitoba to develop an understanding of how Metis seniors experience aging in place. Previous work on aging in place in an urban setting was completed by Janes & Cleghorn (2008). The research questions for this study were adapted from those developed by Janes & Cleghorn, with some modifications made for geography. The specific questions we sought to answer were:

1. What formal and informal resources exist to support aging in place and how are these affected by rurality?
2. What other resources and supports are needed but are absent, inadequate, or inaccessible?
3. How can the community impact relevant policy, programs, and services to enhance supports to aging in place?

Specific objectives of this study were:

- To identify available services that enable Metis 'aging in place'
- To identify the level of support Metis seniors perceive is needed to live well
- To identify ways to extend the time seniors can live at home
- To gain an understanding of the effect of personal care homes on Metis seniors and families
- To identify the best practices for maximizing community services

1.5 Overview of Sections

Section 1 provides an introduction to the report.

In Section 2 the reader is provided with an overview of the MMF, the MMF-HWD, and its holistic approach to knowledge development.

In Section 3 a comprehensive literature review is given to familiarize the reader with current concepts related to aging in place. In particular, supports and barriers to successful aging in place are addressed.

The research design is fully described in Section 4, including the methodology (community-based participatory research); data collection methods (environmental scan, focus groups,

¹ The Manitoba Metis Federation does not use the term 'Metis' with the accent ('Métis') as is done in some parts of Canada. In this report, 'Métis' is used only when referring to sources that use the accented form.

and key informant interviews using the Metis Life Promotion Framework©); data analysis process (Consensual Data Analytic Process); study sample (criteria for choosing the study area and how participants were recruited); ethics; rigour and trustworthiness; knowledge translation; and limitations of the study.

Study findings are reported in Section 5. Several themes were identified from the focus group sessions. These included “Living in a Small Community”, “Issues of Independent Living”, “Attitudes on Aging”, “Limitations of Aging”, “Health Services Required for Aging in Place”, “Supports for Aging in Place”, “Aging and Finances”, “Aging and Metis Culture”, and “Governance and Government”. In some cases the themes identified by focus group participants and caregivers were complementary; while in other cases there were some differences in reported and perceived/experienced services.

Finally, in Section 6, conclusions and recommendations are provided. A discussion on what this study adds to the larger body of knowledge related to aging in place in rural Canada is provided, while emphasizing the knowledge gained about unique aspects of Metis seniors.

1.5.1 *Acronyms*

In this report, several acronyms are used. In an attempt to minimize confusion, the most commonly used acronyms are outlined below.

MLPF©—Metis Life Promotion Framework©

MMF—Manitoba Metis Federation

MMF–HWD—Manitoba Metis Federation Health & Wellness Department

RHA—Regional Health Authority

1.6 **Summary**

Metis citizens from MMF Northwest Region identified a need for further information related to seniors in their rural communities. They wanted to know what existed in those communities to support individuals aging in place and what was needed to enable them to age successfully in their home communities. While there was a lot of consistency with the literature in the experiences articulated by participants in focus groups, in some instances new ideas arose. In particular, the importance of Metis cultural continuity and governance (having a voice) was consistently identified by participants. These experiences add to the growing amount of literature on the topic of aging in place, while creating a space for knowledge about unique aspects of Metis aging in place. Several recommendations arose from this study and the outcomes will augment information that has, until only recently, been known anecdotally. Current and reliable information collected in a Metis-specific holistic manner can help to inform Manitoba Health and the MMF on how to adapt health programs, services, and policies to better meet the needs of Metis seniors. The results will also be shared with the Northwest Knowledge Network and communities involved in the study. Working in collaboration, we can improve the health and wellness of Metis in Manitoba.

References

- Janes, J. & Cleghorn, L. (2008). *Mapping Aging in Place in a Changing Neighbourhood*. Toronto ON: Institute for Life Course and Aging, University of Toronto.
- Martens, P. J., Bartlett, J., Burland, E., Prior, H., Burchill, C., Huq, S., Romphf, L., Sanguins, J., Carter, S., & Bailly, A. (2010). *Profile of Metis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study*. Winnipeg, MB: Manitoba Centre for Health Policy.

Section 2: Overview of the MMF–Health & Wellness Department

Authors: Dr. J. G. Bartlett and Ms. S. Carter

2.1 Introduction

The Manitoba Metis Federation—Health & Wellness Department (MMF–HWD) undertakes Metis-specific health research along with a province-wide process to enhance the use of this research. This section provides an overview of the Metis, the Manitoba Metis Federation (MMF), highlights of the MMF–HWD’s use of a Metis-specific lens, and Knowledge Networks. A more complete discussion of the details touched upon in this section can be found in Chapter 2 of the *Metis Atlas* (Martens, Bartlett, et al., 2010).

2.2 The Metis

The Metis are descendants of early 17th-century relationships between North American Indians and Europeans (Sprague & Frye, 1983). The Metis coalesced into a distinct nation in Manitoba in the late 18th century. After the 1885 fall of Batoche, “Metis were denied a separate identity and ignored for a century” (McMillan, 1995, pp. 312–313). By 1967, with the formation of the Manitoba Metis Federation, the Metis in Manitoba were again asserting their capacity to advocate and function once more in a collective manner. In the 1982 amendment to the Canadian Constitution Metis were named as one of the three Aboriginal peoples of Canada (Government of Canada, 1982).

The Metis make up 33% of Aboriginal peoples in Canada, numbering 389,785 in 2006 (Janz, Seto, & Turner, 2009). More than 18% of Metis in Canada live in Manitoba, with over 10% in Winnipeg alone (Statistics Canada, 2008). The Metis are also the fastest growing Aboriginal group in Canada, with an increase in population of 91% between 1996 and 2006 (Statistics Canada, 2008). Increased rates of self-identification are partially responsible for this change in demographic. According to Statistics Canada data, between 1996 and 2006 the number of self-identified Metis in Manitoba increased from 40,720 to 71,805, representing an increase of 76% (Martens, Bartlett, et al., 2010).

The *Metis Atlas* (Martens, Bartlett, et al., 2010) reported that in 2006 almost half (46.5%) of Metis in Manitoba lived in the urban areas of Winnipeg and Brandon. They noted that the 2006 Metis population was younger than that of all other Manitobans, with 25.4% of the population less than 15 years of age (compared to 19.1% of all other Manitobans). Only 9.1% of the Metis population was 65 years of age or older compared to a rate of 13.9% in all other Manitobans.

2.3 The Manitoba Metis Federation

The Manitoba Metis Federation website (2010) documents that to be an Individual Member or Child Member ² of the Manitoba Metis Federation, one must:

- 1) Self-identify as Metis
- 2) Show an ancestral connection to the Historic Metis Community
- 3) Be accepted by the contemporary Metis Community

² ‘Child Member’ is a new addition by majority vote on a Resolution at the 2009 MMF Annual Assembly.

For 43 years, the MMF has acted collectively to promote, protect, and advance the political, social, and economic interests of Metis citizens in Manitoba. The MMF negotiates with governments to access funding for programs and services better able to meet Metis citizens' cultural norms. Metis citizens live in 139 villages, towns, cities, and unorganized territories across Manitoba (See Figure 2.3.1).

Twenty-one Representatives and a President are elected as the MMF Governing Body every four years. The MMF has seven Regions and a Home Office, along with a number of associated subsidiaries and affiliations. The MMF Governing Body leads, manages, and guides the strategic direction, objectives, and policies of the Federation and its subsidiaries. The President is the Chief Executive Officer, leader, and MMF spokesperson. The MMF has an Executive Director responsible for overseeing the day-to-day operations of the Federation. Each Region is administered by an elected Vice President and two elected Directors.

Figure 2.3.1: Villages, Towns, Cities, or Unorganized Territories Where Metis Live in Manitoba, 2009

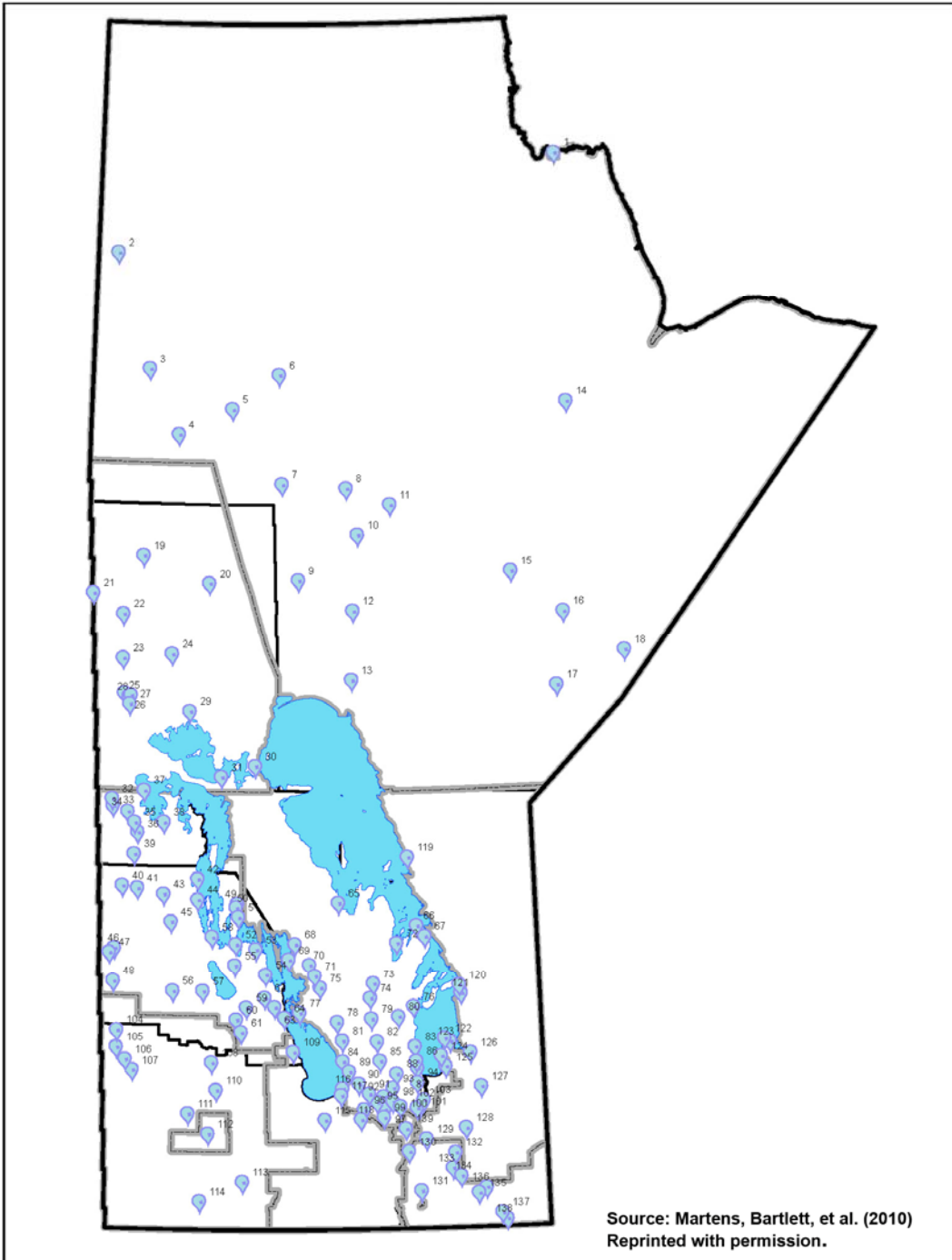


Table 2.3.1: Code Key for Villages, Towns, Cities, or Unorganized Territories (In Regional Order).

Thompson Region		San Clara	47	Warren	95
Churchill	1	Roblin	48	Marquette	96
Brochet	2	Mallard	49	Grosse Isle	97
Lynn Lake	3	Rock Ridge	50	Stonewall	98
Granville Lake	4	Waterhen	51	Rosser	99
Leaf Rapids	5	Spence Lake	52	Stony Mountain	100
South Indian Lake	6	Crane River	53	Lockport	101
Nelson House	7	Cayer	54	St. Andrews	102
Thompson	8	Rorketon	55	Selkirk	103
Wabowden	9	Gilbert Plains	56	Southwest Region	
Thicket Portage	10	Dauphin	57	Russell	104
Pikwitonei	11	Winnipegosis	58	Binscarth	105
Cross Lake	12	Ste. Rose	59	St. Lazare	106
Norway House	13	Laurier	60	Birtle	107
Gillam	14	McCreary	61	Erickson	108
Oxford House	15	Eddystone	62	Amaranth	109
Gods Lake Narrows	16	Bacon Ridge	63	Minnedosa	110
Garden Hill	17	Kinosota	64	Rivers	111
Red Sucker Lake	18	Interlake Region		Brandon	112
The Pas Region		Dauphin River	65	Belmont	113
Sherridon	19	Matheson Island	66	Boissevain	114
Snow Lake	20	Pine Dock	67	Portage la Prairie	115
Flin Flon	21	Fairford	68	St. Ambroise	116
Cranberry Portage	22	Steep Rock	69	St. Marks	117
Wanless	23	Grahamdale	70	St. Eustache	118
Cormorant	24	Moosehorn	71	Southeast Region	
Umpherville	25	Fisher Bay	72	Berens River	119
Big Eddy Settlement	26	Hodgson	73	Seymourville	120
Young Point	27	Fisher Branch	74	Manigotagan	121
The Pas	28	Ashern	75	Victoria Beach	122
Moose Lake	29	Riverton	76	Traverse Bay	123
Grand Rapids	30	Vogar	77	Grand Marais	124
Easterville	31	Eriksdale	78	Beaconia	125
Red Deer Lake	32	Poplarfield	79	Powerview	126
Barrows	33	Arborg	80	Lac du Bonnet	127
Baden	34	Lundar	81	Ste. Rita	128
Mafeking	35	Narcisse	82	Lorette	129
Bellsite	36	Gimli	83	St. Adolphe	130
Dawson Bay	37	Oak Point	84	St. Malo	131
Pelican Rapids	38	Inwood	85	Richer	132
Birch River	39	Winnipeg Beach	86	La Broquerie	133
Northwest Region		Matlock	87	Marchand	134
Swan River	40	Teulon	88	Woodridge	135
Minitonas	41	St. Laurent	89	St. Labre	136
Duck Bay	42	Lake Francis	90	Vassar	137
Cowan	43	Woodlands	91	South Junction	138
Camperville	44	Argyle	92	Winnipeg Region	
Pine River	45	Balmoral	93	Winnipeg	139
Boggy Creek	46	Petersfield	94		

2.4 Manitoba Metis Federation–Health & Wellness Department

The MMF–Health & Wellness Department (MMF–HWD) was created in July 2005 as a Metis-specific ‘health knowledge authority.’ Over time it has solidified a vision of ‘a well Metis community’ with its mission of ‘creating and facilitating the use of knowledge’ to contribute to improving Metis health status. The MMF–HWD is focused on four main strategies intended to move department activity toward its vision. These include:

- Using a Metis culture-based holistic wellness framework
- Building Metis health planning capacity
- Implementing a Metis health research agenda
- Developing as a Metis ‘Health Knowledge Authority’ to advise the health system

For the MMF–HWD, the *Metis Atlas* was the base research setting the stage for a range of new research and related activities intended to positively impact the health and well-being of Metis citizens in Manitoba. ‘The Metis Population Database’ (MPDB) developed for the *Metis Atlas* enabled aggregated data for this (“Aging in Place”) study that provided contextual information for this region.

2.5 Description of a Culturally Coherent Metis ‘Methodology’ or Lens for Wellness

2.5.1 *Ways of Knowing*

The MMF–HWD approaches all departmental activities from a Metis-specific methodology (that is, a Metis perspective or lens). This Metis lens is rooted in the integration of our historic Indigenous and European ancestries to become a uniquely Metis ‘way of knowing’. Adapted from work by Burton-Jones (1999), the MMF–HWD considers the inclusion of both ways of knowing as appropriate for Metis. This Metis way of knowing is holistic, including: Narrative (our story, spiritual); Experience (our experience, emotional); Data (our research, physical); and Information (our synthesis of the first three, intellectual). This simple approach is used to demystify research (See Figure 2.5.1), and to envelop our strategies (See Figure 2.5.2).

Figure 2.5.1: Holistic Research Process

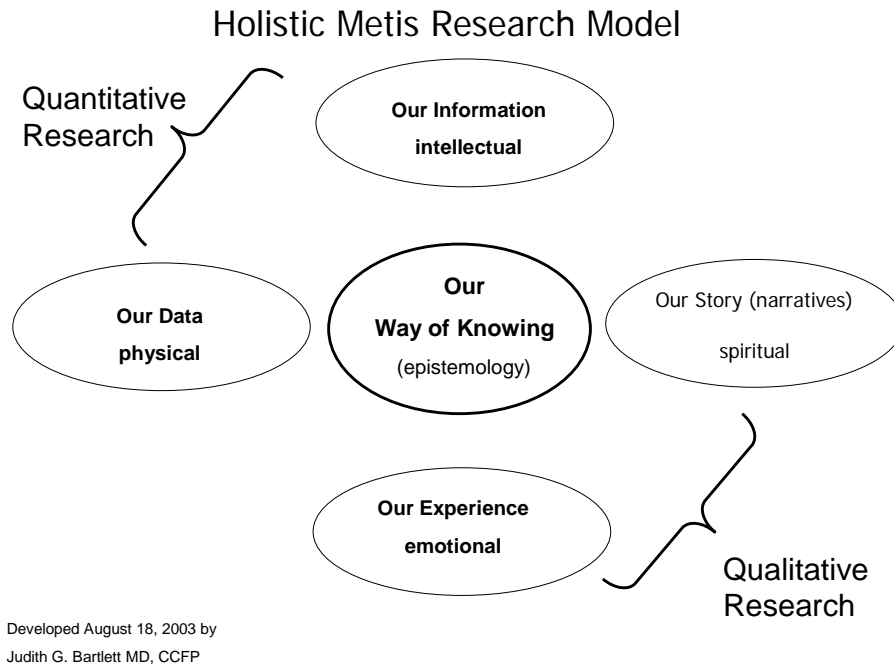


Figure 2.5.2: MMF-HWD Strategies



The MMF–HWD adapted a holistic framework originally developed for use in an urban Aboriginal community health centre (Bartlett, 1995). The framework was renamed the “Metis Life Promotion Framework©” (MLPF©) for use with Metis. The MLPF© includes finding ‘balance’ among 16 important areas that help to “determine how our life unfolds”. These 16 areas—that is, the 16 ‘Determinants of Life’—include spiritual, emotional, physical, and intellectual; child, youth, adult, or elder (senior); individual, family, community, and nation; cultural, social, economical, and political (See Figure 2.5.3). It is critical to keep in mind that the MLPF© is a tool for holistically organizing thoughts and information—it does not *represent* Metis culture.

Figure 2.5.3: Metis Life Promotion Framework© Determinants of Life©

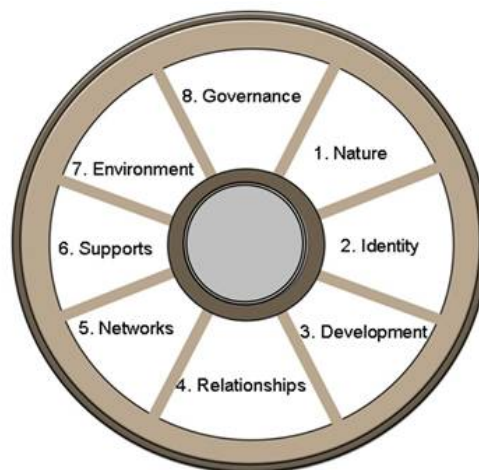
Health can be considered a balance of these 16 areas:



Developed by Judith G. Bartlett, MD, MSc, CCFP, 1995

In 1996, the framework was adapted to consider ‘Wellness’ (Bartlett, 2004). The 16 Determinants of Life were grouped as eight ‘Wellness Areas©’, which made it easier to think about the determinants for health planning and interpretation of research findings. MLPF© Wellness Areas© naturally flow around the spokes of a Red River cart, representing constant motion and change (See Figure 2.5.4).

Figure 2.5.4: Wellness Areas©



Developed by Judith G. Bartlett, MD, MSc, CCFP, 2004

Although not explicitly an accepted Metis lens, this tool allows every person engaged in Metis-related health planning to undertake a process in which they learn how to create Wellness Areas© based on their own life experience. The Wellness Areas© can be used for individuals, families, or groups as well as distinct diseases. Figure 2.5.5 illustrates the use of the Wellness Model for an individual’s health care system experiences. Following this model, Table 2.5.1 demonstrates the types of questions people would be asked about their own experiences.

Figure 2.5.5: Wellness Model for Examining Aging in Place



- Approaching diseases from a wellness perspective
- Needs to occur at both policy & program levels

Developed by Judith G. Bartlett, MD, MSc, CCFP, 2004

Table 2.5.1: Wellness Areas© Question Type

WELLNESS AREA©	QUESTION: How experiences with aging in place affects my:
Nature	Sense of who I really am as a person?
Identity	Experience of how others see me or how I want others to see me?
Development	Sense of age/ability to express the child, youth, adult, and elder parts of me?
Relationships	Ability to respect and care for others?
Networks	Ability to interact with others?
Supports	Body, ability to work and be involved in community?
Environment	Cultural, social, economic, and political influence?
Governance	Ability to choose my destiny and future?

2.6 Knowledge Translation

Knowledge Translation (KT) means using *what we know* from research to influence *what gets done* in health and social programs and services to improve health. Using KT for this study maximizes benefit for Manitoba Metis citizens. Information will be disseminated to the communities in a newsletter, in public sessions, and at the MMF Region meeting. Study results will also be shared with Knowledge Networks involving MMF and Manitoba Health Regional Health Authorities. Any policy issues arising from this study will be taken to the Provincial Metis Health Policy–Knowledge Network for discussion.

Knowledge Networks provide an ideal venue for knowledge dissemination by encouraging mutual learning and knowledge exchange (CHSRF, 2005). For a more detailed description of this process see Chapter 2 in the *Metis Atlas* (Martens, Bartlett, et al., 2010). Knowledge dissemination is an essential part of KT and a critical process enabling translation of evidence into policy and practice (Canadian Institutes of Health Research, n.d.). Such knowledge dissemination places emphasis on ‘action’, providing decision-makers with tools to create processes that will help improve the overall health of Metis in Manitoba. The study results are being used to produce this report for the MMF and the funder.

Table 2.6.1: Knowledge Networks—Association of MMF Regions with RHAs (2010)

Region Knowledge Networks	
MMF Region	RHA
Thompson	Burntwood
	Churchill
Southeast	North Eastman
	South Eastman
Southwest	Brandon
	Assiniboine
	Central
The Pas	Nor-Man
Northwest	Parkland
Interlake	Interlake
Winnipeg	Winnipeg

In June 2012, the RHAs underwent restructuring. The reorganization of the RHAs will result in subsequent restructuring of the Knowledge Networks. It is at this level that this study will have the most impact—in influencing health policy and programs in Manitoba to improve services for Metis living in northern areas.

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Section 3: Literature Review

3.1 Aging in Place

In Canada, seniors aged 65 years and older represent a growing proportion of the rural population (Butler-Jones, 2010). Much of the literature on aging in place in rural communities focuses on challenges for seniors and how they can be overcome (Averill, 2003; Clark & Leipert, 2007; Davenport et al., 2009; Ponzetti, 2003). Both benefits and barriers to aging in place will be addressed in this literature review.

The term ‘aging in place’ refers to the ability of an individual to remain in one’s home and community as they grow older (Schofield, Davey, Keeling, & Parsons, 2006). Being able to age in place is reflected in better personal and clinical outcomes, and reduces long-term health care costs for society (Janes & Cleghorn, 2008). However, good quality of life as we age is highly influenced by the physical and social environments one lives in (United Nations Population Fund & HelpAge International, 2012); therefore, one’s environment should be age-friendly.

The World Health Organization (WHO) (2007) defines an *age-friendly* community as one that “encourages active ageing by optimizing opportunities for health, participation, and security in order to enhance quality of life as people age” and “adapts its structures and services to be accessible to and inclusive of older people with varying needs and capacities”. It also “emphasizes enablement rather than disablement; it is friendly for all ages and not just ‘elder-friendly’”. The WHO lists eight factors that influence a city’s age-friendliness: transportation; housing; social participation; respect and social inclusion; civic participation and employment; communication and information; community support and health services; and outdoor spaces and buildings. They stress *accessibility* as the key to age-friendliness. The UNFPA & HelpAge International (2012) also indicate that successful aging in place relies on accessible communities—ones that are free of barriers and provide assistive support.

The Global Age-Friendly Cities Guide developed by the WHO (2007) provides checklists of core age-friendly features that cities can use to assess their state of age-friendliness, centering on the main topics of outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services.

In conjunction with the WHO’s Age-friendly Cities Project, the Canadian Federal/Provincial/Territorial Ministers Responsible for Seniors (n.d.) endorsed the Age-friendly Rural/Remote Communities Initiative. Their guide is intended to help groups (different levels of government, volunteer organizations, seniors, seniors’ organizations, etc.) to identify barriers and assets in their community in order to support development of age-friendliness. They also provide a checklist of age-friendly features related to each of the main topics discussed. The two main objectives of this Initiative are 1) “to increase awareness of what seniors need to remain active, healthy, and productive within their communities by identifying indicators of age-friendly rural and remote communities” and 2) “to produce a guide that rural and remote communities across Canada can use to identify barriers to aging in place and to foster action that supports the development of age-friendly communities”.

The Chief Public Health Officer's Report on the State of Public Health in Canada 2010: Growing Older—Adding Life to Years discusses the concept of *universal design* as an important component of age-friendly communities (Butler-Jones, 2010). Universal design includes seven principles that promote the design of environments made accessible to all people of all abilities (such as minimal hazards, requiring low physical effort, being simple to use, etc.). The 2006 report *International Best Practices in Universal Design: A Global Review* released by the Canadian Human Rights Commission, as cited in Butler-Jones (2010), includes accessibility criteria that can be used in building designs to make spaces accessible by everyone.

The Government of Manitoba launched the Age-Friendly Initiative in 2008, with a goal to make Manitoba more age-friendly and to support seniors to age in place (Government of Manitoba, 2012). The Government defines an age-friendly community as one where "...policies, programs, and services are designed to make it easier for older adults to stay active and healthy, so they can continue to contribute to their communities". Sixty-six municipalities in Manitoba have joined in this initiative as of 2011 (Community-University Research Alliance [CURA], 2011). CURA (2011) lists respect, safe walking, snow clearing, adequate parking spaces, and adequate road signage as the top five most age-friendly aspects identified by communities. They list lack of paid employment, inadequate public telephone answering services, lack of subsidized housing, long wait times for senior housing, and lack of senior-friendly housing as the top five least age-friendly aspects. Two-thirds of the communities involved in this initiative have started to take steps to make their communities more age-friendly (CURA).

The World Health Organization (WHO) emphasizes the importance of healthy or 'active' aging. Active aging is defined as "the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age" (p.12). This includes maintaining independence and autonomy throughout the life cycle (WHO, 2002). Choice, autonomy, and independence are variables frequently identified for successful aging in place (Schofield et al, 2006).

Successful practices for aging in place focus on individualized home and community-based care management (Janes & Cleghorn, 2008). In the Chief Public Health Officer's Report on the State of Public Health in Canada 2010: Growing Older—Adding Life to Years, Butler-Jones (2010) noted that poor health in seniors tends to be higher when they have reduced access to care and support services, unsafe living conditions, and when they live in isolation. The Government of Manitoba currently has an 'Aging in Place' strategy including home care services for eligible individuals and alternative housing options such as group living, supportive housing, and PCHs (Doupe et al., 2011). The extent to which these services can be accessed by seniors, especially those living in rural areas, is unknown.

