



**Metis Experience with Chronic Disease in Manitoba:
A Discussion Paper
March 2013**

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ACKNOWLEDGEMENTS

We acknowledge the Manitoba Metis Federation (MMF) Board, and in particular the MMF Minister of Health Marielee Nault, for their leadership and support to the Health & Wellness Department.

We acknowledge the leadership of the MMF The Pas Region's, MMF Southwest Region's, MMF Southeast Region's, and MMF Northwest Region's Knowledge Networks identify chronic disease priority areas and who supported the Metis Wellness Workshops on chronic diseases.

We acknowledge the valuable contribution from many Metis citizens who generously shared their knowledge and experience of chronic diseases to inform their Region Knowledge Networks.

We gratefully acknowledge funding support from:

- Public Health Agency of Canada – Chronic Diseases Surveillance Program
- Health Canada via Manitoba Health – AHTF Pan-Canadian and Adaptation

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Executive Summary

Rates of chronic disease in the world are increasing. Until recently little was known about chronic disease in Metis in Manitoba. The recently released *Profile of Metis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study (Metis Atlas)*, showed higher prevalence rates of many chronic diseases in the Metis population compared to all other Manitobans. In order to supplement the empirical data from the *Metis Atlas*, the Manitoba Metis Federation – Health & Wellness Department (MMF-HWD) sought additional sources of information to better understand the risk and protective factors for chronic disease in the Metis population.

Using a Metis-specific holistic approach, Wellness Workshops were structured to gather Metis stories and experiences with chronic disease and the health system. Participants in the workshops were Metis individuals (youths, adults, or seniors) who had experience with a chronic disease. Some were living with the disease; others were family members and caregivers of individuals with the disease. Participants were asked questions based on Wellness Areas© and their responses are reflected as such in this discussion paper. Several individuals took the opportunity to reflect on their experiences, some for the first time.

The information gained from the Wellness Workshops was analyzed and themes were identified and linked to risk and protective factors. Behavioural limitations, influential family and friends, barriers to risk modification, ineffective programs and services, gaps in support services, medical personnel related factors, and a limited understanding of the chronic disease were each identified and in many cases were found to act as a deterrent to seeking help to prevent complications and disability related to their disease. Protective factors included family and friends, health system supports and services, self-help groups, cultural competency, educational resources for understanding chronic disease, and advocacy.

MMF-HWD led a working group to further analyze these themes. The working group adjusted its focus from risk and protective factors, found to be confining, to a broader analysis of the health and wellbeing of Manitoba Metis through the inclusion of the Wellness Areas©. Utilizing the Wellness Areas© facilitated the application of a holistic approach to Metis knowledge deriving key observations and determining action that addressed all areas of experience. Based on our findings conclusions and recommendations were defined according to corresponding Wellness Areas©.

Combining experiential knowledge with the findings from the *Metis Atlas* has resulted in a more holistic base of information to provide direction to Knowledge Networks to work toward improving the health and wellbeing of Metis in Manitoba. We will have opportunity to confirm and build on these ideas as we continue to engage with Metis citizens in Manitoba about chronic disease in future Wellness Workshops and in knowledge mobilization with regional Knowledge Networks.

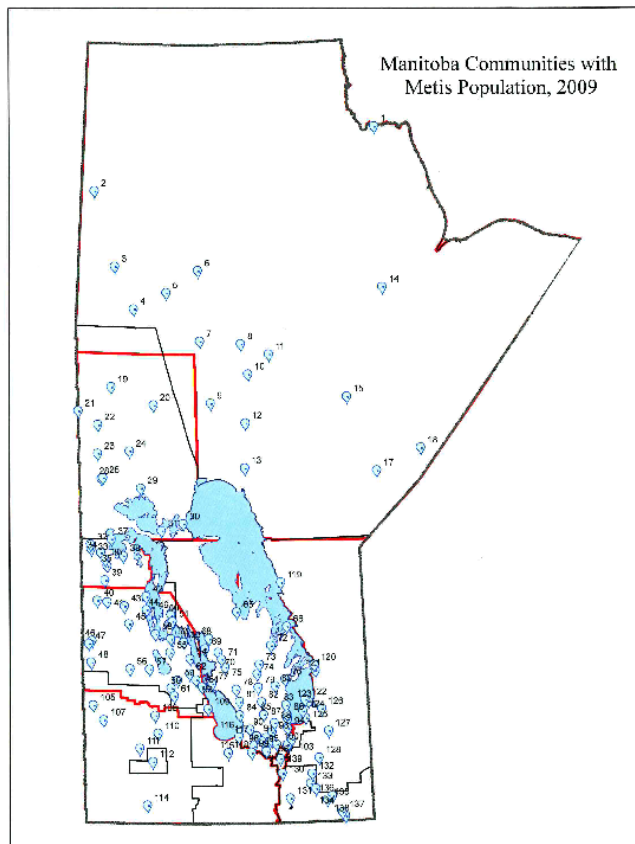
1.0 Introduction

Globally, chronic diseases are becoming increasingly common (WHO, 2005a). Rising rates of morbidity from diabetes, arthritis, mental disorders, and cardiovascular diseases including coronary artery disease, hypertension, and stroke, are reported across all populations (WHO, 2005b). Previously undocumented in the Metis population, the *Metis Atlas* (Martens, Bartlett, et al., 2010) documented that Metis have not escaped higher rates of chronic disease. In that report, rates of diabetes, ischemic heart disease, respiratory morbidity, and arthritis in the Metis population were significantly higher compared to the rest of the Manitoban population. Manitoba Metis Federation – Health & Wellness Department (MMF-HWD) wanted to learn more about this, and in particular to better understand risk and protective factors related to the burden of chronic disease for the Metis people in Manitoba. As part of our Metis Chronic Diseases Surveillance Program, we undertook Wellness Workshops as a form of information gathering. The following document describes the experiences of Metis in Manitoba with chronic disease with relevant associated literature on chronic disease incorporated.

1.1 Metis People in Manitoba

The *Metis Atlas* shows that there are 73,016 Metis citizens residing in Manitoba, while the ‘All Other Manitobans’ constitutes 1,104,672 people (Martens, Bartlett, et al., 2010). Figure 1 below captures the multiple towns, villages, cities and unorganized territories where Metis reside.

Figure 1



Manitoba Metis are similar to other Metis people throughout Canada, with approximately ¼ of their population being less than 15 years old. The *Metis Atlas* reported that children less than 15 years old comprised 25.4% of the Metis population in Manitoba, with only 19.1% of all other Manitobans in that same age group. Metis citizens aged 65+ comprised 9.1% of the Metis population compared to 13.9% for all other Manitobans in that age group.

1.2 Prevalence of Chronic Disease – Metis in Manitoba

In order to provide context to prevalence rates for chronic disease it is important to note the premature mortality rate (PMR) for the Metis population. PMR is a good indicator of the health status of populations (Eyles & Birch, 1993). The *Metis Atlas* reports that provincially the PMR for Metis was 4.0 deaths per 1000 people aged 0-74 compared with 3.3 per 1000 for all other Manitobans (Martens, Bartlett, et al., 2010), meaning that Metis are 21% more likely to die before the age of 75 than all other Manitobans.

Provincially, the *Metis Atlas* reports prevalence rates as follows:

- Cumulative Mental Illness – Metis prevalence rates are similar to all other Manitobans (28.4% vs. 25.9%) at the provincial level, but experience higher prevalence rates at the region and community levels.
- Ischemic Heart Disease – Metis prevalence is 40% higher compared to all other Manitobans (12.2% vs. 8.7%)
- Diabetes – Metis prevalence is 34% higher compared to all other Manitobans (11.8% vs. 8.8%)
- Respiratory Illness – Metis prevalence is 28% higher compared to all other Manitobans (13.6% vs. 10.6%)
- Hypertension – Metis prevalence is 13% higher compared to all other Manitobans (27.9% vs. 24.8%) and this varied considerably from one region to another.
- Arthritis – Metis prevalence is 22% higher than all other Manitobans (24.2% vs. 19.9%)

1.3 Knowledge Development, Mobilization, and Interpretation

The MMF-HWD produces and uses a variety of quantitative and qualitative data. The MMF Health & Wellness Department has developed and implemented Region Knowledge Networks to engage MMF Regions with their affiliated Regional Health Authorities (RHAs) in health planning. Early in their discussions, the Knowledge Networks identify their initial chronic disease priority interests and Metis Wellness Workshops are conducted involving Metis citizens in their region. Eight of the MMF Region Knowledge Networks identified two or three priority areas of interest from the following chronic diseases: cumulative mental disease, ischemic heart disease, diabetes, respiratory disease, and hypertension. For a more in-depth description of knowledge development, mobilization, and interpretation refer to the *Metis Atlas*-Chapter 2 (Martens, Bartlett, et al., 2010).

Knowledge Networks discussions are guided by a holistic framework and documented:

- Health information from the *Metis Atlas* and other MMF-HWD health research reports;
- Stories and experiences shared by Metis citizens;
- Social and economic programs and services delivered by MMF Regions;

- Health programs and services delivered by Manitoba Health RHAs;
- Literature relevant to best practice learned through program research; and
- Discussion around the table is recorded and added

All of this information is analyzed and reported by the Region Knowledge Network. This holistic view is available for direct use by the MMF Regions to support internal social and economic program and service planning. The information is also further analyzed for themes on:

- what the health system might change /duplicate / learn and enhance;
- what the MMF region can complement with social and economic programs to support those changes; and
- how the RHA and the MMF region can work collaboratively to maximize change efforts

2.0 Methodology

Methodology is the philosophical ‘lens’ in which one engages in research. Such a lens envelops all aspects of the project from data collection to analysis to recommendations to knowledge translation. The philosophical underpinning of this work was the Metis Life Promotion Framework©.

2.1 Metis Holistic Approach

This discussion paper is located within the holistic Metis Life Promotion Framework© (MLPF©) (Bartlett, 1995) lens (originally termed Aboriginal Life Promotion Framework©). Developed from Aboriginal philosophy, the MLPF© is a tool for holistically organizing thoughts and information to obtain healing and wellness. Drawing upon an extensive review of the literature and substantial experiential learning from a variety of discussants, Bartlett identified 16 elements of life, with ‘wellness’ predicated upon ‘balance’ among these areas. The MLPF©, Bartlett determined, is a way of thinking about the complexities of life, health, and wellbeing, demonstrating the connectivity of all life determinants. This framework functions equally well at an individual or societal level to assess existing strengths and challenges in our previous experiences, current position, and future desired trajectory.

In the matrix (below) there are 16 elements of life (shown in the white boxes). Individual and societal interactions with these 16 elements will affect your health and well-being. Bartlett (1995) suggested that understanding the meaning of these elements individually, and in groups, enables an individual or society to improve their circumstances and achieve well-being.

Eight Wellness Areas© (shown in blue) have been created to enable readers to improve health and well-being without having to individually address each of the 16 elements. The ‘circular’ wellness areas were obtained by looking at the four elements to the right of them and the ‘quadrant’ wellness areas were developed by looking at the four elements below them. For example ‘Nature’ encompasses the horizontal group: spiritual, emotional, physical and intellectual. And ‘Identity’ looks at the vertical group: spiritual, child, individual and culture.

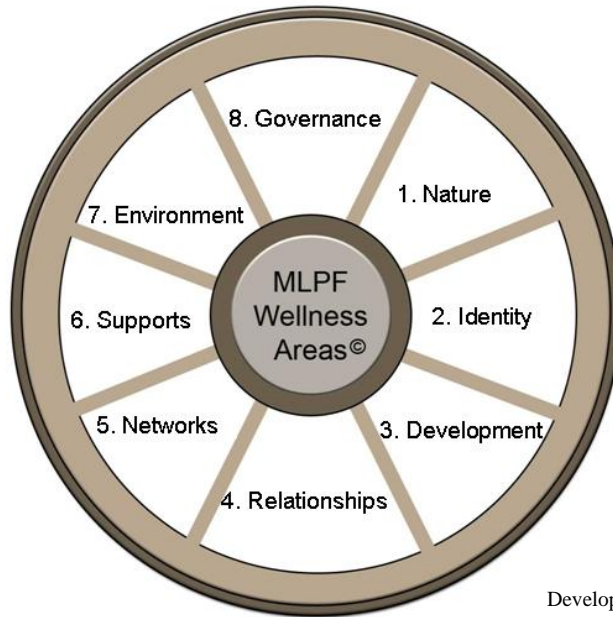
Metis Life-Promotion Framework©
Matrix with Interpretation

Quadrants → Circular ↓	Identity	Relationships	Supports	Governance
Nature	Spiritual	Emotional	Physical	Intellectual
Development	Child	Youth	Adult	Elder
Networks	Individual	Family	Community	Nation
Environment	Cultural	Social	Economic	Political

Developed by Judith G. Bartlett M.D., CCFP (1998)

By placing the elements in a circular diagram (as shown below) we can see the never-ending circle of life and the interconnectedness of the elements. It demonstrates the concept of wholeness and how health is obtained when everything in the environment is equally considered. It demonstrates the

spiritual, emotional, physical and intellectual parts of a child, youth, adult and elder living as individuals, families, communities and nations within their cultural, social, economical and political environments. The meaning of each of these 16 elements is dependant on the individual and/or group using the framework. Below the MLPF[©] is displayed in a red river cart wheel symbolizing Metis culture.



Developed by Judith G. Bartlett M. D. CCFP

These eight Wellness Areas[©] are inclusive of many important aspects of well-being. Using these Wellness Areas[©] will enable an individual or group to develop greater self-understanding and meet needs.

3.0 Methods

3.1 Data Collection

Wellness Workshops

Data was collected through Wellness Workshops, which are focus groups that use the holistic MLPF© Wellness Areas© (Bartlett, 2001) for discussion and data collection. Wellness Workshops provided:

- 1) a forum for sharing chronic disease-related health information that was being examined by the MMF Region Knowledge Network;
- 2) a method for collection of Metis citizen perspective for health planning by individual MMF Region Knowledge Networks; and
- 3) the data for analysis of risk and protective factors related to chronic diseases from a cross-section of Metis citizens in Manitoba.

Participants were Metis individuals who had experience with the chronic disease(s) being discussed – some were living with the disease, while others were family members and caregivers of individuals with a chronic disease. Results are from a total of 23 Wellness Workshops from six of seven MMF Regions in Manitoba including: Thompson, The Pas, Southwest, Southeast, Northwest and Winnipeg. Qualitative research does not rely on a particular number of participants as a representation of a given population. Nevertheless, we are confident that our participants included a sufficient cross-section of Metis youth, seniors and adults living in a variety of regional settings (urban town and small city, as well as rural and northern areas) to provide for saturation of the possible themes arising in the data. At each session, after obtaining verbal consent, Wellness Workshops were audio-taped for later transcription.

