

'The blue arc of the rainbow' - Aboriginal women in the perinatal period and eHealth literacy: A convergent parallel mixed methods study

by

Judy Sturm
BScN, University of Victoria, 1996

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of the Requirements for the Degree of

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Supervisory Committee

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Supervisory Committee

Dr. Lenora Marcellus, School of Nursing
Supervisor

Dr. Francis Lau, School of Health Information Science
Co-Supervisor

Abstract

Supervisory Committee

Dr. Lenora Marcellus, School of Nursing

Supervisor

Dr. Francis Lau, School of Health Information Science

Co-Supervisor

Health disparity research indicates that health illiteracy is associated with poorer health outcomes, greater risk of hospitalization, higher emergency room utilization, and increased death (Collins, Currie, Bakken, Vawdrey & Stone, 2012; Skopelja, Whipple & Richwine, 2013). Health information is increasingly being transitioned to online formats and according to Usher and Skinner (2010) the newest challenge that healthcare consumers face in taking control of their health is their ability to access, evaluate and incorporate the large amount of health information available on the Internet. Achieving a better understanding of the eHealth literacy levels of Aboriginal women and how they use technology to access health information may support better health outcomes in a variety of settings including the perinatal period which is important not only for the mother's health, but her child's as well.

This mixed methods study explored the eHealth literacy knowledge, attitudes and skills of urban Aboriginal women in the perinatal period residing in a small city in British Columbia. A convergent parallel design was used to collect both qualitative and quantitative data from five study participants. Due to the small sample size study findings need to be interpreted with caution. The results may demonstrate that urban Aboriginal women in the perinatal period are comfortable and competent in accessing health information on the Internet. They identified the following as areas for improvement: (1) identifying if the information they retrieve is credible, (2) improving the cultural appropriateness of health information and websites, (3) improving access through continuing to build technology and search skills for Aboriginal women, and (4) supporting better access to the Internet and technology equipment for those Aboriginal women still affected by the digital divide.

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Chapter 1

It is critical for healthcare providers to understand the interconnection between literacy and health as they both greatly impact an individual's overall well-being (Health Canada, 2001; Hemming & Langille, 2006; Kickbush, Pelikan, Apfel & Tsouros, 2013). It has been shown that individuals with low literacy skills have difficulties in accessing health information and services, leading to increased rates of chronic disease and poorer overall health which in turn can result in a lower life expectancy (Health Canada 2001; Murray, Hagey, Willms, Shillington & Desjardins, 2008; Perrin, 1998). Aboriginal peoples in Canada, as evidenced by copious amounts of research, are a population that faces clear inequities across the gradients of health, including health literacy. With continued development of electronic health information (eHealth) they may also experience unequal access to the Internet, often referred to as 'the digital divide' (Reading & Wien, 2009; Zach, Dalymple, Rogers & Williver-Farr, 2011). More research is needed to understand the ways in which a known potentially vulnerable population, Aboriginal women, access and utilize technology to locate and incorporate health information in the perinatal period (Hemming & Langille, 2006).

Research Question

This study was about eHealth literacy and Aboriginal women in the perinatal period. The question addressed was "What is the eHealth literacy level of Aboriginal women in the perinatal period and how does it impact their ability to access and understand health information?".

Background

All healthcare professions including those working in the information management and information technology (IMIT) field should be concerned about the

health literacy and eHealth literacy of healthcare consumers. It is estimated that 40 to 50 percent of adults in Canada and the United States have low basic literacy levels which potentially could affect not only their health status through the inability to access the health and e-health resources available, but also the success of healthcare professionals working to support them (Ingram, 2011; Usher & Skinner, 2010). In navigating through the healthcare system, patients with low literacy face numerous challenges in doing things such as completing healthcare forms, understanding their healthcare instructions, keeping appointments for follow-up care, and self-administering their medications (Ingram, 2011). It is estimated in the United States that individuals with poor health literacy cost the health system upward of \$8 billion which in Canada equates to about 3-5% of the total health care budget (Keleher & Hagger, 2007; Kickbush et al., 2013, p.8; Partnership for Clear Health Communication, 2006).

Yet even with the enormous personal and health system costs, health literacy as an important determinant of health remains a neglected area of public health action and research, and eHealth literacy even more so, especially in Aboriginal populations (Kickbush et al., 2013). The National Association of Friendship Centres (2013) states that “demographically, urban Aboriginal women are more vulnerable to poverty, poor health, and homelessness [than any other population] and have consistently been invisible to policy makers” (p.5). This warrants more research to better understand eHealth literacy of Aboriginal women in the perinatal period to ensure they are not left behind by the digital divide (Donelle & Hoffman-Goetz, 2008; Hemming & Langille, 2006). In order to achieve this, awareness of how Aboriginal women in the perinatal period locate, process and use the Internet to find and evaluate the health information they retrieve is

needed (Donnelly, Shaw and van den Akker, 2008; Manafo & Wong, 2013; McCray, 2005; Neter & Brainin, 2012; Xie, 2012; 2012; Yip, 2012). Having baseline data is necessary for healthcare providers and healthcare organizations to make evidence based decisions in order to provide effective healthcare services and support this population (National Association of Friendship Centres, 2013). Jacobs, Lou, Ownby and Caballero (2014) agree, stating that “few studies have explicitly assessed the significance of race, ethnicity, or culture on participants’ interaction with and response to health information technologies” (p.15). In general, Aboriginal populations are known to be strongly linked to their culture and so a better understanding of the relationship this has to how Aboriginal women in the perinatal period access online health information is important. Currently, we do not know much about the social environment of urban Aboriginal women accessing perinatal health services in an area of Northern British Columbia. We also lack information on what is working or not working in these environments for them in order to both improve their eHealth literacy skills and remove any barriers limiting their ability to improve their and their children's/family's health status (Kickbush et al., 2013).

Chapter 2- Literature Review

Introduction

This chapter focuses on a review of the literature available relevant to this study and related to the concepts of eHealth literacy of Aboriginal women in the perinatal period. Firstly, the search strategy for literature used to inform this study is outlined. Then a summary of the concepts of Aboriginal eHealth literacy will be discussed. The discussion will focus around four concepts relevant to the study: (1) the concept of Aboriginal worldview and literacy, (2) Aboriginal women and the perinatal period, (3) eHealth literacy, and (4) assessment of eHealth literacy. The chapter summary focuses on factors important to consider as discussed in the literature when addressing the eHealth literacy of Aboriginal women in the perinatal period.

A wide-ranging literature review was carried out using a number of databases including UVIC Summon, CINAHL, PubMed, Academic Search and Medline. Additionally, a search of grey literature from governmental organizations such as the British Columbia Ministry of Health and Canadian Council on Learning was performed. As well, other search engines were utilized including: Google, Google Scholar, and Mozilla Firefox. Search parameters included all English language materials. As limited research was found there were no date parameters set. The keyword search strategy included the terms: Aboriginal OR "First Nations" OR Indigenous OR "Native American" OR Métis OR Inuit AND eHealth OR e-health OR "electronic health literacy" AND perinatal OR pregnancy OR postpartum. As the results yielded very limited relevant studies other potential search terms were utilized including "health literacy" and "computer literacy".

Aboriginal Worldview and Literacy

Culture affects how people communicate, understand, and respond to health information. The relationship an individual has with health and literacy is impacted by their life context, thus interventions by healthcare organizations and healthcare providers to improve this relationship needs to be addressed within this context including language and culture (Hemming & Langille, 2006; Rootman & Ronson, 2005; Singleton & Krause, 2009). The Institute of Medicine (2004) report on health literacy defines culture as “the shared ideas meaning, and values that are acquired by individuals as members of a society” (p. 33). Problems in health and eHealth literacy may be contributed to the differing cultural and educational backgrounds between healthcare consumers and healthcare providers (Rootman & Ronson, 2005). Cultural safety is an approach that includes the broader determinants of health within a holistic and community-based context (Brascoupe & Waters, 2009). Cultural safety requires healthcare providers to “competently communicate with a patient by showing respect for and an understanding of the patient’s cultural, political, linguistic, social, economic, and spiritual background, whether the professional be Indigenous or not” (O’Donnell et al., 2010, p. 21).

Actions that make changes to policy, services and information are needed to provide culturally competent care (Birch, Ruttan, Muth & Baydala, 2009). Use of approaches that are grounded in Aboriginal culture, that build on community strengths, and that require care providers to be sensitive to Aboriginal peoples’ socio-cultural needs are core to achieving this (Kornelson, Kotaska, Waterfall, Willie & Wilson, 2010).

Aboriginal Worldview

For centuries prior to contact, Indigenous knowledge systems sustained the health and well-being of Indigenous peoples (Getty, 2010; Skye, 2010). The worldview of

Indigenous peoples is said to represent the importance of the collective, non-hierarchical reciprocal relationships; protection and responsibility for the land, water and resources; and respect for all living and non-living things (Getty, 2010; Wilson, 2001). When reflecting on the traumas inflicted on Aboriginal peoples through colonization and by those ‘well intentioned’ individuals, Smylie’s (2000) statement for individuals, organizations and healthcare providers to have ‘sensitivity’ to these traumas does not feel adequate. The current inequities in both the socioeconomic and health status of Aboriginal peoples has been directly related to the impact of genocide, oppression, racism, discrimination, and unethical human medical experimentation and treatment needs. This requires rightful acknowledgement of these atrocities by governments and general society. There is need to develop a comprehensive action plan that is directed by Aboriginal people and builds on the resilience and strengths of these peoples; a plan that is appropriately resourced in order to implement actions to see sustainable improvements (Best Start Resource Centre, 2012; Getty, 2010; Skye, 2010; Smylie, 2000).

A traditional Aboriginal model of health is thought to be inherently based in the concepts of balance, holism and interconnection where medicine and spirituality are consistently interwoven; and to achieve optimal health, mind, body, spirit, and emotions are in harmony with self, social and natural environment (Skye, 2010; Smylie, Williams & Cooper, 2006; Stewart, Riecken, Scott, Tanaka & Riecken, 2008). It is acknowledged by many that a pan-Indian approach is very inappropriate as there is such diversity in cultures and traditions of Aboriginal peoples including conceptions of health and well-being; yet it is also acknowledged that Aboriginal peoples share some similar core values, beliefs and practices (Skye, 2010). In Canada, the medicine wheel model is used by

many but not all Aboriginal groups to explain varying concepts from wellness to learning (Canadian Council on Learning, 2007). What has been proposed is that any constructions of healthcare for Aboriginal peoples should be based on the Indigenous knowledge systems of those being served, focusing on their strengths not just the deficits, and taking into consideration that Aboriginal communities and individuals within those communities each have unique needs and those needs need to be addressed (Adrian, 2009; Skye, 2010).

Aboriginal Literacy

Aboriginal or native literacy is a continuum of skills that encompasses reading, writing, numeracy, speaking, good study habits, and communicating on a pathway to self-determination and empowerment of spirit (Rootman & Ronson, 2005; Smylie et al., 2006). Antone (2003) adds to this by emphasizing that Aboriginal literacy is about relationships between self, community and nation in the context of everyday life. It is important for Indigenous conceptualizations of literacy to build on Indigenous understandings and perspectives. The Aboriginal rainbow approach to literacy developed by Priscilla George (2000) accomplishes this (Antone, 2003; Rootman & Ronson, 2005; Smylie et al., 2006).

- Red represents – literacy in language of origin of Aboriginal individuals and communities
- Orange represents – oral literacy
- Yellow represents – creative means of communicating with speakers of other languages using symbols, artwork and sign language
- Green represents – the languages of the original European newcomers, French and English – now Canada's official languages

- Blue represents – technological literacy
- Violet represents – balance, the holistic base to Aboriginal literacy, and deals with spiritual, emotional, mental and physical elements

The Rainbow of Literacy model integrates the four aspects of being – spirit, heart, mind and body in developing the whole person (Antone, 2003). The ‘blue’ of the rainbow model speaks to technological literacy, but unfortunately at this time, no school districts report publicly on this for Aboriginal students, leaving little understanding of where Aboriginal students are at when leaving the school setting in this realm.

Aboriginal adults with lower literacy skills are still represented greater than non-Aboriginal adults with low literacy skills by approximately 16 percentage points (Canadian Council of Learning, 2008). As well, any individual with less than nine years of schooling is considered not to have yet achieved sufficient literacy skills (Rootman & Ronson, 2005).

More Aboriginal literacy programs are needed to encourage the positive development of self-knowledge, self-expression, self-affirmation, and self-determination. In order to do this, it is important to remember that literacy is constructed and enacted within social, cultural, and political contexts and is subject to the implications of differing power relationships within them (Smylie et al., 2006). This is another key reason why healthcare organizations, and healthcare providers need to better understand these implications perpetuated by healthcare systems and join in advocating for Aboriginal populations to achieve this end (Smylie et al., 2006).

Aboriginal Women and Perinatal Period

Maternal health continues to be a priority at the global level as identified in the Millennium Development Goals and also is a priority of the British Columbia Ministry of Health (British Columbia. Provincial Health Officer, 2011; Unicef, 2015; World Health Organization, 2004). It is common knowledge that good maternal health is extremely important for both the health of the mother and child, yet close to 20% of British Columbia women in prime childbearing years do not have a regular primary care provider (British Columbia Provincial Health Officer, 2011). Aboriginal women experience perinatal and still birth rates that are twice the national average, have their babies at a younger age, have poorer maternal and infant outcomes than non-Aboriginal counter parts, and do not tend to receive recommended prenatal care in the form of visits to family physicians or midwives (First Nations Centre, 2009; Smylie, 2014). Even with all the evidence known about the significant differences in outcomes for Aboriginal women there are gaps in understanding the maternal health status and experiences of Aboriginal women in British Columbia, which account for almost 5% of the female population (British Columbia Provincial Health Officer, 2011; Smylie, 2014). These gaps make it difficult to effectively address known concerns through comprehensive and targeted action plans.