While the number of seniors in Manitoba increased from 122,200 in 1981 to 158,600 in 2005 and is projected to increase to 263,200 by 2026 (Statistics Canada, 2010), overall Metis in Manitoba are a younger population with 25.4% of Metis 15 years of age or younger, compared to 19.1% of all other Manitobans. In the 2006 census only 4% of Metis in Canada were 65 years of age and older. Differing slightly from the national data, the *Metis Atlas* (2010) showed that 9.1% of Metis in Manitoba were 65 years and older. However, in the MMF Northwest Region, in which this study is focused, 11.3% of Metis in the Region were over the age of 65 (Martens, Bartlett et al., 2010). A large number of these individuals reside in small rural communities. Indeed, 34% of Manitoba Metis seniors live in rural areas,

compared to 19% of non-Aboriginal seniors (Statistics Canada). The Metis senior population is also projected to have the largest growth, increasing from 12,800 in 2001 to 30,600 in 2017 (Statistics Canada).

The WHO (2002; 2007) point to several challenges for aging populations. There is an increasing burden of non-communicable diseases. In Canada, the majority of seniors (89%) live with one or more chronic conditions and one third of seniors aged 80 years and older are living with at least four chronic conditions, such as arthritis, diabetes, heart disease, cancer, stroke, Alzheimer’s disease, glaucoma, anxiety disorders, etc. (Butler-Jones, 2010). Indeed, rates of many of these diseases increase with age.

There are significant rates of chronic disease for Metis in the MMF Northwest Region (Martens, Bartlett, et al., 2010). These include: hypertension (29.80%); arthritis (27.99%); total respiratory morbidity (15.57%); diabetes (12.30%); ischemic heart disease (14.65%); osteoporosis (9.92%); cumulative mental illness (26.27%); and dementia (14.97%) (Martens, Bartlett, et al., 2010).

For the older adults, migration—either in to or out of—rural communities is typically for one or more of three reasons: retirement, social support, and/or institutionalization. At retirement, seniors tend to return to their rural communities as they no longer need to live in cities for employment reasons. When the elderly find they need extra social support from friends and family, and their informal caregivers are unable to meet their needs, institutional support is often necessary. In these cases seniors may find themselves moving away from their homes to where support is provided for them (Davenport et al., 2009).

Individual factors related to success in aging in place are personal health (Schofield et al., 2006), income adequacy (Schofield et al., 2008), home ownership (Davey, 2006; Janes & Cleghorn, 2008), access to services in the community (Schofield et al., 2008), and a person’s expectations about staying in their home (Janes & Cleghorn, 2008). Lack of support and services (especially in rural/remote areas), in addition to health and financial status, means many seniors do not have the option of aging in place (Butler-Jones, 2010). Other circumstances such as the size, design, or maintenance required on their home might also make it difficult for a senior to stay in their home (Butler-Jones). Support for maintenance, renovation, and adaptation to assistive devices in housing allow for more successful aging in place (Davey).

3.2 Benefits to Aging in Place

Despite the challenges of aging in place, in a study of elderly residents who were growing old in rural areas the majority (94%) of seniors felt ‘at home’ in their community (Ponzetti, 2003). Eighty-one percent had at least half of their friends living in their home communities, whereas 53% reported that half or less than half of their family lived there. Residents articulated great satisfaction living in their home community and 88% reported that if they had to move they would regret moving away.

3.2.1 *Supports*

Successful aging in place is dependent on identifying and planning care tailored to meet individual needs and expectations. It also takes into account the burden and difficulties faced by informal caregivers, such as family members. Social support, through both formal and informal activities and relationships, contributes to an improved sense of self-worth,

increased ability to function, and an ongoing contribution to one's community. Healthy aging and wellness in seniors depends on healthy and supportive environments (that contribute to physical and mental health). Building these age-friendly environments involves incorporating opportunity for recreation, physical activity, civic participation, and safe transportation (Butler-Jones, 2010), among other things.

Increased and varied community supports are an important factor for improved health in aging populations (WHO, 2002). Formal supports, such as those offered by a paid professional or by volunteer programs, promote the ability to age in place. These supports could include home repair and maintenance, support with daily activities, mental health services, recreational activities, and meal preparation (Davenport et al, 2009; Davey, 2006). For rural older adults with a progressive terminal illness, community supports become very important. There is a need for information on their illness, 24-hour access to specialized palliative symptom control, and physical support services (Duggleby et al., 2011). Kelley, Williams, DeMiglio, and Mettam (2011) indicate the importance of locally available palliative care to increase access and quality of care for rural adults who are dying.

It was found that in rural areas, seniors—either through necessity and/or cultural norms—tend to have a strong preference for informal supports by family and friends (Clark & Leipert, 2007). Informal support provided by family members, friends, and neighbours factor significantly in an individual's ability to stay in their own setting and helps seniors maintain their independence (Davenport et al., 2009; Janes & Cleghorn, 2008). A recent Health Council of Canada study indicated that, of those who provided informal care to friends and relatives, 75% were employed and 60% were women. Seventy-five percent of informal caregivers were aged 45–64 years and the remainder were seniors (65 years and older) themselves (Health Council of Canada, 2012). For those caregivers, typical services they provide include assisting with transportation, housework, and meals; managing care such as medications, dressings, and blood pressure readings; personal care; and medical care (Health Council of Canada).

3.3 Continuum of Care & Personal Care Homes in Manitoba

In 1994, Ministers of the Organization for Economic Co-operation and Development (OECD) countries agreed that all elderly people, if they wish, should be supported in their homes as long as possible. When this is no longer possible, appropriate shelter and a supportive environment—socially and geographically close to their community—should be provided (Davey, 2006). Manitoba's continuum of elder care consists of community-based care and institutional care that encompasses both informal and formal services and aims to provide services as close to home as possible. The services offered range from informal care by family and friends to formal care and include: personal care, nursing, counseling, family relief, assessment for long-term care, supportive housing, PCHs with meals, daily assistance, nursing care, supplies, prescription drugs administration, laundry, and chronic care facilities (Doupe et al., 2011).

3.3.1 *Trends in Home Care Services*

The Health Council of Canada (2012, p.4) defines home care as “an array of services for all people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family)

caregiver”. Resulting from the expansion of home care programs throughout Canada, there has been a 51% increase in home care recipients, the majority of whom are seniors (Health Council of Canada, 2012). Throughout Canada most home care recipients are women, single or widowed, and aged 85 years and older (Health Council of Canada). Within the Winnipeg RHA, 70.2% of home care recipients were female, 31.2% were married, 83.5% were aged 75 and older, and 1.8% identified themselves as Aboriginal (Health Council of Canada).

The only Metis-specific home care data is related to ‘open’ home care cases. An open home care case, as defined by the Manitoba Centre for Health Policy, is the age- and sex-adjusted percentage of those registered with the home care program for at least one day in the fiscal year for the two fiscal years (Martens, Bartlett, et al., 2010). In the case of the *Metis Atlas* these years were 2005/06 and 2006/07. The *Metis Atlas* reported that Metis in Manitoba have a higher prevalence of open home care cases compared to all other Manitobans (4.2% vs. 3.3%).

The ‘Home Care Program’, funded by Manitoba Health, is a community-based program providing support to all Manitoba residents who need health services or help with activities of daily living in their homes; this service should allow Manitobans to stay at home as long as is safe to do so. Provided services include mobility devices, personal care, transferring in and out of a wheelchair, and, according to the program’s mandate, workers may come into the home to help with meals, light housekeeping, and laundry. Short periods of in-home respite may also be arranged. Services offered are dependent on assessment. There is an appeal process in place for those applicants dissatisfied with their assessment (Government of Manitoba, 2009).

3.3.2 *Transition to Long-Term Care*

If an aging person moves from their residence, it may involve admission to long-term care. Transitioning to a care facility from one’s own home is influenced by many different factors. The decision may be voluntary or involuntary. Individuals may choose to move to a PCH for a variety of reasons, such as health problems that can’t be managed alone, the death of a spouse, loneliness, or inappropriate or dangerous living conditions at home, etc.

There is an adaptation process involved in the transition to living in a care facility, from an initial reaction of feeling overwhelmed and homeless, to acceptance, to either mal-adaptation or adaptation and stabilization (Brandburg, 2007). Having social networks such as friends and family members in close proximity to a new PCH residence can help make this transition process less difficult (Brandburg). In Manitoba, 95% of Metis living in a PCH reside in a PCH within their ‘home’ RHA. Within the Parkland RHA (in which the MMF Northwest Region is located) all Metis residing in PCHs were accommodated in a local PCH (Martens, Bartlett, et al., 2010).

3.3.3 *Trends in Long-Term Care*

According to recent Statistics Canada (2009/2010) data, there were 90 residential, or long-term, care facilities for seniors in Manitoba with 9,682 approved beds. There were also a total of 9,492 residents registered at the end of the reporting year. Of those, the majority (70.9%) were females.

The majority of individuals currently living in care facilities are over the age of 85 (Janes & Cleghorn, 2008). In 2007/08, in Manitoba, only 1.2% of males and females aged 65–74 lived

in a PCH, and 5.4% of adults aged 75–84 years resided in such an establishment. The majority of adults living in a PCH were 85 years and older; of the total number of people living in PCHs, one in five were males aged 85 and older and one in three were females aged 85 and older (Doupe et al., 2011). The largest demographic group recorded was females aged 85 and older, of which there were 4,124 residents (43.5%).

The information available for Metis and PCHs is limited. According to the *Metis Atlas* there is a higher rate of Metis aged 75 years of age and older living in a PCH than all other Manitobans in the same age category (14.2% vs. 12.3%). The overall provincial annual average rate of Metis aged 75 and older admitted to a PCH was 3.1% (Martens, Bartlett et al., 2010).

3.4 Programs for Seniors in Manitoba

As the overall population in Manitoba ages, there will be more demand for formal support services and a larger financial demand on the health care system. To effectively support aging in place, systems—including hospitals and governments—need to ensure that policies support innovative community-based approaches. The literature suggests that for seniors to age in place and remain in their homes as long as possible, supports must be available and accessible to them *regardless of where they live*. For individuals in need of more intensive care, or who choose to move into PCHs, the transition should be made as smooth as possible.

3.4.1 Provincial Government Programs

In the province of Manitoba there are currently several programs available for seniors to help them age in place comfortably. In 2004, the province of Manitoba initiated an ‘Aging in Place’ Policy to help older adults remain in their communities (Doupe et al, 2011). Three housing options the province offers to seniors are: 1) supports to seniors in group living, 2) supportive housing, and 3) personal care homes (PCHs) (Government of Manitoba, n.d.) However, such supports are typically found in communities with a large population base and thus do not meet the needs of many seniors living in rural and remote communities.

There is a Long Term Care Strategy (LTCS) through the province’s Aging in Place program. By providing supportive housing with the Supports to Seniors in Group Living Initiative (SSGL), the program aims to prevent and/or delay entry into PCHs. Within the Parkland Regional Health Authority (PRHA) there is currently a supportive housing unit at Happy Haven Elderly Persons Housing (EPH) in Dauphin, a facility in the Rainbow Lodge EPH in Swan River, and a facility planned for Roblin (Parkland Regional Health Authority [PRHA], 2011).

Another feature of the LTCS is a Supportive Housing Program that promotes the principle of aging in place. This program is a joint program with Manitoba Housing and provides 24-hour support and supervision in a group setting for seniors who cannot manage on their own, but are not yet ready to transition into a PCH (Government of Manitoba, n.d.). The Supportive Housing Program service package includes three daily meals with snacks (where food is served in the ‘family style’), the preparation and clean-up of eating areas, dishwashing, and, in some situations, seniors help with meal preparation. Domestic support is also available and includes daily facility cleaning, garbage collection, in-suite light housekeeping, linen changing, bed making, and weekly laundry service; it is based on the senior’s ability to help with some of these tasks (Government of Manitoba, 2009). Despite these resources, according to the Parkland RHA Community Health Assessment, seniors in

the region felt more support was needed for assisted living and supportive housing (PRHA, 2009, p. 193).

The Support Services to Seniors program works with groups of seniors, community volunteers, and businesses to help maintain or enhance the physical, psychological, and social well-being services that allow seniors to remain independent and in their communities. In 2010/11, there were eight community resource councils supporting seniors (Seniors Resource Network, n.d.). There were twenty-one congregate meal programs providing hot meals and a social atmosphere offered in thirteen communities. In 2010/11, volunteers in this program served 66,605 meals. There is also a ‘Meals on Wheels’ program which, in 2008/09, served 10,154 meals to residents of the RHA (PRHA, 2011).

Although not specifically for seniors, the Telehealth program can help reduce the amount of long distance travel needed for specialist physician visits. This is ideal for those who are no longer confident about driving in cities or for long distances. There are currently Telehealth stations available in Dauphin, Grandview, McCreary, Roblin, Ste. Rose, and Swan River. Some of the specialist services able to use Telehealth include pre- and post-operative consultations, wound assessment, cardiology, dermatology, mental health, oncology, speech language pathology, support groups, pediatric surgery, feeding clinics, general surgery, and infectious diseases (PRHA, 2011). Each of these Telehealth stations is located at least one hour by automobile away from pilot sites.

3.4.2 *Metis Government Programs*

The Metis Elders Firewood Project is a program run through the Metis Community Liaison Department of the MMF. This program assists Metis seniors with winter heating costs by providing them with two chopped cords of wood annually, free of charge (MMF, 2010). In the 2011/12 fiscal year the Metis Elders Firewood Project provided 68 seniors in 23 communities in the MMF Northwest Region with wood (personal correspondence, Frances Chartrand, May 15, 2012).

3.5 **Barriers to Aging in Place**

The Chief Public Health Officer's Report on the State of Public Health in Canada (Butler-Jones, 2010) identified priority areas for action in improving seniors' conditions for healthy aging including issues of access to care and services, valuing the role of seniors and addressing ageism, and building and sustaining healthy and supportive environments. Similar issues were identified by Janes and Cleghorn (2008) as challenges in providing informal and formal health care, including the inequitable distribution of funds, programs, and services in rural areas; for seniors, the added commitment to government of social security and health care costs; and the view that older citizens are a burden rather than active participants in society and assets to their family and communities.

Service access has been cited as a significant issue for seniors in need of health care services. In Manitoba there is currently a ‘continuum of care’ in place (Butler-Jones, 2010; Doupe et al., 2011) that focuses on the varied needs of seniors; however, for many seniors, navigating the health system can be a challenge. In addition, it can be difficult for seniors to coordinate and pay for the wide range of care services that are available to them (Butler-Jones).

3.5.1 *Geographic and Spatial Barriers*

Geography presents challenges to aging in place. Underserved areas, such as rural communities, may not have the necessary resources to meet seniors' needs. Lack of formal supports such as home care services in a community may also pose a barrier. If they are available, services may not be available on evenings and weekends (Janes & Cleghorn, 2008). In recent years, higher numbers of seniors aging in place, and seniors living longer, have created a strain on government services such as home care. As such, many home care services in rural areas have been found inadequate at accommodating the growing number of seniors (Davenport et al., 2009). While informal social supports such as family caregivers help to alleviate this problem, 'out-migration' from rural areas for employment reasons tends to increase the burden on families and decrease important social networks for seniors (Clark & Leipert, 2007). Where such informal social supports are unavailable, seniors may need to move to larger urban centres to access services.

Another impact of geographic location is difficulty accessing adequate nutrition and transportation. Specifically, a lack of appropriate food programs impacts access. Home food delivery has been identified as an important formal support, yet this service is not always available in rural areas (Vitolins et al., 2008). According to the Parkland RHA community health assessment, the elevated cost of food—especially fruits and vegetables—as well as insufficient access to that food in rural areas were significant barriers to continued healthy living. In addition, eating alone was a main reason for poor eating habits due to little motivation to prepare a meal only for oneself (PRHA, 2009, p. 53).

Ensuring that healthy and supportive environments are created for seniors influences seniors' ability and willingness to age well in place. Safe neighbourhoods and safe, adapted homes are foundational to supportive environments. For example, safety is an area of concern in both rural and urban centres as individuals may feel unsafe in their homes or neighbourhoods. In Canada, 28% of seniors live on their own and, for some, this may contribute to increased feelings of insecurity (Butler-Jones, 2010). The physical structure of a senior's home may not be adequate to meet the varied health challenges they face. Homes may not be ergonomically suited, with inaccessible bathrooms or stairs, or public buildings may not be retrofitted for wheelchair access (Brown, McWilliam, & Mai, 1997). Financial constraints related to the rising cost of living, an increase in property taxes, and a lack of affordable rental options may also pose barriers (Davey, 2006; Davenport et al., 2009; Janes & Cleghorn, 2008). There may also be a lack of information about other options or information may not be easily understood and so there may be challenges when negotiating complex systems. Insufficient communication about programs and services available to seniors can be a large barrier when navigating such systems and when making decisions about health needs (Brown, McWilliam, & Mai, 1997).

3.5.2 *Financial Barriers*

Financial assistance for assistive devices is considered a universal challenge for seniors across the country (Ontario Local Health Integration Network, 2008). Lower socio-economic status, gender, and ethno-cultural affiliation affect aging in place (Janes & Cleghorn, 2008). A report from the Ontario Local Health Integration Network (LHIN) in 2008 reiterated many of these issues. Quotes from seniors in this report emphasize that "being a senior is like being unemployed: all of a sudden you're a second-class citizen" and "our society is not built with seniors in mind". Other universal themes in the report focused on the need for

support with daily living, access to affordable transportation, financial assistance, safety, and recreation and socialization.

Coupled with the issues of remoteness and access to services is the issue of affordable transportation. Retaining independence and ability to drive has a positive impact on seniors’ quality of life (Clark & Leipert, 2007). However, for many seniors, private transportation is no longer an option due to health or financial reasons. According to Davenport et al. (2009), a lack of public services in rural areas means that many elderly are dependent on private transportation. This can be an expensive burden and a large barrier to accessing even the most basic services.

3.5.3 *Ageism*

Ageism is the “negative view of aging that devalues seniors based on the mistaken belief that they have little to offer” (Butler-Jones, 2010, p.92). Such views can be seen both from service providers and the general population. Ageism is often found where resources are limited and where funding services and programs for younger populations are prioritized (Bowling, 2007). Another ‘face’ of ageism is the attitude of professionals and family members ‘wanting to do too much’, thus reducing or removing independence (Brown, McWilliam, & Mai, 1997).

3.6 **Summary**

Drawing on the larger body of literature, as well as on Manitoba-specific information, the benefits and barriers to aging in place and the associated continuum of care were addressed in this literature review. Programs for seniors in Manitoba were identified. Despite the growing body of evidence in the literature about the benefits—to both individuals and the health care system—of aging in place, available resources have been found lacking. While information exists about aging in place in Canada and Manitoba, there is no Metis-specific literature on the topic. This literature review has identified a need to supplement the literature with Metis-specific information related to aging in place.

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Section 4: Research Design

4.1 Methodology

A community-based participatory research (CBPR) approach was used in this study. CBPR is “a collaborative approach to research that equitably involves all partners in the research and process and recognizes the unique strengths that each brings” (Israel, Schulz, & Parker, 1998). CBPR aims to engage with community partners—in this case the MMF community—in the research process, and benefits the community by translating the knowledge gained in the research into intervention and policy change (Cargo & Mercer, 2008). This process in turn helps to create social change, build relationships based on trust, improve the quality of life for community partners, and give them a voice (Israel et al., 1998). Guiding principles of CBPR are that the community is seen as a unit of identity. It is co-operative—engaging community members and researchers in a joint process in which they contribute equally. Other guiding principles ensure that CBPR is:

- Conducive to co-learning and a capacity building process
- Empowering for community partners (builds on strengths and resources of community)
- A balance between research and action (for mutual benefit)
- Recognizant of the long-term, cyclical, and iterative nature of the CBPR process

In keeping with the principles of CBPR, this research was conducted in collaboration with members of MMF – The Northwest Region, who assisted with the project every step of the way—from selecting the study area, to recruiting participants, to analyzing and interpreting the data.

4.2 Methods

4.2.1 *Protocol for Entry into Communities*

In recognition of and commitment to CBPR principles, and to strengthen bonds of trust with the Metis community, this study followed a specific process to obtain permission and gain access to Metis communities to collect data. This process engaged community collaborators at each step. A letter of support from the Vice-President of MMF Northwest Region was secured. The Region’s Metis Community Liaison Worker assisted in recruiting participants by contacting the Chairs of the Metis Locals in regional communities and informing them of the research to garner interest among local Metis seniors. The Metis Community Liaison Worker arranged meeting spaces, provided refreshments for the focus groups, and attended all focus groups and interviews to introduce the researcher and assist with note taking.

A letter of support was also obtained from the Parkland RHA to gain access to professional health care workers in the Parkland RHA region.

4.2.2 *Data Collection*

There were several sources of data used. The first source of information was an environmental scan of services listed on the RHA website and of four communities in The MMF Northwest Region in which data collection would occur. Another source of

information was focus groups held with Metis residents aged 60+ in the study communities. A final source of data was 1– 1½ hour key informant interviews with informal caregivers and service providers (formal caregivers).

Participants were recruited using snowball sampling (Miles & Huberman, 1994). In order to inform community members about the study, posters tailored to each community were also displayed in the local post offices, Friendship Centres, MMF Region Office, Metis Local offices, as well as in the MMF regional newsletter. A sample of the poster can be found in Appendix 1.

The Project Coordinator, with guidance from the Co-Principal Investigators, obtained informed consent from each participant. Each individual interested in participating had the study explained to him/her, was provided with an opportunity to ask questions of the researcher, and was asked to read and sign the consent forms. The consent form was explained in detail as required. A copy of the consent form is included in Appendix 2.

The focus groups were carried out in four rural communities in Manitoba Metis Federation Northwest Region. These communities were identified by MMF Northwest Region Community Collaborators and were characterized as rural communities with large aging populations.

Five focus groups, lasting approximately 1½ hours, were held. During the focus groups participants were asked a series of questions based upon the Wellness Areas© (Figure 2.5.3) (Bartlett, 2004) to organize their experiences about services and resources in their communities and about their experiences with aging in a holistic manner. A copy of the focus group questions is provided in Appendix 3.

Throughout the data collection period one focus group was carried out in each community; two were done on one site. The number of focus groups conducted was dependent on the number of participants available to attend and, at one point during the data collection period, extensive flooding rendered roads impassable. For each focus group there were between 5 and 12 participants. A total of 45 participants contributed to focus group discussions.

We had anticipated that translation would be required in two of the communities. To that end we ensured that when we travelled to those particular communities, that a translator (identified by the Manitoba Metis Federation regional research team members) travelled with us to provide translation services. It turned out that translation was needed only for one participant. The focus group proceeded with questions being translated to this participant, and then their response was translated back to the group; the ensuing discussion was quietly translated to the participant as it occurred.

The key informant interviews lasted approximately one hour and were structured with a series of questions pertaining to community strengths and challenges, existing health-related services and programs in the community, barriers to care, and personal experiences. Several community-based participatory research (CBPR) projects use key informants as the sources of data gathered in their research; although, due to a variety of factors related to their position in the community (e.g., their social status or professional role), they might not adequately represent the typical community member (McKenna, Iwasaki, Stewart, & Main, 2011). We used key informant interviews with health service providers in our research in addition to discussions with community members that represent our study population

because they can provide us with additional information on the research question, and from a different viewpoint. These community ‘experts’ have knowledge that can provide further insight into the research problem because they are the ones delivering the services and supports to the local Metis seniors. Not only do they have knowledge with regard to what is available to these seniors but they might also have heard feedback from the seniors themselves or directly observed the efficacy of, or challenges they might face in accessing, these services and supports. The service providers might also have ideas on how to adapt programs and services to better suit the needs of the aging Metis they serve.

There were thirteen key informant interviews undertaken with informal caregivers and health service providers to create a holistic picture of the experiences of caregivers helping seniors age in their communities, including both strengths and challenges. Appendix 4 contains a copy of the key informant interview questions.

For both the focus groups and the key informant interviews, basic demographic information was collected from the participants, was de-identified, aggregated, and is being used for descriptive purposes only. A copy of the demographic form is included in Appendix 5.

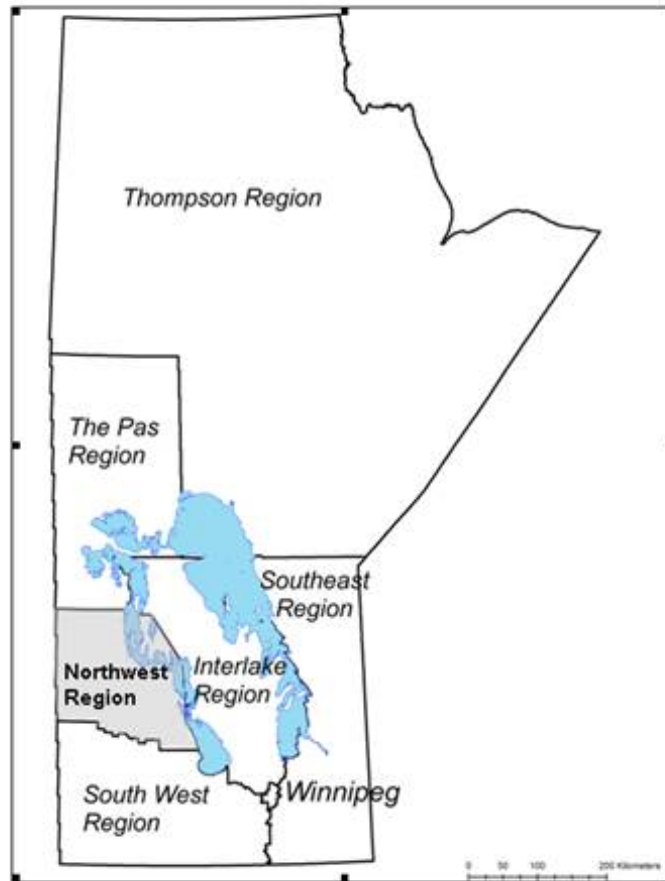
4.2.3 *Data Analysis*

The data analysis was conducted by all members of the research team using the Collective Consensual Data Analytic Process (CCDAP) (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007). Key Informant interviews and focus group discussions were transcribed by the Project Coordinator. Each transcript was reviewed and coded separately by two people—the Project Coordinator and one of the Principal Investigators. In this coding process each narrative was broken down into ideas, and key phrases were identified. These phrases were then printed onto cards. The two coders then compared their coding to ensure consistency in coding. After all of the transcripts had been coded the entire research team met in a facilitated, interactive analysis session. The team worked collectively to cluster the cards under random symbols. Once all the cards were placed on the wall, the clusters were given themes according to the information they contained. For each community, two groups of analysis occurred: one for the health care professionals, and the other for Metis health consumer comments. After this was completed, analysis between communities occurred to identify common areas of needs and strengths, and to answer the research questions. At all levels of analysis core interview data were re-examined and discussed if required to clarify data and to determine if the differences or similarities were real and not simply due to ‘analysis exhaustion’. Results of the analysis are presented and discussed in Section 5. To protect the confidentiality of participants, quotes used in the analysis and results remain anonymous.

4.3 **Study Sample**

Figure 4.2.1 illustrates the location of the MMF Region in which the study occurred. Four rural Metis communities were used in this study. The communities were chosen based on their distance from services and their large demographic of seniors. Throughout the data collection process a total of 45 seniors participated in five focus groups in four communities. All participants completed demographic information surveys. Of all the seniors who participated, 53% were men and 47% were women. Participants were about equally divided between the age groups of 60–69 (49%) and 70+ (45%).

Figure 4.2.1 Map Locating the MMF Northwest Region—Study Region



Source: Martens, Bartlett et al. (2010). Reprinted with permission.