Wellness Areas for Data Collection

A general meaning for each of the eight Wellness Areas© assisted in constructing questions to elicit the lived experience of how an individual or family is impacted by a chronic disease. The MLPF© Wellness Areas© allowed for ease of discussion and organization of information that was gathered to maximize data comprehensiveness. The Wellness Areas© are used to identify how the chronic disease is perceived, how the chronic disease impacts development and relationships, and how networks, supports, and the environment, affect the individual and their ability to be a part of those systems.

Table 1.0: Wellness Area©

Wellness Areas	QUESTION (specific to coping / living with a chronic disease):
Nature	<i>How do you see yourselves as Metis people living in__? How does having a chronic disease affect the way you see yourself?</i>
Identity	<i>How do you think others see you? Do you think having a chronic disease changes the way others see you?</i>

Development	<i>How does having a chronic disease affect the way you function or behave? At what stage (of managing the disease) do you think you are? What characteristics or behaviours do you think it brings out in you and others?</i>
Relationship	<i>Relationships are about how we take care of each other. Do you think you take care of each other and if so, how?</i>
Network	<i>What other programs and services exist or are needed to assist in coping / managing the disease or your lives in general?</i>
Support	<i>What concrete supports are needed or required in order to take best advantage of what is or could be available?</i>
Environment	<i>What other larger environments or institutions are affected by you or have an affect on you in this community?</i>
Governance	<i>In order to have a voice, are there times or situations in which you can be heard more effectively as an individual, as a small group or family, as an organization?</i>

3.2 Analysis

Collective Consensual Data Analytic Process

The CCDAP is a team-based analytic technique utilized to identify overarching themes from information gathered. Adapted by Bartlett et al. (2007) from the Institute of Cultural Affairs’ (ICA Canada, 2004) facilitation and organizational planning process, CCDAP is a clustering and thematic analysis process that utilizes collective decision-making favored in Indigenous cultures. CCDAP utilizes an Indigenous process to ensure research is iterative, culturally-based, and process oriented. The CCDAP process is premised on the belief that “Knowledge gained from Aboriginal-guided research, which respects Aboriginal life stories and lived experience, will result in more culturally appropriate policy and program supports for Aboriginal individuals” (Bartlett et al., p. 2374).

Experiences shared by Metis citizens during the Wellness Workshops were recorded, transcribed, and placed within their associated Wellness Area©. Relevant quotes were extracted from the data and placed on cards for further analysis. Cards, each representing a quote from a Metis citizen, were displayed in the Wellness Areas© on the wall reinforcing a holistic representation of knowledge prior to theming.

Prior to a CCDAP session, the facilitator prepares placeholders (called header cards) depicting symbols that hold no meaning associated with the data for the Knowledge Network members (e.g. triangle, circle). These header cards are placed horizontally across a wall adjacent to the Wellness Wheel. The facilitator begins the session by reading aloud a card randomly selected from the Wellness Area© ‘Nature’ and then places it under the first header card. The clustering process then begins as the facilitator reads the second card and the group determines if that card is similar to, or different from, the previous card. If it is similar, the card goes under the first card; if it is different than the previous card, it goes under a new header card. Moving through the Wellness Areas© the group organizes all of the cards into columns. After all the cards have been placed under a header card they are again sorted by the group as the facilitator reads through the cards and the participants say “pull” if they believe a card does not belong in that column. The pulled cards are then re-sorted into the columns. After all of the cards have been appropriately placed the thematic analysis begins. In this step the participants read through the cards in a column and then collectively assign a theme

that reflects the content of that group of cards. This theme is written on a card and it is placed over the header card.

Observations in similarities and differences between the thematic groups are recorded. Participants are asked “Is there anything here that surprises you?” “Anything that is new?” They are also asked “Does this confirm what you knew?” The themes and discussion gathered in this process can then be utilized for future planning of the Knowledge Network.

Themes arising from the 23 CCDAP sessions have been placed in associated Wellness Areas© for discussion in this paper. The aggregated theme areas identified were: ‘Lack of Understanding of Chronic Disease’, ‘Mental Health Issues’, ‘Substance Abuse’, ‘Misperceptions’, ‘Educational Resources for Understanding Chronic Disease’, ‘Daily Life Adjustments’, ‘Self-Perception of Limitations’, ‘Barriers to Risk Modification’, ‘Unwillingness to Obtain Support’, ‘Self-Management of Chronic Disease’, ‘Mental Illness and Chronic Disease’, ‘Chronic Disease Prevention’, ‘Healthy Lifestyle’, ‘Caring for One-Another’, ‘Burden of Chronic Disease on Family and Friends’, ‘Health Supports and Services’, ‘Socio-Economic Supports’, ‘Informational Supports’, ‘Health System and Medical Personnel Related Factors’, ‘Cultural Competency’, ‘Personal Power’ and ‘Collective Voice’. In the following pages, each of the themes are presented to express the experiences of the Metis participants and compared, when possible, within the context of relevant literature.

4.0 Findings from the Wellness Workshops

4.1 Nature – *How do you see yourselves as Metis people living in___?. How does having a chronic disease affect the way you see yourself?*

The initial work with community members made it abundantly clear that their first priority was learning and knowing as much about the condition or chronic disease they saw themselves as having to manage at some point in their lives. They saw sisters and brothers fall prey to specific illnesses and assumed they were next. Having appropriate information to deal with ‘the inevitable’ was what would give them some sense of control.

Participants had many suggestions on how to share health information. Their preference for creating awareness was to start with children in school by making health information part of a health or science curriculum. There was also a strong interest in assisting the health system in doing this by disseminating information in a more receptive form.

Being given credit for having a basic understanding or the ability to understand a more informative style of communication from health professionals was an initial step in building trusting relationships with those same health professionals.

In contrast to large group presentations there was a preference for receiving information in smaller groups. It was felt that communication in a smaller group was less intimidating. Additionally it was suggested that this approach would allow for less technical information as participants would feel more comfortable asking more direct questions and discussing information using a much less formal vocabulary. This could be coupled with interactive activities which participants felt would be very effective.

Several participants suggested that videos or DVDs be produced for the purpose of relaying important information. In this way participants could review these periodically at their leisure, in their homes. We were also told that a range of literacy skills must be taken into consideration in the production of health information.

Lack of Understanding of Chronic Disease

To prevent the development of chronic disease or anticipated sequellae it is important that individuals have an understanding of causes of disease and associated co-morbidities, and the range of interventions available to them. This is referred to as ‘health literacy’ in the literature (Gazmarian, et al., 2003; Williams, et al., 1998). Health literacy includes awareness and understanding of risk factors and information about complications and treatments. Health literacy contributes to the prevention and management of chronic disease by restructuring attitudes, modifying behaviours, and increasing communication of health knowledge.

There is a relationship between health literacy and health. Those with low health literacy rates are two and a half times more likely to be considered in fair or poor health. Sixty percent of Canadians cannot obtain, understand, evaluate, and communicate health information to self-manage their health (Murray, Hagey, Willms, Shillington, & Desjardins, 2008).

The current structure of the Canadian health care system requires patients to possess strong health literacy skills that will enable them to take responsibility for their own health (Murray et al., 2008). Once individuals are diagnosed with chronic disease they may lack the information needed to make effective changes. This is consistent with what we heard from Wellness Workshop participants who acknowledged that they had limited knowledge of their chronic disease and health behaviour modifications that may prevent further health complications. Participants reflected on the importance of having understanding of treatments and lifestyle modifications that needed to occur to optimize their health.

“They don’t tell you how to get through it, and cope with how you’re supposed to live afterwards and if you should be walking or how much you should be walking and if it’s stressful and what you should be avoiding. And the pamphlets they give you in the hospital tend to be about what happened to you—not what to do now.”

Metis participants reported that prior to being diagnosed with diabetes there were indications from the doctor that it could develop.

“I had a doctor once and he actually said to me before I ever had diabetes and I hate that he said this to me and then I got diabetes, I hate it, but he said ‘Like it was the only two things that mattered – you’re overweight and you’re Metis, you’re going to be diabetic.’ ”

Prior to this discussion with her physician she had not considered herself ‘at risk’ for developing diabetes. Another participant was aware of some of the risk factors for Type 2 diabetes but did not consider herself in the ‘at risk’ category as she was not yet 40.

“It’s like working with the diabetes program, here are the signs: Aboriginal, family with diabetes, overweight... and one of them was over 40. I was think ‘oh! I’m only 35, I’m not gonna get it! I’m all the rest of those things, but I’m not 40’. So when he told me last year... that I had diabetes, but if I watched it I’d be okay... it was the same thing. I’m not 40!”

An intuitive understanding of health literacy (risk factors, screening, and treatment processes) resulted in it being identified by Wellness Workshop participants as an important area to be addressed.

Mental Health Concerns

Mental health issues were of utmost importance to Wellness Workshop participants. A constant theme was the debate of trauma versus heredity, and even though mental illnesses affect both the physical and mental growth they were also confident that the issues were generic in that they believed they had been provided with services equal to all others in the area. The availability of services and the lack of use of those services, suggested to the participants that ‘heredity’ pointed to ‘acceptance’.

Friends and relatives who took control of the disease management often led to perceived increases in issues related to mental health (questioning friendships, losing control, feeling guilty, low self-

esteem, and an increase in the level of those actions which tended to “*throw people off balance*”). All of these tended to increase participants’ anger towards their families, and a feeling of “*suffocating, paralyzed, hopeless, fatigue, and can’t pick up the phone.*”

Several specific concerns were shared including anger management, alcohol abuse, and needing acceptance of mental health issues in order to address the need in the community and in the families.

“...historically there has been a very long difficult struggle to have the Metis population identify as capable, confident and strong people. That influences our ability to admit to vulnerability.”

The participants felt strongly that it is difficult for Metis citizens to discuss mental illness and they also have the experience of years of struggling to be recognized as “*capable, confident and strong*”. This has often worked against them in seeking out services to assist them. The expression of this dilemma was stated as having a mental illness being a sign of weakness, or letting their guard down. Therefore Metis people felt “*caught in the middle*” where they want the issues understood and responded to but, at the same time, cannot be heard and must not be noticed for fear of drawing attention to what is self-perceived as a weakness.

“...so we end up suffering in silence....we don’t bring it out; we actually don’t even share it amongst our families. We say we’re women; we’re Metis; we’re strong. But nobody comes and takes care of us, and we don’t know how to ask. It’s the way we were raised, to shut up, to keep secrets; I’ve kept secrets for 65 years!”

Availability of support was often not evident and families felt left to deal with crises on their own.

“...the social worker....who works for my daughter told me I was a horrible parent because I kept calling the police on her and kept calling CFS on her and that I wasn’t supporting her, but my opinion was the only way I could support her was to call because I couldn’t let the behaviour continue and then the children’s social worker was using me to find out evidence and information about my daughter’s disease so then you start feeling like a traitor, but at the same time her story had to come out so that action could be taken.”

The candor demonstrated by participants as they shared their experiences in what clearly was a very private and emotional area showed us how important this topic was to them.

Substance Abuse

Substance abuse was identified by participants as a condition which created significant impact on relationships, families, and services. Much of the discussion centered on the inability of family members to clearly understand the disease and the extent to which this ‘unknown disease’ affects other family members. While participants expressed their awareness that there are multiple programs in place, and that mental illnesses affect both physical and mental growth, a significant concern was for those with the disease, and those living with / caring for an individual with the disease, and the resulting depression.

4.2 Identity – *How do you think others see you? Do you think having a chronic disease changes the way others see you?*

Throughout the discussion of how chronic diseases affect the way others perceive or look at them, participants related their personal perceptions and experiences.

Misperceptions / Lack of Understanding of Chronic Disease

While each story that was shared was unique, each demonstrated a misperception or lack of understanding about chronic disease that impacted the way the individual was viewed by others.

“...People think I have COPD. No, I have a rare disease. I get defensive quick. I used to cover away but not anymore. I don’t know if they do it because they think I was a smoker or they think I’m Native, but for all the years I put up with the crap now I’m on the edge. I see a counselor now to help hold me back. She’s given me a booklet to follow because I went from being non-aggressive to too aggressive. Little kids always want to know what’s wrong with me and moms are always pulling them away and I say, ‘No, there’s nothing wrong with them asking me’. I want them to know so they’re not scared of people who they see with oxygen tubes. It helps me breathe”

Personal Perceptions

Personal and family relationships at all ages are affected by chronic disease. Young people revealed that their own self-worth was affected by respiratory illnesses and they felt friendships were jeopardized because of the existence of a chronic disease. There was a strong sense of ‘accepting’ the notion that *“they’re not good enough to do this, to go there, to be like others, and that all those people are too good for me; I can’t go play with them.”*

Reactions from one’s own grown children varied and therefore affected family dynamics and relationships. In reference to her own three children, one mother stated:

“[M]y youngest was like ‘you snap out of it now’...and I had one sobbing and ‘come on Mom quit crying, you’re always crying, stop that’ and I had one son that just went the opposite way like he didn’t want anything to do with it.....they wanted their old mom back”

Many were willing to ‘confess’ to the confusing emotions that dominated their relationships.

“He will tell people about how he likes me to be big. So there’s that part of me that wants to not do the work, to watch what I eat, and there’s that part of me thinking, I already have him, I don’t have to pretend I’m someone to impress him. But it’s like, do I want to lose weight so that I won’t die of diabetes? Because I do have to! But part of me is scared too. And then he’ll say ‘we gotta start taking care of you honey!’ Confusing.”

Parent-child relationships are dramatically changed when a chronic disease is present and care must be given. Some participants expressed the increased stress they experienced when they found themselves pulled between a child in the hospital and an aging mother who had lung cancer. Loyalty and commitment are tested by all family members when a family member has a chronic disease and the result often brings a negative impact on the family as a whole. It was felt that this was particularly so when family members (siblings) do not live in the same location as those requiring care.

Participants were able to articulate the specific confusion in role changes.

“When I think of my father, if he were to ask me for help I would have such anxiety because I wouldn’t know how to help. That whole relationship would have to be re-established. If my father told me to do the dishes I would know exactly what he wanted...”

Participants felt that supportive relationships are crucial but also create more anxiety and confusion.

“I was actually diagnosed with borderline personality disorder, and people around me have said that part of why I am that way is because I was mentally abused 10 years by my father, and actually the person in my life who right now is the person who accepts me and helps me out as much as he can is my father and that development is a miracle. Just acceptance. He’s really the only person in the family that accepts my mental illness. He helps me just trying to stay positive. Having him call and come be with me, but it’s also really hard to have him here though.”

Many participants expressed the need to understand the changes that are inevitable in family dynamics as they relate to caregiving. There is a strong sense of isolation, no expectations, no support, and no acceptance.

