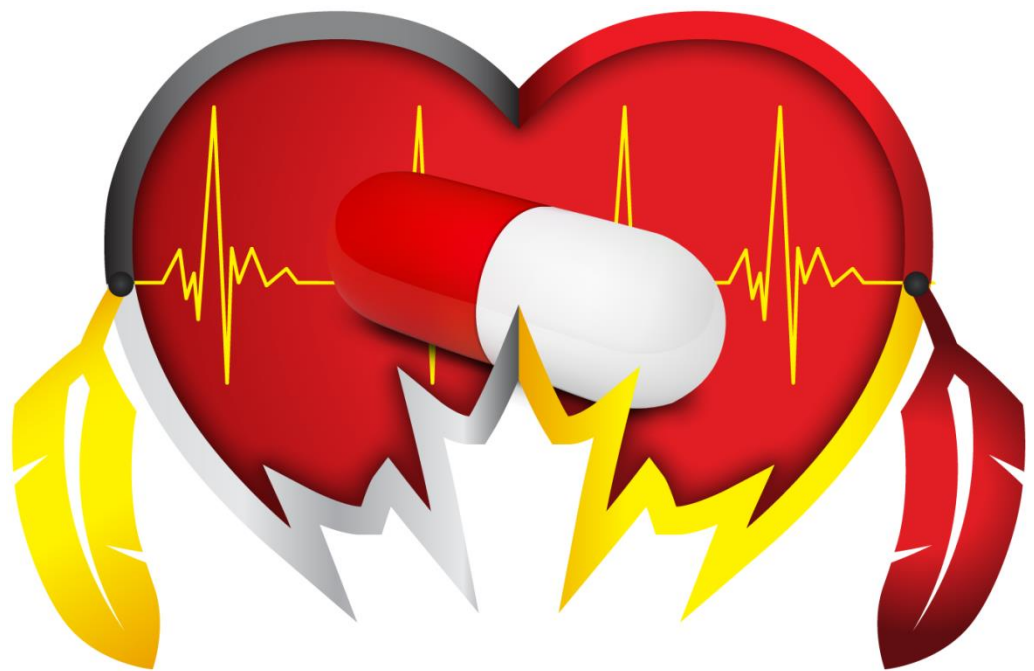


# STRENGTHENING HEALTH LITERACY AMONG INDIGENOUS PEOPLE LIVING WITH CARDIOVASCULAR DISEASE, THEIR FAMILIES AND HEALTH CARE PROVIDERS



7/30/2013

Phase 1 Report

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## ACKNOWLEDGEMENTS

Phase 1 of this project was about developing a culturally appropriate intervention that would assist De Dwa Da Dehs Ney >s - Aboriginal Health Access Centre clients that have been diagnosed or at risk of being diagnosed with cardiovascular disease (CVD) increase their confidence and ability to self-manage CVD and empower interactions with healthcare providers.. The health literacy intervention could not have been developed without their participation and generous sharing of information. The successful development of the CVD health literacy intervention is a reflection of their dedication to tending to their heart.

A special thank - you to all the members of the community research team; Constance McKnight, Michelle Parkin, Fozia Johri, Barbara Loeprich, Bridget Watson, Mike Spoljar, Angela Naveau, Andrea Cherry and Athena Weber; who so generously volunteered their time to guide the study in direction of maximum effectiveness for the clients living with CVD who they serve on a daily basis.

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# Strengthening Health Literacy among Indigenous People Living with Cardiovascular Disease, their Families and Health Care Providers

## PHASE 1 REPORT

### EXECUTIVE SUMMARY

The Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families and Health Care Providers study was undertaken to develop a culturally appropriate health literacy (HL) intervention targeting Indigenous people and their families living with cardiovascular disease (CVD), to increase their confidence and ability to self-manage CVD and empower interactions with health workers. The project was lead by De Dwa Da Dehs Ney >s - Aboriginal Health Access Centre (AHAC - Hamilton and Brantford sites) in partnership with the Centre for Research On Inner City Health (CRICH) at St. Michael's Hospital(SMH) in Toronto.

The study used a community-based participatory research approach. This approach emphasizes shared decision-making and Aboriginal community data governance and management. Community ownership and control of the information collected was protected by a research and data management agreement.

The study consists of 3 phases; this report provides a snap shot of Phase 1. We interviewed 25 AHAC CVD clients and families and 6 staff members, assessed baseline levels of health literacy among client participants and conducted an environmental literacy assessment at both sites. The information collected was used to inform the development of a culturally appropriate HL intervention that would be given to CVD client participants in Phase 2 of the study and measured for its effectiveness.

The 25 CVD client participant interviews consisted of an in-depth semi-structured interview that involved gathering information on their social and health service use context; health literacy; their experience of education about their medications; knowledge, attitude, and beliefs about CVD, medications and health.

Client participants were identified by AHAC staff members at each site based on the following criteria; being diagnosed with either having Angina, Acute Coronary Syndrome, Myocardial Infarct, Stroke and Transient Ischemic Attack or CVD risk factors (hypertension and hyperlipidemia) on two

or more classes of anti-hypertensives or one anti-hypertensive and one lipid –lowering drug. ACE inhibitors and hydrochlorthiazide were considered to be two different classes of medications. Client participants who were diabetics on medication were also included in the risk factor group.

The 6 staff participant interviews also consisted of an in-depth semi - structured interview which gathered information on contextual factors and mechanisms in the health service environment that impact on client access to CVD health literacy and knowledge and their understanding of health literacy and its effects on management of CVD. Staff participants were identified by their position within AHAC.