Participants had lived in their communities for a long time. An overwhelming 82% of participants had been there for more than 30 years, and the remaining 18% had lived in their community for more than 11 years.

Living arrangements varied. Nine participants reported they lived alone (20%), 25 lived with their spouse (57%) and 10 lived with a combination of other family members such as siblings, children, and grandchildren (23%). There were 36 participants who either lived alone or with one other person (80%); the remaining seniors lived with two to seven people.

Participants were asked about the age of their homes and any modifications they had made to continue living there. The age of participants' homes ranged from 5–75 years, with an average age of 38 years. Most of the participants (58%) had stairs in their home. While there were 29 seniors (64%) who had made no changes to their current dwelling, twenty-three people had made changes to their houses by installing grab bars (24%), raised toilet seats (18%), ramps (7%), and lifts (2%).

The final questions were in regard to mobility and mobility aids. The great majority of seniors participating in the study did not use any mobility aids (80%). Of those participants

who used aids, 13% used canes, 11% used walkers, 4% required wheel chairs and 2% reported the use of scooters for ambulation.

While the vast majority of the participants were comfortable participating in the focus groups and interviews in English, translation was needed in one community.

4.4 Ethics

The fundamental tenet of the project is that it was founded within an ‘ethical space’ whereby representatives of the Manitoba Metis community could meet together with researchers through all stages of the research project in order to engage in a constructive dialogue about the intentions, values, and assumptions of each project partner (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010). Constant engagement in this ‘ethical space’ allowed for a deeper understanding of the unique perspectives of Metis community representatives and researchers, the development of common interests for both partners, and the promotion of mutual respect and trust which has continued even after the completion of the research project (Castellano & Reading, 2010; Ermine, 2007). Indeed, the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada (2010) advise that “taking time to establish a relationship can promote mutual trust and communication, identify mutually beneficial research goals, define appropriate research collaborations or partnerships, and ensure that the conduct of research adheres to the core principles of Respect for Persons, Concern for Welfare – which in this context includes welfare of the collective, as understood by all parties involved – and Justice” (p. 110). Principles of Metis-focused research (ownership, control, access, and stewardship) were negotiated and respected throughout the research process.

Ethical approval for the project was secured through the Bannatyne Campus, Human Research Ethics Board of the University of Manitoba.

4.5 Rigour and Trustworthiness of Data

In any qualitative study it is essential to discuss the topic of trustworthiness as it relates to the study findings. There are a variety of methods by which a qualitative study can be evaluated to establish its trustworthiness. One of these methods is to apply Guba & Lincoln’s (1989) set of four evaluative criteria to the study. These four criteria include credibility, transferability, dependability, and confirmability. To meet the first criterion, Shenton (2004) lists a number of steps that can be taken by researchers, some of which include adopting well established research methods; developing an early familiarity with the subjects’ culture; triangulation (the use of different methods such as focus groups and personal interviews); tactics to encourage honesty in informants; peer scrutiny of the project; and examining past research findings to assess congruence with the current research. We believe these steps have been taken in this study, a testament to the credibility of this research. Shenton discusses the difficulty in applying the research findings to other situations and populations but indicates that to allow transferability, the second criterion, researchers must provide enough detail on their study to allow others to do so. In order to meet the second criterion, we have carefully documented the methods used in this study, and have included the tools in our report appendices, in order to provide a clear record of our

process and to facilitate replication of the study by others. Shenton also suggests dependability (the third criterion) is a difficult criterion to meet in qualitative research, but that enabling other researchers to repeat the study should be strived for. Indeed, we have carefully documented the methods used in this study, and have included the tools in our report appendices, in order to provide a clear record of our process and to facilitate replication of the study by others. Shenton discusses confirmability as the researcher's attention to objectivity. In order to meet this fourth criterion, we have taken steps to ensure the findings accurately represent the data and not our own researcher bias by ensuring that the original coding was completed independently by two different individuals and that our analysis process was done collectively. We believe that knowledge has been systematically created that builds on previous literature, and extends the understanding of the experience of Metis aging in Manitoba, which may ultimately lead to better support for Metis aging in place.

4.6 Knowledge Translation

Knowledge Translation (KT) is an important aspect of successful community-based research (Masching, Allard, & Prentice, 2006) that focuses on the interactions or partnerships between the research team and end users, and facilitates the use of research findings in decision making (Shea et al., 2005). This is accomplished by generating and mobilizing research findings into a structured knowledge-sharing platform, ensuring appropriate engagement amongst researchers, policy developers, program deliverers, and communities of interest.

The results of the study are being used to produce this report for the MMF. Reporting of the data will be in aggregate form and no participant-identifiable data will be presented. All publications are subject to prior review by the MMF. Information will be disseminated to the communities in a newsletter, in face-to-face-sessions, and at the MMF Regional Annual Meeting. Participants will also be offered the option of having the report mailed directly to their home. A report will be provided to the funder.

4.7 Limitations

There are always limitations inherent in carrying out a qualitative study. Particular to the *Aging in Place* study, seasonality was an issue. As all focus groups were held in a communal area in participants' communities and some access roads to communities were not fully maintained, the data collection had to be carried out during fair weather months. In the year of data collection, flooding which restricted access was an issue in one community and limited the availability of seniors able to participate in focus groups.

Participation in and of itself posed several additional challenges. Although participants lived in the focus group communities, in some cases mobilizing the seniors to bring them to the focus group sites proved a challenge. Competing physicians' appointments and other errands in town also deterred people from participating.

Another limitation encountered in the study was that the questions were designed based upon the Wellness Areas© (Figure 2.5.4) and we felt that, at times, significant additional probing was needed to gain information. If this study were to be repeated we suggest that the questions be re-worked to ensure clarity and maximize responses while staying true to

intent of the framework. Despite this limitation we feel that sufficient information to be of value to the communities was gathered.

Finally, caregiver interview questions were based more directly on their experiences as formal and informal health care providers, and there were challenges in acquiring a broad group of professionals who provided care directly in the study communities.

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Section 5: Findings

5.1 Metis Voices

The following ideas were gathered from the experiences and opinions of Metis seniors living and aging in rural communities in the MMF Northwest Region who participated in this study. The questions posed to participants were based on the Wellness Areas© (Bartlett, 2004). After conducting a series of focus groups, themes were identified as both necessary elements and advantages to aging in place or as barriers to aging in place. Such themes included living in a small community, issues of independent living, attitudes on aging, limitations of aging, health services required for aging in place, supports for aging in place, aging and finances, aging and Metis culture, and governance and government.

5.1.1 *Living in a Small Community*

There were many aspects of living in a small community that came to light in focus group discussions. These included memories of living in a small community, community safety, the change in community over time, and community volunteer capacity. Each of these themes has an impact on the participants’ ability or willingness to age in place.

Memories of Living in a Small Community

For many Metis seniors living in the study communities, it was apparent that nostalgia played a large part in their experience of aging in place. Their memories of growing up in rural communities included outdoor activities such as baseball, fishing and trapping, time spent with friends and family, falling in love, and raising their families. These nostalgic memories provided them with some incentive to remain in their homes and in their communities over time.

Some participants had moved away for several years to seek employment and raise families, and upon retiring they returned ‘home’.

“This is where you’re born, where you make your friends, and where your family grows up. You go away and the closer you get to home, the happier you are”.

Interestingly, participants also noted that this same trend of returning back to the community exists today in the younger generation.

While some participants had moved away from the community for a period of time in their lives, this was not the case for all participants. Many were life-long residents of their community. They had remained in their communities because of community and family ties, and responsibilities such as the family farm or taking care of a parent. For both groups, community provided a strong social connection and, at times, a financial safety net when people “dug deep” to help a person in need.

“I don’t know if it’s the community or is it just because this is a Metis community that when somebody is in trouble other people will go around and gather money, or put on a benefit or something for that person that might be needy in financial help, you know. You have to dig pretty deep sometimes”.

Change in Community over Time

In many rural communities and small towns across Canada, populations are shrinking as younger generations move to urban areas for employment. The communities in this study are no different and the participants' comments reflected that. One participant noted that his family had been in the community for many generations, but that his son had moved away.

Participants lamented over family and friends moving out of their communities, citing effects such as loss of schools, stores, and other businesses. In addition, seniors connected the out-migration of youth to a loss of local culture due to the increased difficulty of staying connected to local roots. These changes, over time, created challenges to successful aging in place.

Community Safety

Community safety is an important aspect of a senior's ability to continue aging in place. As many of the participants live alone, it is particularly important that they feel comfortable and not feel at risk of being robbed or threatened.

“Because [we] live at home alone you don't know what's going to happen. This little community here—there's lots going on. You're scared to leave. I live down by the beach and the children they run and move there because you never know what happens. Kids they might catch your house on fire. Like how many houses have they burned down?”

Participants considered the lack of activities for youth and society's intrusion into the way parents discipline their children as the root causes of increased rates of theft and vandalism in their communities. They also observed a decrease in youths' respect toward seniors and other community members.

“They [youth] use language that they shouldn't use at an elder you know what [I] mean? Shouldn't talk like that. No respect. Even this gentleman here, I see him go down on his trike, I see those young kids throwing rocks at him...so I yelled at those little boys. I said 'don't do that!'...and they just laughed so [I] went to their houses and told on them. You know they shouldn't do that”.

While this idea was articulated by many participants there were some who felt that they also had some responsibility to the youth. One senior suggested that the youth needed their help, to be counselled by them, and to pass on their values.

“And then again it comes down to children. It's the children around here needs our help I guess, might as well say it, help. Try to get something in their heads to look at what they're doing! Like I think there's old enough people that we can ...set up right now they'll say 'oh we don't want to listen to you, what do you', but if we can get an organization, like form a committee and start counselling those children because it's going to be worse and worse if nothing's being done...it's going to get worse and worse and worse”.

5.1.2 Issues of Independent Living

In the focus group discussions it was evident that independence was strongly valued by participants. Themes identified were those of independent living, perceptions, and being independent while aging. Each of these themes offered insight into the ability of participants to remain independent in their home.

Independent Living

The ability to take care of oneself and be as independent as possible in daily life was consistently identified by participants as inextricably linked to their sense of self sufficiency and was consistent with the way they were ‘brought up’. Many of the participants continued to live in their own homes—either on their own or with family members. A significant motivation for participants to remain in their homes was their desire for autonomy and ability to make their own decisions. One participant joked:

“That’s why we live alone; we’re still the boss!”

Although many participants recognized that their energy levels and physical abilities were not what they used to be, many participants living in their homes still felt able to care for themselves.

“I do my own laundry, I got a washer but not...a dryer. I like hanging...all of them in my garden and I bring my house cleaning because everyday, everyday, I always got a house full, my grandchildren...”

“We like to live in comfort, but then we have to do things ourselves. Like I try to keep my house, I clean my house once a week...That’s one good thing you know”.

Some participants adjusted their routines or methods of doing things in order to compensate for limited mobility or other health conditions. One participant now uses a mop to clean the floor instead of scrubbing on her hands and knees. Another participant explained about changing his approach to living in his home:

“It’s like a blind man, when you teach a blind man to walk, he knows where everything is!”

Many participants also emphasized the importance of physical activity to remaining healthy. Although energy levels and physical abilities have decreased, one senior stated:

“Yeah, and for me, I walk a lot...that’s why I’m healthy today”.

One participant relayed a story about her father teaching her to never “do anything in excess”, in order to stay healthy; but she suggested that now people do not have a choice—they must work at the expense of their health.

“...I always heard my father telling my brothers and sisters, ‘don’t do the excesses. If you smoke, maybe have one, two cigarettes a day, and if you have to drink, one beer. Don’t drink until you’ve fallen down drunk, you know, until you don’t know your own mind. The excess, stay away from that’. And that is also eating and everything. And work the same thing. If you’re going to work 18-20 hours a day then the evenings and weekends are for your family. But in this day and age, most of the time if you haven’t got training, or a good education you don’t - you have to work just to make a living...”

Participants expressed the wish to have their independence respected by others. Many participants are very aware of their limitations and are willing to receive help when needed. However, aging can cause conflict between participants and their adult children. Participants noted that their relationships with their children had changed. In some instances adult children would underestimate their parents’ abilities, saying things like “mother you can’t do that anymore”. Several participants described being treated like children by *their* children.

“She [my daughter] treated me like I was seven, eight years old”.

In some circumstances adult children assumed their parents could do more than what participants were capable of.

In order for seniors to remain in their homes longer they conceded that home care services were a good option; however, they also expressed the concern that those services were very limited.

Supports for Aging in Place

According to participants in this study, there are a number of key factors to consider to age in place well. Maintaining adequate nutrition, transportation, keeping their home warm, and snow removal were all factors that needed addressing.

Eating well was a concern amongst some of the participants. This concern encompassed not only having the *ability* to cook for oneself, but the *urge* to eat a meal.

“And then when you want to cook too, you feel like cooking, but when it’s time to eat you can’t eat because you don’t feel like eating it. You see you don’t have that urge to eat as you get older”.

The best remedy for appetite seemed to be grandchildren.

“The most grateful day when you see your grandchildren. When I cook like, like X. said I can’t eat too...grandchildren show up and I feed everybody, I eat you know - I have a good meal...I can’t eat by myself, I don’t feel like eating”.

Transportation is crucial for seniors living in rural communities, and the ability to drive is an essential part of maintaining independence.

“One thing is nice to know is that you’ve got a vehicle sitting in the yard that you can go and start and go where you need to go. Go for a ride if you get lonely...just go driving”.

While driving locally in a familiar area may have been possible for many people, longer distances and driving in the city are more of a challenge. We were told that:

“the “[m]ajority of us can’t drive in the city...our son [takes us]...we drive highway driving but not in the city anymore”.

For those who do not have vehicles, arranging transportation in to town for shopping and physician appointments can be complicated, and the dependence this fosters is not welcomed.

For many participants, house repair, snow removal, and wood cutting are the most important tasks needed to stay in their homes, but have become difficult jobs. Physical labour and heavy lifting are often no longer options.

Access to firewood was a problem for many participants as the cost of heating a house with electric heat is prohibitively high for those living on a budget.

“We use the electric heat because it’s not easy to get up and down stairs and keep fires but I like to go down and enjoy the fire...it [electric heating] is expensive, but what do you do? You can’t carry a load of wood downstairs anymore and stack it. Sure I can go down stairs throw a stick or two in the fire, but I’m not getting a load of wood downstairs by myself”.

The MMF ‘Firewood for Seniors Program’ was identified as a helpful resource in alleviating some of this burden, but there was still the issue of getting the wood to an accessible location such as a garage or basement.

“I burn wood, the MMF brings me some wood...Yes, if we had wood and I could get it downstairs then I would burn it all the time. But I can’t get it out of the bush. I could probably get it downstairs an armful or two at a time”.

The ability to do chores at one’s own speed and have help with more labour-intensive tasks such as shovelling snow greatly improved participants’ ability to stay in their homes.

“I have to do everything but I hate to mop you know. I don’t like to use a mop but I realize a mop is a lot smarter. I have to rest in between because when I was young I could do a lot of things but now you see yourself as, it’s happening to me you know...”.

“I think if we were looking at aging and what the community needs, it’s more things like cutting grass and shovelling the ramp. Like we get the driveway ploughed out whenever we need but there’s stuff like the ramp, make sure the wood is in for the people who are burning wood. Grass cutting because I know that next summer I’m not sure what we can do and I don’t know if he’ll be up to it yet...”.

5.1.3 Attitudes on Aging

Attitudes on Aging

Aging for most participants in this study has been a positive experience. One participant shared:

“I don’t mind getting old at all”.

Although health and opportunity are important aspects of aging well, we heard that a positive attitude is an essential aspect of aging in place. As one participant put it:

“Attitude means a lot too I guess...it’s what keeps you going”.

Many participants still had periods when they felt young:

“I guess though sometimes, I feel like 16”.

However, this feeling was not always consistent with what they saw in the mirror: “wrinkles” and “grey hair”. One participant resolved this dissonance stating:

“You’re as old as you think you are”.

Continuing to be physically active was considered to contribute to a positive attitude toward aging and a balanced state of mind.

“[L]ike exercise and stuff, chopping wood or whatever. You get their mind on something like that. They’d have no time to think they’re old”.

Participants remarked that acceptance about your situation is also important, stating:

“You got to try your best. Do what you can. Take your time. Just let everything go”.

People responded that aging was:

“Something we don’t have any control over...just go with the times”.

“Yes people are realizing and realizing more. Some people try to do more than what they should be at the age they are. Not me. Actually I just slow right down”.

In the end, one participant summed up her experience about aging succinctly: being healthy and feeling well is essential for maintaining a positive attitude about aging. She asserted:

“I think it all depends on what you have. If they say if you’re not too bad, you know, aging is, you can welcome aging, but if you have health problems, it’s very hard”.

Asset-Based Approach to Healthy Living

For one community it was important to stay close, and take care of each other to stay in their own homes as long as possible. They were:

“Trying to help each other. Trying to stay in [their] own home”.

In taking an asset-based approach to healthy living, many seniors have made adaptations to their homes such as installing grab bars, ramps, and raised toilet seats.

Family members and friends volunteer to help where necessary so seniors can remain in their homes longer. Other people also do as much as they can to help community members maintain their independence.

“Well I, like me, I don’t feel like this gentleman said right here, ‘it’s the way you are’. Like to do things like, I cut grass here in the community for elderly people like, I’m an elder now, but I still do 14 yards here in the community cutting grass and that. Used to be active you know like, I cut all season, wood, like I always have something to do, and this way you don’t feel like you’re getting old or anything you know. Keeps you going, going, going”.

Another participant replied that regardless of ability, “You can always call bingo”.

5.1.4 Limitations of Aging

Limitations of Aging

Although most seniors who participated in the study have had positive experiences with aging, they acknowledged that there are limitations. The adjustments can be physical or emotional. Adjustments, especially emotional ones, are often difficult for those who have lost partners and loved ones.

“It’s kind of tough after living with someone after 40 years and then you’re by yourself”.

For those who have lost loved ones, relationships change within the family as well.

“[P]robably after losing one parent they figure they’d have to look after this one so she’d be okay for awhile then...that’s what they do, they get worried when they lose one parent, they only have one”.

There can also be physical limitations associated with aging. Participants reported that they have less energy and that they need a longer recovery time after undertaking physical activity. One participant said that she loved being a part of raising her grandchildren, but had concerns about their welfare if she fell asleep while they were in her care.

“We’ve had a good part in raising our grandchildren and our great grandchildren you know but we don’t do that anymore - you can fall asleep and they’re gone. You don’t know what happened when you wake up... you can get in big trouble boy. They might decide to just walk on home”.

Participants referred to some of the realities of the aging process. Feeling less energetic and having less physical ability to carry out tasks could be frustrating and some seniors missed the work they once did.

“I miss farming. It was hard work but when you’re young you can work hard. And I miss fishing and hunting and all that. I’ve done that all my life until I got crippled up and couldn’t walk”.

Forgetfulness can become an issue. Memory loss can make finishing a task take longer.

“You’re looking around for a wrench, you got it in your hand and you can’t find it! You’re looking for your glasses and you’ve got them on”.

More importantly, we heard that for some Metis seniors forgetfulness can pose a safety hazard, especially when cooking is involved.

“...And one day he put something on the stove to cook and decided it was coffee time and went downtown and went too long...the boys next door noticed the smoke and broke into the house...”.

Impacts of Aging on Work

For many participants, work took on new meaning when they retired and were no longer in the formal workforce. In our discussions we heard that some participants continued to be self-employed after retiring and continued to work for themselves until it was “no longer fun”. Interestingly, one participant slightly past retirement age observed that he might not be hired because of his age, regardless of his ability to do the job.

“You won’t get hired on because you have to be such an age to get hired on... I could operate a machine today. Although I go on a machine and I’m still all like young yet, but I couldn’t get hired on”.

Community Volunteer Capacity

Volunteers were seen as an important support for aging seniors in the communities. Participants could identify multiple opportunities for volunteering in their communities, but they observed that health problems and limited mobility decreased their own ability to contribute to that aspect of community life. The smaller population also decreased the available pool of volunteers.

“As you get older, your health problems are going to increase, so your ability to help in the community is going to decrease”.

Despite the limited ability to volunteer, participants responded that as they aged they had more concern for their families and friends.

“Well that’s the way I see it. Now that we’re older, we have to look after each other more you know. When you’re young you can do just about anything but, [when] you need assistance that’s all there is to it - you need it”.

Implications of Disease

Disease may be part of the aging process and it impacts people in many different ways. According to some participants, disease makes you feel older than you are, and limits your ability to do work. We were told:

“I might lift maybe once or twice and then it attacks me, my breathing...if I didn’t have that [asthma] I could lift all day”.

This ability to do work in or outside the house, even simple tasks, challenges one's ability to age in place.

Many participants attribute common diseases, such as diabetes, to modern diets and sedentary lifestyle. One participant said:

"I blame the pills and the food".

Participants often reminisced about a time when people were healthier, stating:

"I never heard of a diabetic when I was growing up".

"We never needed a physician a long time ago, never! People healed themselves...we were healthy!"

In one community seniors associated their good health today with their childhood diets, which were rich in fish and country food.

"...We grew up on more or less what you call health food now..."

5.1.5 Health Services Required for Aging in Place

Health Services and Housing Options

We heard that independent housing is a good option and an acceptable transition from living in one's own home. With independent housing, one has their own space, but they do not need to worry about home maintenance and affordable meals are available. Such facilities provide seniors the more specialized help they need to continue living on their own.

"...They give you one meal a day, supper. You can go and have supper. You pay four dollars for your meal...And your rent is a little bit cheaper than other places, it goes according to your income...Well you've got your own home but you don't have to cut your lawn - you don't have to pay taxes and this and that..."

In one community, a conversation revolved around the need for independent living facilities *within* the community so seniors would not have to move away. They identified that a transitional home in the community would be ideal.

"Build[ing] a home care here for older people...in between like home care home and then for older people because it's like when the people get older, some people have to move from their homes when they're sick. They have to be looked after, [they] have to go to a nursing home".

Nursing homes were seen as a last resort, when one is no longer able to take care of themselves.

"Personal care is basically when you're - you can't do anything".

The general perspective of nursing homes is that:

"That is where people go to die".

"There's lots of old people that moved away from here because they have to move to a nursing home and I would like to see a place [here] as already we're getting older but for the younger people the younger generation so they don't have to move away".

"And she was good, like she talked; her memory was good and everything, so they decided to put her in a home care [PCH] in Town. She didn't even last two weeks, she died".

When asked if they would like to have these services closer to their communities, participants replied that they would because being close to their friends and peers is very important to them.

“Well, sure because you have friends. Maybe they’re a bit younger, ten years younger or maybe the same as you, but are healthy and maybe they’d go visit you. But when you’re way out like that [distance], you won’t know anybody.”

While PCHs were seen as an option, we were told that in both of the facilities in town, the wait lists were very long because many people from other areas come to stay as well, limiting spots for local residents.

“...My mother she put her name in there, [the PCH] and it took a year and a half, before her name comes in the top, that’s how many have applied there”.

In addition to long wait lists there was a sense that preferential treatment was given to some people and that you could be placed higher on the list if you “knew someone”.

Inadequate Local/Regional Health and Personal Care Services

In the focus groups, access to health services was an important topic of discussion. It was felt by many that to age in place successfully, it was essential to have nearby access to health services, either from a nursing station, a physician, or home care, as well as faster access to ambulatory services. When discussing access to a physician in an emergency one participant said:

“...And this is, I’m talking about an emergency, and then they tell you ‘How come you didn’t phone yesterday and make this appointment?’”.

It was emphasized many times that accessible, affordable health care is essential for seniors to age in place. To many participants it seemed that the necessary services were not always available.

“It’s hard to see a doctor too you know. My doctor in the city I can’t see him...I saw him in the spring but I won’t see him again until September...They [the doctors] come from another town. It’s hard to see them. It’s something if your pills run out”.

Some participants shared that they travelled out of province to seek medical care as the wait times were shorter there.

“[I]t is that the doctors are more available like you can, within a month or two months, sometimes you could get to see them. In the city it’s sometimes a year, two years”.

The general perception regarding physicians was that they are not thorough enough and many diseases such as diabetes may go unnoticed.

“...You have an infected toe like that, what could that mean? Sure, sugar diabetes, and know, know that we’re all suffering from that here. And then this is what we know, I don’t know...the medical field unless you tell them, they won’t check it out for you”.

Inadequate Home Care

“There’s no back-up plan. Home care is poorly run as far as I’m concerned”.

Overall, individuals felt that home care was an important program to enable people to age in place, but that there were problems with the program. The general consensus among

participants was that home care services are currently inadequate to meet seniors' needs. From the perspective of participants, the service can only provide basic help such as meal preparation and light housekeeping. More complex needs, including medication monitoring, were not within the scope of practice of the home care workers.

“When we get home care, a pensioner like us...depends on your health you get home care...they do meals....and they do house-keeping...not much though...just the basics. They might give you two hours a day. It varies”.

For many, home care services have helped seniors stay in their homes; any extra requirements not handled by home care are typically looked after by a family member.

“[I] have home care. Then I just have to [manage, my daughter] looks after me on Saturday and Sunday”.

Although this service continues to assist many seniors, there were concerns voiced about home care. There was uncertainty about the home care assessment process and eligibility for receiving care. We heard:

“[h]omecare is available to help with this need, but their services are limited and getting assistance is based on a health assessment”.

Another person recounted that:

“I went to ask for somebody to come and help me with home care...They told me ‘not until you can’t do nothing’ ”.

In addition to limitations to the type of care that could be accessed at home there were concerns with the home care workers themselves. Although most home care workers were seen as reliable, it was reported that they have little time per client. Participants found the lack of continuity of care problematic.

Participants understood that there were more home care services available in town than in rural communities. In one community, home care staff travelled from town—this created problems when bad weather struck. One participant offered a solution.

“There was only two [home support workers] from here...but those ones that are coming from town, if there was a storm or something they wouldn’t come. But here, living right in the community we only have to travel maybe five or ten miles at most”.

It was argued by many participants that it would be more cost effective to make home care more accessible to seniors than to have them move into PCHs. However, the prevailing belief was that the service is intentionally limited (or capped) by the government so that seniors are forced to bear the expense out of pocket when they are no longer able to manage at home and, as a result, they move into PCHs.

“Well if the government wants to save money, keep these old people at home, they have to put home care out here...yes, but you’re [the senior] paying for the PCH”.

Health System Awareness

From all the participants in this study there was evidence of a wide range of knowledge about health care services available to seniors. Those with more knowledge were able to access a wide variety of services including supports such as a hospital bed and other specialized health equipment.

“Well right now he’s seeing a doctor for a sleep apnea problem he’s got, so we’re waiting for a call, and finally got him a hospital bed for him so he can prop up his head”.

On the other end of the spectrum, one senior was unaware that home care was provided free of charge.

“Oh...I don’t know, working with home care but it costs lots I guess”.

While most seniors fall in between these two extremes, more knowledge about available services and resources is necessary to ensure the health system supports them while aging in place.

5.1.6 Supports for Aging in Place

Transportation Issues

Transportation in rural communities was an issue of concern for many participants, especially for those who no longer owned private vehicles. The cost and inconvenience of limited transportation services can be a large barrier to aging in place. In one community, limited access to taxi services meant that the problem of medical emergencies and attending appointments not scheduled on days when taxis run must be resolved by paying a neighbour to drive. One person commented:

“But there’s him [indicating another participant], he doesn’t have a car...they have to hire somebody and it’s expensive”.

In the case of an emergency, an ambulance can be sent. However, participants commented that they then had to find their own way home. One participant described his experience:

“...you have to find your own way back...and [the ambulance] took me to a nearby community...lucky my friends were there, my next door neighbours they followed me”.