High costs are currently being paid by all with continued poor health outcomes of Aboriginal populations and this will continue if healthcare organizations and healthcare providers do not pay attention to the key role Aboriginal women play on personal, family and community levels (British Columbia Perinatal Services, 2016). Aboriginal women are considered core to building strong healthy communities and many communities are

working to reclaim their traditional culture and governance structures. Within these structures a woman's ability to give life and raise children places her in a highly esteemed, sacred, authoritative and respected role (Kornelson et al., 2010; Shukla, 2011; Skye, 2010). Although the Aboriginal population in Canada may seem small at about 4.3 percent of the overall population, their growth rate is higher and their average age is lower than the general population. However, they continue to have staggering health disparities, creating urgent need for governments, healthcare organizations, healthcare providers, communities and individuals to finally address this (Employment and Social Development Canada, 2014; First Nations Centre, 2009; Skye, 2010). If the prenatal period can be used as a window of opportunity to positively influence the health outcomes of Aboriginal people, there is potential to not just impact the health outcomes of Aboriginal women, but also the health outcomes of their children, families and communities across generations.

According to the British Columbia Provincial Health Officer (2011) "attention must be given to the inequities among women caused by racism, colonialism, ethnocentrism and heterosexism" (p. xxiii). Aboriginal women may be reluctant to use healthcare services because the healthcare system is based in a world view that does not recognize many of their beliefs, values and practices and continues to perpetuate racism, discrimination and structural inequities (Browne, Fiske & Thomas, 2000; Smylie, 2014). It is important for healthcare providers and organizations to provide culturally relevant maternity services and information ensuring that care is safe, responsive, and recognizes the context of women's lives as these encounters influence Aboriginal women's access and utilization of services (British Columbia Provincial Health Officer, 2011; Smylie,

2014). Cultural needs not being met may result in women avoiding utilization of a healthcare system during pregnancy until critically necessary, followed by early leave taking (Birch et al., 2009). Information and support from healthcare providers to access health information, which is increasingly available online, can help Aboriginal women understand the impacts of their health behaviors and determinants of health and find ways to overcome barriers to achieving good health (British Columbia Provincial Health Officer, 2011).

eHealth Literacy

In order to understand eHealth literacy, it is important to first review the concepts of both health literacy and eHealth. eHealth literacy and methods of assessment will then be reviewed.

Health Literacy

In the late 1980s and early 1990s, health literacy was first recognized as an issue in Canada (Traynor, DeCorby, Graham & Dobbins, 2012). In some countries, literacy is considered one of the strongest predictors of life expectancy, and data suggests that there is an association between health literacy, health-care utilization and healthcare costs (Rootman & Ronson, 2005). The definition of health literacy is consistent across most literature and is described as an individual's ability to access, process, understand, evaluate and act on health information and services in order to make appropriate health decisions in a variety of settings across the life-course and in partnership with healthcare providers (Chiarelli, 2006; Jordan et al., 2010; Levassuer & Carrier, 2010; Mitic & Rootman, 2012; Naidu, 2008; Rootman & Gordon-El-Bihbety, 2008; Wister, Malloy-Weir, Rootman & Desjardins, 2010). The definition of Aboriginal health literacy further expands this by incorporating for Aboriginal people the need to include Aboriginal

traditions and cultural knowledge/perspectives into healthcare services moving away from earlier definitions of health literacy that tended to de-conceptualize literacy assuming a more western socio-cultural context (Antone & Imai, 2006; Smylie et al., 2006).

According to Mitic and Rootman (2012), the characteristics of those that most often struggle with low literacy skills are: “older adults, members of Aboriginal populations, recent immigrants, people with lower levels of education and/or low English or French proficiency, and those who are dependent on social assistance” (p.4). The skills required to obtain, understand and act on health information and services are absent for an estimated 60% of Canadian adults and 88% of seniors (Mitic & Rootman, 2012; Rootman & Gordon-El-Bihbety, 2008; Traynor et al., 2012). This not only has a negative impact on the health and quality of their life, but also exacts a significant financial toll for the health system and society. It was estimated in 2009 that over a year a total of 3-5% of the Canadian healthcare budget was spent related to low health literacy which amounted to approximately \$8 billion (Mitic & Rootman, 2012). Looking at this from the level of individual costs, it is estimated to cost extra anywhere from \$143 to \$7,798 US or \$193 to \$10, 527 Canadian per person when an individual has low literacy compared to an individual with adequate literacy (Eichler, Wieser & Brugger, 2009).

Health Literacy Assessment Tools

On a patient’s initial encounter with the health system, assessment of health literacy levels can alert healthcare providers to any potential concerns and provide a guide for tailoring patient teaching and communication (Heinrich, 2012). Many healthcare settings are not currently using any evidence based assessment tool consistently; instead some judge an individual’s reading ability on their level of schooling

completed which is not a recommended indicator to use (Kutner, Greenberg, Jin, & Paulsen, 2006). Some of the current health literacy assessments available to measure an individual's health literacy fall into the following three approaches: (1) direct testing of an individual's abilities, (2) self-report of abilities, and (3) population-based proxy measures (Jordan, Osborne & Buchbinder, 2011). Examples of health literacy tools available to use today are the "Rapid Estimate of Adult Literacy in Medicine (REALM); the Test for Functional Health Literacy in Adults (TOFHLA) which comes in a shortened version as well; the Word Recognition Achievement Test (WRAT); the Medical Term Recognition Test (METER); the Newest Vital Sign (NVS); and the Adult Basic Learning Examination II (ABLE) (Chen, Hsu, Tung & Pan, 2013; Chiarelli, 2006; Cho, Lee, Arozullah & Crittenden, 2008; Heinrich, 2012; Schaefer, 2008).

Of these tools, the REALM and TOFHLA have shown the strongest psychometric properties, but according to Rootman and Ronson (2005), new measures need to be developed as all of the available tools have some considerations and/or limitations that healthcare providers need to be aware of prior to use (Collins et al., 2012; Frisch, Camerini, Diviani & Schulz, 2011; Jordan et al., 2011). Some limitations for healthcare providers to be aware of when using these assessment tools are: they measure the ability to read, but do not ensure understanding of terms presented; lack cultural representativeness and the consideration for context of use; and are not comprehensive enough to measure the broad range of skills that health literacy entails (Cho et al., 2008; Collins et al., 2012; Heinrich, 2012; McCray, 2005; Rootman & Gordon-El-Bihbety, 2008). There is also no current research on the effectiveness and validity of use of these tools with Aboriginal women in the perinatal period. To tailor health information to a

patient's needs, Jordan et al. (2011) state "a health literacy instrument should ideally be capable of clearly describing an individual patient's abilities and areas that need to be addressed" (p.377).

eHealth

Improvement of health and the healthcare system was expected to happen through the introduction of information and communication technologies - eHealth (Oh, Rizo, Enkin & Jadad, 2005). eHealth, is an all-encompassing term used for a whole range of purposes including to describe the application of information and communications technologies in the health sector from administrative through to health care delivery (Health Canada, 2010). It has been challenging to realize in practice the careful coordination and communication among all stakeholders needed to introduce eHealth technologies into a complex healthcare system (van Gemert-Pijnen et al., 2011). But the potential of eHealth technologies remains if the process and interdependencies of health care delivery between technology, people, their sociocultural environment, and the structural organization of health care can be clarified and technologies that are meaningful, manageable, and sustainable can be created (van Gemert-Pijnen et al., 2011). In this study the various technologies used in eHealth will be referred to as digital technologies. This term refers to, but is not limited to: personal computers, mobile devices or mHealth (i.e. phones and tablets), the Internet and social media (Bautista, 2015).

eHealth Literacy

In today's society, individuals are said to need adequate levels of general prose literacy, computer literacy, and health literacy, as well as technology with Internet access to function effectively (Dominick, Friedman & Hoffman-Goetz, 2009; Zach et al., 2011).

eHealth literacy is defined as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (Connolly & Crosby, 2014, p. 44). Online health information is seen as having the potential to improve an individual’s health literacy, promote self-care, and improve health outcomes and well-being (Anderson, 2004; Dey, 2004; Kirmayer, Raikhel & Rahimi, 2013; Norman & Skinner, 2006).

Digital technologies including the Internet are becoming the most common way for many individuals to access health information. However, those impacted by racial/ethnic group disparities including educational level may not be able to do this to the same degree, creating inequities in societal impact (Jackson, Ervin, Gardner & Schmitt, 2001; Zach et al., 2011). With the rapid advancement of affordable digital technologies that are portable - mHealth, achieving the last is easier causing ‘computer literacy’ to become outdated for some; although for many the costs and fees of mHealth technologies may still be too high (Cashen, Dykes & Gerber, 2014, p.211; Mayisela, 2013; WHO, 2011). There was a prediction that by 2015, conventional desktop Internet use would be overtaken by mobile Web access via smartphones and other small-form-factor Internet devices, such as small touch-screen tablets making the Internet increasingly available to individuals with limited income (Boulos, 2013; Kirmayer et al., 2013; Zach et al., 2011). The convenience of accessing the Internet via a cell phone may have the potential to increase health information seeking among populations that have not previously been users of online health information. Yet research has found that disparities in health-related Internet use is not driven solely by lack of access, but also by racial and ethnic lines as well as educational levels (Zach et al., 2011).

Another major challenge for those with low levels of eHealth literacy and from a range of cultural and language backgrounds is the wide variety of health information on the Internet, with varying degrees of quality and technical information (Dominick et al., 2009; Xie, 2012). Most websites do not currently have the capacity for their web pages to change dynamically to meet the needs of individuals accessing them (Cashen et al., 2014). Understanding an individual's eHealth literacy level has become critical for healthcare providers and organizations to be aware of prior to using eHealth interventions (Collins et al. 2012). At the same time, healthcare organizations and healthcare providers also need to increase their participation in the eHealth environment to assist those individuals who do not possess the level of health literacy needed to access, understand, and implement the health information they find online to make decisions for themselves or others (Bacigalupe & Askari, 2013; Clauson & Vieira, 2011; Hemming & Langille, 2006; McCray, 2005; Usher & Skinner, 2010).

Most eHealth tools used in healthcare have not been designed with the consideration of the needs and characteristics of diverse user groups and therefore provide little value if the intended users lack the skills to effectively engage them (Chan & Kaufman, 2011; Norman & Skinner, 2006). Improving eHealth literacy is seen as an active, lifelong learning process that evolves over time in order to empower and enable individuals to fully participate in healthcare decisions (Neter & Brainin, 2012; Xie, 2012). According to research, “the amount one benefits from e-Health information is directly related to the level of e-Health literacy” one has (Connolly & Crosby, 2014, p. 44). If addressing cultural issues, including different cultural values, beliefs, and customs, can support an individual's care-seeking activities, inspire trust, and foster

adherence to recommended healthcare treatment and self-management plans then more focus from those developing eHealth technologies to do this needs to happen (Cashen et al., 2014). As it has been found that health information on the web which is culturally relevant/sensitive and presented in plain language is more likely to be reviewed by Aboriginal people (Friedman & Hoffman-Goetz, 2007; Friedman & Hoffman-Goetz, 2006; O'Donnell et al., 2010).

eHealth Assessment Tools

Incorporating a validated assessment of health literacy into eHealth assessments and tools is necessary to track levels of literacy and provide evidence indicating whether interventions and tailored technologies should be targeted at low health literacy, low technological literacy, or a combination of the two (Collins et al., 2012). Norman and Skinner (2006) developed the “Lily Model” of eHealth literacy to assist providers to better understand the skills needed by individuals, and to assist in the creation of evaluation tools and system design to ensure a better fit between eHealth technologies and their users (Figure 1). The model is reflective of: traditional literacy and numeracy; computer literacy; media literacy; science literacy; information literacy; and finally, health literacy (Norman & Skinner, 2006). What this model is lacking though is a cultural literacy component, which as described earlier is critical to those healthcare consumers who come from a culture not of the dominant society. Aspects of literacy which are critical to the access and understanding of information including health information are important to individual’s health status.

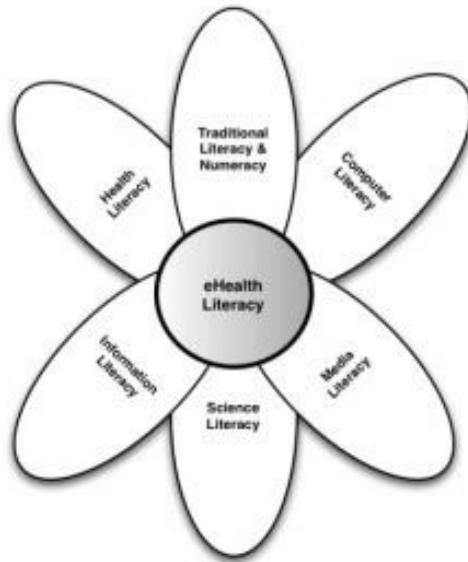


Figure 1. eHealth Literacy Model. Reprinted from "eHealth Literacy: Essential Skills for Consumer Health in a Networked World", by C.D. Norman & H.A. Skinner, 2006, *Journal of Medical Internet Research*, 8(2), e9. Copyright 2006 by the Journal of Medical Internet Research.

The assessment tool created by Norman and Skinner (2006) to measure an individual's eHealth literacy is called the eHealth Literacy Scale (eHEALS). The purpose of eHEALS is to assist healthcare providers in determining the appropriateness of directing individuals to access eHealth information and resources. eHEALS was validated through research with youth, and individual users through reflection of 8 statements using a 5-point Likert scale to self-rate their level of eHealth literacy. Norman and Skinner recommend that the applicability of eHEALS to other populations and settings needs further research. Based on the lack of cultural literacy in the Lily Model, there is concern about its applicability to Aboriginal people (Collins et al., 2012). eHEALS has been translated into other languages, but like other tools related to health literacy caution needs to be used. In one study with Dutch adults researchers found that it

did not effectively distinguish between people with high and low health-related Internet skills (van der Vaart et al, 2011).