Overarching themes that emerged from the client participant interviews included: culture and identity, traditional health beliefs, family, health messaging from others, healthcare experience, access to and quality of care, patient engagement, self-care and empowerment, communication with health care practitioners, personal agency and responsibility for health, and client participant management of medications.

One major theme emerged from the staff participant interviews; namely, the identification of challenges and barriers for client participants with respect to their CVD management. However, multiple strategies were used or recommended by staff to address health literacy issues with the client population.

The environmental HL assessment found that the information available to clients in both clinics was too complicated and not easy to understand.

Key informant interviews with both client and staff participants, and the environmental HL assessment in Phase 1; provided information for the development of the HL intervention content. It is expected that the HL intervention and assessment tool (including the resources used and the method of delivery) will be suitable for use with people with HL needs. For example, we will employ plain language, icons, and pictures. The HL intervention and associated resources will be piloted and modifications made if indicated in Phase 2.

## PROJECT OVERVIEW

Indigenous health researchers from New Zealand (NZ), Australia (AU) and Canada (CAN) are collaborating with Indigenous healthcare providers (HCPs) in the development of a HL program for Indigenous client participants and their families. Five health provider sites in AU, CAN, and NZ will participate with approximately 100 client participants and families at each site. We will provide client participants with a HL program and then assess the effect of this program.

It is expected that this HL program will increase participant knowledge of medications, their confidence and ability to self-manage CVD and empower them in their interactions with HCPs. The HL program aims to also increase HCP knowledge of HL and their skills for working with clients with high HL needs.

This report summarizes Phase 1 of the study, in which we interviewed client participants and staff participants to better understand HL knowledge, needs and processes with respect to CVD medications. We also completed an environmental scan of the clients' Indigenous health services to understand the broader organisational, systemic and policy environment. We used this information to design a HL program and program evaluation.

Phase 2 of the project will involve sharing this HL program and evaluation with Indigenous client participants and their families. Phase 3 of the project will be comprised of analysing, documenting and sharing the study results.

Workforce development and research capacity development are key components of the study. Our goal is to ensure that the results of the study will be useful to HCPs, funders, and policy makers in the health and adult literacy fields.

## INTRODUCTION

Cardiovascular diseases are major causes of mortality and hospitalization for adult Indigenous peoples and there are significant inequalities in CVD morbidity, mortality and the prevalence of CVD disease risk factors between Indigenous and non-Indigenous populations. Health promotion and strategies to assist health professionals to provide high quality care are on-going. However, CVDs are chronic diseases and as such, the patient and their family are the primary 'manager' of these diseases therefore, self-management is central to effective CVD management. Patients and their families can play a vital role in managing heart disease and stroke. Appropriate knowledge and use of CVD medications, and effective communication with health professionals are essential

for the self-management approach and are also critical components of the effective management of CVD risk factors and disease.

There is limited published literature about the knowledge and understanding of CVD medications in the general population, and no available literature on medication knowledge within the Indigenous population. However, published evidence suggests that intermittent use of medications and additional non-adherence with prescription instructions is common. This misuse of medications is associated with worse outcomes, including poorer control of risk factors, increased hospitalization, morbidity and mortality (Smylie 2011)

Health literacy is defined as “the ability to access, understand and act on information for health”. (TAHSC Application, June 7, 2011) Health literacy is also a key driver of knowledge, self-management, and health outcomes. International surveys have found that the majority of the population in Canada, Australia, and New Zealand have inadequate levels of HL to effectively engage in health care.

## PURPOSE OF PROJECT

Health literacy for Indigenous populations can be strengthened through a culturally appropriate HL intervention targeted at client participants and their families. This research project aims to understand whether this is associated with increased confidence and ability to self-manage CVD and empowered interactions with HCPs.

The focus of the first phase of the project was to develop the HL intervention and assessment tools and collect the baseline information required for the case studies at the HL intervention sites. The goals of Phase 1 included:

1. Collect client participant information to inform the development of the HL intervention
2. Collect baseline information for case studies
3. Develop the HL intervention including assessment tools
4. Finalize the design information required for the trial
5. Develop training packages for staff that will be delivering the HL intervention

## PROJECT DEVELOPMENT

In 2009, Dr. Janet Smylie, senior health researcher and Principal Investigator for the Canadian arm of the project, successfully submitted a research application to the Canadian Institute of Health Research’s Call for Proposals: ‘International Collaborative Indigenous Health Research Partnership Grant’ (ICIHRP) entitled: ‘Reducing Burden of disease and inequalities in health arising from chronic disease in Indigenous people’. The Canadian team collaborated with Indigenous research teams in



New Zealand and Australia, which were funded for sister projects in their countries. Dr. Smylie is based at the Centre for Research on Inner City Health (CRICH), at St. Michael's Hospital (SMH) in Toronto. Her academic appointment is as an Associate Professor in the Dalla Lana School of Public Health at the University of Toronto.

Identification and engagement of De Dwa Da Dehs Ney>s-Aboriginal Health Access Centre (AHAC) as a community partner and research team member began in 2010.

## PROJECT GOVERNANCE

A 'Research, Data, Statistics and Publication Agreement' was negotiated between St. Michael's Hospital and the 'De Dwa Da Dehs Ney>s-Aboriginal Health Access Centre (AHAC) Board of Directors and signed in September, 2011. The purpose of the agreement was to ensure that the project was respectful to cultures, languages, knowledge, values, and rights to self-determination of AHAC. It also provided a framework for the use of data collected during the research project. It was intended to support principles of Aboriginal collective and self-determined data management and governance.