Resource Needs and Local Responses

It can be expected that small, rural communities have relatively limited access to resources and services. In order to help participants remain in their communities, it was identified that some basic services were necessary. Those services identified by participants in this study included a store to buy groceries, a gas station, reliable cell phone service, and a minimum amount of employment for residents to support those services. While out-migration from rural areas to larger urban centres has increased over the past decade, it has been difficult for many communities to provide these services to all community members.

Some communities had adapted to redress the imbalance of resources. We heard of local responses such as selling staple foods from private homes [albeit at high prices]; self-employment in odd jobs such as fixing cars, cutting wood, and fishing; and filling up on gas while in town.

Physical Barriers and Isolation

The geographical difficulties of rural life are many. According to the participants, the largest barrier to aging well in such communities is poorly maintained roads, specifically those leading to their homes in winter. Participants in each group noted that there was a clear-cut need for improved road maintenance including clearing snow in the winter for emergency

vehicle access as well as cleaning ditches in the spring to control flooding. There was concern about personal health because of this situation. We were told:

“When the snow comes in I have to walk to the road, and if something happens you know they [the ambulance] can’t drive into my driveway”.

Housing Maintenance/Retrofit for Health

Housing upkeep and retrofits are essential supports for aging in place. While some participants have had supports such as ramps and grab bars installed, some still live with no running water. We heard:

“Well some of us, we need the waterworks...they [indicating other participants] don’t have running water”.

This did not appear to be an unusual situation.

Some participants listed grab bars, ramps, and raised toilets as supports that would aid them around the house. In order to plan ahead for the future, one senior had renovated a main-floor bedroom into a laundry area so he would not have to go to the basement.

“My house only has a partial basement and the dryer and washer now I’ve moved that up about ten years ago. I’ve moved that up to a small bedroom and created the bedroom as a utility room”.

It is this type of forward thinking that seniors say should be considered when their houses are being fixed. We were told:

“[T]hey give you an emergency program to put a couple windows in and a door, but never look at the future. Like’ there’s an old person living here, they might need a wheelchair- accessible washroom”.

The topic of general maintenance and repair to seniors’ properties was a ‘hot button’ for many participants. We heard:

“We need somebody to fix our houses, we don’t get that”.

“The houses are old and they need new remodelling”.

“They need to be redone. The insulation, waterworks...you ask but they don’t even answer”.

Participants felt that there was a need to ensure the provision of safe, well maintained, and warm housing to successfully age in place.

When financial assistance is available for housing maintenance, often the amount is only a portion of the total cost and the senior must pay the rest. Many participants found this an unaffordable option. One participant related that when help was available to pay for retrofits and maintenance, the added financial assistance could be more of a burden in the long run.

“The problem with those programs though... [they are] considered income against you. And there goes your medical thing, like your deductibles on your medical, it goes sky high. So basically you’re getting nothing for it”.

Supports and Needs for Aging in Place

Although many seniors were still able to perform daily tasks such as cooking and light housekeeping, some important physical tasks were becoming more difficult. Among participants, these tasks included snow removal, grass cutting, wood cutting, general house

maintenance, and upkeep such as cleaning windows and driving outside the community. While some have help with such tasks, others must pay someone or, in the case of wood cutting, use more expensive electric heat. The MMF Northwest Region provides some Metis seniors with wood to offset these costs; however, there is still a need to use mixed heating. In one community, seniors said a summer student was hired each year to help cut grass and maintain community buildings.

5.1.7 *Aging and Finances*

Living on a Fixed Income

Seniors living on a fixed income face many challenges. While some participants liked having the security of a regular source of income every month, others said the amount was not enough to cover basic costs of travel, medical care, food, and shelter.

“The cost of living is higher. Everything goes up but our pension...each time we go for groceries, the groceries went up but our pensions didn’t”.

Transportation to and from town was also seen as an expense. Even though some participants are still able to drive themselves, they said that the cost of transportation is a burden.

“I have to pay my own trip, costs \$40 to go to town. I go once a month”.

For those who cannot drive, they must rely on family members or on taxi services. We heard:

“If you take a cab, and you dig in your wallet it’s going to cost you \$200 guaranteed just to go to town”.

Clearly, for those on a fixed income, the added cost of transportation creates a barrier to aging in place.

Heating one’s house in winter was also seen as a problem. Many participants were no longer able to cut and stack their own wood and reported relying on more costly electric heating in the winter.

“Yes, electric heat you know we’re on an equal payment plan and we’re paying \$245 a month to heat our house”.

While furnace upgrades were mentioned as a solution to reducing heating costs, this too was an expensive option beyond many seniors’ financial resources.

While participants reported making many efforts to keep in touch with friends and family far away, the cost of communication and face-to-face visits were both considered too costly for those on a fixed income.

“Our children live in BC and Alberta and we don’t drive as far as we used to...It’s getting harder to drive up there...It takes two days...We have to pay for hotel rooms...Sure there are costs involved when you want to go down [and visit like] the price of gas”.

Despite the high cost of living, some participants maintained that it was more economical to live in a rural community than to move to town.

“If you live in town you got rent to pay, lots of things to pay like...Here we got our own house, our own wood”.

For those seniors living on a fixed income, they must make decisions about what is most necessary to remain healthy. In some cases, participants confided that living on a limited income forced them to make difficult decisions about their health as some essential items and services, such as dental appointments and hearing aids, are not covered by health plans. Consider this experience as related by one individual:

“Then you’ve got to judge what is most important, you need, the other stuff is...! So maybe you save it for a year to get that tooth pulled”.

From another participant we heard:

“Glasses, teeth, hearing aids, whatever. It’s getting beyond what you need. You can’t just go and get it done because you go to places and they want the money, you know. You get the services, you got to pay for it, and we don’t have that money”.

It was evident from the responses in the groups that this was not a unique situation.

5.1.8 *Aging and Metis Culture*

Cultural Change over Time/Issues with Cultural Continuity

Culture is an important component in the lives of Metis people—it is how they define themselves. For the participants in this study, their culture—including values, customs, and work ethic—has changed over time.

We were told that whereas many people used to use herbs, they now rely on physicians and medication to cure them.

“There was no doctor or nothing...only those herbs...make meds that cure you. And what happened to that? Nobody’s doing that anymore. Too much hassle. Did they pass down that tradition to anybody or is that kind of lost? Not very much, certain I guess maybe a few out of this community, maybe three, or four maybe, will know some kind of medicine like that”.

While some Metis celebrations such as Metis Days and other local events were still held each year, participants reported a decreased attendance by younger generations; however, in one community, youth and young adult involvement in community and cultural events is still strong.

“They’re [youth] getting older too, when they were younger they were home all the time but now some of them are graduating and have to go away and stuff, but if they’re all home for a weekend and something is on they’ll be dancing”.

Respect was also a concern. As aging members of their community, participants felt a general respect from community members and their families; however, this respect was felt less from youth.

“Some people really have respect for elders, especially when you go to town...Not everybody is respectful towards the elders. Not the young people”.

In response to this, participants believe that they still have a role to play in mentoring local youth and teaching them about their culture. Participants agreed that while the older generation has a strong connection to Metis culture, youth are confused about their identities.

“But the young people...I think sometimes they’re confused if they’re native or Metis”.

In each Metis community a different social dynamic exists, with differing volunteer opportunities, and differing levels of respect between youth and seniors. In all the communities, one factor remains consistent. Young people are leaving to find employment. As they move away they have less contact with their community, making it difficult to hold on to their cultural identity. While it was thought by some that help was given to ‘northern’ communities, creating opportunities so younger generations can stay close, no such help was in fact provided for them.

“We’re not a community like in the north country³ where they get assistance; they get to keep all their young people in there. This doesn’t happen in this community. There, not here”.

All the Metis participants had wonderful memories of growing up and living in their communities. The shift in demographics has changed that community life. In one community, participants remembered having large holiday celebrations and gatherings, but indicated that now most people celebrate only among their families.

“You do it yourself, if you got a couple of family, pretty much yourself you know. It’s not like before”.

They also said that their language was no longer spoken by as many people.

“Not us, but our children, our grandchildren are losing their language...there’s maybe five or six here that understand, but they don’t speak it fluently”.

Aside from these difficulties, there are still many community events such as square dancing, bingo, and cards. Also, the Metis Local is active and the hall is used enough to generate income for upkeep and community maintenance. Despite the decline of rural life, many participants thought it was important to pass land on to their children so the community could stay alive.

Metis Culture is Inherent and Alive

While many communities have experienced the out-migration of youth and an increased difficulty in promoting community involvement, some communities have adapted. One group of seniors felt that their culture was alive and well. While they said that no formal Metis gatherings took place, there were many community events and everyone that attended was Metis.

“We don’t get together as a Metis community but anything that’s here or anywhere else we’re always with Metis people visiting back and forth and everything. Everybody is Metis I guess”.

They felt that there was no separation between youth and seniors.

“I don’t think we’re separated in any way from the younger part of this community. We all go together. We all have the same ideas and we can all laugh at the same jokes and like the same music and you go from there you know”.

They also commented that youth were “waiting to be called on” to help volunteer at church and community events and that it is now the role of seniors to delegate and provide guidance. In short, it is apparent that Metis culture is alive.

“Good heavens I don’t even think we know we’re expressing it - it’s just there and it’s very normal”.

³ North country as referred to by this participant meant northern Manitoba

Family Caregivers in Aging

Family members play a crucial part in helping to care for aging seniors. It was acknowledged that children and grandchildren cannot always take on the burden of caregiving as they need to make lives for themselves. We heard:

“You can’t depend on your children. You just can’t do it because they have their own life to build”.

Many participants shared stories about being the caregiver for spouses or elderly friends and neighbours.

“Now that we’re older we have to look after each other more you know”.

However, in some circumstances such caregiving has been at the expense of the other spouse’s health. It was recognized that although they enjoy caring for their families and friends, some help is necessary.

“You need somebody coming in. Like me, I can’t leave for two hours [for a doctor’s appointment]. An hour is about the most I have to be back. So really I need somebody to be put in there for me, you know when I’m long gone”.

5.1.9 Governance and Government

While most of the participants in this study were well informed about the political and social issues affecting them, many felt they did not have a strong voice to make themselves heard. On a national scale some felt that the Federal government did not hold up their contract with the Metis people and that, although they were placed under an ‘umbrella’ with First Nations and Inuit peoples, they were not given the same treatment.

“They think, lots of them you see, the white people think ‘you guys get this, what are you complaining for?’. Like even for here, ‘you must be getting grants and this and that to run this place’”.

Many felt that the small population in their communities meant that politicians would not visit and if they did visit prior to elections they would not uphold their promises.

Although they recognized that participation is an important part of community life, participants were concerned that as they became less able to physically participate in political and community life, their voices would not be heard. Within their communities many participants said they attended local council meetings, although they were often given little time to speak. We heard repeatedly of instances in which their voices were not heard by Mayor and Council, or other levels of government.

“Well, I think it is how you age, you can’t participate in everything. So how are you going to have a voice, if you don’t participate... To be heard. That’s my thing”.

Metis seniors look to the younger generation to make changes.

“The only way [we] are going to get out of the situation that we’re in is if you get your own lawyer, your own doctor, your own [leader] and educate them”.

For the participants in this study, gaining and retaining their voice played as important a role to aging in place as did other factors such as access to health care services and physical health.

5.2 Formal and Informal Metis Caregivers’ Voices

The experiences and perspectives in section 5.2 represent those of informal Metis caregivers providing care for seniors aging in place in the study communities, as well as those of formal caregivers providing or coordinating health services to seniors in their homes or to seniors who have relocated to PCHs. These perspectives and experiences are not representative of the entire caregiver population in the Northwest MMF or PRHA Regions, but they do raise arguments for the importance of aging in place, and they provide a better understanding of the current social and health services available to Metis seniors.

5.2.1 *Aging in Place in Rural Communities*

Advantages and Disadvantages of Aging in Place in Rural Communities

There are many advantages and disadvantages to aging in place in a rural setting. Caregivers suggested that home communities are seen as a peaceful, comfortable place for Metis seniors who have lived there all their lives.

“That’s where they grew up and they just want to die peacefully in their own homes. I would want to rather than in the hospital”.

Aging in place also provides Metis seniors with more independence, an important aspect of emotional and spiritual well-being. Metis seniors have:

“Their freedom. They can come and go as they want. They can do what they want”.

“[An advantage to aging in place is] for them to be in their own environment where they know where everything is and they know it’s their home and they know that it’s been their life for how long. It’s their world... Instead of somebody coming in and saying you have to get this done because we have to go for lunch right away or. And then that way if they don’t want to eat at twelve o’clock if they want to cook for themselves, and eat at one or two pm they can”.

Of course there can also be negative aspects to aging in place in some rural communities. While increased independence is a great advantage, there may be limited informal support nearby (namely family members), and this may be a problem.

“It is also a barrier when they are living alone, when the family is living away. In many cases the children may not be living in the community anymore so they may have a real lack of family...and so family, there may not be enough reliable family support to be able to let them continue to live in place.”

This can also be an issue for formal caregivers attempting to coordinate services for their clients.

“[N]ot all family necessarily lives close to one another anymore. So the mom and dad might still be living in their community but their children are not living there so having their natural support system, it might not be easily accessible so I thought that that was some of the more difficult things of that position”.

However, while support from family can be a problem, formal caregivers did emphasize that general social support from other community members was strong; this community strength does not necessarily exist in larger towns and urban centers.

“Well I think the communities are [a] much tighter knit. There is community support and they kind of watch over each other and even though they don’t even realize it, they don’t have to tell you, it does occur”.

“And out here, when someone, there’s always somebody fundraising for something, there’s always somebody chipping, there’s a social happening for this. There’s always, it’s a community effort when someone’s sick. It’s not just health care systems stepping in; it’s so much about the community”.

In the opinion of one formal caregiver, a large advantage to aging in place in a rural community is that formal services are more quickly accessed than in an urban center.

“You know, as well, the nice thing about rural communities that you can access services much quicker than in a larger community”.

This participant also indicated that because communities are close knit, it is easier to identify new clients and work together to get them services they require.

“I think most of our rural communities are very close knit and I would say that the health units, if I get a new referral for somebody in a small community, there’s usually somebody at the health unit [who] is already aware of this person’s situation, and we, it’s so collaborative, we all work together as a team. Small communities, I think that’s such an asset, that there’s such a closeness, you know...”.

Some of the formal care providers had been in their positions for a long time. They suggested that due to the length of time in their positions, they are able to form stronger relationships with clients.

“Well, we don’t have the hustle and bustle of the city for sure. I think it’s more personal, and you really get to know your clients, there’s not a lot of changing, not workers or case coordinators. You know everybody seems to be here for a long time”.

“The strengths of rural communities, generally the...rural people [who] are in positions of caregiving tend to know the community members well so I think that there are a lot of advantages to that for me, most tend to know who the caregivers are. They have personal and family connections and I think that that can be an advantage more than a disadvantage because there is more trust and acceptance for service”.

“[B]ecause we’re small communities, most of the people in the area know of me. They know their neighbour had home care or someone else in the community had home care and yes, I get to know lots of people on a first-name basis right away. And ‘oh yes, that (interviewee name) you call her’ ”.

Formal caregivers commented that some clients or their families were concerned about personal safety. This included both insecurity due to vandalism and theft by youth, as well as personal safety concerns such as falls or the onset of mental illness.

“Not much because there is nothing to do for the kids they are always getting in to bad stuff and doing drugs. Because like the drop in centers are all broken into or something”.

“[A barrier to aging in place is] having dementia, or Alzheimer’s...or having a fall. They’re with it and that, but one too many falls and the family is scared for them”.

Reasons for Aging in Place

Caregivers observed that aging in place allows Metis seniors to stay connected with their culture and their past. This connection and familiar surroundings are important to spiritual and emotional well-being.

“Well just being able to remain in your own home culture, it’s what you grew up with. It’s what your life is. It is quality of life”.

“And you know, they’re just much happier in their own homes, you know, they’ve lived there all their lives, it’s a big stressor having to make that decision to move, you know once you have to move out”.

“The other advantage is for their own personal satisfaction. You know people want to be at home. There aren’t a lot of people who I come into contact with who don’t want to live in their homes any more. I can’t think of very many times when people really wanted to live in a different place...so I think people are happier staying in their home and if we can honour that by keeping them safe living in their home, financially it would be an advantage and it would be an advantage to their spirit”.

According to formal caregivers, the transition from living in one’s own home to moving into a PCH or an apartment in town is a large adjustment and seen as a negative experience. Most seniors prefer to stay in their homes.

“There certainly are those people who want to live in the PCH and want to go into an apartment but that doesn’t happen to the majority. Most people don’t want to live anywhere but where they are right now. And then if you’ve already made a significant move. You know as a senior, they are probably not living in the home that they raised their family in. They probably already lived off the farm and are living in a home in town or an apartment and they’ve already had that loss. And they don’t want another one and they do view it as a loss of independence of their health and they don’t want that and it affects their mood and their identity and their self-worth”.

“Yes, and you know, I always try to make, when we’re talking about having to move to town when you’ve been rural your whole life, a lot of people have been looking ahead to it already, by the time they meet me, they know they’ve already had it planned in their head that eventually they’ll have to move to town. And you know, when we’re looking at apartment living, it’s a big adjustment for someone that’s lived on large grain farm or a large farm”.

“That’s right, and all of sudden you have people around you all the time. And some people really enjoy the rural life, that’s why they’ve lived there all their lives to begin with. It’s a huge adjustment. And personal care home is an even bigger adjustment. I tell people, I told one lady one day, “You know going to personal care home is like going on a cruise that never ends”. I said “Everything’s done for you, meals are made for you, somebody’s going to bring you your pills, you’re not going to have to make your own bed anymore, it’s a totally different environment”. But most of the people I meet are struggling at home; they know that they need help”.

Along with the emotional aspect of staying in one’s own home, formal caregivers commented on the cost effectiveness of remaining at home.

“...You know, you keep hearing it’s more cost-effective in their own homes”.

“The advantages are definitely the cost advantage to it. You know it is less expensive to be able to keep people in their homes because my awareness of having people be in hospital waiting for long-term service is extremely expensive or of being in long-term care”.

Need for Social Engagement in Aging

Social engagement, according to informal caregivers, is an essential part of remaining healthy and happy in advanced years. According to many participants, it is the strong, positive social and familial connections that help seniors remain in their communities.

“Everybody gets along and has fun together. Roots go pretty deep here for... well all these people are sort of related to me, not closely but back to when the [Hudson Bay Company] post was here... “

“That kindness that people have and like I don’t know, if something happens, you know, they’ll all get together and help out the family”.

“We just love it here...The community makes us happy, like we play bingo, and we go to parties, you know, Christmas parties”.

In communities where strong social ties do not exist, the need for social engagement was deemed a problem for seniors who lack opportunities to socialize and thus become lonely. Informal caregivers said:

“I don’t see other people trying to get, I don’t see the community to come together as an informal group for the older people like for, say cards, or knitting, or something like that. There’s pretty much nothing it’s just us, in our own little world taking care of them. And we have to come up with our little things to do with them. It’s not really anyone else, it’s just us”.

“She’s at home...all the time unless she’s...it’s just because there’s nothing available in our community. That’s just it”.

“I don’t know. It’s not even, in our community it’s not even worth trying. There’s no point in trying, it’s because when you try in our community, maybe different communities are different, but in our community when you try something new it’s like, nobody will like come or try or it’s too hard to get them there, you know. They have all these excuses not to go not to participate. It’s just, there’s just, there’s no point of even trying to do anything”.

Informal caregivers explained that many of the social interactions for seniors in their communities revolved around community and Metis cultural events.

“[Other social things seniors participate in are] Old Time dances, and suppers that the community [puts on] at the community center we go to, the seniors’ centre I guess, we go to dinners and play cards and things like that”.

Formal programs and services such as Friendship Centres, Seniors’ Centres, and Meals on Wheels programs also provide seniors with opportunities for social interaction; the former two offering organized events such as bingo, cards nights, and dances. Such formal programs are typically only available in larger communities.

“...They have a multi-purpose senior centre here in town that encourages their members to come out. They have activities in the paper in the town paper. I try to encourage my mom to come out, to say ‘you know what, do you want to go Friday afternoon to bingo there or Sunday afternoon?’ She’s complaining I haven’t taken her on Sundays for awhile so that is something we might start looking into and there are elderly people. They have a Meal on Wheels program if she ever wants to get into that, she can get that for a price but it’s not going to be that expensive. And then they have these dances, she doesn’t dance but of course she can go and watch and then there is Friendship Centre where we take her for bingos and suppers and dinner and dance, at Christmas time I take her there too, she enjoys that...”

For seniors who are housebound or who have cognitive impairments, it is even more important to have formal and informal supports in maintaining social connections and relationships.

“[They may] have Meals on Wheels or something like that or if someone could take them a meal once in awhile. Especially the ones who are housebound and can’t get out or go and visit them. I’m sure a lot of people would like just to have people go visit them... or you know, someone who doesn’t have a car go and take them somewhere every once in awhile and take them for a ride”.

“...I see her but she’s got dementia, so she doesn’t hardly know people but she chatters along and I listen to her...[I visit her] about once a month”.

One informal caregiver commented that once people move to larger urban centres, they lose contact with people from their home communities; this leaves them in isolation as few people “call anymore”.

“...I was surprised at the amount of people that are Metis and First Nations living in the city, I don’t see them all the time I am surprised when I do see certain people that they live here and how long they’ve been here. You don’t connect with them, everybody is living now and texting and emailing and all that, nobody picks up the phone anymore and talks to hardly anybody...”.

According to another informal caregiver, participation in community activities is essential for maintaining social connections.

“Well for myself [as a senior and informal caregiver] I attend church regularly and it’s nice to have a congregation of all the elderly people. You know as we age, that’s nice and they like to go to bingo when we have it in the community and support the community”.

For some, mobility and other health issues limit the amount of social participation they can have each month. While once a month seemed to be insufficient, one informal caregiver ensures that her mother has as much social interaction as possible. Another informal caregiver always encourages her father-in-law to watch his grandchildren play baseball and to spend time with his son.

“She has resigned herself to the fact that maybe once a month, maybe once every two months [we go on a social outing]. We go more often if she doesn’t get tired from her trips to her doctor”.

“No, he doesn’t go anywhere and he’ll only go somewhere if my husband takes him, if community events, like my husband will take him ‘come on, let’s go watch the kids play ball’ because our youth center has a baseball team he’ll take him there, even for a ride to another community because he has got a daughter over there he takes him around, that’s the only time he’ll go out or he’ll go for a walk to his daughter’s or walk down the street, he’s not very outgoing, he’s too shy to actually go out into public places, he’s very shy”.

In many cases, informal caregivers are the main source of social interaction for Metis seniors. While this has helped to foster strong relationships, it is also important to have time apart—a reprieve from caregiving duties for caregivers and new experiences for seniors.

“She [a sister] was here and she took her for three weeks so my mom is not here. She said, ‘well I will get out of your hair for three weeks’. I said that is not what I want but I want you to go and, while she still can and, move around and do things for herself I think she should be out visiting during the summer. And that’s not because I want her to be away I just need her to get a different perspective and come back and she likes her home, she likes it”.

“...my sister would take her to the local establishment and they would go punch buttons if you know what I mean. I’m not saying that she overly exerts, she knows what her limit is and she just has a drink and plays the [slot] machines that’s all. But that’s like only once every, maybe my sister comes around, maybe once every three, four, or five months because [her community] is quite a ways from here. My other sister was teaching in the community, but now has moved to another town so now my mom has another stop to visit there when she goes up to [my sister’s community]...”

Finally, it was expressed that one positive aspect of seniors aging in place is their ability to stay close to family and friends in a familiar environment.

“I’d say just having your family with you, for him I know he doesn’t, he always told us he would never want to go into a senior’s home, he said ‘it would be too lonely’. He said ‘I like being home with you. I like it when I see the family around and the kids all the time’. And my kids are growing up, pretty soon we are going to be alone, we are not going to have no kids with us but he has got grandchildren that come around and visit him. I think that is all the advantages and making him just feel comfortable all the time, he’s comfortable so, he likes that he likes to be comfortable...”

Change in the Community

Caregivers told us that, as can be expected, changes occur in rural communities over time. Many of the seniors living in small communities grew up there, left to find employment and raise families, and returned to retire close to home. Informal caregivers recounted:

“I don’t know. We love living here, we love the country, because we spent years in cities. You know. My husband always wanted to be here. Of course, we’d have to go away and make a living you know...”

“Young people leave, but not the old people”.

While the population demographic of the small towns in this study consisted predominantly of seniors, caregivers identified that seniors were also being forced to leave to be closer to essential services and health facilities. Although many seniors do not want to leave their communities, often they have no choice.

“Very difficult. My dad didn’t want to leave it but my mom made him come and a lot of people see my mom would live in [town], my dad would live in the community still when that transition took place because my mom was getting older and she was working and she retired. She would have worked a little bit longer but because of her, she was failing on her knees we knew she was going to have to get knee surgery. So we were talking about it and you know it’s almost like I think it’s almost ten years since my mom moved to [town] when you think about it, so she wanted to find a place for my dad but dad didn’t want to move here right away it took a little bit encouraging but after she liked it, the doctor was here the stores were here, she had cable and she had family around that would visit so it was, it wasn’t okay, but it was okay at that time. It was mostly the experience of winter weather and being out”.

Although many informal caregivers would consider moving back to their rural communities to care for their family members, often this is not possible because they also have children to care for and employment outside of their communities.

“...There is no way we could move with him because I have to feed my growing teenagers. There is nothing there for me, so the reason I’m still in the city because I don’t want to look for different job because I’m comfortable where I work. I like working here I’ve been here twelve years. I love

working with the kids I work with kids I am always on the go too. ...just basically being able to have family around is going to benefit the elders a lot to stay home in their communities”.

We were told by informal caregivers that, in some cases, properties have been abandoned entirely. People move away to larger towns and cities and are either unable to sell their properties or it is not worth their time and effort to sell them.

“...they live about a mile out of the community on that road going into the community it’s an abandoned house on the right hand side, you’ll see it. But you see the trees in front of the yard, it’s all over grown. Nothing is growing there now, nobody is living there now. My brother used to live there but then my mom had that same situation with my brother having to worry about water and wood and you have to pay for stuff nowadays, nowadays nobody will go get it for you, everything is a cost”.

Aging and Disease

Caregivers told us that chronic disease management can be difficult for seniors living in rural communities. A lack of services, such as a local store, makes buying healthy food not only costly, but very difficult.

“Well lots of them have sugar diabetes. High blood pressure, heart problems, like different things, having that sugar diabetes....and it’s going to do with our diet, I would say it would have to do with our diet cause we don’t eat, we don’t have access to fruits, fresh vegetables, only this time I wonder...in the winter time, it’s frozen stuff, that’s all we have to, cause we don’t have a store in [our] community....store. That’s the biggest problem we’ve had...We don’t, we just cook whatever we have I guess. Even if it contains a lot of fat, or whatever you know what I mean, cause that’s all we have”.

To manage chronic diseases such as diabetes, some seniors have chosen to change their lifestyles and improve their quality of life in order to stay in their homes longer.

Caregivers told us that other challenges seniors experience are memory loss and limited mobility. One informal caregiver said they had walkers in their house for her mother to get around more easily. This can make important tasks such as getting in and out of a vehicle or bath difficult and require assistance.

“I don’t drive her specifically because we need one person just to get her in and out of the vehicle because of her knees; they tend to be a little bit of stiff”.