Another newer tool developed to measure adult healthcare consumers with chronic conditions readiness to use health technologies is the ‘Pre-Hit’ instrument (Koopman, Petroski, Canfield, Stuppy & Mehr, 2014). Again, because this instrument has not been validated with Aboriginal women in the perinatal period it may not be relevant or reliable for use in this population. Finally, what needs to be kept in mind by healthcare organizations and healthcare providers is that as technology constantly changes, eHealth levels may need periodic reassessment and therefore warrants the ‘6th vital sign’ or “universal precaution approach”, ensuring that eHealth literacy is assessed by healthcare providers at regular intervals or care visits as is done with other physical vital signs like an individual’s pulse or blood pressure to monitor current levels and changes (Collins et al., 2012).

Health systems are becoming increasingly fragmented, complex, specialized, and technologically sophisticated creating more health literacy problems as healthcare providers and healthcare organizations expect healthcare consumers to assume more responsibility for their care (McCray, 2005; Naidu, 2008). According to McCray (2005), “in our current healthcare environment there is often a serious mismatch between an individual’s background, skills, and expectations, and the information and services that are available to that individual” (McCray, 2005, p.152). In the age of the Internet, healthcare providers and organizations have the potential to transform their relationships with patients. Adequate eHealth literacy training is needed to support consumers to find, interpret, apply and evaluate the usefulness of health information. Healthcare

organizations need to be a part of finding more efficient and equitable strategies to address eHealth literacy without placing the entire weight of responsibility for it on individuals or healthcare providers (Green, 1984). Healthcare providers and healthcare settings have a responsibility beyond just assessing what the health literacy levels of their patients are, they need to directly play a role in improving their patient's health literacy levels where needed. Healthcare providers need to be able to: recognize varying literacy levels among individuals, understand cultural barriers, and provide the appropriate levels of information in ways that it will most likely be understood, accepted and optimized (Cortelyou-Ward, Noblin & Williams, 2012; Heinrich, 2012; Korhonen, 2006; Levasseur & Carrier, 2010). Strategies to address this include paying attention to the voices of individuals with limited health literacy when planning programs and preparing materials, and recognizing that language, culture and literacy are intertwined (Brach et al., 2012). Investment in strengthening eHealth literacy is likely to yield a substantial return in health and well-being at both the individual and community levels, but it is first important to know where individuals are at prior to making decisions around how best to invest (Kickbusch et al., 2013).

A solution to health literacy will not happen with simply encouraging health information seeking on the Internet as health literacy involves not only the ability to access health information but also the ability to understand it (Zach et al., 2011). Problems may grow as electronic information sources increasingly become important for daily healthcare decisions both from the perspective of individuals and healthcare providers (Eichler et al., 2009). Healthcare providers and healthcare organizations need to view health information seeking on the Internet as more than an information

dissemination process, but as a powerful communication process so that the communication we are talking about is not lost in the technology (McCray, 2005; Ratzan, 2001). It is important to remember that the impact of health literacy arises not just from the interaction of individuals, but from the health context which is mediated by numerous factors. For Aboriginal populations this includes a reflection of their social norms and attitudes particular to their world (Rootman & Gordon-El-Bihbety, 2008; Yip, 2012; Zach et al., 2011).

Summary of Literature Review

In this chapter, I have reviewed the literature available related to health literacy, eHealth literacy, Aboriginal women in the perinatal period, and assessment of health and eHealth literacy. In summary, research studies focused on eHealth literacy of Aboriginal women in the perinatal period are severely limited. Little is known about the way in which eHealth literacy impacts Aboriginal women in the perinatal period. Consideration should be given to the fact that with the emerging utilization of digital health technologies to access health information more evidence is needed to understand the benefits and challenges experienced by a range of consumers. To accomplish this, there is need to develop systematic and comprehensive measures to evaluate health and eHealth literacy in clinical settings, as well as conduct further research to find effective strategies and “best practices” (McCray, 2005; Schaefer, 2008). If the key to long term prosperity of the country and the future health of generations is through investing in the health of mothers and babies, then it is important to address inequities in access to quality maternity care for Aboriginal women in the perinatal and postpartum phases (SOGC, 2008). It is evident that research into eHealth literacy of this population would provide insight into the challenges and opportunities in order to ensure they are able to access,

understand and incorporate the health information available online to address their health needs. The next chapter will review the methodology used in this study.

Chapter 3- Methodology

In this chapter I will identify my personal standpoint as a researcher, describe philosophical and theoretical foundations of the study, outline the methodology, and explain how this methodology is congruent with my research question - "What is the eHealth literacy level of Aboriginal women in perinatal period and how does it impact their ability to access and understand health information?". I will describe the setting, participant characteristics, recruitment and ethical considerations, and then review the instruments and procedures for data collection and analysis.

Personal Standpoint as a Researcher

I am a registered status Indian with Williams Lake Indian Band with Métis ancestry. My mother is also an off-reserve status member of the Williams Lake Indian Band and my late father is a first generation Canadian, his family emigrating directly from Romania. I was born, raised, and now reside in Kamloops, British Columbia. I have been building knowledge and skills in my Aboriginal culture, since my mid-twenties and am new on this journey with still so much to learn. In the last few years, this learning has been parallel to my attempt to expand my nursing knowledge in various specialty areas. This has helped me to view what I was learning in my nursing education in a different light to try and understand the teachings within. I chose this area for my research because in my varied career as a nurse, the work I am most fond of is the work that I have done and continue to do with women, babies, children and families. I wanted from the start to ensure that I did research that would support positive changes with Aboriginal women in the perinatal period, as mothers and women are key to building healthy children, families and communities and hold an esteemed value in my personal and professional life.

Philosophical and Theoretical Foundations

Pragmatism

According to Hannes and Lockwood (2011), the philosophy of pragmatism was “first developed by Charles Pierce (1877) and further advanced by William James (1909) and John Dewey (1939)” (p.1636); along with Oliver Wendell Holmes, Schiller and Herbert Mead (McCready, 2010). The pragmatic perspective draws on employing "what works," through use of diverse approaches, in order to solve practical problems in the ‘real world’ (Feilzer, 2010). Pragmatism as a multi-paradigmatic view also aligns with the focus of nursing as a practical and creative co-action where the multiple models used capture philosophies in a triangulated/overlapping way, yet is also interconnected and iterative providing utility for all involved (Feilzer, 2010; McCready, 2010; Warelow, 2013). This also aligns with an Indigenous approach where methods may be qualitative but could also incorporate quantitative methods to achieve all ways of knowing, and meets the statement made by the National Association of Friendship Centres (2013), that “any kind of demographic research that occurs [with Aboriginal people] should be complex in nature, using a variety of methodological lenses and tackling nuanced urban issues” (Lavallee, 2009; p.39). According to McCready (2010) the most common critique of pragmatism(s)/pragmatists are that “too many or all of its eggs are placed in the basket of practical results and in doing so, philosophy and theory are ignored or outright despised” (p.194).

Aboriginal Research

The Aboriginal world view embraces change and recognizes the intricacies of a holistic and interconnected life (Kenny, 2004). To accommodate Indigenous perspectives in research, new methodologies are being developed and used by Indigenous academic

researchers (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007). According to Getty (2010), an Indigenous ontological foundation or worldview and epistemological approach are the foundation for an Indigenous research paradigm. The methodology of an Indigenous research study needs to be transparent in how it approaches protocols and values; and could benefit from following the “4Rs” – respect, relevance, reciprocity and responsibility (Evans, Hole, Berg, Hutchinson & Sookraj, 2009; Getty, 2010). It is also important that when completing research with Aboriginal peoples to ensure a culturally sensitive approach and ethical conduct utilizing OCAP principles (Campbell, 2014).

Aboriginal research philosophy brings with it a willingness to engage in other ways of knowing and through various methods as long as appropriately covered within Indigenous knowledge and research protocols. (Roy 2015; Tonmyr & Blackstock, 2010). It is critical for effective Aboriginal research to occur in partnership with a focus on how it benefits Aboriginal communities (Kenny, 2004; Roy, 2015). The mixed method approach has the advantage of fulfilling many of the requirements of an effective research methodology because it supports telling “important stories about Aboriginal peoples’ lives” (Kenny, 2004, p. 33).

Study Design

A fixed convergent parallel mixed methods design was used in this study (Table 1). The qualitative and quantitative strands were conducted in parallel with equal weighting, then each strand was separately analyzed, and the results merged. I chose the convergent parallel mixed methods design as the methodology for the study because it is a good fit for the structure and aims of the study and allows for a better understanding of research problem than either approach can do on its own (Classen et al., 2007; Creswell

& Plano Clark, 2011). As well, a fixed design was used as it is recommended for researchers new to mixed methods (Bradt, Burns & Creswell, 2013).

Table 1
Fixed convergent parallel mixed methods design for study

Fixed Convergent Parallel Mixed Methods Design		
	Quantitative	Qualitative
Data Collection		
Procedures	<ul style="list-style-type: none"> Select 8 to 10 self-identified Aboriginal women Implement survey: eHEALS instrument and demographic information in person, over the telephone, or via social media site (Facetime or Skype) 	<ul style="list-style-type: none"> Same participants Conduct semi-structured interviews in person, over the telephone, or via social media site (Facetime or Skype)
Products	<ul style="list-style-type: none"> Numerical item scores 	<ul style="list-style-type: none"> Transcripts
Data Analysis		
Procedures	<ul style="list-style-type: none"> Descriptive statistics 	<ul style="list-style-type: none"> Constant comparative thematic analysis
Products	<ul style="list-style-type: none"> Means, frequencies, percentages 	<ul style="list-style-type: none"> Major themes Quotes Typology of participant perceptions
Merge the Results		
Procedures	<ul style="list-style-type: none"> Cross-tabulate qualitatively derived groups with quantitative variables 	
Products	<ul style="list-style-type: none"> Matrix relating qualitative themes to quantitative variables 	
Interpretation		
Procedures	<ul style="list-style-type: none"> Consider how merged results produce a better understanding 	
Products	<ul style="list-style-type: none"> Discussion 	

Mixed Methods Research

According to Johnson, Onwuegbuzie and Turner (2007), “mixed methods research is an approach to knowledge that attempts to consider multiple viewpoints,

perspectives, positions, and standpoints” (p.113). Mixed methods research is described by Creswell (2014) as “an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks” (p.4). It is an approach that from my standpoint is in alignment with Aboriginal perspectives for working with others through respectful listening and consideration in order to see, understand and know in different ways (Greene, 2008; Greene, 2007).

Of the mixed methods approaches, the convergent parallel design is noted to be the most well-known, and according to Creswell and Plano Clark (2011), “occurs when the researcher collects and analyzes both quantitative and qualitative data during the same phase of the research process and then merges the two sets of results into an overall interpretation” (p. 77). The rationale for this approach is that the quantitative data and analysis provides a general understanding of the research problem that is explored more in-depth through the qualitative data and analysis to provide a fuller picture of the research problem. Other reasons for using the convergent design are to: obtain different but complementary data on the same topic, overcome weaknesses of one method, and triangulate findings for confirmation and validation (Abdul Hadi, Alldred, Closs & Briggs, 2013, p. 343; Creswell & Plano Clark, 2011). A key challenge with this design is that it can be difficult to merge the two separate sets of data and their results in a meaningful way. If the results do not agree, the researcher needs to decide what to do next (Creswell & Plano Clark, 2011).

For this study, the benefits of using a convergent design outweighed the potential challenges. One benefit is that the use of the design is more time efficient as both types

of data are collected at approximately the same time making it a more feasible choice in the presence of time constraints. In this study time constraints were anticipated, as according to the Pregnancy Outreach Program staff I may not be able to access participants for any subsequent visits, and so collected both types of data in one visit to the field.

Research Permission and Ethical Considerations

Ethics approval was obtained through the Human Research Ethics Board (HREB) at the University of Victoria and Interior Health Authority through a harmonized process. Signed informed or verbal consent and information about the purpose of the study was provided to each participant and was in accordance with the protocols of ethical research. The researchers' copies of all consent forms were secured in a locked case which was kept in a locked office. Participants were given assurances that they could withdraw from the study at any point and, should they opt to do so, this would not affect participants continued access to services, nor would it affect the offer of an honorarium. Each participant was compensated with a \$25.00 gift card honorarium to a local grocery store for their involvement in the study and provided a small gift for their children. The interview sessions were digitally recorded with consent of each participant and stored on the researcher's computer in a locked file.

Research with Aboriginal populations is a sensitive matter and researchers have an ethical responsibility to adhere to key ethical principles such as respect, informed consent, beneficence, non-maleficence, veracity and justice. Thus, ethical approval was obtained from the affiliated university and health authority and shared with the Friendship Centre Executive Director and Pregnancy Outreach Program Coordinator.

The document “Protocols and Principles for Conducting Research in an Indigenous Context” (University of Victoria, 2003), in conjunction with the Aboriginal ownership, control, access and possession (OCAP) model (First Nations Centre, 2005) assisted in guiding this process. Both documents are designed to facilitate the ethical conduct of research with Aboriginal people. In the past, Aboriginal people have been researched without due respect, and the university’s guidelines are in place to scrutinize the procedures involved in researching Aboriginal peoples.

Setting

This study took place in a small city in British Columbia. According to the local school district profile, which covers the area where this study was conducted, only about 62% of Aboriginal students entering grade 8 graduated within 6 years with a Dogwood diploma by the year 2014/15 (British Columbia Ministry of Education, 2015). This was improved from 2010/11 when rates were at 38.3%, but still well below the average student rate at just over 79% which is also below the provincial average already (British Columbia Ministry of Education, 2015). This potentially highlights further concern for the region in regards to literacy and health literacy gaps, especially when considering the Aboriginal population as there are many First Nations communities surrounding the study area. The school district reports that approximately 30% of their school population has identified as being of Aboriginal ethnicity, with about 75% of these students living off-reserve (British Columbia Ministry of Education, 2015). In the overall demographic characteristics of the study area population in 2011, 20.6% reported an Aboriginal identity; of those, 77.9% reported identity as First Nations (Statistics Canada, 2016). The

British Columbia Perinatal Registry notes that the local hospital had 346 babies delivered between 2014/2015 (British Columbia Perinatal Services, 2016).