## CANADIAN RESEARCH TEAM

The Canadian 'International Health Literacy Team' includes; Dr. Janet Smylie, Principal Investigator; Dr. Marcia Anderson, Co-Investigator, Ms. Connie McKnight, Executive Director, (AHAC); Nancy Cooper, Indigenous Literacy Expert; Bernice Downey, Doctoral Student Researcher; Conrad Prince, Research Manager and Sanjeev Sridharan, Evaluation Design Consultant.

## RESEARCH SITES: HAMILTON AND BRANTFORD, ONTARIO

The AHAC provides primary care, traditional healing and health promotion programs to nearly 6000 Aboriginal people living in both Hamilton and Brantford, Ontario. Its mission is "improving the wellness of Aboriginal individuals and the community by providing services that respect people as individuals with a distinctive cultural identity and distinctive values and beliefs". (Our Health Counts: Urban Aboriginal Health Database Research Project Community Report: First Nations Adults and Children, City of Hamilton 2011:21)

The city of Hamilton is located in southern Ontario, 50 minutes west of Toronto and 1.5 hours east of London. Located on what was traditionally Haudenosaunee (Iroquoian) territory, Hamilton is situated near two First Nations reserves: Six Nations of the Grand River and the Mississaugas of New Credit. The 2006 Census statistics show that the total Aboriginal population is 13,735 by ancestry comprising 2.8% of the overall population of the city (497,395).

The city of Brantford is located in Southern Ontario. Six Nations of the Grand River is a short drive away. It is connected to Woodstock in the west and Hamilton in the east by Highway 403. The 2006 Census statistics show that the total Aboriginal population is 5,885 by ancestry. The population of Brantford is 93,650.

## METHODS OVERVIEW

A mixed methods community-based participatory action research approach is being used for this multi-phased project. The project's community-based research design means that the research is done in the community and involves client participants in the design, implementation, and documentation. By conducting research in this way, we can ensure that processes are relevant and that the outcomes have tangible benefits for the communities involved. Community-based participatory action research has been widely used and adapted in Aboriginal health research. This project's specific methods and protocols builds on the success of the SMH-AHAC partnership in the research project; 'Our Health Counts: Urban Aboriginal Health Database Research Project Community Report: First Nations Adults and Children, City of Hamilton 2011:23)

In Phase 1 of the project, the research team undertook the following research activities:

- interviewed client participants with cardiovascular disease and their families
- interviewed AHAC staff participants in Hamilton and Brantford
- assessed baseline levels of health literacy among the client participants that were interviewed
- conducted an environmental literacy assessment at both AHAC sites

This information was used to design the HL program and individual level program evaluation that we will apply in Phase 2. It also provided the baseline information for the project case studies. These case studies will be an important part of the program evaluation and will assist in understanding the family, organisational, and community context in which the HL program operates. The case study design is based on Pawson and Tilley's 'Realistic Evaluation' approach. (Pawson and Tilley 1997).

## INTERVIEWS

The research team used an in-depth semi-structured method for the interviews. Interviews were undertaken with client participants who have CVD and take medicines to manage their CVD. Client participants were invited to ask family members to attend and participate.

The interviews collected information from client participants about their social and health service use context; health literacy; their experience of education/information about medications (what have they been told, who by, how effective was it); and their knowledge, attitudes, and beliefs about CVD, medications, and health. A total of 25 client participant interviews were conducted across both the Brantford and Hamilton sites.. (See Appendix 25for 'Patient Interview Guide')

The interviews with staff participants collected information regarding:

- a) Contextual factors and mechanisms in the health service environment that impact on clients' access to CVD health literacy and knowledge and
- b) Staffs' understanding of health literacy and its effect on the management of CVD

A total of 6 staff participant interviews were conducted. (See Appendix 29 for 'Staff Interview Guide') The interviews were audio-recorded (with consent), transcribed, and thematically coded

## CLIENT PARTICIPANT HEALTH LITERACY ASSESSMENT

The HL assessment criteria and levels for client participants were based on the International Adult Literacy Survey levels (IALS | ) and further informed by the two decades of adult native literacy experience of the health literacy consultant. The IALS was conducted in 2006. The descriptions of the 5 literacy levels with regard to reading and deciphering skills are as follows:

**Level 1:** People at this level have difficulty reading and have few basic skills or strategies for working with text. They often can't figure out how much medicine to take from the information on the package.

**Level 2:** People at this level can read, but do not read well. They need material that is simple and clearly laid out.

**Level 3:** People at this level can read well but may have problems with more complex tasks. This level is considered by many countries to be the minimum skill level for successful participation in society. (\*Please note that the Canadian IALS team purchased extra survey findings from urban centres that had higher representation of Aboriginal participants. From this information it was found that many Aboriginal Canadians have an even lower literacy level than the minimum skill level for successful participation in society.)

**Level 4/5:** People at this level have strong literacy skills and many strategies for dealing with complex materials. These individuals can handle new reading challenges and meet most reading demands.

Using these levels as a guideline, the assessment process also included other pertinent peripheral information to determine the literacy/health literacy levels of the interview informants. Determinants and cues such as childhood educational and family experiences, pharmaceutical use/abuse, incarceration, adoption, residential school experience, educational attainment, ease of use of internet, job history and learning disabilities were all taken into account during the interviews to help develop a clearer sense of the literacy level of the client participant.