“Well if she had a bathtub where she could go in herself then she could do it herself...like the walk-in one but in the apartment that she is living in it’s not, maybe eventually, I think my mom because she can’t lift up her arm too much I think Home care is going have to still continue no matter if she can do it on her own. She probably could, but like I said she’s afraid when she comes out that she will slip and fall. Like I said my mom sometimes her mood is like ‘well I just about fell’. Well there are times you are going be like that and she’s afraid of falling, that’s what my mom’s main concern is, is falling and not getting up and hurting her knee all over again. If she hits her knee or bangs it on the door or something it just gives her, because now she’s got two knees that were done and now it’s her back that is bothering her”.

In order to combat mobility issues, the same informal caregiver tries to have her mother move more frequently and walk whenever possible.

“So I am kind of telling my sister ‘when you take mom out, park a little further down and get her to walk a little bit more’. But with the weather being nice now her home care is going to start

walking her around the block and that's what they did, so they are starting to getting her to do stuff more for herself but making sure somebody is around. You got to be around because she can easily have a flash like with her blood pressure, but you know what, her blood pressure has been perfect every time she went to the doctor so I kind wonder at times you know".

Another informal caregiver shared a story about her mother's difficulties with memory loss from Alzheimer's disease.

"She's unable to do things she used to be able to do, she has Alzheimer's so she forgets the things, a few seconds, maybe minutes, tell her something, she forgets right away and she repeats things or doesn't know anymore I guess you would say".

"But it'd be good like to get them together and get them playing cards for whatever, get them doing things together, talking. Because I know, like I've taken my mom to birthday parties and stuff, and she sees people. I know that she remembers people from a long time ago, but she doesn't remember the newer people she met, and when they talk, they talk about like long time ago and it's really neat to see them interact with each other. It just like lights up their face and they see someone and they remember, and you know, it's really good".

Other chronic diseases such as arthritis, common among some groups of seniors, can make completing activities of daily living more difficult.

"She did her own breakfast and stuff she still can do stuff on her own, it's just that sometimes if the milk is, you know her hand with arthritis she might drop it, that's probably about the only thing, once in awhile that will happen, she dropped an egg or something but she cleaned it up herself and that but I will go and of course do a better tidy job".

5.2.2 Caregivers' Experiences

Informal Family Caregiving

The informal caregivers we spoke with in this study had varying levels of intensity in their care roles and cared for a diverse group of seniors. While some informal caregivers assisted several hours a week with driving seniors to their appointments and helping with activities of daily living, others took on informal care as their full-time responsibility.

"No, this is just it, I take care of her and my kids, so that's pretty much just me".

Many of these caregivers have spent many years caring for their elders.

"[I am] an informal caregiver to my mother... [I have been a caregiver] since she moved to the city since she had her surgeries in 2006".

"I have been an informal family caregiver off and on at least fifteen years".

"[I have been an informal caregiver] it'll be eight years...that's over, in October, already, probably because that's when my grandson was born".

Some cared for mothers, fathers, brothers, and sisters, others cared for grandparents, and others still cared for in-laws and spouses. While all informal caregivers saw importance in what they did, some, specifically those who cared for spouses, did not all consider themselves caregivers.

"I am not a caregiver really, per se. I look after my husband".

Many of the informal caregivers helped family members with chronic and terminal illnesses such as cancer, kidney disease, or cognitive disorders.

“[My mother] was here but she was with my dad. My dad was the one who died of cancer so he was more ill and I took care of him too”.

Some informal caregivers in this study were sole caregivers of a family member, with other family members taking responsibilities on occasion. Others, however, did rely greatly on the support they received from their own partners and loved ones.

“My husband is, I think, I wouldn’t have been able to do this without his support so you have to have your support at home in order for you to help look after your elder. If you are on your own you are going to burn out eventually....she [mom] knows that if it weren’t for my husband helping me I probably wouldn’t be able to do half of what I do for her. So you have to have your support there so my husband is my strong, my strong right arm who helps me”.

Family Obligations, Attitudes, and Rewards in Caring for Seniors

While most informal caregivers acknowledge the hard work and effort made in caring for an elderly family member, they also see many benefits and have generally positive attitudes about their roles. Eldercare can be viewed as a burden; however, many informal caregivers in this study did not see it this way. They saw their role as a chance to repay their family member’s own hard work in raising them.

“And taking care of her needs like the way she took care of me when I was young. So I feel like I’m giving back what she did to me”.

“It’s a lot of work; it’s a lot of work to look after an elderly person. But I think it’s worth it because you know they, well he didn’t look after me, he didn’t raise me but he raised my husband you know and this is a way for my husband to show his appreciation towards him instead of pushing him aside and not wanting him and having being forced to go to a senior home or somewhere else, I think it’s just our way to show gratitude towards him, and he knows like he is very appreciative of it... I think it is very rewarding to look after an elderly person”.

“I think most I don’t know how to word it now; I just like knowing that I am looking after him and knowing that he is safe. I try to do my best for him to make him comfortable, he can still get around and that but I like to see that his needs are met and that’s basically why it has been off and on for the past fifteen years he leaves us but then he’ll come back to us so he has been with us for the past four years and that’s the longest he has been with us”.

“[The best thing about being a caregiver is] that I still have her. That’s she’s still around, that I’m there taking care of her, knowing she’s still with us. So I feel like I’m almost keeping her alive, that sort of thing”.

For many informal caregivers growing up in Metis families, having elderly family members live in the same house was normal. This was part of Metis tradition.

“When I grew up being with, I grew up basically living with my grandma most of the time because I was sickly when I was younger and my grandma was also a health care giver if you want to call it for lack of a better term, she would heal all my wounds and she would pick these herbs and I would go with her and she would make these type of, I don’t know what it was, and it would cure me so most of the time I would spend time with her being the oldest of course, the elderly need help too once in awhile, so I was kind of like helping her too”.

However, while in the past many family members were available to care for seniors, this is no longer the case. Often it is only one person who provides the majority of care while others assist only when they have time, regardless of the amount of care needed.

“My sisters come, and they’ll come a few hours maybe, give or take. [If] they’re not busy with their family then, they will come. So it’s pretty much just me”.

“Because I’m the only one that, all of them have jobs. They all work in the community, so. But I’m the only one that stays home with her.

“We were talking about that if I can’t do that then either one of the other girls because there are seven others of us...”.

There may be one primary family caregiver, but other family members play secondary roles such as keeping track of finances or providing transportation.

“My sister actually is [looking after mom’s finances] yes. She’s the one that takes care of it”.

Many informal caregivers also felt that family members would be best taken care of in their own homes rather than in an institution. While they recognize they cannot do everything for their seniors, informal caregivers can provide emotional support and companionship, something not necessarily received in a PCH.

“I think they’re well better taken care of because we know their needs, because we’re with them everyday, we know exactly what they need, how to take care of them. Like there’s medical things we can’t do, then we can take them to the doctor then those can be taken care of, but us, personally, we know them. We know their personality; we know their dislikes and likes. So we can take care of that easier than other people who just come into the house and do what they have to do, then leave. They don’t understand”.

“...it’s almost like a reverse now it’s almost like, I’m not saying I’m the parent but you are parenting right along with them that is what it is. I think personally that is how I look at it”.

Other informal caregivers felt that they were now able to build relationships with their parents that were not possible when they were younger, perhaps because they went away to school or moved out at a young age.

“Well you spend time with your mother, I went to a residential school in [a different community], I moved away when I was 14 and I came back when I was going on 19 so that was five years and when you go to school you get bussed and that is over 7 hrs away from the community if you take a look it’s past [community] kind of an idea where it is, so um you get to know your parents over again”.

Some noted that as they had families of their own and became more mature, they better understood their parents and as a result their relationships changed.

“Because when you leave and you are just a teenager and you know teenagers they think they know everything, but when you are older and you got your own family then you go back to your families like a boomerang effect you have to be like, you got to learn everything all over again, like how your mom and dad lived and how they want to live and how they want to be treated”.

Informal Caregivers Staying Healthy

Informal caregivers shared that it was important for them to take time for themselves, relax, and lead as healthy a lifestyle as possible. Some went for walks alone or with their children.

Others would leave their home environment to go to town or spend time with other friends and family members.

“I watch TV or go for a walk, that’s basically it, spend time with my grandchildren I have 5 grandchildren so I go play with them that’s basically all I do with them...”

“I go for a walk with my kids. Or take a bath. That’s like running away from everybody. Or I go and visit. Just doing little things with my kids just to get away. Or my time is like go to bingo, or when it’s time for me to go to town like I get my cheque, I just go on my own, I don’t take my kids, I just and my sisters stay at home. Just things like that, or talking on the phone, going outside talking on the phone, just letting all my frustrations out and like what’s bugging me and stuff. That’s pretty much how my time is well spent. Because there’s not much to do in the community. I look at trees”.

“...[I] don’t do much traveling because I can’t afford it but I’ll go home, and then I’m stuck there because even if I wanted to leave I can’t until my husband comes back!”

“I go out at social outings. I don’t participate in alcoholic beverages, I haven’t drank for years and I chose not to because I tell people I can still have just as much fun sober as I can drunk...So I go walking or when my sister comes in we’ll go out. Like I said, just sitting outside with my family having a barbeque”.

“I work [to stay healthy] I don’t really do much. I work a lot, I do work a lot but I work with kids too so sometimes it gets very stressful. But the kids, like I work with the square dancers and the Pow Wow and the fiddling and I supervise the youth centre and they go on outings so I try to participate in these outings with them and watch them play baseball and just try to be with them or otherwise I am home, that’s about it. I’m going on holidays next week so I will go back home to [my community] and I am there for about 10 days but I camp right on the [Treaty grounds]. They have their Treaty days so I camp right on the Treaty grounds and that is my holidays for the year I won’t go back until next year but it’s basically the only time I’ll see my family because I have no family here, all my family is in Winnipeg or in the community so that’s the time I get away so I look forward to that”.

Many informal caregivers said they tried to lead healthy lifestyles by eating right, getting exercise, and seeing their physicians on a regular basis. One informal caregiver spoke to us about her own health and the importance of making change to enable her to age in place.

“Well, about three years ago the doctor said you’re border line diabetic so right away I started thinking that I’d go blind and I started to walk. I walk twenty-five minutes every day. And twenty-five because if I make it any longer I’ll get lazy but twenty-five it’s a good time. And I walk and I’ve lost thirty pounds. I just saw the diabetic nurse the other day and she said that everything is great like my blood sugar is where it should be and everything. So I watch what I eat and I exercise...Yes and I’m hoping that I can stay longer in my home”.

Others told us:

“And my husband and I both have diabetes, so we have to watch what we eat. We see a nurse regularly”.

“Well, I try to eat right. And exercise and dance...see my doctor”.

“I have proper rest, to have, you know, meals, most of them boiled stuff, roast like you know”.

Stresses in Informal Caregiving

There are many causes of stress for informal caregivers. As relationships change between family members there is often strain and growing pains. Dependency, communication issues, expectations of each other, multi-generational caregiving (caring for both parents or grandparents and children or grandchildren), and a lack of employer understanding about the caregiving role were central topics that arose throughout the informal caregiver interviews. For those caring for seniors with cognitive impairment, the stresses of caregiving include their need for constant care and their need for reminders about everyday tasks. Caregivers in this situation have little free time and in some cases feel isolated.

At times informal caregivers felt their elderly family members were overly dependent on them. At times they felt that their family members could be more independent, but were unwilling to be.

“[She is] fairly independent, like but she won’t go anywhere without me. Appointments, monthly appointments we make together, I take her shopping after or for supper then I take her home then she is okay for another few days then I will call to see if she needs anything...”

“All of these forms have come to my mom in the mail, she’ll phone and say she doesn’t understand them, basically...I think my mom is just lazy [laughs]. She worked in the school for eleven years as a guidance and nutrition counsellor you would think she would understand. She just wants me to do things for her I think. Kind of like payback for when I was a teenager. For the most part she does know it”.

“My mom will always say, if I don’t phone her every day or every other day, she’ll say something like and this is just her talking, it’s not that she is upset with me but just her voice will say ‘Oh you remembered that I am here’ or something like that you know. I think at least you know what I am doing it purposely and I don’t because sometimes I do forget...”

In other situations, some seniors may feel uncomfortable or embarrassed about a personal problem they have and do not communicate it properly to their caregiver until it becomes a major issue.

“When he doesn’t tell us what’s wrong like its very hard to, when he does get sick he doesn’t tell us things, makes us feel helpless because we don’t know what is going on so I am actually in contact with the dialysis unit and they will let me know what he has to do or else he was cancelling appointments without even telling us he had to go to them, that’s the most difficult part I guess. He doesn’t really talk to me much because I’m the daughter-in-law but he will tell my husband, and my husband will come and tell me and I will be like ‘why didn’t he come and tell me’ especially if he’s not home, but he’s a very shy man and he doesn’t really like to talk to anybody really, so and when I think that’s the most difficult thing...”

Perceptions of unreasonable demands of promptness and accountability can also be problematic for informal caregivers.

“Once in awhile I will take her out to bingo when she is feeling well and she wants to be there at a certain time so she’s how would you say, like being from a community where she has done everything on her own to waiting for somebody, it’s not easy for her, I understand where she is coming from but with the city life you got to understand there are people that are ahead of you that are driving slower, there’s a school bus or [whatever]”.

“[We live in the] same community but it still takes a lot of, like it takes me about five minutes to get to her so she has an appointment at 3 o’clock and I get there five to three she is already a little bit, ‘I thought you said you would be here at ten to three?’. She’s specific, she monitors and she gets upset when her time has come and she is going to be late for an appointments, she doesn’t like being late”.

It was also common for some caregivers to help look after both older and younger generations in their family. While this could bring joy, it was also seen as an added stress.

“And I am talking about my grandma’s husband the one that is 100 years old. My grandfather moved to the city and so before my parents did so I looked after my grandparents before my parents so that’s another thing that people don’t understand is that it’s not one generation, it could be two or three if you are a younger person...”.

*“Like people think it’s just *sigh* and there’s some much complaining. Like sometimes I know I do that, not complain but she frustrates me when I have to repeat things over and over again. And then my son is giving me a hard time and my daughter and it’s just like I just want to scream at the top of my lungs and just run away from them. I tell them once in awhile, I just want to dig a black hole and get in there for awhile”.*

While informal caregivers took their roles seriously, some found that their employers were not understanding about their added responsibilities. Often vacation and sick time is used to run errands and take care of their family member.

“The people that I work for they don’t understand that [taking care of] elderly is not something that you take lightly, and I don’t take it lightly I can take care of my grandmother too if she was here or my uncles or whatever like if they need something”.

“I asked my son to take time off work and he wasn’t compensated for that so my mom gave him enough money to drive there and back but he lost wages because there is nothing in place for them to claim that they are elderly support. There is nothing right now for me. I take my holidays and my overtime in order to do this for my mom. They [employers] should have an understanding, like bereavement leave they give you other than that they don’t help you for elderly support...”

“...Because the way I look at it, I take time off from work and I get it taken off and I have to get it pre-approved so I get a little bit of, how would you say, difficulty at times trying to get the time off and if my mom changes her appointments and I go back to work I don’t take that day off I get a bit of flack. If the appointments are going to change because you took that day already, take it. I don’t feel like staying home and not going to work. I have been working since 1973 or ’74 on and off with a couple of lay-offs here and there but it’s something I have been doing and I don’t want to stop until I retire...”

For informal caregivers aiding family members with cognitive impairments, isolation and insufficient reprieve from caregiving can be a problem.

“[The most difficult part of being a caregiver is] time, it takes a lot of time for me”.

“[The most difficult part of caregiving is] cooking, cleaning, changing her clothes, making her to remember to take care of her pills. Reminding her constantly about things. That’s probably the most stressful, is the reminding. Having to repeat things over and over again. Pretty much her basic needs”.

“Honestly I am. I’m just in my own little world with my kids and my mom”.

Work-life Experiences of Formal Caregivers

Formal caregivers provided an interesting and important glimpse into their work as health care professionals working with Metis seniors. While some caregivers explained that they work just to make a living, most said they liked being able to help others and give back. When asked why they chose this career, the following responses were given:

“[I like] The feeling of leaving [work] and I’ve helped somebody”.

“I just work to pay the bills”.

“[I like] nothing really. It’s a job. That’s all I can say. As long as I can bring home a pay cheque and look after my son I’m happy”.

In general, formal caregivers feel their time is stretched thin due to insufficient human and financial resources.

“There are supposed to be eight aides on each side but usually somebody phones in sick or something happens and they can’t cover that shift so we work short and then there’s always a bath aide and if there is no bath aide then there is only three aides on the floor and the other one has to bath... There are enough staff but people get run down from working short all the time”.

“It’s just that I find that there are not enough workers out there. There are not enough health care workers or not enough nurses out there for anyone. Even when you go to the clinic or to see the doctor you come and tell them and they don’t really even look at you. ‘Ok you get this, or there is nothing wrong with you come back in ten days’”.

Poor communication can also be an issue at times.

“When you tell them something about a certain patient and then awhile later you tell them again and they say ‘well no one told me’. There’s a lack of communication there. Or also when something has happened and then they don’t tell you because there are workers there and they don’t bring it up often, they only say it once and they think that everybody should know already. And then when you go in to work well you can’t do that because this had happened, but I didn’t know”.

For most caregivers, taking time off or calling in sick is not a large inconvenience, but they do realize that others will have to compensate and people still need to be cared for.

“If I’m not feeling good or my kids are sick then I phone them ahead of time and tell them that I won’t be able to make it so that they have that amount of time to phone people to come in to cover my shift”.

“[When there aren’t enough staff you] work short, what else is there to do? These people need to be looked after and things need to be done”.

5.2.3 Formal Caregivers’ Perspectives of Personal Care Homes

Positive Aspects of Personal Care Homes

From the perspective of formal caregivers, there are many positive aspects to seniors relocating to PCHs. Importantly, in such facilities the residents are well taken care of with nurses and physicians making regular visits.

“Oh yes, doctors will come in every two to three weeks to come check on their patients, and the nurses are there to give them their pills”.

Some seniors are reunited with old friends and space is made for couples to remain together.

“Some of them are with the people they were with before. Like for example, say we grew up together and then now we’re together again...They like that, ‘Oh I know this person.’ I’ll be pushing them and they’ll say ‘Oh I know that person’”.

“There have been a few couples. Right now there is only one couple left, but because the other one had passed...They share a room. They have separate beds but they share a room and have their own privacy”.

For those who are often alone, staff and volunteers encourage them to socialize with other residents and partake in communal meals and activities.

“Oh yes, we try to, there are a couple of them who don’t want to come out of their rooms they want to just stay, they come out for supper and then they stay in their rooms and they don’t want to come out. So we convince them to come out and we introduce them to people who like to talk so then they have fun right there. There are those who play cards, we sit and play cards and do puzzles”.

There are many activities residents can participate in including watching black and white movies, doing puzzles, listening to music, helping make perogies, going on outings in town, carolling at Christmas, and family visits. There are also many volunteers who come to help out and spend time visiting with residents and doing activities with them.

“Especially like the working staff after they reach a certain age, retirement, they have nothing to do after that. And they are our volunteers right there. The older generation like, I haven’t seen the new generation come in and volunteer yet”.

“Well volunteers are really good. The older volunteers are really good because they are good with the residents so like as [PCH] staff we are only there to do so much, we [do our jobs] and stuff like that but the volunteers, I’m really happy that there are a lot of volunteers”.

“To me it’s just like the volunteers that do lots. It’s just that the activities workers who do work there they do their part but they don’t do enough for the residents”.

“They go and take them to the beach. I volunteered a few times to go to the beach or to walk them around the hospital a few times or take them to [the local ice cream store]”.

Lack of Cultural Support for Aging

While not the case in all PCHs, in those included in this study, little accommodation was made for the residents’ varying cultural differences. While there were a number of Metis staff on site, there were few considerations for Metis cultural activities and events.

“Oh, not really. The only thing I can see is the fiddling maybe. The fiddlers come in sometimes. Not really, there should be more stuff”.

According to local health care staff, there are no PCHs geared specifically toward First Nations or Metis people in the Parkland Region.

“So you move them out of [home and into] a more mixed nursing home where nobody speaks their language, nobody understands their culture necessarily...I mean what’s important to us is totally not necessarily what’s important to them...And they’re a very strong people so. But I think that’s the biggest, once they get old and there isn’t family support, they know that the only place they’re going to go is totally outside their community and their people”.

Cultural activities they may have taken part in such as smudging are prohibited because of building regulations, thus the responsibility is placed on the family to organize and participate in such activities.

“No. I asked them about that like if my uncle wanted to smudge or something, he would have to go outside because there is no smoke allowed in the buildings. But it would be up to the family members to bring everything in and take him out to do that”.

Formal caregivers suggested that simple activities such as bannock making, beading, making sashes, drum lessons, and providing DVDs and reading material on Metis culture and history would be a good way to make Metis residents more comfortable and ‘reconnect’ them with their culture and community.

Needs in Personal Care Homes

Formal caregivers identified that more activities, including outings, are essential to boost residents’ morale and create an enjoyable experience in the PCHs.

“Well I told you about more outings, like coming to pick them up and take them out. They do that maybe once every three weeks. Take them out more often”.

Not only do residents need more activities, but they also need a wider variety of activities. As one formal caregiver explained, residents get bored with the same activities every day.

“He said there is only so much you can do in your bedroom. Who wants to sit there 12 hours a day watching TV”?

“And yes, more activities. Like right now there is especially for Town there is bingo. Like who wants to go to Bingo every single night. I used to love to play bingo, but now I find it so boring. The last time I went I wanted to bring my kids’ video game to play at the same time to keep myself busy”.

“There should be more because at the care home it’s only the workers who do things. Maybe there should be more like outside of the care home type things. There is one resident and he is young still and he can still walk and he always says ‘I’m bored, I’m bored’. So there should be more stuff for those types of people”.

“I think more things to do because us [...]there are only really two that look after fifteen people to take them to the toilet, do their hair, whatever, and then there’s other ones who are supposed to do stuff with them. Save more of that for the evening because in the evening there are only three [of us] and one nurse on looking after maybe thirty-five people so we don’t have the time to engage but in the evening they’re all, when we have time like I go around and paint fingernails and sit and talk with them or we’ll put on a movie. The movie that they always like is the ones with the animals that talk. So we put that on and you can hear them laugh. And I just talk with them because that’s what they miss the most, someone sitting and talking with them instead of always being on the go. I’m busy, I gotta go, I’ll be right back’. And we don’t have that time at night. So, yes, more activities for them in the evening and not just during the day”.

In addition to organized activities, it is also important for residents to have access to resources that allow them to pursue their own interests.

“I don’t think there is a library there, but there is a church there, a small little chapel”.

The infrastructure in some of the older PCHs also needs to be updated. In some cases new equipment needs to be purchased or the actual building needs maintenance.

“Like even us in the kitchen our equipment fails. Like last week the dishwasher failed and we had to wash dishes by hand for a week and a half. There is a lot of stuff that needs to get done to this place and I wish they would just get it done”.

“The building is very old. Like there is mould. I know there is mould in that place. The equipment is old. Like there is a lot, to fix that building properly would cost a lot of money but it would be worth it. Like these residents spend their whole cheque every month and they should deserve to get what they pay for”.

Loss of Independence

Just as many Metis seniors themselves mentioned that entering a PCH meant losing some of their independence, formal caregivers also commented on this issue. They spoke of how the transition to live in a PCH could be a long and difficult process.

“Yes it [the transition to a PCH] can take a long time. Sometimes it can take a year”.

“Some of them don’t like it they want to go home. ‘I want to go home’ they always say. And then they tend to like it because there are good activities there and they get used to it eventually”.

Often formal caregivers mention that residents reflect on what they “used to be able to do”. Now they must have family permission to go outside. In part this is because of PCH liability for residents, and while this is understood by staff, it can be a source of frustration for residents.

“Yes like my [family member] has been here for six-seven months already and he hasn’t gone outside yet. There has to be a request, I talked to someone, she said I have to get family consent and this is my own [family member] just to take him out and take him around the block he would enjoy the fresh air. But she said ‘you have to get family consent’”.

“Well for us kitchen staff we have to run it through the supervisor to see if it’s all right for us to bring people inside the kitchen”.

“Like some residents will come to me and ask for something to do. But there is a part of me that I’m scared that they’ll cut themselves, fall, get burned. It’s sad for me to say ‘no, you might get hurt’ but they want to do something instead of walking around in a circle all day and watching the same programs. It’s hard but we’re trying to, the residents come first so we just don’t want them to get hurt”.

The most difficult thing for residents is not being able to go outside when they wish and no longer being able to visit family.

“Sometime people just put them there [the PCH] and don’t come and visit them”.

“I don’t know this old man at work called it a ‘jail’. He’s not used to staying indoors all the time. That’s one of the problems that I have with this place is that the activities worker they don’t do, like even to go out for a nice little walk with them just go for a walk”.

5.2.4 Positive and Negative Factors to Aging in Place

Itinerant Services

Itinerant services, or services that come on a regular basis to the community, are home-based services that assist seniors to age in place in their homes, giving them the freedom to make independent decisions about their care while getting the temporary or long-term help

they need to remain independent. Most frequently these are also known as home care services; however others services such as mental health, occupational therapy, and physiotherapy are also provided to clients in their homes.

Although each service serves a different function, they work in collaboration with each other to provide clients with comprehensive services to meet their needs.

“Well because of our initial [home care] assessment, like we’re assessing their needs and so these come up you know? Yes. These services come up and then we just, we’ll ask and if they agree, we’ll refer them to the services”.

“We refer to physio[therapy], occupational therapy, speech and language, we refer to we have Meals on Wheels we have an adult day program. Oh I’m just trying to think what we refer to; we just have lots of things to refer to. Yes, Meals on Wheels, yes”.

Case workers can also make referrals for non-itinerant services as well, such as dieticians, specialists, and community services and resources.

“I can certainly refer to dieticians if there are concerns with their dietary needs. If I see somebody that is struggling with the cost of dietary needs say Boost, Ensure you’re looking at \$3 or \$4 a can to buy them in pharmacies or grocery stores or department stores, I can assist them to order bulk through hospitals”.

The resources themselves, according to formal caregivers, are up-to-date and most people know about the services.

“I think most of them are quite up-to-date, quite up-to-date. Most of our smaller communities have all different kinds of different outreach programs now too for community health, community wellness response, different programs besides home care they’re giving information out to people”.

The typical entry point for most seniors is through home care services. This, according to formal caregivers, is also the primary (and sometimes only) resource for rural communities.

“What we have in most of the rural communities or based out of larger rural communities to age in place would be home care. That is a primary resource...”.

“So there’s basically not a lot so it’s home care, there is like if home care requires an occupational therapy assessment in the home, we do have that availability through our program. Mental health does visit the community, not directly to their home unless they’re housebound”.

According to staff, home care services are referral based. This means that any person who feels their family member or friend needs the service can call and make a referral and a case coordinator will set up an appointment to assess the senior’s needs.

“We would contact the person the concern was about, we won’t necessarily who made the call to us, we would just say that there’s been a concern would they agree to a home care visit and see if we can help, or if there’s anything that can be done. And they have the choice to refuse or accept...Anybody in the community can refer”.

Home care service availability is also varied in rural communities. Communities are typically assessed depending on the number of clients they have, and staff have a set client list they visit on a regular basis.

“Oh, I’d say, I think in that area, they do [two communities] combined, I think we have five or six [case workers] ...Yes. We try to maintain that [serving the same clientele] as much as we can”.

This, however, was not what we heard from Metis seniors themselves.

Assessments with occupational therapists can help clients age in place by getting them the necessary physical supports they need such as walkers, raised toilet seats, and other such equipment.

“Occupational therapists, I’m actually going out with him today we’re going to joint home visit with someone who is struggling with obesity and is not managing in their home, we’re going out to see what we can do, jointly together. So anybody that I see needing help with equipment should have a wheelchair ramp in their home, they’re struggling with bath time, safety issues, cooking, maybe they need some adaptations done to their stove or to their counters”.