“My father is chronically and severely ill and...I can hardly bear to see him because to me his whole purpose on this planet is no longer there...he was a huge authority figure and watching him wither and watching him struggle is very painful...There’s no opportunity for me to redevelop that relationship with my father. My father, is my father, my father, my father, my father, my father and nobody has ever given me the opportunity to look at my father as a man in society.....My father has been my role model and I’ve watched him face this portion of suffering and discontent bravely....if that ever happens to me we’re going hunting...it’s very difficult to watch somebody you care about struggle in any circumstance. And its very difficult to see it as something you better just pay attention to because it might be something that you’ll have to practice one day.”

Stigma

There was a consistent concern that those suffering a mental illness may have deprived themselves of services offered because simply confirming the diagnosis and admitting that whatever is going on would result in further stigmatization. In the Wellness Workshops this idea led to increased discussion on the need for public education, both to provide a better understanding of mental

illness, and to create an environment which was more sympathetic to coming forward and seeking help.

“You have a double label: you’re Metis and you have a mental illness. That makes it twice as bad. And there are a lot of people that deny it on both sides of the fence.....and that’s a battle all the time.....that affects their self-esteem and how do you celebrate who you are if people look down upon you”.

Educational Resources for Understanding Chronic Disease

From the experiences of participants we learned that there is limited knowledge about chronic disease by the general public, producing stereotypes and stigma. Some participants reported being teased and threatened because of their physical limitations. One suggestion was that more attention be given to educating the general public regarding chronic disease and the effect that this may have on that individual’s ability to function at work and in their personal life. It was suggested by youth that this education would help combat these problems.

“Someone could ... talk [about] like how other people treat you... some people treat me differently because I got a respiratory disease”.

Participants of the Wellness Workshops felt that many Metis had a limited understanding of chronic disease and its prevention. Metis residents had experienced stereotypes and stigma by family, peers and professionals due to limited knowledge of the chronic disease and its affect on the individual. Participants felt that the Manitoba health care system can be enhanced by promoting health literacy regarding chronic disease, creating sensitivity within the system and assisting chronic disease prevention initiatives.

“Lazy. Don’t take care of yourself. Don’t eat the right things. If you do this, if you did that, then you wouldn’t be this sick’...But they don’t even realize that at the time we’re eating the same things as other people and doing the same exercises and yet it’s still happening to this culture and not that one. But they still say ‘it’s your own fault. We can only do so much for you’.”

There was a strong sense (recommendation) that *“the more people know the less they fear”*. When the person dealing with the disease is forced to maintain an ‘internal struggle’, the less is noticed by others, and the more difficult it is to secure assistance.

Many suggestions were provided for making significant use of educational opportunities to address the public’s lack of awareness:

- using people in leadership roles as examples of those who have ‘conquered’ a mental illness
- producing and using commercials that explain why the person is forced to do things slower than others (respiratory illness)
- helping teachers responsible for physical education to adjust expectations they hold as a result of misunderstandings

- educate young workers of the dangers of certain work situations and their relationship to older co-workers' situations
- using education to support, monitor, and prevent diabetes conditions
- to assure the public (through education) that those with chronic diseases need not be 'avoided'

Some participants felt that education could be useful for citizens and health professionals rather than viewing chronic diseases as a given.

"I had a doctor once, and he actually said to me....you're overweight, and you're Metis, you're going to be a diabetic..."

Some sensed an unfortunate comfort in numbers, but rather than being educationally supportive, the numbers only provided social acceptance.

"Lots of people in (community) are diabetic, the majority, and no one looks at them any differently....some are skinny, some take insulin, some have lost limbs, some have high blood pressure or high cholesterol and others just have bad sugar."

4.3 Development – *How does having a chronic disease affect the way you function or behave? At what stage of managing the disease do you think you are? What characteristics or behaviours do you think it brings out in you and others?*

Daily Life Adjustments

After diagnosis of a chronic disease some risk modification and prevention activities are usually required to prevent further health complications (American Diabetes Association, n.d.; American Heart Association, n.d.; Becker et al., 2004; Dickinson et al., 2006; The National Asthma Control Task Force, 2000; Williams, Powell, Hoskins, & Neville, 2008). According to the WHO (2005a) up to 80% of early cardiovascular disease and diabetes can be prevented through consuming a balanced diet, engaging in regular physical activity and not smoking. These have all been shown to be important risk factor modifications however socioeconomic and other determinants can be equally as important (WHO, 2008). Participants described having to adapt their diet and activities to accommodate the chronic disease. They commented that the most difficult thing about being affected by a chronic disease was *“incorporating [those changes] into what was formerly your daily routine”*. Participants felt they required more time to devote to a task than they had prior to having the chronic disease.

“You got to develop the qualities, you got to develop different characteristics you can’t do what you used to do before you had this problem. You got to work around it. It takes a little more time but eventually you can do it, if you got the guts to do it you can do it. Take the worst thing of all of it and make a joke out of it. That’s the way you survive.”

Participants were cautious in describing the loss of an activity because this would prompt the next discussion – that of feeling *“more and more alone everyday”*. This was coupled with the fact that they were feeling the desire to resume the life they had before the illness was diagnosed. Interestingly, participants observed that the experience of living with a chronic disease may also have a very positive impact on one’s own attitude.

“I think that for myself, that you really start to impact your life and what you’ve done and I find myself more in tune with everything than I used to be, because you don’t know what tomorrow’s going to bring. With a chronic disease, you don’t know what’s going to happen. I’m flying to Edmonton in a few days for an assessment for a liver transplant. There’s no guarantee. You’re thankful you woke up that day. That’s how I am every day.”

“But I’m alive. Someone asks me how I’m doing, I say, ‘Well, I woke up today, so it’s good’.”

For those who were caregivers, participants were very articulate about the changes to their lives they had made when living with, and caring for, someone with a chronic disease. This caregiver’s experience with alcoholism was described in detail.

“...it really affects my life in every way that you could think of. I don’t have my life any more. I babysit him, I don’t go to visit, I don’t go away from home for

very long. I know my presence there doesn't completely keep him from drinking, but it keeps him from going overboard. So my life is a bubble. Loss of freedom is a good way of putting it."

Witnessing the impact on a loved one who feels limited by their disease is very difficult.

"Now that he's older, his emotions come out when he's limiting himself. It's not so much spontaneously doing something; it takes a lot of planning."

The balance between family member's reactions to a chronic disease and how the person wants to acknowledge the disease are often in conflict.

"But you can't change somebody's lifestyle overnight, and how much is it gonna take for him to change? How scared, and how sick is he gonna have to get before he changes?"

"He doesn't do a lot of the activities he did before, he sees them as contributing to the heart attacks. If he goes out working around the farm, and an hour goes by and he doesn't come in, I worry about him."

Living with hypertension, an invisible disease, was an unfamiliar discussion for most. Very little was known or understood about hypertension by those with the disease and those 'listening'. Seeking clarification and understanding between group members was important.

"Hypertension affects what you can do and you know your body says 'go, you can move' but your brain says 'no, you can't do it'; it doesn't connect."

Self-Perception of Limitations

Chronic disease can create physical limitations and mental strain on individuals affecting their lives and lifestyles. Approximately one in three Canadians aged 12 or older have a long-term activity limitation due to chronic physical disease or mental disorder (Statistics Canada, 2010). This finding is consistent with experiences of living with chronic disease articulated by Manitoba Metis. Many Wellness Workshop participants reported that they faced limitations due to their chronic disease. Such limitations impact upon an individual's sense of independence.

"It is really hard to give up things that you used to do before, like climb a ladder, you know. Because I used to do everything for myself. Now I can't even get on a chair for fear of falling because my legs give out on me."

Some participants reported that they were able to adapt activities of daily living to maintain their lifestyles; others were not as successful at adapting to the challenges presented by their chronic disease. Those who were able to work with their limitations quickly learned about their limitations, and then searched for ways to modify their activities to maximize their independence and reduce risk of further impairment. These participants felt that with additional planning and precautions they could still perform activities they enjoyed.

“Well, there are some activities that you can also compromise... just like don't push yourself too hard... do as much as you can.”

Thoughtful modification of activity was one method that participants identified as influential in promoting their sense of identity, along with supports needed to promote their wellness on a long term basis.

Participants who were less able to adapt their activity identified barriers including an uncertainty of the extent of their abilities after diagnosis and a fear of health repercussions from physical activity.

“Sometimes I lay in bed thinking of the things I wanna do, then I get up and think, what would I want to do them things for? I might be putting a strain on myself!”

Mental Illness & Chronic Disease

Participants were very forthcoming in their recognition that mental illness has far-reaching consequences.

“[W]ell I know for myself, my brother and my friend, they are both sick. That bothers me mentally and physically. I find I'm praying a lot, which I don't mind - I pray anyways, but it seems totally different; like I'm on edge. I just want everything to be right for them.”

Some were not only conscious of the fact that a family member's illness touched them but that it also increased the stress on the family member who is coping with the disease.

“He (brother) has no energy, he has no colour. And it's a big worry for him. He's getting depressed. And when he's getting depressed, the whole nine of us are getting depressed. So, that's how I'm affected.”

Participants reported feeling overwhelmed, suffocated, paralyzed, hopeless, and exhausted, and described that you “can't power yourself up to pick up the phone”. These reported feelings are consistent with those who experienced depression, a mood disorder that has been reported to co-occur with a variety of chronic conditions. Depression results in decreased ability to provide self-care and disease management, increased health complications, poorer responses to therapeutic treatments, and decreased quality of life and psychological well-being (Canadian Diabetes Association, n.d.; Dickey et al., 2002; Gorman, 1998; McIntosh, Kjernisted, & Hammond, 2008; Nichols, 2009; Ruguilies, 2002). Metis seniors discussed their experience with depression:

“Because I hate to say it but when you're sick and you're sick all the time or you're constantly sick, it wears on you.”
“That's like in my heart condition I suffer from chronic pain so when the pain starts you can feel like (sigh) ...[overwhelmed and depressed]”

Self-Management of Chronic Conditions

There were several emotions experienced as participants attempted to self-manage their chronic disease. Participants expressed the personal sense of failure and dismay when their attempts at managing their own condition were unrecognized and unsupported by health professionals.

“They made me feel like a real loser at the pharmacy. I don’t think it was because I’m Metis. It was just the fact that ‘okay, now she’s trying marijuana. She’s on so many drugs as it is’. I was on the Percocet, and I was on the OxyContin, and I was hooked on that for 3 years.”

Another emotion we heard about occurred when participants became frustrated with being ill. Frustration was expressed as getting to the point where “*you’re sick of being sick and you’re willing to take whatever will work*”. For some, another source of frustration was expressed when the health professional assigned to work with them could not relate to how they were feeling or thinking. This made the advice difficult to incorporate.

“They brought in a dietician and a nurse but they’re as white as that cup, and as skinny as that fork.”

We heard from many participants who felt that had they been able to work more effectively with the health care provider, and be provided with more information, it would have given their life and their disease more meaning and make it more manageable.

“...no one took time to explain about her chronic disease so she doesn’t understand what is happening to her and we don’t know what to expect.”

“...it’s not just managing the disease, it’s managing the life with the disease – we need more counseling.”

“...they tell you how to tell if you’re having a heart attack. They don’t tell you how to get through it and cope with how you’re supposed to live afterwards.”

“...this has nothing to do at all with being Metis, a lot of times, you’re not informed of the things that are happening to you.”

However, many participants have resorted to learning for themselves and feeling a sense of ‘control’ over how they feel.

“I use a natural root. It’s not some chemical that was put out by the petroleum industry!”

Limited knowledge, combined with misperceptions of others regarding the chronic disease, led participants to feel ashamed and often deny their condition and treatment options. We were told that individuals might not seek required assistance but rather would mask their chronic disease with an addictive substance or not perform necessary health promotion behaviours. Not wearing medic-

alert bracelets was one example that was given of ‘masking’ chronic disease that had unfortunate consequences. We were told:

“Look what happened to a person whose sugars are too low, and their breath smells [like] alcohol. With the smell on their breath of alcohol, [there is a grey area for misinterpretation] especially in public. But if people don’t wear their bracelets, who’s to know that they are diabetic and not drunk or something.”

Limiting activity was reported by many of the participants as an approach to manage the impact of their chronic disease. At the same time, they also felt that self-perception of limitations was determined by one’s attitude. For some individuals their chronic disease limited their lifestyle; for others readjustment was required to maximize their functional ability.

Some Wellness Workshops participants explained that rather than adjusting their lifestyle, they would rationalize their unhealthy behaviors and normalize their physical reactions to their condition.

“He’s learned to cope with how he feels with it... with the diabetes, if his sugar level is sitting at 17 or 18, that’s the normal, but once his sugar levels go down to 7 or 8. He feels sick, because he’s so used to his sugar levels being so high all the time.”

Metis citizens reported that reduction in unhealthy behaviours rather than cessation of these activities helped them maintain healthier lifestyles. One participant recalled her family’s experience:

“We just found out that... [my grandma has COPD] and bronchitis too... and so now what she’s doing... she stopped smoking except for Sundays. Sunday she smokes...”

Many participants were able to identify risk factors for disease and modifications they could make to their lives to promote wellness; many were also able to recognize challenges that prevented them from making changes.

Barriers to Risk Modification

Risk modification was an area of considerable discussion in the sessions. Participants in the Wellness Workshops identified that denial of their health condition presented a barrier to risk modification.

“I hate to say this, but most people are too proud when they first start noticing things that, that, to go to a doctor right away, to get help right away. It usually becomes a really big serious problem before they go get help. And I hate to say it but most people are too proud to admit that they have a problem and it’s a little problem and you know things can be done about it, they wait ‘til it becomes a very big problem and everybody around them says, ‘Hey, umm you’re doing this’ and they sit there and go, ‘No, I’m not’.”

Another barrier to risk modification that was identified was having a limited knowledge of the outcome of not making recommended lifestyle changes. While seven out of ten Metis adults in the

2006 Aboriginal Peoples Survey reported behaviour modification tactics they could implement to improve their health including increasing exercise, improving dietary habits and smoking cessation (Janz, Seto, & Turner, 2009), those findings were not reflective of many of the Wellness Workshop participants. Lack of information about their disease and complications related to it was often seen as a barrier to being able to identify and modify risk factors. Participants stated:

“A lot of times, you’re not informed of the things that are happening to you and I find that a lot.”

Chronic Disease Prevention

Diet and physical activity can promote and maintain health (Willows, 2005; Young & Katzmarzyk, 2007). A well-balanced diet is considered as one of the cornerstones of health. A diet containing high fruit and vegetable consumption has been shown to prevent certain chronic disease (Statistics Canada, 2010). Participants were well aware that diet and physical activity, are important factors that influence the onset of chronic disease, including hypertension:

“People are getting hypertension because of the food and what’s in the food. They’re not active enough, they just sit inside. We should be more careful what we eat and how we live.”