## ENVIRONMENTAL ASSESSMENT

The environmental assessment or audit was undertaken at both AHAC sites and consisted of observation and analysis of all written and representational information aimed at the client participants and their families, both in the waiting area and in the treatment rooms. This included posters, patient information, booklets, informational signage and community event information. Other assessment factors included; the literacy level that documents were written at; if the documents were written in clear language and if their design made it easy for client participants to decode.

## NEXT STEPS

In Phase 2, a pre – post design with multiple measurement points will be used to assess the effect of the HL intervention. This will be complemented by a 6-month retrospective and prospective analysis of routinely collected data to assess the complexity and stability of medicine regimens, prescription frequency and associated clinical indicators. In addition, ongoing longitudinal client participant and organizational case studies will support an understanding of the HL program and its effects within the family, organizational and community context in which it operates.

Phase 3 will involve country level and international analysis, documentation, and sharing of the study findings.

## RECRUITMENT

Client participants for Phase 1 interviews were identified by an AHAC staff member from each site. Diagnosis selection criteria included: Angina-Acute Coronary Syndrome, Myocardial Infarct, Stroke and Transient Ischemic Attack or CVD risk factors (hypertension and hyperlipidemia) on two or more classes of anti-hypertensives or one anti-hypertensive and one lipid –lowering drug. ACE inhibitors and hydrochlorthiazide were considered to be two different classes of medications. Client participants who were diabetics on medication were also included in the risk factor group.

Efforts were made to recruit a diverse sample of client participants with respect to gender, education levels, socio-economic position, age, occupation/employment, and Indigenous culture and nation. A recruitment flyer was posted in both sites.

Staff participants included doctors, nurses, community health workers and managers working at participating sites. Staff participants were identified by their role in the clinic and were recruited by the Doctoral student.

## RESULTS

### CLIENT PARTICIPANT INTERVIEWS

A thematic analysis of the client participant interviews was undertaken in order to identify common themes and differences across the interviews. This data was then organized into nodes or 'key theme containers' with several of these further classified into sub-nodes or associated concepts. The final key themes included: culture and identity, traditional health beliefs, family, health messaging from others, healthcare experience, access to and quality of care, patient engagement, self-care and empowerment, communication with health care practitioners, personal agency and responsibility for health, and client participant management of medications.

### DEMOGRAPHICS OF PARTICIPANTS

#### HAMILTON SITE

At the Hamilton site, a total of 17 client participants were interviewed. Of the 17 interviewed, 9 were male and 8 were female. The age of the client participants ranged from 49 to 71 years old.

#### BRANTFORD SITE

At the Brantford site, a total of 8 client participants were interviewed. Of the 8 interviewed, 3 were male and 5 were female. The age of client participants ranged from 45 to 73 years old. A total of 4 family members participated; 2 from each site.

### HEALTH LITERACY ASSESSMENT

Client participants were asked to participate in a two-part interview. The first part dealt specifically with their medications, their health care providers, and their traditional/cultural perspectives on health. The second part of the interview dealt with issues such as client participant understanding of written materials, ease of understanding of health care provider instructions, where the client participant accesses health information, and experiences of self-advocacy in health care situations. Analysis of the information gathered in the two part interviews found that many of the client participants did struggle to understand information from their health care providers and relied heavily upon their pharmacist to explain the information provided by the health care provider. Client participants' ability to pronounce the name of their medications and provide information as to why medications were prescribed was also analyzed in order to determine their IALS level.

The majority of client participants scored in the level 2/3 range which means that they would have struggles with comprehension and advocacy when it comes to health information and instructions. The findings are as follows:

| IALS LEVEL | NUMBER OF CLIENT PARTICIPANTS |
|------------|-------------------------------|
| Levels 1-2 | 2                             |
| Levels 2-3 | 12                            |
| Levels 3-4 | 7                             |
| Levels 4-5 | 4                             |

## CLIENT PARTICIPANTS ABILITY TO NAME THEIR MEDICATIONS

### HAMILTON SITE

At the Hamilton site, 8 of 18 client participants (data available for 18 of the 18 interviewed), knew the names and purpose of all of their CVD-chronic disease medications. Of this group, 50% were male and 50% were female. Also, 14 of 14 knew the names and purpose of 50% or greater of their CVD-chronic disease medications.

### BRANTFORD SITE

At the Brantford site, 4 of 8 client participants (50%) knew 100% of the names and purpose of their medications. Of this group, 50% were male and 50% were female). It is important to note that 3 of 4 client participants who knew 100% of their CVD-chronic disease medications, were on only 2 medications with the exception of 1 patient who was on 7 medications. In addition, 7 of 8 client participants (88%) knew the names and purpose of 50% (or higher) of their CVD-chronic disease medications.

## KEY THEMES EMERGING FROM PARTICIPANTS INTERVIEWS

### CLIENT PARTICIPANT PERCEPTION OF THEIR HEALTH AND CVD CAUSAL FACTORS

It was found that generally, client participants perceived their overall health as 'stable' and 'in control'. This perception was similar across both sites. Client participants were able to identify a range of causal factors related to cardiovascular disease. These causal factors included diet, stress, poverty, family history and weight.

### CULTURE AND IDENTITY

Throughout the Phase 1 interview process, it became clear that a majority of the client participants experienced discrimination in the provision of health care. Also, they reported special needs related to diet and illnesses that they are not familiar with and thus, were unable to use traditional approaches to healing.