Recruitment, Sample Size and Participant Demographics

The participants invited to be involved in this study were recruited through the use of non-probability criterion sampling techniques for both the quantitative and qualitative research phases. The establishment of exclusion and inclusion criteria according to LoBiondo-Wood and Haber (2010) increases the precision of a study and strengthens evidence produced. To be included in the study, participants were required to be: (1) at least 18 years of age, (2) female, (3) self-identified as Aboriginal, (4) self-identified as being in the perinatal period¹ (5) self-identified as living off-reserve, (6) have used technology to access health information online in the past 6 months, and (7) consented to research participation.

The Aboriginal identity definition used in this study was developed by Statistics Canada (2007) and is based on their definition from the Canadian Constitution Act, 1982, Part II, Section 35(2), as “Aboriginal peoples of Canada” includes the Indian, Inuit and Métis peoples of Canada”. In British Columbia, the term First Nations is now used in place of “Indian” and so shall be done in this study (British Columbia Ministry of Aboriginal Relations and Reconciliation, 2007).

The goal for this study was to recruit eight to ten participants, which is appropriate for a pilot study involving qualitative data collection. The advantages of a small sample size means that a good rapport can be built between the researcher and participants; it may also solicit more authentic responses, and can facilitate analytical

¹ Perinatal period in this study is defined as the period from conception to one year postpartum

generalizations or case-to-case transfers (Collins, Onwuegbuzie & Jiao, 2007; Munhall, 2007). Qualitative research has no specific rules for the determination of sample sizes, but guidelines suggest that a study's sample size should involve a sufficient number of participants to achieve an adequate breadth of perspective and a complete and accurate picture of this group (Elo & Kyngas, 2008).

I had multiple meetings with individuals working and currently involved at the local Pregnancy Outreach Program running out of the local Friendship Centre. Recruitment/information flyers inviting interested participants to contact the researcher were posted in the Pregnancy Outreach Program facility and participants were asked to inform other Aboriginal women about the study to create awareness about the opportunity to participate in the research (Goodman, 1961). I posted on social media sites where Aboriginal women in the perinatal period were known to access, the local Kijiji community page and on the Pregnancy Outreach Program Facebook. Details of the proposed study were given with my mobile number and email address so that respondents could contact me. All participants were informed of the study via a letter of information, and were required to provide signed or verbal consent prior to participating in the research whether they choose the online, in person, or telephone survey and interview.

I had also provided information about the study to the local hospital and community managers, and both had posted the study recruitment poster at their sites that were accessed by pregnant and postpartum women and forwarded the information to local physicians known to provide services to Aboriginal women in the perinatal period. Information was also shared with local agencies that may provide services to this population – notably the Strong Start Centre, and the Child Care Resource and Referral

Centre. Information regarding the study was also forwarded to contacts that work for and in some of the First Nations communities surrounding the study area to share with any off-reserve members that met the criteria and were living in the study area. Additionally there was an offer to provide further information if needed.

Five women were recruited for this study. Their demographics are reported in Table 2.

Table 2
Characteristics of the study sample

Variable	N	%
Age		
24-29	1	20
30-34	3	60
35-39	1	20
Aboriginal Identity		
First Nation	5	100
Level of Education		
Grade 9-12 Completed	1	20
Graduated high school/dogwood certificate	1	20
Some college or university completed	1	20
Trade/technical/vocational training completed	1	20
College or university graduate	1	20
Total Household Income		

Less than \$25,000	3	75
\$100,000+	1	25
Marital Status		
Single (never married)	1	20
Married/Common-Law	4	80

Note. Table 2 summarizes the demographic and descriptive data collected at the time of the interview. Note N does not equal 5 under the category ‘Total Household Income’ as one participant declined to respond.

Instruments

Quantitative. I used one survey which contained two instruments. The first component of the survey was the eHealth Literacy Scale called the eHEALS instrument (Appendix A). The second part of the survey included 6 demographic questions.

The eHEALS instrument was used to measure the health literacy levels and was developed by Norman and Skinner (2006). eHEALS is a 10-item self-report instrument measuring perceived knowledge, ease, and skills of users to find, evaluate and apply electronic health information. It has shown to have satisfying psychometric properties as a tool for assessing consumer comfort and skill in using information technology for health (Ossebaard, Seydel & van Gemert-Pijnen, 2012). The scale was shown to be reliable with an alpha of 0.88 in the original study by Norman and Skinner (2006) and also demonstrated good internal consistency. This measurement tool was first developed with youth, but has been used in studies with adults and translated into various languages and has demonstrated consistency in assessing the concept of eHealth literacy.

Qualitative. According to Affleck, Glass and MacDonald (2012), semi-structured, open-ended interviews are considered a ‘gold standard’ for use in qualitative research. The qualitative component of the study consisted of 11 semi-structured interview questions and probes that focused on the experiences of participants experiences related to eHealth literacy (Appendix B). Semi-structured interviews allowed for interpersonal interaction and provided an avenue from which to gain information on attitudes, beliefs, and levels of satisfaction, all of which are crucial to improving the eHealth literacy levels of urban Aboriginal women. Interview questions focused on what they used to look for health information on the Internet, what was helpful/not helpful when they were looking for health information on the Internet, and what they felt would be helpful in assisting them further. For a full list of the semi-structured questions and sub-questions please refer to Appendix B.

Data Collection and Analysis

Quantitative. The primary technique for collecting the quantitative data was through administering the eHEALS instrument and obtaining demographic data. The survey questionnaire was paper based and was then entered into FluidSurvey© and rechecked twice to ensure information was entered accurately. Informed consent was gathered prior to the interviews through in-person or verbal consent, to ensure their agreement to participate in the study and complete the questionnaire. Descriptive statistics were used to describe the data collected through both the eHEALS survey questionnaire and demographic data.

Qualitative. Participants received a copy of the interview questions to review when meeting in person. When meeting over the phone, the questions were repeated.

The interviews were taped recorded and then transcribed verbatim, except for the first interview, where the recorder malfunctioned and did not record the interview so the notes taken were analyzed. Three of the interviews were in person at participant's homes and two interviews were completed over the phone.

As I had anticipated participants may not allow or be able to accommodate a second interview, I completed the interview and survey questionnaire during the same time period. I collected all data to maintain consistency. Field notes were recorded as soon after the interviews as possible in order to capture issues or insights related to interview content or process, to provide methodological note for the researcher and to make theoretical connections to other studies and literature.

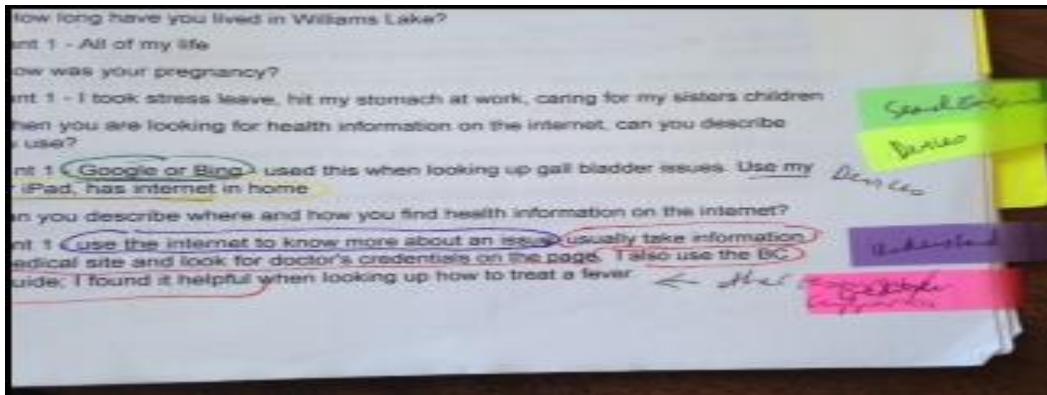
Qualitative data collection and analysis proceeded simultaneously (Merriam, 2009). There are various thematic analysis processes, speaking to the fact that there is no single way to conduct qualitative thematic data analysis. The text data obtained through the interviews in this research project was coded and analyzed through the seven stage process outlined by Braun and Clarke (2013). This process is an appropriate method to follow for someone new to research because it is easy to learn and has a stepwise process to follow (Bradley, Curry & Devers, 2007). I then transcribed all interviews verbatim. Through review of the interview transcripts a sense of the most important themes was developed. Quotes representing emerging ideas were noted. As well, in order to appraise content and construct validity of the eHEALS instrument's, participants were asked to comment specifically on their view of each item on the instrument (Sandelowski, 2000). After completing all five interviews, I engaged in the seven phase process of thematic analysis as described by Braun and Clarke (2013). These phases include: (1)

transcription, (2) familiarizing yourself with the data, (3) coding, (4) searching for themes, (5) reviewing themes, (6) defining and naming themes, and (7) writing and finalising analysis.

Phase 1 & 2. The first step I undertook was to transcribe each of the audio recordings for the participant interviews verbatim, listening and re-listening to the audio recording to ensure the transcription was accurate. Next, I proceeded to review fully the hard copy of each of the transcribed audio recordings a few times prior to starting to inductively identify codes.

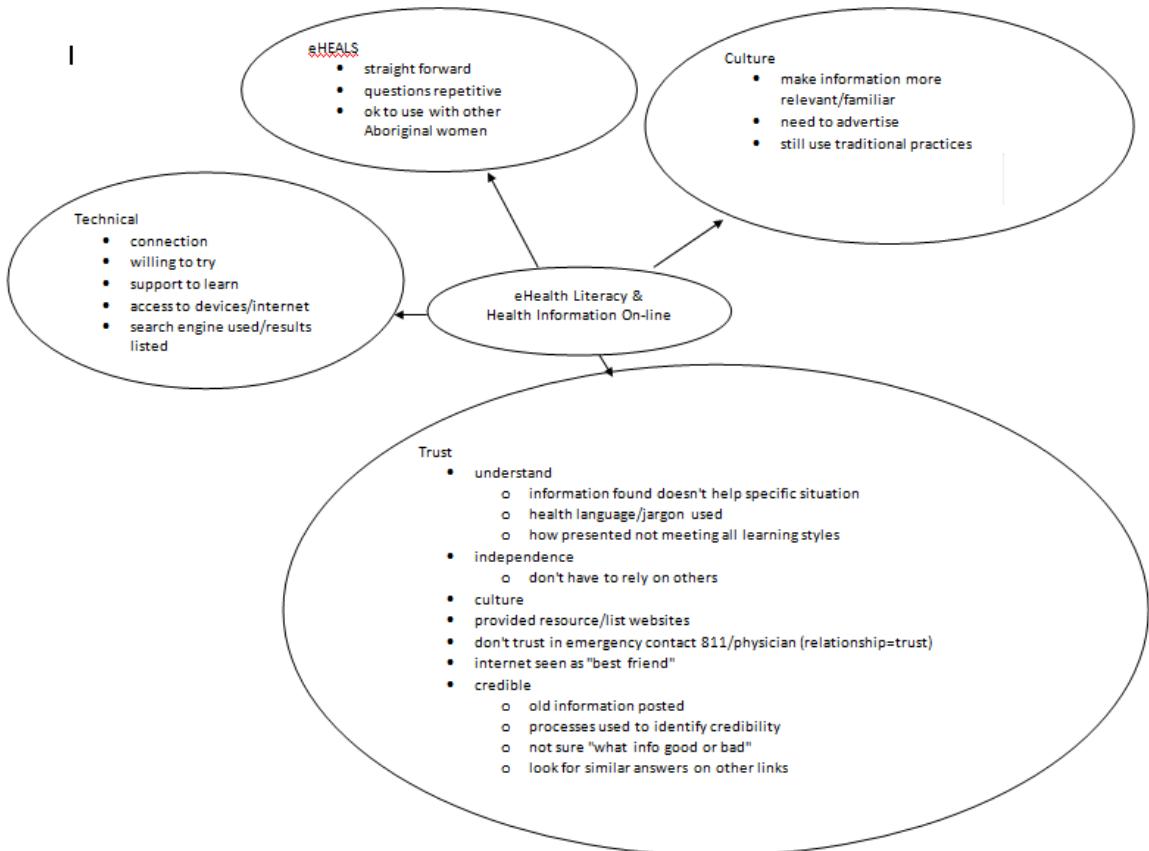
Phase 3. Following this I used different colored pens to underline and identify key phrases relevant to the research question and highlighted these codes with colored tape in each transcribed interview and then reread all other interviews to see if they were present elsewhere (Figure 2).

Figure 2
Example of coding of transcribed interviews



Phase 4. From there, the fourth step I undertook was to analyze all of the codes identified to develop themes. Following this an initial mind map was developed to reflect the emerging themes (Figure 3).

Figure 3
Initial mind map of themes



Phase 5. The fifth step was to review the transcribed interviews multiple times to ensure I had identified all codes and themes. Then I moved around themes, categories and codes and developed an updated mind map (Figure 4 and Figure 5).