Participants were aware that an important chronic disease prevention tool was ensuring that their lifestyle included activity, even if it meant continuing the activities of maintaining a house and yard including mowing the lawn and working in the garden. Another area participants identified as important to prevent chronic disease was the need to recognize, provide, and ‘celebrate’ a healthy diet. They shared tips with each other about substituting frozen for fresh (as opposed to canned), buying in bulk and ways of storing, shopping for what is in season and supplementing the remainder, and an increased emphasis on gardening. Participants supported each other’s insistence that there was a need to learn *“to cook our foods without lard, or sugar...and to concentrate on a more heart healthy and ‘diabetic safe’ diet”*.

However, accessing that diet was always a concern. The lack of stores carrying fresh fruits and vegetables (food security) was an issue. Travelling to the closest store was not always possible. Additionally, life on a fixed-income forced Wellness Workshop participants to make decisions that might not always result in effective chronic disease prevention. There was often a choice to be made between buying fruit and paying a bill, but that doing both was not possible. *“The joking part of being Metis, and that’s the white part of my dad”* is that they were always looking for a ‘deal’, the cheapest food they could buy. This most often resulted in choosing a diet that was not the most nutritious – a decision that affected the health of them, and those around them.

“The problem is that the fixed income that I’m on, I can’t even get fresh fruit. So, we might get from the food bank the odd time, but I see the truth - but I kinda wash it out of my mind. I know I need it but we just can’t get it. We’re cutting back on something else to get fruit or to pay a bill; you know it’s pretty bad”.

Participants also verbalized concern for those living alone and are eating poorly - either as a result of income or just not being motivated to cook for one. These concerns suggested that some Metis might not be in the position to successfully prevent chronic illness.

Another aspect of chronic disease prevention and diet was past experiences with food. Memories of childhood and the ingrained ‘rule of thumb’ that one must eat ‘everything on the plate’ were discussed. The lasting impact this has had on their adult eating habits was discussed as participants reflected on respecting the work it took to hunt, fish, and prepare the food. Without external supports, or a specific reason for committing to a healthy diet, most felt that while they initially can follow guidelines they soon find themselves reverting back to earlier habits.

“When you grow up and when my parents put something in front of me on the plate, you ate it... it took a lot to hunt, it took a lot to do canning, so whatever was put on your plate... [now] I’m eating the North American diet and you go to the restaurant and they put enough food for three people in front of you, I’ll eat it because you don’t leave something on your plate. So it’s breaking those habits”.

Even as participants’ conversation was focused on their own chronic disease prevention, they were also concerned about the health of younger generations. There was considerable discussion regarding the role of the schools in modeling healthy diets, providing refrigeration, and removing ‘junk’ food options as the school is where children spend the majority of their day.

“Even the school here, the cafeteria’s selling hamburgers and French fries. They have lockers, so they can’t take lunch meat, and they have nowhere to warm their lunch up.”

The importance of role modelling for smoking cessation (or not beginning) was also raised in the Wellness Workshops. Participants suggested that smoking cessation be managed at a number of levels including advertizing the dangers and providing information for people. One of the most influential factors was deemed to be parents as role models in encouraging or deterring smoking. A discussion of smoking and its effects on family members brought very strong comments regarding the smoker’s need to think about what she is doing to others.

While individuals suggested that lack of information was a barrier to making change other participants were able to identify several risk factors associated with developing chronic disease and developing further complications when you are living with the chronic disease. Participants reported experiencing difficulty obtaining resources, breaking habits, adjusting food consumption and resisting pressures from family and friends.

“I did that to my mom too when I found out she was diabetic and then she had a heart attack – ‘don’t do that mom, don’t do that’... and then I go and do it. It’s easier said than done.”

“You can be a child – ‘oh I want that chocolate bar’ and can’t stop thinking about it, and if you were a child you’d throw a temper tantrum and then you almost become a teenager; ‘no one’s gonna tell me what to do, I’m gonna get it!’

And as an adult, you say 'well, I can get it' and so you do and when you're done, as an elder, you think 'oh no... that was really stupid'."

Unwillingness to Obtain Support

In several of the workshops, ideas about willingness to approach health professionals for assistance were discussed. Experiences with diabetes care, mental health services, and homecare were voiced lending further insight into this issue. Being independent and not seeking help for chronic disease was mentioned in many of the Wellness Workshops but it was especially noticeable in sessions concerning diabetes and mental disorders; stigma is often associated with both of these diagnoses.

"We need to empower diabetics, get them to admit it and not be ashamed."

"I think it all depends. A person with diabetes, if they don't want people to know that they have it... walking into a store looking for diabetic foods... if they can't find it, they won't ask."

"Mental disease has such a stigma attached to it in this day and age that's why people try to ignore it or don't acknowledge they have it."

Despite the stigma that some felt was attached to a diagnosis of diabetes, an interesting thread throughout the workshops was the belief that Metis will inevitably develop diabetes. As a result, receiving a positive diagnosis for diabetes and living with diabetes was seen as commonplace. Participants suggested the commonly-held understanding of the community affected their willingness to participate in community education workshops. Participants suggested that Metis citizens may see that there is little to be gained from attending education sessions but rather learn to manage and live with diabetes from observing friends and family members.

"...this town is full of diabetics. But then again you look at it and you could say this town is full of diabetes but look at this, we are having a presentation on diabetes and no one comes. People just don't take the time to learn."

"And you know what I don't know what is wrong with people in this community, why they don't want to learn. A lot of people are diabetic and their kids are eventually going to be, and growing up they see their parents living unhealthy lives and they are going to live like them..."

Many participants felt there was an inconsistency in the way mental health programs were delivered. They felt that the need for programming is there, and that there are 'strong programs', but that they are simply not being used. Many expressed the sense that shyness, shame, and mistrust, keep Metis citizens from taking advantage of what was available.

"The last time they had somebody else to help me my kids got taken away from me. Won't do it again. Yeah there's a huge, huge mistrust and justified. So it's really, really difficult to have, to allow anybody into your life. With the fear of judgment and sometimes punishment. What we define as support is not necessarily what the authorities say is support."

Those living in very small communities felt that if the entire community were invited to attend mental health promotion programs there would be no singling out and each would feel the gentle pressure to attend. This would override shame, shyness, and pride.

On the issue of extended care, Metis seniors routinely refused homecare because the seniors did not want others coming into their homes and knowing how they live. Those that are living in personal care homes tended to stay in their rooms with the door closed. This would assure that they were not bothered, nor would they cause 'a bother'.

"I talk to my Metis elders about using homecare. They don't want anybody in their home seeing what they're living through on a daily basis. When I first moved here, I was under homecare and they came for a while and then after awhile 'she' wasn't used to these people so she pulled her hair. They got scared of her. They went to their coordinator and told him we don't want to go back there..."

A specific aspect of homecare services is foot care. This service is available to Metis however participants suggested that individuals refuse foot care stating that it is *"too painful"*. Participants were quick to state that they preferred to believe that they (and their feet) will get better tomorrow and therefore there is no real need to see a doctor!

Finally, many participants felt that educational programs for prevention of smoking, or smoking cessation, would go 'unheard'.

4.4 Relationships – *Relationships is about how we take care of each other. Do you think you take care of each other and if so, how?*

The importance of relationships, and individuals caring for each other, was repeatedly emphasized by participants in the Wellness Workshops, and was identified as having a significant impact on individual's ability to manage with chronic disease. 'Caring for each other' and the 'burden of chronic disease on family and friends' were two of the areas that emerged from discussion of the impact of chronic illness on relationships.

Caring for Each Other

This was an area where the situations expressed varied dramatically. There were participants who had very positive experiences with those who cared about them:

"...pretty fortunate in the fact that all of my family is very supportive of me and what I'm going through. They know what they should or shouldn't do, what I should or can't do, and they're really there for me."

However, the opposite situation was also described.

"I don't have support. Lots of siblings, but they are out in Calgary."

"You can't find someone to date you. Who wants to date someone who's on oxygen or somebody who's sick?"

"You do get stressed out when you have a disease. You're scared. You want to live, you want to get old and make sure you see your kids graduate. I know we don't know what tomorrow's going to bring for anybody, but when you have a chronic illness...I was getting more and more scared again. I had a nervous breakdown and I ended up in a crisis unit..."

The comfort of 'knowing' someone, and knowing that the other person 'knows' you, has an enormous impact on overall health.

"...when you meet people who are Metis, it's just like that; everybody has open arms for you. There is no formality. You can hug openly even if you've only known each other for a week. My food is your food... that's what it's about."

Finding ways to reach out and connect are very important in maintaining a sense of worth and unity.

"I was in B.C. a month ago, and if I saw a Metis logo I would go to that person and I'd say 'Oh you are Metis!'. When I wear my jacket people are coming up to me. So it does go to show you, people are reaching out...Because to look at us you don't know we are Metis. What would make me Metis?"

More than specific programs, emotional support was key in the minds of many who were trying to find ways of coping with having, or caring for someone with, a chronic disease. Knowing that

others were ‘thinking’ of them, made a considerable difference. *“It’s those little things that mean ever so much to make a heart soar.”* For some, support was provided when least expected.

“When I told people I had cancer, oh my god, it was like a swarm of love, a swarm of support. I’m going to cry. It overwhelmed me, how much everyone came. Everybody was just there, all this group, my Metis group, my girls at work, my family, my friends. If I could share half of them, the world would be a better place. It was just wonderful...that’s why I healed so quickly.”

Participants also commented that there is not *“enough respect for those in poverty. If there was real caring many of the problems would not exist.”*

During a discussion of where participants prefer to live, the common thread that ran through the conversation was that people felt comfortable when personal supports are there:

“It’s where they know nothing is really stopping you from doing what you want to do. You know that this is where my family and my support are so this is where things are going to happen.”

When the social/emotional supports are not in place the repercussions on their ability to manage chronic disease are immense. This was most evident for those involved when there is a limitation of activities being experienced. It became a vicious circle where they would witness a lack of activity, leading to loss of friendships, depression ‘moving in’, and a cycle of attempted suicides.

Burden of Chronic Disease on Family and Friends

Life with chronic disease affects emotional, psychological and physical aspects for both the individual diagnosed with the chronic disease and family members. The management of the chronic disease exists in a broader relational context involving not only the individual but their family and friends (Fisher & Weihs, 2000). Wellness Workshop participants found that a chronic disease had impacted their relationships. Family members were often concerned about the health of their loved one.

“If he goes out working around the farm, and an hour goes by and he doesn’t come in, I worry about him.”

This concern may manifest itself as hyper-vigilance on the part of families. Some participants recounted that their families would offer them advice or direction on how to live with the alteration in their lives. This advice was not always welcomed or adhered to.

“Well for me, they [my family] try to help me, they try to help [me] eat all I am suppose to eat but I am not going to listen to them. They [my kids] are there to help me, ‘mom you shouldn’t have this, mom,’ or ‘you should do this’. I am not going to listen to them. No, I just tell them to ‘mind their own business’, but they are trying to help me.”

Management of many chronic diseases may necessitate adaptation of family routines including changes in the functional roles of family members, and the allocation of power and autonomy within the family. Family can respond to changes through the development of collaborative management of the disease or by intentionally or unintentionally undermining disease management initiatives (Fisher & Weihs, 2000). Adjustments to family functioning required by the chronic disease were observed by one participant who stated, chronic disease *“affects relationships currently and into the future”*. Many family members and friends may be required, or feel that it is necessary, to take on a caregiver role. They are often concerned and try to help their loved one make appropriate lifestyle changes.

“With relationships like my dad, he is my dad, but I’m his caregiver... My dad is almost deaf and he has tunnel vision so he wouldn’t see or hear me coming and he’d be sticking his quarter into the slot where you get peanuts and he wouldn’t hear me and I’d be like ‘Dad I saw that!’ and he’ll shove them all in his mouth real quick! Because he knows he got caught.”

Family members may limit the individual’s participation in physical activities by adjusting family activities to accommodate the chronic disease. Participants reflected on their family’s response to their chronic disease:

“I think sometimes family plans change because we are going to be there, due to his heart condition, and diabetes, because of my arthritis. If it is normally going to be an active thing, they change their plans. Not that we are going to try to make them or anything.”

This accommodation may, or may not, always be appreciated.

The adjustment of roles and utilization of coping strategies may leave individuals with the chronic disease feeling overprotected and controlled by their family and friends as they may take some decision-making power away from the individual.

“Don’t tell me what I shouldn’t do. Don’t tell me what I shouldn’t eat. I have a friend, that once I told him I was diabetic, he would constantly be like... we would be on the phone, and he would ask ‘what are you eating?’ Well what business is it of yours? Like, back off Jack! It can bring you closer together if someone is not pushing your buttons the wrong way, but it can put a real strain on your relationship, depending on how you both treat it.”

Participants commented about the frustration of not being able to resume their life after the chronic disease:

“Family might take your decision-making away from you. Once you get beyond it, you are still treated like you have it, can’t trust that that person is capable of getting beyond it.”

Lifestyle changes impact the family and friends of the individual with a chronic disease forcing them to change or modify behaviors and how the family functions. Participants suggested that those close to them may not always understand the importance of behavior modification or the lifestyle changes

necessary to promote health. Family and friends often would provide the individual with food that they were not supposed to eat and were not always encouraging of weight loss endeavors.

“My husband will go to Tim Horton’s and be like, ‘You want anything?’ I’ll say ‘No’, and he’ll be like ‘You know you do’... And he brings me a small muffin. But now it’s like, ‘Oh I love you so much, I don’t want you to die of diabetes. You have diabetes you have to take care of yourself!’ I’m like, I know I’m listening.... It’s like he has to be educated too.”

When an individual is diagnosed with a chronic disease there will likely be an impact on their family and friends. Family and friends can provide a protective or negative impact depending upon their approach to the situation. Family characteristics such as negative or emotional communication and psychological responses to the disease with limited support will likely generate negative chronic disease outcomes. Family support characterized by family cohesion, problem-focused coping skills, and communication regarding the chronic disease will likely provide a protective function against negative chronic disease outcomes (Fisher & Weihs, 2000). Metis residents stressed the need to further educate family and friends on healthy lifestyle choices to ensure support for the individual when making necessary lifestyle changes. Moreover, participants of the Wellness Workshops emphasized a need for community programs to inform families of healthy lifestyle choices, while providing educational and emotional support. They believed that further educational support will increase understanding and improve self-management of the chronic disease.