**"I know the diabetes has a great impact on Native people; like if you have diabetes and you're Native, that's more serious than if you have diabetes and you're Caucasian or whatever it is."**

Client participants also described a bicultural fluidity with some having more than one way of identifying themselves as an Indigenous person. There is also evidence of individualized cultural identity. For example, not everyone would engage in a smudging process as part of their spiritual ritual.

### TRADITIONAL HEALTH BELIEFS

**"I take blood and protection medicine and whatever else that I have to do."**

Ideas surrounding traditional health benefits emerged throughout the Phase 1 interviews. Client participants reported a belief in the practice of Indigenous traditional healers/helpers. They also described an Indigenous value/belief directly related to Indigenous traditional knowledge or medicine. They reported that there were challenges following traditional practices in urban areas. More specifically, there were tensions between western and traditional beliefs. They also

mentioned that they felt strong connections to mother earth. Clients also made reference to the importance of prayer and the application of traditional knowledge and teachings regarding diet.

#### FAMILY

Client participants made connections between family and CVD during the Phase 1 interviews. One or both parents of the patient participants had chronic illness. Collective descriptions of identity and illness emerged throughout the interviews. Additionally, client participants reported that family members were motivators to be well. Family exercise was mentioned during the interviews. In addition, participants made mention of reliance on spouses or partners regarding their medications.

#### HEALTH MESSAGING FROM OTHERS

**“Oh constantly, everybody's always saying, you're strong, you can do it. God never gives you more than you can handle. That is a famous saying in my family. My brother is constantly saying that to me. God never gives you more than you can handle. Never puts more on your plate that you can't handle. You can do it”**

Client participants reported receiving information about health or teachings from various sources that included; family members, community, Elders Traditional Helpers/Healers.

**“It is living the way the Creator wants you to live. But we follow the ways of the world out there and look what happens to us for doing it.”**

#### HEALTHCARE EXPERIENCE

Throughout Phase 1, client participants reported a range of both positive and negative healthcare experiences. The negative healthcare experiences included:

- Lack of access to traditional medicine
- Delays in healthcare
- Feeling they are receiving 'second-best' treatment
- Lack of continuity of healthcare

The positive healthcare experiences were associated with relationships with nurses that ranged from good to very good.



**“I like the nurse practitioners, I can work with them.”**

#### ACCESS TO AND QUALITY OF CARE

**“I have a brother who’s very agitated with change and they screwed around with his pills.....now he has to come here and you can’t get an appointment with a doctor for at least a month now. That not health to me!”**

In regards to access to care as well as quality of care, client participants provided examples which displayed poor access to and quality of care. They reported that they had experienced inadequate medication management by a healthcare provider. Other examples that emerged included; inadequate pain management, wait times, second rate access to Non-Insured Health Benefits (NIHB) and various medical equipment. Lastly, lack of access to traditional medicine was described as an impact which resulted in poor access to and quality of care. These structural factors and client experiences have resulted in poor ongoing care.

#### CLIENT PARTICIPANT ENGAGEMENT

**“I would say yes, because if I didn’t trust him, or whoever is giving me instructions, well, then I wouldn’t do it. I wouldn’t be taking this, that and whatever.”**

Client participant relationships with HCPs varied between ‘good’ and ‘not good.’ It is vital that client participants are able to build a trusting relationship with their HCP. Client participant autonomy varied: some client participants followed doctor’s orders without question, while others listened to advice given by their HCP and then decided what was a good fit for them. Evidence of anger and a power imbalance emerged throughout the Phase 1 interviews. Also, a sense of humour and good relationships coincide.

## SELF-CARE AND EMPOWERMENT

Client participants are making efforts to adapt and learn about their chronic disease. They undertake various activities to manage their own care. They also draw on traditional teachings and support when self-managing their healthcare. They use their personal beliefs and values to empower themselves and they draw on Indigenous traditional knowledge where they experience problems.

Client participants are able to describe one or more causal factors for their heart disease or other chronic illness.

**“I think lack of exercise and I think that its part of my family history. I haven’t smoked in 14 years, and yes there was stress and there were money problems, so its all combined.”**

## COMMUNICATION WITH HEALTH CARE PROVIDERS

Client participants reported a range of both positive and negative experiences related to their overall communication with HCPs.

Positive experiences included:

- Adequate explanation about their medication
- Easily accessible information about their medication
- Use of drawings, technology to explain their medication
- Client satisfaction with the exchange of information
- Written materials as an aid

Negative experiences included:

- Inadequate explanations
- Physician who only prescribes medications
- Lab tests
- Lack of understanding about medications
- Purposefully indirect by HCP
- HCPs supportive but not knowledgeable about Traditional Medicines

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**PERSONAL AGENCY AND RESPONSIBILITY FOR HEALTH**

**“I’ve always believed that I’m in charge of... A person’s in charge of their own destiny. I always believed that.”**

An important factor that may positively influence both the uptake of health information by Indigenous people and their ability to change or self-manage health related behavior is the linkage between personal agency and improved health and well-being. (Tang & Anderson 1999:83) When an individual has a perception of control or agency, they tend to have higher levels of wellbeing. (Dressler et al. 2007; Nicassio et al. 1999; Nicassio et al. 1985; Taylor and Brown 1994 in Hay 2010:260) When people believe that they can accomplish something or have ‘agentic capability’, they become motivated and take action. This is known as self-efficacy.