Mental health services also provide care specifically for seniors. Services are provided in the client’s home but, depending on the client’s comfort level, alternative locations can be agreed upon.

“And it wasn’t very often that people did not want that but if they chose not to see me in their own home they could certainly meet me at a local health office, a local community health office and that was an option, but about 99% of the time I was going in to their homes. And you know seeing people whether they lived in a small rural community or if they lived in remote, rural area”.

Home care workers refer mental health services if they see signs of memory loss, depression, or other mental illnesses.

“Yes we have access to mental health workers. If I get concerned that someone’s cognition is changing or they’re having memory struggles, if our home care workers are noticing some safety concerns, the stove is left on, you know they’re not home when they say they’re going to be home, or anything that kind of cues us to that there may be something going on mentally or if we somebody is really struggling with depression or there seems to be a psychiatric illness that we’re not quite sure, it’s never been diagnosed, we have access to mental health and mental health workers for seniors to do home visits, which is nice”.

Also available to a limited number of rural clients are mental health support workers. These individuals assist seniors to carry out daily tasks such as banking, grocery shopping, and other errands. There are limited resources for this position, and the service is only available to clients who are unable to do such tasks on their own and who do not have informal family support.

“Support workers, they need people, we don’t offer it to all people because if you have family that can be a support to you have that and we wouldn’t offer it. That position is a half time position...Absolutely. We monitor that position. We make sure we pair it up with people who could truly benefit from it because they don’t have any other resources available to provide that. So those are all the resources that are available”.

In some rural communities in the province, home care workers can arrange to have medications delivered directly to the client’s home. This, however, is not the case in all rural communities in this study.

“I mean they do have pharmacy delivery in [community]. So if I have orders and I need medications brought up to a client, I can fax them to The City pharmacy and they can deliver them to [community]”.

Barriers and Gaps in Health Services

Most of the basic needs of clients are met by health care services. However, as with any system there are barriers and gaps, especially for seniors and those living in rural communities. The largest barrier, mentioned by both formal and informal caregivers, was transportation to appointments and vital services.

Another barrier for those living in rural areas was back-up if a home care worker was unable to make a visit to a client's home. Identification of an 'alternative' family member or friend to help the client is established at intake to care. While in theory this is a good system, in reality some seniors living in rural communities may not have the necessary informal support close by. Home care services are not considered "emergency" services and therefore service providers are not required to travel to their clients' homes regardless of weather or illness.

"Yes that's put in place when I go out to do an initial assessment after I've gotten a referral that is part of my assessment and learning package for the client and that's certainly, I verbalize it, we talk about it, discuss it, that you need to have a back-up plan and I give them specific examples of what things can happen that you know, for a meal or a medication reminder or something that is considered essential you know. They need to have a plan for who's going to come over and make them their meal that day or assist them with their medications if home care's not available that has to be. The onus is on the client to make sure they arrange that. It's usually I'd say 90% of the time we can find an alternate worker. There are some areas in the Parkland where we have very limited home care workers though, so resources are not that good".

"Our home care program is not a guaranteed or emergency service. If a home care worker is scheduled to work and there is a snow storm or there is an illness in the family or she's ill herself, we do our utmost to try and replace with an alternate worker but if that cannot be provided the expectation is that every home care client has to have a back-up plan if there's no home care worker available".

"It falls back - like for the home care program each client has to have a back-up system, so either family or neighbour or friend. Somebody that is aware of their needs and is willing to provide this service if home care cannot make it. So if we somehow don't have service for whatever reason, that back-up person is contacted to provide this service".

The RHA offers services, however small, in most communities in their jurisdiction, yet rural communities typically have limited services. Seniors from many small communities must travel to access secondary resources such as recreation and community-based services. The remoteness of some communities can also make coordinating necessary services very difficult.

"It's very difficult for them [seniors] to access any program where they are there [in their community]. It's not like in town where you can you know, walk three blocks to the doctor's office or to the pharmacy or anything".

"Exactly. Now in [a community] we have a congregate meal program that you know in [a different community] which may be close by and people are still able to travel so they would be taking part in but it's how they get there. So for some it may be a barrier if they don't have a ride".

"I would say the most difficult part of being a caregiver would be, being a non-family caregiver, would be trying to organize natural resources like family support and resources that are unpaid for and trying to kind of organize them and identify what I think the need is... what they are willing to

accept and trying to strike a balance to manage their safety and their basic needs of living and trying to come up with a compromise in some communities and areas all those resources aren’t really very readily available. For [the] communities for example, or some of the places where people live, home care doesn’t have a lot of access to because it might be very far away so they may have a difficult time trying to bring staff in to that so sometimes you feel like you are not really meeting peoples’ needs very well because there are lots of barriers. Not necessarily your own program’s barriers, but other programs’ barriers to being able to manage it”.

These limited services may also mean that while services do arrive, wait times can be longer because one staff member may cover a larger area and thus come to each client with less frequency.

“And even though we’re rural we have access to you know all the like occupational therapy and so on that we refer to, although we only have it weekly usually. That is sometimes a little bit of a, you know can be a problem area because you want some service applied right away you usually have to wait so. You always know you have to wait and you tell people then they’re prepared and you know”.

“Just that we only get, like I said, some of the resources like OTs, the PTs, are here weekly. But sometimes if one of these, like say for example, there would be an occupational therapist that is coming in our area, they may not have coverage, they might get coverage once a month. And that doesn’t happen frequently but it does happen. You know, because they don’t have the resources to put out there”.

The emergency telephone service ‘Life Line’ is a service that allows seniors, by pressing a button, to make calls to first response and family members in the event of an emergency. This service is not covered under Manitoba Health, however, and in some communities it does not work with the existing telephone infrastructure.

“Now I do know under some situations social assistance has, or systems have, been put in place where, for medical purposes, a phone will be installed. I don’t know exactly how that all went about. But you know even Life Line is not available in [community]... No. it doesn’t work through their phone systems... They have to have digital lines... So like you know how we tell people you should have Life Line that way if you fell you can just push a button and get help but they don’t even have access to that”.

An important gap in services relates to family needs. While home care services focus specifically on client needs, they do not assess the family or their roles in the process. This can lead to future issues for informal caregivers.

“You know I think that the services that we provide the things that we do are their very best to meet the needs of the general population. There are things that we work especially with seniors there are things that we need to be more generalists as well because we are not always identifying the individual that is our client. Like the family needs support as well, and it is more just for the individuals themselves”.

Transportation was often mentioned as a large barrier to accessing services that do not travel to the community. While home care can assist in the home, many other health services such as dentists, physicians, and even the food bank, must be accessed by the individual in a larger center, typically several hours away.

“So and I know in the past, I’ve even tried to pick up stuff at a second hand store or the food bank to pick up their things when I’m going there, and that’s not possible, so they’d even to come to the food bank they’d have to pay that fee”.

“...On the other half of that challenge, for most people in smaller communities that are seniors, is transportation. That’s the number one issue”.

“I think you know transportation is, and access, transportation, access to adequate nutrition, food supply, like, it’s very difficult for them to get to a grocery store to buy food at all, never mind proper nutrition. Transportation is a huge thing”.

“Because there are lots of services out there but if you can’t get to them...I would certainly like to see some, each community have some form of transportation that was affordable. I would say that if I ever won the Lotto Max [lottery] that’s one thing I would do for my own community is put in some kind of transportation for seniors that was free. And have the yearly upkeep of the vehicle, and there are enough people that are retired and looking for something to do, to volunteer to drive”.

“There’s not really many people that I’ve come across that don’t have some family support that could provide transportation, certainly [in a community]. You’re looking at a 45 minute drive to the closest hospital. There is a small health unit in [a nearby community], which they have access to, they have a doctor there once a week and a physician’s assistant. So there are you know, that is probably a half an hour trip so they do have access with not as great a distance as some of my other clients that are further up north”.

There are very limited services for seniors who are still relatively mobile and independent, but need some extra assistance. Additional assisted living and seniors’ apartments are necessary in the Parkland Region.

“Just have you know the resources, more resources, you know access to the resources would be better. More like an assisted living would be very beneficial. More apartments, you know EPHs [elderly persons housing] for them”.

“Maybe because we don’t have, you know the resources right at our fingertips like the cities do, and you know, the waiting, just for example. I’m trying to think of examples. I have an elderly person in the hospital, they just can’t go home because him and his wife, they’ve only been married, 67 years old, don’t get along but we’re waiting for an apartment in the elderly person’s home, and there’s a shortage big time. There’s no assisted living here, and there’s always a waiting list for clients to get into the elderly person’s home, so that’s definitely a barrier”.

“I think some of the things that are lacking are opportunities for seniors to be able to live safely in their homes longer than they do you know certainly they encounter... physically...and safe in their homes you know when a nursing home [PCH] becomes an option very quickly. We certainly don’t have enough housing options before long-term care for people who are cognitively impaired and not able to be at home but they are physically functioning at a pretty good level in terms of their mobility is good, they can independently feed themselves you know they just need more supervision. We don’t have any in-between resources like elderly persons housing between the PCH. We are getting an assisted living program in the city that will be able to take care of ten individuals at a time”.

For seniors who may live with working family members, there are no known services offering private or public companion support. According to one formal caregiver, such services would have to be negotiated privately between the family and the person offering the service.

“One of the things that is a barrier is that in the rural communities in the Parkland [RHA] we don’t have any companion support. There is no companion care or like you would get in [an urban center] that you would need companions for. We don’t have that in the Parkland. There is no program or independent person who is offering that sort of service so if people do get that it’s usually that they negotiated with somebody they know or they’ve hired personally and independently but not from an agency”.

Travelling to Provide Services

For formal caregivers working with services that provide care in the communities, travel for home visits is a large part of their job. Protocol is different depending on the service. Policies for home care differ from those of mental health services; however, all staff are reimbursed for their travel time and mileage through their employer. Frequency and distance of travel can also vary depending on the region covered and the person’s position. Case Coordinators, for example, may travel to communities once a week to assess clients, but home care workers travel on a daily basis. For the average staff member, the furthest they travel is approximately 1.5 hours one way or 150 km.

“In terms of time the furthest I usually drove was about 1.5 hours. But that would be probably about 150km...I would go on average once a week and that would be one distance - so If I were to go to [community]... that would take me about an hour and a half one way and then I’d travel back another hour and a half. So you know once a week if I went that far it could be three hours of travel. Once a week definitely to Town, that was two hours of travel”.

“The longest distance I’ve had to travel since I’ve started is an hour and a half commute each way...No, I have a pretty large catchment area. I cover all the rural areas in the east district of the Parkland so excluding [several remote towns]. I cover all of it...In a normal week I would say I’m out of the office three days a week”.

Mental health workers are provided with RHA ‘fleet’ vehicles when they travel for home visits, although occasionally a personal vehicle is used, in which case mileage would be covered. A fleet vehicle is a car owned and maintained by the RHA.

“What I would do is that I would take a fleet vehicle. The [Parkland] RHA. I seldom took my own vehicle. The only time I would have to take my own is if all four of the vehicles are already previously booked and I was either...or it was just a last minute call and I had to go. So then I would take my own vehicle and they would pay the government rate for mileage”.

Community Supports for Aging in Place

In the rural communities in the Parkland RHA, there are some formal services to aid seniors aging in place. Formal client-based services include such programs as home care. This service assists seniors with their daily tasks. According to one health care professional, this service seems to be in high demand as there are always positions open for home care attendants.

“I think they have home care workers that will go into the home and help them get through the day and I think they go for the breakfast, lunch, and suppertime and then they’re there to make sure that they took their pills”.

“Oh yes home care maybe because there aren’t many people doing home care...They are always looking for home care attendants not around here, but in the rural areas like that they are always looking for people”.

The Parkland RHA funds initiatives through the ‘Services to Seniors’ program. This program funds the congregate meal program and a number of community resource coordinators who provide information about resources for seniors, and who support seniors in group living and in a supportive housing complex. Supportive living support is located only in larger urban centres in the RHA.

“The programs we fund are the congregate meal programs, the community resource coordinators who are actually people in the community who would be kind of the one stop shop for any seniors to go to if they have any questions or concerns or looking for somebody to help them out or, they would go to that community resource coordinator”.

“[For the congregate meal program] we have twelve communities, we have twenty programs but some of our bigger communities have more than one program, but we have twelve communities. We have eight community resource coordinators that cover nine areas, but then that’s for the Parkland”.

“It [service for the congregate meal program] depends on the community. It’s only three days a week. Now the meals can also be taken out, so somebody could, you know in order for people to have a good meal, you could still go and pick up the meals, if we have volunteers that can be delivered to your house if you can’t get out, but then that’s of course within the community but not them driving all over the [countryside]”.

“So we have the congregate meal program, we have the community resource council, we have the support seniors in group living which is like a community resource coordinator who go in the community where the support services to seniors worker is in an actual building amongst after the people per se in the building like an EPH [elder persons housing] or whatever the case may be. And we also are looking to open up our first supportive housing unit and that will be here in The City”.

In rural communities, formal caregivers acknowledged the importance of home care services for seniors. However, they also emphasized the fundamental role family plays in a senior’s ability to age in place.

“To keep them in their homes they definitely need, you know, home care support for sure, that’s really important, that seems to be the main you know family support is very important but, very important, but home care is very very important also”.

Community volunteers are also essential to supporting many programs in rural communities. Because limited resources exist, most of the community-based services are run almost exclusively by local volunteers. Some community-based programs, such as the congregate meal program, need volunteers to receive funding. If there is insufficient leadership or volunteers in the community to take ownership of the program, funding will not be provided.

“Being able to put dollars in every little community, finding the volunteers to get these sources up and running because they’re non-profit. But those, there’s a lot of onus put on them, they’re hiring so of course there’s a lot of human resources pieces, then they’re just volunteers, they just want to have that program in the community. They don’t want to be doing all the other bits and pieces, of hiring staff and the whole bit...there’s a huge gap”.

“Finding volunteers to assist with the programs and because the programs are all, like we’re the funder for the programs but the communities themselves are the owners of those programs, so to find those boards, non-profit boards to develop and take ownership and try and find staff and stuff to provide those programs. I myself don’t personally provide those programs. We as PRHA provide the funding”.

“Well not per se in the communities, I mean we’ve done a little bit of preliminary work actually with [community] to get a congregate meal program going out there, but the community needs to take ownership of it, and that’s where we lack in, it’s a lot for a community to take on, so then right away seniors get turned away”.

At times, the amount of time needed to run these programs is a big deterrent for those wishing to help.

“Yes. And that scares people away from being involved because they don’t want to have that extra added responsibility, they just want to have a congregate meal program in the community which they know that everybody gets healthy meals, they’re by the Canada Food Guide, everybody’s eating together”.

Social dynamics are different with each Metis community. However, one factor was mentioned by all participants, including formal caregivers. There are insufficient youth, or younger volunteers, to assist with community-based and volunteer programs in rural areas.

“Well we need to figure out how to bring on younger volunteers because what’s happening is that the communities, the volunteers are becoming the participants that need the service...The transportation and we don’t have so many, the smaller communities, we don’t have younger people coming back to the communities so you are relying on each other, which is kind of a vicious circle. We don’t have the volunteers, we don’t have the transportation that they need that but there’s really nobody there taking that over so where it’s going to go in the future. I don’t know, we talked about that, look at the model a little differently because things aren’t the way they used to be”.

Due to financial restraints, other community-based programs funded through the ‘Services to Seniors’ program are typically only run in larger rural communities.

“Yes and no. Taking staff we have out in the rural areas transportation. So if they have somebody who can take them and as long as they have use of a phone they can at least phone the Community Resource Coordinator, but not every community has those either, I mean we only have a certain amount of those and they’re more in the bigger communities as opposed to the real small communities”.

While it is sometimes difficult to recruit volunteers on a regular basis, in many rural communities, neighbours, friends, and family often help seniors by ensuring they are safe and comfortable.

“I think the neighbours too they keep a close eye on the old ones too if they can’t do something or they see something then they contact the police or the ambulance for them and that”.

Knowledge of Services

According to formal caregivers in the PRHA, access to the health care system for seniors is relatively easy. All services in the health care system are integrated and there are many different points of entry for clients. Once a senior has used one service, it is easy for them to find out about, and access, other available services.

“Yes, it’s very much a team effort and I would say, for the Parkland area, we have good resources, and I mean I find the staff who work in community health are very outgoing and will go out of their way to try and accommodate people”.

“I think between, like it’s so much a team effort now from what I’ve certainly learned in the last four years that once you’re in the system, however you’re referred, everybody works together as a team”.

“...Once you’ve seen a Case Coordinator, we seem to coordinate everything...Certainly, I mean you know, basically helping somebody arrange for a one time bath, and suddenly I’m arranging for their chemo treatment. So it’s a very all encompassing job but I love it”.

“Yes it is a very holistic approach now because if I see somebody, if I go out to see somebody or there’s a referral to me from a physician, and I have concerns you know, say I have concerns this person is feeling a bit confused, this person isn’t taking their diabetes medications and they’re frequently hospitalized, as a team we work together to figure out ok, is it just this person’s lacking education? Maybe this person doesn’t have the ability to learn. So that’s just an example how the whole team would work together. You know this person’s frequently in the hospital, they have no family support, even with the maximum home care service we have, they’re still struggling and putting their own health in jeopardy they may look at that person needs to have an alternate living situation. They may need to be in an elderly person’s housing unit where there’s more frequent supervision or supervised supportive housing”.

Although the health care system itself is integrated, some programs such as home care are in higher demand. Others like mental health services are less widely known about and are therefore not used. One health care professional estimated that this service would not be able to handle the workload if people knew about the programs.

“It seems like home care is a pretty well known. People know quite a bit about it, like the general public is pretty aware that home care is available. It’s not consistent from province to province but they know it is available and can get it. But in terms of mental health services I don’t know that that is something that is widely known. I’m not getting many referrals from the clients themselves or their families. It is generally from another care provider that has phoned. It is generally our referrals are coming from the doctor’s office and from home care or the nurse practitioner. I’m not even getting a lot of referrals that are coming from family. So I think that people are not aware of that. That mental health services are available to all. But at the same time the people we are getting referrals from are using the service appropriately. They are making appropriate referrals and they are doing it more and more. So I can’t even imagine what it would look like if there was an increased demand if family members were giving referrals. It would explode”.

For seniors who are not already using services in the health care system, it can be difficult to find out information. Seniors’ centers and community centers are a common place to find out about health programs and services.

“I believe so, each community has their own little community centres as well and the drop-in centers help everyone, call them kind of their own little gathering places, we try and reach out to them as well, provide them with information, but I think I would think that people do, but I could be wrong”.

While finding out about available programs and services is relatively easy for seniors, accessing those services is more difficult. One professional caregiver suggested that the processes, paperwork, and arrangements involved were too confusing for many elders to navigate themselves.

“No. I think lots of times it becomes much too confusing for them, especially if they don’t have good family support or back. You know just, I mean I’ve had to phone systems and try to arrange

funding for a ride into Town, or a medical appointment or whatever, or special approval for certain things. It’s quite a process”.

For community-based services, community resource services seem to be rarely accessed. Neither service programs nor community councils seem to be proactive about providing information to seniors. This can make access for many seniors difficult when they do not know where to look for information.

“I think unless they needed actual services from the community resource, I don’t know if it’s referred that much. It’s more so okay the client needs, they have a system for laundry or housekeeping, automatically there’s a community resource council they’re referred there. The only difference is home care is free where ‘Services to Seniors’ is the seniors pay, there’s a fee for service. But I don’t know, I can’t answer that, how much they”.

“You know, I’m not sure the council office, they never requested through me to provide any kind of home care information or pamphlets or I know their physicians are very well aware and I get many referrals through physicians, through other family members and community members”.

Informal Caregivers’ Knowledge of Home Care Services

Some of the Metis seniors with informal caregivers also received formal home care services from the PRHA. For most informal caregivers, this is the only service in their community they are aware of to assist seniors to age in place. Informal caregivers have varying levels of awareness about the PRHA home care services. For those caregivers with no first-hand experiences of home care services, little is known about the program, including who pays for the services.

“There’s home care workers here but of course, I don’t know how good they are because I don’t know”.

“I don’t know. I don’t have to pay; we don’t have to pay for it [home care] anyway”.

For those who do have experience with home care services, the learning curve has been great. They often know nothing about services available in the community for seniors other than home care.

“We looked at different possibilities, when we started with home care it wasn’t as easy to get the first time but they knew that they were an elderly couple. I think basically at first when she had her surgery I thought that after she got better they would drop her just you know, let her be on her own but they continued to support her...”.

“There is home care, I’m not aware of others [services] in the community we haven’t had to have home care so...”.

Only with time do people become more comfortable with home care processes and formalities.

“She gets updated, she got a visit from home care just to make sure because sometimes they want to know that she’s still there, she’s still getting the treatments, they will go and visit her”.

In most circumstances informal caregivers are comfortable with the level of care their family members receive.

“They do a little bit of light housekeeping, they will prepare her a little lunch, maybe a pot of tea, and they will see if there is anything she needs like if she picked up something and she dropped, you

know like a stool or something, they will pick it up and put it aside so she doesn't drop on it. She could probably do it herself but my mom, I don't want her bending down too much because of her high blood pressure but otherwise I do that, but she has a bath twice a week and she was supposed to do physiotherapy”.

Many caregivers advocated for their family members to ensure they have necessary services. At times, this has been an effective approach.

“...Because he gets pampers or whatever he needs. And he's got a hospital bed... [he has this] because I asked for, I asked for one [through home care services]”.

However, with others such advocacy is met with frustration, especially when dealing with issues of continuity of care on a daily basis. One informal caregiver was often frustrated that her family member could not have the same person provide care, as she considered continuity important to keeping her cognitively impaired family member comfortable.

“See and then, when I asked for that [a constant home care worker] they said it wasn't, they weren't able to do it, it was just who was available at the time. They weren't able to do it. So I was just looking out for her. Like they don't understand as to what I go through, they just understand that this person is available at this time, so they should be there, but in reality, I'm looking at it from her point of view. I'm trying to keep her as comfortable as I can. Like, 'Do you get it?' Like it just, it irritates me. It irritated me when she said that to me, I just like, was so frustrated. I don't know. That's how I view it”.

Another informal caregiver expressed the importance of having Aboriginal or Metis home care workers care for her mother. She felt her mother was better able to connect to such workers and was happier with this type of culturally appropriate service. She had inquired in the past to see if this was possible.

“She doesn't have one on Wednesday. Wednesday is the only day that they don't have anybody and they are non-Aboriginal caregivers also, that's the other thing that I wanted to know is how many Aboriginal caregivers there are and how many can be given to her at least once every few months just so she could have that [relationship] established...”.

Misconceptions of Resources

For both formal and informal caregivers there were some misconceptions about the type and availability of resources. One health care professional explained to us that referrals for the home care system can be made by anyone. This was not widely known by participants in this study. Most clients assumed that a referral can only be made by a physician.

“I mean, anyone can refer someone to our program...It doesn't have to be a doctor, it doesn't have to be the person themselves, it can be a concerned citizen phoning and saying I have some concerns”.

“Usually when I go out to see somebody they've already heard about home care services and heard my name from someone else. And we get referrals from doctors and you know hospitals, certainly give us lots of referrals, neighbours, anybody can make a home care referral. A person has to be accepting of it though. I cannot just go out...That's right. And I have lots of people that are in dire need of some assistance but if they refuse it and they're of sound mind there's nothing [I can do]”.

In some circumstances, resources available in rural communities were thought to be in better condition and more frequently accessed.

“There is [a community health resource center], behind the school in [community]. There is an office building or it looks like a bungalow...That is the PRHA, and that is the community health office and the public health nurse from that works out of [community] and also covers [community]. So I think he’s up there on average of one day a week, otherwise he’s in [community]...”

In this study we observed that the building referred to by the formal caregiver was never used by residents and had no wheelchair access.

“I think so. Certainly you know, I think the Parkland does a really good job of reaching out to people in communities as far as flu clinics and diabetes education, they’re all, every small community has a community health office where the services are provided and they’re always free”.

“You know I think the other services I mean I think they’re as far as the medical part of it, I’m not sure how often social workers actually go up to that community, so I don’t know how much access they have to those services hands on. I don’t know what their policies are. As far as the Primary Health Care Centre, that has improved, they are at the best they can get right now there was a long time where they had a building but no staff”.

One formal caregiver observed that, if necessary, Metis clients had access to the clinic on a nearby First Nation. There are some jurisdictional issues involved with Metis accessing health services on a federally-run First Nation’s Community Health Centre that the formal care provider may not have been cognisant of.

“Well I know there is a Primary Care Centre in [community]. As well they have an assisted Primary Care Center in [another nearby community] which is the regional health care clinic type thing. A doctor visits [nearby community] and the Reserve as well which they [Metis] have access to. I know there is the home care services, which provides the same kind of services as the provincial program, so personal care, meals, cooking, that kind of stuff”.

Maintaining Independence through Seniors Housing

In the opinion of many informal caregivers, seniors’ housing in their own rural communities would be the ideal solution for seniors to maintain their independence and stay close to family and friends, while still getting the extra care they need.

“That’s what I would do, I would try and build something there that they could live, I know they have one in [another community] and it seems to have worked. I know you are moving them away from their home, home is where they’ve lived, but if they were to have a central location and they are still in their community. They started a community garden in the community that I think they could probably assist in some way close by there and it’s not far from the school they could witness kids having fun outside and then there’s the lake, and you know like some place where they could feel comfortable and it’s secure. I would, that’s what I would do [to make the community a better place for those who are aging]”.

One of the primary reasons for moving into seniors’ housing is that their safety is guaranteed. This is crucial for many in small rural communities where there are problems with youth delinquency.

“If she had a place where she know that she was safe, but then the community too, she knows how the community is with young people. There are a few people left in there that she knows, but more young people now so I think if she were to decide she would have to weigh the pros and cons, and if they were to build maybe a seniors centre there, they would have to be secure and I don’t know if you

can give somebody 100% assurance that nobody is going to come and raid you. Home raids have been known to happen”.

While in some rural communities seniors’ housing does exist, there are few units, they have no additional services to assist seniors and, in one instance, their location can make them insecure.

“There are two buildings that are here in the community, [an elderly friend] lives in one of them...’but they are kind of out in the bush somewhere?...mostly sort of yes, that’s where the houses are located...it’s tough...one of them [is built specifically for seniors] well there’s two of them I told you there’s one of them there and another there”.

Seniors’ facilities in nearby communities are ideal for those who need extra attention but want to stay close to friends and family.

“Well they do then to move to, like they have these seniors’ residences in a nearby community where people have moved. That way they’re walking distance from the hospital and they’ve moved from here to there....it not really big, it’s not a two story building, it’s long and they have their own entrance and can sort of look after themselves and get help if it’s needed”.

PCHs, on the other hand, are seen by most as a last resort. For many, this is seen as a loss of independence for seniors. Some seniors become resigned to moving to a PCH when they think they will become a burden to the rest of their family and friends. As caregivers age, they begin to understand these sentiments.

“Yes I think it [moving to a PCH] would be [an option]. I don’t like to think of having to go away from my community, but I guess...I really wouldn’t want to [move]. I have a daughter who comes here, she’s a nurse and I’m hoping that she’ll sort of help us to stay home a little longer, but I don’t want to just have to depend on her either”.

“Oh yeah, she herself says if the day then comes where you know I can’t do anything for myself, like she is willing to go into a personal care home. She doesn’t want to burden, that’s the one thing my mom keeps saying over and over when she phones you is that ‘I know you are busy and whenever you have time I need this, this and this’, and she always says that because she doesn’t want to place any undue hardship onto me, she knows I’m busy, she knows I got other things to do besides looking after her daily, but I keep telling her like you know what this is something that I want to do it’s not something that I am getting paid for, well inadvertently now through Revenue Canada, but somebody has to do it and she choose to move to town, she was even considering moving to [another town] if my sister would move there, she’ll move there, so she’s not set, she has some ideas”.