4.5 Networks – *What other programs and services exist or are needed to assist in coping / managing the disease or your lives in general?*

Individuals with a chronic disease require a variety of networks at an individual, family, community, and nation level to meet their health and wellbeing needs. Wellness Workshop participants identified several different types of networks they needed to be able to manage living with chronic disease.

Health Supports and Services - Individual Networks

Through the Wellness Workshops, Metis expressed concerns over the limited resources available to assist them in understanding their chronic conditions, their limitations and their future prospects. Obtaining supports requires knowledge of available services as well as ability and willing to access these resources. Metis citizens explained that across all nationalities and cultures there are service gaps related to either a lack of programs and services or inadequate knowledge of available resources.

“I’m sure there’s a lot more different programs out there but are they just not advertised enough? Do people not know about them but they are there? I think this really needs to get out that they are there, somehow and people need to be referred to them.”

“I see no supports that I know of that exist to help her; she does everything on her own. She needs help. You gotta be on your deathbed to get homecare.”

The complexity of the health system can leave individuals lacking necessary supports and frustrated. Individuals with chronic disease often sought assistance from family and friends when experiencing gaps in the health system. Equipping patients and their families with information can improve health outcomes through increased program and service access, and enhanced self-management.

“I’d like to see a book for each RHA... with one number that you need for each service. Give a number and what it does. So you’re phoning the right number.”

“People need to know they can ask for help... there are two types of people, those who seek services and ask for assistance and those who do not ask for assistance because they are afraid and do not know who or what to ask. We need to help these people become aware of services that are available to assist them.”

“If nobody tells you about the networks that are out there... what questions do you ask to find out? Because sometimes you can ask, what’s out there to help me and they’ll refer you to the Heart and Stroke Foundation and when you phone them they ask if you want to donate. That turns our people off!”

Health Supports and Services - Familial Networks

Wellness Workshop participants spoke of a variety of informal and formal programs and services that were helpful in dealing with their chronic disease. Family and friends are considered an important informal support. Historically, Metis placed high importance on the value of family. Metis

families were large and bound to each other by loyalty, obligation to represent and advocate for relatives, and to support them materially and emotionally when necessary (Macdougall, 2008). Significantly, within Metis culture, it was the custom for grandparents to ‘adopt’ a child and take care of them. When the child became an adult, it was then their responsibility to care for their grandparent (Hourie & Carriere-Acco, 2006). Today, Metis families still live by many of these familial traditions. Although families are more dispersed, they still hold a sense of responsibility for ensuring their family members are well cared for. Troupe (2009) suggests that the importance Metis women laid on family wellbeing and traditional roles encourages them today to advocate, create and support institutions for themselves, their extended family and communities.

Extending resources beyond the individual to the family unit can equip family and friends to provide enhanced assistance to the individual with a chronic condition as well as enhance healthy lifestyle practices of the entire family. Situating the individual within a collective family unit strengthens the supports available to the whole family and enhances an individual’s formal and informal supports and resources.

“There’s [a support group for caregivers of people]... who have mood personality disorders but you have to have that person living with you... she doesn’t live with us [so] we don’t qualify.”

“[There is a] huge, huge, overwhelming need. There’s no supports for people. I think we need to start something. We need to correct our vision of people as individuals and start seeing them as members of the larger group. You have a family here, a family here, a family here... offering child care for these workshops, offering meals at these workshops... helping, figuring out what it is [that people need] because whatever workshop or whatever program you’re going to offer, you’re asking people to remove that portion of their daily routine.”

Participants reported that they often sought tangible and emotional support from family and friends because they could not always rely on formal support systems.

“Summer time I could go to the store but not in winter time. I have children from Winnipeg who bring me food... if I want something I just give a phone and she’ll bring it.”

Participants accessed informal support around healthy lifestyles and medication from family to ensure they could maintain an optimal level of wellness.

“[If my wife didn’t give me those pills] I wouldn’t be taking them! I think there’s about nine of them when you count them one at a time.”

In other instances having family support served as a protective factor for the development of further disease.

“I have a family member who comes over, it takes a lot of tea but... eventually... you have to be careful not to get involved... validate them as a person... things start coming out.”

Although family networks were highly valued by Wellness Workshop participants, participants acknowledged that at times it is necessary to seek support outside the family due to the family's limited knowledge and resources. Additionally an individual may lack familial support due to family dissolution, limited familial contact, or inadequate familial resources.

“Have to go beyond the family – they don’t have the tools or the knowledge, [it] breaks down the family.”

Health Supports and Services - Communal Networks

A variety of community programs were reported by Wellness Workshop participants including church groups, soup kitchens, community gardens, self-help groups and blood pressure clinics. Organizations and community groups that encouraged healthy lifestyles through activities such as walking programs, nutrition programs, chronic disease classes, aided Metis residents to understand and manage their chronic disease.

“We used to go to Locals and play diabetic games with them, trying to guess how much sugar is in that... We used two nurses to come in and teach patients how to take care of their feet. And then what I did one year was trying to go back to our culture and got an elder to come in and teach us how to can carrots. And then the patients brought a grandchild, to teach it over and over again. We would have patients come in one night and made homemade spaghetti sauce from scratch... no preservatives.”

Culture was frequently regarded as an important component of community supports and services by Wellness Workshop participants. Although additional partnerships can further enhance programming and activities provided by the Manitoba Metis Federation, available services provided cultural connection and support.

“Another thing I find when you walk through this door, you’re identifying with a Metis person, not a white person. You know it supports you when you come in here...you’re immediately respected. Other places, they don’t understand. They judge you; you’re just another stupid Metis.”

Physicians were a large formal communal network, if not the only formal communal network, for the majority of the Wellness Workshop participants. We heard that other health services and resources can assist individuals in managing their chronic disease. Some programs and services were perceived as “unfriendly, unwelcoming and unable to help” because they did not “take the time to listen”. Moreover Wellness Workshop participants frequently reported a lack of effective and appropriate community programs and supports. The limited knowledge of available programs and services may be partially related to the limited navigational supports currently available within the health system.

“I honestly can’t answer what there is out there for Metis people.”

“Workshops and community groups and stuff like that... [are] quite often seen as stab hunters and not really helpful. And I think the reason for that is because

there just... little tellers of information on the individual or participants but [you have] to take those seeds, nurture them and help them grow.”

“Who’s got time to go to these things if they figure they are not going to work anyways? It’s a waste.”

Metis citizens shared concerns for community safety which prevented healthy lifestyle practices and community connection. Participants suggested that community-based programs and services can enhance healthy lifestyles through the provision of space for free or subsidized physical activity, transportation services, nutritional activities and assistance of neighbours.

“I think it would be good if they did come into the community to teach about lifestyles, healthy cooking, share information on what causes heart attacks. It should be something at least once a year.”

“I like the Access Centre in Brandon. I wish they would have something like that here, where they could have a community walking program and cooking classes.”

“When I was out in Calgary a few years back at Christmas I noticed these angels on a bunch of yards... [they were for people who were] not able to shovel snow or rake leaves, if you have a nice neighbour, they’ll go and do it for free.”

Support groups or self-help groups bring together people facing similar issues, whether they are disease, relationship problems or major life changes. People share experience and advice providing benefits to individuals including decreased feelings of loneliness, isolation, distress, depression and anxiety and increased knowledge of the chronic disease and resources available (Mayo Clinic, 2009). Members of support groups have improved coping skills and gain a sense of empowerment and control over their lives. Members of support groups often feel less judged and better adjusted. They have a clearer understanding of what to expect from their situation, and obtain practical advice and information about treatment options (Mayo Clinic, 2009). Participants from the Wellness Workshops expressed desire for support groups in their communities to enable them to obtain support from others experiencing similar issues and to share their experiences. With support groups participants suggested they could obtain information regarding their chronic disease and available treatment options. Participants remarked:

“I could have just made an appointment... and then go home. But if it was a support group, you’d go once a month or so, and hear what everyone has to say about diabetes. Because not everybody is the same. It would be nice to know that what you’re going through is the same or different from what others are going through. There are places for people to go when they are alcoholics...but diabetes? No.”

A Metis youth observed:

“If you’re a person with a respiratory disease and you see another person... [with a respiratory disease] you know... what they’re going through.”

A Metis senior commented:

“I wish there was a group of ladies... that you can phone or get in touch with and tell, tell them your problem and see maybe they can give you, they can talk with you, or support you on what ails you or...”

Access to support groups and community programs and services for individuals and families affected by chronic disease could promote long term wellness.

Health Supports and Services - Nation/Formal Networks

Currently, the Manitoba health care system provides core services in 11 regions around Manitoba. Participants acknowledged formal services available including hospital services, home support, proctoring services, mental health workers, physiotherapy, clinics and treatment centres. Some health professionals provided services outside of their designated parameters to overcome system gaps. Centres that offered informational and emotional support, and adequately attended to their patients were recognized as an important, but infrequent, occurrence. Programs and services that implemented a cultural perspective and approach, such as programs offered through the Manitoba Metis Federation, were well received by Metis in the Wellness Workshops.

“There’s a nurse at the government building, and she checks my feet. There’s no group there, but she said if I need anything that I could come to her and she’d help. That’s the public health nurse. So she’s there if I need her. I like that support.”

Metis seniors residing in a southern Manitoba nursing home reported:

“If it wasn’t for [the activity coordinator] it would be all together different... [with the old activity coordinator, we] had a game night a couple times a week but there was no going for coffee or talking because she worked at the office.”

Availability of high quality health care services is a social determinant of health that affects many Canadians. Many Canadians experience difficulty obtaining necessary services and face financial strains due to high out-of-pocket medical expenses (Mikkonen & Raphael, 2010). Wellness Workshop participants had concerns with the delivery of programs and services in their region, explaining that the current organization of the health system and staffing issues led to poor service quality.

“Our hospital has been known to send people home with heart attacks, and has really had a bad go lately. Our hospital is just not good if you’re sick. If you’re really, really ill, don’t go.”

“I’ve got a mental illness and I’m trying to get a social worker and it’s a seven month wait...[in the mean time I have to just] grin and bear. You get very angry and very discouraged [trying to obtain assistance in the current health system]. Wish there was something to help us.”

Wellness Workshop participants reported the need to be very self-sufficient to obtain available programs and services. Participants reported that the service delivery system was complex and it was difficult to navigate. Health system complexity decreased awareness of programming in the community preventing access and creating frustration with the system often leading individuals to develop their own solutions.

“Somebody I know...talk about insensitive, his wife was bipolar and she’s having a crying fit so he locked her in the back of his...camper...he locked her in there and he drove her to Brandon, to the hospital there and he got somebody to come out and he said ‘either one of us is going to be dead tomorrow morning so if you don’t take her you better take me or you know whatever’. And that’s when he solved the problem, got her in right away but talk about an insensitive way of doing things, this women’s locked in the back of this truck”

Many of the health regions are comprised of small communities from which residents must travel to larger towns or cities for care. Individuals requiring specialized services, especially cardiac or neurological care, are usually referred to Winnipeg. Rural and northern Manitobans experienced gaps in available programs and services within their community (Bartlett et al., 2012; Sanguins et al., 2013). The availability of services in their community would increase access and utilization by preventing barriers to treatment obtainment. Metis may be transported to Winnipeg for treatment without any supports, having to arrange accommodation, transportation for family, and care of children at home all of which may not be covered by Northern Patient Transportation Program (Sanguins et al., 2013). The large geographical boundaries of Winnipeg and lack of formal and informal supports to assist in accessing appointments often lead to stress, negative feelings, and confusion. This lack of support makes it difficult to manage chronic disease effectively.

“Just back and forth from the hospital to the doctor, that’s all I do. That’s all I can do. I’m going to see a specialist in Winnipeg, see if she has any other ideas – the doctor here set it up—he’s a heart specialist, but he doesn’t know what to do”

“Why can’t specialists come up once or twice a month with a list of people that need to be seen?...That way the patients have their specialists, and their care plan, and they can see the specialist, and say...‘yeah, this is working for me or no it isn’t.’”

Gaps in available services and resources left Wellness Workshop participants unable to effectively manage their chronic condition.

“It was a long time before I got a talking glucometer. Which is dumb because diabetes causes blindness...Why aren’t they more accessible? But before that, there was a period where I would sit there and try to guess whether my blood sugar was high or low, and take my chances on how to deal with it. People need to know how to deal with it, and what resources are available to them.”

Within the nursing home, residents reported difficulty obtaining required assistance and maintaining a healthy diet. Metis nursing home residents raised concerns around the nutritional value of food prepared at their care home. The food that was prepared for them was often inconsistent with

health information on appropriate eating. These care facility residents also indicated that they required assistance to eat that was not forthcoming.

“They [nurses] don’t realize how bad you are that you can not do it... I do as much as I could but what I can’t I have to ask for help, that’s why I’m here.”

“When somebody comes and tells you, ‘Oh yeah you could do it’, I say, ‘What do you mean I could do it? I won’t ask you [to help if I could do it]’.”

Many Wellness Workshop participants felt that available programs and services were not being accessed by Metis people because of a lack of awareness of treatment options and resources, and an unwillingness to participate in the programs recognized. We heard:

“[The] RHA has a few centers available, mood disorder group, AA, AFM, narcotics anonymous, gamblers anonymous – they are not working for a big percentage of our people. There are barriers, linkage problems”

Some Wellness Workshop participants voiced experiences of personal and systemic racism within the health system. Experiences with racism created a barrier for some Metis participants as they sought to obtain assistance and to effectively mitigate risk factors for their chronic disease. Feelings of being misplaced, inadequate, or unwelcome as well as cultural and language barriers impacted Wellness Workshop participant’s willingness and ability to access programs and services.

“You’re still looked down on as a Metis. I feel it. I still feel like I’m judged by those in the health services as a Metis. We don’t get the...same treatment I think. I feel it.”

“But I find that if there is a Metis person here and a Mr. X over here, this man is going to get better care. I guarantee it.”

“My daughter looks very First Nations. She’s got very, very dark skin, very dark hair and people would say well...[she has a mental disease] because you’re First Nations and because of alcohol and drugs. And you say, ‘no, that’s a stigma, don’t put that label on me or anyone’.”

“I’m a quite confident person and I know... if I need medical help or if I need something I will go and find it or I will go and ask for it. But even like myself I feel that going into emergency you feel like you are wasting their time. And I’m sorry, but if my doctor’s office is closed and I feel that I need something I’ll go. So I know how they make me feel and like to be someone that suffers already with a mental illness, that may not have a lot of a support system in place. It would be awful. It would be just awful. You would leave there feeling so desperate and just alone, and ‘who cares?’ ‘Who really cares for me?’ ”

“Soon as you walk into Emerg—automatically they’re feeling inadequate and misplaced...”