Indigenous peoples’ agentic capability is also tied to their Indigenous worldviews. Youngblood – Henderson, an esteemed Indigenous scholar states that “Aboriginal understandings, languages, teachings and practices developed through direct interaction with the forces of the natural order or ecology.” Aboriginal people “can understand anything if they are conscious of their relationships to other life forms and the relationship of these life forms to everything else.” (2000:260) Indigenous peoples’ motivation to act is also intertwined with their collective self-determining aspirations to manage and achieve good health.

Client participants were able to identify actions and strategies they are taking regarding self-management of their health.

**“I do the tests even though if I don’t want to do, the MRIs and the ultrasounds and echograms.”**

## CLIENT PARTICIPANT MANAGEMENT OF MEDICATIONS

Client participants generally rely on pharmacy support to learn about their medications rather than their HCPs. They also learn more information from friends and family members. Even so, many client participants are not entirely familiar with their medications. They also have difficulty remembering to take their medications although some utilize artifacts such as dosettes and blister packs. A few client participants reported using traditional medicines; along with their mainstream medications. They sometimes have difficulty reading prescription bottles or understanding pharmacological/generic drug names.

Some client participants will ask their HCP questions regarding their medication but others do hold back or rely on peers. Others rely solely on their pharmacist for information. Client participants also rely on written information received from the pharmacy although they do not always find it easy to read. They will also discuss this information with the pharmacist. They also utilize information from other sources, such as workshops or information placed on bulletin boards.

## STAFF PARTICIPANT INTERVIEWS

A total of six staff participants were interviewed across both sites. These included nurse practitioners, a foot care nurse, a dietician, and a physician. Staff participants demonstrated a vivid conceptual awareness surrounding health literacy. In addition, they identified pertinent health literacy issues for Indigenous clients.. They also expressed a basic understanding of how health literacy is defined.

## IDENTIFICATION OF CHALLENGES & BARRIERS FOR CLIENT PARTICIPANTS

A vital staff participant key theme which emerged during Phase-1 was the identification of challenges and barriers for clients with respect to their CVD management; including knowledge of CVD medications. Staff identified client participant literacy issues including gaps in understanding basic information related to their chronic disease as well as their medications. Staff participants were also aware of stigma issues for clients. (For example: they were sensitive to the potential of embarrassing clients. In addition, some staff observed fatalistic attitudes surrounding chronic disease. Staff participants expressed that they often experienced frustration when faced with HL - related needs of the Aboriginal population. Moreover, staff participants have identified barriers to HL that are related to social determinants of health. Lastly, staff participants identified structural barriers that include lack of adequate resources to ensure adequate staff coverage.

## STRATEGIES USED OR RECOMMENDED

Multiple strategies were used or recommended by staff participants to address HL issues with the client population. It was evident that staff participants engaged and built rapport with clients; as engagement with clients requires the development of a relationship and trust. As such, some staff participants utilized an empowerment approach.

Staff participants had limited time to actively engage in more formal assessments of the HL needs of their clients. However, some staff participants made time to address HL issues and some are using a multi-disciplinary approach.

Improvement is clinician dependant, but there is also a need to gear patience towards the patient's HL level. Staff is not formally assessing client HL levels; however, some staff do follow up with clients who they perceive do not fully understand the health information they are provided with. Some staff participants believe that HL barriers and issues can be addressed on site. Moreover, these staff participants are interested in using innovative ways to address HL but also had worries surrounding legalities and intrusiveness.

Conclusively, the staff participants at both sites displayed vast knowledge surrounding HL which was vivid throughout Phase 1. During the staff participant literacy awareness assessments, staff participants outlined recommendations that they feel are vital to the success and implementation of HL awareness at both sites. Firstly, staff participants were provided with written materials, such as pamphlets and posters, regarding chronic disease. Secondly, staff participants are recommending or utilizing web-based technology (web links and virtual tools, telehealth, video-conferencing, web portal for clients) for medications. Lastly, the staff participants at both sites made many vital recommendations. Of these, recommendations include:

- A multi-disciplinary, culturally relevant HL approach (including peer support) is required
- There is a need for staff expertise and sensitivity to stigma
- There is a need to address education and social policy gaps
- There is a need for organizational support and resources
- More family involvement is needed but s their level of understanding also needs to be assessed.
- The use of dosettes is helpful
- It is important to ask clients to repeat instructions back to the HCP
- Use of televised information in health centre lobby would be helpful

## ENVIRONMENTAL HEALTH LITERACY ASSESSMENT

It was found that, in general, the written information provided for client participants in both clinics was not too complicated or overabundant so as to be overwhelming. At one of the health centres, the information found on the walls of the treatment rooms could be overwhelming for client participants because of the high literacy level it was written in. These specific documents were reference materials for healthcare providers but were in plain sight of all clients. Signage for clients was easy to understand. Staff members were readily available to answer any questions fielded from clients.

## INTERVENTION DEVELOPMENT

Phase 1 of the project included the planning and development of the HL intervention and associated resources. This work was undertaken in collaboration with both the New Zealand and Australian research teams.