Figure 4
Example of review of themes and transcribed interviews

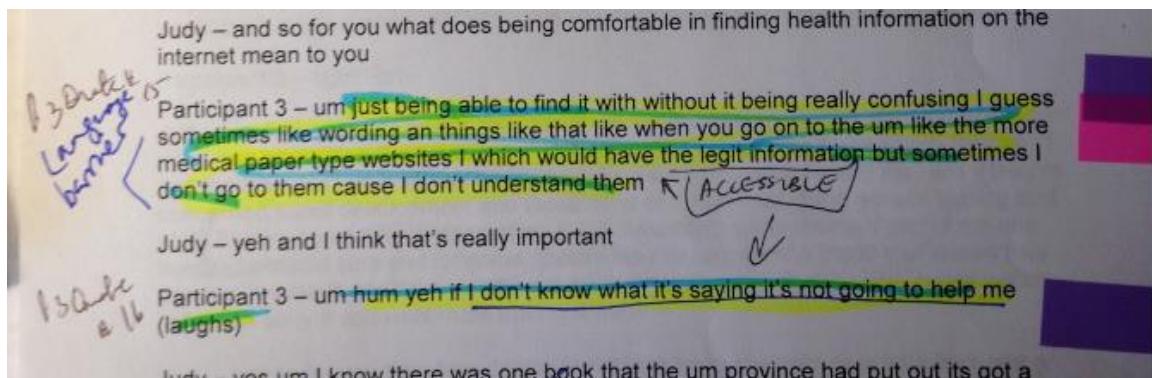
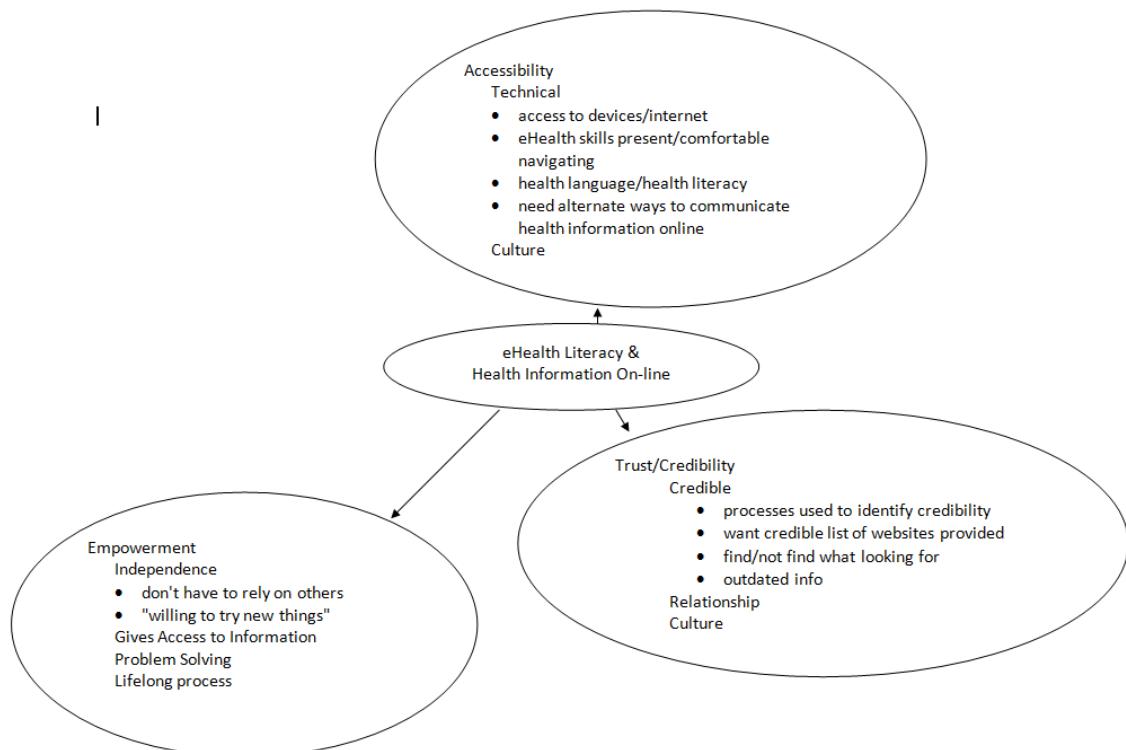


Figure 5
Updated mind map with themes

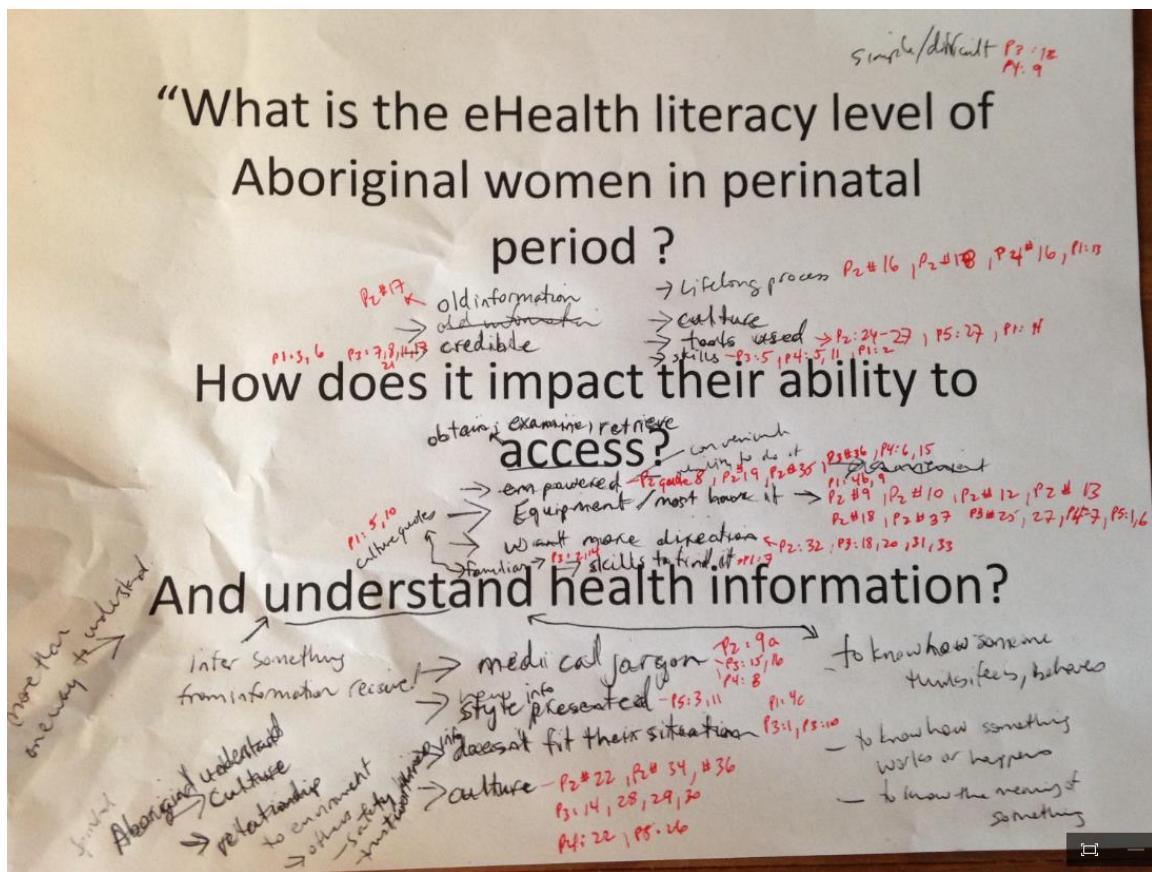


Phase 6. In the sixth step I constructed, defined and named specific separate themes based on the experiences and perceptions of the participants.

Phase 7. The final step I undertook was to review the themes, categories and quotes again ensuring information included was relevant to the research question (Figure 6).

Figure 6

Example of review of themes and quotes



In summary, in this chapter I have described my personal standpoint as a researcher, the philosophical and theoretical positions used to underpin this study, and the specificities of the convergent parallel methodology that was used. I also described the processes for ethical recruitment, and procedures followed for collection and analysis of

the data that emerged from administration of the eHEALS and semi-structured interviews, including steps in merging the qualitative and quantitative data.

Chapter 4 -Results

In this chapter, the results of the study are presented. I will review the responses from the eHEALS instrument, identify and describe key themes that emerged from the semi-structured interviews, and discuss the merged findings.

Quantitative Data Results - eHEALS Questionnaire Responses

Overall, the participant responses to the eHEALS questionnaire were positive. All five of the participants found the Internet useful in helping them make decisions about their health. The majority also found that it was important to be able to access health resources on the Internet. Just over half of the participants were not sure or disagreed that they know what health resources are available on the Internet, yet most participants said they know where and how to find helpful health resources on the Internet. All participants agreed that they know how to use the Internet to answer their health questions and also use the health information they find to help themselves. Half of the participants felt they had the skills needed to evaluate the health resources on the Internet, but half were not sure or disagreed they had the skills needed to evaluate health resources on the Internet. Most of the participants felt they could tell high from low quality health resources on the Internet, but one participant was unsure and the other did not agree. Finally, most participants felt confident in making health decisions using information from the Internet. I had planned to complete tables and graphs to display participants responses by frequency distribution, percentage and count, but due to the small sample the analysis was not included.

There is no definitive overall score for the eHEALS instrument, which would assist in understanding what the eHealth literacy levels of participants are. It is left to

those administering the tool to judge eHealth literacy levels of individuals based on responses. Based on the study participants' responses above, I interpret the responses to mean that most participants had fair to very good eHealth literacy.

Qualitative Data Findings – Semi-Structured Interviews

Three themes were identified from the participant interview data regarding eHealth literacy information: (1) accessibility, (2) trust/credibility, and (3) empowerment. These themes are each described below and a final mind map visualizing the three themes is presented in Figure 7.

Figure 7
Final mind map and themes



Accessibility

The assumption is that the Internet is both convenient and helpful to provide relevant health information. Each participant spoke about the technology they use to access the Internet, for example a cellular phone or a tablet, and mentioned concerns they have with either the Internet or technology or both. The first concern mentioned was limited access to the essential digital technology devices itself.

"I wish they had more resources um where you can use a computer online and stuff but there but it seems like there's not many places" (P5)

Besides difficulties experienced in getting access to a computer, another concern noted was no or limited Internet coverage.

"If you don't have Internet then you can't (find health information on the Internet). You'd have to go to the library or somewhere else that has free Wi-Fi to get information" (P2)

From this view, knowing where to find a working computer and reliable Internet was important. Most participants used either a cellular phone or tablet to access the internet. One participant also had access to a laptop. One participant did not have any access unless visiting the local library.

"When I was living with my boyfriend's mom out on the rez...she didn't have the Internet or anything and that's when I was pregnant with (pointed to an older child) I couldn't and when we moved back to town I was so happy to get Internet and I was like I need Internet, I had to go to the health centre to use Internet out there" (P2)

It is expected that individuals accessing health information online understand health terminology used in information provided. This was an added concern mentioned by some participants.

"Like when you go onto the um like the more medical paper type websites I which would have the legit information but sometimes I don't go to them cause I don't understand them" (P3)

Another concern noted was that although many participants referred to written health information online, some participants also appreciated information delivered through video.

"Yeh I like to watch things well sometimes well actually it goes both ways it's either watchin a video or reading somethings it could be both" (P5)

Some participants also stated that in order to help Aboriginal women to be able to access health information on the Internet more input and information from Aboriginal culture would be helpful

"Like you know Aboriginal sites that would help like more info for Aboriginals kind of thing" (P2)

Overall, no participants spoke of any large concerns in their individual ability or skills needed to find health information on the Internet. The concerns centered around limited access to devices and/or the Internet itself, not really understanding health terminology or language, and lastly being able to access alternate options to receive health information other than written text. Participants had developed a process of searching and scrolling for information based on their questions asked, and had additional

strategies to use if that did not work, such as - asking family members for help or rewording the search question.

Trust and Credibility

Aboriginal women in the perinatal period are expected to find reputable health information online themselves. Finding health information online to better their or one of their family members health can be for some be a confusing task and participants mentioned a few concerns. The participant's first concern was selecting the most appropriate search result to find the most relevant health information for their query.

"That's definitely my biggest thing I don't always know what to be looking for exactly with which websites would be good information useful information" (P3)

Besides knowing where to start in selecting the most appropriate search result, the participants also mentioned not knowing if the information was coming from a reliable source.

"I Google everything and usually am able to find what I'm looking for, challenges are making sure it's credible" (P1)

A few methods being used by participants to identify if information is credible are: looking for doctor's credentials, and looking at numerous sites to see if similar answers were provided or identifying what was different.

"Usually take information from a medical site and look for doctor's credentials on the page" (P1)

Some participants stated through interviews that they felt there needed to be more direction around finding reputable health information resources on the Internet

“Have access to a list of websites that would be um would be good for you or for Aboriginal women like it always the Internet is always made easier when your given resources on navigating it” (P3)

“Maybe someone could help you and be like maybe refer to what site they use for information” (P2)

One participant also suggested creating a magnet with reputable websites or including a list of reputable websites in prenatal packages distributed.

“Yeh a go to list yeh like we get the little magnets for the nurses hot line and things like that like and totally unrelated but something like that would be neat (laughs) ... “well yeh well even if it was something that you know like when you like I said when I went for my first visit I got a little package of things and if it something like that was in that package it would be helpful” (P3)

Another concern mentioned by a participant was that she found it hard to trust the information that she found when the health information was outdated.

“I would see posts that are like dated back to 2004 or something so you know like” ... [“if they find something new or new information should always you know keep the Internet updated”] (P2)

Most participants spoke to their ability to rely on the Internet to get health information they were looking for. One participant spoke of the Internet search tool in relationship based terms

“How are you supposed to search for any health without Google's like my best friend” (P2)

This speaks to the need for individuals to feel they can trust technology. Where this can be an issue is when the information that they retrieved did not meet their expectations. One participant shared that she found that the information was too general to help with her specific need for details on labor and contractions, which led to confusion in how she was supposed to respond.

"They have their general average so I can't even remember what the average as with the contractions it was like two minutes apart for two minutes long or something like that before then go to the hospital but my contractions were totally out of the norm they were every two minutes but they would last only thirty seconds but were really strong but I didn't find that on the Internet so I just stayed at home and when I got to the hospital it was time to go (laughs)"(P3)

This led this participant to seek means other than the Internet to find health information in certain situations.

"It's (the Internet) is convenient but if usually if it's something that I'm really concerned about I will call the nurses hot line just because I would rather talk to someone about what the issue is an I feel that there's a better um not result but like its they understand they kind of understand the situation so they can give you better information like more pertinent to the situation that you're looking for"
(P3)

As well, some participants spoke of how providing health information online specific to Aboriginal women in the perinatal period would be more useful.

"If the information provided was more pointed toward Aboriginal it would feel more I don't know it would feel more useful I guess" (P4)

As stated earlier, the majority of participants interviewed seemed aware of the issue of credible information and generally did things to mitigate this by checking dates of website information, looking at numerous sites to see if information presented was similar or different. Most participants stated they could benefit from knowing how to evaluate health web sites and health information and would appreciate receiving a list of reputable websites from health providers.

Empowerment

Through the interviews participants spoke of finding solutions to deal with health concerns and eHealth challenges which I interpreted as empowering events. The ability to access eHealth information was a way to help improve their own or their children's/family's health. The first positive experience, according to participants was that the Internet provided independence/freedom to solve health problems themselves.