However, having PCHs located in small towns closer to rural communities can help seniors adjust to life there as they are more likely to be surrounded by friends and family they have been around all their lives.

“...But if not then we are considering possibly putting her into a personal care home. And she herself says that she will go because my grandmother, who is still alive, knock on wood, is 100 years old. That’s my mom’s mom she’s in a personal care home in a town nearby. We just celebrated her 100th birthday party in the community at the hall so it was good for people to see her longevity. I am just amazed she lasted, she does not remember, but she seems to be happy in that environment. So my mom is even considering going to that one [PCH]”.

While many informal caregivers have come to accept that PCHs are a viable option for many seniors, they recognize that this is not the traditional way that Metis family members were cared for. This makes decisions to place seniors in PCHs a difficult one for the family.

“...So I think we have resigned, I shouldn’t say we have but I think from what she tells me I guess I can safely say this, is that you’ve learned to accept the non-Aboriginal way of looking after your elders because my grandmother, when I was a kid, my great grandmother was bedridden; my grandmother looked after her until she died. And if you wonder why she is 100 years old I think it is because somebody up there knew she did a lot of work and that’s why she is still with us. That’s the only way I can think of it because my great grandmother was a real handfuf, I was just a kid and I understood. My grandfather too. My grandmother kept both her parents until they passed on. So my mom was considering taking my grandma in but my uncle took her in and kept her right up until they couldn’t keep her anymore, she needed assistance physically to get in and out of bed. My mom was going to do that, but because she was working and my dad was still alive it was kind of like you know, sometimes families don’t always get along like they should. So like you know the in-laws theory well that worked sometimes. But not negatively over the years people get that feeling ‘well your mom never liked me’ type thing but it was not the case but in your mind. So it was a little bit I think at first my mom why she didn’t take my grandma was because of that so”.

Seniors No Longer Able to Live in their Communities

For seniors from rural communities, one of the largest barriers to remaining in their homes is the harsh winter climate and chores such as snow removal and chopping wood.

“Oh we think about it [moving to the city] sometimes...because my husband doesn’t like the cold. In the city we can....he doesn’t have to carry and load [wood] or anything like this you know... and the driveway gets snowed in”.

For others, a lack of amenities such as running water and heating has forced seniors to move to town.

“Like I said my mom didn’t have a choice she had to move away from there, there was nothing. If there was something there for my mom she would have stayed, both my parents would have stayed if they would have had some help somewhere to help them live comfortably and that is running water and heat. Because as they, as the winters go they are harder and then for somebody to come and shovel your driveway too that is another stumbling block, like how do you get out of your driveway on a storm. You have to pay somebody to come and scrape your road”.

Additionally, the costs and logistics of transportation to town for medical appointments and provisions can be a determining factor in seniors’ decisions to move out of their communities.

“Well my dad was getting ill and they knew. They didn’t have running water, they were trying to get it, the house was proving to be difficulty with the roof leaking, they tried to get assistance but couldn’t. My dad still drove, they had a vehicle, they would go to town but those medical trips were to another town and that is costly, but that was their trip in. It was cold in winter then, my dad wasn’t feeling well enough to cut wood and get water, they had to pay so my mom weighed her options and she felt that if she moved to [town] than it would be better for them even in the winter time”.

Health conditions can also force seniors to move closer to health care facilities regardless of their ability to undertake the activities of daily living (ADLs).

“It’s sort of isolated I’d say. Because you are going to town and then you hit a nearby community and there is really nothing close to it, but this was before he went on dialysis I think and then you get to the reserve and then you get the community. So it’s in that area. Yes it must have been about ten years ago that he lived there because then he started dialysis and he moved”.

“They [my parents] could move back in the summertime but eventually the years turned worse for my dad so he stayed here, but he moved back to [the community] and stayed on his own too for awhile when he was able to. My sister would look after him over there, she lives in [another town] so it’s not far from him so she also looked after my father right up until we finally made him come to the city the last year before he passed on and he really wanted to go back home, but he only made it as far as the closest hospital and then didn’t make it after that, that is where he passed away was in the hospital, he had a heart attack”.

In some cases, seniors live in their communities for most of the year, but move to the city or stay with family members during the winter months.

“Because we have a home in town; our daughter’s home now. And we just go there to be away from all the cold weather and snow shovelling and all that”.

Inadequate Resources to Remain in the Community

As in most remote areas, the communities in this study did not have sufficient resources to aid seniors aging in place. When asked if there were any services for seniors in the communities, the overwhelming response was “no”.

“If I wasn’t looking after my mom, who would? You don’t have that elderly outreach worker out there, knocking on doors or whatever”.

One informal caregiver said that to make the community a better place for those who were aging, she would put all the resources in place so seniors could stay in their communities.

“What would I do? I don’t know. Put all the resources in place for them so they don’t have to leave like have everything there for them so that they can stay in their community”.

One informal caregiver suggested having medical services—a physician or nurse—visit their community once a month to provide basic tests like blood pressure and insulin levels.

“Maybe they could have a visit from the doctor or a nurse, or something, once in a while, you know, once a month to check their blood pressure, and their sugar and whatever”.

In addition to medical resources, there are also insufficient community resources. In several of the communities in this study, there are no stores or gas stations, so if one does not have a car it can be very costly to get transportation for long distances to buy groceries.

“If you don’t have a vehicle that’s too bad, because you have to pay lots, and most of them are on social assistance, it’s very hard, it’s not easy huh? You can’t even buy milk, bread...I don’t know how much will it cost, if it’s more than town, but I mean you don’t have any choice if you have to, I guess it’s like any other remote place I guess, huh?”

“Or we go to the city for our groceries... It’s I think about 62 km”.

Seniors’ Self-Advocacy and Care

For seniors, self-advocacy is an essential aspect of aging in place. For some seniors, there can be a tendency to rely on others to speak for them. While having others to advocate for

you is important, informal caregivers understand that their elderly family member must do as much advocating for themselves as possible to remain as independent as possible.

“The other thing that I have been teaching my mom to and I shouldn’t say teaching in a way as in teaching, kind of like a strong word, but my mom doesn’t take any flack, she would phone and say ‘you know what I don’t like this’, I said ‘mom you know what, you got the ladies phone number, phone her, you know if you can’t find it or you are having difficulty give me a call I’ll do it for you’, but when I find it I phone her after a couple of hours she says ‘well I phoned’. I said ‘see, you can do it you can take care of it’. You know like little things I am trying to get her to not be so dependent on me”.

“She goes to her monthly visits and she makes them herself, like when she is there I’ll do it for her but to a point, there are times when my mom feels like as if somebody should do it for her and I think it’s just because she gets into those moods”.

“My father-in-law is 82 years old and lives in the community he’s on his own, his daughter lived with him but his daughter is now retired so he’s now on his own but he has another daughter that lives there and she kind of keeps an eye on him, my father-in-law is also old school, where the woman is the one that makes his dinner for him. If he doesn’t get fed he won’t eat, he will just have a sandwich or something. That’s the type of [thing] so it’s kind of like they are almost the same in mentality nowadays”.

Other seniors can be very outspoken and express themselves, their needs and desires, very well.

“But she is very diligent that when sometimes her home care workers sit there and tell her their problems. My mom is a listener, but she gets irritated sometimes, so she’ll tell the worker ‘if you can’t help me then I think you should go home and help yourself, she’ll send them home”.

“Because she’s had complaints about her home care workers sometimes they change and she doesn’t like so she’ll send them home, sometimes they are late and she’ll say, she expects them like when I said when she expects them at 11 o’clock she expects them at 11 o’clock not 12:30. If they phone and try and buzz her she’ll say ‘You know what? I don’t need you, you are late, you may as well, and I don’t want you here for 15 minutes”.

Another aspect of self-advocacy and care is looking after one’s own expenses. While some seniors require some help to ensure bills are paid on time, those who live on their own still manage most of their own finances and pay their own bills.

“She pays for all her stuff; her meds, her food, she maintains her own budget, and she knows how much she has got. She’ll question me ‘cause I have power of attorney where I can go and get her rent money, I have to pay her rent next week, as a matter of a fact. She is away for three weeks so I go do that and I get a receipt and I put it in her, we developed a place in her home where I put all her receipts so she knows where they are and if there are some missing we dig, and if we can’t find them we don’t worry about it. I don’t think Revenue Canada is going to come knocking at her door to find one receipt, as long as they see January to December. Other than that, she pays for everything”.

Many seniors also understand the time and dedication it takes for their family members to help them. While many typically live on a strict budget from their pensions, informal caregivers told us that seniors will offer what they can to help with extra costs and will show appreciation by compensating family members for their time and effort.

“Basically my mom, my mom will give me [money], I don’t want to take it, but when you are dealing with, I will put it in a generalized comment the older elderly people from my community that I know of, including my mom is that they want to give you something even a few dollars for compensation”.

Maintaining independence and completing daily tasks on one’s own is important for aging in place. Also important is that seniors should be able to advocate for themselves and to seek help from family and friends, or from formal services, when it is needed.

“...To do the laundry and it’s along hallway she’ll take her time. Otherwise she’ll ask me to do it for her. She’s starting to go towards asking me to do things for her”.

At times some caregivers may provide too much care for seniors, making it difficult for them to be independent. While some seniors are able to communicate with their caregivers, and exert their independence, it is entirely dependent on the relationship that exists between the senior and the informal caregiver.

“...We try to do everything for him, but sometime he gets mad at us because he lets us know ‘I can still do stuff’ so that’s why I try tell my husband you know let him do things, he does his own laundry because he doesn’t want me to do it. He does it for himself, keeps his own room...”.

5.2.5 Financial Barriers to Aging in Place

Client Costs for Services

While most health services to seniors are provided free through the public provincial health care system, some services have additional fees. One of such services is the emergency telephone service ‘Life Line’.

“And certainly things like Life Line, that’s a national program that there’s always going to be a cost to. Certainly it’s affordable for the average person, but some people do have struggles with that. Certainly I have assisted some clients through that are on collecting income assistance, on you know how to discuss that with your counsellor, your income assistance counsellor, that this is the necessity and sometimes I’ve written letters and I’ve had doctors write letters to help people get assistance with that too...The Life Line program, I’m not quite sure if it’s a private company, run through your phone lines. And the cost of it is about a dollar a day. So some people that is \$90 every three months, some people do find that a struggle...And some, a lot of seniors are on a very fixed income. Yes, so that is something and it’s certainly really beneficial, for a senior living alone...Remote area, as long as you have a phone line you can have a Life Line. It’s not something that home care provides, but I provide the information about it, and I can certainly suggest that they look into it, I can set them up with the closest distributor, every senior’s resource office in the Parkland has, that’s who we refer them to for Life Line. So there’s senior’s resource in X., and senior’s resource in Y. and between the two places they kind of cover all of that area”.

For all non-itinerant services, the largest cost to seniors living in rural communities is transportation. This can be particularly expensive for seniors who are no longer able to drive. As no public transportation exists, taxi services and private vehicles are the only way to get to larger communities with essential services such as physicians, pharmacies, food, etc.

“Cost of service, having those services available in their community and transportation”.

“Once they’re on pension, everything becomes even more limited. Because just from what I know about private hiring [transportation] to go as far as the city is about \$100 but take that out of your grocery monthly money”.

Some larger communities have access to a Handi-van service, a public transport system; however, there are costs per trip which, according to some health care professionals, is prohibitively high for many seniors.

“We have, in some of the communities, they have handy-van, again cost is an issue...And then they’re having problems finding volunteers to do that. And that’s usually run out of the RMs, the Rural Municipalities in each community, but we find that only our bigger communities have those as well, our smaller ones don’t have that. For them to get the handy van to come in is astronomical”.

“It’s kind of expensive. It would be nice if they could get a big bus for people to go on trips. The Handi-van is a little small. With a big van, eight could get in and go to the beach or something. But it is only small, maybe like two or three could get in there. For example, maybe the walkers could get five or six of them. It’s not so good for wheelchairs. But the ones in the wheelchairs would like to go too”.

For seniors who need to travel to Winnipeg for medical treatments, the cost of food, transportation, and lodging are all paid for out of pocket.

“Exactly, if they’re going for a medical appointment in Winnipeg, I mean, they have to do overnight, and the costs just go up and up and up, and there’s no system for any of that”.

For many rural residents, most out-of-town phone calls are considered long distance. Since many of the services seniors need to access, such as home care or physicians, are located in larger centres, there is an additional long distance charge for many. At this time, home care services do not have a free ‘1-800’ telephone number to call. While residents who do not have long distance access are encouraged to call collect to the home care office, this process is very complicated for many.

“They do know that they can call our office collect, but that is a complicated process for them...No, and that has been discussed. Yes. That has been discussed many times, but no, we do not have a 1-800 number. And again, like we’re still pushing the 1, I tried to use coin phones and call the office and hit the 1 and automatically it goes to the operator. So even the 1-800 number wouldn’t work for them. They’d still have to go through an operator and say 1-800”.

“So it’s not like the access isn’t there, the big problem is though from [community] is that when they are trying to call my office or the Town office is that we’re long distance for them...And most of them don’t have long distance access. Like majority of my clients don’t have long distance access, there is no cell service up there, so like even to push 1 and then a number, it’s not possible”.

For seniors who have more severe cognitive impairments or illnesses such as Alzheimer’s and who live with family members, adult day programs are an option. Currently there is a cost to these programs, leaving families to pay out of pocket. For seniors who need assistance with meals, the volunteer Meals on Wheels program is also an option in some larger communities. However, there is still a fee for service to cover the cost of food and meal preparation.

“Like some of the services they would pay for would be the adult day program, and Meals on Wheels and yes some people complain about it, for sure. I mean they’re on a fixed income so”.

Informal Caregivers’ Knowledge of Financial Barriers and Supports

Informal caregivers often take on a large financial burden in addition to their regular responsibilities for family members. While many have sought support from various organizations, this is often a very long and complex process with little return. While some seniors' medical expenses were covered, none of the informal caregivers were reimbursed for their time. The typical response from informal caregivers was "I haven't been reimbursed for anything".

Many seniors live on a tight budget, often relying on Old Age Security as their only form of income. Knowing this, this money was regarded as seniors' money and informal caregivers did not expect their elderly family members to pay for additional costs such as transportation or medical expenses. These expenses were typically paid for by the informal caregivers, unless the senior offered to contribute.

"He gets old age security. I don't even know how much he gets".

"We pay for them [medical expenses]. If he has money he'll buy something to eat or whatever, but we basically, well I basically pay for everything because my husband is not working right now too. He has been taken off work because he had a heart attack, he has been off work for almost two years now and the doctor won't let him go back and he is not receiving any kind of what do you call that, sick benefits, it's basically me".

"I don't know how it fits in like physiotherapy it was just something the doctor said she had to take after her knee surgery, she doesn't go anymore, she only went for that little time and then the medical appointments. She just gives me a few dollars for gas and that's it because you need, for Revenue Canada purposes, you need to go further than forty kilometres. In the long run, I told her you know what, it's just something that you are going to have to pay for a cab anyway; you can't claim it which, I think is a little Catch-22 situation, where it's okay for people to claim past forty kilometres, but what about the people who are in town? That's one of the things that I would like to see, something that is not in place right now, she doesn't get compensated for her gas or her, she had to take a cab which she did take a couple times because my husband wasn't available, so it takes two people away from jobs to take one person. I could get a cab to pick her up, but then she doesn't have that, she's not, she comes from the old school and what I mean is that she doesn't have that, or she'll feel uncomfortable trusting somebody you know how people, she hears stuff on the radio, so she trusts her family to take her from point A to point B and she's okay with that".

The largest expense for many informal caregivers and seniors is transportation to and from medical appointments. While one informal caregiver was aware of a free service from CancerCare Manitoba for seniors with cancer, she did not know of any other transportation resources.

"It would be good to have someone to drive people to their appointments and whatnot. I do believe that at one time they had CancerCare drive them to their appointments. CancerCare did that but for other problems I don't think they have anyone driving, to drive elders around".

One informal caregiver sought donations from the MMF and other charitable organizations such as the Kidney Foundation to help cover the cost of travel for medical appointments to Winnipeg. However, these donations were limited; so many medical and transportation expenses are covered by informal caregivers themselves.

"Yes, through the MMF and through the Kidney Foundation. MMF has helped us about I'd say four or five times, they can only give you so much, they go by donations so they gave us maybe \$50

more I can’t remember and then with the Kidney Foundation they gave us \$200 card, a co-op gift card [for gas]”.

“That was very hard and that’s basically probably all that’s hard and we did get some help from MMF for gas and the Kidney Foundation did give us too, but we only get it once a year so that if he has more appointments we are on our own”.

Another informal caregiver sought donations from the local Friendship Center to help pay for transportation and other medical expenses. This participant noted that community was also a large support when raising funds for medical expenses.

“It’s close enough to things that we can always rely on somebody like the Friendship Center, they have been a great help to me they have helped me with booking hotel rooms where I just pay for it after when he comes, we don’t have to pay for cash right away, so the Friendship Center has been a big help for us and then again the financial help that they gave us. I think if we needed I think we would find a way like people in the community would find a way to help us get him over there if we couldn’t do it on our own, there are people in town that would help us”.

In some cases, tax credits were sought for those with disabilities. This can be helpful in alleviating some extra expenses and avoiding yearly rent increases. One informal caregiver was compensated for her time through Primary Caregiver Tax credits.

“...I just got her, like I said the disability tax credit we are waiting to hear back from Revenue Canada and I told her this will alleviate your rent increase, hopefully they will give you back a little bit. I am not saying it will be monetary but at least you won’t have to pay that much on your next year’s income tax...”

“I just recently got compensated for my time and I was grateful, but not grateful in the way that you mean. I got primary caregiver tax credit through Revenue Canada so I got \$1000 for two years, they went back to 2009. So that is going to help I think a lot of people like such as myself, but I am not looking at it that way. But a little bit of compensation won’t hurt...”

Another informal caregiver sought help from Veterans’ Affairs to seek compensation for caring for her terminally ill grandfather, who was a war veteran.

“As a matter of fact I looked after my grandparents when they moved to the city from their community, they lived here. My grandfather died here, my grandfather and I fought with Veterans’ Affairs and he took me and we talked to them until we were blue in the face to support me, to give me money to help look after my grandfather who was dying of cancer and he was a war veteran”.

Health Literacy and Cost

Health literacy is an important aspect of maintaining quality of life and aging in place. While some information about health services such as home care is typically provided by a physician, often informal caregivers and seniors do not know where to access it.

“No, well the only time I get information like that is from the nurses at the dialysis unit. If they get something they will say this is something he can look into and then I’ll read it to him or explain it to him, it’s more or less just us”.

“I think they do because if they need home care they’re probably referred to home care by their doctors. They don’t have to look around or anything”.

For many seniors, their main source of health information is at the hospital. This can be intimidating and confusing for some seniors and lead to miscommunication or even refusal

of treatment. One informal caregiver suggested that medical information be provided to more seniors in their home environments, regardless of whether or not they receive home care services. This would make seniors more at ease and better prepared to receive the information they need to make the proper decisions about their own health.

“I don’t know. Maybe having somebody just come out and talk to them. Like even just to sit and explain things to them. Maybe just have, I don’t know what you would call them, like home visit or something like that talk just to let them know like, talk to them about their medical stuff in a home-based thing instead of in the hospital all the time because that is basically where he gets all his information is at the hospital and maybe do like a home based, a home visit, something like that, yes. Try to make them feel comfortable because in hospital I know he gets scared that’s why he cancels appointments and then we have to try to talk him into the appointment again. You know its like even to Winnipeg, he’s like ‘How am I going do this? How am I going do that? ‘Don’t worry about it we are going to be with you’. Like last time he just heard he was going for an appointment on his eye and that was it. And so we had to try and explain to him what they were going to do to his eye and make him comfortable with the idea of going for an operation. Yes so maybe something like that is lacking”.

On several different occasions, informal caregivers stated that both they and the seniors they cared for preferred to have Metis or other Aboriginal health workers deal with them because they felt better taken care of and more readily trusted the information given to them.

“No, Aboriginal social workers that work the Kidney Foundation part of it. And they would walk him through it, they are not just going to take him there and then that’s it, like they will have somebody that will work with him there, so something like that once he is there helps, but I have get him there”.

“From this perspective, well the clinic is here, she has now a family doctor. It was difficult to get one at first, but not that difficult, but now we got one, and she’s Aboriginal, she’s Metis, it’s basically a visiting session instead of a medical visit I think, but the doctor doesn’t put any due pressure on her. ‘Ok your blood pressure is ok now, you can go’. She maintains conversation with her because she knows at times my mom gets depressed. Certain times of the year she does that, they say cabin fever but there could be something else there too”.

“She doesn’t have one on Wednesday, Wednesday is the only day they don’t have anybody and they are non-Aboriginal caregivers also, that’s the other thing that I wanted is how many Aboriginal caregivers are there and how many can be given to her at least once every few months just so she could have that established. She established a rapport with all of them, but she started different ones lately and she seems to be ok with them but she’s happy she looks forward to her Tues and Friday baths that she has. She has phoned home care to let them know she is gone for three weeks”.

At times, seniors and informal caregivers are not informed about the types of services and programs available to them that can help reduce costs. Poor communication between health care professionals and patients can cause problems for families and lead to high, unnecessary out-of-pocket expenses.

“The last time we went he was supposed to stay at a Winnipeg hospital, he was supposed to stay in that, oh I forget what it is called now, some type of dorm type place, he was supposed to stay there, the social worker from Winnipeg was supposed to make arrangements for him to stay there. So we went, we through because the dialysis unit told me here that it was all set that he was going to stay there so the only hotel cost would be for me and my husband and then we took two of our kids

because we figured we’ll take two of them. We got there it wasn’t booked for him and then they wouldn’t let him stay in there because I said ‘Well I will just pay for it. Don’t worry about it I’ll pay so he can stay here’ and they said ‘No, he is not getting his surgery here so he can’t stay here’. So I said “Okay that’s alright” I said ‘Forget it’ so then we took him with us and then we stayed in the hotel room, but then I had to get an extra cot and that meant there were five of us in that one little room for two days and it was crowded so what I did was take my kids out in the morning and went visit family just to give him quietness because he had his surgery and he needed to be in a quiet place, so that’s what we did, we managed, we survived; he laughs about it”.

Out-of-pocket costs are often another concern for many seniors and informal caregivers. Provincial insurance does not necessarily cover important medical treatments, medications, and mobility devices for those on a pension.

“Like if he had appointments there is no place for him to actually go, well maybe they do now, but if he wanted to just get a prescription for cough medicine or something you know just basic little things where you don’t have to make a big trip in to the city or to the town to get a prescription for something or say I don’t know like a little clinic type thing would have been good there, I don’t know if they have it now but I know back then they didn’t have it, something like that I think”.

Even when the treatment itself is paid for, trips to the city, meals, and accommodations are the responsibility of the individual and/or family members.

“...And then another kind of appointment that I had to pay for the hotel room and for the meals and all that and then I had to leave work and take time off of work and although my kids are teenagers I still needed somebody there to wake them up for school”.

“The medical help. Even transportation, I realize they have cabs but really, the money comes out of their pockets for the cabs and things like that you know, like even to shop, he said it was hard to shop they had one store and then there is nothing there for them because we were going out there to pick him up to come in to shop because he didn’t want to take a cab which it was costly so, then again the medical”.

In order to reduce transportation costs, most seniors and informal caregivers combine doctor’s appointments with trips to town for shopping for necessary provisions.

“I took her also for physiotherapies at the one after her surgeries we went downstairs at the physio department here at the hospital, those were also after the first knee surgery and after the second knee surgery. So now I’ve been spending a lot of time sometimes twice a month or three times a month, depending on her physio and her medical appointments, and then of course her trips to Wal-Mart to go shopping, her favourite store after Extra Foods”.

For some medical conditions, seniors are now able to have physician’s consultations using local telemedicine equipment. This has reduced the cost of transportation for some by a significant amount.

“Well now they’ve changed it. It used to be at least twice a year, sometimes three depending what it was for, this year we went three times already but now they’ve changed it where they are going to do it through teleconference. So he just had one yesterday otherwise, if they didn’t do that, we would have had to go to the city yesterday”.

An advantage to living in a small community is that friends and family will often raise money to help cover some of the financial costs to the individual.

“Yes, if someone has a medical problem like cancer or something everyone comes out the dances that they put on to raise money so they can go back and forth for their treatments and that. It’s nice”.

5.3 Summary

The voices of Metis seniors clearly identified issues consistent with any senior seeking to age in place. Metis seniors recounted their experiences in response to aging, access to health, and other services. Additionally, their insights into Metis culture and their identification of the importance of having a voice, both personally and politically, contributed another dimension to our understanding of the experience of Metis in this region who are aging in place.

Themes extracted from caregivers also identified issues that reflect the larger literature on aging in place and paralleled many of the issues Metis seniors identified including: access to services, importance of family relationships, and transportation. There was an area of misconception of services on the parts of both formal and informal caregivers that may be easily remediated.

In the next section key findings arising from this study will be reprised.

References

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Section 6: Key Findings from Metis Voices

There’s No Place Like Home

In the MMF Northwest Region, Metis seniors recognized ‘aging in place’ as the best option for their health and well-being, the sustainability of their rural communities, and their culture. While most participants were retired, living in a rural setting allowed them to keep active by volunteering in the community, maintaining their properties, and helping family neighbours. Economically, many participants noted that rural life was less expensive than urban life, as many owned their own homes—some participants noted that they could not afford to sell their properties and buy a residence in a larger town as the cost of houses and taxes was significantly higher than what they would receive for their current location.

Although living closer to services would be more convenient for many seniors, they and their families made adaptations to changing conditions. Historically, Metis placed high importance on the value of family. Metis families were large and bound to each other by loyalty and an obligation to represent and advocate for relatives, and to support them materially and emotionally when necessary (Macdougall, 2008). Today, Metis families still live by many of these familial traditions. Although families are more dispersed now, they still hold a sense of responsibility for ensuring their family members are well cared for.

Additionally, there is an existing expectation that the homestead will remain in the family and be inherited by children or grandchildren. Younger family members are currently unable to move on to the property as it would be difficult to find employment in the area. Therefore, seniors tend to stay on their land as long as possible, maintaining rural Metis life and supporting their communities through volunteerism and social engagement.

The questions we sought to answer in this research were based on work by Janes & Cleghorn (2008):

1. What formal and informal resources exist to support aging in place and how are these affected by rurality?
2. What other resources and supports are needed but absent, inadequate, or inaccessible?
3. How can the community impact relevant policy, programs, and services to enhance supports to aging in place?

The data collected in this research was analyzed using a CDDAP process—one that has proven effective in analyzing data for Metis-focused qualitative health studies (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007). The key findings from this analysis are presented in this Section. These findings were seen as areas of importance for Metis seniors aging in place in their rural communities. While some of this information does not apply strictly to Metis seniors, it was significant to them. The importance of maintaining cultural continuity and issues of governance were unique to Metis seniors aging in place.

In the following sections, findings consistent with the literature will be identified, as well as new ideas that have arisen through reflection on discussions with Metis seniors and formal and informal caregivers. Suggestions are offered to explore alternate supports/options for Metis seniors. It must be emphasized that this is not an exhaustive list of options to aid Metis seniors to age in place in their communities. This is merely a starting point to open

dialogue among stakeholders and allow them to further engage Metis citizens, allowing their voices to be heard.