The HL intervention consists of general knowledge about medicine use, specific information about the major classes of CVD medications (anti-platelets agents, Beta-blockers, ACE inhibitors, HMG Co-A reductase inhibitors [statins] and warfarin), and communication skills for ensuring client participants receive treatment according to established guidelines. We are also considering developing information for hypoglycemic medications as we anticipate that a significant number of client participants will have diabetes. Medication class - specific information will only be given to client participants who are taking a medicine in that class. (I.e. using a client/patient centered approach). The HL intervention will include information about taking medications, reading labels, understanding instructions, how medications work, common side effects, dangerous side effects, and targets for control of blood pressure (BP), lipids, and glucose. Specific resources are being developed for diabetic and non-diabetic client participants as control targets differ for these two groups.

Key informant interviews with both client and staff participants in Phase 1 provided information for the content and associated resources for the HL intervention. It is expected that the HL intervention and assessment tool (including the resources used and the method of delivery) will be suitable for use with people with health literacy needs. For example, plain language, icons, and pictures will be used. The HL intervention and associated resources will be piloted and modifications made if indicated in Phase 2.

## NEXT STEPS – PHASE 2: IMPLEMENTING THE HEALTH LITERACY INTERVENTION

During Phase 2 we will provide client participants with a customized and focused health education program. This will consist of a community health nurse trained in adult Indigenous health literacy by a specialist in the field providing three teaching sessions to client participants regarding their cardiovascular medications. We will rigorously assess the impacts of the intervention on client’s medication knowledge and HL practices by pre-post education session assessment.

Training of the community health nurse delivering the HL intervention will cover: a review of CVD and CVD management; health literacy; working with people with HL needs; and the HL intervention and assessment tool. We will adopt a competency-based approach to ensure that the HCPs will be able to deliver the HL intervention and assessments.

## CONCLUSION AND RECOMMENDATIONS

The focus of this first phase of the project was to develop the HL intervention and assessment tools and collect the baseline information required for the case studies at the HL intervention sites. The goals of Phase 1 included:

1. Collect client participant information to inform the development of the HL intervention
2. Collect baseline information for case studies
3. Develop the HL intervention including assessment tools
4. Finalize design information required for the trial
5. Develop training packages for staff that will be delivering the HL intervention

The study succeeded in these objectives and based on the findings reported above, De Dwa Da Dehs Ney>s-Aboriginal Health Access Centre (AHAC) has the following policy recommendations:

## IMPORTANCE OF COMMUNICATION WITH HEALTH CARE PROVIDERS

Client participants reported a range of both positive and negative experiences related to their overall communication with HCPs. The AHAC recognizes the importance of enhancing the communication skill sets of its HCPs in order to increase better service outcomes and to decrease negative experiences. The AHAC therefore recommends:

1. That all health care providers (both Aboriginal and non-Aboriginal) employed at AHAC have greater access to traditional knowledge keepers, Elders, and teachings in order to increase their knowledge about traditional knowledge as it relates to medications, treatment of cardiovascular disease and other health issues. This would include

developing an organizational policy that specifically speaks to increasing access of health care providers to traditional knowledge teachings.

## CLIENT PARTICIPANT MANAGEMENT OF MEDICATIONS

Client participants indicated they relied heavily on their pharmacist to supply them with information about their medications. The AHAC would like to better support this relationship and recommends:

2. That the Canadian Pharmacists Association (CPhA) raises the profile of Aboriginal issues within its organization and membership.
3. That the Canadian Pharmacists Association work in partnership with universities, accrediting institutions, and Aboriginal health service providers to develop and implement Aboriginal curriculum and content to better prepare pharmaceutical students on Aboriginal issues, ensuring and supporting adequate resourcing and evaluation.
4. That the Canadian Pharmacists Association implements a pharmacy prescription hotline so patients could call to get information about their medications.
5. That the Canadian Pharmacists Association develop and implement a policy whereby Pharmacists could have patients' medications provided in a dosette after 3 or more prescriptions have been written. (this may lessen the patient's confusion if the pharmacists prepared the dosette)

## INCREASING LITERACY RATES

The AHAC recognizes that poor educational outcomes among Aboriginal people, that result in low literacy rates, are a major barrier to better health. As discussed earlier in this report, over half of the client participants scored in the level 2/3 range on the IALS literacy assessment scale (which ranges from 1 -5) which means that they would struggle with comprehension and advocacy when it comes to health information and instructions. The AHAC therefore recommends:

6. Those municipal, provincial and federal governments commit long term resources and funding allocations for Aboriginal literacy programs.

During Phase 1, preliminary plans were made to develop a more generalized HL training program for the entire health service staff when this study is complete. Our final recommendation is therefore:

7. That the AHAC and the Well Living House - St. Michael's Hospital research team collaboratively arrange for a staff-wide Indigenous HL training workshop once the study is complete.



## APPENDIX ~ 1 ~ PATIENT INTERVIEW GUIDE

Dr. Janet Smylie, MD MPH FCFP

Centre for Research on Inner City Health, St. Michael's Hospital

Study Title: Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and health care providers

### INTERVIEW GUIDE: Patient/Family Member Participants

**Objective:** To explore and increase awareness of cultural and family context

1. Can you share your cultural or family background with us?

**Objective:** To explore and understand the patient's experiences with various healthcare services

2. a) Can you talk a little bit about your health care experience?

b) Have you needed to be in a doctor's care a lot in your life?

c) How would you describe this experience? (prompt if needed: good or bad)

**Objective:** To explore and determine what the patient's cardiovascular (CVD) diagnosis means to them.

3. a) How is your heart health?

b) What do you think caused your heart problems? (ie. Poor diet, lack of exercise, family history, smoking, stress, relationship problems, money problems)

**Objective:** To determine if Aboriginal traditional teachings about health and well-being have contributed to the patient's beliefs about their own health/CVD

4. Do you have your own beliefs about health and well being that you have learned from family, friends or others in your community?