Wellness Workshop participants felt that programs and services were often terminated due to budget cuts. Participants reported they have utilized effective programs that enabled them to manage their chronic disease but found these programs were often terminated or ‘adapted’ once participants felt comfortable accessing the services they provided. These changes created a void in chronic disease services for Metis citizens: “there was so much that we did and now there’s nothing.”

The inconsistency of programs and services, funding restrictions, and the short time span of projects prevented the adaptation of programs to community needs, and left many Metis perceiving community programs and services as ‘stab hunters’ and not helpful. Negative perceptions of programs and services frequently created an unwillingness to attend programs and services that would “waste their time”.

“Stress is addictive. Well, I think one of the ways people get overwhelmed and need these supports is because their life is out of control...it’s a dilemma though because when your life is out of control you don’t have the time to go to the workshops that are functioning during the business day. When you have a family you don’t have the ability to go to the functions...that are being delivered during the evening. I just feel like when things are happening in our world today that they’re not really happening in the holistic way that we’re trying to promote.”

Wellness Workshop participants emphasized the need for informational resources on their chronic disease, limitations, and future prospects as well as treatment options. Alternative approaches were offered to better navigate the health system including increasing program referrals, listings of programs and resources, and navigation services.

“If we had a centre that covered all that just by pressing a button and you didn’t have to hang up and call it, find a piece of paper and pen, and write it all down...You’re already getting to grade 12 there!”

“We need an easier route into the health care system—a Metis person we could have to talk to, and who could provide support and knowledge about the system.”

“When you have to learn about resources through your community members that is not appropriate.”

“How is it that a sister organization could not identify this individual as appropriate for that service?”

Wellness Workshop participants felt that due to the poor quality of programs and services in their region Metis people were not accessing the programs and services currently available. They felt that collaboration between the RHA and MMF regional offices may improve program access. When discussing the limited mental health programs and services for youth in the region, participants stated:

“[When developing mental health programs a] component of the MMF would be connected with youth for support of mental health.”

Metis citizens acknowledged both positive informal and formal networks, as well as opportunities to enhance individual, familial, communal and formal networks to assist in managing chronic disease. Although there are many positive attributes of the current health care system in Manitoba there appear to be gaps and barriers in program, service, and resource, availability and accessibility. Increasing support in system navigation and enhancing programs and services through the establishment of new programs and the adaptation of current programs to meet identified needs can improve self-management of chronic disease around the province.

4.6 Supports – *What concrete supports are needed or required in order to take best advantage of what is or could be available?*

A variety of supports are necessary for those affected by chronic disease. Supports are those things that enable us to be whatever we truly want to be and may be social, financial or physical. Supports serve the function of protecting individuals against developing chronic disease or ameliorating existing disease. Wellness Workshop participants all emphasized the need for increased financial, transportation and medical supports.

Socio-Economic Supports

The social determinants of health are the conditions and circumstances in which people live and work that impact an individual's health and wellbeing, and are responsible for health inequities (Mikkonen & Raphael, 2010). Socio-economic concerns, raised by participants, are known to be positively correlated with health (Statistics Canada, 2010). Income, a social determinant of health, influences an individual's living conditions, psychological functioning and healthy lifestyle choices. Canadians who reside in deprived neighbourhoods experience a death rate 28% higher than other Canadians (Mikkonen & Raphael, 2010).

Some Metis citizens in the province live in rural areas with few resources that can be readily accessed (Sanguins et al., 2013). This was also true of Wellness Workshop participants. In general, rural Canadians have higher mortality rates, higher infant mortality rates, and shorter life expectancies compared to their urban counterparts (Laurent, 2002). In rural areas smoking rates are higher, poverty is more common, mortality rates are higher for most causes of death and the average life expectancy for rural Canadians is three years less than Canadians in urban settings (Hutten-Czapski, 2002). Health status of individuals living in northern Manitoba is significantly poorer than the rest of Manitobans. Those living in the north experience higher rates of diabetes and hypertension, shorter life expectancies, and increased premature mortality rates compared to the Manitoba average (Pachkowski, Moss, Racher, & Annis, 2009).

The resources to which individuals have access determine, to a large extent, health inequalities (Bernard et al., 2007). Health status, health behaviours, and utilization of health care services is associated not only with where people live, but with important access issues (Laurent, 2002). Several barriers have been identified that make it difficult for rural and northern communities to access health services. Incomes in rural regions are lower than in urban regions, with Manitoba having the largest rural–urban income disparity in Canada (Laurent, 2002). Rural residents are also more likely to have lower educational attainment, which has been shown to impact health behaviours negatively (Vanasse et al., 2010). In addition, geographic remoteness, low population densities, inclement weather conditions, high unemployment, as well as the economic activities on which these rural communities depend (mining, forestry, and farming) can all have negative impacts on health (Government of Ontario, 2011; Laurent, 2002; Pachkowski, Moss, Racher, & Annis, 2009). Programs must take into consideration economic barriers experienced in the access to these programs and the lifestyle modifications they recommend. We were told:

“They get you in every way. There is lots of times that like for me I don't have a car and I got to pay to go to Winnipegosis for my shopping and I have a doctor's appointment about four times a month and I have to go and I have to pay for all

that...[with my] pension money, and you know with all my bills and it hardly leaves me with anything you know. It's a shame. "

"The biggest thing I hear was 'Well, I want to go to the gym, but I have family and is there anything you can do?' And I have to say 'no'. There was nothing I could do. 'I can give you a pedometer! Count your steps'."

Wellness Workshop participants requested employment, transportation and financial supports to assist them in maintaining a healthy lifestyle and managing their chronic conditions. Without the necessary transportation and financial supports Metis were likely to delay seeking health programs, services or resources, creating greater illness and sequelae before obtaining medical intervention.

"Cancer Care and Services for Seniors have some charters to help you get around. But you have to be a senior. Like even just to get some of our people to appointments. The Bands here, they've got vans to get people to appointments, but there's nothing for Metis."

"There are a lot of affected people. They have such trouble getting assistance. They live in communities where there is no transportation...they'll stay at home and it gets really bad before they go."

"[when people] have to call for a cab they're hit with 'Well the cabs are already bringing so—and-so in tomorrow. Can't you make your appointment tomorrow?' It's not that easy...I have an appointment and I'm sorry that the cab will have to make one trip. But when they have to rely on somebody else all the time and it's not easy for them to have things like that arranged."

Income Assistance was the only source of financial assistance for transportation available to Metis in many communities around Manitoba. Inadequate employment or affordable housing options increased the use of the Income Assistance program. Many Metis in the Wellness Workshops reported difficulty obtaining adequate employment that could meet high living costs. Affordable housing was also a concern as one Metis participant explained *"when you don't have a place to sleep, obtaining services is the last thing on your mind"*. Other people said:

"I remember in conversation. This one person they asked him if he wanted to work and he said, 'Oh no that is going to screw up my welfare'. So people look at it that way when everything is already being paid... if they work you pay \$800 for rent and there goes your cheques."

"[People around here] are either pensioners or... on social assistance... There is only about 30% of X that work. But there are not too many jobs available around here so what is they scoop it up right away."

Community safety concerns prevented participation in activities outside of the home that could assist with preventing and managing chronic conditions. Without community connections people were less likely to obtain information about programs, services and resources available and felt less welcome to attend available programs. Financial constraints hindered many from participating in

community activities and prevented involvement in healthy lifestyle activities and effected emotional wellbeing.

“I know a big one is going to the gym—would absolutely help anyone. But people cannot afford a gym membership.”

“The expenses stop you. You want to go and try to meet new people or go places but you can’t afford it. You’re on a limited budget.”

“When you realize you have to reduce yourself to begging (using the food banks), you become psychologically broken.”

Wellness Workshop participants emphasized the need for medical supports. Medication and medical supplies are expensive potentially limiting their utilization and preventing the effective management of a chronic condition. Metis do not receive any support aside from the provincial health system and there are no incentives to improve one’s financial position while on social assistance.

“There is no financial support...I work with elders and one of the biggest frustrations that I’m dealing with today is trying to find elders support that they really need. If they need a walker it comes out of their teeny-weeny living budgets. If they need medication...or anything like that. Even Pharmacare. You have to spend out of your teeny-weeny little living budget a certain portion before Pharmacare kicks in... [It’s] not a life I’m looking forward to.”

“She pays for her own medication, and she’s had to stop some and had to take less because of finances. So that’s not good.”

“Elders live on a fixed income and it’s expensive to be a diabetic...when medications don’t work, they don’t get their money back.”

Informational Supports

Health literacy will improve an individual’s health by promoting healthy lifestyle choices, increasing comprehension of health care needs and effective treatments, and assisting individuals in navigating the health care system. Those at greatest need of health information are more likely to have poor literacy skills but the current health information in Canada is often complex and inaccessible (Murray et al., 2008). Individuals in the Wellness Workshops identified that they had learning needs associated with modifying behaviours and risk factors for chronic disease. Participants reported feeling inadequately informed about necessary lifestyle changes to prevent further health complication and tools to assist in managing their chronic condition. Participants felt that they required further educational resources on chronic disease and their prevention and that information available requires revision. There were many ideas forwarded to facilitate this.

“That would be good if they could bring some resources to teach us, they’d be welcome. I think... that it would be a good thing [if] they did come into the community – teach us about lifestyle, healthy cooking, share info on what the cause of heart attacks. It should be something at least once a year.”

Metis participants reported that drug store education programs and some health care professionals provided much necessary support and encouragement for lifestyle changes. Youth participants from southern Manitoba indicated that physician parents of classmates were an invaluable resource for the young adults to access regarding health information.

“There’s a lot of kids in our school whose parents are doctors and they come around quite often [to pick up their kids from school] so if ever we have like questions that we need to ask them we just ask them and they’re always there to help us with stuff.”

Health information related to risk and modifying factors for chronic disease must take into consideration the educational levels of the population. Thirty-two percent of Metis in Manitoba have less than a high school diploma (Janz, Seto, & Turner, 2009). Participants acknowledged experiencing difficulty deciphering pamphlets and brochures, thus decreasing comprehension of, and adherence to, the information.

Delivery of educational information should be done in a variety of formats and presented over varied mediums. Information should be available in plain language with visual models, as informational videos and by insuring effective communication with patients (Murray et al., 2008). We heard that written information should be available in plain language with pictures, and that workshops should be delivered in an interactive format that increases comprehension and retention of the information.

“Readable pamphlets would be better. I mean words with one syllable instead of fifteen thousand, and every third word is this long, and by the time you’ve deciphered the word, you’ve lost the text of the sentence.”

“[Diabetes education needs to be] interactive. And I’m not talking with 100 people, I’m talking 30 or so people, because the more people you have in a room, the more people get antsy and afraid to ask questions. But the less people in a room, they are going to speak out, be more comfortable. You can play a game, divide a room, make it simple.”

Seniors recommended that it would be helpful to have a CD or DVD. In this way the health information could be reviewed several times.

“Something that you could go home [with] and watch it over and over until you’ve absorbed it all.”

Although participants acknowledged some available prevention and health promotion educational resources, such as Health Links, on-line resources, and smoking cessation advertisements, it was felt there was a need for further prevention and health promotion education. More individualized informational support is required to assist with prevention and management of chronic diseases. Given Metis residents’ unfamiliarity with available health resources further information should be made widely available. In addition to educational resources that utilize varied mediums and are available in language that is comprehensible to readers, supports can aid patients in adhering to new lifestyle changes.

4.7 Environment – *What other larger environments or institutions are affected by you or have an affect on you in this community?*

Health System and Medical Personnel Related Factors

In Canada the bottom third of income earners are more likely than the wealthiest Canadians to experience difficulty obtaining necessary appointments with specialists and wait longer for an appointment with a physician (Mikkonen & Raphael, 2010). Janz, Seto, & Turner (2009) reported that 57% of Metis in Manitoba were satisfied with the care received during their previous appointment with a health care professional. Unlike that study, participants of our Wellness Workshops described a different experience citing problems with medical professionals in their community specifically limited availability of service providers and a lack of confidence in the ability of the professionals that were available. This experience has been validated in another study with Metis in Manitoba (Sanguins et al., 2013).

The medical profession was seen to be really intimidating especially when individuals don't understand the system. Communication difficulties between health professionals and patients, either due to an inadequacy of information or difficulty understanding the doctor, led participants to ignore or deny symptoms or become frustrated with the system. Participants recalled:

“I was healthy all the time. I never went to see a doctor and when I went to see a doctor she said ‘Gee I don’t know if I can help you your high blood pressure is terrible’... so she gave me some pills and then... [in] about a weeks time I had a stroke...I went to visit Winnipeg and then all of a sudden my foot starts jumping... My daughter-in-law came and she said, ‘There’s something wrong with you’. I said, ‘What? I’m okay. There’s nothing wrong’. It took me two days before I got the stroke.”

“[The doctors] don’t have the time to take to talk to people. They don’t see it because my daughter’s mental disease, she can be very charismatic and she can work it. She can be, one minute she’s crying and you’ll tell her ‘well we’re going to see the doctor’ and it’s like a switch she turns it off. She walks in the room and people sit there and go ‘you’re the one who’s crazy. There’s nothing wrong with this person’.”

“One thing I found out. A doctor said ‘You don’t have Type 1- you have Type 2. All you have to do is, do this and do that, and you’ll get it under control.’ And I said whoever said that doesn’t know what they’re talking about ‘cause I’m on insulin and my blood sugar will not go down no matter what I do unless I assist it with insulin which means that my pancreas is dead... My biggest complaint is some of the medical profession, some of these young kids coming out of medical school, think they’ve got all the answers, but they don’t.”

Attitudes and approaches within the health system impact the consistency of service delivery. Multiple processes and avenues to seek assistance can complicate the system and leave people experiencing gaps or unable to access treatment required.

“As far as diabetes, I had a cousin who went to the hospital because of his foot, and it took him a very, very, long time for them to diagnose it and by the time they did diagnose it, he was so far gone they had to amputate a couple of his toes. He had gangrene and after that they had to take a part of his leg. And before we even got to that stage they were saying well, ‘you can’t be diabetic’. He was never put on insulin or nothing until he started losing his toes.”

“When a professional from Canada tells you to take [your daughter with a mental illness] to the States [to obtain mental health services] you’ve got to question our system with mental health because there’s nothing.”

“When we found out that my grandson [had a mental illness]... he had a crying fit, he tried to kill a dog and then he tried to kill himself. We took him to the hospital, the hospital [kept him for 2½ hours and then] told me I had to get him in to see his doctor, six weeks to get him into see his doctor. And the doctor wrote out a referral for him to go for a psych assessment. Psych assessment had to go see CFS [which took another four months]. By then I already had him out of our care and into somebody else’s care. He went...to 12 different foster homes because they could not control the behaviour.”

“When I was dealing with my grandson and my daughter we did a crisis call. They never called back.”