"You could pretty much you know do it yourself right and look it up on the Internet" (P4)

"Like I know I need Internet if my doctor is not there to and if I had a question"
(P2)

Another participant spoke of how eHealth or online health information provided access to knowledge and connection with others

"I think without the Internet you wouldn't know too much"..."that's what I like about the Internet like you know if I need to know something or Google something or get a hold of somebody that doesn't have a phone they use Internet" (P2)

In relation to when unfamiliar or unknown health terminology is used in health information online, a few of the participants also spoke of how they used the Internet to research unfamiliar language or medical diagnosis.

"I didn't know that you could get something called a hematoma, it was a first for me. So ...they kind of explained it to me and then I Googled what a hematoma was and how it happened"(P2)

"Um yeh if they have higher words or whatever you can actually Google that to find out what those to right so its all a matter of how smart you are to gain access those kind of things that puzzle you"(P4)

Furthermore, the opportunity to learn new things, like medical terminology, was also important to most participants.

"It's interesting to learn stuff. Like you know I may have had like other kids (chuckles) but still you know I still like find out new things (chuckles)" (P2)

Participants also spoke about how finding health information on the Internet has been a process built over time.

"It didn't like start like you know coming into my life until I was older"..."there was no Internet when I had my son like I didn't use the Internet, I didn't use the Internet for my second child, it wasn't until my third child until started using the Internet to find out info"(P2)

Participants felt they had the knowledge and skills to find health information on the Internet.

"Well you just type in your question on Google and then it press enter and then you know different things pop up and then you know it's all in a row and so you get to choose what one you'd like to go on and sometimes you have to choose one or two or three to finally get where your needing to be right, but I find if you type

your question in properly you get exactly what you want like for terms of what you're looking for"(P4)

Even with challenges to access credible health information online, the participants experience of eHealth options overall can be empowering in terms of improving their understanding of health concerns, and their skills in accessing health information online. Their confidence and skills growing in relation to the number of years using technology devices and the Internet and the number of children they have.

Chapter 5 - Discussion

In this chapter I discuss the findings that developed through merging and comparing the data and themes provided through the quantitative and qualitative data strands. Because of the low response rate these finding need to be interpreted carefully with the understanding they are based on only five participants. I then describe how I integrated the findings of this study and demonstrate how they support and extend previous literature. Following this will be an examination of the limitations of this study, the implications for practice and future research areas needed. The chapter will end with a final summary and conclusion.

Key Findings

Finding 1: Accessibility

According to the eHEALS survey responses, all participants knew where to find helpful health resources and most participants knew how to find helpful health resources on the Internet in order to answer their health related questions. In the interviews, participants also restated they had the ability, understanding and skills to find health information on the Internet in order to answer their health related questions. The findings from both datasets may support that Aboriginal women in the perinatal period have adequate eHealth literacy levels in order to access health information on the Internet.

The data provided by participants may support that it is not a lack of training or lack of interest, but that for some it is a lack of equipment or Internet which is a barrier to Internet access (Zach et al., 2011). This is something that health systems and healthcare providers need to be aware of and assist in offering access and support for individuals. One participant affected by the lack of both a digital device and the Internet spoke to the need for more computers (devices) in communities. It may be an opportunity to utilize

existing health facility equipment and librarians to offer public education to improve both public skills and equipment access to support individuals to retrieve health information. This is something which can occur not just in hospitals, but potentially the librarians can link with non-government health programs like a pregnancy outreach program to offer education and information sessions to vulnerable populations. Health systems and governments also need to work with private business sectors and other industries to expand where computer, Internet and other mHealth technologies and services are available to increase opportunities for those that financially are not able to afford needed equipment or Internet to access health information. Another suggestion may be to develop ‘health mobiles’ which would be similar to mobile libraries for areas where no current health librarians or computer equipment exist (Gillis & Quigley, 2004). These are a few potential opportunities that may help to reduce the “digital divide” and potentially build eHealth and health literacy levels of Aboriginal women in the perinatal period (Kickbush, 2009; Skopelja et al., 2013).

As was noted by participants in this study and supported by the literature, the majority of individuals do not move past the first page of results when looking for information to answer queries. This information is important and could be used by health systems, governments and their information technology specialists to ensure that credible health information is placed on the first page of search engine results. Other possible strategies put forward in the literature to improve the effectiveness and engagement of individuals with health information and services on the Internet are to develop a specific web domain address, i.e. dot health (.health), to globally adopt standards for quality in Internet health information and practices (Clauson & Vieira, 2011). Another potential

strategy is to invest in development of digital literacy programs like the digital literacy hub developed by the Aboriginal Literacy Foundation in Melbourne, Australia (Aboriginal Literacy Foundation, 2014).

One of the other areas of concern noted from participants was around not understanding some of the health terminology used, or if linking this back to the Lily Model, the realm of health literacy. The current recommendation is for websites to ensure health information is written at a Grade 6 to 8 level, but with many websites containing health information at reading levels that far exceed this or containing health terminology/language that users do not understand, demonstrating there could be a need for guidelines around the development of e-knowledge health websites (Usher & Skinner, 2010). It is important for healthcare providers and health systems to remember that health education or social marketing of health messages will only be effective dependent on how understandable people find them (Keleher & Hagger, 2007, p.25). With all systems containing their own language, not necessarily understandable to all, there is need for awareness of health language/health jargon used in health information resources. It may also be important for those developing health information to focus not just on scope, completeness, and credibility, but also to focus on user-centered design looking at the basic reading level needed for most to be able to effectively access information contained (Nowrouzi, Gohar, Nowrouzi-Kia, Garbaczewska & Brewster, 2015; Sentell, Dela, Cruz, Heo & Braun, 2013). In order to build health literacy levels of Aboriginal women in the perinatal period, an opportunity could be for online health information or webpages to have hyperlinks to plain language definitions and/or provide alternatives to

written information through audio options to address different learning styles (Gillis & Quigley, 2004).

Another area of concern brought forward by participants was around the lack of optional formats in which health information is presented on the Internet; or again if looking back to the Lily Model, the area of media literacy. eHealth interventions have the potential to be more engaging than traditional patient information brochures due to the ability to use more audiovisual information (Mackert, Champlin, Holton, Munoz & Damaiso, 2014). All patients can benefit from the use of visual images, but they are noted to be particularly important for those with low literacy levels (Sentell et al., 2013). This could also be important when specifically looking at the needs of Aboriginal populations knowing that historically they are known to be more of an oral and visual society. If undertaken by health systems what will be important to consider is that “signs, such as written text, pictures, videos, slide shows, icons, pictograms, colors and fonts, are not value neutral or independent of cultural norms and identities, and understanding them depend on the cultural and social background of the individual” (Gilstad, 2014, p.8). Another potential solution brought forward by the literature to improve eHealth literacy levels is the use of web portals or health portals (Austvoll-Dahlgren, Bjorndal, Odgaard-Jensen & Helseth, 2012; Lemire, Pare, Sicotte & Harvey, 2008).

Finding 2: Trust and Credibility

According to the eHEALS responses, most participants found the Internet useful in helping them make health decisions. But only sixty percent found they had the skills needed to evaluate health resources found and distinguish between those of high and low quality. In the interviews most participants reinforced that they found the Internet useful in finding health information and answering their question/need. What came forward

from many participants is that there was concern in knowing if the information they find is credible and for one participant she was not sure what to do when none of the information found helped her situation. Findings from both datasets support that there may be concern from Aboriginal women in the perinatal period in their ability to appraise and in some cases apply health information they retrieve off the Internet to solve their health need.

Participants in this study reinforced that they felt they had the skills and knowledge available to find health information on the Internet in order to answer their health questions. Where there was concern, was with their ability to tell if the information they found was credible and what level of credibility it had. If going back to the Lily Model, the areas of information and science literacy would be areas of focus needed. This was reinforced by the literature where it was stated that it is hard for individuals to have confidence in their ability to access credible and trustworthy information posted on the Internet when health information seeking (Lemire et al., 2008; Norgaard et al., 2015; Rempel, Donelle and Kothari, 2016; Zach et al., 2011). Some participants in the study felt that healthcare providers need to provide direction and resources around what credible health websites they could be accessing. This was also suggested by Rodger et al. (2013), who stated that “health professionals could play a more active role in guiding women to websites that are evidence based” (p.310). With the growing number of medical resources online, healthcare providers, educators and health systems could have a role in developing strategies to build patient skills in identifying and assessing for the validity of credible health information as well as a responsibility to direct individuals to accurate, evaluated and approved health websites

(Dominick et al., 2009; Donnelly et al., 2008; Gauld & Williams, 2009; Hoffman-Goetz & Friedman, 2007; Sethuram & Weerakkody, 2010). One of the solutions brought forward from the participants was to be provided a list of credible websites from their healthcare provider or in their prenatal package. Another opportunity is to develop critical questions for Aboriginal women in perinatal period to ask when looking at websites similar to what was outlined in the article by Wilmot, Begoray & Banister, (2013). Other solutions put forward by the research to ensure credibility is to use search engines which are medically focused, or use a dot health top-level domain and/or develop and use an official seal of approval (Clauson & Vieira, 2011). Whatever solution will be sought, it is important to develop more holistic approaches that meet the needs of diverse populations including a focus on the Aboriginal population. As well, there is possibly a need to develop stricter guidelines and regulations on health content being posted on the Internet which could incorporate codes of ethics and content provider accountability (Clauson & Vieira, 2011).

Finding 3: Empowerment

Based on the responses from the eHEALS survey, most participants stated they felt confident in making health decisions based on the information from the Internet and also in their skills in knowing how and where to access health information on the Internet. Based on the interviews most participants stated they felt they had the knowledge and skills to find health information on the Internet and liked the independence and ability to gain knowledge it provided. Findings from both datasets may support that Aboriginal women in the perinatal period are empowered through an adequate eHealth literacy level and the opportunity to find health information on the Internet.

Health literacy may empower Aboriginal women in the perinatal period to utilize eHealth resources in order to fully participate in health decisions to manage and improve not only their own, but their children's' and families' health and wellness and quality of life (Chiarelli, 2006; Donnelly et al., 2008; Korda & Itani, 2013; Neter & Brainin, 2012; Rootman & Gordon-El-Bihbety, 2008; Varkey, Kureshi & Lesnick, 2010). Finding health information on the Internet gave participants the ability to acquire, understand and use information, without needing the help of others, which in turn "may contribute to better self-esteem, a greater range of choices, increased self-determination, more ability to stand up for oneself, and more control over one's own life" (Korhonen, 2006, p. 19-20). If eHealth literacy is about true empowerment for Aboriginal peoples then it could be important for Aboriginal women in the perinatal period to be active participants in determining their goals, materials/activities used, and what constitutes success (George, 2002). It is also important to remember that as women are considered the key seekers and disseminators of health information a strong association exists between the empowerment of women and the health of communities (Dodson, Good & Osborne, 2015). One strategy mentioned in the literature is to invest in building health and eHealth literacy of Aboriginal women in the perinatal women through the use of learning networks (Chiarelli, 2006). Another suggestion is to utilize the extensive existing literacy and adult education classrooms as a platform for reaching individuals (Hemming & Langille, 2006).

Issues Related to the eHEALS Instrument

This study used the eHEALS questionnaire as a means to measure the eHealth literacy level of participants and introduce them to this tool. All participants completed

the questions without any support from the researcher. An interview question focused on whether participants found the tool straight forward and thought it would be a useful to use with other Aboriginal women in the perinatal period.

Repetitiveness

Participants found the questions straightforward, but there was mention of repetitiveness in the items and therefore confusion around what was being asked. The eHEALS assessment tool currently does not ask if individuals have the technology equipment or means to access the Internet. Bautista (2015) states that “it is critical to assess respondents’ use of digital technologies as this will greatly influence their eHealth literacy (p.46). There is a recommendation to add or use an assessment scale like the “Technology Proficiency Self-assessment scale (Bautista, 2015, p.46). This is extremely important information for any healthcare provider to be aware of. This was demonstrated with one study participant who responded positively to many questions, but did not have access to a computer or the Internet without visiting the local library, which made it difficult to access online health information.

Inconclusive Findings Related to Functionality

Another aspect was that the instrument was missing a functional component of health literacy assessment, and it did not conclusively provide an indication of whether or not an individual has the ability to understand if the information gathered is credible and can be trusted (Ingram, 2011; Monkman & Kushniruk, 2015). Even though most of the participants stated that they have the skills to evaluate health resources on the Internet and tell which were high quality resources from low quality resources, their responses provided to the interview questions indicated they still had concerns about the credibility of the information found and most requested health systems and providers direct them to

credible sites and information. According to Batterham, Hawkins, Collins, Buchbinder and Osborne (2016), we need to be aware that patients “may pass the screening questions and so the assumption is that they do not have health literacy needs when, in fact they have substantial needs” (p.7). They also caution around the potential for screening to stigmatize individuals and potentially lead to disengagement from health services (Batterham et al., 2016). Other items the eHEALS survey did not include, but were brought forward from participants was their preferred format to learn information i.e. text vs. video, etc. Another was around the ability to problem solve if they are unable to find health information on the Internet or do not answer positively to questions.

We know that individuals need to have the skills to navigate their way through a multitude of both websites and information contained which can be complicated and questionable. The need for development of new measures and best practice in the assessment of health and eHealth literacy which includes consideration of the persons, their contexts and better reflects the definitions has been documented in the literature (Batterham et al, 2016; Dodson, Good & Osborne, 2015; Heinrich, 2012; Jordan, Buchbinder & Osborne, 2010; Rootman & El-Bihbety, 2006; Rootman & Ronson, 2005). As many physician offices have implemented electronic medical records it will be important to develop validated, computer-based tools to assess health and eHealth literacy in order to embed them into these existing clinical settings and electronic based health information management systems (Collins et al., 2012; Ingram, 2011). There may also be need for health systems to take a universal precautions approach to identify opportunities and support for improvement, as healthcare providers do not necessarily

know which individuals have limited eHealth literacy and skills in navigating eHealth (DeWalt et al., 2010; Dodson et al., 2015; Norman & Skinner, 2006).