**Objective:** To explore the patient's sense of personal agency with respect to their own health/CVD.

5. a) What are some of the ways in which you care for your health?

b) How confident are you in your own ability to improve your health?

very confident – confident – somewhat confident – somewhat not confident - not confident

**Objective:** To explore the healthcare provider-patient relationship

6. a) What is the relationship between you and your care provider like?

b) Do you think that there is a link between this relationship and an improvement of your overall heart health?

c) Do you think that your healthcare provider is able to help improve your health? If so, in what ways?

**Objective:** To explore the cultural context of the healthcare provider – patient relationship

7. a) Do you feel that you have special healthcare needs because you are an Aboriginal person? If yes, can you tell me a little bit about these needs?

b) Do you believe that your healthcare provider understands or takes these needs into account while caring for you?

**Objective:** to explore the patient's perception regarding the information they have been given and about other resources available. To assess health literacy regarding current medication use and information about medications

## 8. Communication with health professionals

a) Did your doctor or nurse etc give you easy to understand instructions about how to take your medication? What did they do to make it easy to understand?

b) Did your doctor or nurse etc explain the possible side effects of your medication in a way that was easy to understand? Why did they explain – did you ask them or did they just do it? What did they do to make it easy to understand?

- c) Did your doctor, nurse etc give you written information or write down information about how to take your medication? What was the information? Why did they write it down? Did you ask them to or did they just do it? Was the written information you were given easy to understand
- d) How often did your doctor, nurse etc suggest ways to help you remember to take your medication? What did they suggest? Were those suggestions easy to understand? Why?
- e) How often were the results of any tests about your medication easy to understand? What made them easy to understand?
- f) How often did your doctor or nurse etc use medical words you did not understand when talking to you about your medication? Did you ever ask them to explain those words? If yes what made you feel it was ok to ask those questions?
- g) How often did your doctor or nurse talk too fast when talking with you about your medication? Did you ever ask them to slow down or repeat what they said? If yes what made you feel it was ok to ask those questions?
- h) How often did your doctor, nurse etc use pictures or drawings to explain your medication to you? What were the pictures/drawings? Why did they show you pictures? Did you ask them to or did they just do it? Were the pictures or drawings you were given easy to understand?
- i) How often did your doctor or nurse answer all your questions about your medications to your satisfaction? What were your questions? Why did you ask them in the first place? Did you make a list of questions before you went to see the doctor or nurse etc or just asked them when you were there?
- j) How often did your doctor or nurse etc give you all the information you wanted about your medication? Did you ever ask for more information? Did you ask anyone else later?
- k) How often did your doctor or nurse encourage you to talk about your concerns about your medication? Was it because they thought you looked like you didn't understand or you told them you didn't understand? How did they do that? How often did they do that?
- l) How often did your doctor or nurse ask you to describe how you were going to take your medication?
- m) Sometimes your doctor or nurse etc. might give you instructions that are hard to follow. What do you do when that happens?
- n) How often did your doctor or nurse ask you whether you would have any problems doing what you need to do to take your medication? For example do they ask you what you will do if you go on a trip or to a funeral or if you forgot?

o) What does your doctor or nurse do if you are prescribed any new medication or change any medication? How do they explain it?

**Objective: to explore how the patient or family member would like to be given information and to identify examples of resources that they believe would be helpful.**

- a) What pamphlets, handouts, written or handwritten material has anyone ever given you about your medication? Do you read any of them? If so which ones and why read them and not others? If you don't read them why not?
- b) Do you find it hard to read information about your medication such as labels or instructions? If you do what do you find hard and why?

## APPENDIX ~ 2 ~ STAFF INTERVIEW GUIDE

Dr. Janet Smylie, MD MPH FCFP

Centre for Research on Inner City Health, St. Michael's Hospital

**Study Title:** Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and health care providers

### INTERVIEW GUIDE: Staff

**Objective: to explore staff awareness and understanding of health literacy and health literacy practice**

1. Can you talk a little bit about what your understanding of health literacy is?
2. What kinds of health literacy issues have you encountered in your work?
3. Do you think that the health service is accessible for people with health literacy needs?
4. What strategies do you use to address and lessen the impact of health literacy in your practice?
5. Are you aware of any other strategies to address and lessen the impact of health literacy barriers on patient/family member health, management of conditions and patient outcomes?
6. The environment that a patient is exposed to is also an important consideration with respect to health literacy.( i.e. office information, posters, pharmacy signage) Thinking beyond your own personal communication style in your practice, what are some of the other environmental barriers/challenges that a patient might experience?. Do you have any ideas about how these barriers and challenges could be addressed in your practice?
7. What are some of the challenges and opportunities in changing health literacy in the service environment?

**Objective: to explore staff awareness and understanding of cultural safety with respect to health service delivery**

1. Can you describe your awareness and understanding regarding the concepts of cultural competency and cultural safety theories in health care service delivery for Aboriginal people?
2. Have you heard of the terms cultural competency and cultural safety before?
3. If so, how would you describe these concepts?
4. How do you think these concepts apply to your work in a practical way?

**Objective: to measure staff self- assessment of cultural competency with respect to working with Aboriginal populations**

1. Do you think that your clinical practice is inclusive of cultural safety principles with respect to Aboriginal clients? How is this demonstrated, can you give some examples?

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