Professional attitudes demonstrating respect and confidentiality are essential to implementing and maintaining appropriate services in communities.

“And not just to rely on the hospitals and doctors and nurses, because sometimes they just don’t care...or bother.”

“I would say the majority [of people who obtained services at my work] would come in. They were all like very meek, very ashamed, and I have to admit a lot of the staff there would not help... they saw themselves as being so superior... and really a lot of the counselors who were there they just made these people feel, well insignificant.”

“I think that [professionals] continually need to be reminded that we are in the business of providing service and that we need to treat people regardless of who they are with respect and kindness.”

Wellness Workshop participants reporting feeling that there was an overreliance on medication in the health care system and a lack of health information regarding their chronic disease or treatment.

“Nothing. He (the doctor) just wrote something on a piece of paper and told me to go get some pills.”

“I am up to 18 different medications every day – some of those have side effects. Medications are evil. They’re so hard on me.”

Enhancement of treatment options utilized by patients can be initiated through increased physician program referrals. In the 2006 Profile of Aboriginal Children, Youth and Adults, 28% of Metis respondents in Manitoba rated the availability of a doctor or physician in their community as poor and 19% rated it as fair (Statistics Canada, 2009). Access to an alternate source of primary care, Nurse Practitioners, is also limited in the province with fewer than 70 registered in the province (Nurse Practitioner Association of Manitoba, 2010). Studies on patient satisfaction have found that patients are often more satisfied with Nurse Practitioners than with physician services as they find Nurse Practitioners spent more time with their patients and provided them with more information (Horrocks, Anderson, & Salisbury, 2002; Kinnersley, et al., 2000; Mitton, Dionne, Masucci, Wong, & Law, 2011; Thrasher & Purc-Stephenson, 2008).

Decreasing patient reliance on physicians and acute care services through increased access to support and advocacy services can improve care and treatment.

“We have a walk-in clinic that is provided for us here...but a lot of people are finding that if they go there they are sitting there for hours. So what do you do? You go to the hospital.”

“And now you can only go see the doctor on Tuesday, Wednesday or Thursday; they have no cabs on Mondays and Fridays. ‘Cause I was trying to go a couple Fridays ago and I was sick, sick and no, you will have to wait ‘til Tuesday. You will not be able to see a doctor on Monday or Friday”

Ability to engage on a regular basis with a care provider is one of the foundational blocks of managing chronic disease effectively – or preventing its development. For the participants in the Wellness Workshops lack of health information, difficulty understanding the health information provided to them by the physician or access to the physician were all factors that were identified that prevented some from developing a partnership with the care provider to proactively engage in risk factor modification.

Cultural Competency

Best practice guidelines emphasize the need for cultural consideration in the development and delivery of programs. Cultural competence identifies and understands the needs and help-seeking behaviours of individuals and families to promote access equality and non-discriminatory practices (National Center for Cultural Competency, n.d.). In the health care system, cultural competency increases comfort, safety, and security among patients utilizing the available services. With the Metis population in Canada almost doubling its population from 1996-2006 (due to increased self identification as well as birth rate) the need for consideration to be given to Metis culture during program development and delivery is increasing (Gionet, 2009). Participants of the Wellness Workshops felt that their needs and concerns were not considered during health program development and delivery leaving them reluctant to attend programs and utilize services. Services that were offered in some centres did not always address the interests or needs of some participants. Centres offering programs and services with a cultural component have increased understanding, representation, tolerance, and recognition increasing a sense of belonging among participants. Those

offering Metis-specific services seemed to be rare with the majority of programs having been developed with a Western or Pan-Aboriginal focus.

“I haven’t been involved in nothing. There’s the drop-in centre but I never [go] when it’s non-Metis and for me I feel like I don’t fit in there. There’s nothing else.”

Linguistic competency is an important aspect of cultural competency defining the capacity of an organization and its personnel to effectively communicate with diverse populations (National Center for Cultural Competency, n.d.). According to the 2006 Profile of Aboriginal Children, Youth and Adults 43% of rural Manitoba Metis are able to speak or understand an Aboriginal language but only 22% of Metis have access to services in their Aboriginal language (Statistics Canada, 2009). Languages spoken by Metis people in Manitoba include English, French, Michif, Cree, Dene and Ojibway (Gionet, 2009). Access to health information is limited for some individuals by language. Wellness workshop participants reported being more comfortable engaging with Metis health professionals explaining that *“a couple words or cultural links make a difference”* and increase understanding. Cultural linkages within the health system led Metis to feel more respected, understood, and recognized. Cultural linkages increased their understanding of health information. We heard:

“Elders feel intimidated. They just sit there and go ‘okay, okay, okay’... and mom is one of those women who she just sits there and goes ‘okay, okay, okay, yes, yes’....And I come in and she tells me that she didn’t ‘understand a word they were saying’.”

“If you’re not Metis, you don’t understand. You can’t relate to things way back. You get somebody white in a chair, would they understand our heritage?... understand us and get the questions out of us?”

“Sometimes these people just want to be heard. They want you to stand there and hear them and not disrespect them or belittle them because they don’t understand what you’re saying. They need someone... who will talk to them at that level...”

Diet was another aspect of culture that arose during the Wellness Workshops. The opportunity to eat food that was consistent with their traditional practices was often not available to hospitalized people who wished to eat traditional foods. Those in hospital were dependent on visitors to provide fresh fish or game for them. This was reflected by participants who said:

“When we go to the hospital, we’re not looked at as who we are and maybe dietary wise, what we tend to eat, like to eat and the food you get at the hospital, I can’t eat anyways. But it’s not anything that I would cook in my home or eat by choice and I think that sometimes that becomes a really big thing for our people because you gotta eat to survive and sometimes if the stuff you eat is funny looking or strange...I don’t eat stir-fry, don’t give me recipes for stir-fry’s!”

A strong sense of community belonging characterized by social attachment, social engagement and participation within the community is linked to improved physical and mental health (Statistics Canada, 2010). According to the 2006 Profile of Aboriginal Children, Youth and Adults, 37% of

Metis in Manitoba reported participation in a Metis cultural activity less than one year ago, while 15% reported that it had been five or more years since their last Metis cultural activity (Statistics Canada, 2009). Participants of the Wellness Workshops felt that community connection among Metis in Manitoba should be strengthened.

“I find that the Metis community and don’t get me wrong but I find that because they’re so spread like you [are], that you meet people at regional meetings or AGM but then everybody goes away and there’s no connection again.”

In the Wellness Workshops, participants emphasized the importance of cultural activities and support in achieving health. Enhancing cultural activities can increase Metis pride overcoming stereotypes currently held by the general population. They discussed the collectiveness of the Metis community and their participation in “*cultural celebrations, [which] draw people out of their homes*”. One participant of the Wellness Workshops explained that “*when you lose your culture [it] can lead into a mental disease*”. When discussing the importance of ‘community’ participants asserted:

“As a community, they keep track of who has diabetes, and who has heart disease... they take care of each other... they do, they know who’s sick, who’s not, and who’s doing the doctor thing this week, so let’s catch a ride and go... they help each other... in a small community they can”

Cultural competency, as defined by the participants in the Wellness Workshops, included inclusive programming and access to information in a language that was used by them. Particularly for Elders who may be more comfortable speaking Michif and more at risk for developing chronic disease, ensuring access to information in their chosen language would be optimal. Access to traditional foods, if desired, and recognition of the strength of family and community support were also considered to be important elements of a culturally competent health care system.

4.8 Governance – *In order to have a voice, are there times or situations in which you can be heard more effectively as an individual, as a small group or family, as an organization?*

Advocacy for self and for others is the essence of the Wellness Area ‘governance’. Advocacy is an act by an individual or group that involves pleading for, supporting, or recommending (Dictionary.com). Individuals, who possess sufficient understanding of a subject, and self confidence, will be able to voice their concerns and obtain necessary support. Areas of governance identified by Wellness Workshop participants included personal power and collective voice.

Personal Power

Individuals are empowered by increasing their knowledge about chronic disease and personal skills to manage it. Health literacy affords this empowerment by providing individuals with the confidence to act and improve their personal and collective health (Murray et al., 2008). Participants of the Wellness Workshops considered that seeking out further information regarding their chronic disease and treatment options was a form of self-advocacy. Wellness Workshop participants understood the importance of healthy lifestyle practices that needed to be self-initiated. To attend to health needs, self management and action that included both physical and mental adjustments was most effective. It was stated that *“sometimes you have to go about it yourself”*. Despite the barriers previously identified in this report, many individuals took it upon themselves to seek out information.

“See, this is why I like that you invite us to come. The MMF sometimes they have a diabetes clinic and I come because I am very interested.”

“It’s a choice—you can choose to participate or you can sit at home and do nothing. It’s a choice.”

Health information can improve an individual’s self-management of their condition and enable them to fully participate in their treatment. By sharing that information about their chronic disease individuals can increase others understanding of chronic disease and the difficulties experienced due to their condition. Participants felt that sharing personal stories will help create change in the system.

“They have to hear, we have to individualize that [to] put the personal aspects into the stories so that we can bring them to the next level. So the next level will listen because if you don’t, they’re not going to listen. If they don’t hear about the hardships and the troubles like you can’t make them look at it from a personal perspective. They can’t turn their story around and say [to] somebody ‘this can happen to you. What would you do if you were in that situation?’ You know, that’s what needs to be heard and I think from there it’s got to go up the chain because unfortunately our, our system here in Canada you have to follow a chain of command.”

“Those are people [who] aren’t going to change the world unless they talk.”

Self-advocacy translated into increased treatment access for participants in Wellness Workshops. Participants felt their voice could improve their treatment experience by reducing discrimination and wait times, and increasing their rate of referrals to specialists.

“Speak up for yourself, because if you don’t, if you’re quiet, then there is nothing wrong in their eyes. And we [Metis] are strong people but we suffer in silence. And that’s our biggest mistake suffering in silence... You have to be very much your own advocate and make your own children and grandchildren strong.”

Collective Voice

For a variety of reasons individuals living with chronic disease are not always able to speak for themselves. We heard that for the participants this might have been related to chronological age, language barriers, exacerbation of disease or previous ineffective encounters with the services. In these instances **family and friends** often sought to intervene to ensure proper care and treatment was obtained.

“People don’t know what they’re entitled to...and when you’re suffering with mental illness you don’t have the fight or that strength to keep going back to stand up for yourself, to fight for what you need. So they just give up...And they suffer. They turn to the drugs and...drink, they deteriorate so quickly...”

One participant recalled a time when she was unable to speak up for herself and that it was solely through the intervention of her daughter that she was able to receive appropriate care. She recounted:

“I was in the hospital room and my daughter kept coming in, and the nurses were seeing that I was in pain, and saying, ‘Give her Tylenol’ and my daughter kept saying, ‘No! Don’t give her anything! Read her bracelet!’ So my kids were my voice. But if they weren’t there...”

Another way families may seek to intervene is to obtain further information to support their loved one in making healthy lifestyle changes and obtaining the best treatment option.

“A lot of information about the disease [is needed]. The family has to know in case someone is cooking and what’s in it, and whether it is safe.”

Individuals without a supportive family may require formalized advocacy and support to meet their health needs. **Health system** advocates were frequently reported to have a strong voice both in patient uptake of services and resources, and in service obtainment. Individualized patient care is an important component of chronic disease management in addition to accessing programs and services. Defining health as the amalgamation of physical, mental, and social well-being reinforces the individualized holistic approach required in the health system (Statistics Canada, 2010). The promotion of programs, services and resources by health system advocates that can attend to individualized determined needs can improve health outcomes. Reinforcing the importance of ‘*compassion in governance*’ through values of respect, kindness and confidentiality can strengthen the health systems ability to meet patient needs. Advocates in the health system can strengthen their roles with a holistic understanding of an individual and by building a collaborative health and wellness system among and between the social determinants of health.

“Because with my dad, he doesn’t always believe the words that come out of my mouth, and will insist that he is having a heart attack when he just hasn’t eaten anything. He needs a doctor or nurse to tell him to eat before he believes it. It depends what role that voice is playing.”

“You come to a town like this you...get all the services for mental illness but then you lack all the services for housing, for understanding and compassion for your family and all those other things so you have to really measure the lesser of two evils.”

Metis citizens felt that collectively **Metis** need a stronger voice to be able to improve their position in the current system. Stigma, racism and discrimination in the health system at times prevented Wellness Workshop participants from obtaining needed health supports and services. Collective strength of the Metis can enhance cultural pride preventing Metis from feeling helpless and continuing to “live in silence”.

“[Metis are] defensive, ‘don’t give anybody any reason to think any less of me’. Like it’s already given a sense of pride, a sense of accomplishment, and a sense of strength that is how we are identified as Metis. So if we’re talking about vulnerability, if we’re talking about chronic illness, if we’re talking about anything that is being less than solid than we try to [hide it]”.

Wellness Workshop participants felt that Metis did not have a space to voice their concerns. Metis continue to fight to ascertain a strong position in Manitoba and meet identified needs. Educating Metis and collectively advocating for Metis rights can improve outcomes for Metis in Manitoba.

“My view is that we’re not Treaty Indian so we don’t have our voices being heard as well; we’re not educated white so we don’t have them thinking we should get the same treatment as them. We’re kind of stuck in the middle where we can’t be heard and we can’t be noticed... And so we end up suffering in silence.”

“My feeling is that there is strength in numbers.”

Individuals with a chronic disease need to be empowered to acknowledge their problems without feeling ashamed. Individuals can advocate for improved care by obtaining information, attending programs and services, and voicing their concerns. Sharing personal stories can improve self acceptance and understanding, as well as enhance the care and treatment obtained by others. Collectively, informal and formal processes can be established to ensure that health needs are met. Family and friends can both provide tools to assist an individual with a chronic disease as well as empower an individual to make decisions themselves. An individual’s family and friends can assist an individual in obtaining the best treatment options and enhancing self-management of the chronic disease. Formally, health system advocates can enhance patient uptake and service obtainment by applying an individualized holistic approach to care. Collectively the Metis voice can strengthen the position of Metis in the Manitoba health care system and meet the identified needs of Metis citizens around the province.

5.0 Discussion and Recommendations

5.1 Reflections on Wellness Areas© Themes for Risk and Protective Factors

It is clear that Metis have reflected upon the issue of chronic diseases and how these impact individuals and families. It is also clear that the participants felt that there were things that could be done differently in terms of factors related to the individual, their family, and the healthcare delivery system. For example, information, although provided, is not necessarily accessible. Some participants spoke of too much information being available; some felt there was not enough information available to them. While families were identified as being important supports for some individuals, other participants noted that families are not always helpful for a variety of reasons, some being related to lack of information. Some participants were keenly aware of the significant impact that having a chronic disease has on personal and family social activities. Others spoke to the issue of individuals who ‘deny’ recognition of their chronic disease. Again, this is not a simple issue since such denial may also be related to a sense of hopelessness about preventing or managing one’s chronic condition. Such a web of complexity is difficult to untangle.