Potential Self-Report Bias

The eHEALS is considered a self-report assessment tool. One of the issues with this type of tool is that the responses only provide those administering the questionnaire with a general impression of where an individual (from the individual's own self-assessment) is at with their ability to both access and understand the health information found on the Internet. This tool does not provide healthcare providers definitive information on an individual's health literacy level, and it also lacks specific information needed to guide practitioners on what to do if an individual does not respond positively to one of the questions. The research by Bautista (2015) also stated that eHEALS may not be a valid measure of eHealth literacy as it does not actually predict an individual's eHealth literacy. If according to Jordan et al. (2011), "a health literacy instrument should ideally be capable of clearly describing an individual patient's abilities and areas that need to be addressed"; then the eHEALS questionnaire needs to be further developed as it does not provide clear directions to those administering it (p.377). Lastly, there is an inherent assumption that healthcare providers have the eHealth skills to appropriately direct and guide individuals when needed based on their response.

As stated above, there possibly needs to be more research to develop assessment tools that better reflect the definition of eHealth literacy; are culturally appropriate in order to measure the eHealth literacy level of Aboriginal patients; that incorporate functional skills and practical questions regarding technology equipment and access to the Internet; but also take into consideration the eHealth literacy skills and context of healthcare providers who will administer them (Collins et al., 2012). The e-health

literacy framework developed by Norgaard et al. (2015) is an example of how the original model is being expanded. As well, in order to assist in improving eHealth literacy of individuals, healthcare providers or education specialists could develop familiarity with utilizing electronic resources (e.g., mobile-Internet, smartphones, iPads, etc.) (Hanik & Stellefson, 2011).

Lack of Culture Lens

The majority of participants in this study felt there was need to have culturally relevant health information and health websites for Aboriginal people. There has been direction in the research literature for healthcare providers, educators and health systems to be aware of Aboriginal people's preference for culturally relevant resources and the necessity to start providing those (Hoffman-Goetz & Friedman, 2007). This was reinforced by the participants in the study; they want to see culturally relevant material and websites for Aboriginal women in the perinatal period. Therefore, this could be taken into account by the healthcare system as it is critical to the message being shared, accessed, interpreted and understood (Smylie et al., 2006). Zarcadoolas, Pleasant and Greer (2005) have noted that, "cultural differences can lead to different interpretations and reactions to the same message" (p.201). Culturally relevant and appropriate health resources do not just help Aboriginal people to feel the information reflects and represents them, but it is said that Indigenous language and symbols teach an entire worldview and are therefore very powerful (Smylie et al., 2006). Understanding and being able to access eHealth literacy is a part of the cultural capital of individuals' and communities' (Kickbusch, 2009). Greater attachment to, or engagement with, traditional culture is seen to create a stronger sense of self-identity, promote resilience and positive sense of community (Colquhoun & Dockery, 2012). The roles of family, social context,

culture and education also need to be factored in the development of all eHealth literacy messages and proposals (Kickbush et al., 2013). At the same time Filippi et al. (2013) cautions around “the idea of representing “Nativeness” on websites “due to the diversity of practices and ideas within tribes” – sometimes referred to as pan-Aboriginalization (p.49). It may be important for those developing this type of information to ensure engagement and participation from Aboriginal individuals, communities, organizations and leaders to ensure endorsement.

It is also critical for information technology departments to keep in mind that eHealth solutions are not developed in a social vacuum and need to be adapted to the end user’s health needs in the contextual but also cultural context. “The content must be presented in media types and in formats that people can relate to and make sense of, be that linguistically or content wise” (Gilstad, 2014, p.8). There may be need to ensure that information communication technology used for Aboriginal populations use an Aboriginal health and wellbeing approach and are grounded in the Aboriginal worldview (O’Donnell et al., 2010). This includes eHealth and health information on the Internet. To reduce eHealth literacy disparities and improve organizational cultural competence healthcare organizations need to recognize that literacy, language, and culture are intertwined and initiatives need to be not only culturally sensitive, but guided by how Aboriginal populations understand and approach health (Brach et al, 2012; Kickbush et al, 2013; Korda & Itani, 2013; Stern & Kaur, 2010).

Integrating the Spiral Model into the Aboriginal Literacy Model

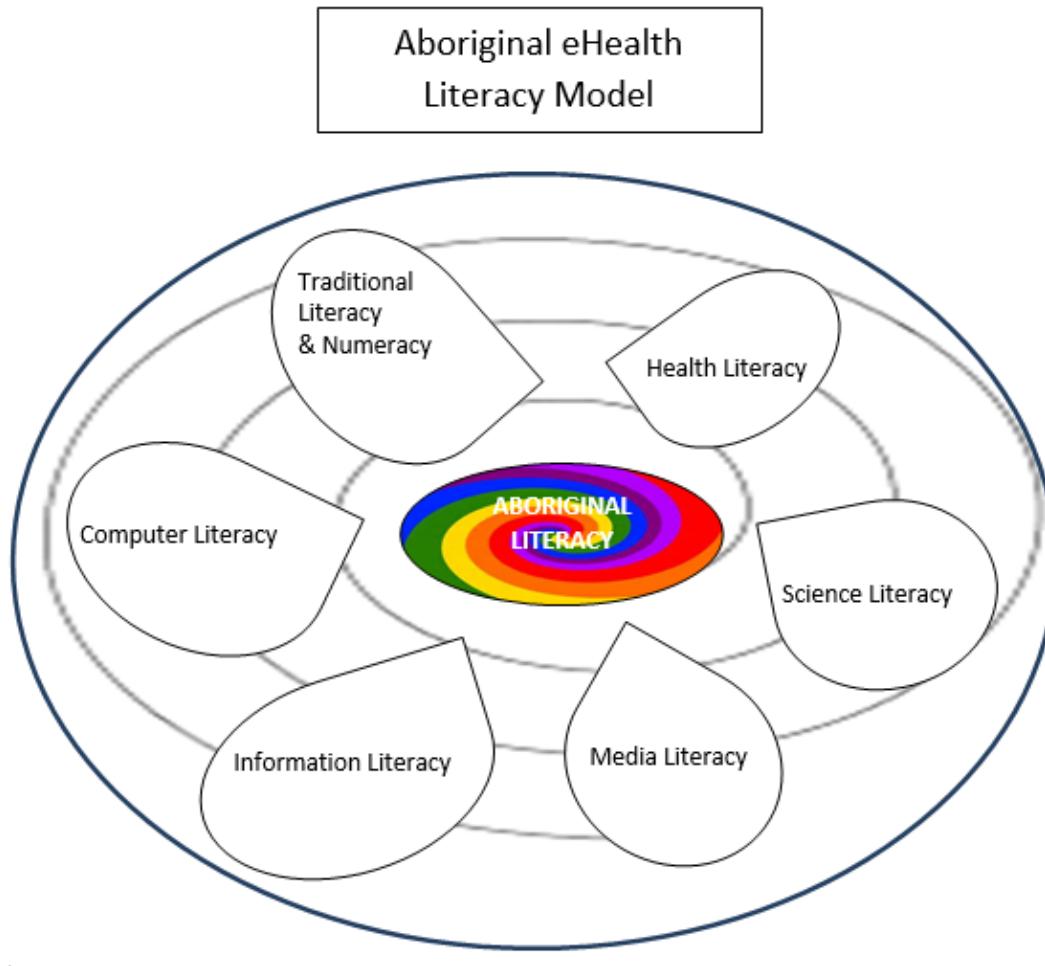
Singleton and Krause (2009) state that culture affects individual and collective experiences that are directly and indirectly related to health. At the same time, cultural

identity is linked to literacy. For this reason a culturally based approach which is specific and relevant to both the individual and community may be needed for eHealth literacy (Rootman & Ronson, 2005; Smylie et al., 2006). Due to the fact that culture was not an element of the eHEALS survey and was not included in the Lily eHealth literacy model (Norman & Skinner, 2006) there is need to ensure that eHealth literacy models reflect an Aboriginal perspective. I have not been able to locate an Aboriginal model for eHealth literacy in the literature, but suggest that there is a need to start to use the Aboriginal model for literacy which has a technology component and is grounded in overall wellness to start to develop a preliminary one (Figure 8).

Although the Aboriginal Literacy model like the Lily model may also have some need for redevelopment to reflect the lifelong process that is spoken to in research related to literacy, health, and eHealth literacy (Neter & Brainin, 2012; Reading & Wien, 2009; Sankhulani, 2007). The lifelong process is something recognized by Aboriginal worldviews, so an improvement would be to incorporate this element into an adapted model (Assembly of First Nations, date unknown; Métis National Council, 2004). A spiral is considered a traditional native symbol representing human possibility and/or a never-ending journey of discovery and can be used as a method for teaching and learning for the whole person over their lifetime (Knudsen, 2004; Hill, 2001). Characteristics of spiral learning are: being observant, making an individual decision as to when to try to do something on their own, and taking responsibility for what to learn and when (Hill, 2001). A combination of the Aboriginal literacy model with the Lily model developed by Norman and Skinner (2006) and incorporation of the spiral model may represent a more encompassing and reflective model. It is also important to reflect that learning is

reciprocal and done in relationship to another as noted with the outer circle in the Aboriginal eHealth literacy model put forward. Aboriginal people perceive that all of creation is interrelated in a circle of life, with no beginning or end. There are no hierarchical structures; all living things, including rocks, vegetation, animals and people are related and interact in a reciprocal manner (Getty, 2010). This concept fits with the relationship being a circular process and not one way from just the provider to patient, or patient to technology which reflects the circular model that is the basis for the Aboriginal worldview – literacy, health and culture are dependent on each other.

Figure 8
Aboriginal eHealth Literacy Model
(Adapted from Lily Model and Spiral Model)



- Aboriginal eHealth Literacy Model**
- Aboriginal Literacy at the core - Rainbow
 - Built in relationship with others i.e. People, technology – Outside Circle
 - Life long process – Spirals
 - Each petal may have its own level of capacity – beginner to advanced (Benner, 2004); and is not constant or unchangeable (Drejer, 2001) so may progress or regress i.e. technology device change, new health/other terminology

Limitations

Although many of the findings of this study are not discussed in previous literature, there are also some important limitations that must be considered when interpreting this study's findings. According to Creswell (2014), "validity using the convergent approach should be based on establishing both the quantitative validity and the qualitative validity for each database" (p.223). Firstly, due to the non-probability sampling method used, results from this study are not generalizable to all populations (LoBiondo-Wood & Singh, 2009). As well, participants who volunteered to participate may already have had the ability and skill to locate health information on the Internet. Another potential limitation is that since data was collected in one general community location findings may not apply to populations outside of this region or urban setting.

I had hoped to recruit a small sample of between eight to ten Aboriginal women in the perinatal period, but was only able to recruit five women to interview. Having recruited a smaller participant sample size than hoped for, I will not meet rigor for qualitative analysis. I also was not able to meet quantitative sampling rigor for "representativeness" based on my need to keep my sampling procedure "practical" (Kemper, Stringfield & Teddlie, 2003). These are both limitations of this study and therefore I will not meet statistically significant or generalizable results and so no correlations to the underlying population can be made; and caution needs to be taken when interpreting the findings presented (Collins et al., 2007).

As well, responses were received from individuals that identified as First Nations only, meaning that it may not represent the experience of those that identify from another Aboriginal identity i.e. Métis. At the same time, there is the chance that researcher/or

participant bias influenced the collection and analysis of the qualitative data. The multiple methods for collecting data was one strategy for addressing this concern.

A final limitation of the study was that the digital recorder for the first interview was not working correctly and did not record the interview and I had to rely on the notes recorded. As the participant could have refused to have the interview recorded notes were collected on all questions asked regardless. Lastly I learned through the process of completing this mixed methods study, that it may have been more appropriate to frame this study as a purely qualitative study due to the limited sample size. As well, another learning is that through all steps attempted to recruit participants, it may have been helpful to have hired a community research assistant from the community of urban Aboriginal women in the perinatal period to assist.

Implications for Practice

It is the responsibility of all involved in healthcare delivery to improve the quality of health and care to those they serve (Smylie et al., 2006). Healthcare and health information technology education and training schools as well as health care employers need to take an active role in ensuring that eHealth literacy curricula and competencies not only exist, but that they are culturally competent and embedded in any role requirements and education opportunities for healthcare providers (Coleman, 2011; Parker, Ratzan & Lurie, 2003; Stern & Kaur, 2010). The next step would be to evaluate this training and then implement the validated assessment tools, and teaching strategies necessary for healthcare providers to put it into practice. It is also important for all those mentioned to develop strategies and programs that engage underserved and difficult to

reach populations, expanding the reach beyond just those that are already accessing healthcare services (Batterham et al., 2016; Laakso, Armstrong & Usher, 2011).

Systematic information is lacking in Canada on levels of health literacy and eHealth literacy in certain populations, including Aboriginal people (Rootman & Gordon-El-Bihbety, 2008). There is need for healthcare organizations to evaluate, or if existing utilize, current analytics to understand the populations they are reaching with current health information they have available. One method currently being implemented by some is the Sharing, Technology, Evaluation, Partnership and Participation (STEPP) approach to eHealth literacy improvement (U.S. Department of Health and Human Services, 2010). At present, neither health literacy nor eHealth literacy is consistently being measured which makes it difficult to interpret and compare at individual and population levels (Jordan et al., 2011).