6.1 Importance of Maintaining Cultural Continuity

This study examined the issue of Metis aging in place. An issue not found in the existing literature on aging in place was the importance to both Metis seniors and caregivers of maintaining their cultural identity. In past generations, Metis families lived together in large extended family households and ensured adequate care for elderly family members was provided within the family unit (Macdougall, 2008). The importance of family and culture to Metis is a source of both individual and community strength.

Connected to their memories of living in a rural Metis community, Metis seniors strongly preferred aging in place in their home communities rather than moving to unfamiliar cities or PCHs. Metis seniors viewed themselves as self-sustaining and prioritized an ability to care for themselves. This independent and rural lifestyle has meant that Metis seniors are intimately connected to the land and culture in which their communities and Metis relations are or have been situated. Drawing on a history of tightly knit communities, Metis seniors derived strength from maintaining cultural and geographic continuity.

Metis culture is intimately connected to the land base in which it is situated—land and culture are interrelated and cannot be separated. The Metis seniors' desires to age in place highlight the importance of contiguity between culture and place. The strengths derived from Metis culture have contributed to Metis seniors' abilities to age in place and highlights the importance of maintaining those community ties and ongoing cultural continuity.

6.2 Help at Home

Consistent with the literature, participants mentioned the need for extra help around the house with more difficult maintenance chores such as lawn cutting, painting, washing windows, cutting and hauling in firewood, and shoveling snow. We heard that the support offered by the Manitoba Metis Federation via the wood program helps alleviate the cost of heating their homes in the winter and offers the convenience of having chopped wood delivered to their residences.

While these were important things in assuring a level of comfort in their homes, an issue raised in the focus groups that was not found in the literature was the notion that there were insufficient younger people available to offer help in their communities. This may be a factor influenced by rurality that warrants further investigation.

6.3 Access Challenges

The complexity and interrelatedness of issues surrounding aging in place in rural communities demands that challenges to accessing services and resources be considered in a holistic manner. The following are areas Metis seniors identified as barriers to aging in place.

6.3.1 *Transportation*

Consistent with the literature, seniors found that having to rely on family and neighbours for transportation, or pay for taxis, was a significant barrier to aging in place. While many participants still drove, the cost of gas, vehicle insurance, and maintenance was seen as a

consistently increasing burden. The communities in this study are too small for the Regional Health Authority to provide a broader array of services such as communal meal programs or Meals on Wheels. Nor do the study communities have local resources such as stores. Thus, transportation becomes even more crucial in accessing most health programs and services, nutritious and affordable food, gas, banks, and other resources necessary to age in place. This is a barrier to aging in place associated with rurality.

An issue not found in the literature, but found important to participants in this study, was the need to have clear roads year round. They noted that emergency ambulance and itinerant services (home care workers) were not able to provide services if they had no access to the community. Having accessible roads means they are clear of snow in the winter, are properly sandbagged to prevent flooding in the spring, are well maintained by a grader, or they are paved. While this is a problem facing most rural communities, this is a barrier for aging members of rural communities not identified in the literature.

6.3.2 *Home Care*

Consistent with the literature, home care services play an essential role in helping Metis seniors to age in place. One of the major issues we heard about involved the importance of continuity of caregivers for building trust and relationships. The informal caregivers providing care to those with mental health issues found this particularly important.

Participants also noted that giving home care workers an expanded scope of practice, thus allowing them to assist seniors with additional tasks when necessary, would be helpful. The perceived current constraint on scope of practice was seen by many participants as a limitation to service. Additionally, while it was understood that home care workers have strict schedules, it was felt that having local home care workers attend to seniors would allow for more flexible work schedules.

Adding to the existing literature, Metis seniors also stated they would like to have locally trained workers as they felt they would have a greater understanding about how they live. They indicated that they would trust local workers more. They also spoke about the problems they faced if a home care worker was unable to drive from town to attend to them. While some had family or friends nearby who could help them, this was not always the case. In extreme cases, family members would have to drive long distances or seniors would have to wait until their next available visit with the home care worker. This may be a factor influenced by rurality that warrants further investigation.

The comments of Metis seniors about the importance of receiving clear information about eligibility and access to health services was another unique aspect of this study. In general, participants were grateful for the services they were provided with, but found that they did not always receive the help they needed because their home care assessments did not reflect their abilities on a daily basis. While health care case workers helped to provide them with information about available health programs and services, Metis seniors were often unaware of many services available to them.

6.3.3 *Other Health Services*

While the seniors in this study did not live in PCHs, they expressed negative opinions about the institutions, seeing them as “places you go to die”. For many, living in a PCH meant giving up their freedom, living in isolation from family and friends, and giving up their way of life. Considering the independent nature of the Metis seniors we talked to, we learned

that, where possible, alternatives need to be sought so that Metis are able to stay in their homes as long as possible and, if they must move, they can retain the greatest amount of independence possible.

Consistent with the literature, there were shortfalls identified in health programming for rural communities. While the RHA provides programs such as congregate meal programs and Meals on Wheels to mid-sized communities, all the communities in this study are too small to receive such services. Thus, seniors wanting to access additional services need to drive to their nearest location, which is a significant barrier for many.

Adding to the existing literature, Metis seniors also discussed the problem of out-migration by working-aged people from their communities due to lack of local employment. This, combined with the high costs of communications and travel, has limited social networks and put a strain on participation in community, available labour resources for property and community maintenance, as well as preserving and passing on Metis culture. This may be a factor influenced by both rurality and by culture that warrants further investigation.

Further adding to the existing literature, Metis seniors talked about the difficulties they faced with accessing physician services. While transportation was a problem for some, traveling to physicians' appointments caused a burden on the entire family. They also felt uncomfortable talking about their health problems with health professionals. Finally, an issue facing many rural residents was the difficulty in obtaining new prescriptions for essential medications at the time they are needed due to the inability of the physician to see them when required.

6.3.4 *Community Resources*

Consistent with the literature, participants observed that small communities typically struggle to keep small businesses such as grocery stores open. When makeshift stores do exist, they consist of individuals selling basic goods such as bread and milk out of their houses at high prices. We heard that this was the case in one community and that due to the large distance and cost of travel to the nearest grocery store, obtaining nutritious and affordable food was a serious issue. Other services lacking in these communities include gas stations and stores to purchase personal health care products. This was a barrier to aging in place associated with rurality.

Adding to the literature, barriers associated with communication were identified. In some areas there are no digital telephone lines. As a result, essential emergency services such as 'Life Line' cannot be installed in clients' homes as the systems are not compatible. Many of the participants in this study related that they cannot afford long-distance telephone plans, and as a result they are unable to call health services such as home care, as all offices are located in the city. Calling collect is an option in some cases; however, Metis seniors and formal caregivers told us that the process of talking to an operator was often too difficult due to language, technology barriers, or hearing impairment.

6.3.5 *Financial Constraints*

Consistent with the literature, financial constraints for aging in place were a theme identified by the focus groups and health care providers. For Metis seniors, although aging in place was their preferred option, they also recognized that this was the only affordable option for them. It was explained that it would be impossible to sell their property and move into town because the cost of housing and taxes were significantly higher there. This was a challenge to aging in place associated with rurality.

Building on existing literature, we heard from Metis seniors that there were difficulties prioritizing between purchasing basic necessities such as food and obtaining dental care or medications.

Adding to the literature, formal health care providers discussed the impact of budget constraints for programming in rural communities. While many larger rural communities received programming, seniors in small communities were expected to travel to access the services. This is also the case for programming that relies on volunteers to function. Seniors in more remote communities do not have the volunteer base to access such programs so they go without. While Metis seniors did receive some basic services such as home care and other existing programs, it was often family and friends, or informal caregivers, who would transport them to access services outside the community. This was a challenge to aging in place associated with rurality.

6.3.6 *Appropriate Housing*

Consistent with the literature, Metis seniors spoke of a need for adapted housing in their communities. In the Parkland Regional Health Authority, assisted housing does exist through the ‘Aging in Place’ policy; however there are insufficient assisted living facilities and all are in larger urban centres. In the participating communities there were no local options for either adapted housing or assisted living facilities for seniors. This was a barrier to aging in place associated with rurality.

The issue of adaptation to housing has been previously identified as a support to aging in place. The Metis seniors in this study spoke of the importance of maintenance and infrastructure supports such as ramps, grab bars, and adapted bathtubs. Something that was not seen in the literature was that the costs associated these improvements were often too expensive for seniors. We heard that although a Manitoba provincial government housing improvement program exists, whereby seniors can receive a portion of the cost of renovations on their house, the remaining cost is often still too expensive for them. Additionally, Metis seniors said that even if they could afford to pay for the renovations, the portion paid by the government was considered income, thereby pushing the senior into a higher tax bracket and defeating the purpose of the financial assistance. This may be an area that requires further investigation.

Adding to the literature about challenges to aging in place was the problem of not having running water or sanitation services in seniors’ homes. While this was not the norm, in some of the study communities this was still an issue. Some Metis seniors continued to haul water in buckets from the local pump station for drinking and washing. The physical demand of these tasks is a clear barrier to aging in one’s own home. This may be an area associated with rurality that requires further investigation.

6.3.7 *Personal Safety*

Personal safety was another challenge raised that was consistent with the literature. While many consider small towns to be quiet and safe, some seniors talked about their personal security. In one community they talked of arson and vandalism by youth as well as theft of medications and other personal belongings. Adding to the literature was the idea that Metis seniors could play an active role in assuring their personal safety by mentoring youth in order to create relationships and teach respect to the younger generation.

Consistent with the literature, another aspect of personal safety identified was that of living alone and forgetfulness. While none of the participants had firsthand experiences, some talked about other seniors forgetting to turn off the stove or put out a candle or cigarette. These types of accidents can be devastating for seniors who live alone or who are in isolated areas with no access to a fire station.

6.4 Informal Caregivers

Consistent with much of the literature on informal caregivers, all the informal caregivers we spoke to in this study were women. They were between the ages of 30 and 55 and were often daughters of a Metis senior. Many had their own families and jobs in addition to helping their family member, although several dedicated all their time to elder care. We found that informal caregivers were often the primary caregiver of their relative, with other siblings assisting intermittently. For those who worked outside the home, they reported often missing work or scheduling their vacations around medical appointments. Many informal caregivers paid out of pocket for expenses related to their elder's health, such as transportation to and from the appointments, some medications, and some food. Metis seniors typically gave money to pay for the added expenses if they were able to do so. The participants shared that while they got a lot of satisfaction out of helping their elder, they also acknowledged the financial and emotional stress that came along with the responsibility. While informal caregivers were aware of services for seniors, they were often uninformed of services and supports to help maintain their own health and well-being. This is an area that may warrant further investigation.

6.5 Inconsistencies in Perceptions

From interviewing formal caregivers and speaking with Metis seniors and informal caregivers, this study found that there were several inconsistencies in perceptions about health programs and services. Often these inconsistencies dealt with communication issues. When formal caregivers were asked about the process they used to provide information for seniors about programs and services, they said they made sure to discuss options and provide them with clear information about service availability. Some seniors and informal caregivers expressed frustration as they often did not know who to contact about the services they needed or did not know how to navigate the system in order to get the needed services.

In one community, formal caregivers explained that a health unit existed and that services could be solicited within the community on a bi-weekly basis. Seniors explained that the health unit was not in a central location and that it was not always accessible to them as there were no wheelchair ramps and snow was not always removed in the winter. Seniors said they did not use the facility for these and other reasons. Also concerning access to health units, it is important to note that some formal caregivers thought that all community members had access to neighbouring health facilities on nearby reserve land. However, Metis seniors were not able to access those federal health service facilities and had to travel up to two hours to seek medical care outside of the community.

Regarding home care services, formal caregivers explained that the contract signed as a condition for services required that seniors have a 'back-up plan' so that if a home care worker was unable to attend to their client, someone could help them. For most seniors this

was clear; however, for some, their primary informal caregiver did not live nearby, thus making the back-up plan ineffective in the case of poor weather or cancellation on short notice. Additionally, seniors noted that it was often complicated to cancel an appointment or to call and inquire about services or problems because they did not have access to long distance calling. Finally, formal caregivers explained that any person could refer a senior to the home care program. Seniors and informal caregivers were under the impression, however, that only a medical professional could do this.

Formal caregivers and seniors also differed in their perceptions about the speed at which one is able to access services. While some formal caregivers thought that services could be accessed faster in rural communities because of the smaller population base, seniors believed services such as home care could be accessed faster in the city where programs are more robust and have more employees.

6.6 Governance

Adding to the literature, we heard that governance, or having a voice, was as important for seniors as access to health services and community resources and other aspects of aging in place. Metis seniors felt that where social problems existed it was because they were no longer able to raise their children the way they saw fit. In their opinion this has resulted in a general disrespect of elders by some youth.

In terms of community governance, Metis seniors were concerned with receiving respect from the Metis community—seniors shared that respect for elders was a deeply held value and wished for that respect from today’s youth. However, they noted that they were not treated as knowledge holders by some younger members of their communities. It is clear that by strengthening the voice of Metis seniors their knowledge and experience will contribute to the important task of maintaining cultural continuity.

Governance was an essential feature in how seniors described quality of life as they age in their rural communities. They said they found it increasingly difficult to have their voices heard in local government as they were not able to attend meetings, and often politicians would only visit their communities during election time. Finally, they spoke of the importance of the younger generation speaking on behalf of the Metis, and that it was important for Metis to represent their interests and work for change in the community.

6.7 Metis Cultural Strengths

Adding to the literature is the notion that the cultural and community strengths of Metis seniors and caregivers contribute to their resilience. The positive aspects of aging and caring for seniors center on the value of cultural continuity, family, and community. These aspects of rural Metis life are important to the continuing well-being of Metis seniors and their communities as they speak to the independence, resilience, and strength of Metis culture and connections. Because Metis cultural practices and continuity contribute to the strength of Metis seniors and caregivers, maintaining cultural continuity and community connections have the capacity to preserve and transmit these strengths to future generations and to current Metis youth. Metis community and cultural practices have the potential to make communities safer by promoting values of independence and resilience as well as respect for elders and the knowledge they hold.

Cultural practices and Metis community are a source of strength and contribute to the resilience of Metis seniors and their informal caregivers. As an Aboriginal people, Metis have an inherent right to practice their culture and therefore any supports or recommendations for Metis seniors aging in place must take into account these cultural specificities (Government of Canada, 1982; United Nations Population Fund & HelpAge International, 2012).

6.8 Summary

This study looked at the experiences of Metis seniors aging in place in rural communities. Through discussions with formal and informal caregivers and Metis seniors themselves, a series of important issues arose concerning information about and access to health and community services, the importance of governance and cultural continuity, and inconsistencies in perceptions about specific aspects of health service provision. Many of the barriers Metis seniors face are a direct result of them living in a rural setting. One of the primary concerns of Metis seniors was the long distance from services—the effects of which were seen in out-of-pocket costs for transportation, home improvements, and purchasing nutritious food and personal health supplies.

The major supports and resources seniors said they needed were:

- Affordable and convenient transportation;
- Better access to affordable, nutritious food, gas, and personal care products;
- Assistance with general home maintenance such as grass cutting, snow shoveling, and washing windows; and
- Organized social activities for seniors

In three of the four study communities, seniors only had access to itinerant health services, including home care, mental health services, and occupational therapy. In the fourth community, a health centre existed but was understaffed and not seen as accessible for seniors and residents; therefore, they did not consider this to be a fully useful resource. There was also limited affordable transportation. This made access to purchasing food, medications, and personal care products difficult.

Interestingly, much of the discussion around aging in place focused on self sufficiency and independence. An important point to take from this was that Metis seniors' resilience is developed enough for them to support themselves wherever possible at whatever cost. Despite what many would consider less than ideal living conditions, Metis seniors seemed very happy living in their homes and participating in their communities. Ideally, if the health system can provide the necessary services to assist Metis seniors to age in place, they will be able to support themselves and their communities well into the future, playing important roles and having a voice in their communities. The voices heard in this report are testament to this.

It is the hope of the Metis seniors who participated in this study that their voices be heard and their needs be taken into consideration. It is not the objective of this report to make suggestions on how this should be done, but to give voice to this population and start a dialogue with stakeholders and community members in order to break down barriers and help improve quality of life for Metis living in rural communities and aging in place. While it is true that each rural community, and in fact each individual, experiences their own unique challenges, literature has shown that many of the experiences described here are not isolated

cases. While solutions should take into consideration local context, they should also look at applicability and assist further dialogue with Metis seniors, informal caregivers, and those aging in place in rural communities across Manitoba.

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Glossary

Aging in Place

The term ‘aging in place’ refers to the ability of an individual to remain in one’s home and community (Schofield, Davey, Keeling & Parsons, 2006). Being able to stay in one’s own home is reflected in better clinical outcomes and reduces long-term health care costs for society (Janes & Cleghorn, 2008). The Chief Officer’s Report on the State of Public Health (Government of Canada, 2010) noted that poor health in seniors tends to be higher when they have reduced access to care and support services, unsafe living conditions, and live in isolation.

Continuum of Care

Continuum of care is the range of health care services available for seniors based on their needs and abilities. In Manitoba, this continuum has two main components: informal and formal services. Within these components services range from community-based care including informal care (family and friends), home care and supportive housing; and institutional care including personal care homes and chronic care facilities (Doupe et al., 2011).

Metis Locals

The seven MMF Regions throughout the province are each divided into community *Locals*, with their own MMF offices and memberships.

Manitoba Metis Federation (MMF) Membership

At the MMF, Metis identity is verified by self-identification, Metis ancestry, and community acceptance through a membership application and confirmation process. By providing a genealogy with supporting evidentiary documents, an individual and his or her family are able to determine whether or not a Metis ancestral connection can be established. Supporting evidentiary documents may include Federal Census records, sacramental records, Manitoba and Northwest scrip affidavits, post records, and journals. All individuals seeking membership in the MMF are required to have a genealogy completed by a recognized institution in order to objectively verify the applicant’s historic Metis nation ancestry. Application for membership begins at the receiving local in the area in which an individual resides (MMF, 2010).

Metis

The Metis are descendents of early 17th-century relationships between North American Indians and Europeans (Sprague & Frye, 1993). The Metis coalesced into a distinct nation in Manitoba in the late 18th century. After the 1885 fall of Batoche, “Metis were denied a separate identity and ignored for a century” (McMillan, 1995, pp.312–313). By 1967, with the formation of the MMF, the Metis in Manitoba were again asserting their capacity to advocate and function in a collective manner. In the 1982 amendment to the Canadian Constitution, Metis were named as one of the three Aboriginal peoples of Canada (Government of Canada, 1982).

Personal Care Home (PCH)

“Residential facilities, also known as nursing homes, for predominantly older persons with chronic illness or disability. They may be proprietary (for profit) or non-proprietary. Non-proprietary PCHs may further be classified as secular or ethno-cultural (associated with a particular religious faith or language other than English) as well as either freestanding or juxtaposed with an acute care facility” (Doupe et al., 2011, p.52).


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Appendices

Appendix 1—Sample Recruitment Poster

There is No Place Like Home – The Experience of Metis Aging in Place



Frank & Margaret Hiebert – Shell River MMF Local




Are you a Metis person who is 60 years of age or older?
Are you an informal/formal caregiver of someone who is 60 or over?
Are you interested in taking part in a study on aging?
Do you live in the _____ area?
If so, we would like to hear from you.

The purpose of this project is to:

- Take a look at existing services in communities.
- Identify approaches to maximize use of existing community services.
- Identify types of supports to live well and maintain independence.
- Identify ways elders can stay in their homes longer.

If you are interested in participating and/or would like further information,
please contact:

Principal Investigator – Dr. Judith Bartlett



*Photo used with permission

Appendix 2—Sample Consent Form

'There is no Place like Home' – The Experience of Metis Aging in Place



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OF MANITOBA

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RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: "'There is no place like home' – The experience of Metis aging in place"

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Mr. Ken McIvor, BSW Knowledge Network Coordinator
Manitoba Metis Federation Northwest Region

Sponsor: Network Environments in Aboriginal Health Research (Canadian Institutes of Health Research)

'There is no Place like Home' – The Experience of Metis Aging in Place

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to study the experience of Metis of aging in place or growing older without having to move out of their home. The specific objectives of this study are:

- To identify the available services that enable Metis 'aging in place'
- To identify the amount of support Metis seniors perceive is needed to live well
- To identify ways to extend the time seniors can live at home
- To gain an understanding of the effect of personal care homes on Metis seniors and families
- To identify 'best practice' for maximizing community services

A total of 50 people will participate in this study.

Study Procedures

Data will be collected from an environmental scan of the communities, from key informant interviews with caregivers and service providers, and from focus groups with individuals aged 60+ in the communities. Participants will be recruited using snowball sampling and word of mouth. Posters will also be displayed in the local post offices, Friendship Centres, Metis Federation Office, Metis local offices and will be placed in the MMF regional newsletter. The Project Coordinator, with guidance from the PI, will obtain informed consent from each participant. Each participant will have the study explained, provided with an opportunity to ask questions of the researcher, and be asked to read and sign the consent forms. The consent form will be explained in detail as required. In one community a translator will be engaged to translate the consent form and focus group questions into Sauteaux.

Participation in the study will be for one interview or focus group only. Key informant interviews lasting 1-1½ hours will be conducted with informal caregivers and service providers, including MMF community liaison/community outreach, about existing resources in community. Semi-structured interviews with seniors and/or focus groups with seniors (aged 60+) will be set up in three communities which have been identified by the MMF Northwest Region as having aging populations, few resources and being geographically distant from services. These are [REDACTED]

There will be two visits made to each community for data collection. When necessary an interpreter contracted by the Manitoba Metis Federation will be used to ensure participants understand questions and that the responses are translated back. At the end of each focus group the ideas that were discussed that day will be reviewed.

‘There is no Place like Home’ – The Experience of Metis Aging in Place

Interviews will be taped and transcribed. Anonymous identifiers will be attached to the transcripts. The list of identifiers will be kept separately from the data and will be accessible only to the Study Coordinator. No personal information will leave study site. All data, including tapes, transcripts and questionnaires will be stored in a locked file in the Study Coordinator's office and will be kept for the duration of the study and will be destroyed three years after the completion of the study (March 2015) or after publications and presentations have finished. All paper documents will be shredded, audio tapes will be erased and computer files will be deleted.

Once all of the information from the study has been reviewed it will be presented back to the community at a meeting at the local hall, and as an item in the newsletter ‘Northwest News’.

Risks and Discomforts

We do not believe that there will be any physical risk to you from participating in this research. You may experience some anxiety related to the potentially personal nature of the questions.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other Metis people by adapting health services to help them age in place in the future.

Costs

The interviews and focus groups, which will be performed as part of this study, are provided at no cost to you.

Payment for participation

You will be compensated for expenses incurred as the result of your participation in the study. You will receive a \$50.00 flat rate to cover transportation and other costs.

Confidentiality

Every attempt will be made to uphold your confidentiality. Everything said in the interviews or focus groups will be held in confidence and will not be repeated outside of the focus group. Interviews and focus groups will be tape recorded and transcribed into text. Once this is completed the text will be electronically stored. All data from interviews will be given an anonymous number and will be referred to by that number.

All records will be kept in a locked secure area and only those persons directly involved in the research will have access to these records. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba. All data, including tapes, transcripts and questionnaires and will be destroyed three years after the completion of the study (March 2015).

Information gathered in this research study may be published or presented in

public forums; however your name and other identifying information will not be used or revealed.

Despite efforts to keep your personal information confidential absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board and/or the Canadian Institutes of Health Research may review records related to the study for quality assurance purposes and to ensure the research team is in compliance with ethics requirements.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first. We do not anticipate that there will be any serious result of suddenly withdrawing from the study. Your decision not to participate or to withdraw from the study will not affect your ability to take part in MMF activities.

If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the study doctor and the study staff: Dr. Judith Bartlett or Dr. Julianne Sanguins at (204) 586-8474.

For questions about your rights as a research participant, you may contact the University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Dr. Judith Bartlett or Dr. Julianne Sanguins and/or their study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

** 03/09/2011**

Page 3 of 4

PARTICIPANT INITIALS ____

‘There is no Place like Home’ – The Experience of Metis Aging in Place

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study Yes _ No _

Participant signature: _____ Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant’s legally acceptable representative and that consent to participate in this study was freely given by the participant.

Witness signature _____ Date _____
(day/month/year)

Witness printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ Date _____
(day/month/year)

Signature: _____

“Role in the study: _____

Relationship (if any) to study team members: _____

Appendix 3—Sample Focus Group Questions

Focus Group Questions ‘There is No Place Like Home - The Experience of Metis Aging in Place’

1. Many of you have lived for many years in this community. What is your favourite memory of living here?

Today we want to find out about your experiences living here. Let’s begin.

Prompt	Questions
NATURE	2. How does aging affect how we see ourselves?
IDENTITY	3. How does aging affect how others see us?
DEVELOPMENT	4. How does aging affect our ability to express our child, youth, adult and elder qualities?
RELATIONSHIPS	5. How does aging effect how we care for each other?
NETWORKS	6. How does aging affect our ability to maintain important networks with a) other individuals, b) with our family, c) community, or d) Metis nation?
SUPPORTS	7. How does aging affect our ability to be comfortable in our home?
ENVIRONMENT	8. How does aging affect our ability to work and contribute to our community? 9. How does aging affect our (a) cultural, (b) social, (c) economic and (d) political (voice) environments?
GOVERNANCE	10. How can we manage the course of our life while aging?

11. Of all the things we discussed, what to you is the most important?

Review the purpose of the study and then ask the participants:

12. Thinking about what we’ve talked about today, is there anything else that comes to mind that you would like to mention?

Thank participants for coming and their contribution.

Appendix 4—Sample Key Informant Interview Questions

Appendix 4

Key Informant Interview Questions

1. Are you a formal or informal caregiver?
2. How long have you been a caregiver?
3. What do you enjoy most about being a caregiver?
4. What is the most difficult thing about being a caregiver?
5. How far do you have to travel to provide care?
6. How are you reimbursed for your expenses?
7. If you cannot go care for your elder, what happens?
8. What are some of the resources/services currently in place in your community to support elders to age in place and maintain their independence?
9. Are these resources/services accessible to the elders?
10. Are these resources/services affordable for the elders?
11. Are these resources/services still applicable or do they require updating/improvements?
12. Are these resources/services reaching their target audience i.e., Do elders know about these programs?
13. What do you see as the strengths of this community?
14. What do you see as lacking in terms of resources/services to elders here?
15. What do you see as the largest barrier that prevents elders from aging in their community?
16. What do you see as the advantages to keeping elders in their homes?
17. If you could do one thing that would make the community better for those who are aging, what would you do?
18. What things do you do to take care of yourself?
19. Is there anything else you would like to add?

Ensure you thank participants for coming and their contribution

Appendix 5—Sample Demographic Questionnaire

Demographic Questionnaire

There’s No Place like Home - Metis Aging in Place Study Participant Profile

Please indicate the response that best represents your personal situation for each category.

Identifier				
Age	Under 20	20-29	30-39	40-49
	50-59	60-64	65-69	70-74
	75 -79	80 and over		
Sex	Male		Female	
How long have you lived in current community?	0 – 2 years	3 – 5 years	6 – 10 years	
	11 – 20 years	21 – 30 years	More than 30 years	
How long have you lived in the house or apartment you are now?	0 – 2 years	3 – 5 years	6 – 10 years	
	11 – 20 years	21 – 30 years	More than 30 years	
How old is your home?				
Who do you live with?	By myself	Spouse/Common Law	Daughter/Son	
	Grandchildren	Other	--	
How many people do you live with?				
Does your place have stairs?	Yes		No	
Have there been any changes made to your house?	Grab bar in tub Raised toilet seat Lift		Other: (please specify)	
Do you use any aids to help you get around?	Cane Walker Wheel chair Scooter		Other: (please specify)	