One method to simplify this complexity is by reflecting on the themes that arose from analysis of the data while keeping in mind the general meaning of each of the Wellness Areas. One begins to see a pattern whereby the themes in the first four Wellness Areas© seem to be have a personal and internal locus of control, while the themes in the later four Wellness Areas© seem to be more external and system-based. Although more analysis would be required, such a view may support a balance of focus on change or activities for the individuals/families and the system.

INTERNAL / PERSONAL	EXTERNAL / SYSTEMIC
<p>Nature – <i>How do you see yourselves as Metis people living in ___?. How does having a chronic disease affect the way you see yourself?</i></p> <p>Lack of Understanding of Chronic Disease Mental Illness Substance Abuse</p>	<p>Networks – <i>What other programs and services exist or are needed to assist in coping / managing the disease or your lives in general?</i></p> <p>Health Supports and Services Individual Networks (information) Familial Networks (tangible and emotional) Communal Networks (social and cultural) Nation/Formal Networks (health system)</p>
<p>Identity – <i>How do you think others see you? Do you think having a chronic disease changes the way others see you?</i></p> <p>Misperceptions/Lack of Understanding Chronic Disease Personal Perceptions Stigma Educational Resources for Understanding Chronic Disease</p>	<p>Supports – <i>What concrete supports are needed or required in order to take best advantage of what is or could be available?</i></p> <p>Socio-Economic Supports Educational Resources for Understanding Chronic Disease</p>
<p>Development – <i>How does having a chronic disease affect the way you function or behave? At what stage of managing the disease do you think you are? What characteristics or behaviours do you think it brings out in you and others?</i></p>	<p>Environment – <i>What other larger environments or institutions are affected by you or have an affect on you in this community?</i></p>

Daily Life Adjustments Self-Perception of Limitations Barriers to Risk Modification Chronic Disease Prevention Unwillingness to Obtain Support Self Managing Chronic Disease Mental Illness and Chronic Disease	Health System and Medical Personnel Related Factors Cultural Competency
Relationships – <i>Relationships is about how we take care of each other. Do you think you take care of each other and if so, how?</i> Caring for One Another Burden of Chronic Disease on Family and Friends	Governance – <i>In order to have a voice, are there times or situations in which you can be heard more effectively as an individual, as a small group or family, as an organization?</i> Personal Power Collective Voice Family and Friends Health system Metis governance

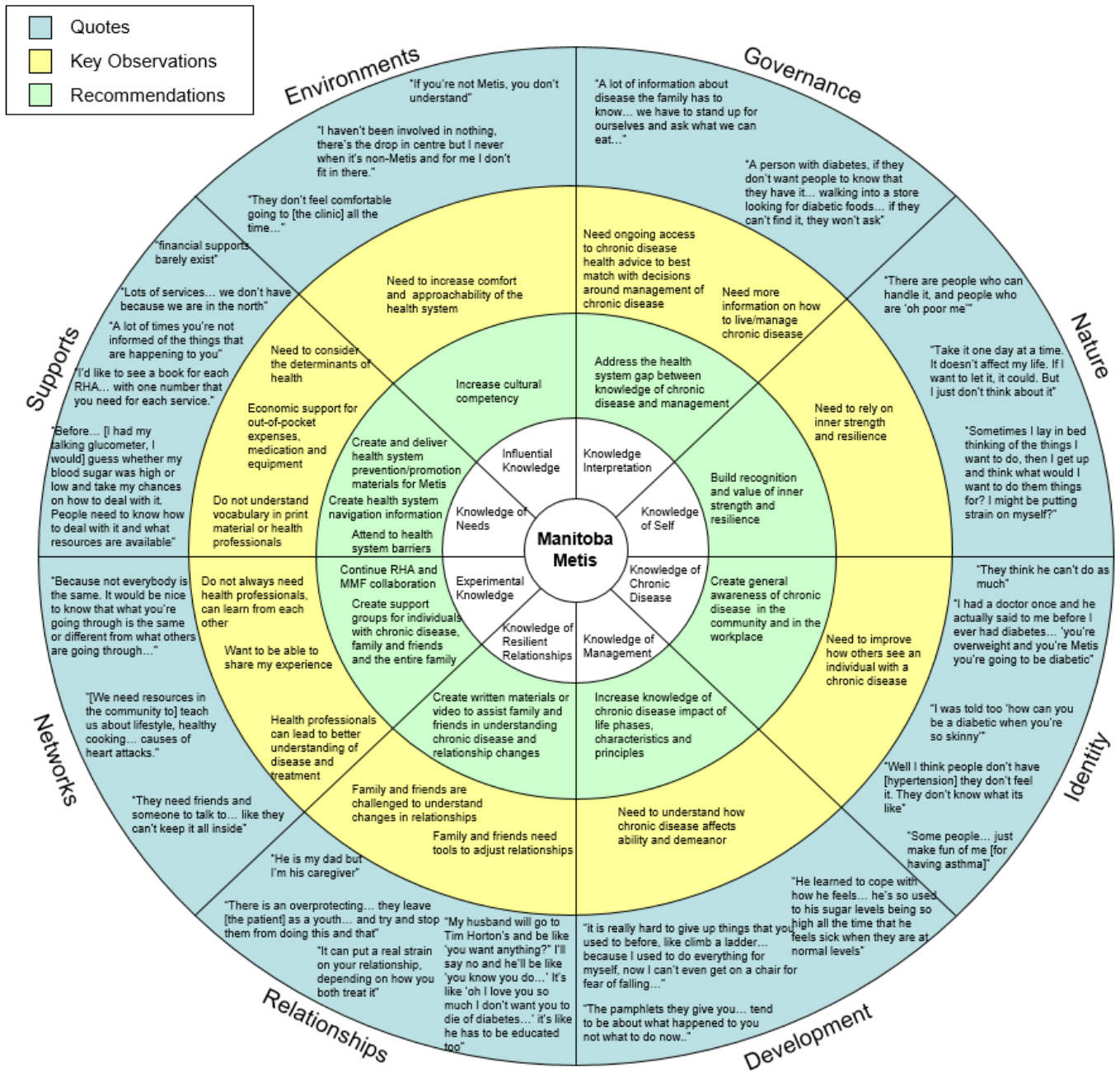
In addition to the above observations, one can reflect that those themes in the first four Wellness Areas© seem to be related to ‘risks’ an individual and their family might face when dealing with or trying to prevent a chronic disease, while those themes in the latter four Wellness Areas© seem to be factors that might lead to more ‘protective’ for individuals and their families when dealing with or trying to prevent a chronic disease. To further balance these thematic perceptions, one might wish to articulate and develop activities to increase protective factors for individuals and their families, while at the same time articulating and developing system-based risk factor mitigation. Both of these approaches would be of benefit to the burden of suffering and to costs to society when chronic diseases are not well addressed.

5.2 Needs and Recommendations Scoping Exercise

Undertaking analysis of Metis citizen knowledge on chronic disease and living with a chronic disease, we chose to again use our holistic approach to organize Metis citizen needs. This broadened our initial scope, of characterizing Metis knowledge and experience as risk and protective factors, into promoting health and wellbeing through transforming a holistic collection of knowledge into action (knowledge translation). This conclusion and its related recommendations were determined through the utilization of the Wellness Areas to capture the complete experience of Metis citizens in relation to a chronic disease, depicted in Figure 2.

By placing Wellness Workshop participant’s quotes into their corresponding Wellness Areas© we were able to translate overarching needs into key observations. Equipped with an adequate understanding of these needs and experiences, the analysis working group was able to define and plot recommendations in each Wellness Area© that would meet the corresponding needs of Metis citizens. Assessing key observations and recommendations within each Wellness Area© the working group further defined the recommendation by determining its appropriate knowledge translation method. To complete the process, the experiences and recommendation of all the Wellness Areas© were amalgamated to an underlying conclusion discussed in all Wellness Workshops: the need for a holistic approach to knowledge translation.

Figure 2: Wellness Wheel Analysis



5.3 Recommendations

A holistic approach was used to gather Metis citizen knowledge around chronic diseases. Analysis was focused on knowledge translation that takes into consideration all areas of an individual's life as it relates to their health and wellbeing. Knowledge translation (KT) includes the synthesis, dissemination, exchange and application of knowledge that will lead to improvements in health and wellbeing. KT encourages and supports community members to 'take up' or use research findings and new knowledge in 'evidence-based' policies, service delivery plans and in practice. Ultimately the goal of KT is to influence political and social change by closing the gap between 'what is known' and 'what is currently done' in practice settings" (Masching, 2006, p.1). Knowledge translation activities linking health research to practice in Aboriginal communities have been overlooked and when it does occur, there is little adaptation of mainstream approaches within the Aboriginal community context" (Smylie et al., 2003).

To effectively achieve knowledge translation, further information on the health sector and the determinants of health including social and economic factors are necessary. Accumulated information will assist in determining how policy and/or programming modifications can resolve concerns conveyed by Metis citizens.

1) Nature: Knowledge of self

To effectively manage a chronic disease Metis citizens described the need to rely on inner strength and resilience. Metis citizens required knowledge of themselves to effectively cope and manage their chronic disease.

Recommendation: Provide accessible programs and information to build recognition and value of inner strength and resilience among Metis citizens.

2) Identity: General knowledge of chronic disease

Metis citizens discussed the need to improve perceptions of an individual with a chronic disease by providing health information regarding the chronic disease and its management. Management of a chronic disease is enhanced through the utilization of appropriate health literature to promote a broader acceptance of the chronic disease by the individual, family, friends and the community. Social support emphasizing understanding and compassion will ensure appropriate lifestyle modifications are implemented and proper care and treatment is obtained.

Recommendation: Create general awareness of chronic disease in the community.

Recommendation: Create general awareness of chronic disease in the workplace.

3) Development: Knowledge of chronic disease management

Metis individuals commented that they often experienced limitations due to their chronic disease that reduced their sense of independence and altered their demeanor. Metis emphasized the need to better understand how a chronic disease will affect their physical

ability and character/personality, and how to overcome barriers and challenges associated with appropriate lifestyle changes that may be required of the individual.

Recommendation: Increase knowledge of impact of chronic disease on life phases, characteristics and principles. Information on accessible programs and information to assist Metis in understanding the impacts of chronic disease including behaviour adaptation that may be necessary, will improve their health and prevent further complications.

4) Relationships: Knowledge of resilient relationships

Relationships with family and friends were often impacted by chronic disease as family dynamics changed and lifestyles were modified. Family and friends are challenged to understand changes in relationships as a result of chronic disease and require tools to adjust relationships. Family and friends are a key support in assisting an individual with the effective management of their chronic disease. They require knowledge of appropriate assistance to provide support allowing them to coordinate activities with necessary behaviour adaptation.

Recommendation: Create written material or a video to assist family and friends in understanding the chronic disease and associated changes in relationships.

5) Networks: Experiential knowledge

Metis emphasized that although health professionals can contribute to a greater understanding of their chronic disease and appropriate treatment options, they do not always need to rely on a health professional to learn about their chronic disease. Metis found it beneficial to learn from each other by sharing experiences of living with a chronic disease. Metis felt individually obtaining and collectively sharing information contributed to their ability to cope and effectively manage the disease.

Recommendation: Create support groups for individuals with chronic disease. Support groups will enhance their capacity to take control of their health by increasing awareness of resources available and promoting long-term wellness.

Recommendation: Create support groups for family and friends of individuals with a chronic disease. Support groups will allow family and friends to discuss coping strategies and enhance their ability to assist in management of chronic disease.

Recommendation: Create support groups for the entire family including the individual with the chronic disease, family and friends and appropriate health professionals to ensure a positive environment for the effective management of chronic disease. These support groups will promote positive relationships comprised of understanding, support and compassion facilitating the acquisition of the most suitable care and treatment options given the immediate circumstances.

Recommendation: Continue collaborative work between the Regional Health Authorities and the Manitoba Metis Federation to enhance the health system culturally and holistically to increase its ability to attend to the health needs of Metis citizens.

6) Supports: Knowledge of needs

Metis emphasized the need to consider the social determinants of health, including economic and cultural factors in programming development and implementation. Understanding and working within the parameters of a patient's economic situation will improve access to and maintenance of treatment options. This includes providing economic support for out-of-pocket expenses and assistance with obtaining affordable prescription drugs and health equipment. Increasing cultural competency within the system will enhance support, security and comfort while utilizing programs and services, enabling Metis citizens to feel their needs and concerns were considered and addressed.

Recommendation: Create information to assist with the navigation of the health system ensuring Metis citizens are aware of available programs, services and resources. Knowledge of the health system will increase access to appropriate services improving the health and wellbeing of Metis across Manitoba.

Recommendation: Continue to increase knowledge of health system access barriers for Metis by sharing Metis experiential knowledge through the region Knowledge Networks. This collaborative table will support development of solutions to influence social and economic barriers to health system access experienced by Metis citizens. Community wellness development focus will also serve to seek and implement solutions at the community level.

Metis citizens have found health information is limited and is insufficient in meeting their needs. They admitted that they are usually unable to understand the vocabulary in printed material and have experienced times when they did not understand discussions they had with their health professional regarding their chronic disease and treatment. Metis often found that the one-time-only approach to health information is insufficient. They explained that information regarding the chronic disease is usually provided at time of diagnosis when they are not in a place emotionally to obtain and retain necessary recommendations from the health professional. Some Metis reported that the delivery of chronic disease information was not appropriate for their learning style, emphasizing the need for interactive teaching methods in addition to appropriately developed print material.

Recommendation: Create health system health promotion and disease prevention materials that can be accessed by Metis citizens.

Recommendation: Health promotion and disease prevention materials should be developed using a variety of media and at a variety of literacy levels.

7) Environment: Influential knowledge

The current organization of the health system presents some gaps and challenges for Metis citizens in Manitoba. Metis were concerned about their ability to effectively attend to their needs without a culturally appropriate approach to health service development and delivery. The inability of Metis to confidently approach health professionals and obtain needed supports and services hindered chronic disease management and treatment.

Recommendation: In collaboration with the Manitoba Metis Federation increase cultural competency in the health care system by applying representative health workforce principles, and developing and delivering Metis cultural competency training.

8) Governance: Knowledge interpretation

Health information, including handouts and discussions with informed individuals, strengthens an individual's ability to manage their condition and enables full participation in treatment. Metis reported requiring more information on how to live with and manage chronic disease emphasizing the need for ongoing access to consistent chronic disease health advice.

Recommendation: Address the health system gap between knowledge of chronic disease and managing chronic disease.

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