There has been a call by Gibbons et al. (2013) for providers and the healthcare systems to proactively deploy technologies to improve clinical care, facilitate greater patient participation in the care process and enhance healthcare disparities research and not always wait for governments to mandate or provide mechanisms to do this. At the same time, all levels of government need to be involved in developing, supporting and requiring policies and programs related to eHealth literacy (Rootman & Gordon-El-Bihbety, 2008). The five themes presented by the First Canadian Conference on Literacy and Health (Canadian Public Health Association, 2001) represent a good guiding framework for all to use when trying to make improvements in not only health literacy but the next generation of this - eHealth literacy: (1) making health services and health information easy to use for all Canadians, (2) looking for ways to improve the training of

health professionals, (3) learning more through research, (4) learning from those using the system, and (5) building literacy and health partnerships. As well, another suggestion is to integrate the six principles outlined by the U.S. Department of Health and Human Services (2010) to create and sustain action to improve health literacy: (1) actions should be cross-disciplinary, (2) actions should be strategically planned and based on evidence, (3) actions should be evaluated, (4) actions should involve continued public education on the extent and associations of limited health literacy, (5) actions should include law, policies, and similar institutional supports that facilitate health literacy, and (6) actions should involve communities and individuals that are most affected by limited health literacy. This also could be supported by accreditation organizations as a core requirement for successful accreditation. A first step may be to evaluate health organizations for health literacy according to the ten attributes outlined by Brach et al. (2012).

The ownership alone does not lie with the healthcare system, health literacy is said to be a policy issue at the intersection of health and education requiring both to be full participants in advancing health literacy (Parker et al., 2003). It was recommended by Rootman and Gordon-El-Bihbety (2008) that “ a comprehensive, coordinated, cooperative and integrated Pan-Canadian Strategy on Health Literacy be developed, funded and implemented to improve the level of health literacy in Canada” (p.38). It is essential that this strategy focus on eHealth literacy in order to lead to the improvements needed in population health and concomitantly the reductions in health costs needed by all (Rootman & Gordon-El-Bihbety, 2008). Remembering that statistics represent real people and that research has demonstrated that what is learned as a youth is retained,

then we also need to focus strategies upstream and teach eHealth literacy skills to Aboriginal youth and find ways to reinforce them across the lifespan (Kickbush et al., 2013; Parker et al., 2003).

e-Health tools are often designed and aimed at patients who have better digital and health care access and have not been deliberately built to reach the most vulnerable populations. This may maintain or potentially widen health care inequity; therefore, the needs of the underserved populations must be considered and the ways in which they are already using social media in order to address health disparities” (Bacigalupe & Askari, 2013).

eHealth solutions should be tailored for the intended user group, and representatives of the group should be consulted in the development; secondly they should use several media types in order to make the information easily understandable to groups with various eHealth literacy levels; thirdly, teaching and training programs, preferably with promoters’ in the user group, helps users trust and feel confident about their use (Gilstad, 2014, p.9).

The first sentiment was shared by Monkman and Kushniruk (2015), they state in order for content online to be useable and understandable e-health projects need to take into consideration end users literacy needs in their user-centered approach. Or individuals may not benefit from the information contained as they see no value or cannot use it effectively.

Directions for Future Research

Research needs to start to identify how often and how best to measure health literacy and eHealth literacy in order to improve it (Heinrich, 2012; Mackert, Champlin,

Holton, Munoz & Damasio, 2014; Parker et al., 2003). Therefore as stated above, the assessment of health and eHealth literacy as part of the quality data that is collected on patients within the healthcare system is needed (Heinrich, 2012). This would assist policy makers, educators in really understanding the current situation related to eHealth literacy of the population and is even more important when addressing the health of the most vulnerable population.

Specific research is needed to develop and evaluate more culturally appropriate and culturally informed models and assessment tools for eHealth literacy. More research is needed to understand what technologies are used by Aboriginal women in perinatal period, how they use the Internet, and to evaluate the quality of health information they retrieve from it (Donnelly et al., 2008; Jacobs et al., 2014). It is important to develop specific tools to assist Aboriginal populations to identify credible health sites and resources and to translate medical jargon. eHealth literacy initiatives work best when they customize approaches based on understanding the diversity of how individuals and communities approach health.

There is also a definite need for further quantitative and qualitative research on eHealth literacy among Aboriginal women in the perinatal period using larger samples, recruiting with random sampling methods, and using comparison groups which can provide additional information for program development and policy making on eHealth literacy.

In summary, in this chapter I discussed the merged findings from the quantitative and qualitative data strands under the three findings of accessibility, trust and credibility, and empowerment. This was linked to research literature and implications were

discussed. Other topics covered were related to limitations of the eHEALS survey.

Limitations of the study and implications for future practice and research identified.

Conclusion

Use of the Internet provides a virtual and limitless set of tools and opportunities to both empower and deliver health information assisting individuals to take a more active and informed role in improving their health (Gibbons et al., 2011; Mackert et al., 2014; Manafo & Wong, 2013). This can only be realized if technology and information is designed with the end users in mind, as many but not all have ready access to the Internet, but they may not have the ability to fully utilize it for health (Mackert et al., 2014; Norman & Skinner, 2006). Knowing that the Aboriginal population remains a vulnerable population, it is critical when developing the content and format of digital tools and health information to consider the cultural contexts and health issues faced by them in order to successfully reduce known barriers and healthcare disparities (Bacigalupe & Askari, 2013; Kickbush et al., 2013). This study begins to explore the importance of building and supporting the eHealth literacy for urban Aboriginal women in the perinatal period. It also possibly suggests that some of these women still experience issues with accessing health information online. This opens significant opportunities for collaboration, partnership and investments across multiple sectors and stakeholders in order to remedy this (Bacigalupe & Askari, 2013; Norman & Skinner, 2006; Parker et al., 2003). In order to begin, there may be need for a redefined eHealth literacy model that better fits Aboriginal peoples in order for the Aboriginal population to achieve the ability to walk in two worlds – the traditional and the technological (Canadian Public Health Association, 2001). The challenges may be to ensure the

significant diversity of Aboriginal peoples is reflected, and also to recognize that the definition of what it means to be eHealth literate may continually change (Mitic & Rootman, 2012).

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Appendix A

eHEALS & Demographic Information Questionnaire

eHEALS – (Donnelly, Shaw & van den Akker, 2008, p.502)

1. How useful do you feel the Internet is in helping you in making decisions about your health? Please circle your answer.
 - a. Not useful at all
 - b. Not useful
 - c. Unsure
 - d. Useful
 - e. Very useful
2. How important is it for you to be able to access health resources on the Internet? Please circle your answer.
 - a. Not important at all
 - b. Not important
 - c. Unsure
 - d. Important
 - e. Very important
3. I know what health resources are available on the Internet. Please circle your answer.
 - a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly Agree
4. I know where to find helpful health resources on the Internet. Please circle your answer.
 - a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree
5. I know how to find helpful health resources on the Internet. Please circle your answer.
 - a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree
6. I know how to use the Internet to answer my questions about health. Please circle your answer.
 - a. Strongly disagree
 - b. Disagree

- c. Undecided
 - d. Agree
 - e. Strongly agree
7. I know how to use the health information I find on the Internet to help me. Please circle your answer.
- a. Strongly agree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree
8. I have the skills I need to evaluate the health resources I find on the Internet. Please circle your answer.
- a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree
9. I can tell high quality health resources from low quality health resources on the Internet. Please circle your answer.
- a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree
10. I feel confident in using information from the Internet to make health decisions. Please circle your answer.
- a. Strongly disagree
 - b. Disagree
 - c. Undecided
 - d. Agree
 - e. Strongly agree

Demographic Questions

11. What is your age? Please check ✓

- Less than 18
- 18-23
- 24-29
- 30-34
- 35-39
- 39+

12. Do you self-identify as being Aboriginal, that is, First Nations, Métis or Inuit? Please check ✓

- Yes

No

13. If you answered yes to the question above, Do you identify as First Nations, Métis or Inuit? Please check

- First Nations
- Métis
- Inuit

14. What is the highest level of education you have completed? Please check

- Less than grade nine completed
- grade 9 – 12 completed
- graduated high school or have dogwood certificate
- some college or university completed
- trade/technical/vocational training completed
- college or university graduate

15. What was your total household income before taxes last year? Please check

- Less than \$25,000
- \$25,001 - \$34,999
- \$35,000 - \$49,999
- \$50, 000 - \$74,999
- \$75,000 - \$99,999
- \$100,000+

16. What is your marital status? Please check

- Single (never married)
- Married/Common-Law
- Separated
- Widowed
- Divorced

Appendix B

Interview Guide

Hi there, my name is Judy Sturm, and I am the researcher in the study. The government and other agencies are putting a lot more of their health information to help people on the Internet. Today I will be asking questions to better understand how you feel about having to find more health information on the Internet.

To help ensure that I capture everything you have to say, I would like to tape record our conversation today. I will be the only person to listen to the tape and it will be destroyed after it is used to type up what you said. As well, I will be reviewing the consent form and asking for your signature. Essentially, this form says that (1) all information will be confidential, (2) your participation is voluntary and you may stop at any time if you feel uncomfortable. Thank you for agreeing to participate.

I have planned this interview to last between 45-60 minutes. During this time, I will ask you to complete a questionnaire called the ‘eHEALS’ which includes some personal information questions at the end. Then I have several questions that I would like to ask you to better understand your experience and understanding of health information on the Internet.

Introduction

This research project focuses on how Aboriginal women who are pregnant or have a baby get and understand health information on the Internet. I am trying to help improve how Aboriginal women who are pregnant or have babies access and understand health information on the Internet and ultimately improve their health.

Do you have any questions before we start? Do you need to get a glass of water or go to the washroom? Just make yourself as comfortable as possible?

1. Questionnaire

Here is a pen and the questionnaire called the ‘eHEALS’ for you to complete. There are 10 questions in total, and of the questions relate to your thoughts about health information on the Internet. At the end of the questions, you will see a personal information section. Let me know at any point if you have any questions.

Questionnaire provided to participant for completion.

Once the questionnaire is finished.

2. Interview

Is it okay with you if I turn on the recorder and check the sound?

If participant okay with recorder, turn on and check sound, if doing phone or Skype/FaceTime interview ensure recorder close to microphone. Once equipment checked and ready, begin with questions.

- a) Can you tell me a bit about yourself?
- b) How long have you lived in Williams Lake?
- c) How was (has) your pregnancy (been)?
- d) The next thing that we will do is move into the interview part of our visit. I have a few questions to go through with you. The first is when you are looking for health information on the Internet, can you describe what you use?
 - a. Can you describe where and how you find health information on the Internet?
 - b. Do you think it is easy to access health information on the Internet? What are the barriers and challenges?
 - c. How important is it for you to be able to look at or get health information or health resources on the Internet?
 - i. If I gave you a scale of one being not very important to get health information on the Internet and 10 being very important to get health information on the Internet can you let me know what number describes how you feel?
- e) What kinds of things help you or get in the way of you using the Internet to get health information?
- f) Tell me about a time when it was easy to get health information on the Internet?
- g) Tell me about a time when it was hard to get health information on the Internet?
- h) How can we help you or other Aboriginal women be able to get health information over the Internet?
- i) What does being comfortable in finding health information on the Internet mean to you?
 - a. How have things changed over time, tell me about when you first started finding information on the Internet, has that changed, why and how?
 - b. How could we help you become better at getting health information on the Internet?
- j) From the view of your own Aboriginal cultural practices and knowledge, how does using health information over the Internet work for you? What would your Aboriginal friends say?

- a. How does your family or community view technology and finding health information on the Internet?
 - b. How could health information on the Internet be more culturally appealing and inviting for Aboriginal women?
- k) Can you describe how you see the eHEALS instrument being used with other Aboriginal women who are pregnant or have a baby?
- a. If we were to make a checklist that helps us understand how well Aboriginal women who are pregnant or have a baby are able to find and use health information online what would you say needs to be included?
 - b. What information and skills are important for Aboriginal women who are pregnant or have a baby to use health information on the Internet well?

Closing

I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know that we have not covered?

I should have all the information I need. I will quickly review what I heard you say, so please let me know if I need to change anything I heard to make it more accurate.

I am going to turn off the recorder now. Thank you again for all the information and help you provided me.

Appendix C

Sample Recruitment Letter

Dear Pregnancy Outreach Program Participant,

My name is Judy Sturm and I am a graduate student from the Nursing and Health Information Science program at the University of Victoria. I am inviting you to participate in a research study about the experience of Aboriginal women in accessing health information on the Internet in the Williams Lake area.

You will be eligible to be in this study if you say yes to all of the next items:

- Are either pregnant, or have a baby under one year of age,
- You self-identify as an Aboriginal woman,
- Are 18 years of age or older,
- Are currently living off-reserve,
- Lastly, have accessed health information on the Internet in the last 6 months.

If you decide to participate in this study the steps you will follow will be

- Meet with me for a 45-60 minute interview either in-person, over the telephone, or over social media (Skype or FaceTime).
- Review information about the study and give consent to participate.
- Once the consent is complete you will be asked to fill out a questionnaire, and share your story.
- You can decide to stop participating in the study at any point in time.

A \$25 gift card to Walmart or a local grocery store will be provided for your time. If childcare or transportation is needed, compensation for either or both of these will be provided.

If you'd like to participate or have any questions about the study, please contact me by phone or text at 778-257-0341 or on my email at jsturm@uvic.ca

Thank you very much.

Sincerely,

Judy Sturm

Appendix D Research Study Poster



Health information on the Internet - Research Study Advertisement

ARE YOU AN ABORIGINAL WOMAN WHO IS PREGNANT OR HAS A BABY?

**Volunteers are needed for a study about health
information on the internet**

You are invited to take part in a study to find out what Aboriginal women who are pregnant or have a baby have to say about their experience with accessing health information on the internet.

Why this study is important:

A person's health and their ability to read health information are connected. More awareness about how Aboriginal women who are pregnant or have a baby get and understand health information on the internet is needed.

What will I have to do?

You will be asked to fill in a questionnaire and share your story. The sharing will take about 45-60 minutes and can be done face to face, over the phone or through Skype or FaceTime. You can pick a day and place to meet.

All women who share their story will be offered a \$25 gift card to Walmart or a local grocery store for helping, and if needed there is assistance for child care or a ride.

Who can join in the study?

- Currently pregnant or have a baby under 1 year old
- Aboriginal women
- 18 years of age or over
- Living off-reserve
- Used the internet to look at health information in the last 6 months

Sharing is voluntary: You can stop helping at any time.

How do I help or get more info?

You can contact:

Judy Sturm, R.N., B.S.N.
Graduate Student – Principal Researcher, University Of Victoria
jsturm@uvic.ca or Tel: 778-257-0341